



Thyroid Cancer Canada
Cancer de la thyroïde Canada

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Surviving ≠ Thriving: Exploring the Impact of Thyroid Cancer on Young Women's Quality of Life

by Shali Manuel

Editor's note: As thyroid cancer is now the #1 cancer diagnosed in young women (age 15–29) we find the following research study conducted by one of our members, is very timely.

For my thesis research project, I studied the impact of thyroid cancer on young women's quality of life. The motivation for my project came from my personal experience as a young adult thyroid cancer survivor. I was first diagnosed in 2000, and with a recurrence in 2003.

Over the years, as I attended thyroid cancer events and searched the literature, I noticed that young adults were never strongly represented. In my personal experience, there were unique challenges in the young adult thyroid cancer journey, such as issues around finishing school, starting a career, starting a family, etc. Therefore, I decided to embark on this research project to learn more about how young women were coping with thyroid cancer.

Nine young women participated in the study. Based on eligibility criteria, they were between the ages of 17 and 29 at the time of diagnosis and had completed treatment between 1 and 5 years ago. On average, participants were two years post-diagnosis and ranged in age from 19 to 33 at the time of their first interview. Eight women were from Nova Scotia and one woman was from Western Canada.

Data collection consisted of 2 face-to-face, in-depth, semi-structured interviews that lasted approximately 1 to 2 hours each. One of the 18 interviews was conducted over the phone, based on travel limitations. All interviews were audio-recorded, transcribed, and analyzed to identify the shared themes among the participants.

This is the 28th in a series of seasonal newsletters, from *Thyroid Cancer Canada*. Your comments and suggestions are most welcome.

Please direct your comments to the Newsletter Committee at newsletter@thyroidcancercanada.org

Editor's Note:

(Sarah Lyons and Stephanie Wylie, Co-Editors)

Greetings!

Allow me to introduce myself: my name is Stephanie Wylie and I am sharing editing duties, along with Sarah Lyons, who is away on maternity leave.

In this issue, Shali Manuel explores the psychological effects that surviving thyroid cancer can have on young women in particular, and Charna Gord takes a look at thyroid cancer survival rates, increase in incidence as well as treatment options for patients and doctors alike.

And don't forget: September is Thyroid Cancer Awareness Month.

Until next time,
Stephanie

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The findings showed that surviving does not necessarily equate to thriving. In other words, thyroid cancer’s excellent prognosis was not associated with excellent

psychosocial outcomes. The following table outlines the themes and sub-themes:

Surviving ≠ Thriving		
Disruption of Taken-for-Granted Assumptions and Behaviors	Lost Sense of Normalcy	Increased Psychosocial Support Needed
<ul style="list-style-type: none"> • Lost sense of invincibility • Lost trust in body • Lost sense of control • Changes to faith • Increased sense of appreciation 	<ul style="list-style-type: none"> • Feeling different than pre-cancer selves • Feeling stigmatized and alienated • Changes to social roles and relationships • Changes to career paths • Struggling to regain a sense of normalcy 	<ul style="list-style-type: none"> • Gaps in emotional support • Gaps in informational support • Gaps in instrumental support

While it’s impossible to do justice to the study in this article, I’d like to share some key findings with you .

Almost all of the women described a lost sense of invincibility and heightened awareness of mortality, which was especially difficult to adjust to as a young adult. Many women also described a loss of trust in their bodies, which resulted in a hyperawareness of their bodies:

“And after receiving a diagnosis of cancer, anything that comes up in my head and neck region, like any little bump that I didn’t notice before, automatically, like [hushed tone], “Oh! I have cancer”. And I’m Googling thing and like, “Oh, could it be this, could it be that?”. Once you’ve heard the word cancer, you think that everything’s cancer.” (Stacey)

While trying to make sense of their cancer diagnoses, more than half of the participants looked to their religious faiths for meaning and support. For a couple of women, lifelong beliefs in God were called into question, and one woman completely renounced her religion. A couple of women became more spiritual, while the remainder reported little change to their faith.

Being labeled as a cancer survivor sometimes increased risk of discrimination and imposed limitations to goal achievement. For example, one woman wanted to open her own business but did not qualify for the necessary

insurance. Another woman wanted to buy a house, and also ran into insurance barriers. As young adulthood is the phase in the lifecourse when individuals are expected to begin establishing the foundation for the remainder of their lives, it was significant that several participants were delayed in doing so based on their cancer diagnoses.

