
One Size Doesn't Fit All:
Finding Support that Fits Young Adults with Cancer

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There seems to be support and information for kids or adults.
The in-betweens get missed a bit.”
- Participant -*

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Abstract

This report presents findings and recommendations concerning supports needed by young adults as they cope with cancer diagnosis and treatment. The study involved in depth interviews with four young adults between the ages of 16 and 29 who were diagnosed with cancer. The report briefly comments on existing materials that are available and provides numerous quotes from the interviewees explaining the impacts of cancer on their lives. It concludes that because of their age and stage of life, young adults face particular issues such as concerns over fertility and forced dependency at a time when they are first having independence. The available information and supports are adapted to the needs of children and older adults and do not address the concerns and needs of young adults. The report concludes with recommendations of specific materials and supports identified by the interviewees that would be helpful for young adults. The research study arose out of the author's experience as a young adult with cancer and the inadequacies of the information and support services available to her.

*“There were times that I felt awful, that I needed support.
But it was also one of the most independent times of my life.
No one could understand what I was going through.
No one could understand how alone I felt.”*
- Participant -

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1. Introduction

Anyone who has been diagnosed with cancer will probably tell you that it was the most terrifying moment of his or her life. Suddenly, the foundation of your world is violently shaken and your entire existence is thrown into question. Fortunately, there exist organizations and agencies that try to minimize the emotional effects of a cancer diagnosis by providing much needed solid ground.

However, according to recent research by the National Cancer Institute of Canada (NCIC) the vast majority of cancer patients are over the age of 55 so most of the information and support that is available for cancer patients is directed at this age group. Unfortunately, for the many young adults diagnosed with cancer, very few relevant resources exist to help them through their experiences. This can leave them feeling lost and alone on top of all of the other emotions that come along with an experience with cancer.

The following study looks at the experiences of four young cancer survivors in Victoria who experienced cancer between the ages of 16 and 30. I discussed their experiences with cancer and their thoughts about the support resources they received. Cancer affects individuals differently based on different life stages. (Huchcroft 1996). In order to offer adequate support, cancer organizations and agencies must understand the differing values of individuals in different age groups.

In this report, I hope to illustrate the experiences of these local cancer survivors and outline their concerns and values as young adults with cancer, pointing out any themes and connections. I will compare the experiences and wishes of the featured young adults with the resources offered in Victoria in order to highlight any discrepancies between the two. Finally, I will use this analysis to make recommendations for improvement of the support resources in Victoria to better meet the wants and needs of young adults with cancer in the Victoria area.

2. The Need for this Study: What's Wrong with What is Available

Information that is relevant to young adults with cancer is currently hard to come by. A search of the Vancouver Island Cancer Centre's library catalogue with the term "young adults" yields no results of any available books or videos. A further look in the library uncovers the books "Young People with Cancer: A Handbook for Parents" published by the Canadian Cancer Society. This is information for the parents of young people with cancer, who in this case are considered children up to 12 years old.

There is also the book "*Help Yourself: Tips for Teenagers with Cancer*" written by a 19-year-old cancer survivor. The tips contained in this booklet are aimed at younger teenagers, with suggestions of "start a stamp collection" or "write a letter to your favourite actor." There are three paragraphs at the end of the book reserved for "older teenagers" in which they are encouraged to ask their doctors and people at the hospital who "may not be able to give you all the answers... but they will give you whatever information is available" (Flaharty 34). The design of the booklet is similar to that of a children's activity book, even

including a crossword puzzle.

Other general information seems to be slanted toward older cancer patients. This is expected, since, as mentioned above, cancer is predominantly a disease of older people, so the literature reflects this. For example, the booklet “Chemotherapy and You” published by the Canadian Cancer Society, contains age-specific information such as tips about how to carry on with work, how to treat your dentures throughout treatment and that the cost of wigs is often “covered by private health insurance from work.” Readers are encouraged to keep themselves occupied with simple tasks like “needlework, building models or painting.” (CCS 2002, p.58) Again, young adults are encouraged to discuss relevant issues with their doctors. Furthermore, the illustrations in the booklet are of mostly older people. While this information is entirely accurate for the majority of cancer patients, young adults find it irrelevant. As one participant said, “There was a lot of info that went right over my head because it didn’t even remotely apply to me.”

3. Personal Context

I am approaching this study as a cancer survivor. I was diagnosed with Hodgkin’s disease at the age of 19, while I was a second year student at the University of Victoria. I was living with five friends of mine at the time, in our own house. None of my friends knew how to deal with the news any better than I did.

I was immediately given names, numbers and appointment times that promised to explain what was going on. When I visited the Vancouver Island Cancer Centre for the first time, with my best friend and my mother who had flown across the country to help me cope, I was surrounded by people thirty years older than me and magazines called *Fifty Plus*.

I was prescribed eight months of chemotherapy and was faced with a very difficult dilemma. I desperately wanted my life to be normal but knew it wouldn’t be. I wanted to stay in school and live with my friends but I also knew that my immune system would weaken considerably and that my friends had never dealt with someone their age who had cancer. The pamphlets and books that were provided offered little guidance. I was told how to tell children about my disease, how to maintain a marriage, and I was told that some people manage to continue working throughout treatment. I wasn’t told how to balance post-secondary education and a “disease of older people” as a younger person.

After much deliberation, I decided to move home to my parents in Eastern Ontario. Receiving my treatment in Ottawa, I found that the resources available there were quite similar to those in Victoria. Nothing spoke to me as a young adult with cancer. I was concerned about being only 19 years old and having a disease that is a notorious killer. I had so recently begun life on my own, a fitting victory after fighting tooth and nail for my independence throughout adolescence. Now I was going to move back in with my parents. I didn’t know how my friends would react and I really didn’t know how my peers would act - people I know well enough to explain what was going on but who were still capable of questioning stares. I was going to lose my hair and my immune system. I was encouraged to avoid sick people and crowds. In the midst (or on the brink) of my prime mating years, I was

never told how to deal with relationships or how to think about the risk chemo posed to my fertility.

