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**Abstracts: Presentation sessions**

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## **Contents**

<b>Ambulance staff's experiences of delivering patient care whilst wearing a chemical, biological, radiological or nuclear (CBRN) suit: An exploratory study</b>	<b>451</b>
<b>A meta-ethnography of qualitative research on organizational culture in family practice teams</b>	<b>451</b>
<b>Analysing group interaction in focus group research on alcohol use: Impact on data content and the importance for public health</b>	<b>452</b>
<b>An Exploration of Lay epidemiology and cancer</b>	<b>453</b>
<b>A Participatory Approach to Online Education and Support Curriculum Development for Families of Children with a Heart Transplant</b>	<b>453</b>
<b>A Qualitative Longitudinal Approach to Exploring Service User Experiences of Lay-Led Health Improvement Interventions</b>	<b>454</b>
<b>Assisted reproductive technology within the public health sector in Brazil: qualitative case studies</b>	<b>455</b>
<b>A theory of adjustment to pediatric multiple sclerosis</b>	<b>455</b>
<b>A Time to Decide: Patient Perspectives on Breast Cancer Treatment Decision Making</b>	<b>456</b>
<b>A torturous journey: GLBT accounts of achieving mental health</b>	<b>456</b>
<b>Audio Field Diaries: Listening to Trauma-based Professionals Speaking in Real-time</b>	<b>457</b>
<b>Avoiding participant dissatisfaction: Reflections on research that explored motherhood and reproductive choices of HIV-positive women in Australia</b>	<b>457</b>
<b>A World without Wheat: The Journey Toward Acceptance Of A Diagnosis of Celiac Disease</b>	<b>458</b>
<b>Beyond recovery: Reframing the aftermath of spousal abuse</b>	<b>458</b>
<b>Body Image and Marital Status in Middle-aged Latter-day Saint (LDS) Women: A Comparative Case Study</b>	<b>459</b>
<b>Bringing Pilates Off the Mat: Rethinking women's 'healthy' bodies through functional movement</b>	<b>459</b>
<b>Building Partnerships in Community-Based Dementia Care: A Critical Constructivist Grounded Theory</b>	<b>460</b>
<b>Burn in blame culture: Parenting experiences of families of children with burns</b>	<b>460</b>
<b>Challenging cultural discourses and beliefs that perpetuate Domestic Violence in South Asian communities – a discourse analysis</b>	<b>461</b>
<b>Chronic joint pain, self-management and risks: a qualitative exploration of knee pain sufferers' understanding and management of risk factors</b>	<b>462</b>
<b>Considerations of Keyword Analysis as an Adjunct to Qualitative Interpretations of Gender Difference in Cancer Communication</b>	<b>462</b>

<b>Delta – a simulation game for the coordination of research, policy and practice</b>	<b>463</b>
<b>Development and Progression of Matrices in the Process of Grounded Theory Data Analysis</b>	<b>463</b>
<b>“Different Smokes” – Using film-making to generate reflexivity amongst tobacco control practitioners</b>	<b>464</b>
<b>Dilemmas and complexities in educating about co-sleeping in Western Australia</b>	<b>464</b>
<b>Discourses about future fertility perceptions of young adults with cancer and their professional carers</b>	<b>465</b>
<b>Eliciting values of decision makers and members of the public in healthcare priority setting</b>	<b>466</b>
<b>Employing Content Analysis to Understand the Outcome of Expressive Arts on the Oncology Experience</b>	<b>467</b>
<b>Empowering Homeless Youth: An Evaluation of a Participatory Action Research Based Program</b>	<b>467</b>
<b>Ethical considerations in qualitative research with children: The quest for safety, dignity, and voice in the research process</b>	<b>468</b>
<b>Experiencing the Impact of Child Sexual Abuse within Intimate Partner Relationships</b>	<b>468</b>
<b>Exploring Thai views of children’s play: An action research study in collaboration with the Foundation for Child Development in Thailand</b>	<b>469</b>
<b>Exploring the methodological and theoretical diversity of participatory visual research methods</b>	<b>469</b>
<b>Facets of parenting a young child with hypoplastic left heart syndrome: Using interpretive description to inform parent intervention</b>	<b>470</b>
<b>Facilitating and studying the development and implementation of buprenorphine opioid treatment within HIV primary care in NYC</b>	<b>471</b>
<b>Factors impacting on persons with T1DM ability to assimilate the Dose Adjustment for Normal Eating (DAFNE) principles into their daily lives and how these factors change over time</b>	<b>471</b>
<b>Faux Hegemony: Masculine Identities among College Men who Experience Depression</b>	<b>472</b>
<b>Feeling Respected with Fathers Witnessing the Births of their Children</b>	<b>473</b>
<b>Female Views of Access to Help for Problem Gambling</b>	<b>473</b>
<b>From Data to Action: Community-based Cancer Education for Native Americans in the Northeastern United States</b>	<b>474</b>
<b>Genealogy of Fetal Alcohol Spectrum Disorder (FASD) in Alberta</b>	<b>474</b>
<b>Getting Personal: Reflections from a White Graduate Student Researcher’s Exploration of an Indigenous Research Paradigm</b>	<b>475</b>
<b>Governmentality as a source of disempowerment of older patients and staff in acute care settings</b>	<b>475</b>

<b>Gypsies and Travellers accessing primary health care: interactions with health staff and requirements for 'culturally safe' services</b>	<b>476</b>
<b>H1N1 Knowledge Translation for Pregnant Women and Seniors</b>	<b>477</b>
<b>Health Disparities among Young Adult African-Americans with Disabilities</b>	<b>477</b>
<b>Health professionals' beliefs regarding responses to domestic violence against women in Vietnam: A pilot study</b>	<b>478</b>
<b>"He's more typically female because he's not afraid to cry": Connecting heterosexual gender relations and men's depression</b>	<b>478</b>
<b>Homeless Students – a Hidden Population</b>	<b>479</b>
<b>How Do Nursing Faculty Navigate Conflicts and Tensions Within the Disjuncture of Education and Practice?</b>	<b>480</b>
<b>HPV and HSV: Students Share Lessons for Health Professionals</b>	<b>480</b>
<b>Identifying the Health Care Supportive needs of Adolescents and Young Adult Cancer Patients and Survivors: Preliminary Findings from a Qualitative Study</b>	<b>481</b>
<b>Influence of gender and income in shaping parental negotiations about preventing children's injuries</b>	<b>482</b>
<b>Is Having a Period a Lifestyle Choice? Pharmaceutical Shaping of Menstruation</b>	<b>483</b>
<b>It's a Touchy Subject: Latino Adolescent Sexual Risk Behaviors in the School Context</b>	<b>483</b>
<b>"It's Not about Food": An Interdisciplinary Peer Facilitated Mechanism for Change in Female University Students with Eating Issues</b>	<b>484</b>
<b>"Labels are for pickle jars": Gay men talking about identity</b>	<b>484</b>
<b>Let Me Tell You Sister: Seeking Women's Health Care in Deployed Settings</b>	<b>485</b>
<b>Locating fatherhood: Exploring the ways that place and space influence father's consideration of risk, safety and supervision.</b>	<b>485</b>
<b>Making Sense of End Stage Heart Failure</b>	<b>486</b>
<b>Making sense of evolving health information: Women's experiences with medical uncertainty</b>	<b>487</b>
<b>Measures of Effectiveness Indicators Related to Health, Stress and Strategic Outcomes on USNS COMFORT: A Pilot Study</b>	<b>487</b>
<b>Modeling Critically &amp; Ethnographically Derived Transformative Knowledge Exchange</b>	<b>488</b>
<b>More than a Moment: The Role of Significant Others in Medical Decision Making</b>	<b>488</b>
<b>Needs of South African Adolescents Orphaned by AIDS: Evidence from Photography and Photo-elicitation</b>	<b>489</b>

<b>Nurses, pain scales, and the search for “legitimate” pain in the Emergency Department</b>	<b>489</b>
<b>Optimizing Health Literacy and Community Engagement in Relation to Active Living with Edmonton’s Newcomer Young People and their Families</b>	<b>490</b>
<b>Parenting under pressure: a grounded theory of parenting young children with complex congenital heart disease</b>	<b>490</b>
<b>Patients’ Transition - What is it like in the Intensive Care Unit?</b>	<b>491</b>
<b>Pediatric Thoracic Transplantation: A Transformative Process</b>	<b>492</b>
<b>Photoelicitation interviews and research with children: Practical considerations from the field</b>	<b>493</b>
<b>Physical Fitness and Developmental Disability: A Grounded Research Study</b>	<b>493</b>
<b>Policy makers’ perceptions of the outcomes of advanced practice</b>	<b>494</b>
<b>Postpartum Anxiety in First-Time Mothers</b>	<b>494</b>
<b>Practical Considerations and Patterns of Collaboration in the Marriage Relationship Among Persons with Disabilities</b>	<b>495</b>
<b>Producing Better Nurses: Using qualitative methods to incorporate students’ perceived success in simulation</b>	<b>495</b>
<b>Professionals’ Experiences of the Relations between Personal History and Professional Role – Qualitative Health Research 2011 Conference Submission</b>	<b>496</b>
<b>Qualitative research in India: Data generation challenges</b>	<b>497</b>
<b>Reflections of the insider organisational researcher</b>	<b>497</b>
<b>Reflections on the Utility and Versatility of Case Study in the Health Sciences</b>	<b>498</b>
<b>Representing Trauma: Challenges and Alternatives</b>	<b>498</b>
<b>Reproductive Tourism: Narratives of transnational surrogacy</b>	<b>499</b>
<b>Research-based theatre as a catalyst for transformation</b>	<b>499</b>
<b>Research on Research: A Parallel Qualitative Study</b>	<b>500</b>
<b>Research with QLGBT Migrants: Respecting the meaningful, material and contested in queer lives</b>	<b>500</b>
<b>Scottish prescribing governance and normalisation process theory</b>	<b>501</b>
<b>Sense making and interaction: change and resistance in frontline health practices</b>	<b>501</b>
<b>Sharing the Reins: PAR with deaf young people</b>	<b>502</b>
<b>Situated social identities: How Tlicho high school graduates storied lived experiences of resilience</b>	<b>502</b>

<b>Smile for the camera: Digital stories as a transformative method for prevention</b>	<b>503</b>
<b>Street involved youth: Examining genuine partnership with street youth in qualitative research</b>	<b>503</b>
<b>Succeeding in Level 1 of a BScN Program: A Grounded Theory Inquiry</b>	<b>504</b>
<b>Symbolism of the Heart as a Transplanted Organ: You realize you have someone else's heart and it's kind of weird"</b>	<b>505</b>
<b>Synthesis Review of Qualitative Studies in Autism</b>	<b>506</b>
<b>Talking Trials: Communication Dynamics around Clinical Trials from the Cancer Patient Perspective</b>	<b>506</b>
<b>Telephone interviews in qualitative health research</b>	<b>507</b>
<b>Tell Me about Your Childhood... Using Life Grids to Gather Information on Health-Related Behaviours and Experiences across the Life Course</b>	<b>508</b>
<b>Texting Teens in Transition: Considering the use of social networking technology in research</b>	<b>508</b>
<b>The Discourses of Patient Care in Learning to Practice Occupational Therapy</b>	<b>509</b>
<b>The Ethical Word. Discourses in Clinical Supervision in Nursing Education. Implications for Moral Education</b>	<b>509</b>
<b>The experience of health care professionals who are assisting women with postpartum depression in Brazilian context</b>	<b>510</b>
<b>The Experience of Women who gave Birth in a Brazilian Birth Center</b>	<b>511</b>
<b>The Identity Conundrum: 'Naming' Research Participant Communities</b>	<b>511</b>
<b>The influence of studying Michel Foucault's notions of askesis and parrhesia on the development of an experimental fiber artist</b>	<b>512</b>
<b>The lived experience of women on long-term endocrine based oral treatment for breast cancer</b>	<b>512</b>
<b>The meaning of authentic participation for families of children with complex care needs</b>	<b>513</b>
<b>The Nature of Relationships between Care Aides and Residents in Long Term Care Facilities</b>	<b>513</b>
<b>The Pathway to Making Change: How Parents Promote Health for their Overweight or Obese Child</b>	<b>514</b>
<b>The Role of Childhood Cancer Camps and Survivorship</b>	<b>515</b>
<b>The role of secondary data analysis in programs of qualitative research</b>	<b>515</b>
<b>The Role of the Clinical Skills Laboratory in Preparing Students for the Real World of Practice: A Qualitative Multiple Case Study</b>	<b>516</b>
<b>The Use of Photovoice in Understanding Risk for Older Adults</b>	<b>516</b>

<b>“They’re her boobs, it’s up to her, it’s not up to me”: Gendered dimensions of infant feeding decisions</b>	<b>517</b>
<b>Through the lens of experts: Tackling stumbling blocks of access to health care services in GTA</b>	<b>517</b>
<b>Toward a dialectical hermeneutics of cancer narratives</b>	<b>518</b>
<b>Treatment Burden and Chronic Heart Failure: Why We Need More Person Centred Care</b>	<b>518</b>
<b>Understanding stigma and discrimination as social processes: Analyzing narratives of suffering and agency from people living with HIV/AIDS in Delhi, India</b>	<b>519</b>
<b>Understanding the construction and consequences of ‘accepting’ persistent pain in older age</b>	<b>520</b>
<b>Using life history to explore the experience of living with a rare chronic illness, lymphangiomyomatosis (LAM)</b>	<b>520</b>
<b>Using Mixed Methods to Evaluate Multi-Cultural Survey Questionnaires</b>	<b>521</b>
<b>Using photo-elicitation methods to understand fathers’ attitudes towards injury and risk</b>	<b>521</b>
<b>Using Walk-Along Interviews to Examine Perceptions of Landscapes for Play</b>	<b>522</b>
<b>Utilizing hermeneutic phenomenology in a secondary analysis to understand the lived experiences of patients with chronic obstructive pulmonary disease</b>	<b>522</b>
<b>Views of nurse and union managers about staff retention in South Africa</b>	<b>523</b>
<b>Wait, Won't!, Want: A Qualitative Study of Barriers to Health Care as Perceived by Medically and Socially Disenfranchised Communities</b>	<b>524</b>
<b>“We Are All in the Same Boat:” Nurses’ Experiences of Working in a Shared War Reality</b>	<b>524</b>
<b>What Am I Supposed to do Now?: Patient Perceptions of Communication Needs and Preferences Associated with the End of Initial Cancer Treatment</b>	<b>525</b>
<b>What influences prescribing behaviour in general practice? An ethnographic exploration</b>	<b>525</b>
<b>What is shared in a social representation?</b>	<b>526</b>
<b>When is a focus group not a focus group? Use of online technology within qualitative research</b>	<b>527</b>
<b>Where is home? Using theatre to facilitate the empowerment of immigrant youth to uncover challenges and opportunities that influence wellness</b>	<b>527</b>
<b>White Man’s Sickness: Understanding Heart Problems and Healing Expectations in Aboriginal Women</b>	<b>528</b>
<b>Who are qualified for surrogacy</b>	<b>528</b>
<b>Why Men 50 Years and Older Do Not Get Screened For Colorectal Cancer?</b>	<b>529</b>
<b>Youth involvement in health care decisions in the context of chronic illness</b>	<b>529</b>

**Ambulance staff's experiences of delivering patient care whilst wearing a chemical, biological, radiological or nuclear (CBRN) suit: An exploratory study**

Julia Williams

*University of Hertfordshire*

Nicholas Castle

*Frimley Park Hospital & Durban University of Technology South Africa*

James Bowen

*University of Hertfordshire*

Working in an emergency situation which has been identified as a chemical, biological, radiological or nuclear (CBRN) incident poses significant challenges for frontline ambulance service staff. This presentation will discuss findings of the qualitative component of a mixed method study which assessed participants performing a range of clinical skills on a manikin whilst wearing level-C CBRN suits. The level-C suit is a fully encapsulating suit with integrated hood and mask, gloves, and boots with air entering only through filtered air vents designed to protect the wearer against contaminants in a CBRN event.

The aim of this phase of the study was to explore ambulance staff's experiences of delivering care whilst in a CBRN suit and the emotional experience of working under these conditions.

Reflexive interviews were undertaken with a purposive sample of practitioners who had participated in the evaluation of their clinical skills in simulated conditions. Data were subject to rigorous processes of interpretative thematic analysis that facilitated identification of recurrent patterns and themes.

Findings highlight key challenges of working in CBRN suits including the impact on practitioners' performance of clinical skills which varied according to the complexity of the skill. It appeared that wearing CBRN suits created a feeling of alienation from colleagues and served as a barrier to addressing the emotional needs of patients. Experiences of disassociation from reality and disengagement from the clinical scenario were frequently described. Reports of feeling indestructible provided a false sense of security which could lead to increased risktaking in potentially dangerous situations.

**A meta-ethnography of qualitative research on organizational culture in family practice teams**

Suzanne Grant

*University of Dundee*

The impact of organizational culture on clinical performance is of growing interest to both researchers and policy makers, with healthcare policy increasingly invoking notions of 'cultural change' as a means of achieving new forms of professional working and performance improvement. As reportedly small-scale 'personality-driven enterprises' (Chesluk & Holmboe 2010), family practice organizational responses to recent managerial reforms are potentially highly varied. Organizational culture, and how it mediates healthcare policy, is therefore central to understanding how clinical performance within family practice teams can be improved. This study comprised a systematic search and meta-ethnography of international qualitative research to



understand the key characteristics of organizational culture in family practice teams in relation to wider quality improvement initiatives.

Following a systematic search and critical appraisal, 16 papers were identified as fulfilling the pre-defined inclusion and quality criteria. Key themes and concepts were extracted and synthesized using the meta-ethnographic approach described by Noblit & Hare (1988) to identify similar and contradictory findings across the studies. The papers were then 'reciprocally translated' (ibid.), with 28 'second order constructs' (ibid.) identified, centering on the themes of practice characteristics, teamwork, workload, professional identity, professional boundaries and communication. A 'line of argument' (ibid.) synthesis was subsequently conducted.

Instead of resulting in a wholesale transformation of professional values and behavior, family practice teams are engaged in varying levels of negotiation between their 'core' cultural values of professional autonomy and holism and newer managerial modes of governance, resulting in increasingly fragmented organizational forms and new professional and managerial subcultures.

### **Analysing group interaction in focus group research on alcohol use: Impact on data content and the importance for public health**

Mette Grønkjær

*Aalborg Hospital, Århus University Hospital*

Tine Curtis

*Implement Consulting Group*

Charlotte de Crespigny

*The University of Adelaide*

Charlotte Delmar

*Aalborg Hospital, Århus University Hospital*

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## **An Exploration of Lay epidemiology and cancer**

Sara Macdonald

*University of Glasgow*

Una Macleod

*Hull York Medical School*

**Introduction:** Disease prevention via behavioural change is challenging. There is widespread recognition that for behaviour to be better understood there is a need to understand the context in which it occurs. 'Lay' epidemiology illustrates the sophistication of belief formation, mechanisms for risk estimation and the motivation for behavioural choices.

If as much as 70% of cancers are preventable by behaviour modification alone, it seems timely then to consider 'lay' beliefs about cancer, and to explore whether lay epidemiology is useful in better understanding beliefs about cancer. This study aimed to explore 'lay epidemiology' in the realm of cancer.

**Method :** A series of 31 in-depth interviews were conducted in two communities in Glasgow, United Kingdom. The sample was designed to access an 'ordinary' view. Cancer sufferers were excluded from the study. The interviews and focused on participants' experience of cancer. Although the study did not adhere to a strict grounded theory approach, the analytic method of constant comparative analysis was followed.

**Findings:** Participants derived meaning and understanding from their experience of cancer. Borrowed narratives were used to evidence beliefs. There were typical cancer narratives, highlighting the importance of the cultural representation of illness. The complexity of lay epidemiology resonates but risk tended not to be accepted unconditionally. Candidacy for cancer was equivocal. Many 'anomalous cases' (those without obvious explanation) were proffered. Lifestyle factors alone could not explain cancer and ultimately the randomness of cancer was emphasised.

**Conclusion:** Lay epidemiology, and candidacy in particular, is less salient in beliefs about cancer.

## **A Participatory Approach to Online Education and Support Curriculum Development for Families of Children with a Heart Transplant**

Samantha Anthony

*McMaster University*

David Nicholas

*University of Calgary*

Lori West

*University of Alberta*

Simon Urschel

*Stollery Children's Hospital*

Bernadette Dodd

*Stollery Children's Hospital*

Ingrid Larsen

*Stollery Children's Hospital*

Luis Altamirano

*Stollery Children's Hospital*

Tammy Olthuisen

*Stollery Children's Hospital*  
Kristin Simard  
*Stollery Children's Hospital*  
Rochelle Duff  
*Stollery Children's Hospital*  
Gwen Alton  
*Stollery Children's Hospital*  
Jennifer Ellis  
*Stollery Children's Hospital*  
Nicole Devlin  
*Stollery Children's Hospital*

Pediatric heart transplantation (HTx) offers life-saving treatment for young patients with cardiac disease. This innovation extends life; however, it also introduces a complex sequelae that imposes formidable psychosocial challenges for children and their families. Accordingly, parents of children with a HTx must mediate the complex relationships and considerations associated with family life development, health uncertainty, demand for HTx care, and children/adolescents' growing independence. The provision of meaningful and effective education and social support is critical to families' navigation of the complex terrain associated with HTx. To address this need for effective education and support interventions for families, this project has comprised the development and evaluation of curriculum for online parent education and social support, using qualitative approaches.

Participatory methods consist of the involvement of key stakeholders including interdisciplinary HTx team members (cardiac medicine, surgery, nursing, social work, rehabilitation medicine, nutrition, education and research methodology) as well as families affected by pediatric HTx. Input from key informants has been integral to the development and refinement of the resulting curriculum and plan for its implementation. This participatory approach has involved a process akin to "member checking" and data refinement such that the emerging curriculum is increasingly reflective of stakeholder experiences, convictions and priorities. In so doing, an aim of this qualitative inquiry has been to authentically amplify families' and stakeholders' voices. Study findings, implications and recommendations will be discussed.

### **A Qualitative Longitudinal Approach to Exploring Service User Experiences of Lay-Led Health Improvement Interventions**

Shelina Visram  
*Northumbria University*  
Charlotte Clarke  
*Northumbria University*  
Martin White  
*Newcastle University*

Lay health advisors (LHAs) have been widely used to deliver primary care and health promotion programmes. Although there is some data to support their efficacy, reviews have consistently found insufficient evidence to assess which LHA strategies are likely to be most effective. Furthermore, there is a dearth of research exploring service user views and perceptions. This paper aims to contribute to evidence and theory in relation to lay-led models of working with health deprived communities. By adopting an interpretive, longitudinal approach informed by grounded theory, the intention was to provide insight into the users' experiences and the mechanisms underlying the intervention outcomes. In-depth interviews with service users (n=26)

were conducted at 0, 3, 6 and 12 months, and with LHAs and supervisors (n=18) at 0 and 12 months. The interviews were audio-recorded, transcribed verbatim and analysed using the constant comparative method. LHAs were found to employ a holistic, asset-based approach that takes into account the context of a person's life and their access to resources for health. This builds upon the salutogenic theory of health, and is in direct contrast to the paternalistic, deficit model traditionally found in public health medicine. This research is one of few qualitative studies investigating the role of LHAs in the UK. Furthermore, the use of a longitudinal approach is innovative and likely to produce results that have high policy relevance. It represents an important application of a user-focused perspective affording new insights which may also be applied to other complex health interventions.

### **Assisted reproductive technology within the public health sector in Brazil: qualitative case studies**

Maria Makuch

*Center for Reproductive Health Research (CEMICAMP)*

Karla Simonia de Padua

*CEMICAMP*

Maria Jose D. Osis

*CEMICAMP*

Luis Bahamondes

*University of Campinas*

In Brazil, access to infertility care, including assisted reproductive technology (ART) procedures is restricted. The objective was to assess the perspective of health professionals and patients with respect to access to ART within the public health network. Based on a quantitative study, following the criteria for purposeful sampling five centers located in different regions of the country were selected for qualitative case studies. Nineteen health professionals based at these centers and 48 patients (men and women) were interviewed. Data were analysed using thematic content analysis. All visited services had implemented ART using resources already available within the institution, and except in one center patients had to pay for the drugs used for the procedures and/or a fee to cover operative costs. For the patients these charges were incompatible with their financial possibilities and required planning and much effort. Health professionals recognized that payment was a limitation of access for low income patients; however, according to their perspective payment was the only possibility of maintaining these services for patients who otherwise would not have access to ART in the private sector. Patients and health professionals referred that waiting time for access to ART procedures varied between three months and six years. Health professionals did not have a clear idea of the difficulties patients encountered to schedule the first appointment. Patients felt very fortunate gaining access to these services. Results uncovered possibilities of organizing ART services within the public health sector and patient's difficulties and limited access to these services.

### **A theory of adjustment to pediatric multiple sclerosis**

Jennifer Thannhauser

*University of Lethbridge*

Imagine being diagnosed with a disease that is chronic and incurable, with unpredictable disability and discomfort over a normal life expectancy, that can have physical, emotional, cognitive, social, and financial effects that last a lifetime: Now imagine you are 16 years old

facing this future. This is the reality confronting adolescents with multiple sclerosis (MS). Although the incidence of MS in children and adolescents is rare in comparison to adults, it is becoming well documented. Thus it becomes critical to address the overall wellbeing of the children and adolescents affected by the disease. Unfortunately, research addressing the psychosocial experiences of those diagnosed with pediatric MS is very limited. Using Charmaz' constructivist grounded theory methodology, this study identified the process of adjustment experienced by adolescents with MS. Matched parent-adolescent pairs recruited from rural and urban settings across Western Canada participated in separate interviews and online blogs. The core of the theoretical model focuses on a cyclic grief process. Other important components in the theory include connection and disconnection with relationships and the role of resiliency in moving through grief. Results are discussed in the context of counselling interventions and inter-professional strategies to better facilitate adjustment to life with MS for children and adolescents with the disease.

