

ORIGINAL RESEARCH

Comparing urban and rural young adult cancer survivors' experiences: a qualitative study

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ABSTRACT

Introduction: Large administrative data set analyses demonstrate that geography has a significant impact on access to health care and subsequent health outcomes. In general, rural populations have poorer access to healthcare services. This article explores the reality of this issue for young adult cancer survivors.

Methods: Data was of a subset of 30 participants from a larger qualitative study that examined cancer survivorship issues for young adult cancer patients in Canada. The subset of participants are from New Brunswick, a predominantly rural province in Eastern Canada with a population of 750 000 spread out over a large geographical area, and from Canada's largest metropolis center, Greater Toronto Area, with a population of around 6 million.

Results: Analysis of the qualitative data using constructivist grounded theory revealed several expected and unexpected differences between the two geographically distinct groups. The rural group of young adult cancer survivors reported more frequent episodes of delayed diagnosis and lower levels of community support compared to the urban participants. The urban young adult cancer survivors discussed out-of-pocket expenses for cancer treatment more often than the rural participants. Many rural participants made it clear that they were keenly aware that not all cancer care services were readily available where they lived, and yet they reported considerably higher levels of satisfaction with the cancer care that they received than the urban participants.

Conclusion: Despite the lack of important cancer services in rural areas, rural young adult cancer survivors expressed higher levels of satisfaction with their care than did urban cancer survivors. It appears that levels of satisfaction are related to expectations. Rural participants were aware of the more limited services available and felt that their cancer care practitioners provided the best



care possible given the limited resources. Urban participants may have higher expectations of cancer care and felt that the cancer care they received fell below expectations. In the future, researchers may want to focus on cancer care expectations, satisfaction levels and psychosocial outcomes in greater detail.

Key words: cancer, rural-urban, young adults.

Introduction

Epidemiological and other studies have indicated that where you live can have an impact on your health. People living in rural areas, due to limited or lack of access to health care, have overall poorer health outcomes than people living in urban areas¹⁻⁵. This is also the case for cancer patients in developed and underdeveloped countries^{6,7}. A 15 year analysis of cancer survival data in England concluded that inequalities in care exist between the rural North and urban South of England, with patients in the South receiving better care. Another British study concluded that the further away one lives from a tertiary healthcare center (more rural), the higher the death rate from cancer, with the exception of breast cancer. The greater the distance patients lived away from the hospital, the higher the probability that their cancer was diagnosed post-mortem⁸. The authors of the study did suggest that the age of the patients may have played a role in their health outcome, with older, perhaps sicker, people forfeiting treatment due to travel problems.

In many countries there is an intersection between rural living, the elderly and poverty⁹. In Australia, New Zealand and the Pacific Rim, cancer survival is poorer for rural cancer patients^{7,10,11}. Two European studies indicated that cancer patients living far away from cancer centers are less likely to receive optimal cancer treatment^{12,13}. Rural patients also perceive that they have reduced access to healthcare services¹⁴. In Canada, rural women with breast cancer reported having less access to cancer support services than their urban counterparts¹⁵. Other Canadian studies have indicated similar disparities in access to cancer care between rural and urban patients^{11,16}. A systematic review concluded that distance away from healthcare centers is a significant variable that determines

access to cancer therapy and palliative radiation for cancer patients¹⁷.

In addition to the above-mentioned difference between urban and rural cancer care, young adult cancer survivors have unique needs compared to the older cancer population. The unique needs are related to fertility, disclosure, social relations and issues such as work and study, healthcare system issues (supplemental private health insurance)¹⁸⁻²¹. It is important that for young adult cancer survivors, physical, psychological and social morbidity is minimized because they have potential long and healthy years ahead of them²². In short, the transition from cancer care to survivorship is very important for this age group^{23,24}.

The evidence thus far supports the notion that rural cancer patients have poorer access to healthcare resources. This article examines this notion from the perspective of a unique group of cancer patients: young adults. Qualitative methodology was used to compare the experiences of young adult cancer patients regarding their cancer care in two distinct areas of Canada: New Brunswick, a rural Eastern Canadian province, and Toronto, Canada's largest metropolitan center.