As I made my way through treatment, I spent almost half my time feeling sick. I worried about how long I'd really last, if I'd last. I yearned to be back in Victoria as my friends told me about their weekends or about their midterms. I fought through various trips to the emergency room with mystery infections that threatened to be the end of me. I met a 22-year-old with cancer who inspired me, only to hear about her death four months later. I gave myself 75 injections into my stomach over the course of 6 months to boost my immune system high enough for it to be knocked down again. I developed permanent lung damage caused by one of the drugs that was saving my life. I put my hands to my forehead and stared at the ceiling with tears in my eyes when my oncologist told me it was all over – the cancer was gone. I gained an entirely new perspective on life after I was forced to stand in shoes that I didn't know existed, and that terrified me, only to find out that they were my own. To this day, over two years later, I still find myself astounded that this happened to *me*.

These are not normal concerns or experiences of a young adult. These are not normal concerns of older cancer patients. But, as this report shows, these are very typical concerns and conditions of young adults with cancer. Finding resources to help one cope with these circumstances and issues, however, is more difficult than it should be.

4. Age Demographics of Cancer

Cancer is very rarely found in anyone under the age of 30 but statistics are difficult to interpret. Studies of childhood and teenage cancer look at patients between the ages of 0 and 19. The next standard age bracket is 20 to 44 years. To get an idea of age and incidence rates, 9546 children and teenagers between 0 and 19 were diagnosed with cancer in Canada between 1985 and 1992. British Columbia was home to 1050 of these cases. (Huchcroft 1996). Recent statistics compiled by the National Cancer Institute of Canada (NCIC) estimate that 1250 people between 0 and 19 will have been diagnosed with cancer this year in Canada. The same report estimates that 132,600 people over 40 will be diagnosed. The report makes this inconsistency very clear, stating that, "Cancer is primarily a disease of older Canadians." (NCIC 2003)

These statistics are represented in Victoria. Between July 1, 2002 and June 30, 2003, the Vancouver Island Cancer Centre treated 32 patients between the ages of 18 and 30. (Downie 2003)

5. Research Methods

I was put in contact with four cancer patients, or survivors, in the Victoria region through researchers at VIPIRG, my own contacts, and with the help of a social worker at the BC Cancer Agency. Participants ranged in age from 21 to 30. Three were one to five years

past treatment and in remission. One participant was still undergoing chemotherapy. There were 3 females and one male. Three were treated in Victoria and one resided in Comox, B.C. and received treatment in Vancouver.

I interviewed participants either face to face or via e-mail. Participants were e-mailed a copy of the interview guide at least four days before the interview to give them time to think about their answers and know beforehand what issues I was interested in discussing with them. This was also a method of reducing any possible emotional risk. Participants were advised that they were free to decline any question or stop the interview at any time, either permanently or temporarily, and were given contact information for a counsellor who would discuss any emotional concerns that arose through the interview. Face to face interviews were audio-recorded and took between 45 and 90 minutes.

Interviews were partially transcribed and then each interviewee's responses were paraphrased into brief synopses of their experiences. All informants have been given pseudonyms in this report to protect their identity and as a condition of their participation. Their responses were then categorized according to concerns and lifestyles relevant to being a young adult with cancer such as: relationships, physical effects, financial situation, living arrangements, employment/ education, future/lasting effects.

6. Participant Profiles

JENNIFER, 21

Jennifer was diagnosed with acute lymphoblastic leukemia (ALL) when she was 16 years old. She spent the next two and a half years undergoing chemotherapy. She is now 21 years old and the cancer is in remission, though the physical and emotional effects of her experiences still linger. Before she was diagnosed, Jennifer led a typical teenage life, going to school, coaching gymnastics and snowboarding. She had a boyfriend of a year and was working on getting her driver's license. Living up-island, she had to travel to the children's hospital in Vancouver for much of her treatment. Because of the frequency of appointments, Jennifer's mother took a year off work.

Her life was drastically changed as soon as she was diagnosed but she learned very early on that dragging herself down in negative emotions would get her nowhere. She says she was scared and panicked. One of the most overwhelming feelings she experienced was disbelief.

"I just thought 'How could my body be doing this, this whole time, and I didn't even know? Why does this have to happen to me? I don't want to do this.' You think that nothing is going to happen to you and that it'll always happen to someone else. But you don't really have a choice."

She was treated at a children's hospital and at least one of her parents accompanied her on her trips to Vancouver. Despite the foreign situation in which she found herself,

Jennifer found that her independence strengthened. She didn't want her parents in the room for procedures or appointments.

"I really wanted to know that if they couldn't be there that I could handle it. I think in that sense I did grow more independent. I was very adamant that I wanted to be in control of everything."

On the other hand, the physical and emotional effects of cancer and chemotherapy changed her normal routines and she couldn't forge on ahead as independently as she had been.

Her close friends were very upset by the news of Jennifer's diagnosis but were supportive throughout her treatment. They were all willing to shave their heads but Jennifer didn't want them to. Though her friends were initially very shocked, the circumstances became the norm and the shock and upset subsided. Her larger community of peers was not always as supportive.

"I've had people come up to me and make fun of me straight to my face... It's really difficult, especially if you're 16, to have people pointing and you and staring at you."

Jennifer took about a year off school and returned in the middle of grade 11 after completing some courses through correspondence. Her blood counts were up and down so she was in and out of school to avoid infections. Though she was still doing maintenance chemo, she was able to go to school full time in grade 12. With a still weakened immune system, she realized quickly that returning to her normal life wouldn't happen over night.

"I still wanted to go out and have fun. A couple of days later I'd have an infection and I'd be in the hospital for over two weeks. So I was like, "OK, maybe I shouldn't be doing this." Sometimes I'd be able to do more and sometimes I'd have to do less, but it was worth it because I hated being in the hospital. So I just got used to not going out because I was sick. But I think people felt way more sorry for me than I felt sorry for myself. I didn't want to get sick."

