## In Sickness and in Health

5th International Conference / 5ième conférence internationale

## From the Margins: Radical Thoughts for Health Practices and Research

18-20/07/2013 Hyatt Regency, Montreal, Canada

Program and Abstracts / Programme et résumés



## Dear colleagues

It is with the greatest pleasure that the organizing committee of the 5th In Sickness and in Health International Conference welcomes you this year to Montreal. The conference program is sure to please all those who have chosen to participate either as speakers or attendees. This year's program includes papers that were carefully selected to fit the broader theme of critical, even radical, thinking regarding health practice and research. The choice of this year's theme is not arbitrary. Indeed, this year's co-chairs, professors Dave Holmes and Amélie Perron, have opted for a return to critical work inspired by postmodern thinkers of all persuasions who have characterized the first In Sickness and in Health conference. If the Montreal conference proudly returns to these roots, it is also a continuation of an initiative driven by marginal intellectuals who were and still are interested in pressing and often provoking critical questions in the field of health.

## Chers collègues

C'est avec le plus grand des plaisirs que les membres du comité organisateur de la conférence *In Sickness and in Health*, 5<sup>ième</sup> édition vous accueillent cette année à Montréal. Le programme de la conférence plaira à coup sûr à tous ceux et celles qui ont choisi d'y participer, et ce, à titre de présentateur ou d'auditeur. Les communications incluses au programme ont été sélectionnées avec minutie afin de s'aligner avec la thématique de la conférence orientée vers la pensée critique, voire radicale, en lien avec la pratique clinique et la recherche en santé. Le choix de cette thématique n'est pas le fruit du hasard. En effet, les co-présidents de cette édition, les professeurs Dave Holmes et Amélie Perron, voulaient un retour à des présentations critiques inspirées par les travaux de penseurs postmodernes de toutes allégeances qui ont caractérisé la première édition de *In Sickness and in Health*. Si cette édition montréalaise s'enorgueillit de revenir aux sources, elle s'inscrit aussi dans la continuité d'une initiative portée par des intellectuels marginaux qui s'intéressent à des questions impérieuses et souvent provocantes dans le domaine de la santé.



### The Conference has been organized with the collaboration of/ Conférence organisée en collaboration avec

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Dave Holmes (Canada)

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And / Et

Faculty of Health Sciences, University of Ottawa, Canada/ Faculté des sciences de la santé, Université d'Ottawa, Canada

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Aporia - The Nursing Journal/

Aporia – La revue en sciences infirmières



### 18/07/2013: Thursday/*Jeudi*

### Viviane Namaste, Professor University Research Chair Concordia University

## Montreal by night: Critical reflections on radical health research

### Keynote / Plénière

Viviane Namaste is Professor in Concordia's Simone de Beauvoir Institute. She completed both a BA (Carleton, 1989) and MA (York, 1990) in Sociology before coming to Quebec to undertake doctoral work in Semiology at the Université du Québec à Montréal. Prior to joining the faculty at Concordia, she worked to set up a community health project with sex trade workers and intravenous drug users at a local needle exchange, CACTUS-Montréal. Dr. Namaste is also recognized as an expert on transsexual health. She has published three books in this regard: Invisible Lives: The Erasure of Transsexual and Transgendered People (Chicago: University of Chicago Press, 2000), Sex Change, Social Change: Reflections on Identity, Institutions and Imperialism (Toronto: Women's Press, 2005), and C'était du spectacle! L'histoire des artistes transsexuelles à Montréal, 1955-1985 (Montreal: McGill-Queen's University Press, 2005).

Dr. Namaste's current research considers questions of bisexuality and HIV/AIDS. Surprisingly, there remains no HIV/STD education in Canada that is specifically addressed to bisexual men and women. Dr. Namaste's research seeks to explain this absence. Moreover, working with a community of local activists, the research aims to develop and distribute appropriate educational materials that are adapted to people who have sexual relations with both men and women. The research is informed by critical studies of epidemiology, institutional ethnography, and participatory action research.

This presentation will consider both epistemological and methodological challenges in conceptualizing and enacting health research, particularly with regards to sex and sexuality. Taking the city of Montréal as a point of departure, we will consider the populations recognized in public health research (notably in the field of HIV), as well as those that have been excluded. We'll contrast the knowledge created in public health and university research settings with different kinds of knowledge about health in Montréal, drawing on some empirical field research on HIV prevention. The presentation will encourage participants to think otherwise about imagining and doing health research. And we'll learn a thing or two about Montréal and its history along the way!



### 20/07/2013: Saturday / Samedi

Adrienne Chambon, Professor Factor-Inwentash Faculty of Social Work University of Toronto Politiques et esthétique de la santé: histoires d'archives

(Simultaneous Translation in English)

### Keynote / Plénière

Dr. Chambon's scholarship has moved from research and teaching on immigration and refugees to transnational social work. She is part of a network of scholars in this area with a forthcoming co-edited book on Transnational Social Support, Routledge Publisher. She is interested in expanding the scope of social work theory (cf. Reading Foucault for Social Work, Columbia University Press). Her critical interpretive research links material and discursive activities drawing from the social sciences, the humanities and the arts. She is currently involved in two main directions: what art practices can bring to social work for social change; and archival research re-examining the history and memory of the social work discipline and bringing to light multiple voices, debates and linkages between past, present and future - both with SSHRC funding.

Prenant appui sur des textes de Michel Foucault sur la généalogie des politiques de la santé, cette communication tirera profit d'un travail de recherche financé par le Conseil canadien de la recherche en sciences humaines (CRSH) sur l'émergence du secteur d'aide organisée en milieu nord-américain Anglophone, qui a été mené à partir d'archives. Le domaine de la santé se révèle être un des filtres les plus puissants de la question sociale au début du XXème siècle. La santé cerne tout un chacun(e), et met en lumière les effets de distribution du bien-être et du mal être dans la population. La santé met à jour le scandale. Le pouvoir grandissant que prend le domaine de la santé dans les institutions locales se retrouve dans des documents les plus divers et dans des collections de photographies; cette nouvelle technologie de pointe, 'réaliste', étant mobilisée pour impressionner, voire modeler, les points de vue du grand public et des autorités. Mises ensemble, ces traces circonscrivent un vaste champ qui articule la santé avec les domaines du politique et de l'esthétique.

Une telle confrontation ouvre la voie à une relecture contemporaine des matériaux du passé, et à un questionnement dans le présent sur la nature prismatique des pratiques et des savoirs de la santé. La théorie agonistique de la démocratie formulée par la politologue Chantal Mouffe sera évoquée, en conclusion, pour nous aider à nous interroger sur les contributions que le domaine de la santé peut aujourd'hui apporter à une démocratie plurielle possible.



### Concurrent sessions / Sessions concomitantes

Negotiating through care trajectories. Home care allocation in Norway

Helene Aksøy, Mia Vabo

The paper focuses on complexities associated with needs assessment in home care. Home care in Norway is an important element in a cohesive continuum of publicly funded eldercare. This presentation departs from an empirical study of home care organizations in three Norwegian municipalities. The focus will be on the ways in which needs are assessed as an frail elderly person applies for services the first time and also on how needs are reassessed over time. It is of vital importance to recognize that the process of needs assessment always will be discretionary, interactive and negotiated. Aim: To explore how different organizational arrangements influence on allocation routines and the way home care staff and service users come to agreements about needs and care-provision. Theory: The analysis is informed by the negotiated order theory (Strauss 1978) presuming that both the structural context and the negotiation context will influence on negotiations. Method: Case studies based on: (1) participant observations of daily routines, (2) interviews and informal talks with care recipients/families, managers and staff on different levels, (3) analysis of instructional documents, assignments, citizens charters etc. Conclusion: The negotiation context of home care is influenced by new organizational arrangements e.g. by narrowing the options for negotiation or by limiting the number of issues possible to negotiate. Still informal arenas of negotiation and the established egalitarian culture of home care continue to mediate day-today decisions. The dynamic and contingent aspect of needs assessment demonstrates that service allocation is not just about 'clear entitlements' and 'fixed standards'. Service allocation is filtered through the expectation of both service-staff and citizens and is mediated by time constraints, staff-client continuity etc.. The paper contributes to ongoing debates about the protection of the most vulnerable citizens.

Les transitions volontaires vers une situation de handicap : repenser les collaborations entre les études critiques sur le handicap, *queers* et en santé

### **Alexandre Baril**

La transcapacité, aussi nommée Body Integrity Identity Disorder se définit comme la volonté, chez des personnes en situation de non handicap, de transformer leur corps en vue d'atteindre une situation de handicap (cécité, surdité, amputation). Les écrits scientifiques sur ce sujet révèlent que, pour une majorité de chercheurs de diverses disciplines, il est inconcevable d'accueillir favorablement les requêtes personnes transcapacitaires. Des études quantitatives montrent que les professionnels de la santé présentent des attitudes plutôt négatives vis-à-vis la possibilité d'opérer ces personnes. Ces mêmes études indiquent que, dans la population générale, parmi les motifs évoqués pour le refus de potentielles opérations, figurent les coûts pour le système de la santé, le fardeau pour les proches et l'incompréhension du désir transcapacitaire. En nous inspirant des analyses queer questionnant la notion de normalité et des études critiques sur le handicap soulignant la construction du handicap, nous postulons que les professionnels de la santé ont, comme la population en général, des conceptions normatives des corps (a)normaux pouvant influencer leur degré d'ouverture à l'égard de la transcapacité. Cette communication permettra d'effectuer une généalogie critique de systèmes normatifs dominants (capacitisme/néolibéralisme) qui structurent en partie les réactions négatives vis-à-vis la transcapacité. L'incompréhension du désir transcapacitaire pourraitelle être sous-tendue par l'idée qu'il est préférable d'avoir un corps non handicapé et productif dans un néolibéral? Nous soutenons transcapacité suscite des résistances en mettant au défi les normes capacitistes et néolibérales des corps valid(é)es. Notre réflexion permettra de mettre en lumière ces normes et de repenser les liens entre les études sur le handicap, queer et en santé.



Analyse critique de la culture de sécurité face aux risques biologiques et pandémiques pour les infirmières

La « santé mentale » : du renversement épistémologique à la coercition – justice civile et normalisation

#### Laurence Bernard

Les maladies émergentes telles que le SRAS et la grippe A/H1N1 ont amené une prise en charge des risques biologiques et pandémiques et à l'élaboration de mesures d'urgence pour maîtriser ces risques: développer une culture de sécurité est devenu une priorité de recherche de l'OMS (2004). Malgré tout, peu d'écrits existent face à cette volonté de sécuriser la santé par une série de dispositifs au sein desquels les discours occupent une place importante. Ce projet avait pour but d'explorer la culture de sécurité face aux risques biologiques dans le contexte d'un Centre de santé et de services sociaux québécois (CSSS) à l'aide d'entrevues, d'analyse documentaire, d'observations auprès des infirmières et de la tenue d'un journal. Les résultats de l'analyse de cette étude ethnographique critique nous portent à croire qu'un ensemble de rituels de purification et de protection sont privilégiés au CSSS. Pourtant, les infirmières sont peu formées à ces rituels de prévention et contrôle des infections (PCI). L'hygiène du corps physique pour assurer la PCI est à la lumière du corps social: elle tente de rétablir un ordre normatif dans le désordre qu'imposent la maladie et l'incertitude. Cette étude contribue à l'avancée des connaissances dans le champ de la PCI dont la spécialisation vient d'être reconnue au Québec pour les infirmières qui exercent un rôle majeur dans la surveillance et la régulation populationnelle des maladies infectieuses tel qu'entendu par Foucault (1975, 2004).

### Emmanuelle Bernheim

La notion de « santé mentale » n'est pas seulement l'absence de troubles mentaux, mais bien, selon l'Organisation mondiale de la santé, « un état de bienêtre » permettant à chacun de « travaille[r] avec succès de manière productive et [d']apporter sa contribution à la communauté ». Alors que la discipline psychiatrique visait à délimiter le normal et l'anormal - empruntant, comme l'ont montré Michel Foucault, Georges Canguilhem et Thomas Szasz. les épistémiques de la science médicale -, la santé mentale est une notion si large et indéterminée qu'elle constitue plutôt une forme de continuum du plus au moins normal. Mais auprès de qui permet-elle d'intervenir de manière coercitive? Quelles situations, quels « problèmes de santé mentale », justifient l'intervention judiciaire en matière civile? Plus précisément: à qui et pourquoi impose-t-on des hospitalisations et des soins, retire-t-on les enfants? À partir d'observations et de l'analyse de la jurisprudence, je ferai d'abord un portrait des personnes concernées par des demandes de garde en établissement, d'autorisation de soins ou d'intervention de la direction de la protection de la jeunesse (DPJ). Puis, je présenterai comment, sous couvert d'une rhétorique psychologique ou psychiatrique liée à la santé mentale, l'intervention judiciaire vise dans les faits la répression des comportements marginaux ou originaux et l'injonction à la « vie normale ».