Context

The original research questions were based on the cancer follow-up care experiences of young adult cancer survivors. The authors identified a serious gap in follow-up care for this cancer population. Overall, regardless of the stage of the disease, acute or follow-up care, the participants identified the lack of age-specific care. The participants felt that they have unique needs which are not being met²⁵. It should be



noted that, although the focus was on cancer follow-up care, in reality, cancer patients seldom differentiate between diagnosis, acute treatment and cancer follow-up care when discussing their experiences with cancer. For many patients, it is all 'cancer care'.

Analysis of the data revealed issues related to overall cancer care, and it appeared that the patients' experiences were influenced by where they lived and where they had received their cancer treatment. Being aware of the fact that much of the literature makes a strong case for the inferiority of healthcare services in rural areas, it was felt that it would be valuable to compare the experiences of rural and urban participants in the sample.

Setting

New Brunswick is an Eastern rural Canadian province with a population of approximately 750 000. New Brunswick has three major cities. These cities and their surrounding communities have populations ranging from 57 000 to 70 000²⁶. The Greater Toronto area (GTA) has a population of 5.5 million. The geographical area of New Brunswick is roughly 10 times larger than the geographical area of the GTA. New Brunswick is a sparsely populated geographical area with a homogenous population; Toronto is a densely populated multicultural metropolis.

Canada is a loose federation of provinces and territories with a governance system that gives provinces much autonomy. For example, social programs such as universal health insurance and education are provincially run with some federal oversight. Each provincial government is responsible for the delivery of universal healthcare services. By law, every Canadian citizen has access to basic medical coverage. These services include physician and tertiary care services. Medication coverage is not included in the provincial insurable healthcare services. In addition to the basic healthcare insurance, many Canadians purchase private supplemental healthcare insurance to cover the costs associated with medications, orthotics and other non-medicinal aids, and allied health professional treatments such as psychological

counseling, and physiotherapy. There is great variability in the medications and services covered by private insurance policies.

The GTA is home to three large cancer hospitals that serve the entire GTA population. The Princess Margaret Hospital is the largest cancer center in Canada and the world, while the Sunnybrook Hospital focuses on three specific cancers, and Women's College is a leader in breast cancer treatment and research. All three hospitals combined treat more patients in one given year than the entire population of New Brunswick. In addition, they have very active cancer survivorship programs and cancer research programs. On average, GTA patients would not be more than 40 to 50 kilometers from a cancer hospital that can be reached by public transportation. New Brunswick has three major hospitals, although only two provide comprehensive cancer care that includes surgery (to all types of cancer), chemotherapy and radiation therapy. None of the New Brunswick hospitals provides cancer services specifically focused on young adults or extensive cancer survivorship programs. Cancer research is also limited in these three tertiary hospitals. Many patients must travel between hospitals for treatment, a distance of more than 120 km, and some patients must travel out of province to larger tertiary care hospitals in Nova Scotia or Quebec to seek adjuvant cancer therapies. Cancer patients who do not live in the three urban centers in New Brunswick will have to travel by private means for hours for cancer treatment. New Brunswick has a very poor public transportation system.

Methods

Definitions

This article is based on a qualitative study that examined the experiences of young adult cancer survivors with cancer follow-up care in Canada²⁵. The term 'young adult' is not uniquely defined in the context of cancer²⁷. The authors chose to include people who were diagnosed with cancer between the ages of 18 and 39 years of age as 'young adults' in this study. The rationale for this definition is a combination of factors that are patho-physiological (non-epithelial vs. epithelial cancers) and psychosocial in nature^{19,28}. The young adult cancer patient's life stage is uniquely



characterized by the quest for independence, educational credentials and parenthood¹⁹.

Participants

Young adults diagnosed with any kind of cancer between the ages of 18 and 39 were recruited 1 to 5 years post-diagnosis. Participants were required to speak either English or French, and capable of providing informed consent. Participants received a \$20 gift certificate for participation. The recruitment strategy included posts on social networking sites (ie *Facebook*), online classified websites (ie *Kijiji*), newsletters and online messages boards at cancer advocacy groups (ie *Young Adult Cancer Canada*), posters in various oncology clinics, newspapers and other media articles and interviews. This strategy was used across the country. As with many studies, participants were self-selected²⁹. In general qualitative data is not generalizable to the larger population, but it provides in-depth insight in patients' experiences that cannot be obtained from data-set analysis or survey data³⁰.

