

WOMEN'S HEALTH & MENTAL WELLBEING SPEAKERS SERIES



Fall 2012 – Winter, Spring 2013
Organizer: Dr Nazilla Khanlou
Echo's Chair in Women's Mental Health Research
Faculty of Health, York University

SUMMARY OF PRESENTATIONS

Presentation	Summary
<p>November 20, 2012</p> <p>Dr. Sannie Tang Assistant Professor School of Nursing York University</p> <p>Title: Filling in the puzzle of a social justice framework for critical health research: Lessons learned from Iris Young and Paulo Freire</p>	<p>Dr. Sannie Tang, an assistant professor with the School of Nursing at York University, spoke at the <i>Women's Mental Health and Well-Being Speakers Series</i> held at York University. Using the lessons she has learned from Iris Young, she discussed the social injustices that many racialized populations face once they arrive in a new country. She found that social structures not only separate individuals into classes, but also deny those populations the same access to opportunities. Dr. Tang spoke from her own personal experience as an internationally educated nurse of colour, who is trying to obtain her licence to practice as a registered nurse in Ontario. She has found that social structures, including the rules and regulations of the governing bodies of nurses, make it particularly difficult for those professionals who were 'foreign trained' to obtain recognition for their educational qualifications and past working experiences outside of Canada. By doing so, individuals are discouraged from seeking positions of higher standing in the mainstream society. She emphasized the need and importance of changing social structures. These structures are complex and multifaceted as they greatly influence the social determinants of opportunities, as well as other aspects of daily living. Dr. Tang's lecture finished with insights on how to change the future of these</p>

injustices through critical examination, research, and by promoting equity at the structural level.

January 23, 2013

Dr. Deborah Davidson
Assistant Professor
Department of Sociology
York University

Helena Stahls
Mother & Active community
member

**Title: Maternal grief the
need for social support**

Dr. Deborah Davidson, an assistant professor of Sociology at York University, and Helena Stahls, a bereaved mother, spoke at the *Women's Mental Health and Well-Being Speaker Series* held at York University. Using the lessons Dr. Davidson learnt from her research interest in bereavement and memorialization, perinatal death, and her experience as a bereaved mother, she spoke of grief as a normal reaction and a multidimensional response to loss. Davidson focused on maternal grief which she described as one of the most intense and complex forms of grief, with griever experiencing a variety of both psychological and physical symptoms. She described how death is a taboo subject in today's society making it difficult for people to talk about. Even from those who try to console the griever, there may be unintentional harm through, for example, some of the language used. Dr. Davidson recalled her experiences in the 1970s where her babies were born prematurely and died shortly thereafter. She remembered being told by healthcare professionals to go home and "forget it", and for years she grieved alone and in silence, with no psychosocial support and with no outlet for her to grief. She talked of how the biomedical focus, which considers grief as pathology by trying to "fix" bereaved mothers and expecting them to "get over" their loss, is not helpful. She noted some of the profound changes in today's healthcare settings with healthcare professionals acknowledging and responding to maternal grief. Unfortunately, however, acknowledgement and helpful response is often not the case outside of healthcare settings.

"I felt into a huge hole." Those were the words of a bereaved mother Helena Stahls who also spoke about the impact of the death by suicide of her 34 year-old daughter Donna. Although her daughter died more than 10 years ago, the pain Stahls experiences from her death continues. She talked about the sustained lack of social support, social acknowledgement, and related losses, such as the loss of friends, loss of a direct link to grandchildren, and the loss of energy that bereaved mothers experience. Stahls described the experience of picking out her daughter's burial outfit as one of the most painful in her life. She described triggers to her grief that occur around events including anniversaries, birthdays, and her grandchildren's graduations. Stahls also highlighted how she worries that her daughter will be forgotten and to keep Donna's memory alive, she has established an annual fundraiser called Just Gotta Skate, now in its 12th year. The event has raised more than

\$100,000 for the Cohn's and Colitis Foundation of Canada.