### **A Time to Decide: Patient Perspectives on Breast Cancer Treatment Decision Making**

Suepattra May

*Palo Alto Medical Foundation Research Institute*

Katharine Rendle

*University of Michigan*

Nicole Ventre

*Palo Alto Medical Foundation Research Institute*

Dominick Frosch

*Palo Alto Medical Foundation Research Institute*

Allison Kurian

*Stanford University*

Information about breast cancer treatment, whether grounded in evidence based medicine or layperson accounts, is abundantly available in the print and electronic media. Advances in oncology care are rapidly changing the landscape of breast cancer treatment options; and at the same time patients are being encouraged to more actively participate in clinical decision making. Accordingly, patients are confronted with diverse images of their disease and within this context are forced to understand their diagnosis and make decisions amidst a bewildering array of information sources. This study describes the lived experiences of breast cancer patients, examining how they traverse the complex pathways of breast cancer diagnoses, treatment options, and decision making across their journeys. We conducted five focus groups among women diagnosed with breast cancer and receiving support services at a breast cancer resource organization in California (N=50). Each group centered on a different aspect of the decision making journey including being diagnosed, surgery and reconstruction, systemic therapy, radiation therapy and survivorship. Data were coded for key themes using ATLAS.ti Qualitative Data Analysis software. Participants describe their emotional, physical, and logistical journey from the day they learned of their diagnosis to their present state of survivorship, highlighting the way treatment decisions and subsequent implications shape illness experience. These narratives highlight the critical need to understanding how patients make treatment decisions and provide insights that can inform the provision of decision support.

### **A torturous journey: GLBT accounts of achieving mental health**

Jeffery Adams

*Massey University*

Pauline Dickinson  
*Massey University*  
Lanuola Asiasiga  
*Massey University*

A range of international research has clearly demonstrated that gay, lesbian, bisexual men and women, and trans people experience poorer mental health than other men and women. This presentation draws on the findings of a qualitative needs assessment undertaken in New Zealand that utilized 19 key informant interviews, an online survey completed by 124 GLBT people and an email survey of service providers to explore how GLBT sought to maintain their mental health, and to identify enablers and barriers to achieving good mental health. The key findings were that although many GLBT reported a range of personal strategies to achieve and maintain good mental health, there was a lack of publicly available mental health services for GLBT people and that mental health services were only readily available to those that lived in large urban areas and were able to pay for private mental health services. In addition to this the negative impacts on mental health that arose from stigma, homophobia, and poor social acceptance and connection were discussed as key factors explaining why some GLBT experience poorer mental health. A range of actions to address these issues will be provided.

### **Audio Field Diaries: Listening to Trauma-based Professionals Speaking in Real-time**

Patrice Keats  
*Simon Fraser University*

Audio recordings have been used as a research method to a very limited degree in mental health research. In this paper, I describe the use of audio field diaries in studying the cultural and organizational factors that influence or add to the already high stress levels of people who work in trauma-based professions. Audio field diaries offer an opportunity for participants to describe real-time experiences in any and all contexts they encounter during their work (e.g., experiences of preparation for trauma encounters, personal interactions/conversations in the workplace or work situation, managing or coping with the aftermath of trauma when at home). Although this method may be useful for exploring many different trauma-based occupational cultures, a specific example of how participants' use the audio field diaries and the types of data that is possible to collect is offered in this oral presentation. A study with Canadian journalists assigned to national or international trauma or disaster events is described. Discussion at the initial interview and brief written guidelines (for recoding and gaining permissions) were provided to assist participants in the creation of their audio field diary and use of the recording equipment. This report describes compliance to using the diary, the types of information that the diaries yielded as a research tool, and the reflections of participants in using the diaries.

### **Avoiding participant dissatisfaction: Reflections on research that explored motherhood and reproductive choices of HIV-positive women in Australia**

Karalyn McDonald  
*La Trobe University*

Participant dissatisfaction is rarely discussed by public health researchers; perhaps because it seldom comes to our attention. Dissatisfaction with the research process can occur at any point: from recruitment, through data collection, to participants' understandings and expectations of research outcomes and dissemination. As researchers we are very mindful of the importance of ethical codes of conduct and ethical review of research, but how often do we consider

participants' expectations beyond their act of participation?

In this presentation, I will consider this issue through discussion of an HIV-positive participant's experience of dissatisfaction with the research process identified several years after the event. I will discuss the methodology I employed for subsequent research, drawing on my research project that explored the reproductive decision-making of 34 women diagnosed with HIV during their child-bearing years. Using a narrative theory framework, I developed a method that enabled women to remain engaged with the research process if they so wished. This included research newsletters for a period of six years updating participants on both the research process and dissemination. Women also had access to their transcripts to validate their stories and the ability to edit their narrative. This ensured that the women were satisfied with any information being used and published in the public domain.

I will conclude this presentation by reflecting on this method and its broader applicability to qualitative health research.

### **A World without Wheat: The Journey Toward Acceptance Of A Diagnosis of Celiac Disease**

Sonya Quinlan-Jacob

*St. Stephen's Theology College*

A medical diagnosis can change the life of a person forever. The purpose of this narrative inquiry was to explore how women in their twenties had been given a celiac disease diagnosis and their journey toward acceptance of the diagnosis. Three women were individually interviewed over 40-65 minute period. The interviews were audio recorded. Following a close analysis of the interview transcripts, the related experiences of the women were placed in a story-map to better visualize their past and present experiences as well as their concerns about possible future complications and questions they had about the future. Six common themes were easily identified in all of the women's stories: 1) experiencing symptoms of undiagnosed celiac disease; 2) importance of communication in the diagnosis process; 3) concerns related to following a gluten-free diet; 4) emotional aspects of acceptance; 5) the role of supports in the journey to acceptance; and 6) changes in self-identity. The role of spirituality was considered as an aspect of the women's experience. This study helped to identify what made it possible for these women to journey toward acceptance of their celiac diagnosis.

### **Beyond recovery: Reframing the aftermath of spousal abuse**

Sophie Tamas

*Queen's University*

This paper draws on qualitative doctoral research which questions the recovery paradigm within which life after leaving spousal abuse is typically understood. While its active, hopeful tone emphasizes the resourcefulness and resilience of survivors, recovery may be read as a reductive label which obscures the complexity of women's experiences. It invokes a simplistic understanding of testimony which disregards the epistemic impact of trauma and presumes that stable modernist subjectivities remain both useful and viable. It relies too heavily on making sense within dichotomous analyses of power and blame, and its depoliticized emphasis on the emotional needs of survivors perpetuates the status quo.

The paper ends by suggesting alternatives, drawing on the terms used by survivors to describe their own experiences.

### **Body Image and Marital Status in Middle-aged Latter-day Saint (LDS) Women: A Comparative Case Study**

Janette Olsen

*Idaho State University*

Amy Bergerson

*University of Utah*

Multiple components influence and interact with the construct of body image and health related behaviors. Two of these components are marital status and religion, and it is important to understand how the lens of these two components impact body image. This study explored marital status and body image of middle-aged lifelong female members of The Church of Jesus Christ of Latter-day Saints (LDS), which specifically teaches sanctity of life and the importance of marriage and family. A comparative case study design was utilized with ten participants: 5 married, first marriage, with children; and 5 single, never married, no children. Participants were asked to personally describe experiences and observations through three semi-structured interviews and three journals. Between the second and third interviews participants answered journal questions verbally, using a micro-cassette recorder, or electronically. All recordings were transcribed and all documents were analyzed for themes. All participants had similar beliefs of marriage and motherhood and each group described unique challenges related to body image. The relationship between personal choice (consciously choosing personal physical acceptance) and being chosen (allowing others to influence personal physical acceptance) in and out of a marriage relationship was evident. However, marriage and grandchildren seemed to assist in the acceptance of the aging body. Body image can be a sensitive discussion topic and the audio journals were effective at eliciting lengthy and in-depth responses. As body dissatisfaction rises throughout the world it is important to recognize possible positive and negative influences of religion and marital status on body image.

### **Bringing Pilates Off the Mat: Rethinking women's 'healthy' bodies through functional movement**

Marianne Clark

*University of Alberta*

Girls' and women's engagement in physical activity has long been a target of health promotion efforts. However, many of these discourses focus on the utilitarian aspects of physical activity (i.e., it can lower risk of obesity and chronic disease). This approach means bodily movement for its own sake is rarely explored and the life of the body is largely overlooked. Mindful fitness pursuits such as Pilates may provide important insights into a more embodied approach to health and movement. Therefore, this ethnographic study explores the experiences of women who practice Pilates regularly at a small studio in Alberta. The author engaged in an advanced Pilates class for one year and conducted informal and formal interviews with eight women in the same class. Research questions included, 'How do women who practice Pilates cultivate relationships with their body through their practice?' and 'Does an activity such as Pilates hold potential to disrupt dominant notions of health and the feminine bodily ideal?'

Results revealed that Pilates practice enhanced bodily functionality and made everyday activities easier, an effect women referred to as being able to 'bring it off the mat'. Participants also noted that through the bodily practice of Pilates they were able to achieve a greater integration of mind-body awareness and expressed feeling strong both mentally and physically. None of the participants cited body shape size or disease prevention as a motivator or an effect of Pilates



participation. Instead they expressed how Pilates allowed them to think more broadly about health and fitness.

### **Building Partnerships in Community-Based Dementia Care: A Critical Constructivist Grounded Theory**

Catherine Ward-Griffin

*University of Western Ontario*

Carol McWilliam

*University of Western Ontario*

Marita Klosek

*University of Western Ontario*

J.B. Orange

*University of Western Ontario*

Carol Wong

*University of Western Ontario*

Ryan DeForge

*University of Western Ontario*

The purpose of this critical constructivist grounded theory is to explore relationships among older adults with early stage Alzheimer's Disease (AD), their familial and formal caregivers, in the delivery of community-based dementia services from one or more of six community agencies in the SW Ontario. Through collaborative activities with an Advisory Group and based on theoretical sampling, eight persons with AD and their familial/professional caregivers were invited to participate in multiple in-depth interviews over 16 months. Field note data were analyzed along with the interview transcripts according to the tenets of Charmaz's constructivist grounded theory. This presentation will share the preliminary findings of a substantive grounded theory that critically examines partnerships in community-based dementia care. Based on the study findings, the interrelated processes of navigating community dementia resources and partnering among the person with AD, family members and providers are shaped by both individual and organizational factors. Findings suggest that access to community-based services by persons with dementia requires both the ability to navigate and partner. In addition, the challenges and opportunities for refining system access and navigation approaches to enhance the quality of community-based dementia service delivery and care are identified. Study findings will contribute to evidenced-based knowledge about (un)successful navigation of community-based dementia resources and services, and ultimately, improving the quality of community-based dementia service delivery as experienced by persons with AD, their families and care providers. For this to occur, collaboration among people with dementia, their families, practitioners and policy makers is essential.

### **Burn in blame culture: Parenting experiences of families of children with burns**

Vinitha Ravindran

*University of Alberta*

Gwen Rempel

*University of Alberta*

Linda Ogilvie

*University of Alberta*

This study is informed by my clinical observations of burn injured children in South India who

survived their burns but returned to the tertiary centre with disfiguring scars, contractures and functional impairments. The assumption among health care providers was that the parents were to blame for not bringing their children for regular follow up visits. There is limited empirical evidence on the course of rehabilitation after hospitalization and the experiences of parenting children with burn injury in countries like India. Adopting constructivist grounded theory methodology, I explored parenting processes within 12 families with burn injured children from the perspectives of multiple family members. The burn trajectory involved the injury phase, wound phase and the scar phase. Blame evolved as the core category related to parenting burn injured children through all of the three phases. Parents experienced self blame, blame from family members and blame from health professionals. Within a context of being blamed for the burn injury and in some cases for not securing appropriate health care from the outset, parents focused on doing their best for their child. The parents' concerted efforts to care for their children irrespective of personal and environmental constraints was fuelled by their devotion to their children and their fear that in the future their burn injured children would blame them as parents for the life-altering consequences of a childhood burn. These findings emphasize the need to develop interventions that focus on parental support during all phases of the burn trajectory.

### **Challenging cultural discourses and beliefs that perpetuate Domestic Violence in South Asian communities – a discourse analysis**

Janki Shankar

*University of Calgary*

Sabrina Atwal

*Indo Canadian Women's Association*

Gita Das

*Indian-Canadian Women's Association*

Veena Khatri

*Edmonton City Council*

South Asians are one of the fastest growing immigrant communities in North America. Often assigned the status of a 'model minority' by mainstream American society, many members from these communities, especially women are forced to maintain silence about the abuse of power and privilege that occurs in many South Asian families. Domestic violence (DV) in the South Asian community is at least as prevalent as it is in the general population yet is massively underreported thus contributing to maintaining the model minority myth.

Several reasons have been cited for the silence of immigrant women about DV, such as, maintaining family honor, financial dependence on spouse, the loss of supportive social networks due to migration. However there are some cultural discourses and beliefs specific to South Asian communities that are commonly used by families to perpetuate practices that lead to DV, thus giving the impression that there is cultural sanction for DV.

The authors of this paper undertook a discourse analysis of two historical texts and discussions with experts in order to verify the origins of these cultural discourses and beliefs. This paper presents the results of this analysis and provides evidence that challenges the dominant cultural discourses and beliefs that are commonly used by south Asian immigrant families to silence women. The findings have important implications for health and well-being of South Asian women experiencing violence and for developing culturally sensitive interventions and supports relevant to the needs of these women.

Key words: Domestic Violence; South Asian Community; Cultural Discourses.

### **Chronic joint pain, self-management and risks: a qualitative exploration of knee pain sufferers' understanding and management of risk factors**

Andrew Morden

*Keele University*

Clare Jinks

*Keele University*

Bie Nio Ong

*Keele University*

Research and UK policy highlight a number of 'risk' factors related to conditions like knee pain. These include being obese or overweight and not taking regular exercise. Self-management is encouraged as a key strategy in clinical management and health education. Research paints an equivocal picture of people's existing knee pain self-management and knowledge of risk factors. The aim of this qualitative study was to explore people's existing knowledge of risk factors and self-management for knee pain.

22 people with knee pain participated in the study. Participants were recruited from an existing longitudinal joint pain survey. Baseline in-depth interviews, a diary study for the following 6 months, and follow up interviews were used. Analysis was undertaken using a Grounded Theory approach. This paper reports upon participants' self-discovered strategies for self-managing knee pain. Participants did not explicitly talk about 'risk factors'. They learned from corporeal experience which made them realise the benefits of motion and weight loss. Conjointly participants rationalised the impact of weight gain and the consequences of inactivity against their beliefs about bio-mechanics and physiology. The overlaps between lay knowledge, policy and bio-medical definitions of risk will be discussed. We propose that 'risk frameworks' are not utilised by people. Thus, it may be inappropriate for clinicians and public health educationalists to employ the language of 'risk' when communicating with patients or formulating public health campaigns. Rather it may be beneficial to start from lay people's existing knowledge base.

### **Considerations of Keyword Analysis as an Adjunct to Qualitative Interpretations of Gender Difference in Cancer Communication**

Sally Thorne

*University of British Columbia*

John Oliffe

*University of British Columbia*

Kim Taylor

*University of British Columbia*

As a qualitative analytic approach developed for health research by medical sociologist Clive Seale, keyword analysis involves the generation of content category term frequencies in large data bases using the automated indexing capacity of qualitative software. In his own work, Seale has demonstrated that new insights about phenomena can be generated by strategic and purposive keyword analysis under thoughtful conditions. Having conducted a series of large sample qualitative studies on patient perceptions of their communications with health care providers, we were intrigued about the potential of keyword analysis for fine-tuning our interpretation of apparent language similarities and differences with which men and women describe their helpful and unhelpful interactions with cancer care providers. In this presentation, using the findings from this analysis in contrast to that which could be ascertained inductively from more conventional qualitative analytic strategies, we examine the nature of the new information that

can be generated in this manner, while paying attention to the limits of interpretations made on the basis of this form of analysis, and critically reflecting on the potential of this approach for further applications in qualitative health research. The exemplar of gendered expressions related to helpful and unhelpful cancer care communication illustrates the inherent complexities of work in this field, the risks and benefits associated with using mathematical patterns for inductive analysis, and the intriguing potential to capitalize on software to render visible certain elements within the phenomena we study that might otherwise be obscured by the limits of our interpretive positioning.

### **Delta – a simulation game for the coordination of research, policy and practice**

Rik Wehrens

*Erasmus University*

A crucial challenge in public health relates to the coordination of scientific research, policy, and practice. Structural partnerships between researchers, policymakers and professionals are often presented as solutions for this challenge. In the Netherlands, a large funding organization financed nine structural partnerships: Academic Collaborative Centers for Public Health.

We empirically investigated the workings of these partnerships. We conducted two interview rounds with the coordinators of the ACCs and four case studies in which we analyzed the coordination and interaction processes between the actors, providing us with insights into the strategies that are used to bring researchers, professionals and policy makers together.

Our research also aims to create learning opportunities to foster change. We used the research findings to develop a simulation game (Delta), aimed to facilitate a collective learning process by making the participants become aware of each others' priorities and dilemmas. Its main purposes are threefold: 1) making visible which tensions and dilemmas arise within science-policy-practice partnerships; 2) showing the underlying motivations, expectations and incentives of the different groups; and 3) showing which creative solutions are possible.

The simulation game has been played with professionals, researchers and policymakers in the field of public health in April 2010 and is slightly adjusted on the basis of their feedback. Our presentation highlights the added value of Delta as a training tool as it realistically depicts the processes of coordination and legitimation in structural public health partnerships.

### **Development and Progression of Matrices in the Process of Grounded Theory Data Analysis**

Lana McLouth Kanacki

*Loma Linda University*

Patricia Roth

*University of San Diego*

Jane M. Georges

*University of San Diego*

Patti Herring

*Loma Linda University*

Novice researchers are drawn to qualitative research to address new phenomena arising from clinically based situations. Their question is: What to do with all that data?

In analyzing data in a grounded theory study the emergent theory is not immediately apparent to researchers nor should it be. Corbin and Strauss (2008) provided direction for this approach to theory development. Exemplars are derived from the data analysis of the qualitative research study entitled, *Shared Presence: Caring for a Dying Spouse*.

The core phenomenon "being there" emerges from the data. The identified themes are awareness of impending death, forming connections, and realizing sense of self. In these examples of the development and progression of matrices the evolution of the theory becomes more apparent.

There are challenges in putting abstract thoughts into matrices and further refining themes in the process of data analysis and evolution of matrices. These matrices may assist new qualitative researchers in analyzing their data, identifying themes, and establishing relationships to form an emergent theory.

### **“Different Smokes” – Using film-making to generate reflexivity amongst tobacco control practitioners**

Katherine Frohlich

*Université de Montréal*

Rebecca Haines-Saah

*University of British Columbia*

Blake Poland

*University of Toronto*

Michael Wright

*Catholic University of Applied Sciences Berlin*

This presentation addresses research-based film-making as a tool to generate reflexivity among practitioners working in tobacco control. Reflexivity or reflexive practice seeks to unpack power relations and the ways in which asymmetries of power pervade in society. Reflexivity invites us to think about what we are doing as a field and our relationship to those that we are trying to reach. This means questioning taken-for-granted assumptions embedded in our work and considering how tobacco control is experienced by different groups of smokers.

Our film *Different Smokes* was created as the outcome of a Canadian Institutes of Health Research project, new approaches to addressing social inequalities in tobacco use among youth. The script was based on transcripts of focus groups with youth that smoke and interviews with tobacco control practitioners in Montreal and Vancouver. It highlights the role of social inequalities in shaping tobacco use, and contrasts how practitioners think about smoking with how young people view smoking in the context of their lives.

We present the challenges and opportunities we faced in producing a film for this purpose. We also describe the process of collaborating with a team of tobacco control practitioners from across Canada to disseminate the film to their local communities of practice. Our findings to date suggest that film can be an engaging method for opening up conversations about how tobacco control practice needs to change in order to be more sensitive to the needs of marginalized youth smokers.

### **Dilemmas and complexities in educating about co-sleeping in Western Australia**

Jennifer Dodd

*Telethon Institute for Child Health Research*

The development of a co-sleeping policy in Western Australia has been initiated following a coronial inquest requesting information on the development and implementation of a state wide co-sleeping/bed-sharing policy for use across all state maternity hospitals.

The aim of this evaluation was to investigate the effectiveness of the implementation and dissemination processes of this directive for maternity and child health professionals and workers and for providing information and education to women about co-sleeping.

Methods included an analysis of the co-sleeping directive, other hospital based guidelines and information brochures and web-sites on co-sleeping designed for parents as well as those for health professionals. Questions were then developed for an audit which was sent to government maternity units, private hospital maternity units and child health nurses. Focus groups and in-depth interviews with a range of health professionals and women explored in depth some of the more sensitive and complex issues emerging from the initial findings of the audit about co-sleeping and revealed this topic as being highly contested.

The presentation of the findings will discuss the usefulness of qualitative methods in uncovering and allowing space for the discussion of the complexities and sensitivities that health professionals grapple with when providing education about co-sleeping to parents within health systems. They highlight the importance of building trust, relationship building and also providing health professionals with adequate professional development and knowledge about how to respond sensitively to the individual needs and lifestyles of women, particularly those who may be vulnerable or from culturally diverse groups.

### **Discourses about future fertility perceptions of young adults with cancer and their professional carers**

Rosaline Barbour

*The University of Dundee*

Maureen Porter

*University of Aberdeen*

Val Peddie

*University of Aberdeen*

Siladitya Bhattacharya

*University of Aberdeen*

It is argued that looking at reproduction through the lens of cancer provides some important new insights.

A purposive sample of patients, 18 women and 16 men; aged from 17-49 years, was recruited from oncology, haematology and urology clinics and professionals, including oncologists, haematologists, psychologists, nurses, radiologists and andrologists were also interviewed. The study highlighted important gaps in professional knowledge, and variation in readiness to discuss fertility, with cryo-preservation frequently being presented as 'experimental'. Whilst the issues involved are ethically complex, matters can be over-complicated by unnecessarily cumbersome procedures and ethical issues can, at times, be used in order to justify professional responses. Both patients and professionals had to deal with the tensions surrounding the conflicting trajectories of cancer treatment and lifecourse decisions.

In particular, the paper will critique the theoretical framework of biographical disruption, questioning whether this represents the sort of crisis commonly assumed in the literature. Rather than biographical disruption, to a previously-envisaged future, we may be witnessing a process of biographical inception or biographical acceleration, with individuals in new relationships or those who are currently single having to make decisions that impact on a potential imagined future. The focus, both of fertility specialists and researchers, on the couple as a unit will be interrogated. It is argued that both patients and professionals tend to adopt accounts of cancer that privilege urgency and also to reify the notions of choice and control over reproductive issues.

### **Eliciting values of decision makers and members of the public in healthcare priority setting**

Evelyn Cornelissen

*University of British Columbia - Okanagan*

Craig Mitton

*University of British Columbia*

Neale Smith

*University of British Columbia*

Stirling Bryan

*University of British Columbia*

Stuart Peacock

*British Columbia Cancer Agency*

Janet Joy

*Vancouver Coastal Health*

Our project purpose was to understand values as they are manifest in a hypothetical priority setting exercise for two groups: the public and healthcare decision-makers. This research will help determine whether healthcare decision-makers' resource allocation decisions are consistent with their values, and how their values compare to those expressed by the public.

We conducted separate focus groups, one with the public (n=8) and one with decision-makers (n=12), each consisting of: a hypothetical priority setting exercise; an education session on ethical and economic considerations in priority setting, and principles for effective deliberation; then a repeat of the exercise. Participants were later interviewed to debrief their experience. Interview and focus group questions aimed at: identifying participant values, determining if participants align their choices with their values, and understanding the influence of the exercise and education.

Both groups approached the exercise similarly. Participants individually assessed options and collectively discussed what process the group should use to set priorities, criteria to consider when prioritizing options, and what options to fund.

Both groups appeared to include client and health system impact among their values. However, how these criteria were manifest in the exercise differed. Criteria were more explicitly formulated by decision-makers. The public paid greater attention to alternatives, questioning the status quo. While the public did not get to a single ranked list, they leaned towards funding some similar options as the decision-makers.

This work represents a novel addition to the literature and should provide insight for healthcare decision-makers in using public input in decision-making.

## **Employing Content Analysis to Understand the Outcome of Expressive Arts on the Oncology Experience**

Erin Bantum

*University of Hawai'i Cancer Center*

John Kim

*Tripler Army Medical Center*

Janell Pulido

Maureen Kirchhoff

Pat Nishimoto

*Tripler Army Medical Center*

**Background:** Due to advances in treatment, there are over 11 million people who have survived cancer (National Cancer Institute, 2011). Finding ways to express and put meaning around the experience of cancer can be helpful (Stanton et al., 2002). As a way to help facilitate this process, an expressive arts intervention was conducted.

**Methods and Theoretical Approach:** As part of an expressive art workshop conducted at Tripler Army Medical Center participants (oncology patients and family members) were invited to join a study involving a face-to-face interview about their experience and a focus group (one with oncology patients and one with family members). The interviews and focus groups were transcribed. Participants who engaged in the interview, focus group, and provided a narrative about their artwork (n = 12) were included in the analyses. The Colaizzi method was used to identify themes. In addition, the Linguistic Inquiry and Word Count (LIWC) program was used to identify emotion.

**Findings:** Content analysis revealed four themes as being relevant: Qualities of the Art-Making Experience, Experiencing of the Art, Shared Journey, and Authentic Self. LIWC analyses revealed that, on average, 3.6% of the interviews consisted of positive emotion words, and less than 1% of the interviews consisted of negative emotion words.

**Implications:** Participants reported a number of beneficial aspects to participating in this expressive arts intervention. Using qualitative analyses to identify common themes for participants, along with quantitative methods to compare the use of emotion provided a rich framework for understanding of their experience.

