



# Seeds4Hope

A program of the Windsor Essex County Cancer Centre Foundation



## 2009 SEEDS4HOPE GRANT RECIPIENT

*Dr. Eleanor Maticka-Tyndale*

### **“Gynecological Cancer: Women’s Experience of HDR Brachytherapy Treatment and Post Treatment Sexuality and Quality of Life”**

#### **SUMMARY OF RESEARCH PROJECT**

With greater numbers of patients surviving cancer, knowledge about the experience of cancer treatment and post-cancer quality of life becomes increasingly important. This study examines the experiences of women during and after treatment for gynecological cancers, focusing especially on the effects of gynecological cancers and their treatment with high dose rate (HDR) brachytherapy on their sexuality and intimate relationships. The goal of this research is to contribute to enhances quality of life for women experiencing gynecological cancers, both during and after treatment.

The study has two main components. First, it follows throughout their treatment with multiple administrations of HDR brachytherapy to understand their experience at each step of the treatment process. Women’s perceptions of their treatment is the focus of inquiry, exploring their treatment experiences, symptoms associated with the treatment, and coping methods. The knowledge acquired in this component of the research will contribute to the development of Practice Guidelines that are responsive to women’s needs. In the second component of the study, women’s quality of life from 3 months to 5 years after treatment will be explored, focusing particularly on their sexuality and intimate relationships. Women participating in the study will complete questionnaires and participate in one-on-one interviews where they will be given the opportunity to tell their own stories of surviving gynecological cancer.

#### **HOW THIS RESEARCH HELPS ADVANCE CANCER CARE IN THE COMMUNITY**

This proposed research responds to a National Research Corporation study in which the majority of cancer patients treated in Windsor and region reported that they had insufficient information to deal with quality of life challenges during treatment and survivorship. A particular area of concern for women cancer survivors was the inadequacy of information about the effects of cancer and cancer treatment on their sexuality. This study speaks directly to these women and focusing especially on the effects of their cancers and treatments on their sexual well-being and intimate relationships.

The proposed research will produce the evidence required to meet the goal of the Erie St. Clair Regional Cancer Program and Cancer Care Ontario to improve the patient experience along every step of the cancer journey. Two stages of this journey are addressed in this research - treatment and follow-up care. Cancer Care Ontario has no Practice Guidelines for pain and symptom management in brachytherapy treatment for gynecological cancers. The first component of this project addresses the patients’ experience of this treatment, including levels of pain and anxiety at each stage of treatment, and will provide research evidence to inform the development of Practice Guidelines for high dose rate brachytherapy treatment for gynecology cancers. The second component of this project addresses the chronic nature (p. 40 Ontario Cancer Plan 2008-2011) of treatment outcomes, specifically those related to women’s sexuality and its implications for their intimate relationships and quality of life. This component will provide research evidence to inform improvements in



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post-treatment supportive care in an area that women have identified as of particular concern. Together, the two components of the proposed research will provide evidence to inform the development of supportive treatment interventions, improvement in supportive care, and provisions of information to assist women in the Erie St. Clair Region to make informed decisions about their care and treatment.

*“Thanks to the Seeds4Hope grant, the results of this study will provide an excellent foundation for developing information and support to address women’s concerns and promote an improved quality of life after treatment for gynecological cancers.”*

**Dr. Eleanor Maticka-Tyndale**



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### PROGRESS REPORT

#### Data Collection:

Study Group	Target # of Participants	Actual # Completed	% of Target Completed
Group 1: HDR Brachy patients	12 to 15	14	100%
Group 2: Post Treatment	32 to 40	36	100%

We anticipated that data collection would require 18 months to complete. At 14, conscious sedation was becoming a more standard practice at WRCC, therefore data collection was no longer possible or necessary. Also at this time we reached saturation of qualitative data for group two. These events marked the end of recruitment for both groups. Final interviews and data collection were completed one month later.

	Approached	Agreed	Participated
Group One	18	16 (89%)	14 (77% of approached; 88% of agreed)
Group Two	59	42 (71%)	36 (61% of approached; 86% of agreed)

A much higher proportion of women agreed to participate in the study than we had estimated. Prior, similar research reported participation rates between 10 and 15%. However, about 80% of eligible women agreed to participate in this study and 68% completed participation. We believe this reflects two things: the importance of the topic to women and the full-time employment of a skilled Research Associate on the project. We believe our success in recruitment and level of participation is, to a sizable degree, because by working full-time, our research associate has been able to be present on site for recruitment, has insured rapid follow-up with potential participants, and has been available to respond to participant questions, concerns and scheduling needs in a timely manner. A part-time or less skilled associate would not have been able to meet these requirements.

#### Data Analysis:

Data analysis for both groups of patients was conducted coincident with data collection. This is the approach in qualitative research facilitated decision-making related to new and enhanced lines of questioning and adjustments to recruitment strategies as the study proceeded that maximize the diversity of results. Data analysis continues.

#### Knowledge Transfer:

On September 30, 2011 preliminary findings of the study were presented to the Windsor Regional Cancer Program's Oncologists and staff. Attendees received a copy of the findings presentation.

We are preparing targeted summaries of specific subsections of our findings for appropriate sectors of the Cancer Program. These will be patients (what we know about women's sexuality and coping), and regional cancer program (delays in diagnosis).



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## **PROGRESS REPORT *cont'd***

For researchers, we will be submitting abstracts to appropriate nursing, cancer and sexuality conferences and preparing papers for publication. We anticipate preparing 3-4 papers for publication. One will focus on women's experiences of HDR Brachytherapy; 1-2 on sexuality post treatment and its relation to quality of life; and 1 on methodological issues.

### ***Conference Presentations:***

**Eleanor Maticka-Tyndale, Maureen Reynolds, & Dale Rajacich:** On September 30, 2011 preliminary findings of the study were presented to the Windsor Regional Cancer Program's Oncologists and staff. Attendees received a copy of the presentation.

**Eleanor Maticka-Tyndale, Maureen Reynolds, & Dale Rajacich:** Promoting the Sexual Health of Women Post Treatment for Gynaecological Cancer August 28, 2013 - International Union for Health Promotion and Education, Thailand

**Eleanor Maticka-Tyndale, Maureen Reynolds, & Dale Rajacich:** Sexual Functioning, Relationship and Quality of Life in Women Post Treatment for Gynaecological Cancer: A Paradox. September 23, 2013 – 21st Congress of the World Association for Sexual Health