The chemotherapy caused many physical side effects that are completely foreign to a typical 16 year old and forced Jennifer to deal with issues that normally affect people much older than her. Hearing the lists of possible side effects frightened and shocked her. She lost her hair and even suffered a stroke after a year of chemotherapy because of one of the treatments she underwent. She simply had to roll with the punches though, knowing that there was still a year and a half of treatment ahead of her and wondering if, only after 17 years of life, she'd ever walk again.

“The stroke was very upsetting. I didn’t know if I would walk again or talk again. That was just horrible. I was in the hospital on my 17th birthday, and that was the first day that I walked along my floor, holding a wheelchair. That was the best birthday of my whole life because I was so happy that I’d walked and I knew that I was going to be able to walk again.”

She was concerned about the treatment’s possible effect on her fertility so raised the issue with her oncologist. She inquired about the possibility of freezing an egg just in case. She was told that there would be no risk and that freezing an egg was an extensive procedure and wasn’t worth it. This past Easter she received a letter from the hospital explaining that they’d just learned that there is a risk, though only slight.

There are no support groups for younger patients in her hometown. The Canadian Cancer Society helped her mother get time off work and pay for transportation costs to Vancouver. A local organization called ‘You Are Not Alone’ also contributed financial assistance to her family. Most of her emotional support, however, came from family and friends.

Jennifer met many other young cancer patients because she was treated at a children’s hospital, though she often found herself as the oldest of the bunch. She enjoyed meeting these other patients and they offered her “pure understanding”, something crucial that other friends weren’t able to offer.

“When you have cancer, nobody will ever understand what it’s like to have cancer unless you’ve gone through it or somebody really close to you has gone through it. And that was something that really my friends at home couldn’t offer me. They could offer me support but [understanding] was something I really appreciated from the people at the hospital.”

She enjoyed this contact with other patients but was particularly fond of instances where conversation developed naturally, rather than in a prearranged setting.

“I’m not the type of person who likes to be forced into the situation where I’m supposed to share [feelings]. I’d rather let it happen naturally. Sometimes if I was sharing a room with someone, we’d end up talking and then I’d really like it.”

Her oncologist was able to answer all of Jennifer’s questions adequately and she enjoyed the nurses. But she felt something was lacking.

“It’d be nice to hear, ‘How are you feeling? How is this affecting you?’ That’s something that I guess is not really a doctor’s place to say but it is

something that would be nice for people in the future - to know that they are all thinking about you emotionally not just how your blood's doing. Maybe [doctors and nurses] should be more in tuned with the patients, what is going on in their minds and their emotions. You're not just a machine that's getting pumped full of chemicals. This is having an effect on you forever."

As she made her way through treatment, her new routine became normal.

"I got used to it. I got used to the needles and the drugs and everything. As long as everything was just going in its regular routine, I was OK and didn't get upset or anything. But I guess I just sort of longed to be normal again. But it just seemed like such a far off thing. I didn't think I'd ever be normal again. And then it's hard sometimes to believe that I'm here now and that was almost six years ago. It's weird."

Getting back to "normal" wasn't as easy as she had hoped it would be.

"After awhile [chemotherapy] just becomes your regular life. When you go to the hospital all the time for two and a half years, going to the hospital is normal for you. When you have to leave that way to go back to school, it's just a shock to your system. It's like 'I'm not used to this anymore. I'm not used to hanging out with my friends.'"

She feels that she was rushed back into school because the transition is so huge, almost as significant as the initial transition into a life of appointments, doctors and drugs.

"One thing that I would have liked would have been not being pushed to go right back into school. I finished my hard chemo and I did another year and a half of just maintenance chemo. I had a stroke three weeks prior and then I was right back into school. It's such a shock to have to go through such changes in your life. Maybe easing back into normalcy is healthier than just ploughing back into it head on. I'm fine and I'm OK but that was a huge transition."

One of the biggest issues with her return to school was her weakened immune system. Though not as low as it had been, the maintenance chemo still affected her white blood cells and her body's ability to fight infection.

"When you go back to school, and nobody has ever heard of a white blood count, it's so stressful. When I was sick I developed obsessive-compulsive

disorder for about a year just because of washing my hands and keeping everything so clean. When my counts were low and when I had to worry about it, I was so paranoid that I was going to get an infection.”

As her immune system improved, these thoughts faded away.

She believes there are certain pros and cons of having had cancer so young. On one hand, being young means she approached her treatment and its side effects with a young healthy body. Older individuals may not be at that advantage and would consequently have a much harder time with the procedures and treatments. On the other hand, a cancer patient who is much older than her would be at a certain advantage.

“You’d be concerned about losing your life but you’d be able to say ‘I have lived 60 years and I’ve had kids and grandkids. When you’re 16, it’s like, ‘I’m just living, I just began to live. I don’t want to stop now.’ To put your life on hold that dramatically, at 16, it’s really difficult. When you’re older, it’s not so out of the ordinary. Back then, none of my friends had cancer at that time. All of a sudden, you’re really brought out of everything that you know. And you have to deal with so many other things. It’s really traumatic. Sometimes still now I just get so upset because I feel like this happened to me and I haven’t really dealt with it. Maybe for a 60 year old, they wouldn’t really have those feelings because they’ve already lived a long life.”

Jennifer still has follow-up appointments every 6 months in Victoria. She gets worried whenever they come up but reminds herself of the progress she has made so far, like reaching the five-year anniversary of her diagnosis, a huge milestone for her. She doesn’t think about it as much as she used to but she says, “I don’t want to forget about this. I don’t want to forget how this affected me and not have learned anything from it.”

Some of her plans for the future have changed because of her experience with cancer. She originally planned to have children later in life, but now she wants to have them in her 20s because of a doctor’s recommendation. The lasting physical side effects will always be a reminder of what she went through.