## **Empowering Homeless Youth: An Evaluation of a Participatory Action Research Based Program**

Pushpanjali Dashora

*The Ohio State University*

Homeless youth face numerous challenges including substance abuse and mental and physical health problems. Homelessness is embedded in a social system. Regardless of this, interventions for homeless youth have focused on individual characteristics associated with homelessness. The current study proposes to develop and evaluate a participatory action research based program for homeless youth.

Fifteen youth (between the ages of 18-24 years) were recruited from the streets and homeless service agencies in the Columbus area. Questionnaires were administered and a life history interview was conducted with youth. Information from interviews was used to develop a video.



Three groups of two to four youth per group participated in approximately five sessions of video making. During the final video-making session, questionnaires were administered and a focus group interview was conducted with youth. The video was shown to five policy makers and a focus group interview was conducted afterwards. The purpose of showing the video to policy makers was to provide homeless youths' voices to policy makers.

The findings of this study suggest that a variety of factors in homeless youths' ecological environment influence the onset and maintenance of homelessness. Further, the study details the strategies youth utilize in order to persevere under adversity. Finally, this study found the significance of the video in influencing policy makers' perceptions about homelessness. This finding supports a bottom-up approach rather than a top-down approach to policy making.

### **Ethical considerations in qualitative research with children: The quest for safety, dignity, and voice in the research process**

Shanon Phelan

*The University of Western Ontario*

E. Anne Kinsella

*The University of Western Ontario*

Despite a growing body of research involving child participants, little has been written about the unique ethical considerations that arise when conducting research with this population (Mishna, Antle, & Regehr, 2004; Phelan & Kinsella, In Press).

The purpose of this paper is to examine ethical issues in the conduct of research with children, including both general considerations as well as particular issues that arise when using visual methods. The authors draw on a review of the literature and their own experiences using grounded theory and photoelicitation interview methods with children to consider ethical issues pertinent to research with children.

Ethical issues are examined pertaining to: obtaining informed consent and assent from children, maintenance of privacy and confidentiality, anticipating risks associated with disclosure through interviews and the use of visual methods, representation of the findings, and issues of power between children and adults in positions of authority (Barker & Weller, 2003; Phelan & Kinsella, In Press; Mishna et al., 2004; Wang & Redwood-Jones, 2001). Processes of reflexivity may assist researchers in wrestling with complex ethical issues (Davis, Watson, & Cunningham-Burley, 2000) and contribute to children's safety, dignity, and voice in the research process.

### **Experiencing the Impact of Child Sexual Abuse within Intimate Partner Relationships**

Angela Thorpe

*University of Saskatchewan*

Dr. Stephanie Martin

*University of Saskatchewan*

The purpose of this study was to illuminate the experienced impact of childhood sexual abuse (CSA) within the context of intimate relationships. Few studies have examined the lived experience of CSA within the context of a relationship from the perspective both partners. Further, previous research in the area of CSA has primarily focused on the trauma experienced by the survivor, thus excluding the impact of CSA on the couple relationship. Examining the impact of CSA on intimate relationships is important as those individuals in close relationship with the

survivor may also experience the impact of the long-term sequelae associated with CSA.

Interpretative phenomenological analysis (IPA) was used to explore the lived experiences of individuals who have experienced CSA and their partners. Data generated during two joint interviews with three participant couples were transcribed and analysed using an interpretative phenomenological analysis approach. An over-arching theme of hope and healing: past yet present, healed yet healing emerged from the data; this theme was impacted by the additional themes identified throughout the analysis process. The additional three themes were: living with the unknown, (barely) surviving, and commitment. Given the limited research on the impact of CSA on intimate partnerships and the focus of existing studies on the more negative aspects of the impact CSA has on relationships, the theme of hope and healing: past yet present, healed yet healing provides a valuable contribution to the literature. These themes are discussed along with implications for counselling practices and future research.

### **Exploring Thai views of children's play: An action research study in collaboration with the Foundation for Child Development in Thailand**

Son Truong

*University of Alberta*

Mike Mahon

*University of Lethbridge*

Children's play has emerged as a global discourse (Fleer, 2009). Studies from diverse theoretical traditions have examined the role of play in child development; however, the dominant discourse of play has largely privileged Western European-heritage cultural practices, and as a result, pedagogy that has been developed in the global North is often prescribed to the global South (Fleer, 2009; Penn, 2005). While there is increasing acceptance that play is universal (Frost, Wortham, & Reifel, 2008), it must also be recognized that there is still relatively little that is known about children's play in non-Western and developing contexts (Göncü, Jain, & Tuermer, 2007). Therefore, this action research study contributes to this growing body of literature by exploring Thai views of children's play.

The study was conducted with a Thai nongovernmental organization called the Foundation for Child Development, and was carried out at a play centre in an urban low-income congested community in Thailand. Data collection took place over two research trips totalling 18 months, and included participant observation, interviews, focus groups, and participatory photography. The study was guided by a cultural-ecological conceptual framework. The findings suggest that play is a culturally structured activity that may contribute to children's development and wellbeing; however, trends towards urbanization and modernization are rapidly changing the landscape of childhood for the participants in this study. Actions resulting from this study included increasing children's participation in the planning of their play space and a children's photo exhibition to raise awareness of the child's right to play.

### **Exploring the methodological and theoretical diversity of participatory visual research methods**

Margot Jackson

*University of Alberta*

Solina Richter

*University of Alberta*

Vera Caine

*University of Alberta*

Within qualitative research many forms of participatory visual methods exist and they continue to be significant yet underutilized resources. It is important for researchers to be able to understand the differences of the ontological and epistemological underpinnings of these visual methods as their frameworks and purpose can vary considerably. Research questions, research findings, and the overarching use of the research methodology, influence the degree of participation and collaboration and the methods researchers utilize in the field. As a result, knowledge of various visual research methodologies is crucial for the emerging researcher as well as those skilled in other forms of research.

This presentation will present an overview of five participatory research methodologies including: visual narrative inquiry, photovoice, visual ethnography, visual sociology, and documentary photography. Within each methodological approach we will further inquire into the similarities and differences in visual methods chosen. As well, we will highlight the practical, theoretical and ethical considerations for visual research to be undertaken. The ability to differentiate between the diverse participatory methods will enhance methodological commitment and thus the quality of the respective research undertaken.

### **Facets of parenting a young child with hypoplastic left heart syndrome: Using interpretive description to inform parent intervention**

Gwen Rempel

*University of Alberta*

Laura Rogers

*University of Alberta*

Vinitha Ravindran

*University of Alberta*

Joyce Magill-Evans

*University of Alberta*

Parents play a critical role in healthy family functioning and optimal child development. Evidence regarding effective interventions to support parents of children with congenital heart disease who require complex care and monitoring is limited. Interpretive description enables researchers to understand phenomena and directly inform clinical practice. Prior research led to a conceptualization of extraordinary parenting in parents of children with hypoplastic left heart syndrome (HLHS).

The purpose of the current study was to further understand parenting in order to guide health care providers in supporting parents. Participants were 25 parents and 28 grandparents of 15 young children who had undergone the Sano surgical approach for HLHS. Single interviews with each participant (n=53) were digitally recorded and transcribed. Numerous readings of each interview, analytic memoing based on coding, and comparing parent data with grandparent data constituted data analysis. A multi-faceted conceptualization of extraordinary parenting was described: (1) uncertain parenting, (2) expert parenting, (3) disconnected parenting, (4) survival parenting, and, (5) supported parenting. Our interpretive description purports a view of parenting in the lives of their children with HLHS that affirms parental resilience and directs health care practitioners to acknowledge parents as key allies and offer intervention to support the parents' vital care giving role.

This paper illustrates how each facet constitutes a critical component for educational and/or psychosocial intervention for parents of children with complex heart conditions that is informed by our study findings, our clinical practice, and the child health literature.

**Facilitating and studying the development and implementation of buprenorphine opioid treatment within HIV primary care in NYC**

Nancy Murphy

*City University of New York, Graduate Center*

This implementation research seeks to improve health outcomes for individuals with HIV/AIDS (and their families and communities) by enhancing the service delivery system for this population. To this end, the researcher, working with a team of interdisciplinary colleagues, is currently facilitating and studying the development and implementation of buprenorphine opioid treatment within two (primarily publicly funded) HIV primary care clinics in NYC.

This presentation will discuss the important contribution that the working principles of relationships, communication, participation, reflective consultation and inclusion that is focused on knowledge and power sharing can make to the field of implementation research. Using these principles in obtaining patient, staff and leadership support, assembling the team, training and education, as well as gaining access and utilizing both local and extra local informants, implementation research becomes more than just problem solving. Framing the research this way offers new opportunities for capacity building for the researcher, the individual clinician and the organization, while cultivating new patterns of practice and thinking which is expected to positively impact on the implementation process. The implications for theoretically driven, interdisciplinary, patient centered outcome practice research will be discussed.

**Factors impacting on persons with T1DM ability to assimilate the Dose Adjustment for Normal Eating (DAFNE) principles into their daily lives and how these factors change over time**

Dr. Dympna Casey

*National University of Ireland, Galway*

Kathy Murphy

*National University of Ireland, Galway*

Julia Lawton

Florence Findlay White

Sean Dineen

Structured education programmes, such as DAFNE, result in many positive outcomes for people with Type 1 diabetes including a decrease in HbA1c and reductions in hypoglycaemia. While there is evidence that some of these outcomes are maintained, we do not know at present what factors are most important over time.

This paper presents the finding from a longitudinal descriptive qualitative study which examined participants' ability to assimilate DAFNE over time into their daily lives. Interviews were undertaken with 40 participants who had attended DAFNE in one of 5 study sites at 6 weeks, 6 and 12 months. Confidentiality and anonymity was guaranteed and the study was approved by the university Research Ethics Committee. The interviews were transcribed verbatim, verified by participants and data were analysed within and across time. Four themes were identified; these were embedded knowledge, continued responsive support, enduring motivation and being

empowered. Support at the 6 month period was found to be crucial to continued motivation.

Understanding the factors that influence people's ability to assimilate DAFNE principles over time generates research data that can facilitate changes in the way health professionals give focused responsive support that will help people with diabetes become more empowered. Recognising that continued support matters, particularly around 6 months, is important as health professionals can influence good management by providing appropriate support and enhancing motivation.

### **Faux Hegemony: Masculine Identities among College Men who Experience Depression**

John Oliffe

*University of British Columbia*

Mary Kelly

*University of British Columbia*

John Ogrodniczuk

*University of British Columbia*

Paul Galdas

*University of Sheffield*

Christina Han

*University of British Columbia*

Vicky Bungay

*University of British Columbia*

Melanie Phillips

*University of British Columbia*

**Background:** Depression is a significant problem among college men, and college-life related stresses can trigger or exacerbate an existing depression. Yet, depression is especially hard to recognize in college men as many of their behaviors are synonymous with young men's masculine ideals.

**Methods:** Twenty-five Canadian-based college-men ranging in age from 19-28 years-old, who self-identified or were diagnosed with depression completed individual, semi structured interviews. The research question, what are the predominant masculine identities among college men who experience depression guided our analyses and inductively derived findings.

**Theoretical Approach:** Incorporating a social constructionist masculinities framework, we also interrogated the fit of our results with findings drawn from survey studies using the gender role conflict scale and the conformity to masculine norms index.

**Findings:** Three masculine identities were revealed: 1) the angry man: where anger manifested as a safe, masculine way to communicate pain and dissipate depression-induced frustrations and irritability; 2) the solitary man: men's self-imposed isolation was used to conceal depression and maintain emotional control; and, 3) the risk-taker: men embodied negative health practices to self-manage depression. Each of these identities aligned with idealized masculine performances.

**Implications:** Faux hegemony while often passing as idealized masculinity can be especially detrimental to men who experience depression and those around them. The findings remind us of the challenges for identifying depression in college men amid re-asserting, that despite assertions about strength-based aspects of masculinity and men's health there is great potential for downstream outcomes of self-harm, violence and suicide to emerge from undiagnosed

depression.

### **Feeling Respected with Fathers Witnessing the Births of their Children**

Geneva Oaks  
*California Baptist University*

Feeling respected is a universal experience important to health and quality of life. Knowledge is limited regarding the human experience of feeling respected (Parse, 2006). The phenomenon was considered with fathers as they bore witness to the births of their children. Standards for care of childbearing families espouse family centeredness (Davidson, London, & Ladewig, 2008). Society has expectations for fathers to attend birth (White, 2007; Wockel, Schafer, Beggel, & Abou-Dakn, 2007). While engaging with birth, fathers are integral to positive maternal and infant outcomes (Borjessen, Paperin, & Lindell, 2004; Bronte-Tinkew, Carrano, Horowitz, & Kinukawa, 2008; Wanless, Rosenkoetter, & McClelland, 2008). Birth involvement of fathers enhances parenting (Garfield & Chung, 2006) and improves health for children (Sloand & Gebrian, 2006). Fathers report dissatisfying labor support experiences and occasions of disregard (de Montigy, & Lacharite, 2004; Kao, & Long, 2004; Salonen, Kaunonen, Astedt- Kurki, Jarvenpaa, & Tarka, 2008; Sauls, 2004; Waldenstrom, 1999).

The Parse research method, connecting with the ontology of humanbecoming was used to answer the research question: What is the structure of the lived experience of feeling respected? The purposes of this research study were to discover the structure of the experience of feeling respected, to contribute to nursing knowledge, and to expand the knowledge of feeling respected while illuminating health and quality of life for childbearing families. Participants were 10 fathers. The humanbecoming school of thought provided the theoretical perspective underpinning this study (Parse, 1981, 1998, 2007).

Keywords: humanbecoming; family; Parse; respect; birth; quality; labor support

### **Female Views of Access to Help for Problem Gambling**

Gaylene Sorochuk  
*SIAST, Kelsey Campus*

As opportunities to gamble have increased, the prevalence of problem gambling is increasing. The negative impact on these individuals, their families, and society at large is substantial. Societal costs include (but are not limited to) serious financial costs, loss of employment, legal court costs, criminal justice costs, health care costs, social services cost, and acts of crime. Due to the negative impact gambling has and the increase in prevalence of gambling there will be an increase in problem gamblers who want to access health care services. Only 4% to 7% of problem gamblers seek treatment, women are underrepresented in treatment, compliance with treatment is poor, and drop-out rates are high.

Research knowledge on problem gamblers, particularly females and their access to services for a gambling problem is limited. This qualitative study, utilizing an exploratory descriptive design, elicited the needs and issues of women accessing help for problem gambling.

Utilizing a focused interview guide, the causes of discontinuity and how these participants felt continuity in care could be improved were explored. The findings revealed women experienced several delaying factors/barriers in seeking treatment, specific motivating factors led women to

access treatment, perceptions of treatment services varied, and women accessed various services to overcome their gambling problem and its effects. The session will end with time for questions and feedback from the audience and stimulate discussion about how these findings may increase access to services, increase retention in all forms of treatment, and as well, enrich the health planning process.

### **From Data to Action: Community-based Cancer Education for Native Americans in the Northeastern United States**

Mary Canales

*University of Wisconsin-Eau Claire*

Diane Weiner

*Boston University*

In the United States, Native Americans in Connecticut and Rhode Island have limited access to culturally relevant cancer education programming and resources. In an effort to meet the cancer education needs of tribal groups, our multidisciplinary project team employs a community-based participatory model for mentoring and training community members as educators and advocates; for building local capacity; and creating a foundation for program sustainability.

This presentation will highlight our methodologies and results from five inter-related cancer education and survivorship projects (2006-2011). Qualitative data, collected through individual and group interviews, provided the framework for the creation of 5 cancer education modules. Through the incorporation of local qualitative data, these modules are culturally relevant and respectful of Natives from the region. Through qualitative analysis, we also identified the importance of intergenerational learning approaches for delivering cancer prevention, early detection, treatment, and survivorship messages. Our programs center on education strategies that balance clinical data and formal cancer resources with local experiential knowledge and informal resources.

Guided by the Northeastern Tribal Cancer Advisory Board, we have conducted 23 Wellness and Cancer Prevention Education Circles, 9 health information booths, and 5 community educator trainings since 2007. These activities are complemented by the development of a Native cancer survivors' archive and the creation and dissemination of Native-created breast cancer awareness artwork and education messages. These community-based projects are a main source of cancer screening, prevention, and survivorship education in two Northeastern U.S. states and serve as models for other cancer education programs that target underserved communities.

### **Genealogy of Fetal Alcohol Spectrum Disorder (FASD) in Alberta**

Irene Shankar

*Mount Royal University*

All understandings of health and illness are shaped by the social and political context from which these understandings emerge (Foucault 1978). In this paper, I will discuss the importance of examining the sociopolitical context in which diseases and health disorders develop and become accepted as a public health concern using Fetal Alcohol Spectrum Disorder (FASD) as a case study. This paper traces the genealogy of FASD in Alberta and highlights the implications of this history on the current FASD understanding and representations.

The data for this qualitative study were collected through 23 semi-structured interviews,

document analysis, and archival research and were analyzed using discourse analysis. The findings reveal that in an attempt to secure funding and governmental support for FASD programs early advocates strategically used images of “hurt children.” Current public FASD campaigns continue to rely upon the discourse of “hurt children” manifested through images of unborn child being “at risk” for FASD and the mother being “responsible” for creating this risk. Through this focus, the complexity of addiction and the structural constraints under which women consume alcohol (such as poverty, mental health issues, access to and availability of treatment facilities, marginalization, and racism) are erased from public FASD discourse. This history of FASD demonstrates the crucial impact of emergent discourses of health disorders, such as FASD, and points to the necessity of situating dominant understandings of health disorders within their historical, and contemporary, sociopolitical contexts.

### **Getting Personal: Reflections from a White Graduate Student Researcher’s Exploration of an Indigenous Research Paradigm**

Andrea Schneider

*University of New Brunswick*

Indigenous people are some of the most researched people in the world, however their communities have not benefited from the majority of past research which has usually been initiated and carried out by non-Indigenous personnel. In recent years, Indigenous scholars have organized to reframe the research endeavor, infusing it with Indigenous beliefs, knowledge, cultural values and customs in order to authentically address the needs of Indigenous communities. This has culminated in the articulation of an Indigenous Research Paradigm (Wilson, 2008).

The purpose of this presentation is to relate how I, a non-Indigenous, White female graduate student researcher, have come to understand and utilize this Indigenous Research Paradigm in order to conduct respectful, responsible and collaborative research with First Nations students. Specifically, this presentation will provide (a) a detailed description of the Indigenous Research Paradigm, including its ontological, epistemological, axiological and methodological components, (b) a reflexive account of my own positioning and transformations in relation to my research, the paradigm, and within the academy, and (c) a discussion regarding the importance of the paradigm in a variety of human and social research settings involving Indigenous people. By illuminating some of the taken-for-granted understandings of the research process and by focusing on collaborative research designs, this presentation also has general methodological implications for qualitative researchers striving to enhance the cultural appropriateness of their work, particularly those working with Indigenous communities and people.

### **Governmentality as a source of disempowerment of older patients and staff in acute care settings**

Lynne Slater

*University of Newcastle*

Discourse analysis and Foucauldian concepts were used to explore the construct of care for older people in the acute care setting. Negative attitudes were acknowledged by health care staff including ageism and poor discursive attitudes. Worldwide there is an ageing population with an associated ageing health care staff that will impact the workforce, patient outcomes and hospital budgets. The acute care system is now controlled by acuity, funding and political demands that don’t always recognise the specific demands of the older person.



Using discourse analysis revealed discourses of rationalisation. That is, reasons were given by both health care staff and patients for negative attitudes being responses to the current construct of acute care. Patients and health care staff felt disempowered, recognising the power of bureaucracy but unable to exercise their own power to address issues leading to negative attitudes. Foucault's concepts of governmentality provide understanding of how staff counters their attitudes towards older people in this context. Governmentality has a tripartite focus on how governing bodies can still exercise power over the public, notwithstanding claims of autonomy and person-centred care inherent in modern health care.

Although Foucault feels that knowledge can impact power, this controlled environment is a pyramid where power is exercised by knowledge of economics and budgets – not care of the patient. Technologies of self and the docile body impact acceptance of exercised power by the health care system. Foucault's framework exposes the influences that governing processes and systems have on staff attitudes and the patients themselves.

### **Gypsies and Travellers accessing primary health care: interactions with health staff and requirements for 'culturally safe' services**

Patrice Van Cleemput

*University of Sheffield*

Jenny Owen

*University of Sheffield*

Glenys Parry

*University of Sheffield*

Gypsies and Travellers in the UK are socially excluded, vulnerable populations who experience significant health inequalities. An earlier study provided greater understanding of the associations between their health status and beliefs, attitudes and experiences of health care.

In this study, I used a participatory action research approach to understand communication processes between Gypsies and Travellers and primary health care staff, and to explore how perceived barriers to accessing health care might be overcome.

Guided by principles of hermeneutic phenomenology, I conducted separate focus groups for Gypsies and Travellers and for health staff in primary healthcare settings, to elucidate the nature of communication barriers and enable sharing of their ideas as partners in the research process. Narratives were used as an additional inquiry method in the focus group discussions, using a story template as a discussion tool.

Findings revealed how Gypsy and Traveller experiences of discrimination and racism contribute to a sense of devalued identity, characterised by feelings of shame and humiliation. Similarly, health staff reactions to Gypsy and Traveller patients are contextual, shaped by the broad social climate, but also by their role and status, organisational structures and policies, and team ethos. By focusing on processes of co-constructed communication, specific patterns of tension and mistrust were identified.

These findings have implications for effective service delivery to excluded minority groups of patients, for example by addressing the limitations of current training methods for promoting cultural competence among health care staff.

## **H1N1 Knowledge Translation for Pregnant Women and Seniors**

Cindy Jardine

*University of Alberta*

Leah Lechelt

*University of Alberta*

Irene Wenger

*University of Alberta*

Tania Bubela

*University of Alberta*

Lisa Given

*Charles Stuart University*

The 2009-10 H1N1 outbreak and subsequent vaccination program presented many challenges for public health agencies. Information availability, knowledge translation and communication are known to be critical strategies for potentially allaying public fears and promoting informed decisions on appropriate health protection behaviours. But did these factors achieve their intended results, especially with vulnerable populations?

Between Oct. 29, 2010 and Mar. 17, 2011, 17 focus group sessions were held across Alberta to ascertain the experiences of two vulnerable populations: seniors (65 years and older), and women who were pregnant or breastfeeding during the outbreak. Participants were asked about their knowledge of H1N1, their information sources, feelings of risk, vaccination information and decisions, and personal experiences. Although most people were initially only casually interested in the possibility of a flu pandemic, concern increased with reports of serious illness and deaths of younger Canadians. Traditional media coverage was the dominant source of information for both groups, with everyone commenting on the degree of “media hype”. Although most pregnant women also used the Internet (including email and social media), this source was used by very few seniors. Family and friends (particularly those working in health care fields) were cited often as trusted sources of information. Most seniors were vaccinated, treating this decision as routine. However, pregnant women had more difficulty reaching the “right” decision, with concerns about vaccine safety. In general, the results indicated that H1N1 knowledge translation was not completely effective for these populations, with much confusion about vulnerability, vaccine availability and vaccine safety.

## **Health Disparities among Young Adult African-Americans with Disabilities**

Tiffany Ricks

*The University of Texas at Austin, School of Nursing*

Of the 54 million people living with disabilities in the United States, approximately 15.3 million are between the ages of 18 and 44 (US Census Bureau, 2008). While existing literature reveals valuable insight into the social, personal, and contextual factors surrounding the disablement (Verbrugge & Jette, 1994) experience among elderly persons, little is known about the disablement experience of young adults, minority youth in particular.

The purpose of this qualitative descriptive study was to examine disablement as experienced by young adult African-American men and women. The data was collected using one interview with each participant. The sample consisted of 10 African-American men and women between the ages of 22 and 39 with mobility impairments. Content analysis was used to identify themes related to the disablement experience.

Two primary themes were identified: Cumulative Losses and Innate Desires. The results of this study suggest that despite significant losses of autonomy, identity, financial resources, and intimacy, innate human desires remain intact. Among this group, basic desires for independence, shared intimacy, and psychological and physical health were not diminished by physical limitations and may serve as the impetus for health within illness (Lindsey, 1996) to become possible and even probable for young persons with disabilities.

This study provides health care providers with a greater understanding of the disablement experience as well as evidence of the need for further exploration of health promotion and protection in the context of disability for African-American young adults.

### **Health professionals' beliefs regarding responses to domestic violence against women in Vietnam: A pilot study**

Huong Thi Thanh Nguyen

*Hanoi Medical University*

Debra Anderson

*Queensland University of Technology*

Michael Dunne

*Queensland University of Technology*

Huong Thanh Nguyen

*Hanoi School of Public Health*

Domestic violence against women is a global health issue which recently has become an important concern in Vietnam, especially in rural areas. As stated by the World Health Organization, health professionals should play an important role in identifying, providing support and referral for the victims including provision of specialist services. Unfortunately, the majority of health professionals in Vietnam have limited experience in this field.

This qualitative study was carried out in Vietnam with the purpose of eliciting underlying beliefs that influence intentions to respond to the victim of DV among nurses and doctors.

Nineteen nurses or doctors working in emergency or consulting units of 2 district hospitals participated in this study. They were interviewed by using a structure interview guideline suggested in the Theory of Planned Behaviour. Content analysis was adopted. Three main themes were then abstracted including behavioural beliefs, normative beliefs and control beliefs.

This study makes contributions to the body of knowledge of health professional's response to domestic violence globally, and more significant for the Vietnam literature where this type of topic is the first time conducted. Further studies on the extent that underlying beliefs influence factors determining the intentions to respond of nurses and doctors are recommended.