I try to develop a net around each patient: On the development of relationships in home care

Kristin Björnsdóttir

Home care services are provided at the intersection between the private world of patients and relatives and the public world of institutions. Most home care clients, the frail elderly and those who suffer from long-term conditions, need complex and flexible services that accommodate individual preferences and needs. Their care is shared among patients, relatives and health care workers and the boundaries of responsibility and expertise are fluid. Good care rests, among other things, on the development of working relationships participants. But what ideals understandings should guide the development of such relations? A number of studies have shown that care giving relationships can be demanding and difficult and are often fraught with all kinds of ethical issues and dilemmas. Studies have also highlighted the mismatch between prominent ethical and policy discourses and the actualities of the care giving situation. My intent in this paper is to contribute to the conceptualization of what good home care might constitute by exploring the development of relationships between different actors. It is based on findings from an ethnographic study that I conducted of home care in Iceland. The nurses who participated in this study used the net as a metaphor to describe how they develop relations with patients, relatives, team members and different specialists. The development of such relations depended on opportunities for conversations around different issues related to care and to elaborate various options. These conversations seemed to be of key importance in developing ideals, values and objectives that guide practice. This is where Pols's articulation of empirical ethics in the care giving situation is helpful. Similarly Cooper's (2007) re-evaluation of the caring literature is insightful and her findings are helpful in conceptualizing relationships in the practice of home care.

Évolution des valeurs interpersonnelles et maintien de l'abstinence au cours du temps au sein des mouvements d'entraide aux personnes en difficulté avec l'alcool

Isabelle Boulze, Michel Launay, Bertrand Nalpas

Si la recherche se confine habituellement à des laboratoires, nous présenterons une étude innovante de 3 ans, financée en 2012 en France par la Mission Interministérielle de Lutte contre les Drogues et les Toxicomanies. Dans cette étude un laboratoire de recherche universitaire en psychologie, l'Institut national de la santé et de la recherche médicale et les usagers (six mouvements d'entraide nationaux) ont mutualisé leurs forces pour travailler ensemble. Notre hypothèse est que l'adhésion à un mouvement d'entraide aux personnes en difficulté avec l'alcool favoriserait le dépassement du sentiment de solitude de la personne alcoolique grâce au partage de valeurs interpersonnelles (relation à autrui) ; la restauration stable des liens sociaux serait alors un facteur favorisant le maintien de l'abstinence dans le temps qui permettrait aux personnes de sortir marginalisation et du risque de désinsertion sociale. Les participants à l'étude sont des personnes en difficulté avec l'alcool, récemment sevrés, venant chercher aide et soutien auprès d'une association. Ils sont recrutés, sur la base du volontariat, par des membres des associations partenaires constituées en réseau, et à qui est conféré un rôle de coinvestigateurs. Ces derniers recueillent les données du bilan initial comportant des variables alcoologiques. Les valeurs interpersonnelles sont évaluées par le questionnaire Inventaire des valeurs interpersonnelles », mis au point par L. Gordon. Ce questionnaire est administré par téléphone tous les 3 mois par un enquêteur recruté à cet effet ; il est complété par un bilan du comportement face à l'alcool. La durée de suivi est de 12 mois. Au total, deux cent participants seront recrutés sur la base du volontariat. L'anonymat des participants et celui de l'association d'entraide à l'origine de l'inclusion est totalement respecté.



Le positionnement social en soins de longue durée : un regard différent sur les personnes âgées vivant avec la maladie d'Alzheimer qui crient

Anne Bourbonnais

Dans les centres de soins de longue durée (CHSLD), entre 48 et 82% des personnes âgées vivant avec la maladie d'Alzheimer (ou une affection connexe) crient, c'est-à-dire qu'elles manifestent des comportements vocaux ou verbaux qui semblent anormaux aux aidants familiaux et aux soignants. Toutefois, la position sociale que prennent les personnes âgées, leurs soignants et leurs aidants familiaux dans la communication et ses effets sur les cris ont été peu étudiés. Pour mieux comprendre ce phénomène, nous avons procédé à une analyse secondaire de données provenant d'une ethnographie critique qui avait initialement permis de comprendre les sens des cris des personnes âgées. Cette analyse secondaire visait à décrire le positionnement social au sein de triades d'acteurs incluant une personne âgée vivant avec la maladie d'Alzheimer qui crie, son aidant familial principal et ses soignants. La théorie du positionnement de Harré et Van Langenhove (1999) a servi de cadre de référence pour cette nouvelle analyse. Cette théorie présente le positionnement comme des patterns continuellement en changement qui sont exprimés entre les personnes et qui s'appuient sur des droits et des devoirs perçus par chacun. Toute position prise par une personne est relative à celle de l'autre et peut être contestée. Sept triades ont participé à cette étude. Des entrevues et des observations ont été utilisées. Une analyse (Spradley, 1979) a été effectuée. Les savoirs découlant de cette étude normalisent un comportement généralement perçu comme pathologique (les cris), en faisant plutôt ressortir les capacités relationnelles et sociales propres à l'être humain que possède toujours cette population de personnes âgées marginalisées par les troubles cognitifs. Ce regard différent permet d'identifier des pistes d'intervention pouvant contribuer à l'humanisation des pratiques de soins et augmente notre compréhension des relations de pouvoir en CHSLD.

(In)Equity and home care policies in Spain: Austerity as excuse to impose neoliberal agenda

A Bover, D Gastaldo, D Meyer, M Miró, R Miró, C Moreno, C Muntaner, E Peter, C Zaforteza

Currently the provision of formal and informal homecare is a major social challenge in Spain, due to a very high proportion fo senior citizen. Although the family has traditionally been the leading provider of caregiving at home, family structure has changed significantly in recent years, to a point that caregiving maybe jeopardized in the future. The impact of caregiving on health is determined by social factors as gender, generation and public policies, among others. During the last decade Spain has implemented policies to try to balance gender and generational inequalities in homecare, for example, the Law of Attention to Dependence and the Law on Equality between Men and Women. However, the current context of economic crisis and increasing austerity policies are causing significant changes in the implementation of such policies. In this presentation we discuss some of the results of a research funded by the Spanish Ministry of Health (FIS-PI1100123). The main goal was to analyze how male and female family caregivers perceive the impact of these policy changes on their health and caregiving practices. We will explore the evolution of equity discourses in these policies from 2006 to the present. Methodologically, we made a policy analysis of national, state, and local, i.e., Balearic Islands, legal documents. Results show the presence of progressive or conservative equity discourses depending on the ruling party, although both are strongly influenced by growing neoliberal trends in European institutions pointing to austerity as the only solution to the economic crisis. We will discuss possible policy implications of how these changes, which along with others policies limiting universal access to health that undermine the already fragile Spanish welfare state, can cause a rapid increase in social inequalities in health.



### Critical physical therapy

### Perspectives on adherence in the context of everyday lives

#### James Brennan

Critical Physical Therapy (CPT) is physical therapy practice that is able to self-critique, that recognizes how the hegemonic nature of biomedicine disempowers and marginalizes persons with disabilities, is able to deconstruct authoritative physical therapy knowledge and practice, and co-creates interdependence with persons with disabilities, in order to facilitate a more liberating and democratic health care practice. Critical Physical Therapy includes the following; a radical deconstruction of the body to transform it from its biological-pathological reductionism to a recognition of biology and pathology and their contexts, as variability, with all bodies possessing insight, wisdom and important tacit knowledge; the demystification of scientific/medical language; the non-medicalization of non-medical problems, and the recognition of the power that ableism confers. Critical Physical Therapy (CPT) focuses on the societal conditions that create disadvantage for people whose individual characteristics are outside the societal norm. The shift of physical therapy practice is one from an exclusively individual level to one, whereby the individual is consciously situated in a particular social or community environment. Context is critical. In CPT, physical therapist clinicians and their patients, help to transform fundamental social, economic, political structures to create equal access, equal power, and equal participation. Society with the patient actively and visibly situated in it would become the unit of analysis, not just the individual. This approach is grounded in theories of power and influence, community and social changes and development, and social and economic justice.

#### **Neils Buus**

Adherence to health care interventions is an intractable clinical challenge, because many patients have difficulties following clinicians' recommendations and/or prescriptions. Chronic/recurrent disease and the treatment of chronic/recurrent disease are not isolated parts of patient's lives, and it is within this wider context of patients' lives that the introduction of new health care interventions inevitably will be in conflict with and compete with already existing habits regarding time and attention and maybe will be in conflict with identity related issues. This presentation is based on a comparison of two interview studies concerned with adherence to health care interventions in the wider context of peoples' lives. A particular emphasis is placed on people's changing beliefs about the effective/ineffective constituents of a given health care intervention and how people understand it as having/not having an affect on their personal agency and space for action in their everyday lives. In one study, informants were people with low back pain who were encouraged to exercise, and in the other study, informants were people with depression who were encouraged to take antidepressant medication. The aim of the presentation is to discuss and identify similarities and differences between the two groups' ways of managing the interventions and to use these differences and similarities to problematize previous research in this field.



Responsible citizens, vulnerable states: Older people, self-care and shifting technologies of government

## Who's listening anyway? The intersection of feminist action research and narrative practice

### **Christine Ceci**

Although the present preoccupation with self-care seems a relatively benign strategy to manage health care costs, there is also something profoundly normalizing about the current injunction to self-care, in particular, the extent to which it encodes changed expectations for older people both in terms of what they might expect from governments but also the expectation that they age with little or no illness. As Pickard (2011) argues, health, closely associated with ideals of autonomy and self-fulfilment, has become a defining feature of moral citizenship. The good citizen is the citizen who actively manages his or her health such that few claims are made upon the (precarious) resources of the state. In this configuration it is the state, particularly the future sustainability of relevant state institutions such as health care systems, rather than the citizen, that is 'at risk'; good citizens take care to remain healthy in order to protect the (vulnerable) state from burdensome demands. Positioning older people as burdensome is not new but what seems new is the requirement that they should do something to resolve the issue - that is, a 'new' responsibility of older people is to avoid being a burden to the state. Interestingly, there is a whole world of shifting relations of care and dependence that disappears in this requirement for independence from the state. In this paper I want to try to sort out the effects of what seems to be an ongoing restructuring of older citizens' expectations - both in terms of what they can expect from government but also what governments now expect from them - in a Canadian context by analysing those documents meant to set out a framework for governing an aging population.

### **Cathrine Chambers**

Participants in the research project, "Understanding for a change: Interrogating effects from 20 years of denying women access to an abortion in PEI" are participating in small "action groups" where they are developing ideas for further advocacy and policy change regarding reproductive health and justice issues in PEI, and sharing their stories of how participating in this research project has impacted upon them. One of the key processes being utilized in the action groups is outsider witnessing. Outsider witnessing is a narrative practice informed and inspired by feminist theory and poststructuralist discourses about de-centred positioning, the co-construction of stories, not knowing, power relations, marginality and invisibility. This practice supports people to share important stories of their lives with an audience, allowing for deep reflection, de-construction of dominant social narratives and the co-creation of meaning. Narrative practice focuses on the effects of telling stories in particular ways and in particular contexts and thus resonates with the longstanding feminist commitment to enable women to tell the stories of their lives with supportive audiences in order to make new meaning and transform experience. Outsider witnessing, which has traditionally been utilized in therapeutic contexts, is offered as an action research methodology that offers participants the opportunity to give voice to previously silenced experiences regarding prohibitive access to abortion services on PEI. Feminist ethical concerns about power in the research process are addressed and implications for future research, particularly in contexts where interpersonal and structural violence have resulted in various types of oppression, are discussed.



### Gift cards, free meals and fivedollar bills: A critical analysis of incentivized HIV testing

## Nobody asked me: Narratives of Iranian immigrant survivors of domestic violence

### Luc Cormier, Marilou Gagnon

In recent years, there have been numerous calls for more aggressive forms of HIV testing, surveillance and treatment. New technologies (such as rapid HIV testing) have led to the expansion of testing far beyond the walls of the clinic and the implementation of testing in settings where testing was virtually impossible a few years ago. HIV testing is now conducted in vans, shelters, community centres, gay bathhouses, housing facilities, drop-in services, community events, and so forth. Material and monetary incentives have been lauded by many as innovative ways to implement HIV testing in non-clinical settings and effective strategies to increase the up-take of HIV testing within "high risk" or "hard to reach" populations. The aim of this presentation is to critically analyze the deployment of incentivized HIV testing in nonclinical settings. Drawing on the work of Michel Foucault and foundational texts in ethics, this presentation offers an in-depth examination of the bio-political and ethical implications of incentivized HIV testing. It also addresses concerns of paramount importance for health care providers (especially nurses) by challenging the idea of informed consent and shedding light on the coercive effects of incentivized HIV testing.

### Mahdieh Dastjerdi

Background and purpose of the Study: As immigration has become a reality in many countries, the well-being of immigrants is one of the main concerns of health care providers. Although Iranian immigrant women, like many other immigrants, experience some degree of loss and disassociation after being dislocated, some of them have to stay in violent relationship. These experiences have affected their mental health, social cohesion and general well-being--all of which are key elements in continuing with the normal process of integration in Canada. Expanding, contextualizing, and creating social change are vital to improving. This research discusses life experiences as narrated by immigrant and refugees women living in Canada and why they stay in violent relationship and do not leave their abusive husbands. The purpose of this study was to explore and understand why immigrant women do not leave the abusive relationship. Method: Using narrative inquiry, three in-depth unstructured interviews were conducted with 9 first-generation Iranians (5 immigrants and 4 refugees) who were adults (at least 18 years old) and who had immigrated to Canada within the past 15 years. Results: Data analyzed with respect to gender and intersectional perspective. The main theme emerged from this study was "Keeping My Face and Honor". They defined silence as a mean to freedom and enable them to leave abusive relationship safely. It revealed that they were resilient to gain their rights but in their own way through silence. Conclusions and Implications: Listening to immigrant women voices in narrated life experiences can provide an opportunity for Canadian institutions to create programs and supporting services that are tailored to immigrants women's needs and will improve their well-being. The result of this study suggests that health care providers should move beyond holistic care and understand that health is shaped within the context of everyday life experiences.