“I can’t run because of my stroke, so that’s something that really upset me. There are just a lot of physical things that happened from the chemotherapy that I didn’t realize while I was on chemo how it was going to affect me for the rest of my life.”

There are emotional effects that still remain as well.

“I think about it a lot and I do talk about it a lot. It does make me think more about things. I’m not thinking about my health all the time but I’m

always hoping and praying that it never happens again. It's that little lingering thought in the back of your head that will never go away."

DYLAN, 30

At the age of 29, Dylan was living in Tokyo with his girlfriend when he began feeling unwell. After eight months of unexplained illness, he was diagnosed with Hodgkin's disease. Upon diagnosis, he returned to Canada. The insurance company that funded his return trip decided Victoria was closest to Tokyo and he began his treatment at the BC Cancer Agency shortly after his return. At the time of his interview, Dylan had turned 30 and was three quarters of his way through eight months of chemotherapy.

The initial diagnosis was double-sided for Dylan. He was relieved to finally be able to attribute his symptoms to something, but at the same time it came as a shock to discover that cancer had been the perpetrator.

"I think when you're young you feel pretty invincible, when something like this happens, all of the sudden you realize you're not invincible any more and that might come as a shock to some people when they're younger."

"When you're older you've lived a big chunk of your life so you might have a different outlook on what you're going through. You might have more wisdom. Some people might be like, 'well you know, I've lived 65 years really happily without any health problems and now I'm going through this but oh well, that's the way it goes.'"

Moving back to Canada was stressful not only because Dylan knew he was about to face treatment, but because he and his girlfriend had to start from scratch and had very little money. They relied on the help of friends and strangers to find a place to live and fill it with furniture. Dylan's girlfriend was able to find work after three months however, Dylan decided not to work throughout his treatments.

"You kind of just realize what needs to be done right now and work definitely isn't one of them, and I don't really care that I'm not working."

Dylan and his girlfriend considered options for financial assistance. He didn't qualify for disability, though, nor was he old enough to receive Canada Pension Plan Benefits. They have been able to receive welfare, but they are only given \$800 each month between the two of them. He thinks that there needs to be more options to assist people in unique circumstances like his own.

The day before his first chemo, Dylan was informed that his treatment could pose a risk to his fertility. He asked about storing sperm, just in case. His oncologist had no answers, nor did any nurses he talked to. So he was sent through a maze to find answers.

“I talked to my oncologist and she didn’t know. Then we found out that the only place we could donate sperm was at a sperm bank in Vancouver. So we were going to take a sample, my girlfriend was going to stick it under her armpit and she was going to get airlifted to Vancouver, because you only have half an hour, and she was going to get picked up by an ambulance and then driven to the sperm bank. It was really confusing and no one had any definite answers. Then, finally, we found out that there was an embryologist who had a sperm bank here in Victoria, but we couldn’t get in touch with the embryologist and I was supposed to have chemo in a couple hours.”

Eventually, the issue was sorted out and Dylan was able to store a sample before his treatment began.

As he’s made his way through treatment, Dylan’s social life has slowed down considerably. He spends most of his time at home, laying low. But he does get sick of the monotony and likes to get out.

“I try to get out when I feel like it because it’s really nice to be around people. Even if I don’t necessarily feel like it, sometimes forcing myself, just to switch it up a bit and make me feel a little more normal.”

With his weakened immune system, he faces risks of being around sick people but he tries not to focus on this risk.

“Obviously, it’s a concern, but I try not to be too paranoid about it. You can pick up bacteria from anywhere. I understand to use caution but at the same time I’m not going to lock myself up in my apartment. I want to try and live life.”

Dylan’s main source of support has been his girlfriend. He hasn’t met anyone with Hodgkin’s disease or anyone around his age with cancer. He has attended a relaxation support group at the Cancer Centre, which has offered him unique support that he can’t find elsewhere.

“It’s really nice to be in a room with people that are all going through the same thing as you are. Even if you don’t say anything or they don’t say anything, you can feel it and that’s been wonderful. It’s been good because when I first got diagnosed, I didn’t want to talk about the fact that I had cancer and I didn’t want to hear any other people’s problems related to cancer. And that group has helped me open up to that.”

Most of the cancer patients he's met so far have been middle-aged women.

"I think my only contact with other people who have cancer are middle-aged women, so if I was able to chat with people my age, that would help out for sure, it would give another perspective."

He thinks that informal meetings with same-aged cancer patients or survivors would be best.

"The less formal you make it, the more people will open up. If you're all sitting in a room, in a circle with all the chairs facing each other, it can be pretty sterile. It's hard for people to open up. When you're in a more conducive environment, say at the park or a picnic, it would make people more comfortable and able to open up as a result of that."

He is excited about the future, though he is not certain what he will do once he completes chemo. He hopes to eventually pick up on the travel plans he had to put aside for chemotherapy.

"I'm looking forward to being finished and who knows what's going to happen in the future but I'm just going to be happy to be done chemotherapy."

RACHEL, 27

Rachel was diagnosed with Hodgkin's disease when she was 21 and a student in her final year at the University of Victoria. Newly married, the news came to her and her husband as a complete shock. She underwent four chemotherapy treatments and twenty-one radiation treatments. She has been cancer-free for six years.

Telling her parents about the diagnosis was the most upsetting part of it all. Just before her diagnosis, she accepted a job in Ottawa and was preparing to move. Once she was diagnosed, she and her husband moved back to Campbell River for financial reasons and to be closer to family. They were able to live with Rachel's friend and her friend's parents for no charge - a move that Rachel is still grateful for.

She traveled once every two weeks to Victoria for treatment. The traveling was tiresome but she says she was more confident in the treatment she could receive in Victoria.

When she was learning about the disease and as she made her way through treatment she was desperate for information.

"I am a 'tell me everything' kind of girl. I can then make my own choices. I wanted to know rates of survival, what organs it had spread to, what was

typical, what treatments were available, what the details were for my treatment, et cetera. I could not have gotten through this bout of cancer if I hadn't been proactive about learning about my disease."