### **“He’s more typically female because he’s not afraid to cry”: Connecting heterosexual gender relations and men’s depression**

John Oliffe

*University of British Columbia*

Joan Bottorff

*University of British Columbia*

Mary Kelly

*University of British Columbia*

Joy Johnson

*University of British Columbia*

Sabrina Wong

*University of British Columbia*

**Background:** Men's reluctant help-seeking behaviour and fragmented pathways to mental health care result in much of the management of men's depression taking place at home. For heterosexual men, women partners are often their primary health advisors, and effective couple and self-management strategies are central to overcoming the adverse effects of depression on men and their families.

**Methods:** Twenty-six heterosexual couples in which the men were formally diagnosed or self-identified as depressed participated in this interpretive descriptive study. Couple-dyad summaries were completed based on individual interviews and analyzed using a gender relations framework.

**Theoretical Approach:** Drawing on Connell's complicit, subordinate, marginalized, and protest masculinities framework while integrating Howson's emphasized, ambivalent, and protest femininities schema we categorized couples' gender relations in the context of the male partner experiencing depression.

**Findings:** Three patterns were identified: 1) Trading places: couples embodied some atypical masculine and feminine roles to compensate for the men's depression-induced losses; 2) business as usual: couple co-constructed men's alignment with masculine workman ideals and women's support of their partner as a means to counter and conceal men's depression induced-deficits; and 3) edgy tensions: a mismatch of gender expectations fuelled resentment and dysfunction that threatened the viability of some relationships.

**Implications:** Overall, the limits of women's resilience and care-giving were evident, yet men's management of their depression was directly influenced by their partner. Opportunities for couples to assess their relationship dynamics within a broad range of gender relations might support couples' connectedness and life quality amid the challenges that accompany men's depression.

### **Homeless Students – a Hidden Population**

Solina Richter

*University of Alberta*

Kathy Kovacs Burns

*University of Alberta*

Yuping Mao

*University of Alberta*

Gordon Gow

*University of Alberta*

Shirley Mogale

*University of Alberta*

Lyla Goin

*University of Alberta*

Moira Calder

*University of Alberta*

Marco Adria

*University of Alberta*

The homeless population in Edmonton increased approximately threefold in 2008 since the first count in 1999. The majority of homeless people are between the ages of 31 and 54 (63%), and 19% between 17 and 30 years of age. It is a subgroup of this latter group that was of interest in this project. Little is known about homelessness in post secondary student populations.

The purpose of the study was to describe how the university community perceives and manages student homelessness on or off campus. A sequential mixed method design was implemented to gather factual and narrative experiences from members of the university community. We conducted an online survey of a random sampled group of students. Individual interviews were conducted with a few key persons at the university and students with housing related problems. 558 surveys were completed. A large percentage of the participants indicated that they didn't know where to find help if needed, that housing related issues affected their daily activities and that rent control was necessary.

The qualitative findings focus on themes such as homelessness-related issues experienced by students such as housing and financial issues, knowledge of support systems, cause/solution beliefs factors, and knowledge items. Data generated helped with the public awareness raising, community engagement and planning of services to address housing financial problems, and prevent homelessness in the student population. It is apparent that the university administration, faculties and campus generally need to be made aware of students' personal needs to be successful at their studies.

### **How Do Nursing Faculty Navigate Conflicts and Tensions Within the Disjuncture of Education and Practice?**

Katherine Fukuyama  
*Vancouver Community College*

The purpose of this narrative study is to explore how nursing faculty make meaning of their experiences of the disjuncture or gap between what is taught about best practice in nursing schools and nursing practice found in many clinical practice sites that do not meet these standards.

The goal of this exploration is to point to some educational and action oriented interventions to assist faculty and students in navigating the liminal space of the practice-education intersection. Data collection consists of interviews and group interviews. The narratives are the lived experiences of individual nursing faculty when they are supervising students and navigating within practice-education disjunctures. With a better understanding of the experience, nursing faculty can help students to navigate the whirlpools of practice more skillfully. The causes of poor nursing practice may have strong structural dimensions, but an understanding of the disjuncture needs to be taken up as part of nursing students' education. A deeper understanding of the structural dimensions of the health care system and how that dimension has bearing on nursing practice needs to become part of the nursing curriculum. This understanding could potentially provide a basis for organizing action for faculty and students to enact best practices within and with these structures. There are implications for the curriculum as these kinds of encounters can be teaching moments about taking action.

### **HPV and HSV: Students Share Lessons for Health Professionals**

Christopher Hirschler

*Monmouth University*  
Andrea Hope  
*Monmouth University*  
Mary Ann Troiano  
*Monmouth University*  
Laura Jannone  
*Monmouth University*  
Laura Kelly  
*Monmouth University*

An online, mixed methods survey focusing on human papillomavirus and herpes simplex virus was completed by 268 participants from a private university located in the Northeastern United States. Grounded Theory (Strauss & Corbin, 1990) was used to code and systematically analyze the qualitative data. Quantitative and qualitative data suggest that students believe health educators should reconsider how they approach lessons that focus on sexually transmitted infections (STI). Denounced were lessons that include photos designed to scare students into abstinence and strategies that provoke stigma. A 19 year old female wrote, "I do not think it is right to tell people to be abstinent... some gross pictures may cause them to be that way without telling them to be." Respondents cautioned educators against using practices that foster shame or embarrassment and suggested lessons include practical ways to reduce infection for the majority who choose not to be abstinent. Infected persons indicated a need for more attention to be focused on methods of coping with a STI. Many reported struggling with intense negative emotions and repression of sexual activity. Responses by males indicated that a majority do not understand that there is currently no HPV test for males. A significant number of infected participants reported failing to inform sexual partners about their STI. Health professionals need to understand the reasons why infected individuals do not inform partners and suggest ways to communicate STI status in ways that are likely to be implemented.

### **Identifying the Health Care Supportive needs of Adolescents and Young Adult Cancer Patients and Survivors: Preliminary Findings from a Qualitative Study**

Elena Tsangaris  
*McMaster University*  
Jessica Johnson  
*McMaster University*  
Denise Bryant-Lukosius  
*McMaster University*  
Graeme Fraser  
*Juravinski Cancer Centre*  
Ronald Barr  
*McMaster University*  
Anne Klassen  
*McMaster University*

**Background:** Current cancer programs in Canada manage adolescent patients in pediatric centers and young adults in adult centers. An initiative is underway in Hamilton, Ontario to develop an AYA-specific program to address and meet the needs of this group. The aim of this qualitative study is to identify health and supportive care needs of AYA patients and use information gathered to inform development of this new program.

**Methods:** A qualitative descriptive approach is used. A purposive sample of AYA patients and

survivors aged 15 to 25 years are interviewed. Participants are recruited from Hamilton's adult and pediatric cancer programs. Interviews are digitally recorded and transcribed verbatim. Line-by-line coding is used to establish categories and themes. Constant comparison is used to examine relationships within and across codes and categories.

Results: Preliminary findings are based on 14 interviews 8 survivors and 6 on treatment; 9 adolescent and 5 young adults who have a range of different types of cancer including lymphoma (6); acute lymphoblastic leukemia (3) osteosarcoma (2); Ewing sarcoma (1); colon cancer (1); and hypothalamic glioma (1). Participants describe a range of health and supportive care needs that we categorized into the following themes: physical health, psychological health, social health, client/family centered care, coping, information, health facility/amenities and health behaviours. Within each theme important subthemes have been identified (e.g., delivery of information).

Discussion: Interviewing will continue until no new themes emerge. Information from our study will inform development of a new AYA healthcare program. Identifying patient priorities will ensure new services will attain maximal benefits for AYA patients.

### **Influence of gender and income in shaping parental negotiations about preventing children's injuries**

Lise Olsen

*University of British Columbia*

Mariana Brussoni

*University of British Columbia*

John Oliffe

*University of British Columbia*

Genevieve Creighton

*University of British Columbia*

Parental safety behaviors and income related factors play important roles in childhood injury prevention. To date, however, there exist major gaps in our understanding of how couples' perspectives related to childhood safety differ and how they negotiate these differences in the care of their children. The goal of this project is to better understand how gender relations among mothers and fathers living in different socio-economic circumstances influence their attitudes and practices towards children's injury prevention.

Data analysis is guided by a gender relations theoretical framework. An intersectionality research perspective is also used to examine how gender and income factors can influence mothers' and fathers' views and practices regarding their children's safety. The study sample includes mother-father dyads with children aged 2 to 7 years old who participated in in-person interviews. We are using purposive sampling to ensure inclusion of parents living at varying levels of income. Specific data analysis procedures are guided by grounded theory methods.

Mothers' and fathers' described their comfort levels with children's risky activities and how these were negotiated between them. Interactional processes between parents related to child injury prevention and how these may be impacted by gender and economic circumstances will be highlighted in the presentation. Enhancing the relevance of interventions to both mothers and fathers and to those living in a variety of economic circumstances can serve to improve the relevance and effectiveness of parent-focused child injury prevention strategies.

## **Is Having a Period a Lifestyle Choice? Pharmaceutical Shaping of Menstruation**

Colleen McMillan

*McMaster University and Wilfrid Laurier University*

Amanda Jenkins

*University of Waterloo*

Menstruation is a physiological and emotional benchmark in a woman's life. Commencement of the menstrual cycle is symbolic of a healthy body, the ability to reproduce and a definitive marker of femaleness. Yet Western culture shrouds this normal process with messages of shame and secrecy that is perpetuated by menstrual product advertisements and menstrual advertisement. Cessation marketing frames menstruation as "messy" and "inconvenient" suggesting that medical controlled amenorrhea may be "healthier" reducing the possibility of certain cancers.

To explore how current marketing may shape perceptions of young women toward menstruation, and if such perceptions resulted in changed behaviours, an exploratory qualitative study was undertaken guided by the question "How does the advertising for menstrual shape women's perceptions around the normalcy of having a monthly period?"

Ten women between the ages of 18 to 25 were shown commercials sponsored by pharmaceutical companies promoting menstrual cessation. After viewing the commercials, their perceptions were collected using open ended interviews guided by questions regarding the concepts of normalcy and healthy. Discourse analysis was used to analyze the transcripts. Three different discourses were used including marketing, medical, and feminist discourse.

Rigor was achieved by member checking of the transcriptions and identified themes. Multiple iterations of the data through three discourses served as theoretical triangulation.

Findings revealed a tension existing between accepting menstrual suppression as 'normal' and 'healthy' while acknowledging 'convenience' as one benefit of menstrual suppression. Artificial menstrual cessation of a normal regulating process signals a tenuous precipice of medicalization of the female body.

## **It's a Touchy Subject: Latino Adolescent Sexual Risk Behaviors in the School Context**

Kim Larson

*East Carolina University*

Adverse sexual health outcomes remain disproportionately high for Latino adolescents. Between 2004 and 2005 we conducted an ethnographic study to examine the sexual risk behaviors among a purposeful sample of Mexican-origin adolescents living in rural North Carolina. This analysis is based on field observations in the school and community, in-depth interviews with Latino adolescents (n=25), their parents (n=18) and their teachers (n=13), and the review of school- and community-related documents. One major finding was that gender-specific latino cultural norms clashed with mainstream U.S. norms. Themes that made up this finding were: la fiesta de los quince años, boyfriend as husband, and libertinaje (sexual freedom). A second major finding was that cultural stereotypes and (mis) understandings by school personnel left them questioning whether any action was warranted and if so, whose obligation it was to inform, monitor, and control sexually risky behaviors. "It's a touchy subject [sex] here" exemplified the reluctance of addressing sexual risk behaviors. The Centers for Disease Control and Prevention has called for the urgent replication of evidence-based sexual risk reduction programs to eliminate health



disparities. One of these programs, ¡Cuídate!, designed for Latino adolescents, uses cultural beliefs and practices to frame abstinence and condom use as culturally acceptable ways of taking care of oneself and one's partner, family, and community. This presentation will conclude with a description of the active involvement of the Latino community in the early stages of the ¡Cuídate! program in rural North Carolina.

### **“It’s Not about Food”: An Interdisciplinary Peer Facilitated Mechanism for Change in Female University Students with Eating Issues**

Kathleen Pye

*University of New Brunswick*

Kate Weaver

*University of New Brunswick*

Eating issues have significant consequences, including physiological, psychosocial, cognitive and academic impairments. In response to rising rates among female university students, an interdisciplinary Harrison-McCain research and collaborative practice project called “It’s Not about Food” (INAF) was developed. Under the direction of various campus health providers from Student Health and Counselling Services, nursing students were supervised as peer facilitators to engage with eating disordered university women via weekly psychoeducational support group meetings. A mixed methodological (quantitative and qualitative), multi-year analysis was designed to: 1) identify the efficacy of peer facilitation and perceived barriers and preferences to support, 2) develop an understanding of how women overcome secrecy and social isolation associated with eating disorders, and 3) examine motivations for change. In this oral presentation, we will discuss the experiences of the university women with eating issues and their perceptions of and reactions to peer facilitated support. Analysis of qualitative interviews revealed narrative threads of hiding my dirty little secret, finding common ground, jumping off towards recovery, investing in self, and practising self-love within an overarching story of “Stepping Outside my Comfort Zone.” The research suggests that INAF serves as a mechanism for personal change, profoundly impacting sense of self and eliciting a transformed view of the world. Overall, the findings highlight INAF as a supportive, practical and cost-effective innovation aimed at reducing eating issues within university settings. This study is part of a large-scale research agenda focused on understanding the stigma, secrecy and social isolation associated with eating disorders and related issues.

### **“Labels are for pickle jars”: Gay men talking about identity**

Jeffery Adams

*Massey University*

Understanding sexual identities within the population are important in all spheres of health policy and practice. However despite at least two decades of research focusing on sexual identity and HIV/AIDS risk, gay men as a ‘category’ continues to be treated in an uncomplicated way or alternatively issues of sexual identity are ignored and behavioral focus (men who have sex with men) dominates. This presentation argues that understanding how gay men experience ‘being gay’ provides information vital to investigating and enhancing public approaches to gay men's health. Using data gathered from 11 focus groups with 45 gay men in New Zealand the lived experience of being gay is explored. The research found that gay men negotiated and renegotiated their identity. Many did not like being labelled as gay, only a few proclaimed their gayness, and many used a strategy of minimal disclosure to control or downplay aspects of their identity. While some

men reported that it was easy to be gay, many reported direct and immediate consequences impacting of their daily lives. These widely different views of being gay suggest that a gay identity is not a singular or uncomplicated category. These findings challenge conventional conceptions of the gay male population held by many mainstream health promoters and policy makers and must be incorporated if gay men are to be appropriately represented in health policy and included in service provision.

### **Let Me Tell You Sister: Seeking Women's Health Care in Deployed Settings**

Candy Wilson

*Lackland AFB*

Military women are regularly deployed to austere settings for war and humanitarian missions. The deployed population consists of 10% women. Women's sex-specific health care needs pose a special challenge for women and health care providers in an austere or ship setting where anonymity cannot be guaranteed, self-care supplies are limited, and health care professional's lack confidence to care for private gynecological concerns. The purpose of this study was to gain a better understanding of the illness behaviors of deployed military women in regards to their genitourinary (GU) health. Ethnography was used to explore and analyze the data because the military has been described as its own culture. The sample consisted of 43 military women from the US Army, Air Force, and Navy who were either deployed or had been deployed within the past year. The researchers uncovered three themes, which included (1) The Sphere of Control, (2) The Dynamics of Trust, and (3) Life in a Deployed Setting. This study is significant to nursing research because it exposes the influence of culture on GU symptom management. Recommendations from this investigation include: (1) a need for better incremental, pre deployment and in theater education for women and medics; (2) informing leaders about the need to ensure the supply of self-care treatments and women's feminine hygiene products are available; and (3) promoting the role of family support stateside as a resource for information, supplies, and emotional support. This study was funded by the TriService Nursing Research Program (N08-P03).

### **Locating fatherhood: Exploring the ways that place and space influence father's consideration of risk, safety and supervision.**

Genevieve Creighton

*University of British Columbia*

Mariana Brussoni

*University of British Columbia*

Lise Olsen

*University of British Columbia*

John Oliffe

*University of British Columbia*

As fathers take greater responsibility for childrearing, their role in preventing childhood injury is becoming increasingly salient to researchers. While dominant ideas about masculinity influence men's orientation towards fathering, there is little known about how this impacts upon how they consider risk in their own child's life. How are attitudes towards safeguarding children from injury and supervision practices influenced by social and geographical space?

This study used a social constructionist perspective to investigate the way that space and place influenced a gendered construction of fathering. The study sample included mother-father dyads

with children aged 2 to 7 years old who participated in in-person interviews. Photo elicitation was used to augment and provide richness to the interview data. Purposeful sampling ensured data was collected from two distinct urban and rural environments within British Columbia

Initial findings suggest that each city produces different ideals of masculinity that, in turn, influence the fathering role adopted by men. Differential physical spaces influence the degree of emphasis placed on gaining skills for survival in and the enjoyment of the outdoors. Likewise, a fathers' gendered identity has bearing on father's definition of protective and overprotective actions in regards to parental responsibility.

### **Making Sense of End Stage Heart Failure**

Susan Browne

*University of Glasgow*

Deborah Morrison

*University of Glasgow*

Una Macleod

*Universities of Hull and York*

Carl May

*University of Southampton*

Frances Mair

*University of Glasgow*

**Background:** Heart failure is a terminal condition, yet it has been demonstrated that health professionals (HPs) lack confidence diagnosing end stage heart failure (ESHF) and communicating a poor prognosis to patients.

**Aims:** The present study explores patient and carer understanding of the diagnosis and prognosis, how ESHF patients plan for the future, and what part HPs play.

**Method:** Semi-structured interviews with 22 ESHF patients and their carers exploring their knowledge and understanding of the condition and its prognosis. Qualitative data analysed using thematic analysis informed by Normalization Process Theory (NPT). Inclusion criteria: at least Grade 3 NYHA classification HF; symptoms despite optimal therapy; a history of admissions for ESHF.

**Results:** While patients and carers understood that the patient had heart problems and that their condition could not be 'cured' or reversed, there was little evidence they were aware of its terminal nature. Patients seldom described themselves as having "heart failure", rather, they described long histories of heart "problems" and perhaps consequently failed to recognise the deterioration of their condition.

Some reported discussions with health professionals where end of life issues had been broached: conversations about future care, about the role of the hospice, and about deactivation of implanted cardiac defibrillators. These conversations caused confusion as patients and carers were unable to reconcile them with their understanding of the seriousness of the illness.

**Conclusions:** This study highlights the continuing problem of ESHF patients and carers lacking understanding of poor prognosis and the difficulties this poses for planning end of life care.

### **Making sense of evolving health information: Women's experiences with medical uncertainty**

Shelagh K. Genuis

*University of Alberta*

While much is written about evidence based practice, little attention is paid to the changing, emergent and incomplete nature of health evidence and to the challenge this presents to individuals making health decisions within everyday life contexts. In these contexts people are interacting with and integrating health information mediated by a wide range of formal and informal sources; and information gathering commonly occurs before, following, and sometimes instead of formal information seeking. Using qualitative interviews with women and health professionals (HPs), this study focused on information behaviour in a situation where health evidence is explicitly evolving: management of health and wellbeing during the menopause transition. Two strategies were used during women's interviews: a semi structured, narrative approach revealed construction of health information, and elicitation was used to explore response to evolving health information encountered in the media. Semi-structured interviews with HPs provided insight into themes emerging from women's interviews and roles HPs play in facilitating the translation of knowledge into practice. A social constructionist framework and social positioning theory provided a lens for exploring the dynamic aspects of information encounters. Findings reveal that women construct evidence as research, material object, negotiated belief, and lived experience; and that multiple 'storylines' are used intentionally and unintentionally to construct identity within social interactions and between women and HPs. Findings have implications for shared decision making and raise new considerations related to knowledge translation as an ongoing process of social construction taking place within everyday life contexts.

### **Measures of Effectiveness Indicators Related to Health, Stress and Strategic Outcomes on USNS COMFORT: A Pilot Study**

Darya Pilram

*The George Washington University*

Michael Rudmann

*National Naval Medical Center*

U.S. Military Medical Stability Operations (MSOs), through collaborative health engagements, have done much to deliver visible health assistance to strategic regions. The majority of available data surrounding past Humanitarian Assistance (HA) missions have been related to Measures of Performance (MOPs) (e.g. number of surgeries performed, number of patients treated), which demonstrate "outputs", or the actual products and services resulting from an intervention. Little can be deduced from these MOPs in terms of mission effectiveness in achieving medium- and long-term strategic objectives. As such, the reported results of these efforts have been met with criticism from the international development community, citing a lack of metrics for measuring and evaluating impact, and limited transparency related to project operations and sustainability.

This exploratory, pilot project utilizes semi-structured, in-depth interviews with key personnel involved with the Continuing Promise 2011 (CP11) humanitarian mission to explore and identify the complex, interrelated issues associated with short-term military medical interventions. The primary objective is to examine the effects of short-term MSOs through the perceptions of host nation patients, providers, and local healthcare experts. Data will be used to develop Measures of Effectiveness (MOE) indicators appropriate to operational realities and local environments. Our

aim is to establish indicators that will evaluate medium- to long-term outcomes of ship-based MSOs and incorporate this data into strategically relevant recommendations to those who design, participate in and evaluate collaborative health missions.

### **Modeling Critically & Ethnographically Derived Transformative Knowledge Exchange**

Ryan DeForge

*The University of Western Ontario*

Steeped in theory, this proposed doctoral dissertation features a model by which the culture of care in a long-term care home is to be critically examined. Its genesis rooted in critical realism and critical pragmatism, the axiological drive of the project is to catalyze transformative change within/across the culture of care delivery in this particular home, particularly in terms of dementia care. The transformative process begins with a critical ethnography a la Carspecken (1996), replete with hermeneutic reconstructive analysis and validity horizon analysis of the interactive power claims observed during data collection.

Drawing on Ellingson's (2009) engagement with crystallization, a multi-genred re-presentation of the ethnographic findings will conflate with the effect of my having been 'in their field' to serve as the catalytic moment(s) in which transformation begins, manifest first as critical reflection, then as facilitated critical discourse. The third and (tentatively) final phase of transformation - the realization of change - signals the need (perhaps) for the nature of the facilitation to transition from a holistic to a more task-focused facilitation. The foci of this presentation will be to introduce the entire model in a stepwise fashion, then to hone in on the hermeneutic reconstructive analysis that will serve to deepen my own and staff members' understanding of the social organization of power within their long-term care home. Implications for 'knowledge translation' researchers and practitioners will be elucidated, as will yet-imagined possibilities for innovation in long-term dementia care.

### **More than a Moment: The Role of Significant Others in Medical Decision Making**

Suepattra May

*Palo Alto Medical Foundation Research Institute*

Katharine Rendle

*Palo Alto Medical Foundation Research Institute*

Nicole Ventre

*Palo Alto Medical Foundation Research Institute*

Allison Kurian

*Stanford University*

Dominick Frosch

*Palo Alto Medical Foundation Research Institute*

Shared medical decision making (SDM) has been lauded by advocates for its potential to democratize the patient-physician relationship. However, the practice of SDM is still conceived of as largely a dyadic moment that exists between the patient and the physician or care team. Few studies have looked at the role of others (family members, spouses, partners, and friends) in shared decision making or considered how discussions and actions that occur in spaces external to the consultation room affect a patient's medical decision making process. This study considers the impact of significant others in the decisions of breast cancer patients engaging with the shared decision model. Using data from focus groups and interviews examining patients' experiences with treatment decision making more generally, transcripts were analyzed to explore the degree to

which patients described how they deliberated treatment decisions with others in their lives; and the extent to which others are reported to influence decision making. While studies have shown that demand for shared decision making by patients is high, medical practice remains reductionist. Patients in our data report making decisions in concert with family members representing multiple points of view. Patients also stressed the need for clinicians to view patients beyond their body or diagnosis, and recognize that they are part of a larger social network of care, which frames any decision making conversation. Our findings underscore the need to understand the role of significant others in medical decision making processes.

### **Needs of South African Adolescents Orphaned by AIDS: Evidence from Photography and Photo-elicitation**

Gloria Thupayagale-Tshweneagae  
*University of South Africa*

Adolescents orphaned by HIV and AIDS represent a population vulnerable to mental health risks. Stressors due to the loss of a loved one are highly context-specific and often difficult to avoid. Although several studies have revealed the needs of orphans in South Africa, very few studies have focused on adolescents and hence their needs have been subsumed under the needs of orphaned children. The purpose of the study was to determine the needs of adolescents orphaned by HIV and AIDS and to ascertain the extent of their loss through pictures.

A phenomenological study using photography and photo-elicitation was used on 15 adolescents aged between 14 and 18 orphaned by HIV and AIDS. Participants captured different objects which were grouped under different themes including symbols of death, valley, people and hope. Photo-elicitation followed the captured objects. Needs of adolescents orphaned by HIV and AIDS were discerned as love and caring, safety and security, support and inclusiveness.

Photographs taken represented so many emotions and have relevance to the needs of orphaned adolescents orphaned by HIV and AIDS. It was also intriguing to learn that memories of loved ones could be captured in different ways and represents strong feelings.

### **Nurses, pain scales, and the search for “legitimate” pain in the Emergency Department**

Denise Drevdahl  
*University of Washington Tacoma*  
Joane Mocerri  
*University of Washington Tacoma*

Studies consistently demonstrate deficiencies in how health care providers in U.S. Emergency Departments (ED) practice pain management. However, little is known about how ED nurses manage patients' pain as most studies evaluate ED physician practices. We report findings from a study whose purpose was to better understand how ED Registered Nurses (RNs) made decisions concerning pain management.

RNs from five EDs in Washington State participated in the study. After completing the Knowledge and Attitudes Survey Regarding Pain, individual interviews were conducted with 16 RNs. All interviews were tape-recorded and lasted approximately 1 hour. Following transcription, the interviews were analyzed using qualitative content analysis.