Interested young adults who contacted us to indicate their willingness to participate were screened to ensure that they met the inclusion criteria. A consent form was sent by email, and a telephone interview date and time were set. Before the telephone interview commenced, the participant and the interviewer discussed the consent form to ensure that the participant was fully aware of the study procedures, risks and benefits, and oral consent was obtained over the telephone. Further, the participants were asked to consent to the audio recording of the interview. If the participants did not consent to being audio recorded, the interviewer took notes. In the larger study, 67 young adult cancer survivors from across Canada contacted us and 55 individuals participated in a telephone interview. Some people did not fit the inclusion criteria and others chose not to be interviewed after the initial contact. The interviews lasted between 45 and 90 min. Theme saturation (no new information reported by the participants) was reached at approximately interview 35; however, recruitment continued in order to ensure a diverse sample of participants based on gender, geographic location, and cancer type.

Data collection

Qualitative interviews were conducted using an interview schedule with open-ended questions. The first two questions were designed to make the participants feel comfortable and to have them tell their story regarding their cancer journey. Question 3 asked about current cancer follow-up care and questions 4 to 9 asked about broad cancer follow-up care issues that can be characterized as physical, psychological, relationship and social. Questions 10 and 11 related to experiences and satisfaction with current care, and recommendations for improvement. After the interview, sociodemographic information was collected to create a profile of the participants. Two research assistants, a male and female, conducted all of the interviews; the interviewees and the interviewers were gender paired. Data was collected over a 12 month period between 2010 and 2011.

Analysis

A *Constructivist Grounded Theory* (CGT) approach was used to analyze the data. CGT rejects the notion of an objective reality. It views realities as social constructs that may have multiple meanings/realities and that knowledge is mutually created, or in other words a co-construction of meaning by the 'viewer and the viewed'³¹. This, in the authors' view, is a more relevant interpretation of qualitative data than the objective reality promoted by grounded theorists³². CGT methods are often used in health research when researchers wish to hear the 'voices' of participants^{33,34}. After the interviews were conducted they were transcribed verbatim and proofread. Four team members read the same three transcripts independently and developed a coding scheme. The remaining transcripts were coded line-by-line by one researcher to ensure consistency, using the constant comparison method and through continued discussions among the team members³⁵⁻³⁷. The coding process was facilitated by using the qualitative data analysis program NVivo 9 (www.qsrinternational.com). The sociodemographic information was analyzed using the statistical data analysis program Statistical Package for Social Sciences v15 (www.spps.com).



Ethics approval

The study was approved by Dalhousie University (#2009-2098) and Memorial University (#10-46) research ethics boards.

Results

This article focuses exclusively on two subgroups: 15 young adults from New Brunswick and 15 young adults from the GTA. These two subgroups were not specifically recruited for the sub-study; it was serendipity that one group of 15 participants was living in New Brunswick and the other group of 15 was living in the GTA. Hence, a more detailed sub-analysis of these two groups was conducted.

The mean age of the participants was 29 years at time of diagnosis and 32 years at the time of the interview (Table 1). The cohorts of study participants are similar, except for the types of cancer, with a higher number of thyroid cancer patients in Toronto and a higher number of lymphoma patients in New Brunswick. The Toronto cohort also has higher levels of education and higher levels of income.

Themes

The three major themes identified in the data were 'delayed diagnosis', 'cost related to cancer treatment' and 'community support'. Further, the 'satisfaction with care' question was analyzed.

Delayed diagnosis: Three quotes that relate to the theme of 'delayed diagnosis' are presented (Table 2). The first patient describes how her complaints were dismissed for years. In the second case the physician did not take the patient's complaints seriously, and in the third example, physicians made the assumption that the patient was too young to have this type of cancer. Overall, more New Brunswick participants discussed a delayed diagnosis than did the GTA participants. For the New Brunswick participants, more than half reported having experienced a delay in their diagnosis, compared with 1 in 3 for the urban participants.