She also used the Internet to find information.

Her life changed over the time of her treatment and she and her husband didn't go out as much as they had before. She got most of her support from her parents, her in-laws and her friends, though some of them were better at coping than others.

"One of my friends couldn't be around me because they felt it was too hard. Another of my friends was right there to tell me that my wig was on straight. My husband was a devastated tough guy."

She says their support is what got her through the treatment, though there were times that she didn't feel well.

"There were times that I felt awful, that I needed support. But it was also one of the most independent times of my life. No one could understand what I was going through. No one could understand how alone I felt."

The physical effects of chemotherapy and radiation also impacted Rachel. Her hair fell out, her face got swollen and the radiation caused burns.

"This certainly wasn't my most beautiful hour; however, I had a supportive husband who made me feel loved and supported me through every change. Really, the physical changes were part of the deal and although I was acutely aware of them, they were not my first worry - survival was."

She was told that the treatment would decrease her ability to conceive children by 10%. This risk resonates with Rachel more now than it did at the time.

"I try not to think about this as a factor, and I believe that when I want to get pregnant I will be able to. It scares me a little because this experience has made me sure that I want children at some point."

She didn't use any of the services available at the BC Cancer Agency because she was living in Campbell River. She says she would have liked to and that it would have been especially useful to her after she completed treatment.

"Young adult[hood] is a funny age for cancer. There seems to be support and

information for kids or adults. The in-betweens get missed a bit.”

Cancer still affects Rachel today, including her relationship with her husband.

“We didn’t plan anything long term for several years as we didn’t trust we could.”

There are lingering reminders of what happened that arise regularly. Fears still hover around and the physical and financial effects are continually coming up.

“There are people who still look at me differently, give me that extra tight hug and ask ‘how are you doing?’ in a way that tells me the answer might scare them.”

“It certainly has left me much more comfortable with the inevitable end of all of us. I think young cancer patients affect other people more. My father-in-law can still be brought to tears by the mere mention of my illness. It scares them to think if someone so young is so fragile, what about them?”

“I still feel sometimes that I am on borrowed time... I think the fear that it could come back never goes away. I fear the damage that the treatment may have done to my body and future health.”

“My health record is shot. Mortgage companies and life insurance companies do not care that I have passed the five year mark”

SARAH, 23

Sarah was diagnosed with Hodgkin’s disease when she was 22 and in her final term at the University of Victoria. Though from Vancouver, Sarah decided to live with two of her best friends, whom she’d known since high school, in Victoria.

“I deliberately remained in a city that wasn’t my hometown, in order to avoid my parents being too overbearing. I am an only child; they’re a little prone to overreacting.”

She graduated and began working throughout her treatment, but she wasn’t able to work full time. She was unable to be as financially independent as she had hoped. She found fatigue was one of the biggest issues throughout her three months of treatment.

“I was often very tired, and I felt I wasn’t capable of being a better employee. I often found this very frustrating. I also found that, at the end of the day, I had little or no energy for socializing.”

At the same time, she was rarely alone and her friends and roommates provided her with most of her emotional support.

“Although I was generally quite lucky in terms of side effects, there seemed to be a constant need for me to have someone around me ‘just in case’.”

People treated her differently though, and most of them were people she didn’t know well.

“People I barely knew began acting as if we had been closer. I couldn’t decide if I was disturbed by it or deeply touched.”

At the same time, meeting new people brought additional reactions.

“I found meeting people to be difficult. First of all, I had low energy and low self-confidence. When I did meet people, I found that they were put off when I told them about my condition.”

Part of her reduced self-confidence came with the physical side effects of her treatment.

“I lost most of my hair, and learned a lot about myself in the process. I had long curly hair, and I came to realize how much I had relied on it for my self-confidence.”

Sarah still finds it difficult to believe that cancer happened to her. She does feel though, that her age might have put her at an advantage.

“I was always healthier, stronger, and luckier... I met at least two other Hodgkin’s patients during my chemo. Both were older and both were facing an uphill battle. Although I didn’t have it easy, my chances were always ten times better than theirs.”

This age difference was obvious to Sarah. She never met anyone her age with cancer during her treatment; however she has met some since completing treatment. This lack of a connection triggered her reluctance to participate in a support group.

“Part of the reason [I didn’t attend a support group] was that all of the support groups I found consisted of a far older age group. I also find sitting around talking about cancer to be kind of depressing.”

She would have enjoyed more contact with people her age who were dealing with similar circumstances - and part of this has to do with her feelings of guilt associated to her age and resilience.

“It would be nice to be surrounded by my peers, however, a lot of that has to do with the fact that I felt guilty. All of the patients I met were old and weak or young and tragic. I don’t know if I really needed support for the fact that I was too healthy to be in with the ‘more serious’ cases. However, it would have been nice to see others in my age group.”

She didn’t use support groups or the counseling services at the BC Cancer Agency, however she did use the counseling services at UVic.

She found much of the support information that was given to her to be irrelevant.

“Some of it [spoke to me as a young adult] but there was a lot of info that went right over my head because it didn’t even remotely apply to me.”

She used the Internet for support since “it offers a far greater range of people, and therefore a greater likelihood of finding people one can relate to.”

She is currently in remission but she’s often reminded of what she went through.

“Although I often act blasé about the whole thing, I think I’ll always have nightmares about my falling ill again and having to go through it all over again.”

7. Discussion

These four young adults share many concerns and thoughts on their experiences with cancer. The common themes that emerged from their experiences and stories concern the shock of receiving the diagnosis, a forced dependency at a time in their lives when they are seeking independence, the effects on their social lives of compromised immune systems, the physical effects of treatment, concerns regarding fertility, financial hardships caused by cancer and its treatment, and the ongoing and future effects of cancer in their lives.