## Shaken and attired: An analysis of media discourses in the Shaken Baby Syndrome debate

# Shaping health research and researchers in Canada through the discourse of knowledge translation

### Rochelle Einboden, Trudy Rudge, Colleen Varcoe

Shaken Baby Syndrome is a relatively new medical diagnosis that emerged in the later part of the 20th century with advances in medical imaging technology. In absence of other signs of physical trauma, subdural haemorrhage, retinal haemorrhage and cerebral oedema form the diagnostic trinity for Shaken Baby Syndrome. Weaving together medical and legal discourses, this diagnosis makes claims about the mechanism and timing of injuries. Recently, dissenting pathologists and paediatricians have begun challenging the science behind Shaken Baby Syndrome resulting in initiation of case reviews and overturned convictions by justice systems. Although Shaken Baby Syndrome represents a tiny fraction of cases of child abuse and neglect, imagining that a caregiver could shake a baby to death is compelling, and has generated significant media attention. A sample of popular media texts that engage this debate (i.e. documentaries, news, magazine articles) will be analysed using a critical discursive approach. Evaluation of the strength of the evidence to support this diagnosis is relevant, but not the focus of this analysis. Instead, this analysis investigates the ideologies that underpin the Shaken Baby Syndrome diagnosis and debate, such as: beliefs about technology, science and medical knowledge; narratives of good and bad parents, parenting, babies and behaviours; understandings of violence; and social positions of perpetrators and victims. Considering the debate about Shaken Baby Syndrome as a signifier of deeper social issues, rather than the essential problem itself, this paper offers a perspective that goes beyond superficial understandings of truth. It offers insights into how society prophesies and profits from this spectacular construction of violence, while it continues to allow children to be positioned as targets of on-going structural violence. Ultimately, this analysis aims to offer ideas as to how we might influence social change for children in more meaningful ways.

### Kathy Ellis, Jessica Polzer, Anita Kothari, Debbie Rudman

Knowledge translation is a dominant discourse in the governance of health research in Canada, constructing new roles and responsibilities for researchers and decision makers. Major health research funders now require explanations of how research results will be applicable to decision makers (e.g. clinical, health policy) and/or the inclusion of decision makers as part of research teams. There has been little critical examination of the impact of knowledge translation on health research or researchers despite evidence suggesting challenges in balancing these new responsibilities with existing demands. Informed by a governmentality perspective, this study uses critical discourse analysis to explore how the discourse of knowledge translation operates to shape the directions of health research and the activities of health researchers in Canada. Findings from analysis of key public documents pertaining to knowledge translation by the Canadian Institutes of Health Research (CIHR), a major funder of health research in Canada, will be presented. Included are a consideration of how the discourse: (1) positions knowledge translation as the solution to a "gap" between health research findings and their application in practice and policy; (2) how knowledge translation becomes the mechanism through which the use of health research addresses multiple accountabilities; (3) constructs ideal types of health research and de-emphasize the importance of other kinds of health research; and (4) specifies particular roles and activities for health researchers while discursively constructing subjectivities. The implications for the transformative potential of knowledge translation in the governance of health research will be considered.



## Vocational rehabilitation as a governmental technology: The pursuit of normal life

### Joanna Fadyl, David Nicholls, Kathryn McPherson

Vocational rehabilitation could be described as a process of compelling and enabling people to overcome disability so they can work, involving many, and sometimes diverse, strategies and programmes to achieve this aim. The importance of vocational rehabilitation as a practice within governmental agendas in Aotearoa New Zealand, and in many other countries around the world, has been demonstrated in a number of recent policies and reports, emphasising an imperative that disabled people are enabled to obtain work in order to achieve equality and maintain social systems. Scientific studies showing that unemployment is associated with poor health, and that individuals want to return to 'normal life', are often cited to support this pursuit. This paper is a discussion of findings from a study that discursively analysed the social practice of vocational rehabilitation in Aotearoa New Zealand using the work of Michel Foucault - in particular, his discussion of 'bio-politics' and 'governmentality'. When investigated from a Fouaculdian perspective, vocational rehabilitation can be seen as a governmental technology, drawing on historically and culturally specific notions of economic systems, 'normal life' and 'disabled' to construct appropriate practices. These practices are shown to be normalising, as well as reproducing notions, such as 'disability', which describe the problems they seek to address. Identified in this study, however, was a trend in some emerging practices towards a normalisation of disability itself, which has the potential to considerably shift the focus of vocational rehabilitation practices and associated governmental tendencies. The discussion will include a consideration of what opportunities are presented, and what may be constrained, in the context of this finding.

### The social marketing of stroke prevention care

### Sarah Flogen, Sioban Nelson

People at risk of stroke are highly motivated to take up health professionals recommendations and participate in the investigation and treatment plans. Drawing from population known to experience less health advantage in Toronto, a doctoral research project was conducted to understand the patients work in stroke prevention at a local Secondary Stroke Prevention Clinic. This project used institutional ethnography to examine both the local clinic setting, the texts at play, and the organizing external organizations. Eight stroke patients were interviewed and observed to ascertain their experience and 'health work'; external informants were interviewed to explicate the social organization of stroke care. One substantial discovery that emerged from this project was that patients who attended appointments at a Secondary Stroke Prevention Clinic used symptoms captured on refrigerator magnets to self-identify being at risk for stroke, and subsequently activated health care. A dramatic Heart and Stroke television commercial was also named as an activating source. The magnet and commercial were traced to the Heart and Stroke Foundation of Ontario where they were created as a social marketing health promotion tool. This presentation highlights these patient stories and makes visible the social organization and social marketing of stroke care in Ontario.



Towards a critical theory of nursing action: Can the concept of recognition be a critical perspective for nursing?

### Thomas Foth

This paper critically explores the concept of reification, an important concept in German Critical Theory, further developed by Honneth. According to Honneth, reification is a form of misrecognition and can therefore only be understood against the backdrop of recognition. Honneth defines recognition in several ways but makes a key claim that cognitive attitudes are primary founded in affective relations: involvement, concern, reciprocal relations and different forms of caring. In contrast, reifying practices negate or distort this paramount form of 'being involved', particularly through distanced forms of observation and instrumentalization. According to Honneth's ethical approach, nursing actions must be conceptualized as communicative actions based on mutual recognition. This approach seems especially useful for a critical theory of nursing action. In contrast, this article will emphasize that nursing carries several aspects of violence and aggression. If we do not define recognition as something that has a particular moral value before it is expressed in action, then we have to acknowledge that we are struggling with ethical demands that can be answered through different affective responses (and any of these possible responses can be defined as morally good). We could call this kind of engagement 'recognition' because it is an emotional engagement with the Other. Nurses not only play a crucial role in constructing patients' identities (through, for example, their observations and nursing reports) but may also be directly involved in violent acts against 'abjects'. These aspects of nursing care may bring to light the limitations of a theoretical approach based on recognition.

## Treatment adherence redefined: A critical analysis of technotherapeutics

### Marilou Gagnon, Jean Daniel Jacob, Adrian Guta

Treatment adherence issues in the context of chronic illnesses have become an important concern worldwide and a top priority in the field of health care. The development of devices that will allow health care providers to track treatment adherence and monitor physiological parameters with exact precision raises important questions and concerns. The aim of this presentation is to interrogate the use of these new technological devices which allow for previously unavailable data to be recorded on an ongoing basis and transmitted via a tiny microchip inserted into the body. Drawing on the work of Michel Foucault, we analyze how this anatomo-political and bio-political instrument serves to discipline chronically ill individuals and govern the health of entire populations who suffer from chronic conditions. In order to support our analysis, this presentation comprises three sections. First, we introduce the concept of technotherapeutics. Then, we explain how technotherapeutics concern the government of bodies and conducts at the individual level and population level more generally. Lastly, we provide examples of how this analysis can be connected to various fields of practices.



## Who's time is it really? The partogram, power and the shifting boundaries of normal labour

'This is my way': Disability, Deleuze, and the connected self

### Hilary Gatward, Maralyn Foureur, Deb Davis

The partogram is a graphical representation of labour in childbirth. Physiological signs are plotted on a graph measuring labour progress against the passage of time. These features include a record of dilatation of the woman's cervix and the descent of the fetal head down the birth canal. In practical terms the partogram is a useful document as it allows surveillance of labour from the end of the bed or office. However the partogram situates care and the women's progress in labour within a fixed time frame allowing for little individual variation of progress. Researched and designed in the mid-1950s by Friedman and Kroll, the partogram has had little review since then. Some minor changes to the lines of progress within the chart have been made but few have questioned its usefulness in non-medical models of care such as midwifery. From a critical point of view, using a mathematical chart to record and measure physiological activity seems to be at odds. The partogram assumes that all women's bodies will labour to the same rate and rhythm and within the same timeframe, with changes occurring hour-by-hour. If women's bodies exhibit different (usually slower) rates of progress intervention is frequently initiated to speed up the process to align with the predetermined rate. This hourly fragmentation of time appears to confer more benefits to the observer of labour, than to the labouring woman. Foucault refers to this practice as 'temporal dispersion' where the successive serialization of activities creates more opportunities for control over each moment of time. This changes the emphasis of care from progress to time. This paper explores the use of the partogram with its practice of temporal dispersion and questions who it really serves.

### Barbara Gibson, Franco Carnevale, Gillian King

Postmodernism provides a radical alternative to the dominant discourses of western societies that emphasize autonomy and independence. It suggests a reimagining of the relationship between the self and the body and the increasingly blurred boundaries between biology and machine. Dependency has a negative social connotation that can be challenged through the exploration of dynamic connectivities. In this presentation I will explore subjectivity and in/dependence through discussion of interconnectedness of persons with disabilities, their carers and assistive technologies. Drawing on the work of Deleuze and Guattari, I discuss the interconnections inherent in disability experiences through the case example of Mimi, an adolescent girl with severe physical impairments. I consider how Mimi, her assistive technologies and her parents can be viewed as assemblages of bodies/technologies/subjectivities that together achieve a set of practices which can be both disabling and enabling. An examination of these assemblages suggests connectivity can be embraced to explore multiple ways of being-in-the-world for all persons and problematizes the goals of independence inherent in health practices. Connectivity offers an alternative lens for conceptualizing relationships between disabled people, their technologies and caregivers. I conclude with a discussion of the implications for health care and rehabilitation.



## Resistance and possibility: Alternative discourses for progressive practice in healthcare

Examining the relevance of Foucault's "ethic" for research ethics: Lessons from the Canadian HIV community-based research movement

#### Karma Guindon

The helping professions have been generally slow to embrace contemporary concerns and relationships associated with globalisation and climate change. For example, social work has been largely reluctant to embrace the overwhelming evidence that links human health and wellbeing with the health of the natural world. This is ironic given that social work is a systemic profession that utilises an ecological, or person-inenvironment, approach to practice. This approach allows individuals to be conceptualised more holistically and expands the lens with which to appreciate the difficulties experienced by individuals, families, and groups. Nevertheless, social work has largely remained focussed on internal, individual processes and the influence of immediate social relationships on their clients' health and wellbeing. The maintenance and implications of this conservative stance will be examined through a Foucauldian lens. This lens reveals the continued dominance of modernist and patriarchal discourses, and the increasing influence professional practice. neoliberalism on discourses construct fragmented and increasingly financially-driven understandings of human health and ethical practice that can have limiting effects on social workers and other helping professionals. Fortunately, there are alternatives to these discourses. These alternatives include ecological systems ethics, which has the potential to better position helping professionals to recognise and resist limiting understandings of their clients' health and wellbeing. If widely embraced, ecological systems ethics could also contribute to a shift in professional practice that is more inclusive and better addresses contemporary concerns relationships.

### Adrian Guta

There has been a recent resurgence of interest into the implications of Michel Foucault's final works on "ethics" and self-formation. A number of scholars have adapted Foucault's ethical imperative of "care of the self" to examine power relations in medicine, education, and research. This paper contributes to this scholarship by considering the implications for thinking about ethical practice in community-based research. This approach to research is said to transgresses the boundaries and hierarchies imposed by existing ethics review frameworks and the larger bioethics enterprise. This analysis draws on interview data collected from Canadian HIV community-based researchers (CBR), comprising of a national sample of university-based researchers, clinician scientists, and researchers housed in community-based organizations. Results are presented with an attention to Foucault's framework for examining the "morality of behaviors." This paper demonstrates that many HIV CBR practitioners have an appreciation of formal research ethics codes, but also adapt them in practice to account for the realities of participant's lives, the needs of community-members involved in the research, and the community as a whole. These adaptations often challenge what it means to be an ethical researcher and blur the boundaries between research, advocacy, intervention, and community development. Ethics here becomes a shared responsibility with decisions being made between the stakeholders in a research partnership. These partnerships represent an ethical terrain in which the participants challenge themselves to work differently with communities, and as a result cared for themselves and others in ways that resisted domination.