Out of pocket cost: Several issues are listed (Table 3) that relate to healthcare costs and the unique position of young adults who are often not permanently employed, are still in school or dependent on their parents. The first illustrates difficulties experienced by some students when they are diagnosed with cancer and must withdraw from university or other schooling. This usually results in the loss of supplemental health coverage. As the patient in the second quote illustrates, similar difficulties are experienced by part-time workers who do not have paid sick days and limited supplemental health insurance.

While the goal of many young adults is to become independent, cancer can have a significant negative impact on this quest as illustrated in the third quote. This young man became entirely dependent on his parents due to the financial hardships associated with his cancer treatments.

Community support: Specific questions about community support were not asked, but several participants brought this up. Few rural participants discussed community support. One rural participant was grateful that her community had organized a benefit breakfast to provide her with some financial and emotional support. None of the urban participants described any such event, but many more urban participants described receiving support either from faith communities or from cancer support organizations such as WellSpring. Cumulatively, urban participants reported receiving almost three times the level of community support received by rural participants. (Table 4).

Satisfaction: The final theme is related to the satisfaction levels with cancer care, and it was found that the urban participants reported higher levels of dissatisfaction (negative experiences) with their care compared to the rural participants. A substantial number of negative comments were related to the fact that participants felt that they had not received enough information about what to expect after their acute treatment was completed. Interestingly, many rural participants said they were satisfied with their care but this was qualified by the acknowledgement of the limited resources in their community. Many rural participants had low expectations of their care, so when they received more than expected, they were inclined to be satisfied (Table 5).



Table 1: Demographic characteristics of participants

Characteristics†	New Brunswick N=15	Toronto N=15
Females – %	53	87
Mean age at interview (years)	29.5	34.6
Mean age at diagnosis (years)	27.3	31.6
Having children – %	47	60
Number of children (average)	1.5	1.4
Average age oldest child (years)	8.3	9.1
Type of cancer – %		
Breast	20	27
Thyroid	7	54
Hodgkin/non-Hodgkin	33	13
Other	40	6
Marital status – %		
Single	40	47
Married/Common law	60	53
Caucasian/White – %	93	80
Highest Level of Education Completed – %		
Junior High School Diploma	7	7
High School Diploma	47	13
Community College Degree	20	27
University Degree	7	40
Graduate Degree	20	13
Employment – %		
Full-time work	40	47
Part-time work	13	13
Homemaker/Sick Leave/Disability	34	20
Social Assistance	–	7
Student	13	13
Family Income Levels – %		
< \$20,000	7	–
Between \$20,001 and \$30,000	7	–
Between \$30,001 and \$40,000	–	20
Between \$40,001 and \$50,000	7	7
Between \$50,001 and \$60,000	7	7
Between \$60,001 and \$70,000	13	–
Between \$70,001 and \$80,000	–	13
>\$80,001	33	33
Does not wish to answer	27	20
Supplemental Health Insurance – %	73	80

†Not all categories total 100% because of rounding.



Table 2: Theme: Delayed diagnoses

Problem with diagnosis	Quote
Dismissed complaints (FNB04)	I had a bump in the roof of my mouth for years.... I went to the family doctor and he said it is nothing. I went to the dentist and he said it was nothing. Five years went by.... One day a little cyst showed up beside it. I was sent to an oral surgeon, 8 months went by and a biopsy was done. Three days later and It's low grade cancer, mucoepidermoid. Later it turned out to be intermediate.
Wrong diagnosis (FNB07)	I started to go see Dr X in the Spring and I kept telling him that it felt like everything inside my stomach was going to fall out of my crotch, my vagina, onto the floor... He kept treating me for a bladder infection.... I went to him in August and I said: "it's not a bladder infection." ...he sent me for an ultrasound, but that took one month. ...He said it looks to me like you have 20 to 30 tumors in your abdomen...
Unusual age for diagnosis (FON12)	[Daughter] was born in August. In December ...we went to the doctor and told him we are feeling a lump. [He said] don't worry about it. ...you do not have any risk factors. I breast fed for 3 years, then I developed pain in the breast [finally the doctor ordered a mammogram in July]. [On] November 18 th , I was diagnosed with invasive ductal carcinoma.