The Shock of the Diagnosis

The shock of a cancer diagnosis is shared by individuals at almost any age and some of the subsequent concerns of these young adults are, presumably, also similar to those of older patients, such as life expectancy, required changes in routine and so on. However, due to young adults' different lifestyles and relationships, these concerns take an entirely different spin.

Every one of them was shocked by their diagnosis since it came at a time when they were just "beginning" to live. Jennifer was just about to finish high school, Dylan had moved to Tokyo and was looking forward to travelling, both Rachel and Sarah were about to graduate from university and Rachel was newly married. Their diagnoses came as interruptions in their efforts to start new chapters in their lives.

On the other hand, Dylan, Jennifer and Sarah said they felt as though their age put them at an advantage compared to older patients. As young adults, their physical strength gave them durability and resilience that older patients may not have.

Older patients may also have more life experience behind them to help them cope with such traumatic circumstances.

Imposed Dependency

At this stage in life, young adults are growing increasingly independent of their parents. Cancer, however, forces individuals to regain some of this dependence, whether on their parents or others. Lisa, still in high school and living at home, relied greatly on her parents for support and transportation and had to postpone certain independence-gaining activities like getting her license. Dylan, at 29 years old, had moved away from home and was living with his girlfriend. Unable to work, he relied on his girlfriend for financial support. Rachel was newly married and both she and her husband had recently graduated from university. She was about to accept a job offer in Ottawa when her diagnosis changed her plans and she ended up moving in with a friend's parents in her hometown of Campbell River. Sarah made a deliberate decision not to return home to her parents for the duration of her treatment and decided to remain in Victoria, living with two friends. Though this required more independence on her part, she still found herself much more dependent on her roommates than she otherwise would have been.

Social Life and Compromised Immunity

The social lives of all of these young adults are obviously very important factors of their lives. They wanted to be out and about, with friends, while they were doing their treatment, but their immune systems were compromised, so this type of behaviour was risky. Since much of a young adult's social interaction takes place in public or crowded areas, the risk for contracting a potentially deadly infection is increased. Both Lisa and Dylan explained how this impacted what they did. Lisa would go out with friends only to end up in the hospital days later. Dylan says that he realizes his risk for infection is a serious concern, but he still wants to get out and see people. In this sense, he realizes the risk but may ignore it and then suffer the consequences. All of the interviewees either said or implied that they just wanted to be normal.

Furthermore, Sarah pointed out the difficulties she faced when meeting new people. Physically, she was left tired and self-conscious from her treatment. Socially, she found that people were "put off" when she explained her situation.

Physical Effects

The physical effects of cancer treatment are a separate issue all together. The visible side effects, such as hair loss, weight gain/loss, burns from radiation, and so on, were duly noticed by the interviewees but they managed to push them aside since they had more important things to think about, like surviving. They were able to recognize the side effects as temporary, and in the case of Sarah, even learn something about themselves in the process.

While the three females who had completed treatment described their feelings about visible physical effects as insignificant, some of them described experiences in this situation as being negative. Jennifer had people make fun of her because she had no hair and Sarah explained that she felt self-conscious. Rachel said that she was “acutely aware” of the physical effects but that she knew there were larger matters at hand. From this, it seems as though retrospect can impact these feelings. In the long run, these effects are seen as minor, however, at the time, they may carry more weight.

Fertility Concerns

Invisible physical side effects drew more concerns from these young adults. The issue of fertility was important to all but one of the interviewees. Both Jennifer and Dylan expressed that they approached their oncologists about risks to their fertility since their doctors had not addressed the issue. Jennifer was told that there was no risk, and that saving eggs was an unnecessary procedure, only to find out six years later that there is a slight risk that she may not be able to conceive children. When Dylan asked his oncologist about the risks, he was told there was a slight risk to his fertility but she had no information for him to help avoid or minimize this risk. He wanted to bank sperm but had a very difficult time finding information about the procedure. Rachel was told there was a risk of a slight reduction in her ability to conceive children however she maintains that though this risk is scary, she tries not to think about it and believes she will be able to conceive children. Interestingly, both Rachel and Jennifer professed that their experiences with cancer have made them certain that they want to have children at some point, despite the risks.

Jennifer has withstood many other physical side effects due to her treatment. Most significant was a stroke she experienced at the age of 17, leaving her wondering if she'd walk or talk again. She can do both, but she is left with slight brain damage. Due to bone damage, she has undergone surgery to repair a fractured foot, and still sees lingering effects today. These physical changes are very rare for people of this age and this makes dealing with them and their implications a daunting task.

Financial Hardships

The financial costs of cancer are still a burden despite Canada's health care system. Dylan, Rachel and Sarah were unable to work full time – Dylan and Rachel not at all and Sarah only part-time. Consequently, their income was considerably less than they would have anticipated for this period of their lives. Dylan relies on welfare and his girlfriend for financial assistance. Dylan is unable to receive Pension Plan benefits or claim disability. The social safety net, according to Dylan, isn't proving itself to be very useful.

Rachel moved back to her hometown and lived with her friend's parents who offered them free rent in a separate apartment, in order to save money.

Ongoing and Future Effects of Cancer and Its Treatments

When all is said and done, and the cancer has been defeated, these young adults still have concerns that lie in the future ahead of them. Physically, cancer treatment can cause many lasting effects including infertility and future cancers. Mentally, there are concerns that persist long after treatment ends. Dylan, who was still in treatment, didn't have much to say about his future, just that he wanted to be done with chemotherapy. The potential risk of a relapse is a lasting concern for the three participants who have completed treatment. They each expressed fear about this risk, saying that they never want to go through it again but realize that the risk exists. Interviewees were also made more aware of their impermanence and mortality – topics that are often not considered until later in life.

Friends and relatives share these concerns for the future, as Rachel pointed out. Though her cancer is in remission and she is leading a normal life again, others still behave differently toward her.