## Building a baby: The ethical implications of pre-implantation genetic diagnosis

### La théorie *queer* et les revers de l'allaitement

#### Rebecca Guttman

Preimplantation genetic diagnosis (PGD) is a reproductive technology whose goal is to screen embryos in vitro for the presence or absence of specific genes. Screened embryos are transferred to the uterus. PGD raises questions on the moral acceptability of choosing embryos to implant. Classical ethical theories inform these issues by guiding development of effective frameworks for policy formation and decision making. Analysis includes the classical theories of Kant, Feminism and Judaism, as well as scientific publications and media sources. Social sex selection and gene selection raise the potential to commoditize the reproductive process, making eugenics possible and extending parental control over children's futures. Physicians may use this technology to screen out nonviable embryos and select which viable embryos to transfer; best medical practice as well as patient preference can inform this process. While it is possible to select for embryos that possess specific genetic traits, this degree of selection is not often practiced. However, in the future it may become common and acceptable to do so. Kantian philosophy questions whether technologies are performed with good intent, rationality and respect for one's duty to others. Feminist theory examines whether entrenched discrimination has impacted or will impacted usages of PGD. Jewish ethics aims to balance respect for life, natural variation and obligation to heal. These perspectives provide guidance towards policy on PGD that respects individual autonomy and a child's right to an open future. This paper examines the contribution each ethical theory makes in developing a method for complex decisions about PGD. We will be faced with difficult decisions to make about the acceptability of designing children to meet desired standards, while simultaneously respecting parental autonomy and natural diversity. It is necessary to have established ethical frameworks from which to draw decisions about acceptable practice.

### Marjolaine Héon, Patrick Martin

Que ce soit par des politiques, des lignes directrices ou des recommandations, les organisations nationales et internationales de la santé déploient des efforts afin de promouvoir, soutenir et protéger l'allaitement. Par ces moyens, elles cherchent à instaurer une culture d'allaitement forte et à faire de l'allaitement une norme nutritionnelle infantile tant à l'échelle nationale qu'internationale. Bien que l'allaitement soit bénéfique pour la santé des mères et celle de leurs enfants, un regard critique, teinté par la théorie queer, et plus particulièrement par les écrits de Judith Butler et de Michel Foucault, nous permet de prendre conscience des effets potentiellement insidieux de la promotion de l'allaitement sur la construction de l'identité maternelle. La sédimentation des normes du genre féminin en contexte de maternité, la fabrication de phénomènes sociaux tels que la « bonne mère » ainsi que la définition de l'identité maternelle à partir d'idéaux socioculturels sont les possibles effets pernicieux de la promotion de l'allaitement maternel.



### Contrasting views - reflections on a luminary gaze

## Hermeneutic potentials of the body in professional nursing: Mimesis and intersubjective interpretation

### Richard Horwood, David Nicholls

Musculoskeletal physiotherapists sit in a lofty position from which to observe their subjects interaction within the machinery of medicine. Time spent in assessment and treatment leads to the formation of a series of views. These vistas are often disturbed, however, by the reflection of captured images that sit outside of the body as subject. The emergence, and now reliance, of medical imaging to build portraits of a subject's condition has once again changed the landscape of the medical gaze. This presentation draws on Michel Foucault's analysis of Velazquez's painting 'Las Meninas', and the paradoxical relationship between reality and representation, to argue that the dependence on medical imaging in the construct of a modern day consultation has shifted a process of twoway discussion into a triangular relationship where the subject, the observer and the illuminated image form an inwardly looking scene. The geometry of this picture has constructed an invisible barrier making it impregnable to those who view from outside the frame whilst reinforcing the luminary gaze of those who observe within it. In doing so it commands attention by putting into focus a snapshot of time that empowers one and denies the view of others. This visual penetration, deep into the body of one with the eyes of another, has led the observer and the subject to sit diametrically opposed to one another whilst the image holds judgement on their focus. This portable canvas has allowed the observer to see what lies within but in so doing positions its subjects in such a way as to create a reality that sits outside of them. No longer do they need to be present in the creation of their own portrait, rather the power of the image has added a luminance that was not foreseen.

### Manfred Hülsken-Giesler

A special challenge to professional nursing lies in taking the ways others experience their own illness as a specific point of departure for care work. While this standard of hermeneutically substantiated care has recently been discussed in international circles, this discussion has focussed on the relevance of language for the process of professional care and was justified, for example, with help of the works of H.G. Gadamer. This presentation aims to bring to light the bodilysomatic aspects (in German terms: Leib) of intersubjective interpretation in diverse nursing situations. In a Foucauldian perspective, the body is mainly seen as being subjected to societal processes of normalisation and disciplining. The aim here is to open up the process of nature being disguised through nurture through the concept of mimesis, which serves to account for professional care work in its various situated bodily-somatic expressions (Hülsken-Giesler 2008). Mimesis is thus seen as conditio humana, enabling different ways of being-human as well as social interaction and societal life (Gebauer/Wulf 1995). The view of mimetic capacities as part of the bodilysomatic constitution points to the importance of prerational and performatively applied forms of knowledge in care. Concentrating on mimetic processes can provide a way to overcome the inherent lingual reduction of specific experiences (being-ill) to general concepts (illness).



### Racial carbopolitics as biopedagogy

Structural stigma: Towards an understanding of place in the construction of disruptive subjectivities

### Maki Iwase, Sioban Nelson

Jean Daniel Jacob, Amélie Perron, Pascale Corneau

In this paper, I bring together two contentious topics in clinical practice: carbs (i.e. short for carbohydrates) and race. The effect of pairing these two terms becomes more apparent when one thinks of the cliché: 'We are what we eat'. This cliché resonates because food & subjectivity are so closely intertwined. When you can't eat the food you want (as in the case of people living with diabetes), then it raises the question: who are you? This is precisely the question that undergirds clinical encounters between practitioners in diabetes education and people who seek help with diabetes selfmanagement in the era of the diabesity "epidemic". However, something interesting happens pedagogical practice when carbs are used to stand in for race/ethnicity. The intention of this paper is to open up a discussion on the ways in which particular kinds of carbs are employed as a proxy for race/ethnicity and then mobilized in biopedagogical practices to govern the food practices of racialized bodies. In this paper, I elaborate on the notion of racial carbopolitics and biopedagogy in order to capture how racial politics are enacted in the clinical setting. By examining the types of carbohydrates consumed by particular ethnic groups, I will elucidate the ways in which racial carbopolitics as a biopedagogical strategy plays out as normalizing and regulating practices that enable the governing of bodies in the name of health. It will be argued here that biopedagogical practices privilege white cultural practices associated with normative carbohydrate consumption which in turn constitutes the cultural practices and the non-white bodies of colour as 'Other'. I argue that such biopedagogical practices not only reify race, they have the effect of assimilating bodies from different ethnic background to whiteness.

This presentation draws on qualitative data from a research project that explored the nursing management of violent patients in one emergency psychiatric unit. As an extreme site where bodies are scrutinized, analyzed and controlled, the psychiatric emergency unit participates in the production of subjectivities rooted in location. Guided by individual accounts from both providers of mental health services (nurses) and recipients of care (patients), the results of this research highlight the multiple contextual factors inadvertently give therapeutic significance to controlling interventions. Drawing on the works of Rose, Foucault and Goffman, our analysis will highlight the tensions that exist between nursing care and the micro-politics involved in its place of practice; thus positioning the psychiatric emergency unit as an anomaly in the emergency department and a key factor in the way patients are conceptualized and subsequently treated.



## Emancipatory nursing knowledge and practice: Conceptualizations and challenges

Independence? Citizenship? Possibility?: Constructions and government of disability in selfmanaged attendant services

### Paula Kagan, Peggy Chinn, Marlaine Smith

In preparing a, yet to be published, major text focused on emancipatory approaches in nursing research and practice (Philosophies and Practices of Emancipatory Nursing: Social Justice as Praxis, Routledge), we have identified a range of conceptualizations that have been used in nursing to define the concepts of "critical theory/methods," "socio-political knowing," emancipatory knowing." We believe that a wide diversity of approaches to critical scholarship and practice is both necessary and desirable, and understanding the various approaches will facilitate further development in this area. In this presentation we will explore the range of conceptualizations that emerged from the contributors and that are used by both major and upcoming nurse scholars in the area of critical perspectives in nursing, and identify the implications that are inherent in each of the contrasting conceptualizations.

### Erika Katzman

Self-Managed Attendant Services (SMAS) is a selfdirected/direct payment model for delivering support services for disabled people in Ontario, Canada. SMAS represents a significant and important achievement of local disability rights and independent living movements. However the discourse surrounding selfmanagement appropriates a rhetoric of independence and self-sufficiency, a discourse which works within and may serve to reinforce not only traditional conceptions of disability, but limited conceptions of 'normal' (neoliberal) citizenship. This paper explores the paradoxical conceptual underpinnings of SMAS, drawing on insights from contemporary critical disability studies and radical disability activism. A Foucauldian lens is used to consider hidden operations of power in the SMAS discourse, analyzing the discourse of selfmanagement as a mode of governance that, while purporting to enforce inclusion, may simultaneously (although unintentionally) contribute marginalization of certain disabled subjectivities. While SMAS facilitates the construction of a new genre of disabled subjectivities, it may also be seen to reinforce contemporary networks of normalizing Consequently, while SMAS contributes to the very important project of creating new possibilities in the lives of disabled people, on a discursive level it may work against efforts to reconceptualize disability as a means of gaining broader social acceptance for a full spectrum people who are labeled 'disabled'. A secondary aim of this paper is to consider the value of Foucauldian analyses to contemporary 'critical' disability studies.



### Unsettling policy: Disabled women at the margins of health

Scientification of nursing and the construction of authoritative knowledge: A critical historical perspective

### Sally Kimpson

Research that draws from accounts of the everyday lives of marginalized individuals is by definition a radical move, if we subscribe to the meaning of radical as "proceeding from the root." In this paper, the concern is the health and well-being of women living with disabling chronic illnesses receiving provincial disability income support in British Columbia (BC), Canada, and the challenges inherent in achieving health due to marginalizing economic policies (structural poverty), social exclusion, barriers to employment, unequal access to health care, and disabling attitudes. Western democratic governments have erected a vast apparatus, including income support programs, to secure the well-being of their citizens. However, in the case of the BC government these programs fall short of their stated goals "to ensure access to supports enabling disabled citizens to become independent and participate in community." If to govern is to structure the possible field of action of others, the everyday lives of disabled women receiving BC disability income support are constructed in relation to government policy and programs in unsettling ways. Subsidies and supports are constantly under threat as the neoliberal economic and political regime of the BC government seeks to reduce deficits by cutting programs and changing policies in ways that make access to these programs and services increasingly difficult or impossible. I will present narrative accounts constructed (radically) from the ground of disabled women's lives specifically to problematize policy governing the health and well-being of some of Canada's most marginalized citizens. By asking, "What version of health do these women enact, and how is this accomplished?" this paper reveals the effects of disabled women's everyday exposure to management regimes, thus contributing to critical work on bio-power, disability/marginalization, and the health disabled women.

### Susanne Kreutzer

The "scientification of the social sphere" is a key aspect in the development of twentieth-century Western societies. Experts in human sciences - representatives of disciplines as diverse as medicine, law, economics, psychology and social sciences - gained interpretive power with regard to social reality, interpersonal relationships and personal wellbeing. In nursing this led to a dramatic shift in the conception of authoritative knowledge. According to Brigitte Jordan, authoritative knowledge is the knowledge that is seen as dominant in a field and that has the power to define "facts". Authoritative knowledge is recognized by the majority of agents in a particular field as the natural, only sensible form of knowledge. The paper explores the shift in how authoritative knowledge was conceived, using the example of West Germany. It argues that the scientification of nursing created a new field of conflict that is referred to by German nursing scholars as doppelte Handlungslogik (dual "rationale of action"). How can the theoretical, science-based mainstream knowledge with its claim to universality be united with the hermeneutic approach that validates the specialness of individual patients and their subjective experience of illness? This contradiction, which underlies all actions in person-related service professions, is particularly problematic in nursing. Because of their focus on the patients' body, nursing professionals rely on implicit forms of knowledge that cannot be cognitively and rationally explained and that lost their significance with the scientification of healthcare. The paper argues that a research perspective that challenges the establishment of a hierarchy between scientific and experience based, intuitive forms of knowledge would led to a significant re-evaluation of progress and backwardness in nursing history. It would through a new light on the hitherto so called role models and latecomer in the scientification process.



### Constructing persons: Clinical perspectives

### Construction identitaire de l'usager des services de santé mentale

#### Anastasia Kucharski

The concept of "person" has evolved over the past two millennia so that it is now used interchangeably with "self" and "ego". Philosophers who try to elucidate its phenomenology rely on fantasy and hypothetical brain transplants instead of illustrations from everyday life. Daily examples range from brief instances of déjà vu to the profound loss of identity seen in late dementia and major psychoses. These states can be viewed as disorders of the experience of the self since they affect a person's ability to know who they are and how they live. They are divided into two groups based on discontinuities of time and space. Temporal discontinuities include dementia and dissociative states. People with dementia lose memory and may forget who they are. In dissociative states people can function but have no recollection of what they did. Recurrent episodes can be grouped into multiple personalities. In these cases the continuity of events necessary to construct identity is weakened. Spatial discontinuities include misidentification syndromes, depersonalization/derealization, anosagnosia, borderline personality disorders. In misidentification syndromes like Capgras and Fregoli people either think a stranger is a family member or vice versa. These states can occur in schizophrenia, traumatic brain injury and delirium. Central to these spatial discontinuities is an appreciation of a boundary between a person and the environment. Boundaries help people organize their world, perceptions and agency. Defenses like projection, delusions and hallucinations are examples of weak or non-existent boundaries. Looking at the concept of the person from the perspective of the psychological phenomena in disorders of spatial and temporal experience provides an opportunity to rethink our idea of the person and to review our clinical and research approaches to these illnesses.