Table 3: Theme: Cancer care cost

Cost issues	Quote
Medication costs (FNB10)	I was covered as a student under 25 on my parents plan, but as soon as you stop being a full-time student you're not covered. Drugs were expensive... Neupogen, I don't know, \$200 or \$300 for a little vial. ... I would say I was put on welfare ...just to have my medication covered.
Part-time work, lack of sick leave and limited health insurance coverage (FON15)	I took [time] off from my [part-time] church work I got three sick days. ... The [health] insurance has a \$600 or \$800 deductible....if I do go to the dentist or my son goes to the dentist or my husband gets prescription drugs, or whatever, we always have to fork it out. So yes, I do have a health plan, but it hasn't been helpful....
Reliance upon parental assistance (MNB03)	Like I have no money right now. ... my parents pay for everything... They are even paying for my medications cause I can't even afford those. There is nothing. There is nothing to help me...

Table 4: Theme: Community support

Examples	Quote
Benefit events (FNB06)	... a lot of people came to my [benefit] breakfast.
Meals (FON09)	...the head of the sisterhood arranged to have meals sent to me every day from December 2006 to the fall of 2007. It was amazing.
Meals and support from friends (FON10)	I had a good network of friends who made meals and delivered meals and provided a lot of support. ...that is really helpful, like grocery shopping and meal-making...
Cancer Organization Support (FON07)	...and I went to them a lot while I was in treatment and post-treatment for certain things before I went back to work. My only complaint with WellSpring would be that they're only open in ... during the day.



Table 5: Satisfaction levels (positive and negative)

Negative aspects of care	Quote
Lack of Information and support (FNB06)	...I felt there wasn't enough ... I guess, information when you are released from the hospital.
FON12	...like I don't feel satisfied like, it's just that like, you know, I just don't feel that my questions are answered.
MNB03	...they take care of you and they do the blood test to make sure you're not going to get sick again, but besides trying to help me with my life, I get no help...
Regional Issues (FNB07)	... I mean this is New Brunswick, you know. There were times when I thought geez, I have cancer and it's taken two months to get in to start my chemo, this should be bang, bang, bang.
(FNB09)	I think they're doing the best that they can do with the resources that they have...
Positive aspects of care	
Top class cancer facility (FON07)	I was lucky enough to live in a place where two of the top cancer hospitals happen to be. ... there is a number of services available to me as... forever. ... I mean that includes everything: social workers, psychologists, dietician, you name it!
Intense follow-up screening (MNB02)	I am able to go in every three months and get an x-ray, it's really ...reassuring, I guess.

Discussion

The profiles of the 30 young adult cancer survivors described in this study are similar except for three characteristics. There was a difference in the proportions of cancer types between the rural and urban groups, not an unusual finding given the number of participants in groups. Rural participants have lower educational achievements, less full-time employment and therefore lower average incomes. This is in keeping with the overall patterns for the two provinces: New Brunswick and Ontario (GTA)^{38,39}. A greater variety in participants' ethnic backgrounds was expected, given that the GTA is multicultural; however, ethnicity was not selected as an inclusion criteria. Considerably more rural participants discussed having experienced a delay in their cancer diagnosis than did the urban participants. The issue of delayed diagnosis is complex. Sometimes patients delay seeking medical assistance, and sometimes the delay rests with the physician or the system^{40,41}. A previous study, conducted exclusively in New Brunswick with young adult cancer survivors, also identified a problem of delayed diagnosis for young adult

cancer patients⁴². It is not always clear if a delayed diagnosis leads to higher mortality, but it is clear that a perceived delayed diagnosis adds considerably to the stress experienced by the patient^{18,42}. Nevertheless, delayed diagnosis may lead to more physical and psychological morbidity, which, in the long term, can have very negative consequences for young adult cancer survivors.