Both Davidson and Stahls emphasized that active listening with empathy and without judgment is the best way to offer support to bereaved mothers. They finished their presentation by offering some helpful tips on how to provide support to bereaved mothers - validate, listen, learn from their experience, provide support such as running errands, allow them time to talk, let them direct the conversation, and educate others. For additional information please see:

"Don't expect bereaved mothers to 'get over it', says speaker", YFile (2.02.2013),

http://yfile.news.yorku.ca/2013/03/01/research-probes-health-impacts-of-gendered-senior-care-work/?utm_source=YFile_Email&utm_medium=email&utm_campaign=MorningEmail

March 13, 2012

Dr. Lisa Seto Nielsen
Assistant Professor
Department of Nursing
York University

Title: Dying at home: the normalization and silencing of women's caregiving roles in palliative care

Dr. Lisa Seto Nielsen, an Assistant Professor of the School of Nursing at York University, spoke at the *Women's Mental Health and Well-Being Speaker Series* held at York University. Using the lessons she learnt from her research in palliative care, home care, death, dying, and immigrant health she found that in Chinese immigrant families caring for a family member with terminal cancer, how women took up the caregiving role was potentially different from men, but it was highly contextual. Most importantly, the pragmatics of dying at home took priority over adherence to essentialized cultural "beliefs" such that the social and material conditions of participants and the enormity of dealing with death and dying provided more insights into patient's experiences of palliative home care. Her presentation was informed by her doctoral dissertation which explored the palliative home care experiences of Chinese immigrants with advanced cancer in the Greater Toronto area. Even though her dissertation did not focus solely on gender, gendered aspect regarding dying at home did emerge.

Using postcolonial theory, a critical perspective of culture was adopted that viewed culture as dynamic and fluid, rather than a set of static beliefs. Of particular interest was the work of Bhaba (1994/2004) and the "Third space" as a space for cultural transformation and cultural hybridity. A postcolonial perspective provided an critical analysis that highlighted how different roles and the positioning of the other created vulnerabilities for both men and women caregivers.

"... getting up, washing, dressing and cooking, a little cooking. (I: Does your family help you?) Oh, when they come home from work in the evening, they help a little because they have to work and don't have a lot of

time.... even if there's pain, I still have to get up." (CR4, translated). Those were the words of one of the study participants who was describing the impact of being a terminal cancer patient, wife, and caregiver. Using lessons learned from her research, Dr. Seto Nielsen elaborated on how caregiving roles are still mostly carried out by women but this was due in part because immigrant family members could not take time off work because of lack of job security. Dr. Seto Nielsen also described how this issue is complex and should not be looked at solely from a gender perspective but also to include social and material conditions immigrant women are living in.

She spoke of how some men still categorized doing groceries as women's work and that one male caregiver in her study spoke comfortably about doing meal preparation and household chores, but not personal care. As such, a key aspect of whether Chinese immigrant women would move from home to hospice is whether they were able to provide their own personal care. The female care recipients indicated that they would consider being admitted to a hospice or palliative unit when they could no longer bathe or toilet themselves. Thus male care recipients were able to stay at home to die because they could reject personal care from outside providers as they could depend on their wives to provide that care. In doing so, the male care recipients could avoid the vulnerability of exposing their bodies to strangers, but inadvertently became dependent on their wives for their care. She concluded her lecture by answering questions from the audience and offering some helpful discussion on social and spatial complexity of palliative home care.

April 24, 2012

Dr. Isolde Daiski
Associate Professor
School of Nursing
York University

Title: Women living with homelessness: they are (almost) invisible

Dr. Daiski's presentation discussed the perspectives of extremely poor and marginally housed, women who live in shelters, on the street or are marginally housed. The data presented was from recent qualitative research projects downtown, as well as in a suburb of Toronto. The data has composites according to three age groups: Young, middle-aged and older women and narratives were presented to reveal common themes and experiences, as in the narrative hermeneutic approach. The presentation drew on the works of Foucault and Kearney and was situated in the context of Neoliberalism.

The research found that homelessness arises from the same issues and problems in downtown and the suburbs. However, the intensity of the problems is much higher in the suburbs, where no homelessness is supposed to exist and where the resources are even scarcer than in urban environments. Common threads found in the research indicate four pathways to homelessness: abuse/domestic

