

2010. Shields, L., Molzahn, A., Bruce, A., Stadjuhar, K., Schick, Makaroff, K., & **Beuthin, R.** *Storylines of life-threatening illnesses*. 16th Qualitative Health Research Conference, Vancouver. October.
2009. Shields, L., Molzahn, A., Bruce, A., Schick Makaroff, K., Shea, L., & **Beuthin, R.** *Liminal Space of spirituality amidst narratives of living with life-threatening illness*. 5th International Multidisciplinary Academic Conference: Spirituality and Health: Working Together for Optimal Health, Calgary. September.
2009. Shields, L., Molzahn, A., Bruce, A., Stadjuhar, K., Schick, Makaroff, K., Shea, L., & **Beuthin, R.** *Re-stor(y)ing life within life-threatening illness*. Qualitative Health Research Conference. Vancouver. October 4-6.
2008. Stephenson, P., Holroyd, A., **Beuthin, R.**, McGee, P. & Vegsund, B. *Developing Collaborative Health Research and COACH-NCR: How one team made it happen*. Vancouver Island Health Authority Research Day Showcase, Victoria. November.

Refereed Academic Poster Presentations

2013. **Beuthin, R.** *Metaphors of aging with HIV*. InspireNet Fall 2013 Conference. Connect 2013: Health Services Research at Work: Using Evidence to Transform Care. Vancouver. September 16.
2013. **Beuthin, R.** *Metaphors of aging with HIV*. 17th National Conference on Gerontological Nursing: Personhood and caring: Honoring the older adult's life journey. Richmond, BC. May 30.

Knowledge Translation Activities

- Bruce, A., Schick Makaroff, K., Shields, L., Molzahn, A., **Beuthin, R.**, Shermak, S., & Stajduhar, K. *Symbols of living in-between: Re-stor(y)ing life within life-threatening illness*. Art Exhibit.
- 2014: Patient Care Center, RJH, Victoria, BC.
- 2013: BC Ministry of Health. Victoria, BC.
- 2012: Maltwood Gallery, University of Victoria.

Shields, L., Molzahn, A., Bruce, A., Stajduhar, K., Schick, Makaroff, K., **Beuthin, R.**, & Shermak, S. (2012). *Life-threatening Illness Brochures ((life with chronic kidney disease, life with cancer, life with HIV) & Vignettes (Seven videos of first person narratives)*. University of Victoria. Available at www.UVic.ca/illnessnarratives

Select Public Presentations

2014. Island Health Series. Advanced Chronic Illness: Experiences of Patients and Families. RJH, Victoria. Shields, L., Schick Makaroff, K., & **Beuthin, R.** *Narratives of living with life-threatening illness*. June 9.
2014. Bruce, A., Shields, L., Schick Makaroff, K. & **Beuthin, R.** *Keeping secrets: Living with life threatening illness*. Presentation at CIHR Café Scientifique on Aging (2013-2014 series) in Sidney, BC, May 7.
2014. **Beuthin, R.** *How We Make Sense of Illness Through Sharing and Storytelling*. Invited presentation for Embrace Aging Month at Yakimovich Wellness Centre, Victoria. March 20.
2010. Schick Makaroff, K., **Beuthin, R.**, & Shermak, S. *Rethinking constructivism: Social constructionism as a philosophical approach to social justice in nursing*. Invited presentation for the University of Victoria, School of Nursing, Chocolate and ReseBeuthin arch Conversations, Victoria. September 29.



University
of Victoria

Graduate Studies

PROGRAMME

The Final Oral Examination
for the Degree of

DOCTOR OF PHILOSOPHY
(School of Nursing)

Rosanne Beuthin

1996
1981

University of Victoria
University of Manitoba

MN
BN

“Stories of Aging with HIV: (Un)Certainty and Sense Making”

Thursday, September 4, 2014
9:00AM

David Turpin Building, room A144

Supervisory Committee:

Dr. Laurene Shields, School of Nursing, University of Victoria
(Co-Supervisor)

Dr. Anne Bruce, School of Nursing, UVic (Co-Supervisor)

Dr. Donna Trueit, School of Nursing, UVic (Member)

Dr. Marie Hoskins, School of Child and Youth, UVic (Outside Member)

External Examiner:

Dr. Jasna Schwind, Daphne Cockwell School of Nursing, Ryerson
University, Toronto

Chair of Oral Examination:

Dr. Perry Howard, Department of Biochemistry and Microbiology,
UVic

Abstract

To live HIV positive and age into older adulthood is a new phenomenon. Research is helping to identify how the body is biologically impacted by the complex convergence of the virus, antiretroviral drug treatment, and aging. And yet there is more. One has to live in their body. Believing that stories of living with illness hold meaning, we also need to understand the lived experience of persons aging with HIV. When we engage and listen to stories of everyday lived experience, we are afforded a way to gain insight into particulars of aging with HIV, and this in turn generates understanding and compassion that can connect and teach all of humanity about the broader experience of life.

The intent of this dissertation is to present the narrative inquiry I have undertaken over a five year period. I begin with an introduction to the phenomenon of aging with HIV and then present four manuscripts, two that highlight research findings related to metaphors and themes within stories, and two that focus on the interview process and narrative practice. In a concluding chapter I weave together my emergent understanding of what it means to age with HIV, narrative inquiry, and discuss implications of the findings that may take nursing and nursing care forward.