Thyroid cancer also had a significant impact on social roles and relationships. Negative changes to physical, emotional, and cognitive well-being limited a few of the participants’ ability to fulfill their social roles (e.g. wife, mother) to a level that felt satisfying and met their pre-cancer expectations. This was often associated with ongoing feelings of guilt. Some romantic relationships and friendships ended, while others were strengthened.

The findings showed that thyroid cancer had a significant impact – both positive and negative – on several of the participants’ vocational choices and career outcomes. A couple of women switched university programs because cancer reminded them that life is short and they should do what makes them happy.

Of the women who were already on their career paths, the majority decided to give up plans for future advancement. One woman reported that she could not complete the necessary upgrading courses due to cognitive impairment. One woman decided that it was more important to spend time with her family than to work all the overtime necessary to earn a promotion. And



as mentioned earlier, one woman was unable to secure the necessary insurance to open her own practice.

Overall, the majority of participants experienced initial impairment to quality of life, but appeared to be returning slowly, yet steadily towards a place of wellness:

“You don’t have to be the person you were before. It’s a life-altering experience and if you don’t change, I’d be more concerned than if you do... My new outlook that... it’s okay to do one task at a time. And you don’t have to finish everything. You don’t have to be all things to all people. You can just sort through it. And I think in some ways that sort of change in mindset has contributed to my quality of life.” (Rosie)

In a couple of cases, thyroid cancer inspired important changes that enhanced the women’s quality of life:

“It hasn’t been the worst thing that’s happened to me, you know. And... I definitely see a lot of positives that I’ve gotten out of it too. And I just try to focus on those... I feel a lot more spiritual since I’ve had thyroid cancer... I’ve learned to listen to my body a lot more... And I feel hopeful in a lot of ways too... (Alice)

Some participants were still struggling with ongoing symptoms, such as fatigue, cognitive impairment, and weight gain to a degree that continued to impair their quality of life:

“Right now I feel like I will never be my normal self again. Honestly, I do. Because I just feel like it’s changed me so much. You know, health-wise and emotional-wise too. Just having to go through it with kids and, and that too – that I feel like it’s always going to haunt me for the rest of my life.” (Alexis)

“I don’t know how long I’ve felt like this, so I don’t know what’s normal anymore... I think about [having thyroid cancer] every day... I just think about what if it didn’t happen. I think a lot about that. Like where would I be now if this wasn’t a part of my life? What kind of person would I be, and how would I feel, do you know what I mean?” (April)

And finally, one participant reported that thyroid cancer had little to no impact on her quality of life:

“I didn’t think so much about it as everybody else did... For me, it was just like, yeah, I have cancer, but in a sense, it’s just like a little lump that it’s staying isolated where it’s at right now. And there’s no risk of it spreading any further. And they’re just going to go in and remove it. So, I didn’t think that it was anymore of a big deal than somebody having surgery anywhere else – just, like, to fix a body part or something. So, I still don’t really think of it as a huge deal...” (Amanda)

Although the overall impact of thyroid cancer on the participants’ quality of life varied, it was clear that it was associated with significant – and often life-altering – changes. Many of the challenges described by the participants were common to survivors of all ages. However, this study showed that there are unique challenges inherent in the young adult thyroid cancer journey that deserve further attention. If you would like more information about this study, please e-mail me at shali.manuel@gmail.com.

REMINDER

September is Thyroid Cancer Awareness Month!

Will you be seeing your doctor this month or within the next few months? If so, are you willing to pass on sample copies of our new publications and let him/her know about Thyroid Cancer Canada? If you can help out in this way, please let the Ambassador Project know by contacting us at info@thyroidcancerCanada.org or 416-487-8267





Lunch 'n Learn about the Low Iodine Diet

On May 29, 2010 it was our pleasure to be hosted by the Presidents' Choice Cooking School for a Lunch 'n Learn interventional event with 'Low Iodine Diet Cookbook' author Norene Gilletz. This special event included learning about the Low Iodine Diet, cooking tips, preparing several delightful dishes at preparation stations, and then eating our own delicious feast! The almost 30 participants were thrilled to interact in a supportive and fun environment. Both the Cooking School staff (lead by Chris Attard) and our special chef Norene, made us all feel very welcome and nurtured. The event, held in Toronto, attracted attendees from the London, Ottawa and southern Nova Scotia area! After the wonderful lunch, we held our Annual General Meeting.



Norene Gilletz explains the use of salt in a Low Iodine Diet to Paula Smith at the Lunch 'n Learn

Paula Smith of Yarmouth, Nova Scotia provided the following description of her experience at the event:

On May 29th, 2010 I had the privilege of attending our Lunch 'n Learn/AGM in Toronto. If you have never been, it is worth your consideration for next year. I believe you will find it to be more than "just" an annual meeting. It's actually "A Great Meeting" venue.