	<p>violence, extreme poverty, job losses (layoffs, injury, ill health) and a fragile social safety net. The women interviewed, commonly expressed a desire to belong, and to give back or do volunteer work. They also expressed feelings of 'invisibility', and being 'othered' and dehumanized.</p>
<p>June 6, 2013</p> <p>Jennifer Noseworthy RN, MScN Lillian Wright Maternal Child Health Graduate Scholar 2011 and Public Health Nurse in a First Nations Community in Labrador</p>	<p>Jennifer Noseworthy, Graduate of the School of Nursing—Master of Science in Nursing program at York University, Lillian Wright Maternal Child Health Graduate Scholar 2011, and Public Health Nurse in a First Nations community in Labrador, spoke at the Women's Mental Health and Well-Being Speakers Series held at York University on June 6, 2013. Jennifer presented her thesis research entitled, A Solitary Journey: Interpretive Description of Women's Experiences of Perinatal Loss in Labrador—a research study completed in Labrador that explored how women in these remote and isolated communities experience the ending of a pregnancy at any time before or during birth, or the death of a newborn in the first month after birth (Limbo & Kobler, 2010). Whether or not women described receiving support and companionship from others as they grieved the loss of their baby, it was clear that some aspects of grieving perinatal loss must be navigated alone. The concept of being alone-not alone permeated all aspects of women's experiences of perinatal loss that were described in the interviews.</p> <p>Noseworthy used an interpretive descriptive method (Thorne, 2008) to answer the research question: How do women experience perinatal loss in isolated, northern regions such as Labrador? Jonas-Simpson's (2011) research-based documentary, Enduring Love: Transforming Loss, was used as a tool for participants to reflect on and share their own experiences of perinatal loss in an interview or in a focus group. The women described their experience as a solitary journey where they are simultaneously alone-not-alone. Jennifer shared that women might encounter times in which they share their sorrow and grief with other women, their partners, and their other children, as well as experiencing times when they remain silent about their sorrow with others. Women may choose to share their grief with other women who have experienced, or are experiencing, perinatal loss as a way to offer comfort to others; however, women often described deriving comfort and support themselves when sharing their experience with other women. In spite of this, participants in the study also discussed the social 'taboo' of speaking about perinatal loss and how it might cause them to hesitate to discuss their own loss with other women who have had a similar experience. In addition, some women noted that they might choose to remain silent about their loss at times when their grief is too raw. Differences in how women and their partner may navigate their grief were identified; partners might become silent about their loss after some time, while women would like to continue sharing their feelings about their baby and their loss with their partner. Partners may silence their own feelings of loss and grief, perhaps with the belief that this would help the women to move on; this may result in women also silencing their own loss and grief as they notice their partners'</p>

reluctance to discuss their loss. While some participants had shared their loss with children who are still living, others believed it was important to do so but struggled with knowing how to tell their children about their loss.

In remote and isolated regions, women may be marginalized as they grieve their loss due to factors such as lack of supports and resources, reduced accessibility to services, and discomfort and lack of acknowledgement by others with respect to the loss of their baby. Although women may be marginalized in their loss and grief, it was also recognized that women might find creative ways to navigate through their grief and connect with others who have experienced similar loss. Given the small population that exists in these communities, it might be possible to identify other women who have experienced perinatal loss (despite lack of formal supports), however, it was also recognized that this is largely dependent on "who you know" and, thus, might not be equally available to everyone. While the remote and isolated context of these communities might be seen as a barrier to the provision of supportive resources and services, this geographical context was also described as a potential strength which could be drawn upon for the development of future supportive resources and services since these communities are often very small and close-knit. Women may derive comfort or be further isolated within the context of the setting in which their loss occurred, or religious and cultural practices and beliefs. Comfort within the context of loss generally occurred when services, care, responses of others, and religious and cultural practices are congruent and responsive to the meaning that women and their partners assign to the loss of their baby. When there is lack of congruence and responsiveness in these areas, the isolation that women and their partners may already feel may be further intensified.

Women described a wide range of responses that others (ie: family, friends, health professionals) had to their loss; sometimes the response was very hurtful, while other times the response was very supportive. The response of health professionals, in particular, to perinatal loss leaves a powerful imprint on the experience and memories of women and their partners. Some participants in this study recognized that hurtful responses were, perhaps, due to others' discomfort with perinatal loss and well-intended. The most powerful and meaningful response by others was when the loss of their baby/pregnancy was acknowledged as a loss, and when others simply said, "I'm sorry."

Although women were physically separated from their baby that died, they described a continued connection to their baby.

Noseworthy explained that women maintained a place for their babies in their every-day lives through keepsakes and mementos, maintaining a grave or memorial site, naming their babies, remembering anniversaries, and through symbolic representations of their babies (ie: angels, teddy bears).

Women who were not able to have a grave or memorial site, or did not see their baby, expressed regret. As one participant shared regarding the absence of a memorial for her baby, "I don't have nowhere to go! And sometimes I think I need that!"

Perinatal loss was never described as being 'resolved' by the

participants. The solitary journey that women embark upon when they experience the loss of a baby at any time during pregnancy, birth, or within the first month of life, is not a linear journey that has a distinct ending. Instead, it can be seen as a cyclical journey in which one searches for a way to make their loss ("the pieces") fit within the fabric of their lives as they themselves change and evolve. This journey is not one that others can journey for them or with them, "the search for meaning is a solitary and personal journey that must be travelled alone" (Noseworthy, 2012). Although this is a solitary journey, enhanced understanding of how women (and their partners) experience perinatal loss can help others respond better to their needs and offer comfort, guidance, and support on their journey.