### Katherine Larose-Hébert

La personne ayant reçu un diagnostic psychiatrique possède un statut social spécifique au sein de la société québécoise. En effet, ses expériences et sa souffrance sont majoritairement interprétées au sein du registre médical, qui les considère souvent comme étant les signes et symptômes d'un dysfonctionnement neurobiologique. Dès lors, il apparait que le discours « de » la folie, la subjectivité du fou rendu « malade », ne puissent être que l'expression même de sa maladie : sa forme discursive. Le savoir qui s'en dégage sensible, expérientiel - se trouve alors positionné à l'extérieur du pouvoir et de la raison, exclu en grande partie du traitement auquel le malade doit se soumettre. L'organisation des soins en santé mentale au Québec ne fait guère exception et n'offre gu'un espace restreint au discours de l'usager. Cette organisation est d'autant plus minutieusement orchestrée pour faire les éléments critiques qu'elle englobe, tel que le discours des ressources alternatives. Or, il est selon nous nécessaire d'intégrer le vécu subjectif de l'usager à l'évaluation des services qui les cible. Afin de traduire et comprendre leur expérience, la dégager de ce qui la contraint et possiblement la module, nous nous appuierons sur un cadre théorique alliant à la fois un regard microsociologique des transformations de l'identité à travers le parcours et un regard macrosociologique des relations de pouvoir qui soustendent ces transformations (Foucault, 1976). Sur le plan théorique. notre recherche permet la réactualisation du concept de « carrière morale » de Goffman (1968) en le situant hors des murs de l'asile. En effet, si le système de services en santé mentale au Québec a connu des restructurations majeures depuis les débuts de la désinstitutionnalisation, il reste encore à évaluer l'influence de cette réorganisation des soins sur la construction identitaire de l'usager.



Decision making as a moral tool in home based nursing: Balancing diverting demands to achieve good practice

Sites d'injection de drogues supervisés: entre panoptisme, savoirs savants et subjectivation

#### Hilde Lausund

The many formal and informal system and contexts, including law and administrative regulations, knowledge, experience and patient's individual needs provide different premises for the exercise of professional practice. Home based nursing is under constant pressure in terms of ensuring quality of practice. Formal decision making is one of the important measures towards meet this requirements. The aim of this paper is to explore how these measures structure and shape nursing practice, as well as how practitioners balance between the administrative, legal and individual demands and expectations in order to achieve good practice. With reference to Charles Taylor's moral philosophy, the degree of morality in humans' life depends on the contrast concerning reasoning and reaction, weather practice is grounded on more or less spontaneous reaction or as a reasoned responds. Morally speaking practice involves both acting subjects and tools which support the acting subjects towards achieving good practice. In terms of Taylor's moral philosophy, I define the formal decision as a moral tool: What work to the decisions understood as moral tools do? How are they integrated and activated in practice, and with what consequences? What kind of relationships and boundaries are established between the involved acting subjects and these decisions? The study used an ethnographical design including participant observation of home based nursing interventions, qualitative interviews and focus group interviews of the observed nurses. Practitioners experience an inconsistency between the identified need of care formulated in the decisions and the many individual demands. Practitioners more or less put the decision aside, make their own professional assessments and "do what is needed". Data and analysis is based on a PhD project and work in progress will be presented.

### Heidi Lepage

La mise en place des sites d'injections de drogues supervisés (SIS) semble inquiéter les villes de Québec et Montréal depuis quelques années. Décrétés légaux par la Cour Suprême du Canada en septembre 2011et même si plus d'une étude a démontré leur bénéfice quant à la qualité de vie des utilisateurs de drogues injectables (UDI), la mise en place tarde à se concrétiser dans l'Est du Pays. Inspirés des travaux de Foucault et à partir d'observations effectuées au SIS de Genève, le Quai 9, nous constatons que les SIS se comparent à un panoptique, tant par la disposition de leur espace architectural que par la surveillance et la correction normative qui s'y font. Dans cette communication, nous verrons dans un premier temps comment la dyade sujet-objet a été modifiée par les contours d'une histoire montrant que la prohibition des substances psychotropes a été teintée par le racisme. Par la suite, nous verrons comment le SIS permet une objectivation du sujet, sujet qui est au coeur des procédures disciplinaires en devenant l'objet d'une orthopédie sociale. Cette gouvernementalité permet la construction d'un savoir savant autour des UDI, savoir normatif visant la transformation du sujet. En effet, pour le sujet, devenir l'objet du discours des intervenants du SIS le conduit vers un mode de subjectivation. En somme, nous tenterons de mettre en lumière le lien qui existe entre ce mode de subjectivation des individus et la production de savoirs savants sur les UDI. Enfin, nous tenterons de trouver des solutions éthiquement acceptables à cette problématique en explorant ses diverses facettes. La solution se trouverait-elle dans la décriminalisation, ou dans la production de nouvelles subjectivités de l'ordre d'une esthétique de l'existence menant les UDI à développer le souci de soi?



Discours normatif sur la distance professionnelle et traitement du dégoût

### Anne Marché-Paillé, Étienne Leblanc

Cette présentation pose un regard critique sur les prescriptions du discours normatif des pratiques de soins gérontologiques et montre notamment que, dans le cas de la confrontation au dégoûtant, la norme de « distance professionnelle » crée chez les préposées aux bénéficiaires (PAB) un dilemme éthique qu'elles résolvent en transgressant la règle de la distance entre soignant et résident. Le travail d'assistance aux soins personnels des personnes âgées en hébergement collectif est socialement assimilé au « sale boulot », à la part ingrate du travail des soins infirmiers. Les PAB ont à se défendre de l'insupportable du dégoût et de la menace éthique qu'il représente pour le « travail de care ». Du point de vue professionnel, le dégoût est considéré comme une émotion inadéquate pour le milieu. Pour certains, le dégoût est l'émotion paradigmatique du jugement moral. Il fait porter un jugement de désapprobation sur les objets constituant une menace pour la subjectivité. Une grille d'analyse ad hoc a été conçue à partir du modèle des oppositions structurales du domaine du dégoût. Cette grille a été appliquée à un corpus narratif recueilli auprès de vingt préposés (femmes n=17; hommes n=3) travaillant en établissements d'hébergement et de soins de longue durée, publics et privés, au cours d'entrevues approfondies. L'analyse a permis de mieux comprendre comment les préposées aux bénéficiaires se défendent contre le dégoût grâce à un ingénieux travail sur la distance subjective reposant sur des techniques du corps et une clinique du rapprochement. Ce travail protège de l'abomination du dégoûtant et de son effet de contamination pour elles-mêmes, leurs collègues, mais avant tout, pour les résidents.

Pratiques émancipatrices d'infirmières québécoises politiquement engagées au regard des conditions d'exercice de la profession infirmière

### Patrick Martin, Louise Bouchard, Dave Holmes

L'infirmière soignante occupe une place sociale importante dans le système de santé notamment en ce qui a trait à l'humanisation des soins. Or, la crise économique des années 1990, entraînant une refonte de l'organisation des services publics a eu et aurait encore des répercussions sur les conditions d'exercice de la profession infirmière. Peu de chercheurs ont exploré les pratiques émancipatrices issues du discours d'infirmières soignantes engagées politiquement qui œuvrent dans des centres hospitaliers. L'objectif de notre recherche est de décrire les pratiques émancipatrices de ces infirmières à partir de leurs expériences de soins et de leurs perceptions des contraintes liées aux conditions d'exercice qui limitent leur potentiel humain et leur liberté. Les pratiques émancipatrices sont définies comme les prises de conscience (quant à ce qui est, mais aussi quant à ce qui est souhaitable), les idées et actions mises de l'avant par les infirmières pour favoriser leur affranchissement des contraintes et des structures de domination qui ont notamment pour effets de compromettre leur pleine réalisation de soi et leur autonomie professionnelle. Cette définition repose, entre autres, sur les écrits philosophiques de Honneth (2008), Rancière (1995) et s'articule autour de la perspective postmoderne de Boisvert (1997) comme grille d'analyse sociopolitique. La méthode de recherche utilisée est une approche qualitative utilisant des entrevues individuelles (n = 21) et des groupes de discussion (n = 18). L'analyse préliminaire des données recueillies nous permet de dégager ces quelques résultats : il y a dégradation des conditions d'exercice des infirmières, elles sont contrôlées par de multiples dispositifs qui misent sur la peur, elles subissent les répercussions d'une gestion à caractère néolibéral et elles ont mis en place des actions permettant des formes de résistance à ces phénomènes.



Space, stimulus or care: Are emergency departments conducive places for optimal care of marginalised people?

### Blisters to seizures: Does Mardi Gras medical make a difference?

#### Jem Masters

There has been much written about the use of space in the provision of health care especially in regards to mental health services and the need to provide environments that facilitate healing. However there is limited information on the Emergency department's (ED) environment, as it pertains to people with mental health issues. The focus of this paper looks at the where, why and how patients with mental health issues, are managed within the environment of busy (ED). As the excitement of trauma, emergency or life and death situation doesn't perceive to apply to mental health patients. ED nurses are aware that the over stimulating environment needs to be managed in order to provide optimal care for people with mental health issues but have to balance safety and risks. Foucault's concept of the panopticon is pivotal to understand the practices of ED nurses that emphasise physical management of mental health from the point of contact (triage, electronic data bases), the location within the ED, to discharge or admission. Mainstream health care sees the ED, as the front door to the health care system and ED professionals as the gatekeepers. In the case of people seeking assistance with mental health issues, the gate keeping reflects concerns about the proper location of mental health patients within the emergency department. Little attention is paid to the environment particularly in regards to people attending ED with mental health issues. It can be argued that there is a need to develop strategies to manage the space required to care for mental health patients within ED. This paper draws on the initial data collected from emergency nurses in relation to the space required to provide care to mental health patients and the over stimulating environment that is an emergency department/room

### Jem Masters

This paper looks at the health risks of patrons at mass gatherings over the past 10 years and how the party culture has changed the behaviours of patrons, particularly with stronger government and police involvement. It particularly looks at how marginalised health care providers worked parallel to mainstream health care and have influenced event management health care provision. The past 35 years has seen the political struggles for acceptance, equality and the same basic human rights of the Gay, Lesbian, Bisexual, Transgender, Queer and Intersex community (GLBTQI) reflected in health care provision. During this timeframe there was the emergent of the HIV and AIDS with all the fears, prejudice, discrimination and normalization of treatment and care. However, out of the need for care of young men dying of AIDS, attending their last party, grow a unique group of medical volunteers. Since the early 1980's Mardi Gras Medical has provided first-line pre-hospital care for the GLBTQI community at mass events. While no government funding has been given for the medical team, the services have set the benchmark for other service providers and government policies in regards to raves and dance parties. Similarly the medical team has been actively involved in the development of national and international risk management campaigns: Safe Sex, Substance Misuse and Save a Mate. Over the last decade, dance parties and raves have seen a shift in patrons' behaviour and their need for medical support especially during festivals and mass gatherings. Therefore ensuring the safety of patrons and reducing the demand on the health care system. This paper draws on the data and care provide by Mardi Gras Medical. It is a "tough job" providing health care to fit and healthy people who are compromised medically due to; blisters and seizures, intoxication, substance misuse or just shear excessive partying.



The necessity of dangerous practices: Nursing work, youth with disabilities and sexual health

HIV risk intervention for young men who have sex with men in Canada: Subjectivities in health promotion rhetoric

### Janet McCabe, Dave Holmes

Modern biomedicine is driven by strategies that attempt to normalize and medicalize the individual, and individual practices. Nurses consistently engage in the assessment, measurement and documentation of the patient status and experience against 'the norm'. This presentation will be divided into two sections. First, we will present information gathered from a critical ethnography of nursing work related to sexual health and youth with disabilities. This will provide a starting point to critically examine the implications of normalization and medicalization processes. Second, we will present a theoretical discussion that juxtaposes these processes in relation to sexual health as both useful and inherently 'dangerous' (in the Foucauldian sense). The presentation will draw on work of Michel Foucault on subjectivity and caring agents, Erving Goffman's discussions of the total institution, and Margrit Shildrik's attention to the neglect of the corporeality of the individual in the medical environment. In doing so, the goal of this presentation is to shed light on the difficult position that nurses occupy in institutional settings for youth with disabilities; advocating for patients and their right to be sexually active, supporting the overarching goals of an institution, and doing both within the understanding that this all occurs in the context of a relationship with the family as a whole.

### Cameron McKenzie

In the past decade there has been an increase in bareback sex (BBS) (unprotected anal sex) among Men Who Have Sex with Men (MSM), and especially Young Men Who Have Sex with Men (YMSM) in the USA and Canada. This analysis looks at the variables impacting this "unsafe" sexual behaviour, including but not limited to: identity construction, social constructions of masculinity, gay culture and community, racial and socioeconomic characteristics, and perceptions of "safe sex" health rhetoric among MSM. It is shown that these factors can be traced to broader socio-political structures within liberal welfare states specific to the absence or failure of sexual health rhetoric targeting atrisk YMSM. The current "condoms only" approach to safe sex education emerges from neoliberal, white dominant, heteronormative society that marginalizes queer men, especially racialized queer men, as social outliers and outcasts. This failure results from an overemphasis on individualized causes of risky sexual behaviours, such as drug and alcohol use, psychosocial factors, and individual notions of risk, while largely ignoring the social context within which such behaviours occur. The final paper will include qualitative data from my semi-structured interviews with six YMSM from my recent participation in the Totally OutRIGHT leadership program for young queer men in order to gain a better understanding of reasons behind increases in BBS. Furthermore, I hypothesize that the men who attend this workshop are already fairly selfaware leaders in their own right who mostly engage in safer sexual practices, and the program is thus not reaching the demographic where it is most needed.