In the first manuscript I address tensions that arose and troubled my narrative interviewing approach. Tensions arose when a) presence was tempered by performance, b) power by equality, c) leading by following, d) insider by outsider, e) being non-influential by social influences, and f) trust tempered by responsibility. These tensions, which I refer to as a dynamic process of breathing in the mud, can act as catalysts that ignite clarity and advance narrative interviewing. In the second manuscript I explore metaphors within the stories of 5 adults' experiences of aging with HIV. Metaphors reveal a complex struggle of living in-between tensions of uncertainty and hope, of facing death and living in the moment, and of hurt amidst joys of evolving identity. The overarching metaphor of "shadows and sunshine" reveals that to age with HIV is to survive and live in a fragile state, balancing multiple shadows such as stigma and side effects with joyful experiences of support and belonging. In the third manuscript I present results of a narrative analysis exploring HIV and aging stories of five adults, age 55-62, who have lived with HIV for 13-24 years. In analyzing the co-constructed stories, six common storylines were identified: the illness embodied, the journey of sense making of, intimacy with death and loss, ongoing secrets and stigma, evolving identity, and living in connection. These findings illustrate the vitalness of telling one's illness story, as sense making happens in the telling and supports one to adapt. The final manuscript is a call to action and emphasizes cultivating a narrative sensibility in nursing practice. I offer the mnemonic STORIED to help nurses weave together essential elements of a narrative practice approach: Subjective, Tell/Listen, Openness, Reflection, Invite/Intention, Engage, and Document.

Awards, Scholarships, Fellowships

2012-2014: Island Health Scholarships
2013: Nephrology Nsg Journal Research Writing Award
2012: University of Victoria Graduate Award
2009: University of Victoria Fellowship
2008: BC Network for Aging Research Seed Grant
2008: VIHA Continuing Health Services Research Award

Referred Publications

Beuthin, R., Bruce, A. & Shields, L. (2014). Storylines of aging with HIV: Shifts toward sense making. *Qualitative Health Research*. In press.
Beuthin, R., Shields, L., and Bruce, A. (2014) Shadows and sunshine: What metaphors reveal about aging with HIV. *Canadian Journal of Nursing Research*. In press (September issue).

Beuthin, R. (2014). Cultivating a narrative sensibility in nursing practice. *Journal of Holistic Nursing*, 32(2). Published online June 5, 2014. DOI: 10.1177/0898010114536633
Beuthin, R. (2014). Breathing in the mud: Tensions in narrative interviewing. *International Journal of Qualitative Methods*, 13, 122-134.
Beuthin, R. (2014). Making sense of illness through story telling. Cornerstone Newsletter (Eldercare Foundation), May 2014.
Bruce, A., Shields, L., Molzahn, A., **Beuthin, R.**, Schick-Makaroff, K., & Shermak, S. (2014). Stories of liminality: Living with life-threatening illness. *Journal of Holistic Nursing*, 32(1): 35-43.
Bruce, A. Schick-Makaroff, K. Shields, L., **Beuthin, R.** Molzahn, A. & Shermak, S. (2013). Arts-based Approach for Knowledge Dissemination: Lessons learned. *Nurse Researcher*, 21 (1): 23-8.
Molzahn, A., Shields, L., Bruce, A., Stajduhar, K., Schick Makaroff, K., **Beuthin, R.**, & Shermak, S. (2012). Perceptions regarding death and dying of people with chronic kidney disease. *Nephrology Nursing Journal*, 39(3), 197-204.
Humphries, J., & **Beuthin, R. (2012).** A Shining Light: Doctoral Student Leadership. *Communique: UVic School of Nursing - Research and Scholarship Publication*, Spring 2012
Molzahn, A. Shields, L., Bruce, A., Stajduhar, K., Schick Makaroff, K., **Beuthin, R.**, & Shermak, S. Case study: Model patient or impression management? *Nephrology Nursing Journal*, Nov/Dec 2011, 38(6), 511-513.
Beuthin, R., Holroyd, A., Stephenson, P., & Vegsund, B. (2011). Metaphors and medication: Understanding medication use by seniors in everyday life. *Canadian Journal of Nursing Research*, 44(3), 150-168.
Molzahn, A., Shields, L., Bruce, A., Stajduhar, K., Schick Makaroff, K., **Beuthin, R.**, & Shermak, S. (2012). People living with serious illness: Stories of spirituality. *Journal of Clinical Nursing*, 21, 2347-2356.
Holroyd, A., Vegsund, B., Stephenson, P., & **Beuthin, R.** Medication use in the context of everyday living as understood by seniors. *International Journal of Qualitative Studies in Health and Well-being*, May 2012, 7: 10451 - <http://dx.doi.org/10.3402/qhw.v7i0.10451>

Select Conference Presentations

2013. **Beuthin, R.** *Troubling narrative interviewing*. UVic School of Nursing Research Conference: "Both/and" not "either/or": Valuing multiple modes of inquiry. Victoria, BC. May 10.
2013. **Beuthin, R.** *Climbing mountains: The lived experience of being in practice and a student*. VIHA Nursing Research Forum, Victoria, May 11.
2012. Bruce, A., Schick Makaroff, K., Shields, L., Molzahn, A., **Beuthin, R.**, Shermak, S., & Stajduhar, K. *Symbols of living in-between: Re-stor(y)ing life within life-threatening illness*. 6th Annual School of Nursing Alumni Award of Excellence, Victoria. May.
2011. Shields, L., Molzahn, A., Bruce, A., Stajduhar, K., Schick Makaroff, K., & **Beuthin, R.** *Storylines of life-threatening illnesses*. School of Nursing Research Day, Victoria. June.
2010. **Beuthin, R.** *Pause before entering: Acknowledging the liminal space prior to entering a nurse/patient interaction*. 14th International Philosophy of Nursing Conference Vancouver. September.
2010. Shields, L., Molzahn, A., Bruce, A., Stajduhar, K., Schick, Makaroff, K., & **Beuthin, R.** *Storylines of life-threatening illnesses*. Human & Social Development Research Conversations. October.