While they all wanted to “be normal again”, returning to this state was often more difficult than they anticipated. Jennifer had a lot of difficulty returning to high school after completing her treatment. Not only were the side effects, including a reduced immune system, still present, but it was a shock to her system to return to hanging out with friends and going to school after having spent two years around appointments and treatments. Rachel said that she and her husband avoided making any big plans for a few years because, after being shaken up temporarily, they weren't sure they could make plans with any reliability.

These lasting effects and concerns that persist into the future are quite possibly the most significant of them all due to the age of young adults with cancer and the increasing incidence and survival rates for this age group (NCIC). More young adults are being diagnosed with cancer and more are surviving and going on to live full lives. As Jennifer said, “This is having an effect on you forever.” The younger you are, however, the longer this ‘forever’ has the potential to be, as opposed to older cancer survivors, who no longer have their entire lives ahead of them. Therefore, the future implications are much greater for those who survive cancer at a young age.

8. So, What Do They Want?

If we look at the experiences and concerns of these young adults, we can come up with a fairly good picture of what they want (and don't want) in terms of support. They all agreed that a support group specifically aimed at young adults would be beneficial. Only Dylan attended a non-age-specific support group and found that he felt like somewhat of an outsider since most of the other attendees were middle-aged women. He would welcome another perspective. Sarah didn't attend a support group for this reason – everyone else was far older than her. She also felt a certain degree of guilt around older patients. She felt that, as a young person, she was at a certain physical advantage and that, with Hodgkin's disease, a very treatable cancer, she was better off than older patients with less favourable prognoses. She said, “I was too healthy to be in with the ‘more serious’ cases.”

Only Jennifer met other cancer patients around her age since she was treated at the children's hospital in Vancouver. However, as an older teenager, she found herself often as the oldest of the bunch.

Standard support groups, however, were not terribly appealing to these young adults. Jennifer said she doesn't like being forced into situations where she's encouraged to share her feelings with others. Dylan thinks that the less formal a support group, the better, as informality encourages people to open up. He also noted that simply being in the same room with other people is support enough – talking isn't always necessary. Sarah said that talking to a bunch of people about cancer can get “depressing”. She would have, though, welcomed contact with people her age.

Jennifer agrees since she believes that people her own age, who have experienced cancer, can offer “pure understanding” something that older patients, or her own peers who haven't experienced cancer, can't offer. Rachel expressed an interest in talking with young patients after she completed treatment to help with the transition back to ‘normal’ life.

Presumably, these young adults also want information that addresses the concerns that they found themselves with. Fertility was a huge area in which individuals had difficulty obtaining information. Financial assistance and information would be welcome along with information about education, relationships with family, friends and significant others as they pertain to young adults and guidance in terms of returning to normalcy and living and coping with the potential risks and concerns of cancer survival.

9. Recommendations

Although the sample size in this study was small the participants identified numerous supports and services that would help a young adult who has been informed that they have cancer. These can be grouped together into categories of information specific to their needs, support groups, and activity programs. In addition the existing support services should be educated about the needs of young adults who have cancer.

Recommendation 1: Information

Being diagnosed with cancer and undergoing cancer treatment is one of the most traumatic experiences a person can face. It affects almost every aspect of life. Despite this, young adults coping with this experience have few sources of information to help them. The following are the types of information that participants stated would be helpful for young adults facing cancer:

- a) Education options during cancer treatment
- b) Cancer and fertility, information and options
- c) Cancer and finances, options for income support
- d) Cancer and socializing, managing with compromised immunity
- e) Cancer and intimate relationships
- f) Cancer and working
- g) Community referrals and organizations for support
- h) Internet sites for cancer information and support

- i) The transition from cancer treatment to normal life
- j) The implications of living as a cancer survivor.

This literature can be as simple as one-page pamphlets that explain cancer in general to young adults in relevant terms and contexts. Of course, these would have to be fairly general since the implications vary from cancer to cancer. These could be made available at the BC Cancer Agency library and counseling office. The need for this information is highlighted by the fact that participants found much of the information that is available is not relevant to their needs.

Examples of useful information would be as follows.

An information sheet on education would explain that most schools offer distance or correspondence courses for those who cannot participate fully in on-campus courses. The BC Open University, based in Burnaby, offers courses and programs through correspondence that can be completed anywhere in British Columbia (or the world) via mail or the Internet and can be applied as transfer credits toward a degree from other institutions.

Financial options available to young adults with cancer are mysterious to most, if they even do exist. Dylan explained his difficulty in obtaining adequate support and resorted to welfare, an option not typically seen as a resource for cancer patients. Rachel had to put career plans on hold and move away from Victoria to afford housing. If there are options available, these young adults were not made aware of them.

Information for community referrals should be expanded to address the concerns of young adults. The most pressing concern of these young adults that could be addressed through community referrals is that of fertility risks. Dylan, especially, had to jump through hoops to get the information he wanted and needed. This information and referrals to members of the community who can offer assistance (an embryologist in this case) should be readily available for those who need it.

An avenue that is not typically considered for support is the Internet. Websites like Planet Cancer (www.planetcancer.org) offer forums specifically aimed at young adults with cancer. Its popularity is gained, in part, from its international scope. However, with its increasing reputation, especially among young people, it should not be overlooked as a resource. The BC Cancer Agency and the Canadian Cancer Society have their respective websites, but perhaps a section dedicated to young adults that includes information, support resources, an online discussion forum, and so on, could be useful. This doesn't have to be limited to Victoria residents only, and could likely reach provincial or national usage.

Recommendation 2. Support Services

The desire of the participants for support groups was qualified in several respects. Many participants found that the available support groups were with people who were much older and they desired a support group of their peers. Most preferred that a support group be informal in nature and preferred if it occurred naturally rather than being structured. In this situation people are more likely to open up. Many of the interviewees stressed that the formality and rigidity of traditional support groups are intimidating and gloomy.

The obstacles to having a support group is that there are few young adults who are diagnosed with cancer, and that with different cancers people face different physical effects in

treatment.