I arrived from Yarmouth via Halifax on Friday and was picked up and taken to supper by Despina. We had already been "forum buddies" for the past couple of years. We hugged, talked, hugged, cried, hugged, laughed, and hugged some more. We drank coffee and ate maple pecan danish until late evening and even then parting came too soon.

Saturday morning, another member, Kathy, picked me up. She was so warm and welcoming. We talked non-stop to and from the AGM and it felt like we had known each other forever. More hugs!!

From the minute we arrived at the event, I felt like I had known everyone for a very long time. It was like a family reunion. Now I was able to put faces to all those forum signatures. Everyone was so friendly and happy to see each other. It was absolutely awesome.

We began our Lunch 'n Learn with Norene Gilletz, author of the Low Iodine Cookbook. First, Norene spoke about the diet itself and then we gathered in groups around work stations where each group prepared a LID-friendly food. There was a lot of chattin' and choppin' goin' on. (Some say I talk funny --- LOL.) Norene was a hoot and everyone had lots of fun listening to her stories. I know the food was delicious because I ate a couple or three platefuls just to be sure it passed the taste test. I love my work!!! Now you may think that those extra helpings have something to do with my weight gain but I choose to say that it's because my thyroid meds need to be adjusted. LOL as we say on the Forum.

After we were completely satiated, there was a recognition ceremony. Five persons, myself included, were presented with pins representing on volunteer work with TCC providing thyroid cancer awareness and support. Some very kind words were spoken about each of us. It truly touched my heart as I felt that each and every one of us there were one—we were all in the same battle—comrades, buddies, we had each other's backs. I have never felt like that anywhere before in such a large group of people



The General Meeting took place in the afternoon and was very informative. I learned a lot.

Before I knew it, business was done and it was time to say goodbye.

"Wonderful" doesn't cover the experience. Even awesome falls short.

As I winged my way home to Nova Scotia you would have thought I just had my RAI. I was absolutely "glowing" with happiness.

Thank you Thyroid Cancer Canada for making the Lunch 'n Learn and AGM possible for me. Words will never be enough to express my gratitude.

Thank you Board of Directors and thank you to each and every person I met. You have truly blessed my life.

POEM

The Surgeon

by: Janice Veri

Stark white lab coat
Crisp and pressed-
Sneakers
Peeking below scrubs

Above the mask
Eyes reassure-
Smiling-
Kindly, sincerely

Gentle soul with
Magic hands-
My life
Cradles within

I will soon wake
To find my life
Altered -
I feel no fear

I drift to sleep
Hearing his
Comfort echo,
Echo

in my
brain

**TCC welcomes you to send your poetry to
www.thyroidcancerCanada.org**

Sharon's Fundraiser

In past years, *Thyroid Cancer Canada* has benefited from activities that members have organized on their own to support our charity. For example, our members or their friends have held small parties, special events, and school projects and raised several hundred dollars each.

Recently, one of our members, Sharon Docherty, held a women's gifts sales party and raffle with the proceeds going to Thyroid Cancer Canada. She decorated her lovely home and garden in a butterfly motif, called several local businesses for donations, and held an event on June 4, 2010 that raised \$600 in total for our group! That generous donation represents the support of 60 new members via our popular Welcome Package program. You can view photos of the event at www.ubgiftsensations.com/

Big thanks to Sharon, her friends, and supporters!



A supply of lovely 'goodies' for sale, with a portion of the profits benefiting TCC.



Sharon Docherty speaks with her guests.



Thyroid Cancer Survival Rates and Increase in Incidence

An article review by Charna Gord, BASC, MEd, RD

Charna Gord is a Registered Dietitian working as an Education Coordinator in an Ontario public health unit. She underwent a total thyroidectomy for thyroid cancer in December 2007. This is the tenth in a series of thyroid cancer related journal articles and other resource reviews that Charna has undertaken for Thyroid News.

In this review, Charna summarizes the findings of the following journal article and the invited commentary:

Davies, L, Welch, H.G. Thyroid Cancer Survival in the United States. Observational Data From 1973 to 2005. *Archives of Otolaryngology - Head & Neck Surgery.* 2010;136(5):440-444

Sturgis, E.M, Sherman, S.I. Should Papillary Thyroid Carcinoma be Observed? A Word of Caution. *Archives of Otolaryngology - Head & Neck Surgery.* 2010;136(5):444-446

Journal Article Main Message:

Drs. Davies and Welch argue that because papillary thyroid cancer confined to the thyroid gland is highly treatable and curable, and that because there is epidemiological evidence to show that whether patients are treated immediately or not there is a similar survival outcome, that therefore patients and their doctors should consider the timing and aggressiveness of treatment.