The use of pain scales as a critical aspect of pain management decisions for ED RNs emerged as

an important theme. Nurses working in EDs exerted great effort to administer and interpret the pain scales. A major concern was identifying patients who RNs believed were experiencing “legitimate” pain compared to those they viewed as “drug-seeking.” Although mandated to use a pain scale by regulatory organizations, participants found that the process of pain management was much more complex than simply noting the number patients used to rate their pain.

These findings add important information to the literature on nurses’ decision making in the ED and can be used to inform future interventions, especially related to helping nurses manage the pain of those patients nurses identify as “drug-seeking.” Additionally, these findings raise questions about why nurses feel compelled to monitor and control access to narcotics through the ED.

### **Optimizing Health Literacy and Community Engagement in Relation to Active Living with Edmonton’s Newcomer Young People and their Families**

Gina Higginbottom  
*University of Alberta*

Solina Richter  
*University of Alberta*

Helen Vallianatos  
*University of Alberta*

Sophie Yohani  
*University of Alberta*

Yun-Csang Ghimn  
*University of Alberta*

Edmonton is the 4th fastest growing metropolitan city in Canada and had a population of 1,023,820 in 2006. This study focused on health literacy and active living among newcomer young people and their families. Evidence suggests that many immigrant and refugee parents and children do not have sufficient health literacy. A significant number of refugee children speak little or no English, and are suffering from the experiences of war and living in refugee camps. The purpose of this study was to obtain an understanding of health literacy and active living amongst young immigrant and refugees, and factors that promote the engagement of newcomer families in school-based dimensions of active living and healthy eating in two Edmonton School clusters.

Our research was informed by the tenets of health literacy and community engagement models. We utilized a mixed methodological approach using a systematic review, quality of life tool, photo-voice and interviews as the method to gather data. We use a statistical software package program (SPSS for Windows) for the quantitative analysis and Roper and Shapira’s framework for the qualitative analysis. Thirty-eight young people and 20 parents from various ethnic backgrounds participated in the study. The findings reflect upon mechanisms to support and promote or enhance health literacy for newcomer young people and their families and factors that promote the engagement of newcomer families and their children in school-based dimensions of active living. Recommendations include best practice policies focussing on cultural competency issues, and community engagement activities related to newcomer families.

### **Parenting under pressure: a grounded theory of parenting young children with complex congenital heart disease**

Gwen Rempel

*University of Alberta*  
Vinitha Ravindran  
*University of Alberta*  
Laura Rogers  
*University of Alberta*  
Joyce Magill-Evans  
*University of Alberta*

Technological advances have improved the survival rates for young children with life-threatening congenital heart disease (CHD). While extensive hospital-based resources are invested in these children initially, parents safeguard their child's ongoing survival with minimal support and guidance from health care professionals. The aim of this grounded theory study was to describe the process of parenting young children who have survived hypoplastic left heart syndrome (HLHS) to provide direction for health care provider involvement with family members of the child. Participants were 25 parents (15 mothers, 10 fathers) and 28 grandparents (17 grandmothers, 11 grandfathers) of 15 young children (6 months to 4.5 years) who had undergone the Sano surgical approach for HLHS. Fifty-three interviews were digitally recorded, transcribed, and analyzed using open and selective coding, memoing, and constant comparative analysis.

The process of "parenting under pressure" was characterized by four overlapping and re-emerging phases: 1) realizing and adjusting to the inconceivable, 2) watching for and accommodating the unexpected, 3) growing increasingly attached, and, 4) encountering and anticipating new challenges. Parents acknowledged the life-threatening nature of their child's HLHS and took responsibility for monitoring for potential problems while growing increasingly attached to their child. In-depth understanding of the phases of "parenting under pressure" provides direction for health care providers to support parents and families of children who survive HLHS. A multidisciplinary approach is required to address issues of parental grief and vigilance, and parent-child attachment in the context of persistent stress and uncertainty related to their young child's illness trajectory.

### **Patients' Transition - What is it like in the Intensive Care Unit?**

Salizar Mohamed Ludin  
*International Islamic University Malaysia, Malaysia*  
Paul Arbon  
*Flinders University, Adelaide, South Australia*  
Steve Parker  
*Flinders University, Adelaide, South Australia*

Providing support for critically ill patients throughout their transition(s) while in the Intensive Care Unit (ICU) and following transfer is an important element of the nursing process during hospitalisation for critical illness. As nurses are the primary caregivers in critical care contexts, understanding of patients' transition experience is important and can facilitate better nursing care. To date, apart from the associated discussion of discharge planning issues, little is known about nurses' understanding of critically ill patients and their families' experience. Thus this paper presents what it's like for patients and their families to be in the ICU.

An interpretive descriptive research approach was used to describe transition experiences and followed by interpretation of findings from an ethnographic stance. Focus group (n=25), and in-depth individual interviews (n=10) were conducted sequentially in four Malaysian tertiary hospitals (7 ICUs) within a seven month period, in 2008. Data were subjected to qualitative



thematic analysis.

The findings were categorized into patients' and families' experience and seen as transition of location, health and illness, skill and care, knowledge need, hope and faith, and coping. In conclusion, the findings demonstrate the breadth of transition concerning the patients' and families' experiences and the journey of care in ICU. The major implication of this study is to understand that critically ill patients' transition experience is complex and extends beyond simple concerns of discharge planning and after care which have been previously the clinical focus of health organizations and care plans.

### **Pediatric Thoracic Transplantation: A Transformative Process**

Samantha J. Anthony  
*The Hospital for Sick Children*  
David B. Nicholas  
*University of Calgary*  
Cheryl Regehr  
*University of Toronto*  
Anne I. Dipchand  
*Hospital for Sick Children*  
Melinda Solomon  
*Hospital for Sick Children*  
Radha MacCulloch  
*Hospital for Sick Children*  
Lori J. West  
*University of Alberta*

Despite the growth of heart and lung transplantation as life-saving therapies in children and adolescents, little research has focused on the biopsychosocial impact of the transplant process. This study addresses a significant gap in knowledge and captures subjective, quality of life experiences of pediatric patients, providing much needed insight into the impact of care trajectory and life changes following transplant. This qualitative study explored how adolescent patients construct their worlds and the meanings they ascribe to their transplant experience. A grounded theory approach was implemented and guided data collection, data analysis and theoretical formation. A total of 32/37 heart or lung transplant patients (21 female, 66%) participated (median age 15.9 yrs; range 12 18.4 yrs) at a median time of 2.7 yrs post-transplant (range 0.3 11.1 yrs).

Results illuminate pediatric thoracic transplant in its potentially transformative nature. Findings unveil three dimensions of positive transformations experienced by participants: 1) enhanced self-perception, including a greater sense of personal strength and recognition of coping abilities, 2) greater meaningfulness in interpersonal relationships, including enhanced appreciation for relationships with family and friends, and 3) perceived improvement in one's view and philosophy of life. Accordingly, these findings uniquely point to an emerging 'transplanted self', and a theoretical model that posits transplant as a potential catalyst for growth and personal transformation. These data suggest that transplant has offered hope, personal change and reflectiveness. Recasting transplant as potentially a generative, hopeful condition and opportunity offers important implications for practice and research.

## **Photoelicitation interviews and research with children: Practical considerations from the field**

Shanon Phelan

*The University of Western Ontario*

E. Anne Kinsella

*The University of Western Ontario*

The purpose of this paper is to examine the use of photoelicitation methods in research with children. Photoelicitation interviewing (PEI) is a method of visual data collection used in combination with an interview process to draw out the viewer's response (Harper, 2002). Prosser and Burke (2008) suggest, "Words are the domain of adult researchers and therefore can be disempowering to the young. Images and their mode of production, on the other hand, are central to children's culture from a very early age and therefore empowering" (p. 407). In addition, children may find it difficult to express their experiences with abstract social issues verbally (Croghan, Griffin, Hunter, & Phoenix, 2008). Photographs on the other hand offer a means by which children can approach the social and cultural dimensions of their experience in different ways (Phelan & Kinsella, In Press).

The authors are currently working on a grounded theory research project, using PEI to examine how participation in childhood activities shapes the process of identity formation with children with physical disabilities. Drawing on a review of the literature and examples of current research, practical considerations when engaging in the PEI method will be discussed. These include: issues of voice and power in the research process, flexibility, sensitivity to time demands, developing rapport with children, and the use of digital versus disposable cameras. The potential of PEI methods when conducting research with children is of practical (i.e., gathering meaningful data), as well as moral significance (i.e., overcoming disempowerment) (Phelan & Kinsella, In Press).

## **Physical Fitness and Developmental Disability: A Grounded Research Study**

Peter Speers

*University of British Columbia-Okanagan*

In this paper I will present the findings from my qualitative research project on the social processes that affect the physical fitness activities of people with developmental disabilities.

**Introduction:** The literature on physical well being and people with developmental disabilities is unequivocal in its conclusion that people with developmental disabilities are among the least fit of all persons. As people with developmental disabilities age they become far more susceptible to hypo kinetic disease than do their peers in the "typical" population. In essence, these diseases are the result of a sedentary life style which promotes obesity, reduces well being and fosters greater dependence on assistance with activities of daily living. In addition people with developmental disabilities suffer from an inordinately high rate of lifelong impairments such as diabetes and cardio-vascular disease. As this population ages they are having a profound affect on both disability support resources and those of its sister system, the health related support network. Exercise, sport and recreational activities have been seen to reduce the risk of disease and lessen the impact of impairment. Despite this understanding the well being of this population remains imperilled.

**Methodology:** The social processes that affect the fitness choices of people with developmental

disabilities remain unexplored. The barrier to fitness experienced by people with developmental disabilities is not well understood. Using the grounded theory methodology my research engages the voice of people with developmental disabilities to formulate a theoretical explanation for their lower level of participation in fitness activities.

Discussion: Concluding this paper I will discuss my findings and outline the implications for policy and practice in the health and human services which support this population. Finally, I will map potential venues for knowledge exchange.

### **Policy makers' perceptions of the outcomes of advanced practice**

Kathy Murphy

*National University of Ireland Galway*

Cecily Begley

*Health Science*

Adeline Cooney

*Medicine, Nursing and Health Science*

Agnes Higgins

*Health Science*

The SCAPE study was a mixed method focused evaluation of the clinical services provided by clinical nurse/midwife specialists and advanced nurse/ midwife practitioners in Ireland. This paper describes the interpretative third phase of the study, which utilised a descriptive, qualitative design. Following ethical approval and informed consent, data were collected through telephone or face-to-face interviews with 12 key policy-makers to gather views on the draft findings, and to ensure that key policy issues were included in the final report. Participants included representatives from a number of relevant organisations that govern or shape health policy in Ireland. An outline of the draft findings was used to develop the interview schedule and participants were asked to comment in relation to the wider health-service context nationally and internationally.

All interviews were transcribed verbatim, verified by participants, data were anonymised and content analysis was undertaken. Five themes emerged: perceptions of the role, clinical and professional leadership, research and audit activity, resources and challenges, and future directions. Participants believed that specialist and advanced practitioners had made a significant contribution to the development of nursing and midwifery practice. They suggested that they had good organisational and leadership skills, provided better continuity of care and follow-up, and they perceived that this led to improved care for service users and enhanced compliance. Concerns were raised in relation to resources, research, and sustainability of posts. These findings have implications for future development of specialist and advanced nursing and midwifery posts in the health services of many countries.

### **Postpartum Anxiety in First-Time Mothers**

Andrea Wardrop

*Canadian Cancer Society*

Natalee Popadiuk

*University of Victoria*

The transition to motherhood is a developmental issue that greatly impacts many women's health, well-being, and social roles. Although there are often great joys associated with new motherhood,

many women also face significant challenges such as anxiety in the postpartum. The existing evidence about new mothers suggests that this anxiety might be obscured by the more dominant discourse of postpartum depression in North American culture, health care, and the accompanying body of research. Therefore, in this interpretive study we explored the experiences of first-time mothers dealing with anxiety in the postpartum as a way of broadening the dialogue about women's childbearing experiences. We interviewed six women about their experiences of anxiety in the transition to motherhood and using the feminist biographical method as a structure for our research, conducted a thematic analysis of the transcripts. Our participants discussed their experiences of anxiety, the expectations of a new mother, issues of support, and the experience of motherhood as a transition. Our findings point to the need to specifically recognize and name the varying experiences of postpartum distress, rather than using the umbrella term of postpartum depression. We discovered issues of agency, perfectionism, and societal norms in the transition to motherhood, as well as the connection between women's health and the cultural context of childbirth and early parenting for urban professional women. Implications for professionals are discussed.

### **Practical Considerations and Patterns of Collaboration in the Marriage Relationship Among Persons with Disabilities**

Celia Schulz

*The University of Texas-Pan American*

This study reports on a subset of data obtained from a larger study. A qualitative study of persons with disabilities was conducted to examine the phenomenon of collaboration with others in their lives. Participants were administered two semi structured interviews about their experiences with collaboration and were observed as they collaborated with others in their lives in two participant observation sessions.

Since not all participants were married, data relevant to the marriage collaboration from interviews and participant observation sessions of a subgroup of four married study participants were then isolated and coded using open coding analysis. Accuracy of data was insured through the use of triangulation via multiple coders and member checking. Five overarching categories emerged.

This presentation will focus on two of these categories and their subcategories: Practical Considerations [Division of Tasks and Roles According to Abilities; Collaboration About the Environment; Problem Solving; and The Use of Technology]; and Structures and Patterns of Collaboration [Stating One's Needs; Requesting Assistance With a Physical Task; Anticipating Needs of One's Spouse; and Temporal Element].

Data indicated that participants collaborated with their spouses in a variety of ways over time. Some unique issues in the marriage collaboration for people with disabilities also emerged, such as feelings of imbalance in the contributions to the marriage regarding physical tasks.

### **Producing Better Nurses: Using qualitative methods to incorporate students' perceived success in simulation**

Linda Hansen-Kyle

*Azusa Pacific University*

Anna Hefner

*Azusa Pacific University*

Cheryl Boyd

*Azusa Pacific University*

Melinda Dicken

*Azusa Pacific University*

Patricia Perry

*Azusa Pacific University*

**Aim:** The aim was to use a qualitative method to evaluate simulation from a student perspective.

**Background:** Healthcare is complex and nurses must quickly react to constantly changing environments. Nursing education has added simulation as learning tool for quick decision making. The effectiveness of simulation is based on anecdotal information or perceptions of faculty members. Little research has been done on student perceptions of simulation. Although, some researchers found simulation provides a setting for the development of task and skills training, communication, decision making and teamwork, student perceptions of their competence before and after the simulation experience have not been studied.

**Method:** Sample: A descriptive focus and emergent design was utilized with 94 students from a prelicensure program in nursing. Students were informed of the nature of the evaluation and participation was voluntary. A questionnaire format, developed by faculty and content experts, was used to gather individual stories of simulation.

**Data Analysis:** Analysis of the data through coding for themes and dimensions in the tradition of Corbin and Strauss were utilized. Major recurring themes were grouped and relationships identified. Theoretical statements based on the thematic discoveries were developed.

**Findings:** Students identified four major thematic threads: increased self-awareness; teamwork; knowledge and skills base; and clinical reasoning. They indicated the simulation scenarios were an important and necessary component of their education.

**Implications:** Simulation adds an important element to basic prelicensure education. Students embrace and learn from simulation.

### **Professionals' Experiences of the Relations between Personal History and Professional Role – Qualitative Health Research 2011 Conference Submission**

Hege Sjølie

*University College of Buskerud*

Bengt Karlsson

*University College of Buskerud*

Per-Einar Binder

*University of Bergen*

Research on health workers often focuses on the professional aspects of their lives. Their experience of their personal background and how they feel it contributes to their interest and motivation for their work is relatively little explored. The purpose of the article is to explore whether and how workers in a crisis resolution team (CRT) experience the relationship between their personal history and professional role. The study is based on 13 in-depth interviews with health professionals working in a CRT. The interviews were analysed using a hermeneutic-phenomenological approach.

Participants expressed that there is a relationship between their personal history and professional role. Three themes are highlighted as particularly important in this, namely family related experiences, work related experiences and experiences related to the participants as individuals. Family related experiences are divided into experiences with family members with mental health problems and experiences with family members working in mental health services. Experiences related to the participant as an individual consist of personal qualities and personal interests. While work related experiences can be described as profound personal experiences in a work context.

The participants give meaning to the relationship between their personal history and professional role. By exploring their own life stories in the interviews, they work on forming meaning and identity.

### **Qualitative research in India: Data generation challenges**

Vinitha Ravindran

*University of Alberta*

Gwen Rempel

*University of Alberta*

Linda Ogilvie

*University of Alberta*

Multiple cultural and environmental factors affect the way qualitative data are generated, transcribed, analyzed and theorized. Although qualitative research is becoming popular in India both in health and social sciences, little is known about the challenges in conducting individual interviews, involving multiple family members, or resolving transcription and translation issues. Adopting constructivist grounded theory methodology I explored parenting processes within 12 families in India with burn injured children from the perspectives of multiple family members. Although individual interviews were planned, in some families the interviews became a family interview. The environmental constraints related to place of interview, noise levels and intrusions of neighbours or animals necessitated adjustments with the recording system, place of interview or occurrence of intervals during interviews. Initial difficulties related to power relationships were modified in later interviews by downplaying the nurse researcher and the doctoral student part. Consent procedures had to be constantly emphasized as participants were not familiar with the procedure of consent. An understanding of what was meant by transcription of interview data was limited. Translating the transcripts was time consuming. Translators found it difficult to understand the concept of verbatim transcription and translation in qualitative interviews.

Modifying the data generation methods and the environment in which data is collected is a necessary part of qualitative research in India. Participant and professional awareness about the philosophies and principles of qualitative research and the need for training in interviewing, transcribing and translating qualitative data are essential initial steps in developing qualitative research in India.

### **Reflections of the insider organisational researcher**

Belinda Watts

*Anglia Ruskin University*

This paper focuses upon a research design which comprised of a single case study, formative evaluation and a hermeneutic phenomenological approach to portray the roles and experiences of

Inquiry Based Learning (IBL) facilitators in nursing and social work at a UK university. A purposive sample was used comprising of 34 open ended interviews and a range of secondary sources including non-participant observation and semi structured interviews with senior managers.

The main research findings were that IBL facilitators found their roles complex and challenging but that organisational leadership and management did not optimise organisational learning and the impact of this was projected in the classroom where disempowered facilitators did not think in terms of 'leading the learning'.

The researcher undertook the study in her own organisation and takes the debate beyond the boundaries of the three common research positions proffered by Reed and Proctor (1995) namely insider, outsider and hybrid researcher. Drawing upon the work of Brannick and Coghlan (2007) she affirms the value of the insider researcher and the dynamics and the issues with this role from four positions. These include access, pre-understanding which encapsulates knowledge and understanding prior to engagement in the research process, role duality within the context of the situationally created self and, finally, managing organisational politics and the related tensions with presenting negative findings to senior management.

### **Reflections on the Utility and Versatility of Case Study in the Health Sciences**

Carole Myers

*University of Tennessee-Knoxville*

Marian Roman

*University of Tennessee, USA*

Meanings attributed to health and health care emanate from the complex, dynamic interaction of personal, interpersonal, and societal influences and time. Experiences are highly individual, value-laden, and variable. Two nurse scholars with divergent research interests but a common appreciation of the value of case studies in the health sciences will explore the utility and versatility of case study research for understanding health and health care. Key understandings gleaned from the conduct of eight distinct case studies, that comprise their own research experience and the supervision of four students' doctoral dissertation, will be presented. The portfolio of case studies includes single and multi-case studies of persons in a recovery community, public health and educational programs and processes, and a medical mission trip. Insights about data collection, analysis, interpretation, and the transformation of findings via inductive reasoning and a technique known as bricolage will be highlighted. Case study research, at its best, captures the complexity and nuances of social phenomena, revealing many facets and dynamics. The findings of well-researched case studies increase the knowledge base necessary for actionable policy and practice recommendations that have relevance to practitioners and the clients they serve.

### **Representing Trauma: Challenges and Alternatives**

Sophie Tamas

*Queen's University*

How do we speak usefully about unspeakable things? This paper draws on my doctoral research into the aftermath of spousal abuse to address the methodological and ethical challenges of producing knowledge within and from sites of trauma. Writing what we cannot know, in spaces where we have lost trust in language, connection and cohesive modernist subjectivity raises

complex representational problems. This paper explores the limits of making sense, and proposes alternative approaches, through writing wonder, writing dirty, being haunted, and troubling genre, illustrated by their application in my own work. Rather than offering shaky promises of recovery and mastery, these ways of writing through trauma reach for the redemptive possibilities of thought.

### **Reproductive Tourism: Narratives of transnational surrogacy**

Kristin Lozanski

*King's University College at UWO*

Irene Shankar

*Mount Royal University*

As medical tourism becomes more prevalent, there are an increasing number of couples seeking transnational surrogates to carry their children. In this paper, we will provide preliminary insights into the narratives of globalized surrogacy from the perspectives of professionals who work in related industries and intended parents. The data to be analyzed will be collected using ethnographic methods along with semi structured interviews at a large international conference (Global Reproductive and Fertility Tourism Congress & Expo) that is dedicated to “reproductive and fertility tourism with special focus on surrogacy and egg donation”. Written materials made available at the expo, along with relevant websites, will also be included as sources of secondary data. The GRFTCE will bring together professionals from reproductive clinics, law firms, insurance companies, government and other relevant organizations. This conference and expo is a significant site of interrogation as it not only highlights the industry networks at play, but also centres the global south as the site of globalized reproduction and makes an explicit connection between globalized reproduction and tourism.

To this point there has been virtually no empirical socio-cultural analysis of the phenomenon of medical, or specifically reproductive, tourism. In this paper, as we examine how those involved in reproductive tourism understand and engage in practices that facilitate transnational surrogacy, we will not only introduce some of the logistical and procedural considerations for transnational surrogacy, but will actively situate these empirical data within the context of post-colonial feminism.

### **Research-based theatre as a catalyst for transformation**

Ryan DeForge

*The University of Western Ontario*

Catherine Ward-Griffin

*The University of Western Ontario*

Mark Speechley

*The University of Western Ontario*

In the care of the elderly, dementia is one of the main areas of knowledge where gaps have been identified. To better understand the negotiation of dementia care practices, a critical ethnography examined the inter-subjective processes among people living at home with dementia and their family and formal caregivers. This study included 52 interviews with participants from nine families in southwestern Ontario.

Realizing the shortcomings and limitations of conventional knowledge translation (limited access to conferences and journals; the privileging of text and the erasure of embodied knowledge and



experience), the research team collaborated with a playwright in order to transform the research findings into a stage play. As an alternative medium for knowledge exchange, dramatic performance offers audiences findings that preserve the embodied, experiential immediacy of embodied expressions of selfhood. Having 'workshopped' then 'field-tested' the play, a facilitation guide was developed in order to enable, potentially, the transformation of viewers' perspectives of dementia care, particularly the social, cultural, and affective components of the learning/change processes.

In this presentation, the theoretical driver of the facilitation guide - perspective transformation theory - is described both in terms of how it gleans from the research-based play the most salient catalytic moments, and in terms of its challenges, namely the creation of a safe(r) space in which to engage in critical reflection and discourse, and knowing where and how to transition (or exit) from a reflexive facilitator to a more conventional knowledge broker.

### **Research on Research: A Parallel Qualitative Study**

Nan Burgess-Whitman

*KJT Group*

Ken Tomaszewski

*KJT Group*

Research results stemming from online qualitative studies are often called into question when compared to more traditional face to face methods. This presentation addresses whether methodology really does matter or can you derive the same qualitative insights using an online method versus face to face approaches? Greater clarity about method differences, specifically online versus in person, will strengthen the discipline of qualitative research by enabling more appropriate and informed choices during research design and result in more informed researchers engaging in qualitative research.

### **Research with QLGBT Migrants: Respecting the meaningful, material and contested in queer lives**

Sharalyn Jordan

*University of British Columbia*

A critical qualitative inquiry conducted in partnership with Rainbow Refugee began with the question "How do QLGBT refugees engage in settlement?" The research process comprised collaborative narrative interviews (Arvey, 2003), contextualized through ethnographic observation, and interviews with community organizers and lawyers. Dialogical interpretation of participants' accounts conveys the relational patterns QLGBT asylum seekers used to survive under persecution and negotiate safety and belonging during precarious migrations, the asylum application, and settlement. Findings explore how persecution, stigma, erasure, and intersectional exclusions contribute to complex (re)traumatization, and raise implications for settlement support including physical and mental health care.

Research with QLGBT communities poses analytical challenges with important social justice implications: how to conduct research with people who live transgressive sexualities or genders, without further entrenching essentialized understandings of identity; how to acknowledge the contested nature of identities, while respecting the ways that identities are meaningful in everyday life; how to conceptualize human beings and their social worlds in a manner that acknowledges the productive power of discourse, without theorizing away the possibility of creativity, agency,

and resistance. Through examples, I will discuss these tensions, and ways that a dialogical approach potentially provides an analytical framework that respects the meaningful, contested and agentic in Queer lives.

### **Scottish prescribing governance and normalisation process theory**

Aileen Grant

*University of Dundee*

Tobias Dreischulte

*University of Dundee*

Bruce Guthrie

*University of Dundee*

New UK government policies define a course for safer, higher quality service, delivered locally. NHS England has emphasised top down performance management and markets. In contrast, NHS Scotland has favoured greater autonomy for regional boards. These regional health boards are responsible for improving prescribing quality and safety and use a range of 'soft governance' mechanisms.

'Data driven quality improvement in primary care' is a research programme which aims to develop and test a soft governance intervention to improve prescribing quality and safety. As part of this research programme two phases of semi-structured qualitative interviews were conducted with practitioners across two regional health boards. Phase one aimed to understand the context, attitudes and use of current soft governance mechanisms. Findings from the first phase of interviews were used to inform the design and delivery of the pilot intervention. Phase two interviews aimed to understand the pilot process and the barriers and facilitators to implementation.