The literature shows that the traditional support group format for young adults is not completely unsuccessful. Roberts et al. (1997) conducted a study in which they developed a support group for young adults to determine its impact on coping mechanisms for the young adults involved. They recruited 20 cancer patients (8 had completed therapy) to participate in a support group co-facilitated by a female clinical social worker and a male social work graduate student. Participants were initially surveyed to determine how well they were coping. The group met for 6 sessions held once a week for 90 minutes. Participants were given a topic at each meeting, which was discussed by the co-facilitators and then opened up for discussion. The topics covered included: anxiety about health, loss of physical well-being, worry about children, financial and vocational concerns, problems in relationships and feelings of unattractiveness. An additional meeting was added, due to interest levels, in which participants were free to discuss what they wanted.

Participants were then surveyed again to determine if and how the support group had been beneficial to them. The most considerable changes were in the areas of fatigue, confusion and total mood disturbance. The authors compiled the comments that were made about the benefits of the program and categorized them as follows: universality of shared experiences, meeting cancer survivors in own age group, therapeutic group atmosphere and receiving information.

From this study, it seems that young adults are content to have a designated meeting spot in which they can largely control the direction of the conversation themselves. Basic structures are helpful, especially at the beginnings of the meetings, to get the ball rolling. The point being that the topics discussed are relevant to young adults; as opposed to the topics discussed in more general support groups that typically draw in an older crowd and dissuade younger individuals from participating.

Recommendation 3. Educating Existing Support Services

Young adults diagnosed with cancer find that the existing resources and support services and agencies fail to respond to their particular needs. This is likely because young adults are a small minority of those who are diagnosed with cancer. This research study indicates that the existing cancer support groups, including the counseling service at the Cancer Centre and the Canadian Cancer Society should learn more about the needs of young adults with cancer, and to make available information to them. This would be very helpful as it can be difficult to do the searching for information in the busy and stressful time following cancer diagnosis.

Recommendation 4. Activity Programs

In addition to information and support groups, there are other more creative possibilities for supporting adults diagnosed with cancer. An alternative form of group therapy tried by Elad et al. (2003) was a form of “adventure therapy”. They followed 17 young adult cancer survivors on a jeep trip throughout Greece. “Adventure therapy” is a form of therapy that has been successfully applied to various groups including child and teenage cancer patients and disabled people, in which group members gain assistance through activities. In this case, participants were between the ages of 20 and 29 and were at least one year out of treatment. Throughout the journey, the authors interviewed participants and

compiled categories of their most salient concerns. These were: coping with uncertainty, dependency versus autonomy, social isolation, body image, sexuality and fertility, intimacy and separation and individuation.

The authors believe the natural setting (versus a more formal, clinical setting) to be a contributing factor in the success of the program. The outdoor/adventure situation also reinforced feelings of freedom and physical well-being. Participants were very happy about the opportunity to share their thoughts and experiences with others. In the year after the trip, most of the participants were still in touch.

A program as large-scale of this would of course be near impossible in a city the size of Victoria. But the success of the program is very telling. Smaller-scale activities could generate the same results, such as informal gatherings outside of the Cancer Centre, picnics in the summer, as an example used by Dylan, or other weekend retreats, et cetera. Activities such as this wouldn't need to be held that frequently, since the initial meeting and making contact with other patients would allow for these patients to stay in touch on their own terms. Scheduling for these activities shouldn't be too difficult since, like most of the above interviewees, young adult cancer patients are either not working, not in school or only working part-time.

10. Further Research

Due to the small-scale nature of this study, there is plenty of room for further research. More participants would definitely widen the scope of the information gathered in this report. While the information gathered from the four individuals interviewed for this report is entirely valid and useful, more information from a wider range of individuals could bring new concerns and perspectives to the table.

First of all, only one male was interviewed for this project. The experiences of males with cancer are presumably quite different from females. Furthermore, three of the interviewees had or have Hodgkin's lymphoma, a cancer common to young adults but also renowned for its high survival rate. For these patients, the risk of death is quite slim, so the issues and concerns that arise from low survival rates are not a predominant fear. Cancers with lower survival rates would bring entirely new aspects to coping with cancer as a young adult.

When it comes to determining the extent and focus of support that would be useful, it would be valuable to do further research to determine what kinds of activities young adults with cancer want to participate in, with other cancer patients, as a form of informal support therapy. The above individuals stressed a desire to be "normal" so these activities should reflect the activities they would normally participate in.

One point that was raised by some participants was that they felt their youth put them at a physical advantage when it came to being treated for their diseases. They felt they would be less fatigued, and less physically affected by the treatment. It would be interesting to discover whether young adults are indeed at a physical advantage and if so, how this advantage could be used and acted on in terms of support. Speaking for myself, I had the energy to continue snowboarding throughout the winter during which I was getting chemotherapy treatment. This was something I loved to do and offered me an escape from the routine life of being a cancer patient. Is this type of activity feasible for many young

adults with cancer?

11. Conclusion

Young adults are a unique group of humans whether or not they have cancer. Their concerns, fears and lifestyles are their own and need to be addressed in ways that are as distinct as the individuals who own them. The rarity of cancer among this age group has hindered much research about it and there is limited information for both professionals and the patients themselves.

One of the most prominent factors that was shared among all of the people I interviewed is that they all consider themselves to have coped just fine with their disease. Their family and friends were, and are, wonderful to them. The point is not that these young adults are scrounging for support and are suffering without it. Humans are wonderful adapters and can find their footing in almost any situation, even when that situation sees you diagnosed with cancer at 20 or 25 years of age. The people I interviewed said they were content with the support they received, though the vast majority of it came from family and friends. Young adults with cancer will get by. But much of the information they need is not available and certain aspects of support are difficult to access. There is no sense in simply ‘getting by’ or ‘making do’ with what’s available when there is plenty of room for young adults to get what they want. The recommendations above offer a step toward support and information that fits young adults.

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