Research Background: Drs. Davies and Welch introduce their research article with a brief discussion on possible explanations for the increased rate of thyroid cancer and in particular papillary thyroid cancer. In the United States, the detected incidence of papillary thyroid cancer has increased 3-fold in the last 30 years, and most of the tumours found are less than 2 cm. There has been debate in the medical community on why there is increased incidence. On one hand, researchers argue incidental autopsy findings as early as 1947 show evidence of papillary thyroid cancer and

further that every thyroid gland might be found to have a cancer if examined closely enough. On the other hand, ultrasound and fine-needle aspiration biopsy has provided a means for early detection of cancers which might in part explain the rapidly increasing numbers. In light of this, Drs. Davies and Welch are questioning how aggressive treatment should be for newly found cancers confined to the thyroid gland. Do these patients need immediate treatment or can the physician watch and assess over time?

What was the research objective? Drs. Davies and Welch compared the survival rates of patients with papillary thyroid cancer limited to the thyroid gland who did not have immediate treatment (as long as one year or more after diagnosis) as compared to those who had immediate treatment (total or hemi-thyroidectomies with or without Radioactive Iodine Therapy).

How was the research conducted? Using the US National Cancer Institute Surveillance, Epidemiology, and End Results database (1973-2005), information on 35,663 patients with localized papillary thyroid cancer was considered. Localized papillary thyroid cancer was defined as a tumour of any size confined to the thyroid gland with no lymph node metastases or extraglandular extension at time of diagnosis.

What were the research findings? There is already consensus in the medical literature that survival outcomes of patients who have papillary thyroid cancer of any size confined to the thyroid gland, with no evidence of lymph node metastases or extraglandular extensions, are highly favourable. The findings of this research demonstrated that whether or not patients underwent treatment within a year of diagnosis of localized papillary thyroid cancer or not, long-term survival rates were similar; 97-99% survival rate at 20 years. Drs. Davies and Welch suggest that this finding, in light of the favourable survival outcome, helps put management decisions in perspective.

What were the final recommendations? Doctors and patients should feel comfortable to discuss when and how to treat the disease, including considering if they wish to watch for a year or longer to see how the cancer behaves. These discussions could include considering the risk of surgical



complications (permanent hypoparathyroidism, damage to laryngeal function) versus the benefits of treatment.

Invited Commentary Main Messages: Drs. Sturgis and Sherman provide a cautionary follow-up commentary, and in particular advise that there is risk of recurrence with an inadequate initial evaluation and/or treatment. They agree with the research findings that there are some clinically unimportant papillary thyroid cancers being detected and treated when perhaps they only require observation; however there is literature and guidelines to define this.

Further to this, they state that there is a risk of applying population based data on to an individual cancer patient as well as an anxiety many patients would go through while the doctor is watching the cancer grow before deciding on treatment. The surgical risks mentioned by Dr. Davies and Welch don't take into account (1) surgeon experience and (2) the increased risk associated with the size of the cancer, extent and recurrence.

Invited Commentary Recommendations: Drs. Sturgis and Sherman suggest that a better understanding of (1) which papillary thyroid cancers will progress to clinically relevant cancers and (2) which nodules should not be biopsied is still required before a physician suggested observation is a safe option.

Final Recommendations: Patients should discuss their treatment options and surgical concerns with their surgeon.

Editor's Note:

It should be noted that some authors have purported that subsequent data analyses contradict the Davies/Welch research. *Enewold et al* (for example) contend that the rate of incidence of thyroid cancer tumours of all sizes have increased proportionally. They write, "Medical surveillance and more sensitive diagnostic procedures cannot completely explain the observed increases in papillary thyroid cancer rates. Thus, other possible explanations should be explored." See <http://cebp.aacrjournals.org/content/18/3/784.full?cited-by=yes&legid=cebp;18/3/784>

Research Opportunity

If you live in the Toronto area, or can travel there, you may be interested in participating in the following study:

Website Study

Thyroid cancer physicians at University Health Network in Toronto are recruiting individuals with papillary thyroid cancer who have had their thyroid completely removed at surgery (surgery on or after September 1, 2009) for a randomized controlled trial comparing the use of educational website about radioactive iodine treatment, compared to usual medical care (without seeing the website). The investigators are interested in learning whether the website may improve patients' knowledge about radioactive iodine treatment. Potentially eligible individuals should be aged 18 years or older and be able to communicate in English and be able to use a computer. Participants should not have received radioactive iodine treatment for thyroid cancer in the past and may be eligible whether they plan to receive radioactive iodine or not. Participants would need to provide a copy of their thyroid surgical pathology report or allow investigators to contact their physician to review their pathology report (to confirm eligibility). This study involves one visit to Toronto General Hospital and 1 or more telephone interviews. The total reimbursement for completion of the visit and phone follow-up(s) is \$200 per participant.