Normalisation Process Theory (NPT) was applied to this data. NPT is a theoretical model designed to understand how mechanisms become normalised in everyday work. It is made up of 4 main concepts; coherence, cognitive participation, collective action and reflective monitoring, each with four sub-constructs.

NPT distinguished important differences definitions of prescribing quality improvement. Current soft governance mechanisms were so normalised practitioners struggled to reflect however, important values and opinions were identified. Preliminary phase two analysis shows richer NPT data when practitioners have a new intervention. These findings will be available by the time of the conference.

### **Sense making and interaction: change and resistance in frontline health practices**

James Conklin

*Concordia University*

This presentation reports the results of a qualitative inquiry into the social dynamics of knowledge translation in a long-term care facility in Ontario. The study focused on the sense making capacity of the interaction pattern in this frontline practice, and on how this pattern responded when an attempt was made to introduce new knowledge and approaches into the practice. The study made use of ethnographic and case study methods, and data was gathered over a period of three months. The presentation will focus particularly on the analytical techniques used to identify and depict the ongoing pattern of interaction evident in this

workplace; including the construction of an “interaction map” that reveals the affordances and limitations of existing patterns of work. The technique for constructing this map is based on the work of Chris Argyris, and the resulting map shows how a single-loop learning system might function in a caregiving setting. The presentation will review the significance of the findings in terms of prevailing theories of resistance to change: whereas the management literature often portrays resistance as an objective force within a stubborn group, the findings of this study aligns with more recent scholarship that sees resistance as arising from the pattern of interactions within specific social contexts. The presentation will conclude with a discussion of the study’s implications, which highlight the importance of qualitative methods for implementation science, and which suggest that change might best be pursued through small-scale interventions that are designed with an awareness of prevailing interaction patterns.

### **Sharing the Reins: PAR with deaf young people**

Robert Kirkwood  
*University of Brighton*

Reports from UK frontline staff suggest that deaf or hearing impaired young people are at greater risk of experiencing social and emotional isolation than their hearing peers. This problem is also highlighted in the wider literature. However, there has been minimal research conducted using collaborative methods that support deaf young people themselves to explore their own identities on their own terms.

This presentation describes the ‘See Yourself’ project, a year long participatory action research project involving 2 small groups of hearing impaired young people: the first group, attending local mainstream schools; the second, attending a local school for the deaf. The researcher/facilitator first developed partnerships with local services and agencies before initiating a therapeutic space for the young people to explore and articulate their own situations through activities. The young people created two short films as outcomes from the project; screened locally at deaf events and through a local deaf community website for wider dissemination.

Findings from the data, captured within the facilitator’s reflexive research log and analysed using immersion and crystallisation, have focused upon: the relationship between the young people and facilitator as co-researchers and subjects; the balance between the process and outcome of the project in bringing about meaningful change; the role of the facilitator to help challenge the social hegemony in which the young people may live.

The thesis presents one example of partnership working that challenges current practice within health and education, including occupational therapy, the facilitator’s profession.

### **Situated social identities: How Tłı̨chǫ high school graduates storied lived experiences of resilience**

Susan Hopkins  
*University of Phoenix*

The social phenomenological inquiry explored lived experiences of 11 Tłı̨chǫ high school graduates from the Indigenous community of Behchokö, Northwest Territories. A blended identity-based and ecological lens facilitated holistic understandings of resilience processes, lifecourse patterns, and domains of meaningful learning. Narratives revealed a bi-cultural tension

embodied in late Elder Elizabeth Mackenzie's call for Tłı̨cẖ youth to become "strong like two people": competent and confident in both an Indigenous and nonIndigenous cultural world. Deeper understandings of social identities and resilience-enhancing supports, resources, and contexts informed the development of a model of dynamic resilience for Tłı̨cẖ students and three broad educational policy recommendations. A relational research model to guide researchers working qualitatively in cross-cultural contexts or with marginalized populations also emerged.

### **Smile for the camera: Digital stories as a transformative method for prevention**

Jennifer Mullett

*Vancouver Island University*

Tanis Dagert

*Non profit*

Jessica Chenery

*Non profit*

The Vancouver Island and Coastal Communities Indigenous Foods Network initiated a strategy to reconnect First Nations with cultural teachings in order to reduce the negative health impacts of eating unhealthy introduced foods. Youth created digital stories of traditional food gathering and cultural practices and interviewed elders. Learning and using this method of documentation appeared to be a transformative experience for the youth involved. Follow up research sought to extend this experience while determining the impacts of creating and watching the stories. A participatory approach was used to train youth to do interviews and focus groups and data analysis with the researchers acting as co-facilitators to the youth in a supportive role. Each phase was documented with photos. Findings indicate that the digital stories were effective not only in conveying a prevention message to adopt healthier eating and exercising habits but addressed the psychological aspects of health as well. The youth felt a greater connection to their community, to their culture and history, more self confidence and a greater sense of pride in their identity. Some had made significant changes to their eating habits while the elders felt valued and appreciated. The format of the report to the funder is a digital story that documents the process to train the youth and the main findings. This digital story, presented metaphorically as a mystery to uncover the key successes, will be shown to the audience. Implications include investigating the transformative applications of this method with youth in other prevention contexts.

### **Street involved youth: Examining genuine partnership with street youth in qualitative research**

David B. Nicholas

*The University of Calgary*

Mandi Newton

*University of Alberta*

Avery Calhoun

*The University of Calgary*

Anne Marie McLaughlin

*The University of Calgary*

Faye Hamilton

*Grant MacEwan University*

Margaret deJong-Berg

*Glenrose Rehabilitation Hospital*

Peter Smyth  
*Child and Family Services*

Matthew McCoy  
*Royal Alexandra Hospital*

Janki Shankar  
*The University of Calgary*

Ernest Khalema  
*The University of Calgary*

Kathryn Dong  
*Royal Alexandra Hospital*

Karen Latoszek  
*University of Alberta Hospital, Stollery Children's Hospital*

Boyd Edgumbe  
*Royal Alexandra Hospital*

Collin Peterson  
*Royal Alexandra Hospital*

Lynett Kane  
*Stollery Children's Hospital*

The number of homeless youth in Edmonton and Calgary under the age of 18 is currently estimated at 509. Additionally, there are many youth involved in high-risk activities and lifestyles who are not yet classified as 'homeless,' but who have inconsistent access to food security, shelter, and health care. The purpose of this research is to examine street involved (SI) youths' experiences and needs related to Emergency Room (ER) services, and to develop recommendations for optimizing ER accessibility, responsiveness and impact with SI youth.

A participatory approach is used in the study as the literature reports a disconnection between SI youths' experiences and values relative to those of "experts" who conduct research and provide ER care. Our participatory research design is occurring in three phases: 1) engagement of SI youth, 2) focus groups with SI youth and service providers exploring existing needs, services and gaps, and 3) Delphi consultation involving SI youth, ER and community services providers and policy planning personnel. Our expectation is that the results of this study will lead to the development of a more seamless, integrated approach that addresses the multi-dimensional needs of SI youth, including health, well-being, life skills and safety. The focus of this presentation is our approach and the challenges we have encountered in ensuring a genuinely participatory approach with street youth. These ideas and the processes of project implementation will be discussed in the aim of advancing scholarship and attention to this important element of research implementation.

### **Succeeding in Level 1 of a BScN Program: A Grounded Theory Inquiry**

Carrie Mines  
*Mohawk College*

Shery Boblin  
*McMaster University*

Lynn Martin  
*McMaster University*

Jenny Ploeg  
*McMaster University*

A qualitative study using a constructivist grounded theory design was conducted at the site of a

collaborative university BScN program in south-western Ontario to look at the social processes involved in student success for the Level 1 nursing student. Recognition of the importance of the first year of post-secondary education in terms of ensuring degree completion is growing however there remains a gap in Canadian educational and nursing literature. This work will contribute to that gap and offers a substantive theory on the processes involved in succeeding in Level 1. Fifty 1:1 semi-structured interviews were conducted with Level 1 and 2 nursing students (28) as well as Level 1 nursing faculty (8), academic advisors (3) and a librarian. Four themes: Learning, Connecting, Balancing and Becoming emerged and describe the processes that the nursing students engaged in to be successful. The students described succeeding as passing, meeting my goals and being able to apply what I have learned. As the students moved through Level 1 they were learning many things: course content, stress/coping skills, time management, learning from mistakes, learning to accept their new lower grades and learning the program methodology. Establishing connections with peers, tutors, senior students and the community of nursing was crucial to their success. Balancing work and play, healthy lifestyle activities and their old vs. their new life was important. Finally during this first year they were actively engaged in becoming an adult and a professional nurse. This very personal journey brought level 1 to a successful conclusion.

**Symbolism of the Heart as a Transplanted Organ: You realize you have someone else's heart and it's kind of weird"**

Samantha J. Anthony  
*The Hospital for Sick Children*

David B. Nicholas  
*University of Calgary*

Cheryl Regehr  
*University of Toronto*

Anne I. Dipchand  
*Hospital for Sick Children*

Radha MacCulloch  
*Hospital for Sick Children*

Lori J. West  
*University of Alberta*

The mythological and symbolic qualities ascribed to the heart can complicate heart transplant (HTx) patients' acceptance of the new organ. It is posited that any change to the body inevitably transforms the self; hence this qualitative study explored possible disturbances to embodiment and personal identity which may be associated with pediatric HTx. A grounded theory approach guided data collection, data analysis and theory development. A total of 27/31 HTx patients (18 female, 67%) participated (median age 15.5 yrs; range 12.2-18.4 yrs) with a median age at time of Tx of 12.3 yrs (range 1.7-17.5 yrs) and a median time post-Tx of 3.2 yrs (range 0.3-11.1 yrs). Results indicated that many adolescent patients had emotional and psychological concerns regarding accepting a foreign organ as their own and the meaning they associated with the donated organ. This manifested in a range of responses such as sadness or guilt regarding the death of the donor and/or thoughts about potentially acquiring personal qualities or characteristics of the donor. Many participants speculated extensively about the donor and longed for donor information. A complex relationship with the imagined donor emerged, including a sense of identity assimilation. Our findings point to the psychological and meaning-making processes adolescent transplant patients encounter as they grapple with the presence of a foreign, life-giving organ within their body. This research highlights the complex process of integrating and adapting to HTx and invites future exploration of the potential impact on adolescents' concept of self and

identity which may emerge following HTx.

### **Synthesis Review of Qualitative Studies in Autism**

David Nicholas

*University of Calgary*

Lonnie Zwaigenbaum

*University of Alberta, Glenrose Rehabilitation Hospital*

Margaret Clarke

*Sinneave Family Foundation*

Wendy Roberts

*The Hospital for Sick Children*

Joyce Magill-Evans

*University of Alberta*

Michael Saini

*University of Toronto*

Lucyna Lach

*McGill University*

Radha McCulloch

*McGill University*

Deborah Barrett

*Autism Society of Edmonton Area*

Marg Spoelestra

*Autism Ontario*

The impact of autism is substantial and the need for resources often occurs on a daily basis and across the lifespan. As there is a current lack of certainty about best treatment for autism, a synthesis review was conducted to evaluate the perceived impacts and experiences of autism interventions for children and adults. Using a meta-study approach, we reviewed both qualitative and mixed method primary studies. Areas assessed in this qualitative review include theoretical base, study methods, rigor, identified outcomes, and participant experiences related to intervention. Findings from this synthesis generally convey that the provision of therapy increases positive outcomes, yet there continues to be a lack of consensus regarding best treatment for particular needs or case presentation. Further, there is a lack of clarity about approaches and their experience or perceived impact over the lifespan.

Generally, behavioral, social and pharmacological approaches have most frequently been the focus of intervention studies in ASD. Qualitative findings, although less present relative to quantitative scholarship, have an important role in amplifying rich meanings and lived experience. However, there continues to be a notable lack of qualitative studies addressing interventional experience for older adolescent and adults. This presentation will focus on qualitative scholarship in addressing the context of experience and meanings related to autism intervention. Findings, gaps and recommendations will be addressed.

### **Talking Trials: Communication Dynamics around Clinical Trials from the Cancer Patient Perspective**

Sally Thorne

*University of British Columbia*

Kim Taylor

*University of British Columbia*  
Jennifer Stephens  
*University of British Columbia*  
Charmaine Kim-Sing  
*British Columbia Cancer Agency*  
Gregory Hislop  
*University of British Columbia*

In the context of an ongoing longitudinal qualitative cohort study of cancer patients' needs and preferences across the trajectory of the cancer journey, we have harvested a subset of data pertaining to conversations between patients and their clinicians around clinical trials. Recognizing these conversations as a departure from the more routine discourses of clinical care, in that they enter into new dimensions of investment and motivation on the part of clinicians, we engaged in both secondary analysis of banked data and focussed interviewing of additional cancer patients to answer the question: How do cancer patients describe their needs and preferences for communications in relation to decisions pertaining to clinical trials participation? Our sample was generated to accommodate maximal variation in that it represents patients at various stages of their journey, including both initial and adjuvant treatment, and with a diversity of disease sites and situational contexts.

Using constant comparative techniques informed by the Interpretive Description approach to applied qualitative methodology to guide a systematic analysis of this set of data, we have documented patterns and themes across patient accounts. We contrast this thematic depiction of clinical trials discourses from a patient perspective with patterns apparent in the professional literature to tease out those aspects of communication dynamics that are particularly amenable to disruption within this delicate and nuanced communication process. Findings from this study will have implications for our understanding of the complexities of cancer care communication at the delicate intersection of patient care and knowledge generation.

### **Telephone interviews in qualitative health research**

Davina Banner  
*University of Northern British Columbia*  
Kathryn M. King-Shier  
*University of Calgary*

Telephone interviews have been used widely in large survey-based research studies; however, increasing numbers of researchers undertaking qualitative studies are using telephone interviews. Telephone interviews are a valid and useful data collection tool that can reduce costs and enable rapid data collection. For the participant, telephone interviews can be convenient and limit the intrusion caused by the presence of a researcher in their home. For the researcher, they may yield more authentic data, as participants may experience greater comfort as a result of their 'anonymity'. Additionally, telephone interviews can promote the inclusion of a wider range of research participants, particularly those living in the rural and remote communities that might otherwise be excluded from qualitative research studies on the basis of their geography. Potential disadvantages include the exclusion of households without telephones and difficulty connecting with the interviewer for those who would prefer face-to-face contact.

In this presentation, the authors will discuss the process of planning and undertaking telephone interviews and will draw upon examples from their own research programs. This includes detailing the development of an interview schedule, recruiting participants, scheduling interviews,



building rapport and responding to technical difficulties.

### **Tell Me about Your Childhood... Using Life Grids to Gather Information on Health-Related Behaviours and Experiences across the Life Course**

Shelina Visram

*Northumbria University*

Charlotte Clarke

*Northumbria University*

Martin White

*Newcastle University*

Socio-economic status and conditions are known to be key determinants of health and inequality. These factors exert influence over the life course, with both past and present health experiences being shaped by the wider social, economic and cultural context. Numerous epidemiological studies have employed a life course approach to investigate the ways in which health-damaging exposures or health-promoting opportunities contribute to social inequalities in health. Individual responses to these exposures are socially patterned and also influenced by experience. Qualitative research can be used to explore life experiences by emphasising a temporal and social perspective.

This paper examines the role of biography and context in shaping the health experiences of individuals living in socio-economically disadvantaged communities. In-depth interviews were conducted with a purposive sample of 23 participants in a lay-led health improvement intervention. A life grid approach was used to explore associations between past experiences and present health-related behaviours, and to reach a holistic understanding of different aspects of behaviour change. This paper will describe the life grid as a data collection method, present findings to offer insight into the participants' biographies, and discuss the contribution of multiple, cumulative disadvantage across the life course to contemporary health inequalities. Improved understanding of the factors that influence health behaviours and the likelihood of successful behaviour change will be of interest to policy makers and service planners. The paper also highlights the advantages and disadvantages of using a life grid approach in social (as opposed to epidemiological) research.

### **Texting Teens in Transition: Considering the use of social networking technology in research**

Gwen Rempel

*University of Alberta*

Kathryn Rankin

*University of Alberta*

Louisa Fricker

*University of Alberta*

David Nicholas

*University of Calgary*

Joyce Magill-Evans

*University of Alberta*

Andrew Mackie

*University of Alberta*

Rapidly evolving social networking technologies are emerging as data generation sources and

merit examination of risks and benefits for researchers and research participants. In an intervention study for youth with complex congenital heart disease (CHD) to prepare them for transition to adult care, texting was employed in the week following the intervention. The teen could ask further questions and the nurse could elicit data regarding intervention effectiveness. Six of eight teens indicated a preference for follow-up by texting; among these, contact by texting occurred for all. An anticipated risk of texting was that the topics addressed would be limited. In fact, a range of topics were addressed including the teens informing the nurse whether or not the transition-based 'health passport' they jointly created during the intervention was in their wallet, with whom they had talked about their health passport, and asking questions about birth control and implications of their CHD for their offspring. Texting elicited conversations that may not have occurred easily with other forms of communication. Further benefits of texting teens in research is convenience in that teens continue with their activities while they are texting as does the researcher, and the content of the encounter is recorded and thus ready for analysis. However, the richness of data for qualitative analysis remains in question. A potential risk is that sensitive information is discussed through an emerging technology that has not been widely used in research. These substantive and methodologic issues will be explored in this presentation.

### **The Discourses of Patient Care in Learning to Practice Occupational Therapy**

Darene Toal-Sullivan  
*University of Ottawa*

The current acute care setting in Canada is characterized by time-sensitivity, new models of service delivery, complexity of care, and evolving regulatory requirements. In this climate, there is relatively little understanding of how health professionals learn to practice. In particular, research is limited concerning how patient stories and health professional discourses contribute to new practitioners' learning, situated in a workplace community of practice.

This qualitative study conceptualized from a sociocultural paradigm, used an ethnographic approach to understand how beginning occupational therapists learn to practice in an acute care setting. Five practitioners with less than two years of work experience were recruited from a large teaching hospital in Canada. Semi-structured interviews, observations of clinical practice, and participant and researcher journals were used to gather data. The results suggest that patients mediated occupational therapists' learning through their stories of how they coped with illness, their level of function, expectations for treatment and plans for discharge from hospital. The patient's voice contributed to the occupational therapy assessment and shaped the development of the therapist's intervention plan. The patient chart, team rounds, and informal collaboration with colleagues were also critical discourses for learning, mediating the construction of clinical knowledge and enabling engagement in practice.

Participation in an acute care community of practice with its shared stories, activities, experiences, and traditions, is important for developing knowledge and skills among beginning occupational therapists. Identifying how to gather, understand, and use patient discourses to support initial and lifelong learning among health professionals, should constitute a research priority.

### **The Ethical Word. Discourses in Clinical Supervision in Nursing Education. Implications for Moral Education**

Guri Brit Nielsen  
*Akershus University College*

Katie Eriksson

*Department of Caring Science*

Clinical supervision is a core activity in nursing education aiming at the unification of theory and practice. The aim of the study is to explore clinical supervision as a teaching-learning activity and to develop a tentative theoretical model of clinical supervision. 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 perspective, learning in a socio-cultural perspective and using discourse analysis as the methodological approach. The participants in the study are students, clinical preceptors and 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.

The findings which will be shortly presented and illustrated with extracts from talks indicate: 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' is uncovered in the interaction and 4) the 'theory-practice gap' is upheld positioning 'theory' as dominant. Finally the findings will be discussed in an ethical perspective based on caring ethics and discourse ethics and implications for moral education will be outlined.

### **The experience of health care professionals who are assisting women with postpartum depression in Brazilian context**

Hudson Santos Junior

*University of São Paulo*

Dulce Gualda

*University of São Paulo*

Natália Rejane Salim

*University of São Paulo*

Wendy Hall

*University of British Columbia*

Postpartum depression (PPD) is a topic that has received minimal research attention in Brazil. PPD has also been neglected by management bodies, health services, and professionals. As a result, the aim of this study was to understand the experience of nurses and doctors assisting women with PPD. This was a qualitative descriptive study, conducted in Campina Grande, Brazil.

The study site was the Family Health Strategy program, which is responsible for primary care in the community. Data were collected by interview with nurses and doctors and by a field journal and participant observation. Data were analyzed inductively to produce themes.

The results showed few of the professionals considered whether women were suffering from PPD in the postpartum period. Furthermore, they had no detection strategies, such as screening tools. When a problem was identified, it originated from family members pointing out signs and symptoms. Thus, the lack of health care professionals' knowledge was directly reflected in the clinical care of women in the community. Because professionals were unsure how to manage PPD, they referred women with PPD to a specialist psychiatric service. The referrals generated further distress for women because attending the specialist psychiatric service incurred more costs and delays in diagnosis and treatment for women. In addition, because psychiatric services

managed women's PPD, the women were more likely to be exposed to unnecessary treatment, and harm to social and family relationships.

The study findings suggest health care professionals require training to detect and treat PPD in primary care.

### **The Experience of Women who gave Birth in a Brazilian Birth Center**

Natália Rejane Salim

*University of São Paulo*

Dulce Gualda

*University of São Paulo*

Hudson Santos Junior

*University of São Paulo*

Wendy Hall

*University of British Columbia*

The goal of this study was to describe experiences of women who gave birth at a birth center in Brazil.

This ethnographic study is currently being undertaken in Casa Angela, located in Monte Azul Community, a poor district on the South side of the City of São Paulo. Data are being collected by participant observation, field notes, and interview with women who gave birth at Casa Angela. The interviews were transcribed and inductive analysis was undertaken and categorized according to the similarities.

The results show categories, such as: women reported the way they learned about the birth center and factors which influenced their decisions for giving birth in that setting. Their decisions were influenced by the warm manner in which they were received and reports from friends and relatives who had difficult experiences during their births in hospital contexts. They linked attending prenatal care, participating in discussion groups, and having previous contact with the labor-assisting professionals with positive birth experiences. Respect and care were essential for the women during labor. The women indicated having partners, relatives, and friends present during the moment of the birth, immediate contact with their babies, and breastfeeding during the first hour of life were important for the quality of their birth experiences.

Given the high incidence of medicalized birth in Brazilian hospitals, with high rates of caesarean sections and disrespect shown for women during birth, the care modeled by the birth center provides a positive alternative for a childbirth experience for women and their families.

### **The Identity Conundrum: 'Naming' Research Participant Communities**

H. Bindy K. Kang

*University of British Columbia*

With today's climate of global migration, identity has become even more complex with hybrid, hyphenated and diasporic identities. When conducting research in ethnically, religiously, culturally and linguistically diverse countries, such as Canada, 'naming' aspects of identity respectfully can become a contentious issue. As researchers, working with these often marginalized communities, a greater responsibility is bestowed on us to safely and truthfully represent the voices of our participants. Additionally, we are obligated to find respectful ways to

identify their communities. As someone who shares South Asian (SA) identity, and also occupies the role of a qualitative health researcher working with the SA Diaspora, I share my reflections on 'naming' participants involved in several programs of research. This presentation will review key challenges when identifying participant communities including 1) selecting the identity label(s); 2) compounding identity markers; 3) bridging different identity labels for similar communities; 4) self-identification; and 5) colonial underpinnings. Research vignettes will serve to illustrate the identity conundrums that were revealed during discussions regarding 'naming' participant communities. The presentation will conclude with a guiding framework that will highlight practical critical engagement, self-reflexivity and cultural proficiency.

### **The influence of studying Michel Foucault's notions of askesis and parrhesia on the development of an experimental fiber artist**

Cindy Owre

*University of New Brunswick*

In this paper I explore the influence that the in depth studies of Michel Foucault's lectures on askesis and parrhesia throughout the course of doing research for my master's thesis in interdisciplinary studies (MIDST) has had and continues to have on my development as an experimental fiber artist. For my MIDST thesis I have been conducting a textual analysis of the autobiographical writings of sociologist Rod Michalko and the MFA thesis of Blackfoot multi-media artist Adrian A. Stimson. In my written work I suggest that Michalko and Stimson unknowingly emulate the Hellenistic/Roman notion of the conversion to the self as discussed by Foucault in his 1982 lectures at The College de France thus showing that these observations of 'becoming' and 'conversion of the self' in ancient Greece are still relevant in contemporary western culture.

As a part of my program I combine sociology, education, and fine arts. For the fine arts portion of my work I have been creating a body of visual work out of fiber while writing my thesis. Studying Foucault's later works and the autobiographical writings of Michalko and Stimson has indirectly influenced how I continue to understand and create myself as an artist that I can be happy being. It is this indirect influence of theory/method on my own development that I will be exploring in this paper

### **The lived experience of women on long-term endocrine based oral treatment for breast cancer**

Jane Flanagan

*Boston College*

Loren Winters

*Massachusetts General Hospital (MGH)*

Karleen Habin

*Massachusetts General Hospital (MGH)*

Barbara Cashavelly

*Massachusetts General Hospital (MGH)*

More than 80% of the breast cancer cases in women over 45 years of age are estrogen receptive (ER) positive. Treatment for this form of cancer includes a combination of surgery, radiation and/or chemotherapy. At the conclusion of this yearlong, aggressive treatment period, women are expected to initiate 5-10 more years of endocrine based oral therapy (EBOT). To date, little is known about this phenomenon. Therefore, the purpose of this study was to describe the lived

experience of women on EBOT.

The hermeneutic phenomenological design of Van Manen (1990) guided both the data collection and analysis. Four focus group interviews with 4-6 participants meeting inclusion criteria were purposively sampled from a large outpatient cancer center in the northeast United States. Five major themes were indentified. They are: 1) Being more than my disease; 2) Getting old before my time; 3) Needing to be in the driver's seat; 4) Saving face and braving the storm for others; and 5) Discovering new priorities and being vulnerable.

Women a) identified a gap in support from healthcare providers once prescribed EBOT, b) expressed a desire to tell their personal stories, and c) wanted to have a more active role in decision making around treatment. More intensive, individually tailored long-term follow up for women on EBOT is necessary and should include on an ongoing basis assessment of psychosocial support needs, side effects, and ability to adhere to the treatment plan. Women on EBOT should be offered more frequent follow-up visits and phone calls as appropriate.