The sources of out-of-pocket expenses for cancer patients during the cancer journey are many. While medications administered for in-patients are provided free of charge, the provincial health insurance programs do not cover the cost of medications used outside the hospital setting. Private, supplemental health insurance pays all or some of the medication costs. In addition to medication costs, cancer patients may be burdened with a number of other expenses related to treatment or cosmetic issues following those treatments, such as travel and lodging, prostheses, and wigs. Some cancer patients have generous sick leave benefits from their employers, while others have either no health benefits or limited benefits. Students lose their supplemental health



insurance when they stop attending on a full-time basis. Approximately 1 in 3 Canadians do not have private supplemental health insurance⁴³. These patients may face considerable out-of-pocket expenses for cancer treatments. Although there was no data to support this fact, the authors believe it is likely that few young people have supplemental health insurance. Thus young adults with cancer may face higher out-of-pocket expenses than similarly stricken older persons. Travel expenses can add considerably to the financial burden of cancer patients^{44,45}. From the literature, it is known that rural patients often are more adversely affected by out-of-pocket cancer treatment expenses^{44,45}. It is not clear why the present study rural participants discussed out-of-pocket expenses less often than did their urban counterparts. It may be that travel costs are considered 'normal' for the rural participants and that they do not consider them 'out-of-pocket' cancer expenses.

Social support is important for cancer patients⁴⁶. The authors were struck by the difference between the rural and urban study participants in their discussions of the level of community support. Although it appears that urban participants received more community support than the rural participants, this may also be the result of how the term 'community' was individually defined and interpreted by the participants, as this was not specifically defined for them. Community can be broadly defined as a specific group with which one is associated (eg church group, support group). An important finding from the present study was that despite the fact that it is often assumed that urban dwellers lack a sense of community due to large population size and urban sprawl, many urban participants relied on their personal 'communities' for support in difficult times, such as church groups and parent groups. Some studies have concluded that community support for cancer patients is not very different between urban and rural patients⁴⁷. The present study cannot conclusively make a statement about more or less community support based on geography; however, good evidence was found that cancer support organizations, mostly associated with urban centers, have a positive impact on urban cancer survivors. Institutions such as WellSpring⁴⁸ or dragon boat racing⁴⁹ were reportedly much appreciated by the urban

participants. Unfortunately, many rural cancer survivors do not have access to such services.

Rural participants reported having less trouble with out-of-pocket expenses, even though it can be assumed that they have at least as many, if not more, out-of-pocket expenses as their urban counterparts⁴⁶. Rural participants also reported less community support and higher levels of delayed diagnosis. Despite these 'negative' experiences they reported higher levels of satisfaction. This is not an unusual finding; a study in the USA also reported that rural participants reported higher levels of satisfaction with health care than urban participants⁵⁰. In the present study, rural participants seemed to have had low cancer care expectations, and most considered themselves to be lucky to have received the best care possible given their location and available services.

The authors acknowledge that provinces with small populations and large geography are not able to provide optimal cancer care for young adult cancer survivors, but they hope that with new technology some of these care impediments can be bridged, particularly in the area of psychological and social care issues.

Limitations

The study results are based on a theoretical sample and therefore cannot be generalized to all young adult cancer survivors. A larger proportion of female than male participants in this study is acknowledged, but this is very common phenomenon; females often participate more easily in research than males^{42,51}. Nonetheless, the authors are confident that the participants represented a wide variety of young adult cancer survivors, and included diversity in the types of cancers and participants from a variety of geographical areas. As in most research, particularly in self-referral studies such as this one, participants who have experienced significant challenges may have been more inclined to participate than young adults who did not.



Conclusion

Administrative data supports the notion that, in general, rural cancer patients have less access to cancer care than urban cancer patients. This study examined the experiences of cancer care for a group of urban and rural young adult cancer patients. The rural participants were less likely to speak about the financial burden of their cancer experiences, less likely to speak about significant community support, spoke more often about a delay in their cancer diagnosis, and yet expressed a higher level of satisfaction with their cancer care. They were aware of the limitations of the treatments that were available to them, and yet felt positively toward their care providers who they felt did all that was possible under the circumstances. There is no evidence to support the notion that this level of satisfaction translated to better overall psychosocial health for this age group but would think that this association would exist, and it is believed that this needs to be studied further through intervention studies. Further, the authors feel it is important to test new technologies to bridge the gap between rural and urban cancer care for young adults.

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