If interested in this study, please contact Dr. Sawka at (416) 340-4800 ext 5886.

The study is registered at the NIH trial website and the website is listed below:

<http://clinicaltrials.gov/ct2/show/NCT01083550?term=thyroid+cancer&recr=Open&type=Intr&intr=decision+aid&rank=1>

Call for Participants:
Thyroid Cancer Research Study

- Have you recently had surgery to remove your thyroid and been told you had papillary thyroid cancer?
- Has your doctor mentioned radioactive iodine treatment for thyroid cancer?
- Do you want to learn more about the choice to take radioactive iodine treatment?

If you answered YES, you may be interested in a research study, in which we are testing an educational website explaining the potential benefits, risks, and choice, relating to radioactive iodine treatment for early stage papillary thyroid cancer.

- We are currently looking for adults who:
 - Have had their thyroid completely removed by surgery since September 1, 2009 and also were told they had papillary thyroid cancer
 - The thyroid cancer must have not spread outside of the thyroid (with no spread to lymph nodes)
 - Participants should not have had radioactive iodine treatment before taking part in this study (you may be eligible if they are on a treatment waiting list)
- What does this study involve?
 - This study is a randomized controlled trial in which half of participants will receive the educational website and half will not. The study involves one visit to the Toronto General Hospital as well as some follow-up by telephone several months later.

Compensation is provided for participation in this study.

Thyroid Cancer Decision Aid Trial
A.M. Sawka, MD, Toronto General Hospital
Phone: (416) 340-4800 ext. 5886

Dr. Sawka's Office



LID RECIPE BOX

Broccoli & Sweet Potato Soup - Serves 10 This recipe was supplied by Norene Gilletz .

2 large onions, chopped
 2 stalks celery, chopped
 1 Tbs canola oil
 3 carrots, chopped
 1 bunch broccoli (about 4 cups, cut up)
 2 medium potatoes, peeled & cut up
 2 medium sweet potatoes, peeled & cut up
 7 cups vegetable broth (homemade or salt-free)
 1/2 cup chopped parsley
 2 Tbs fresh basil or dill, chopped
 1 cup water (or Oat Dream milk)
 1 tsp unsalted tub margarine (Fleishmann's)
 Windsor Coarse Salt & pepper, to taste

- 1 In a large soup pot, sauté onions and celery in oil for 5 to 7 minutes, until softened. If necessary, add a little water to prevent burning. Add carrots. Cook 3 to 4 minutes longer, stirring occasionally.
- 2 Add broccoli, potatoes, sweet potatoes and broth. Bring to a boil, reduce heat and simmer for 20 to 25 minutes. Add parsley and basil. Purée part or all of the soup. Add oat milk and margarine. Season to taste.
- 3 Reheats and/or freezes well



Thyroid Cancer Canada has recently assembled all recipes that have been shared with us by patients, in a new document on our website. View the Low Iodine Diet section of the website at www.thyroidcancercanada.org.

Community Events

Thyroid Cancer - Skills for Healing weekend retreat

October 1-3, 2010

Friday evening to Sunday evening

Halifax, NS

with Dr. Rob Rutledge, Radiation oncologist
 Dalhousie University, Nova Scotia Cancer Centre
 and

Tim Walker, PhD, Eastwind Stress Reduction

Learn about:

- Complete cancer care including diet / complementary Rx
- Stress reduction techniques
- The body-mind-spirit connection
- Meditation, relaxation and group discussions



Free for people with a diagnosis of thyroid cancer and an accompanying family member or caregiver.
 \$80 deposit.

Limited bursaries will be provided to cover travel and childcare - based on need and availability of funds.

For more information:
 Call Helen at 902 473-3887 or visit
HealingandCancer.org

Like you, we have been touched by thyroid cancer. We are a non-profit organization and we are all volunteers. If you would like to donate or to become a volunteer please visit www.thyroidcancercanada.org.

Donation cheques may be made payable to: Thyroid Cancer Canada

Mail to: Thyroid Cancer Canada

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