### **The meaning of authentic participation for families of children with complex care needs**

Dr. Roberta Woodgate  
*University of Manitoba*  
Marie Edwards  
*University of Manitoba*  
Jacquie Ripat  
*University of Manitoba*

Although there is a growing body of literature focusing on the experiences of families with children with complex care needs, warranted is work that details how the changing geographies of care impact on their ability to participate in communities. We utilized multiple data collection methods (open-ended interviews, ecomaps, photovoice) to detail, longitudinally, how 40 families of children with complex care needs participate within communities. This study revealed that the changing geographies of care influenced the participation of all family members. For the families in this study authentic participation was equated with having a life. Having a life referred to being engaged or involved in a place where families feel that they belong, are accepted, and are able to contribute to the landscape. The decision to choose to participate became contingent upon accessibility and the availability of resources, and the parents' ability to harness them. Harnessing resources referred to the work parents must do to obtain the necessary resources to make it possible for them and their children to have a life. Having a life for families of children with complex care needs required significant physical, mental, psychological and spiritual work by parents. At times the personal resources of parents were so taxed that the possibility for authentic participation was minimal. The families' stories raise questions of justice and societal obligations to promote authentic participation. This study provides grounding for strategic improvements that may enrich the lives of children with complex care needs and their families.

### **The Nature of Relationships between Care Aides and Residents in Long Term Care Facilities**

Elizabeth Andersen  
*University of Alberta*  
Judith Spiers  
*University of Alberta*

Long term care (LTC) facilities may be home for residents for months or years. Contemporary approaches to organization of these settings prioritize a home-like atmosphere as much as possible. However, there is very little research exploring how employees experience this as a workplace context. In most LTC facilities care aides are the employees in closest contact with residents. The purpose of this focused ethnography, with 22 care aides from five LTC facilities in a western Canadian city, was to explore their perspectives of their roles and relationships with residents. Experiential interview data was collected and analyzed utilizing constant comparison to identify common themes. Preliminary findings indicate that the dominant Eden Philosophy of Care, an elder-centered approach promoted to improve the quality of life for residents in long-term care institutions, has had an opposite effect for quality of work life for care aides. To incorporate the Eden Philosophy, aides in the five facilities were assigned to "families" of residents. However, this resulted in care aides working alone when caring for their "families", and feeling very much alone at work. The "family" philosophy also led to an increase in care aides' overall responsibilities and stress. Many expressed a desire to return to teamwork for collegial companionship and support. There is a paucity of research evaluating the effects of this type of assignment for care aides. These findings will be of interest to practitioners and policy makers who are considering the implications of this type of philosophy of care.

### **The Pathway to Making Change: How Parents Promote Health for their Overweight or Obese Child**

Jennifer Laurent

*University of Vermont*

**Background:** The U.S. is experiencing levels of child overweight and obesity that are among the highest in any country in the world. An estimated 31.7% of American children are overweight or obese. Despite the prevalence and numerous approaches developed to prevent or treat overweight or obesity in children, many parents remain unaware of their child's weight status, and weight loss efficacy and long-term outcomes are deficient.

**Objective:** The purpose of this study was to describe the experiences of parents as they promote the health of their overweight or obese child and elucidate the complex matrix influencing their knowledge, choices, actions, and reactions during this process.

**Method:** Grounded theory methodology guided data collection, interpretation, and analysis.

**Results:** The findings included the construction of a theoretical model that represents how parents came to know their child was overweight or obese and the process of promoting health based upon this knowledge. This model consists of a social process called the Pathway to Making Change, which encompasses 5 major categories: Parental Discovery, Taking the Lead, Making Change, Engagement, and Teamwork. Each category comprises subcategories that detail the facets of the parental experience.

**Discussion:** This model highlights the complexity associated with obesity awareness, parenting and promoting the health of an overweight or obese child in our current obesogenic environment. Several new themes emerged during this study warranting further investigation such as the process of discovery and parental awareness, the tipping point, the role of the healthcare provider, food intimacy, and team building.

## **The Role of Childhood Cancer Camps and Survivorship**

Asher Beckwitt, Ph.D.

*Asher Consulting, LLC, American University*

Childhood cancer camps provide support and information for children and their families during and after the diagnosis period for cancer. Little is known about the ongoing role childhood cancer camps continue to play in Adults Surviving Childhood Cancers (ASCCs) lives. The purpose of this study was to examine ASCCs camp experiences, to understand the role camps play in enhancing their psychosocial well-being and access to resources overtime.

This research study employed a qualitative content analysis approach to examine twenty-three ASCCs in-depth interviews. Participants were recruited from nine childhood cancer camps located throughout the United States. Participants were 18 years old or older at the time of the interview. ASCCs were identified as having cancer between the ages of 1 and 18 years old. Most of the participants were white non-Hispanic (n= 19). In addition, participants were Asian American (n=2), Hispanic (n=1), and African American (n=1).

Results suggest that childhood cancer camps play an important role in providing ASCCs with emotional and informational support overtime. ASCCs who returned to camp as counsellors or attended retreats experienced opportunities to relate to campers and one another, develop close friendships, and connect to the cancer community. ASCCs also identified receiving important information at retreats regarding physical late-effects, navigating the healthcare system, financial matters, and personal issues. Further research is necessary to investigate how to utilize childhood cancer camps to provide ongoing psychosocial and educational support to ASCCs.

## **The role of secondary data analysis in programs of qualitative research**

Gwen Rempel

*University of Alberta*

Laura Rogers

*University of Alberta*

Vinitha Ravindran

*University of Alberta*

Catriona Blythe

*University of Alberta*

The purpose of this paper is to explore methodological implications of linking qualitative studies within a program of research using secondary data analysis to expand on original research findings. This work is set within a research program focused on delineating processes for parenting children with complex heart disease. We will outline new questions that have grown out of the findings of each study and the studies collectively, and show how we have reanalyzed our existing data sets to begin answering these questions. We will discuss our work within the methodological literature on secondary analysis and show how we use sensitizing concepts as developed by Charmaz, cross validation and analytic expansion as developed by Thorne, and supplementary analysis as developed by Heaton. Topics for discussion include: 1) How does secondary analysis differ from original data analysis? 2) Under what circumstances is secondary data analysis appropriate? 3) What aspects of rigour need to be considered when doing secondary analysis? 4) What are the ethical issues in secondary analysis? 5) What are the implications for secondary analysis for publication? This paper will be of particular interest to early career researchers and students who are planning their programs of research.



## **The Role of the Clinical Skills Laboratory in Preparing Students for the Real World of Practice: A Qualitative Multiple Case Study**

Dympna Casey

*National University of Ireland, Galway*

Catherine Houghton

*National University of Ireland, Galway*

David Shaw

*Chilterns University College*

Kathy Murphy

*National University of Ireland, Galway*

The aim of this presentation is to discuss research exploring the role of the Clinical Skills Laboratory (CSL) in preparing student nurses for the real world of practice. This qualitative investigation employed a multiple case study design. Five case study sites were selected from 13 Higher Education Institutes (HEI) that offer the Bachelor of Nursing Degree Programme in the Republic of Ireland. Data were collected using semi-structured interviews, non-participant observation in the clinical setting and documentary analysis.

The analysis revealed two principal themes. Firstly, Creating a Bridge to Practice described the teaching and assessment strategies in the CSL and explored participants' perspectives of the role the CSL in creating a pathway from theory to practice. Secondly, The Reality of Practice discussed the factors that facilitated or hindered students' implementation of skills in clinical practice. Key factors in this theme included the support and supervision given to students and how students "fit in" while on clinical placement. The documentary analysis provided the context for the process of student learning during the four year programme.

The exploration was guided by learning and socialisation theory. The discussion centred on how students learn and adapt to the clinical setting. The role of the CSL was then clarified relating to how it could prepare students for the real world of practice, namely with the provision of authentic learning opportunities that help in the development of students' confidence, communication skills, critical thinking and ability to reflect.

## **The Use of Photovoice in Understanding Risk for Older Adults**

Kathy Rush

*University of British Columbia Okanagan*

Mary Ann Murphy

*University of British Columbia Okanagan*

Photovoice is a qualitative, participatory research method designed to give voice and language to research participants' most significant concerns and priorities. It was used to study how older adults construe risk; a common, complex, but little understood concept in gerontology and geriatrics. Photovoice provided an opportunity to access the complexity of risk while anchoring it to what older adults believed to be relevant to their situation. It recognized older adults as experts in their own lives, partners in the research, and creators of images and text. Through photographs, logs, and individual interviews, 17 community residing older adults provided a subjective view on living with, experiencing or anticipating a variety of risks that could affect their health, quality of life, or ability to live independently. Additionally, participants were invited to share their perspectives of photovoice. Participants conveyed balanced views of risk; often beyond risks health care professionals admonish older adults to consider. Drawing on study findings, this

presentation will offer a critique of the merits and challenges of using photovoice with older adults and as a way of understanding the phenomenon of risk. It will address questions such as: Did it facilitate an inclusive approach to understanding risk for older adults? Did it bias what was accessed in terms of risk? Were photographs necessary to assess risk? Images will be used to illustrate the critique and highlight implications of what was, and was not, included in the visual depiction in representing risk perceptions of older adults.

### **“They’re her boobs, it’s up to her, it’s not up to me”: Gendered dimensions of infant feeding decisions**

Helen Prosser

*University of Salford*

Increasing breastfeeding rates is an important public health issue and a key priority for tackling health inequalities, particularly for women in low socioeconomic status (SES) groups who are less likely to initiate and continue breastfeeding. Despite much attention on factors influencing mothers’ decision-making about breastfeeding, less attention has been directed to the role fathers’ play. Drawing on a wider qualitative study of factors influencing infant feeding choices in an area of low breastfeeding rates in the UK, semi-structured interviews were conducted with 24 fathers of babies who were formula or breastfed. This paper explores the role of fathers in decision-making around infant feeding, and highlights the gendered influences and attitudes on participation in decision-making. Fathers reported little active engagement in decision-making and findings highlight how feeding choices are often framed as mothers’ responsibility. Regard for women’s governance over their own bodies, together with notions of infant care-giving as primarily a female activity featured prominently in fathers’ rationalisations. However, while some fathers do conform to traditional gender norms, when analysed closely accounts suggest a more complex set of gender roles where some fathers are keen to become active participants in decision-making and breastfeeding support, but often lack the knowledge of how to do so. The net outcome is that the gendered nature of decision-making positions mothers as responsible for breastfeeding success, and without support, renders them vulnerable to early breastfeeding cessation. Interventions to promote and support breastfeeding should proactively encourage the inclusion of fathers.

### **Through the lens of experts: Tackling stumbling blocks of access to health care services in GTA**

Mahdieh Dastjerdi

*School of Nursing, York University*

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. Creating social changes are vital for improving immigrants’ well being, integration, and self-sufficiency. The specific aim of this research was to understand and identify obstacles in accessing health care services through the lens of Iranian healthcare professionals and social workers in Greater Toronto Area (GTA). Using narrative inquiry method, I conducted 20 in-depth semi-structured interviews with 15 health care professionals, and 5 social workers. To capture the essence of issues, interviews were followed by one focus group with health care professionals and one focus group with social workers. Four primary themes emerged from the study as follows: “lack of knowledge of Canadian healthcare services/ systems”, “search for shortcuts and alternatives”, “negotiate to understand the problem”, and “standing on their own

two feet and becoming self-sufficient". Although language is a key factor, findings recommend that appropriate, effective, acceptable, and responsive services play an important role in the way Iranian immigrants access to the health care services they need. In conclusion, to attain equitable, adequate, and effective access to healthcare services, immigrants need to be educated and informed about the Canadian health care system and services it provides. Health care providers should build a strong relationship with their own communities and provide them basic information about health care services/system in Canada.

### **Toward a dialectical hermeneutics of cancer narratives**

Chad Hammond

*University of Saskatchewan*

Ulrich Teucher

*University of Saskatchewan*

Cancer can be talked about in a number of different ways. Within this presentation I look at two common discourses, or cultural narratives, about cancer. The first is a "death discourse", in which cancer is defined as a tragic loss of identity, ability, meaning, and eventually life. The second discourse is a "spunky survivorship discourse" (Sinding and Gray, 2005), in which cancer is portrayed as a positive experience of existential awakening, a triumphant return to health and 'normalcy', and maintenance or discovery of ability. Neither of these two discourses is attentive to the diverse ways people actually talk about their cancer experiences, opting instead for some absolute truth about 'the' cancer experience. In resistance to these dominating discourses, I offer a form of non-absolute interpretation of cancer narratives, a form of 'dialectical hermeneutics'. This methodology has an eye for tensions in the act of interpreting a narrative, especially those that make it difficult to arrive at a singular interpretation. I apply this methodology to research interviews with a few aging cancer patients, showing how the two discourses above are negotiated and contradicted by individual narratives of cancer. I argue for a more dialectical approach to studying narratives, which may help researchers and health professionals to better appreciate the complexity of each person's experience of cancer.

### **Treatment Burden and Chronic Heart Failure: Why We Need More Person Centred Care**

Frances Mair

*University of Glasgow*

Susan Browne

*University of Glasgow*

Katie Gallacher

*University of Glasgow*

Deborah Morrison

*University of Glasgow*

Fiona Smith

*University of Glasgow*

Una Macleod

Hull and York Universities

Victor Montori

Mayo Clinic, Rochester, Minnesota

Carl May

University of Southampton

**Introduction & Aims:** Heart Failure (HF) is a major public health problem and it is acknowledged that HF symptoms have a negative impact on the daily lives of those afflicted with the condition. The aim of this study is to examine patient experiences of managing their condition, with a particular focus on their “treatment burden,” defined as the “work” they do to undertake self care and respond to the requirements of healthcare providers. It is essential to understand these issues if we are to be able to design more person centred services.

**Methods:** This study involves semi-structured interviews with HF patients with HF severity ranging from mild/moderate to end stage and examines the work they do to manage and “live” with their condition. Qualitative data analysed using framework methods informed by Normalization Process Theory (NPT).

**Results:** Forty individuals with HF identified. The key components of treatment burden were identified, with most clearly being secondary to the way health care systems are currently organised with an emphasis on disease centred rather than person centred care. Main themes identified included: logistical burdens (e.g. chasing up test results); technical burdens (e.g. coping with polypharmacy); relational burdens (e.g. coping with discontinuity of care); and sense making burdens (e.g. learning about management strategies).

**Conclusions:** This study has identified factors that increase the burden on those suffering from heart failure and highlights potential targets for personalising care and lessening burden.

### **Understanding stigma and discrimination as social processes: Analyzing narratives of suffering and agency from people living with HIV/AIDS in Delhi, India**

Shamshad Khan  
*University of Manitoba*

The HIV/AIDS pandemic, despite some early signs of decline, calls for urgent attention to addressing stigma and discrimination which continue to remain pervasive and are major barriers to effective interventions. A critical analysis of stigma shifts the gaze from narrow socio-psychological conceptualizations to a more structural understanding that shows how stigma is inextricably linked to other social inequities and how they converge in relation to HIV/AIDS.

In this paper, drawing on a critical ethnographic research done in India, and using narratives and case studies, I focus on the experiences and struggles of people living with HIV/AIDS (PLWHA). In particular, I critically examine the socio-economic conditions that made them vulnerable to HIV, their varied experiences related with counselling, testing and disclosure of their HIV status, experiences within their families and communities, and finally with the health services system and employment. In addition, I draw links with the policy and power relations in which their lives are deeply embedded.

Drawing on the experiences of PLWHA and using them as a set of lenses to understand policy and broader social relations is critical as it not only brings forth alternative perspectives, often blocked by the dominant discourse, but potentially changes the PLWHA from being objects of research to becoming active subjects. This paper showcases HIV/AIDS as a socially mediated illness and highlights the urgent need to address socio-economic contexts of people’s lives to effectively deal with issues of stigma and to increase access to effective healthcare for PLWHA.

## **Understanding the construction and consequences of ‘accepting’ persistent pain in older age**

Fiona MacKichan

*University of Bristol*

Joy Adamson

*University of York*

Rachael Gooberman-Hill

*University of Bristol*

Prevalence of persistent pain increases with age, and older adults face unique challenges living with and responding to pain. Despite its known impacts, relatively little is understood about the experiences of older adults with persistent pain, or how these relate to illness behaviour. Under-reporting of pain is commonplace and has previously been attributed to age related expectations and ‘stoicism’.

This paper reports the qualitative findings of a mixed-method doctoral study that sought to explore the construction of persistent pain in older age and how this informs illness behaviour. Thirty one in-depth face-to-face interviews, drawing on biographical research methods to map interviewees’ pain ‘careers’, were conducted with adults aged 67 to 92 experiencing persistent pain purposively sampled from a community-based postal survey of 2,962 adults living in South West England.

Through a constructivist grounded theory analysis, a model for adaptation to persistent pain in older age was developed whereby normative views, and experiences of seeking help, can engender both a literal and a moral imperative to ‘accept’ pain. Acceptance is dynamic, with consequences that may be both beneficial and detrimental to health and wellbeing in older age.

This research draws links between aspects of persistent pain in older age which helps to account for low rates of help seeking, highlighting potential unmet need and providing insight into the social construction of ageing. As well as reporting research findings in this paper, I will reflect on the use of constructivist grounded theory and biographical methods in the study.

## **Using life history to explore the experience of living with a rare chronic illness, lymphangioleiomyomatosis (LAM)**

Denise Haylen

*The University of Sydney*

Murray J. Fisher

*The University of Sydney*

Joanna Patching

*The University of Sydney*

Life history can be used effectively in qualitative health research to investigate the experience of living with chronic illness. This method is holistic and captures multiple aspects of the illness experience across time, including critical events and how they impact on the whole life, the physical effect of the illness, personal meaning and social context.

A case study is presented using life history to explore a 35 year old woman’s experience of lymphangioleiomyomatosis (LAM) over her life course. LAM is a rare, incurable, chronic condition characterised by progressive cystic lung disease and eventual respiratory failure, affecting almost exclusively women, usually during their childbearing years. Prevalence is 3-5

per million people and can affect women of all races.

Data was obtained from two semi-structured interviews with Anna (pseudonym) and her medical record. Analysis, using Rosenthal's (1993) method of narrative analysis, included the life story as narrated by Anna; construction of the Biographical Account, the objective facts of the illness; and reconstruction of the Life History, in which Anna's experiences were reconstructed in chronological sequence representing her past perspective. Differences in the significance of experiences between Anna's subjective perspective and the objective medical view were revealed by contrasting her life story with the Biographical Account. Comparison of the narrated life story with the reconstructed Life History demonstrated how the meaning of the illness experience changed over time. LAM was experienced by Anna as a series of biographical disruptions and transformations influenced by her social context and the rarity of the illness.

### **Using Mixed Methods to Evaluate Multi-Cultural Survey Questionnaires**

Gordon Willis

*National Cancer Institute, National Institutes of Health*

The testing and evaluation of survey questionnaires often makes use of qualitative methods such as cognitive interviews and focus groups. Alternatively, researchers apply quantitative methods, including statistical analysis of interviewer-respondent interaction paradata, and analysis of Differential Item Function (DIF) through Item Response Theory (IRT). It is rare, however, to incorporate these respective approaches within the same study, according to a mixed-methods approach. Further, researchers have not identified the degree to which these methods produce information that is unique versus redundant, or complementary versus divergent. The current investigation evaluated the functioning of health survey items across multiple cultural and linguistic groups (including Non-Hispanic White, Hispanic, Black/African-American, Chinese, Korean, and Vietnamese), applying cognitive interviewing as a qualitative method, DIF-IRT as a quantitative method, and behavior (interaction) coding in a form having both qualitative and quantitative elements. I will compare the results obtained through application of each method, and determine whether these in fact converged to produce systematic results and conclusions. Finally, I will make recommendations concerning the use of mixed survey pretesting methods, especially regarding the key challenge of balancing the relative strengths and limitations of each. The results of this study will serve to augment the expanding literature on the use of mixed methods in social-science and health research.

### **Using photo-elicitation methods to understand fathers' attitudes towards injury and risk**

Mariana Brussoni

*University of British Columbia*

Lise Olsen

*University of British Columbia*

Genevieve Creighton

*University of British Columbia*

John Oliffe

*University of British Columbia*

Anne George

*University of British Columbia*

Pierre Maurice

*Institut national de santé publique du Québec*

The unique roles fathers play in encouraging exploration and risk taking requires further research. In our CIHR-funded study, we are using qualitative methods to investigate fathering as it relates to child injury prevention. We are interviewing mothers and fathers of children aged 2 to 7 years old in rural and urban settings in BC and Quebec. In addition, fathers are provided with a camera and asked to take photos of any injury related concerns as well as risk activities they engage in with their children. In a subsequent photo-elicitation interview, we obtain their narrative regarding their photos. A social constructivist gendered perspective is providing a lens from which to consider fatherhood, masculinity and the construction of parental roles related to child injury prevention. To date, fathers and mothers have provided a wealth of material and the photo-elicitation method has proven a fruitful source of data, adding depth and texture to our understanding of their experiences. For example, a dominant theme identified in the interviews relating to the role fathers perceive risk to play in their children's lives has been richly illustrated in the photographs. Many photos have depicted a variety of risk environments, use of protective equipment, as well as engagement in risk activities with their children. In this presentation, we will present some of the fathers' photographs to illustrate our findings.

### **Using Walk-Along Interviews to Examine Perceptions of Landscapes for Play**

Homan Lee

*University of Alberta*

Carrie Millar

*University of Alberta*

John Spence

*University of Alberta*

Nicholas Holt

*University of Alberta*

The purpose of this presentation is to evaluate the use of a unique interview approach used for the purposes of understanding the individual, social, and environmental influences of play. Our study examined the places, meanings, and experiences young people associate with the 'playscapes' where as children they engaged in active free play.

Thirteen undergraduate students (4 male and 9 female; age range = 18-21) who lived in Edmonton and surrounding area for at least 10 years participated in this study. Data collection techniques were adopted from Kevin Lynch's work in creating an "'image of the city'" to focus on the issues of play. We will discuss the use of a semi-structured interview followed by a 'walk-along' interview. The semi-structured interview was reflective in nature, focusing on the participants' memories of play. Following this, the research assistant and participants visited the remembered playscapes (i.e., playgrounds, parks) and asked participants to walk through and describe the environment, their memories, and any changes that had taken place since they were a child. The walk-along interview provided a unique context and may effectively access memories of places using the built environments. Examples and practical suggestions concerning the effective use of walk-along interviews, coordinated analysis of data, challenges associated with the approach (e.g., logistical factors, dropout), and ways in which the techniques may be adapted to other research issues examining perceptions of 'places' will be discussed.

### **Utilizing hermeneutic phenomenology in a secondary analysis to understand the lived experiences of patients with chronic obstructive pulmonary disease**

Jane Flanagan

*Boston College*

It has been suggested that patients who have experienced abuse early as children may have consequences related to chronic illness as adults, yet when adults present with chronic disease, the focus is on immediate treatment and symptom management. This approach does not consider the whole person or their lived experiences.

Fourteen participants meeting inclusion criteria were interviewed in their home at 3 time points post hospitalization using Newman's (1994) Health as Expanding Consciousness Methodology. Findings from this analysis provided insight into the life processes and patterns of individuals who recently had an exacerbation of COPD.

An across analysis approach to the data is not supported by Newman (1994), yet in this preliminary analysis, it was noted that all of the participants described abuse and/or abandonment early in life. Therefore, it was necessary to utilize a philosophically congruent approach to conduct a secondary analysis across participants. In using Van Manen's (1990) hermeneutic phenomenology (HP) four themes were identified: 1) It's just the way things are; 2) Keeping it in the family; 3) Finding a way out before being trapped; 4) Persisting or resigning, but always carrying the sorrow for what could have been.

While Newman's (1994) methodological approach provided insight to individual choices and potential, there were limitations. Applying Van Manen's (1990) HP was philosophically congruent approach for a secondary analysis. These findings have implications for screening those with or at high risk for chronic illness for childhood loss and/or abuse to determine linkages, and the need for early intervention.

### **Views of nurse and union managers about staff retention in South Africa**

Zethu Nkosi

*University of South Africa*

**Background:** South Africa is experiencing a shortage of nurses due to poor retention strategies. The highly skilled nurses are leaving the country to go and work in developed countries. The remaining nurses are overburdened with work which led to job dissatisfaction. This project is part of the bigger study which was analyzing the relationship between leadership styles, organizational factors and retention of professional nurses in public health care facilities in KwaZulu-Natal.

**Objective:** The aim of this study was to explore the views of both nurse and union managers on the retention of professional nurses.

**Design:** A qualitative approach, using individual in-depth interviews was held with all participants Chief Professional Nurses (4) and union managers (4) formed part of the study.

**Results:** The themes that emanated from the study showed positive and negative views from both managers in terms of retention. There were also conflicting views between the union managers and the chief professional nurses.

**Conclusion:** The findings suggest that nurses will stay in their organizations if the leadership style of nurse managers is visible and accessible. Government support was also rated high in retention of nurse. Lack of information in terms of Labour Relations Act was also a stumbling block to the efficient management of the departments.



### **Wait, Won't!, Want: A Qualitative Study of Barriers to Health Care as Perceived by Medically and Socially Disenfranchised Communities**

John M. Clochesy

*Case Western Reserve University*

Lisaann S. Gittner

*Case Western Reserve University*

Ronald L. Hickman, Jr.

*Case Western Reserve University*

Jerry E. Floersch

*Rutgers University*

While it has been recognized that there are patient-level and system-level factors that contribute to healthcare disparities, much of the effort to date to reduce health disparities has focused on the composition of the healthcare workforce, the cultural competence of providers, the role of community participation, changing access to care and mobilization in promoting health. However, healthcare workforce and system changes can only go so far. Health outcomes can be optimized only when individuals take a more active role and contribute to their own healthcare. Individuals who recognize that they are partners in their healthcare understand that self-management assures their health is appropriately managed. Healthcare is delivered in a provider-patient partnership where both parties make contributions to the treatment plan.