## Change fatigue: Concept exploration utilizing critical management studies

A Foucauldian examination of patient subjectivity: A case study of patients with advanced cancer receiving further medical treatment

### Kimberly McMillan, Amélie Perron

Growing critique of the types and rates of change in health care are raising questions of how much change is too much. Change in health care has become rapid and continuous for many reasons, largely because of fiscal influence and restraint, as well as swift advances in health care technology, managerial structures, and scopes of practice for both regulated and non-regulated health care workers. The vast majority of research on the subject of change comes from management, business and organizational studies, supporting differing and often conflicting conclusions about efficient and sustainable ways of devising and implementing change in health care settings. Very little research is available on the impact of change for those employed in rapidly changing workplaces, such as nurses. What little research completed to date highlights is that workers experiencing large amounts of change can experience what has been identified as change fatigue. This experience can cause workers to become withdrawn, burnt out, exhausted, and it greatly influences their decision to leave the workplace and even their profession - issues that already affect the workforce in disproportionate Organizational change research continues to be theoretically driven by managerial frameworks that under represent the voice of nurses. The concept of change resistance remains the focus of organizational research, making little room for the concept of change fatigue to be explored. Vast differences exist and are worthy of exploration. To better understand nurses' experiences of organizational change we must change the way in which we theoretically ground organizational research. Frameworks such as Critical management studies can offer new avenues for knowledge development. Critical management studies will allow for the critical examination of current organizational practices, whilst enabling the incredibly invaluable, yet often under represented voice of nurses to be heard.

#### Shan Mohammed

Patients with advanced cancer sometimes receive disease-modifying medical treatment (e.g. clinical drug trials), despite uncertain prognostic outcomes and the likelihood of suffering. Framed by neoliberal assumptions about health choices, the current literature has focused on patients' inabilities to understand the severity of their disease or their unwillingness to accept death. Few studies have considered the rationales for engaging in these treatments from the perspective of patients. By using Foucauldian ideas of subjectivities, power/knowledge, and care of the self, this study expands on the current view of further treatment to include broader discourses. The main research question is: How does obtaining further diseasemodifying treatment constitute patients as subjects in the context of advanced cancer? Seven qualitative case studies were collected that included 21 semi-structured interviews with patients with severe metastatic cancer, family members, nurses, oncologists, and palliative care physicians. Cases also included field observations and numerous documents (e.g. self-help books and websites). Six types of patient subjects were constituted by further treatment: (1) The cancer expert subject; (2) The proactive subject; (3) The productive subject; (4) The mistrusting subject; (5) The obedient subject; and (6) The positive thinking subject. Certain subjectivities were rewarded by the healthcare system, whereas others were discouraged. These subjectivities were constituted bv power/knowledge relations with medicine. entrepreneurial ideas about responsibility for health, and self-governing forces to be an active agent in prolonging one's life. Rather than invest in relationships with healthcare providers, patients actively invested in their own capacity to treat their disease. Few studies have used poststructural ideas to theorize advanced cancer. The findings of this research help illuminate the "new" subjectivities at play in cancer treatment.



## Marginalizing hospitalized older adults through discourses of functional decline: A critique

### "Correctional Services": Forensic psychiatry as neoliberal norm

#### Jeannine Moreau

Functional decline in hospitalized older adults is considered a critical health care issue as it often results in prolonged hospital stays, poor discharge outcomes, dependence, and/or mortality. presentation offers a radical critique of a discourse of functional decline in hospitalized older adults that, in my opinion, dominates in health care literature. Discourse is identified as social practices within language that constitute the objects of which they speak (Foucault, 1972). I problematize how this concept of functional decline that emerged in the 1980s embedded in biomedical discourse was and continues to be deeply influenced bv politics of neo-liberalism biomedicalization in health care. I discuss the dangers of this kind of politicization, i.e., how functional decline discourse marginalizes older adults by its power, influence and capability to establish desired norms of functional ability; how it serves to produce objective authoritative knowledge for predicting, assessing, standardizing tools/models for effective/efficient health care practices. I illustrate effects of this power by describing how biomedical discourse of functional decline is informed, produced, controlled and organized by certain knowledge, values, beliefs and ideologies represented through statements in language. I propose that understanding these elements and dynamics of such discourse can reveal the power and effect of discourse, e.g., how functional decline is considered a profound marker of morbidity and mortality in hospitalized older adults. Underlying assumptions and taken-for-granted notions of subsequent health care practices are questioned in relation to how they position and represent older adults in particular ways. The intent is to open up possibilities for offering more appropriate, meaningful approaches to care for hospitalized older adults within constraints of organizational structures of care shaped by neo-liberalism and biomedicalization.

### Stuart Murray, Sarah Burgess

The authors examine the forensic psychiatric treatment of patient-prisoners caught between care and incarceration. While the Mental Health Act stipulates equal access to healthcare for all citizens, including prisoners, the neoliberal and biopolitical regulations that govern correctional institutions supervene prisoners' "right" to health. Using Foucault's concept of biopolitics as a theoretical lens, this chapter offers a critical examination of two events: the case of a child being born in captivity to an incarcerated mother (Julie Bilotta), and the case of a young woman (Ashley Smith) committing suicide in her cell. In both cases, correctional officers watched (and in Smith's case, filmed the event) from outside the cell, refusing to intervene and failing to provide even basic medical care. While these cases represent specific failures in the penal system vis-à-vis mental health, in a broader context they are also occasions to reflect on how forensic psychiatry itself often operates as a "correctional service" informed by juridical and biopolitical discourses. From the beginning of life to its end, from the birth of one incarcerated life to the death of another: The two cases provide extreme instances of biopolitical power, summed up in Foucault's slogan, "to make live and let die." The study brings us to a deeper ethical question. Who--or what--within the forensic psychiatry setting has the responsibility for life, to foster it or to neglect it to the point of death?



La généalogie de Foucault: approche critique pour l'analyse des fondements épistémologiques de la discipline infirmière The touch of Eros: On the importance of discipline, desire and transgression in physiotherapy practice

### Évy A. Nazon, Amélie Perron

Les fondements épistémologiques de la discipline infirmière ont fait l'objet de plusieurs recherches. Cependant, il est fréquent dans l'analyse de la construction des savoirs infirmiers de passer sous silence les contextes historiques, politiques. économiques et sociaux qui ont influencé leur développement. En effet, la majorité des écrits recensés sur le développement des connaissances en sciences infirmières ne sont pas sortis des cadres traditionnels. Les chercheurs utilisent des méthodes éprouvées reposant sur des explications causales universelles. De telles méthodes amplifient l'importance de certaines personnalités infirmières dans la construction des connaissances tout en minant la complexité du processus épistémologique de la discipline. Une telle problématique incite à l'adoption de l'approche généalogique de Foucault qui permet une compréhension radicale du domaine contemporain dont font indéniablement partie les sciences infirmières. Cette présentation vise à examiner en quoi l'approche généalogique de Foucault peut contribuer à enrichir les recherches sur l'épistémologie de la discipline infirmière, notamment en remettant en question les savoirs et théories jugés comme étant fondateurs de la discipline, mais que l'on a, historiquement dénués de tout contenu politique. La généalogie incite à scruter le savoir et le pouvoir qui force à agir et qui devient une manière de gouvernement de soi et des autres. Tisser un lien entre les écrits infirmiers et la notion de gouvernementalité permettra d'analyser plus en profondeur la relation complexe entre le champ infirmier et le champ médical et de reconstituer la base politique des savoirs infirmiers.

### David Nicholls, Dave Holmes

In this presentation we examine the innate sensuality of touch as it applies to physiotherapy practice. We argue that the ability to effectively discipline therapeutic touch continues to be a defining characteristic of physiotherapy. While these disciplinary approaches may have been vital to the early growth and development of the profession, we argue that it is time to revisit these 'technologies' and transgress them. Drawing on the work of three postmodern philosophers: Michel Foucault, Gilles Deleuze and Georges Bataille, we analyse the disciplinary strategies that have historically underpinned physiotherapy's affinity with particular forms of therapeutic touch. We explore Deleuze's notion of desire as a way of understanding the intimacy of touch, and draw on Bataille's notion of transgression to argue that new ways of thinking are needed for the long term health and wellbeing of physiotherapy practice.



HIV management and the public health apparatus: Include, differentiate, and manage

Biomedical knowledge, power, and legitimacy: Moral judgment marginalizes women with chronic pain in the healthcare system

### Patrick O'Byrne

Because recent studies have hypothesized that persons unaware of being HIV-positive are involved in the majority of incident HIV infections, a major focus of public health HIV prevention has been the identification of such individuals. The goal of this process has been to reduce onward HIV transmission by inducing both the behavioural changes and the medication-induced viral load suppressive outcomes that often occur after a person receives an HIV diagnosis. While some authors have discussed the potential impact this approach may have on HIV transmission, others have critiqued the biotechnological implications of such HIV prevention techniques. Few authors, however, have examined the biopolitical processes that underpin the overarching strategy of HIV testing, diagnosis, and treatment, particularly when it occurs to prevent HIV transmission. To address this gap, Hardt and Negri's work on imperial expansion--specifically, the tripartite imperative of the empire--will be used. More precisely, Hardt and Negri's three-pronged imperial process differentiation, and management will be used to explain how the public health focus of identifying persons unaware of being HIV-positive not only is about mitigating the factors that dissuade people from voluntarily undergoing HIV testing, but also, and more importantly, is about personal constructions and feelings of vulnerability and risk (at-risk specifically). This analysis, therefore, will explore how HIV prevention, i.e., management, is the outcome of differentiation, i.e., HIV testing, both of which rely on persons' voluntary inclusion in a state-run system of differentiation and management. In this way, Hardt and Negri's explanations of inclusion situate everything from anti-stigma campaigns about HIV to enhanced opportunities for timely and culturally appropriate HIV testing to mass media releases about HIV statistics as components of the overarching biopolitical, public health, HIV prevention movement.

### Margaret Oldfield

Around the world, chronic pain is more prevalent among women than men, and women have higher rates of pain-related impairment. Because chronic pain is invisible, often medically unexplained, and therefore contentious, women with chronic pain may be stigmatized. One much-maligned women's pain condition is fibromyalgia. It affects a surprisingly large number of Canadians, 440,000, of whom 80% are women. When women with fibromyalgia seek legitimacy for their invisible impairments, they often look to physicians, who hold the dominant knowledge about health and are therefore gatekeepers in the process through which illnesses gain social legitimacy. Many Canadian physicians, although not all, are skeptical of fibromyalgia's legitimacy and discredit women with fibromyalgia through moral judgment. This judgment takes the following forms: not believing the pain that women report, blaming women for their suffering, assuming that any new symptoms they report are caused by fibromyalgia, accusing women of being unmotivated to get better, and regarding women with fibromyalgia as a frustrating waste of time. Moral judgment marginalizes women with fibromyalgia, impeding their health care needs from being met. Indeed, 31% of Canadians with fibromyalgia report unmet heath care needs, double the percentage of Canadians with uncontentious illnesses. To counter moral judgment, I profile three clinical practices that could mitigate it: listening to the life stories of women with fibromyalgia, validating their pain experiences, and empathizing with them. These practices take into account that women's chronic pain can both originate in, and be worsened by, the conditions and contexts of their lives. Understanding how women with contentious chronic-pain conditions are morally judged and marginalized in healthcare can bring clinical practice closer to meeting these women's unmet healthcare needs.



## Co-creating a community of belonging for enhanced person centred healthcare

"Failure to recognize": Nurses and quality in residential care for the elderly

### Frances Power, Richard Hovey

Becoming a patient is a traumatizing experience where person centred care requires a shift from a focus on the sciences of medicine to be inclusive of the art of medicine, where the science meets the person in context (Gadamer, 1996). Treatment of the person necessitates a transformational shift toward the relational perspective which emphasizes communication styles, reflection, quality of the relational, generosity, and compassion within the framework of being a person centred in healthcare. This philosophy challenges how interdisciplinary, transdisciplinary or interprofessional teams configured, related to each other and operationalized. Haider et. al., (2009) suggested that person centered care could be achieved through a reconceptualization from a team into one defined as a community of care. Through this proposal of person centred care that includes community of care, we offer a reconceptualization of patient centred care. The challenge for this change necessitates a radical shift transcending our understanding of inclusion to evolve into a community of belonging that segues towards the co-creation of a "community on the basis of vulnerability and loss" (Judith Butler, 2004, p.20).

### Mary Ellen Purkis

The everyday context of residential care for older adults has changed markedly over the past 20 years. The numbers of registered nurses are dwindling. Regulated functions such as medication administration are being handed over to Practical Nurses while the majority of physical and social care has been passed over to unregulated care workers. The paper's title is derived from a common expression used in contemporary literature bemoaning current practice conditions in which there is a "failure to recognize" the contributions made by registered nurses to a high quality environment for older adults in residential care. My reading of contemporary practice in residential care is thoroughly shaped by my experiences as a registered nurse, as a teacher of registered nurses, and as an ethnographic researcher. It is also shaped by my experience of being a daughter whose mother lives in residential care. This paper explores methodological ground available to someone like me who wishes to make a meaningful contribution to debates about skill mix and quality of care. Can I legitimately reference my personal history while not delegitimating my contributions to a constructive dialogue of improvement in the residential care environment? Crapanzano's (1977) work on life history in anthropological fieldwork offers a rich theoretical source against which I can consider my interests. In this paper, Crapanzano "confronts the taken-for-granted world of the anthropologist" (p. 3) and, in so doing, acknowledges that, "that which we constitute as a legitimate subject for scientific research may, in the most profound sense, be nothing more than a sector of a world contingent epistemological space" (p. 4). The paper will seek to construct an epistemologically robust argument that can be advanced within the empirical world of making a positive contribution to the development of high quality health services delivery for frail older adults in long term care.



## Meeting expectations: Improving care standards through effective public involvement

# Care - existential goods - bipartisan justice: Ethical aporia of helping professions

### Jan Quallington

Health care in Britain is facing challenging times; both economic and reputational. There have been some widely reported care scandals. The most significant of which has led to a lengthy Public Inquiry, which has identified systematic failures at all levels of care organisations. Whilst this Inquiry relates to one organisation, many of the findings are generalizable. However, are inquiries the best means of using the public voice to improve care? Public inquiries enable investigation of serious issues under public scrutiny. They enable society to call individuals and organisations to public account, and they provide a forum for discussion of public expectations. Public Inquiries make recommendations for change. However, Public Inquiries are expensive, lengthy and have no legal power to impel the changes recommended. Where change occurs it is often an increase in regulation. This further removes personal responsibility from professionals for their decisions and behaviours and does not effectively tackle the values, culture and leadership deficits which allowed the failings in the first place. A central tenet of British health policy is the statutory requirement to 'involve' patients and the public in health care to ensure that services meet public needs and expectations. However, recent failures in care suggest that the public have only a peripheral role in monitoring and influencing health care provision. This paper reflects on how public involvement in partnership with professionals could negate the need for Public Inquiries in the future.

### Hartmut Remmers

Helping others in existentially threatening situations presents one of the historically invariant phenomena of human societies. Assistance is morally coded and thus independent of random or affective activating conditions. reliability of professionally institutionalised help (medicine, nursing), however, seems to also depend on affectively anchored motivations. The philosopher E. Levinas presents the affective motivational drive of personal helping behaviour (being touched by the vulnerability of others) as the moral basis of asymmetric interpersonal relations. The question posed in this presentation is whether or not this view on relations of care can be claimed for professional services in the context cultural modernity. Levinas' approach is fruitful with regards to professional (human-centered) services in the realm of motivational anchoring. It does, however, seem to fall short of two universal standards: respecting a biographically unique history of subjectivation and the creation of fair conditions, in which such biographically unique subjectivation can be realized in the future (M. Foucault). To accomplish this, a perspective that ensures distance from affective conditions is needed (J.Habermas). Questions of distributive justice can also be answered in light of persons that might be constricted in their ability to autonomously represent themselves. for example through responsibly representing their interests. In this context, the presented affective drive to personal helping behaviour of Levinas seems to claim universality. It touches upon socio-anthropological fundamentals human behaviour in general.



Semiotic entities and hybrid associations: Actor-network theory as a radical framework to examine primary health care nurse practitioners' integration within Interprofessional contexts of care

Annie Rioux-Dubois, Amélie Perron

Research consistently shows that Nurse Practitioners (NPs) are effective and safe; that they positively influence patients' health outcomes; that they increase access to quality care as well as decrease health care costs. Despite these significant impacts, studies indicate that NPs often experience interprofessional conflicts within clinical settings, which often results in NPs not being able to practice to their full scope, and, in one third of cases (according to one study), in NPs leaving their position. Researchers confirm that NP integration within the health care system can lead to substantial difficulties. The supposed lack of clarity around NPs' role is often cited as a barrier to seamless integration, despite clear legal and professional delineation. I suggest that factors other than role clarity are at play, that explain why, after three decades, NPs' integration within the Canadian health care system remains modest at best. New, critical frameworks are needed to uncover the various contingencies that mediate their integration process. The purpose of this presentation is to explore how Bruno Latour's Actor-Network Theory can provide a radical framework to critically analyze contemporary issues in health care. Using the integration of NPs in the health care system as an exemplar, Latour's concepts of networks, translations, hybrid associations, and semiotic entities are outlined, as well as their relevance for nursing and health research.

Exploring the limits of care-of-theself: One's knowledge capacity to know one's corporeal body

### James Ronan

The growing complexity of 'biomedical sciences' calls into question the knowledge capacity of individuals to exercise technologies of the self on oneself as acts of freedom concerning one's health. Increasingly, pedagogies of the corporeal body are inaccessible without 'expert interpreters' to translate or decipher meaning, actions, and consequences. The net effect results in a subjectivity whereby care-of-the-self cannot exist without 'proxy guidance' that represents simultaneously the 'normalizing' de-politicizing effects of disciplinary power and bio-power. indecipherable knowledge dilemma is actionable and consistent with the advent of neo-liberal realities in western sovereign states over the last half century whereby government of populations has shifted from within society to governing without society. Society has been reconstructed as a plethora of autonomous groups or communities operating from a pragmatic legitimacy inherent in such activities as 'business', 'technocratic', 'accounting', 'consumer', 'medical', or 'epistemic' communities. The resulting 'codes of conduct' or 'disciplinary inferences' are characteristic of governing at a distance and have the indirect consequence of the translation of political programs articulated in rather general terms--health, national efficiency, democracy, equality, enterprise--into ways of seeking to exercise authority over persons, places, and activities in specific locales and practices. With health, these diffuse 'normalizing' activities have resulted in 'marketable' discourses that conflate expert knowledge into individualizing products that are designed to discipline as well as to extract a profit. I will problematize the limits of care-of-the-self in terms of resistance or 'counter-power' to normalizing events inherent in knowledge complexity within a neoliberal context. Recreating pathways to a viable ethos for careof-the self is an imperative stand-point for 21st Century practices of freedom.



## Public private partnerships in global health governance: The neoliberalization of public space

# Calls to policy central: Analyses of editorial, commentary and other marginalia in nursing

### Arne Ruckert, Ronald Labonté

Public Private Partnerships (PPPs) have become a prominent feature of global health governance (GHG), with almost 100 PPPs currently operating on a global scale. PPPs in global health have been widely welcomed in the literature as a novel way to raise additional revenue, improve efficiencies, and enhance governance processes. The paper presents some of these positive features of PPPs but cautions that there are number of challenges inherent to PPPs that are only infrequently acknowledged in the literature. On the one hand, most PPPs focus narrowly on infectious diseases and attempt to address health problems through vertical program interventions. This can be seen in the Bill and Melinda Gates Foundation's approach that follows a long line of technocratic initiatives in global health cooperation that place emphasis on biomedical fixes to the world's health problems, with little regard for the socio-economic root causes of many health problems. On the other hand, the way in which PPPs reshape public authority and policy making is rarely problematized, such as the lack of democratic accountability and legitimacy of private actors contributing to policy development and implementation at the global level. The paper draws theoretically on Gramscian conceptualizations of private and public, to develop a better understanding of how PPPs are reshaping the porous boundaries between the public and the private realm of governance activity. The paper argues that this reshaping represents a further deepening of the neoliberal management of individuals and populations, ultimately undermining the attempt to significantly improve global health results. To do so would require a shift away from privatized forms of GHG through PPPs towards embracing an approach that focuses on addressing the inequitable distribution of social determinants of health (SDHs) through and equity-oriented progressive public policy interventions.

### Trudy Rudge

Research and consultancy outcomes in health care research abjure applicants to show proof of how money invested, equals outcomes toward the government of populations. While seldom expressed in such direct terms these encouragements and invitations to utilitarian and neo-rationalist aims for research are common in grant competition rounds run by governments and non-governmental organisations. While adding to the tomes of policy advice can seem attractive and an easy reach, Foucault suggests in Fearless Speech (2001) that academics contributing to policy advice and its writing enter a cul de sac: a governmental dead end for their work. The aim of this paper is to explore through a discourse analysis of editorial and commentary texts in health and nursing journals, as well as professional websites to account for what has drawn nursing to this pathway to power. Tracing the answers from health and nursing centred in opinion and editorial work provides a history of the relation between such thinking and what is believed to be the situation of nursing in/visibility. It provides an analysis of how this problem is presented and such answers found as axiomatic. The call to policy central is a particular answer, by some, to the problem of nursing visibility and power. In tracing the effects of such moves evoked by nursing's marginalisation in the centre of health care policy, the paper lays out a 'partial' history of the interactions between this problem, this answer and the specific situation of nursing's place in health.



### (Re) thinking nurses' actions in adolescent health promotion

# Discursive obligations in the migration of nurses as live-in home caregivers

### Maureen Ryan

Guided by the philosophical oeuvre of Michel Foucault, in the first part of my presentation I locate and discuss how the discursive formation adolescent health promotion defines the conceptual possibilities and determines the boundaries of nurses' thinking and acting toward young people and their health. In the second half, I will argue that nurses, often overlook how they are legislated into who, what, when, where and how they might engage with young people about their health decisions. Thus, I call attention to how political power and authority influences how nurses might practice with young people. Taking up Foucault's ideas, I question to what purpose nurses maintain a powerful practice tradition in adolescent health promotion that makes 'objectivist knowledge' the classifying criteria through which adolescents are disciplined and selfregulated. I do this by tracing the emergence of such knowledge, and question how this knowledge maintains power and influence on nurses' thinking and doing in adolescent health promotion. My work proposes that if nurses' are to practice differently with young people and health, they must first understand the ways they currently think, and act toward young people and the political implications of their practices. I suggest that nurses' have in some way(s) 'de-politicized' health promotion, and as a result, their thinking and practices with young people are often at odds with the values purported by the discipline. I offer my work as an opportunity to reflect on the usefulness of nurses' contemporary adolescent health promotion practices through a historical critique of the political powers that have defined and sanctioned those practices.

### Bukola Salami, Sioban Nelson

Even though literature has commented on the deskilling of internationally educated nurses, there remains a paucity of literature on the migration of nurses to destination countries to work as unskilled home caregivers or domestic workers. Despite the shortage of nurses in Canada and globally, evidence suggests that nurses migrate to Canada through the Live-in Caregiver Program to work as unskilled temporary migrants. Live-in caregivers provide care to children, the elderly, and the disabled while living in the client's After working as live-in caregivers for a minimum of 22 months and a maximum of 4 years, these workers qualify to become permanent residents in Canada. Drawing from interviews of 15 live-in home caregivers and 9 policy stakeholders and using the transnational feminist concept of global care chains, this study illustrates the contradictions in class mobility as nurses migrate to destination country to work as unskilled live-in home caregivers. Findings of the study shed light on the lack of alignment between the policy of the Live-in Caregiver Program and these nurses' expressed goal of regaining their occupational identity in Canada. Due to this workers migration path as livein caregivers, they experience added challenges in integrating into the nursing workforce in Canada. While the Canadian government recognizes that nurses migrate through this route, no policies exist to support these workers as their initial obligation in Canada is to work as live-in caregivers. However, given that the Live-in Caregiver Program involves an eventual goal to permanent residency, no policy exists specifically for nurses who migrate to Canada to work as live-in caregivers to achieve Canada's goal of long term economic integration of permanent residents in Canada. Hence, what exist are the divergent obligations between three statuses: status as a live-in caregiver, status as nurses, and status as prospective permanent residents in Canada.



The Francis inquiry: Media representations of health care governance in the context of crisis in health care

Jay Shaw, Wendy Martin, Christina Victor, Pia Kontos

In June 2010, the Secretary of State for Health in the United Kingdom (UK) announced a Public Inquiry ("The Inquiry") into the roles plaved commissioning, supervisory, and regulatory organizations in the "failure" of care provided at a local National Health Service (NHS) Foundation Trust. The purpose of the Public Inquiry was to determine why serious problems in health care delivery at the NHS Foundation Trust in question were not identified sooner, and how improvements may be made in local NHS governance to prevent similar "failings" in care delivery in the future. The findings of the Public Inquiry will be published and presented to the public on February 6th, 2013. The purpose of this study is to explore the representations of health care governance in popular newspapers in the UK in response to the findings of the Francis Inquiry. Specifically, a critical discourse analysis guided by the governmentality theory of Peter Miller and Nikolas Rose will explore the representations of health care commissioning, supervisory, and regulatory organizations in four UK newspapers: The Guardian, The Mail, The Mirror, and The Sun. Newspaper articles mentioning the report will be sampled over an eight week time frame (two weeks prior to publication and six weeks after publication of the Francis Inquiry). Analysis will compare the discourses of "health care governance" found in the Francis Inquiry report with those found in the four newspapers, situating each within broader cultural discourses about politics, health and health care in a time of austerity in the UK. Insights will be drawn regarding the ideological understandings of health care in the UK, political messaging in relation to health governance reform, and the re-presentation of key messages regarding governance in both the Francis Inquiry and popular news media.

The social construction of individual conduct, compliance and chronic illness in magazine articles about fibromyalgia

### Michelle Skop-dror

Fibromyalgia (FM) is a contested, gendered, and chronic illness of unknown origin. Symptoms include widespread pain, fatigue, and sleep disturbances. FM affects 3% of Canadians of whom 80-90% are women. Research studies have identified that within healthcare discourses FM is often erroneously labeled a psychosomatic illness. However, few studies have examined perceptions of FM outside of the healthcare context. Thus, the purpose of this presentation is to report the findings of a qualitative study examining how women with FM have been represented in the media. The sample consisted of 25 magazine articles written between 1987 and 2010. They were drawn from a list of English language magazines with high circulation rates in both Canada and the U.S. Using Foucauldian discourse analysis, articles were coded line-by-line to identify overt and covert messages. This study found that magazine articles reinforced the neoliberal discourse that women have a moral duty to manage and even recover from their chronic illness. Women with FM were constructed as "good patients" if they were proactive and took charge of their health through daily routines consisting of medication, diet, and exercise. These treatments function as technologies of the self, a form of self-government and self surveillance, because they situate recovery as a product of individual conduct and compliance, thereby minimizing the responsibilities of the healthcare system. The representation of the good, compliant patient sends the message that women are "at risk" for remaining ill if they are not self advocates who take responsibility for their own recovery process. This research study could aid health care providers, who work with women with FM, by improving their understanding of the biases and stereotypes within popular culture.