We explored barriers to healthcare as perceived by members of medically and socially disenfranchised communities by conducting focus groups with 28 women and 32 men from Northeast Ohio who identified themselves as African-American, Hispanic/Latino, lesbian/gay/bisexual/transgender and/or Russian immigrant using a Gestalt approach.

Participants described their experiences of waiting, things they won't tolerate, when they won't participate, and what they want from providers. They described behaviors, actions and relationship characteristics that they want from their providers and characteristics that they prefer in health systems. Additionally, a potential cognitive and behavioral strategy, SBAR3, was identified based on successful self-management practices described by the participants. Future efforts should focus on testing patient-centered strategies that address the themes identified to increase engagement to increase self-management of health. "

### **"We Are All in the Same Boat:" Nurses' Experiences of Working in a Shared War Reality**

Hadass Goldblatt

*University of Haifa*

Background: The Israel-Hezbollah war of 2006 placed the entire civilian population of northern Israel under missile attack, creating imminent danger and a shattered sense of security. Healthcare providers had to be immediately available to work with war victims, while exposed to their clients' traumas alongside their own and family members' anxieties. In this situation, survivors and their helpers experienced similar traumatic events during a specific period of time. Research on shared war reality is relatively new, emphasizing mainly psychological distress, but also positive change and growth among practitioners. Nurses, specifically, have received sparse attention. This study explored the experience of Israeli nurses who shared a war-related reality with their patients in summer 2006, and its impact on their professional and private life domains.

Methods: In-depth semi-structured interviews were conducted with a purposive sample of 12

nurses, men and women, Jewish and Arab, working in two major northern Israeli hospitals. Interviews were tape-recorded and content-analyzed.

**Findings:** Nurses experienced hospital space, peer support and their own strong commitment to their nursing role as anchors for security and empowerment. Provider-patient relationships were unusually manifest through mutual concern, transforming meanings of traditional provider-patient relationship boundaries. These themes will be discussed using phenomenological concepts of human experience (time, space, significant others and intentionality).

**Implications:** The study findings can enrich the understanding of states-of-war and terror worldwide, where professionals faithfully provide assistance while exposed to the same hazards as their patients. Consequently, the work milieu becomes a source of meaning, protection and personal growth.

### **What Am I Supposed to do Now?: Patient Perceptions of Communication Needs and Preferences Associated with the End of Initial Cancer Treatment**

Kelli Stjduhar

*University of Victoria*

Sally Thorne

*University of British Columbia*

Joanne Reimer

*University of British Columbia*

Cancer patients reach the conclusion of their initial course of active treatment with an expectation that life will return to normal, and that the level of expert care they have been experiencing in the cancer care system will evolve into a coherent follow-up approach protecting them into the future. Instead, many encounter end of initial treatment as an abrupt end to the services and relationships upon which they have come to depend, and the beginning of a new and highly complex survivorship process. In the context of an ongoing longitudinal qualitative cohort study of cancer patients' needs and preferences across the trajectory of the cancer journey, we have gathered a subset of data pertaining to patient accounts of communications with their clinical care providers around the end of treatment experience. Analysis of common patterns and themes in these accounts guided by an interpretive description approach has yielded numerous contradictions, confusions and paradoxes associated with the experience. Patients' recollections of what was said and done, how it felt, and how their clinical communications influenced their practical and psychosocial worlds reflected both common patterns and variational diversities that illuminate the complexity of this particular element of the cancer care trajectory and confirm the inadequacy of current understandings in relation to how we can optimally support patients during this transition. The findings of this study provide a lens through which we can critically reflect on and ultimately improve standard practice in guiding patients toward this complex experiential phase in their cancer journey.

### **What influences prescribing behaviour in general practice? An ethnographic exploration**

Aileen Grant

*University of Dundee*

While the new health management and audit cultures emphasise the importance of research evidence, the persistence of prescribing variation in general practice suggests some resistance to these control measures. This raises questions about 'what influences prescribing in general

practice’.

An ethnographic study, involving participant observation, semi-structured interviews and a review of practice documentation allowed an in-depth comparative study of three different general practices in Scotland. These findings revealed that prescribing decisions were made in two contexts; macro and micro, and were influenced by different factors.

Macro prescribing decisions were collective; population decisions considering the average patient and were influenced by research evidence and clinical governance. Micro prescribing was made during patient consultation and considering their unique circumstances. When making micro prescribing decisions GPs relied on internalised personal formularies and clinical judgement. The macro prescribing analysis drew on Weick et al’s (2001; 2005) work on organisational sensemaking. The micro prescribing analysis drew on Gabbay and le May’s work on knowledge management ‘mindlines’ (2004).

It is argued that practices had an identity, shaped by their practice values, organisational structure and communication channels. Practices engaged with research evidence and clinical governance mechanisms which were aligned with their values and identity. At the micro prescribing level GPs drew on personal formularies and clinical judgement, informed and updated by social networks. Current managerial initiatives seeking to influence prescribing focus on macro prescribing, which limits their effectiveness. Further research is required to understand the complexities of micro prescribing and the mechanisms through which evidence becomes internalised.

### **What is shared in a social representation?**

Jose Alfredo López Huerta

*Universidad Autónoma de San Luis Potosí*

Rocío Angelica Gonzalez Romo

*Instituto de Investigacion y Posgrado*

The purpose was to identify the contents of information shared between patients and caregivers about cancer. To get this information we focused on the next techniques: Semi standardized interview and focal groups.

We interviewed 22 primary caregivers and 14 patients and until the moment we did two session with focal groups only with primary caregivers. Our research question was, what is shared in a social representation?

The shared information come from similar people, it’s mean living similar situation. In their speech we could identify through content analysis the next categories:

Social support, economics factors, seriousness and explanation about illness and alternative treatments.

Based on these categories, the original representation is reconstructed up to a new representation of cancer. This reconstruction is as follows: The emergence of signs, diagnosis about illness, adoption of a representation principally from the media, uncertainty about the ignorance surrounding the disease, familiarity with the disease and the new environment, acceptance phase and finally emerges a new representation. Throughout this process, the categories are the contents that shaping a new representation.

In conclusion we note that the background nearby the person is more relevant than information from doctors in the construction of the representation of the disease. As a proposal we believe that the same patients or caregivers should be involved with the doctors at the time of diagnosis communication, and subsequently integrate support groups. This would greatly help patients and their primary caregivers in their disease process.

### **When is a focus group not a focus group? Use of online technology within qualitative research**

Julia Williams

*University of Hertfordshire*

Qualitative research continues to grow with regard to new methods of data collection embracing different forms of information technology (IT) and its associated contributions. One noticeable area of development is the increasing popularity of online focus groups. This presentation explores some of the challenges of employing these modes of data collection examining both synchronous and asynchronous online focus groups and looking at when it is most appropriate to use the different types. Drawing on published literature and illustrating the presentation with examples from my own work involving paramedics and student paramedics in the United Kingdom in online focus groups, the discussion will include a comparison of these approaches with face-to-face focus groups identifying practical and philosophical considerations of the new methods. This will include topics such as challenges to effective facilitation of online focus groups; how to keep the momentum of the discussion going in asynchronous online focus groups; whether it is essential to have rapid keyboard skills to participate in online focus groups; ethical issues and the related challenges to anonymity and confidentiality. By exploring some of their strengths and limitations it is intended to address the following questions: should these online approaches really be referred to as focus groups? Are they more similar to commercial chat rooms or group discussion facilities frequently found in virtual learning platforms in many universities? Is it time for online focus groups to be assigned a new name and recognised in their own right as valid and unique data collection methods?

### **Where is home? Using theatre to facilitate the empowerment of immigrant youth to uncover challenges and opportunities that influence wellness**

Yasmine Kandil

*University of Victoria*

Sarah Fletcher

*University of Victoria*

Immigrant youth are often forced to navigate multiple identities in multiple social and cultural contexts, a process that can result in high levels of stress. For the past two years a theatre project at the Victoria Immigrant and Refugee Centre Society has worked with immigrant youth to develop theatre pieces presenting the experiences of immigrant youth to the wider community. The performances were of great value to both the youth involved and the wider community audience, but it was the participatory action research influenced process of developing the theatre pieces that highlighted the potential of this method for engaging marginalized youth in research. The youth engaged in discussions and scene-work, uncovering the multitude of influences that can cause challenges or facilitate opportunities in the lives of immigrant youth. The theatre work revealed coping strategies and factors that can contribute to resilience and success for immigrant youth, as well as the challenges in their lives. Focusing on the process of engaging youth in

theatre work, this paper will present the use of theatre as methodology for engaging marginalized youth in research and empowering youth to explore their experiences. This discussion will provide recommendations for those hoping to engage in this type of research in the future. Focusing on the ability of theatre to facilitate discussions of difficult issues at a phenomenological level and for bringing youth out of isolation, highlights the potential of theatre as a method that can work to build a sense of connection and community among marginalized youth.

### **White Man's Sickness: Understanding Heart Problems and Healing Expectations in Aboriginal Women**

Maria Medved

*University of Manitoba*

Jens Brockmeier

*University of Manitoba*

Judy Morach

*Opaskwayak Health Center*

Lori Chartier

*Sagkeeng Health Center*

Aboriginal women present with the highest rate of cardiovascular disease (CVD)—a disease commonly viewed as a “white man’s sickness,” and as a consequence they also have the highest CVD mortality of any population group in Canada. At the same time, little research is available with regard to the way in which these women perceive and deal with this disease. Against this background, this study seeks to examine Aboriginal women’s understandings of their heart problems and their healing and rehabilitation. Sixteen Aboriginal women from two First Nations who had heart problems for at least five years participated in in-depth interviews that were interpreted using narrative-discursive methods. The stories indicate that one function of the women’s illness stories is to localize themselves within a familial genealogy of sickness, linking past to present, and ancestors to themselves. Only one of the women explicitly mentioned seeking traditional Aboriginal medicine, whereas the others referred to Western recovery strategies. While the women indicated they were willing to take pharmaceutical medications, they expressed ambivalence and in many cases anger in relation to recommended heart healthy lifestyle management practices, which they perceived as a form of control. The findings will be interpreted within the context of the history of colonization, and suggestions for a culturally sensitive approach to heart health will be offered.

### **Who are qualified for surrogacy**

Tayebe Ziaei

*Golestan University of Medical Sciences*

Fatemeh Ziaei

*Gorgan Educational Organization*

Khadijeh Ghobadi

*Golestan University of Medical Sciences*

Mohammad Reza Ziaei

*Technical and Professional School*

In surrogacy, it is expected that the circumstances during pregnancy and birth may influence parents' thought, feelings, and behavior with each other and towards their child. Therefore, it is

important determine eligible criteria for who should be a surrogate mother.

This qualitative research was performed using semi structured individual interview on 22 female and 26 men. They recruited by theoretical sampling and saturation of data determined the number of them. The researchers analyzed Participants' responses for content with regard to gender.

Content analysis showed that, both gender believed that as well as demographic factors, mental , physical health, the marital status of surrogate mother is very important as an eligible criterion too. In contrast to men, women agreed more with married women surrogate rather than with widow or divorced women. The main reasons that women mentioned were: support of husband during pregnancy and also they worried about forming of emotional relationship between their husband and surrogate mother. The main reasons which men objected with married women were: limitation of marital and sexual relationship during long period of pregnancy and also the problems due to physical-psychological changes of pregnant woman during this time that influences on the normal life.

According to the participants' opinion, factors such as educational and marital status could affect the choosing of an appropriate family as a gestational surrogacy. In order to get an appropriate answer it is necessary to do various individual and group interviews with different social, gender and age groups.

### **Why Men 50 Years and Older Do Not Get Screened For Colorectal Cancer?**

Galen Louis

*Idaho State University*

Salima Vasani

*University of Massachusetts*

Janette Olsen

*Idaho State University*

This study explains Colorectal Cancer (CRC) screening behavior among unscreened men in Idaho by utilizing the Health Belief Model as the framework. Phenomenological analysis of responses from a focus group of nine men 50 years and older revealed that perceived barriers, like lack of insurance and lack of CRC knowledge, prohibited men from seeking a colonoscopy. Other themes that emerged were attitudes and beliefs like fear of cancer, gender related concerns, competing priorities, and enabling factors like family/friends diagnosed with cancer and doctor's recommendation. Consistent with past research findings, perceived susceptibility and perceived benefits were low in unscreened men, and high perceived severity did not encourage CRC screening. Individuals wanted to know more about CRC, hence providing information in a manner that is easily accessible and easy to understand has tremendous potential. This study provides relevant insights into unscreened men and some reasons for low CRC screening in Idaho. Therefore it is pivotal for public health professionals to address the concerns illustrated in the study by participants, to develop effective and acknowledged interventions that would possibly enable men in Idaho to actively seek CRC screening.

### **Youth involvement in health care decisions in the context of chronic illness**

Roberta Woodgate

*University of Manitoba*

Marie Edwards

*University of Manitoba*

Pam Wener

*University of Manitoba*

Decision-making in health care is becoming ever more challenging due to the many advances in chronic and genetic disease management and health care technology. When youth are involved, decision-making can become even more complex given the triad relationship among youth, parents, and health care professionals. This is an area where further study is warranted to ensure high quality health care for youth experiencing chronic illness. Accordingly, we conducted an ethnographic study that explored the perspectives of youth, parents, and health professionals about youth's involvement in decision-making in the context of chronic illness. This presentation focuses specifically on the youth's perspectives. Fifty-five youth (ages 10-23 years) from different illness treatment decision-making scenarios and with different illness histories participated in individual open-ended interviews. Analysis resulted in a detailed account of the domains of meaning relevant to youth's perceptions and experiences in decision-making. Youth's chosen level of involvement in health care decisions as well as their overall satisfaction with their involvement was especially influenced by the degree of trust that they experienced within the triad relationship. Definite preferences were articulated regarding how parents and health care professionals can best support them in making health care decisions. Recommendations grounded in the youth's perspectives are discussed that may be used to help guide health care professionals who are concerned with overcoming the challenges and fostering positive change with respect to involving youth in health care decisions.

### **Author Index**

- |                                |                                  |
|--------------------------------|----------------------------------|
| Adams, Jeffery, 456, 484       | Boblin, Shery, 504               |
| Adamson, Joy, 520              | Bottorff, Joan, 478              |
| Adria, Marco, 479              | Bowen, James, 451                |
| Altamirano, Luis, 453          | Boyd, Cheryl, 496                |
| Alton, Gwen, 454               | Brockmeier, Jens, 528            |
| Andersen, Elizabeth, 513       | Browne, Susan, 486               |
| Anderson, Debra, 478           | Brussoni, Mariana, 482, 485, 521 |
| Anthony, Samantha, 453         | Bryan, Stirling, 466             |
| Anthony, Samantha J., 492, 505 | Bryant-Lukosius, Denise, 481     |
| Arbon, Paul, 491               | Bubela, Tania, 477               |
| Asiasiga, Lanuola, 457         | Bungay, Vicky, 472               |
| Atwal, Sabrina, 461            | Burgess-Whitman, Nan, 500        |
| Bahamondes, Luis, 455          | Burns, Kathy Kovacs, 479         |
| Banner, Davina, 507            | Caine, Vera, 470                 |
| Bantum, Erin, 467              | Calder, Moira, 479               |
| Barbour, Rosaline, 465         | Calhoun, Avery, 503              |
| Barr, Ronald, 481              | Canales, Mary, 474               |
| Barrett, Deborah, 506          | Casey, Dympna, 471, 516          |
| Beckwitt, Asher, 515           | Cashavelly, Barbara, 512         |
| Begley, Cecily, 494            | Castle, Nicholas, 451            |
| Bergerson, Amy, 459            | Chartier, Lori, 528              |
| Bhattacharya, Siladitya, 465   | Chenery, Jessica, 503            |
| Binder, Per-Einar, 496         | Clark, Marianne, 459             |
| Blythe, Catriona, 515          | Clarke, Charlotte, 454, 508      |

- Clarke, Margaret, 506  
Clochesy, John M., 524  
Conklin, James, 501  
Cooney, Adeline, 494  
Cornelissen, Evelyn, 466  
Creighton, Genevieve, 482, 485, 521  
Curtis, Tine, 452  
Dagert, Tanis, 503  
Das, Gita, 461  
de Crespigny, Charlotte, 452  
de Padua, Karla Simonia, 455  
DeForge, Ryan, 460, 488, 499  
dejong-Berg, Margaret, 503  
Dashora, Pushpanjali, 467  
Dastjerdi, Mahdieh, 517  
Delmar, Charlotte, 452  
Devlin, Nicole, 454  
Dicken, Melinda, 496  
Dickinson, Pauline, 457  
Dineen, Sean, 471  
Dipchaud, Anne I., 492, 505  
Dodd, Bernadette, 453  
Dodd, Jennifer, 464  
Dong, Kathryn, 504  
Dreischulte, Tobias, 501  
Drevdahl, Denise, 489  
Duff, Rochelle, 454  
Dunne, Michael, 478  
Edgecumbe, Boyd, 504  
Edwards, Marie, 513, 529  
Ellis, Jennifer, 454  
Eriksson, Katie, 510  
Findlay White, Florence, 471  
Fisher, Murray J., 520  
Flanagan, Jane, 512, 522  
Fletcher, Sarah, 527  
Floersch, Jerry E., 524  
Fraser, Graeme, 481  
Fricker, Louisa, 508  
Frohlich, Katherine, 464  
Frosch, Dominick, 456, 488  
Fukuyama, Katherine, 480  
Galdas, Paul, 472  
Gallacher, Katie, 518  
Genuis, Shelagh K., 487  
George, Anne, 521  
Georges, Jane M., 463  
Ghimn, Yun-Csang, 490  
Ghobadi, Khadijeh, 528  
Gittner, Lisaann S., 524  
Given, Lisa, 477  
Goin, Lyla, 479  
Goldblatt, Hadass, 524  
Gonzalez Romo, Rocío Angelica, 526  
Goberman-Hill, Rachael, 520  
Gow, Gordon, 479  
Grant, Aileen, 501, 525  
Grant, Suzanne, 451  
Grønkjær, Mette, 452  
Gualda, Dulce, 510, 511  
Guthrie, Bruce, 501  
Habin, Karleen, 512,  
Haines-Saah, Rebecca, 464  
Hall, Wendy, 510, 511  
Hamilton, Faye, 503  
Hammond, Chad, 518  
Han, Christina, 472  
Hansen-Kyle, Linda, 495  
Haylen, Denise, 520  
Hefner, Anna, 495  
Herring, Patti, 463  
Hickman, Jr., Ronald L., 524  
Higginbottom, Gina, 490  
Higgins, Agnes, 494  
Hirschler, Christopher, 480  
Hislop, Gregory, 507  
Holt, Nicholas, 522  
Hope, Andrea, 481  
Hopkins, Susan, 502  
Houghton, Catherine, 516  
Jackson, Margot, 469  
Jacquie Ripat, 513  
Jannone, Laura, 481  
Jardine, Cindy, 477  
Jenkins, Amanda, 483  
Jinks, Clare, 462  
Johnson, Jessica, 481  
Johnson, Joy, 479  
Jordan, Sharalyn, 500  
Joy, Janet, 466  
Junior, Hudson Santos, 510, 511  
Kanacki, Lana McLouth, 463  
Kandil, Yasmine, 527  
Kane, Lynett, 504  
Kang, H. Bindy K., 511  
Karlsson, Bengt, 496  
Kelly, Laura, 481  
Kelly, Mary, 472, 478  
Keats, Patrice, 457  
Khalema, Ernest, 504  
Khan, Shamshad, 519  
Khatri, Veena, 461



- Kim, John, 467  
Kim-Sing, Charmaine, 507  
King-Shier, Kathryn M. , 507  
Kinsella, E. Anne, 468, 493  
Kirchhoff, Maureen, 467  
Kirkwood, Robert, 502  
Klassen, Anne, 481  
Klosek, Marita, 460  
Kurian, Allison, 456, 488  
Lach, Lucyna, 506  
Larsen, Ingrid, 453  
Larson, Kim, 483  
Latoszek, Karen, 504  
Laurent , Jennifer, 514  
Lawton, Julia, 471  
Lechelt, Leah, 477  
Lee, Homan, 522  
López Huerta, Jose Alfredo, 526  
Louis, Galen, 529  
Lozanski, Kristin, 499  
Ludin, Salizar Mohamed, 491  
MacCulloch, Radha, 492, 505  
Macdonald, Sara, 453  
MacKichan, Fiona, 520  
Mackie, Andrew, 508  
Macleod, Una, 453, 486, 518  
Magill-Evans, Joyce, 470, 491, 506, 508  
Mahon, Mike, 4769  
Mair, Frances, 486, 518  
Makuch, Maria, 455  
Mao, Yuping, 479  
Martin, Lynn, 504  
Martin, Stephanie, 468  
Maurice, Pierre, 521  
May, Carl, 486, 518  
May, Suepattra, 456, 488  
McCoy, Matthew, 504  
McDonald, Karalyn, 457  
McLaughlin, Anne Marie, 503  
McMillan, Colleen, 483  
McWilliam, Carol, 460  
Medved, Maria, 528  
Millar, Carrie, 522  
Mines, Carrie, 504  
Mitton, Craig, 466  
Mocerri, Joane, 489  
Mogale, Shirley, 479  
Montori, Victor, 518  
Morach , Judy, 528  
Morden, Andrew, 462  
Morrison, Deborah, 486, 518  
Mullett, Jennifer, 503  
Murphy, Kathy, 471, 494, 516  
Murphy, Mary Ann, 516  
Murphy, Nancy, 471  
Myers, Carole, 498  
Newton, Mandi, 503  
Nguyen, Huong Thanh, 478  
Nguyen, Huong Thi Thanh, 478  
Nicholas, David, 453, 506, 508  
Nicholas, David B., 492, 503, 505  
Nielsen, Guri Brit, 509  
Nishimoto, Pat, 467  
Nkosi, Zethu, 523  
Oaks, Geneva, 473  
Ogilvie, Linda, 460, 497  
Ogrodniczuk, John, 472  
Oliffe, John, 462, 472, 478, 482, 485, 521  
Olsen, Janette, 459, 529  
Olsen, Lise, 482, 485, 521  
Olthuisen, Tammy, 453  
Ong, Bie Nio, 462  
Orange, J.B., 460  
Osis, Maria Jose D., 455  
Owen, Jenny, 476  
Owre, Cindy, 512  
Parker, Steve, 491  
Parry, Glenys, 476  
Patching, Joanna, 520  
Peacock, Stuart, 466  
Peddie, Val, 465  
Perry, Patricia, 496  
Peterson, Collin, 504  
Phelan, Shanon, 468, 493  
Phillips, Melanie, 472  
Pilram, Darya, 487  
Ploeg, Jenny, 504  
Poland, Blake, 464  
Popadiuk, Natalee, 494  
Porter, Maureen, 465  
Prosser, Helen, 517  
Pulido, Janell, 467  
Pye, Kathleen, 484  
Quinlan-Jacob, Sonya, 458  
Rankin, Kathryn, 508  
Ravindran, Vinitha, 460, 470, 491, 497, 515  
Regehr, Cheryl, 492, 505  
Reimer, Joanne, 525  
Rempel, Gwen, 460, 470, 490, 497, 508, 515  
Rendle, Katharine, 456, 488  
Richter, Solina, 469, 479, 490  
Ricks, Tiffany, 477

- Roberts, Wendy, 506  
Rogers, Laura, 470, 491, 515  
Roman, Marian, 498  
Roth, Patricia, 463  
Rudmann, Michael, 487  
Rush, Kathy, 516  
Saini, Michael, 506  
Salim, Natália Rejane, 510, 511  
Schneider, Andrea, 475  
Schulz, Celia, 495  
Shankar, Irene, 474, 499  
Shankar, Janki, 461, 504  
Shaw, David, 516  
Simard, Kristin, 454  
Sjølie, Hege, 496  
Slater, Lynne, 475  
Smith, Fiona, 518  
Smith, Neale, 466  
Smyth, Peter, 504  
Solomon, Melinda, 492  
Sorochuk, Gaylene, 473  
Speechley, Mark, 499  
Speers, Peter, 493  
Spence, John, 522  
Spiers, Judith, 513  
Spoelestra, Marg, 506  
Stephens, Jennifer, 507  
Stjduhar, Kelli, 525  
Tamas, Sophie, 458, 498  
Taylor, Kim, 462, 506  
Teucher, Ulrich, 518  
Thannhauser, Jennifer, 455  
Thorpe, Angela, 468  
Thorne, Sally, 462, 506, 525  
Thupayagale-Tshweneagae, Gloria, 489  
Toal-Sullivan, Darene, 509  
Tomaszewski, Ken, 500  
Troiano, Mary Ann, 481  
Truong, Son, 469  
Tsangaris, Elena, 481  
Urschel, Simon, 453  
Vallianatos, Helen, 490  
Van Cleemput, Patrice, 476  
Vasani, Salima, 529  
Ventre, Nicole, 456, 488  
Visram, Shelina, 454, 508  
Ward-Griffin, Catherine, 460, 499  
Wardrop, Andrea, 494  
Watts, Belinda, 497  
Weaver, Kate, 484  
Wehrens, Rik, 463  
Weiner, Diane, 474  
Wener, Pam, 530  
Wenger, Irene, 477  
West, Lori, 453  
West, Lori J., 492, 505  
White, Martin, 454, 508  
Williams, Julia, 451, 527  
Willis, Gordon, 521  
Wilson, Candy, 485  
Winters, Loren, 512  
Wong, Carol, 460  
Wong, Sabrina, 479  
Woodgate, Roberta, 513, 529  
Wright, Michael, 464  
Yohani, Sophie, 490  
Ziaei, Fatemeh, 528  
Ziaei, Mohammad Reza, 528  
Ziaei, Tayebe, 528  
Zwaigenbaum, Lonnie, 506