Les dispositifs de sexualité et d'alliances confrontés empiriquement: construction de la sexualité des adolescents vivant en situation de pauvreté dans une ville d'Amazonie brésilienne

### Cintia Maura Jorge Soares, Michel Perreault

L'objectif de la présente recherche était de dégager les constructions possibles d'un ou de dispositifs de sexualité et d'alliance chez des adolescent(e)s vivant en situation de pauvreté au Brésil. Cette recherche ethnographique repose sur un ensemble de données empiriques recueillies par entrevues, observations et recherche documentaire. Quatorze adolescents vivant dans la communauté de Belém ont été rencontrés de même que leurs parents. L'analyse des données empiriques révèle des dispositifs de sexualité et d'alliances, décrits comme « dispositif du sexe sécuritaire » et « l'alliance des puissants », respectivement. Ces résultats de recherche, qui reposent sur un usage novateur de concepts foucaldiens, permettent de reconsidérer certains mythes entourant la construction sociale de la sexualité des adolescents vivant en situation de pauvreté.

Problematizing wealth creation in the relational spaces of health care practice and research

### Rusla Anne Springer, Michael Clinton

This paper troubles the effects of pharmaceutical industry incursion into the relational spaces of health care practice and research. Drawing upon a Foucauldian discourse analysis that revealed the subjectivities of nurses and physicians who uncritically took up the role of advocates for disease modifying therapy (DMT) in the treatment of Multiple Sclerosis (MS), we focus our analysis on how external discourses 'order' subjectivities. More specifically, we draw attention to the 'technologies of the self' health care providers engage in as they promote the financial interests of the pharmaceutical industry. By focusing attention on 'technologies of the self', the paper reveals how subjectivities are formed and transformed through regularities of time, activities and actions to promote the interests of the pharmaceutical industry. The paper problematizes the pervasive and self-interested presence and influence of the pharmaceutical industry in health care practice and research generally, and calls for critical dialogue and analyses of the place wealth creation occupies in the relational spaces of health care practice and research.



Examining social inequities in overseas volunteer 'health work': How gender, race and class shape Canadian non-government organization (NGO) services in Tanzania

Oona St-Amant, Catherine Ward-Griffin, Helene Berman, Arja Vainio-Mattila

NGOs play an important role in serving impoverished and marginalized groups across diverse areas of health development. includina healthcare. Many Canadian NGOs face organizational challenges, such as limited infrastructure, limited longterm funding and project-specific funding models, donor reliance and volunteer reliance, and a high turnover of personnel. It is important to understand the broader context in which NGOs exists and how this impacts the delivery of healthcare services. The purpose of this institutional ethnographic study is to critically examine the social organizations within Canadian NGOs in the provision of HIV/AIDS healthcare in Tanzania. This study addresses the following questions: 1) How are power relations enacted by paid and unpaid workers?; and 2) how do these power relations shape the experiences of health workers? Multiple, concurrent data collection methods, including text analysis, participant observation and in-depth interviews were utilized. Data collection occurred over approximately a 12-month period of time in Tanzania and Canada. Interviews were conducted with healthcare professional volunteers, NGO administrators and other staff and bilateral/multilateral organization employees.

Data analysis revealed that inter-connected power such gender, relations as race, age class/professional status shaped health care worker's scope of practice in Tanzania. For example, participants described working either above or below their Canadian standards of practice based on their social locations. Furthermore, most participants described having unrealistic pre-departure expectations of culture and social justice related to 'health work' in Tanzania. These findings illuminate the need to generate additional awareness and response related to social inequities in international volunteer 'health work'.

Gender relations in hospice palliative home care: A critical analysis

### Nisha Sutherland, Catherine Ward-Griffin

Hospice palliative home care is significantly influenced by social relations of gender. Occurring within the context of relationships between clients, family caregivers and health care providers, hospice palliative home care involves the gendered division of paid and unpaid work, affording privileges and challenges for men and women, and potentially leading to inequities, or barriers and opportunities for optimal health and health care access. Research in this context has shown that family caregivers are predominately women and more likely to experience negative physical and psychological effects than their male counterparts. Furthermore, emotional support for men has often been overlooked by providers. For analysis beyond differences, what is needed is a critical examination of how gender relations shape experiences in hospice palliative home care. A critical feminist lens is used to examine the social and political conditions within which gender processes are embedded. The purpose of this critical ethnographic study is to examine gender relations in the context of hospice palliative home care for seniors with cancer. This approach uncovers takenfor-granted assumptions that shape policies and practices, while exposing power relations that reinforce inequities. Data were collected from 6 caregiving triads consisting of a senior with cancer, family caregiver and primary nurse. Data from in-depth interviews. observation and document review afforded insights into assumptions and power differentials in everyday hospice palliative home care. Analysis elicited themes and patterns informing the complex ways in which gender relations shape hospice palliative home care experiences for seniors with cancer. A comprehensive understanding of the context and interplay of gender inequities is essential to better inform policies and practices to promote strategies for quality, equitable hospice palliative home care.



Improving access to cervical cancer screening among sex trade workers: An unconventional approach

### Naomi Thulien, Ed Kucharski; Catherine Moravac

Sex trade workers are likely at highest at risk for developing cervical cancer yet less likely to engage in screening. A collaborative initiative between Women's College Hospital, St. Michael's Hospital and the Sherbourne Health Centre - all based in downtown Toronto, Canada - sought to improve cervical cancer education and screening at a time and location most convenient for women in the sex trade industry to access preventive health care services. Each week between the hours of 10pm and 1am, a former sex trade worker, nurse practitioner and community outreach worker boarded a mobile health bus with the purpose of offering cervical cancer education and screening to sex trade workers in downtown Toronto. This ground-breaking initiative was piloted over a 12week period. Feedback from the women was overwhelmingly positive as they appreciated health care services being offered at a time and location most convenient for them. Connecting with a peer leader was key to gaining their trust. The nurse practitioner was able to perform cervical cancer screening on 18 women who hadn't had a Pap (Papanicolaou) test in at least three years. In addition, the team was able to reach out to many more women involved in the sex trade industry, connecting them with appropriate health care, housing and social supports. This novel and unconventional approach to cervical cancer screening offers promise as a way to improve cervical cancer screening rates among sex trade workers and could be piloted among other marginalized groups.

### Telecare and dementia care: New ideals and types of care

### Hilde Thygesen

Telecare and dementia care: new ideals and types of care Telecare, or the provision of care at a distance, is a hot topic on the welfare-political agenda in Norway, as in many other countries. The context of this development is the challenges of the ageing of society; of meeting the expected care needs of a rapidly increasing ageing population. Many health economists, politicians and others point at the possibilities of telecare technologies. The argument is that the new technologies will give cheaper, more efficient and better care services all at the same time. The underlying assumption is that people want to grow old in their own homes, and that telecare technologies can provide the necessary safety and support, which makes it possible for them to maintain their independence for as long as possible. However, and at the same time, many old people and their carers fear that the technology will replace necessary human care, and that the introduction of telecare technologies will make old persons even more vulnerable, isolated and lonely than they are today. In this paper, drawing on ethnographic material from studies of the use of telecare technologies in dementia care practices, I will show that the picture is much more complex than this polarized discussion opens up for. New technology does not just support and supplement care, but neither is technology a foreign element in care, impoverishing care. The argument is that the new technologies generate new forms of care, with new ideals, actors, tasks, relations and compositions of the care collective.



The culture of consumption and the construction of youth at risk as a health issue

Working evidence-based policymaking: A critical view into the daily practices of health policy workers

### Martha Traverso-Yepez, Jill Allison

While modern science and technology increasingly governs the task of caring for our health, disease and pathologies usually dominate discussions about people's well-being. Within this trend, the goals of fostering autonomy and participation within a broader concept of social health, citizenship, and agency remain largely underachieved. Our presentation will reflect on a predominant dualistic thinking in health research and intervention that emphasizes either individual, microlevel explanations of health or macro-level, structural ones, failing to address the constant interaction between the two levels. Our theoretical analysis will bring examples from qualitative data from two research projects to illustrate how health subjectivities are enmeshed in social and economic conditions. We analyze the fact that in the context of a rural community, people perceive and make sense of particular health problems related to youth as signs of change in both community life and the way health is defined. Opportunities for healthy participation in activities such as sports and safe social events are understood as structured commodities and are largely unavailable, while accessible alternative ways of being healthy and active, such as unstructured play and sports, are less socially supported. The main demand is for increased reactive service provision aimed at "youth at risk" for substance abuse. While such problems are part of the social environment, the ongoing efforts to address these behaviours have been institutionalized, medicalized, and relegated to a health domain. It is in this cleavage between a lack of essential social structures that promote and produce health and the health structures that medicalize the resulting problems, where the conditions that perpetuate a model of consumer behaviour reside. This entails that we look not only at the opportunities for preventing problems, but rather at redefining what constitutes healthy environments for youth to thrive.

### Catherine Van Mossel

Many Canadians are aghast at the current federal government's disregard for science. Those offended by this disregard allege that the truth science offers is being trumped by ideology. I am in the uncomfortable position of joining those who challenge the government's contempt for science, while, at the same time, wanting to problematise the central tenet that science offers the comfort of such fundamental truths. This presentation seeks to explain how the oft-lauded "evidence-based policy-making" works in a health policy-making setting. The concept "evidence-based" is now well established in policy-making practice settings across many disciplines; its proponents have been successful in bringing it from the margins to the centre at least in claims of practice. In response to literature extolling its virtues, which includes removing politics and ideology from policy-making and relying upon the "truth" only science can produce, there are wellestablished critiques that counter these assertions and problematise their assumptions. However, there is little research that explicates how policy workers engage with/in the discourse of "evidence based" in their daily practices. My research delves into these practices, specifically as they relate to managing the increasing "burden" of chronic disease. The analysis reveals contradictions between: the (perceived) valuing of evidence, scientific method and rigour, and the stories of daily practice; what policy workers say they are doing and their descriptions of that work; and the practices of different workers. Either frankly or sotto voce, many policy workers scorn a fundamental assumption of evidence-based policy-making: that policy-making should - and even can - be apolitical. Using a Foucauldian understanding of discourse to understand "subtle workings of power in complex policy processes" (Sharp and Richardson 2001 198), I intend to show how policy workers enact the all-too political work of evidence-based policy-making.



## Striving for balance: Gendered inequities in double duty caregiving

Catherine Ward-Griffin,
Oona St-Amant, Nisha Sutherland,
Judith Brown

Although there is increasing research of work-life balance particularly among employed caregivers, how gendered inequities are socially constructed within double duty caregiving (DDC) is virtually unknown. Based on data from a feminist constructivist grounded theory study, we argue that health inequities are gendered at both the individual and structural levels that will require a different set of policies in order to improve health outcomes for those who provide care both at home and at work. In-depth telephone interviews at two time periods were conducted with 32 male and female nurses caring for elderly relatives in three Canadian provinces. Using the constant comparison method, the core dynamic process, Striving for Balance, illustrates how the participants actively negotiated the interface between formal and familial caregiving. Moreover, study findings revealed three DDC prototypes which reflect varying degrees of boundary blurring, from smallest to largest (Making it Work, Working to Manage and Living on the Edge), whereby those Living on the Edge experienced the poorest health, followed by Working to Manage, and Making it Work. Findings suggest that gender shaped the types of strategies (e. setting limits) used by the participants, and the resulting health experiences. Although the nurses' knowledge and skills typically positioned them as the 'expert' in familial care, they attempted to set limits or resist expectations to provide care to family members. However, more women than men experienced an increase in the blurring of familialformal care boundaries over time, stress, and ill health. Because gender plays a dominant role in determining who may be more at risk in experiencing ill health, it is crucial to develop appropriate workplace and governmental policies that will redress health inequities among men and women double duty caregivers that will ultimately improve the health of Canadian nurses.

'Living well?': Experiences of women living with metastatic breast cancer

#### Karen Willis

In most western societies, strategies to reduce morbidity and mortality from breast cancer have focused on early detection and early treatment. Positive messages prevail in both the social and medical space following a diagnosis of primary breast cancer. For example, celebrity success stories provide inspiration and hope about cure. There is a growing group of women who are not represented within such medical and social discourses - those who have 'failed' to be cured. With advances in medical treatments, women with metastatic disease are now living for longer with the disease in the knowledge that rather than being cured they are living in 'contracted time'. This paper reports on a project that explored the experience of women with metastatic breast cancer. Fourteen women with metastatic disease participated in semi-structured interviews about strategies they used to 'live well' with their illness. The findings provide insights into the diversity of illness experience in this group of women. We discuss three themes from the data: First, 'thinking about the illness'- while drawing on dominant discourses about 'thinking positively' about their illness, almost universally they discuss the importance of not thinking about it, of the need to 'get on with their life'. Second, trust in medical treatment to prolong their life (despite side-effects of medication that are often debilitating); Third; in societies where social support is seen as an important part of living with an illness, these women identify that social support mechanisms can give voice, but can also be exclusionary and silencing for those who do not fit the expected disease trajectory.



