

ACCESS TO CANCER SERVICES IN MANITOBA

**THE PATIENTS PERSPECTIVE
FOCUS GROUP REPORT
DECEMBER 2008**

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1. INTRODUCTION

This interim report summarizes the results of six focus groups conducted by Pele Research on behalf of the Canadian Cancer Society (CCS) and the Canadian Cancer Action Network (CCAN) between September 10th and October 22nd, 2008.

The purpose of the focus group study was to gain information and insight into the cancer patient experience of accessing cancer services in Manitoba, highlighting its strengths as well as areas requiring improvement.

Specifically, the CCS and CCAN wished to develop an understanding of:

1. Experiences of access to services during the various phases of the cancer journey;
2. Experiences of wait time and the impact of waiting or not waiting on the experience;
3. Access to support services;
4. Financial impact of a cancer diagnosis and adequacy of the social safety net; and
5. Differences, if any, in the rural, northern, First Nations or Winnipeg (urban) experience.

A total of six focus groups consisting of cancer caregivers and cancer survivors were gathered for the purpose of this study. The number of participants and dates of the sessions were as follows:

Group	Location	Size	Date of Session
1	Brandon	11	September 10, 2008
2	Morden	12	September 11, 2008
3	Winnipeg	10	October 8, 2008
4	Dauphin	12	October 21, 2008
5	The Pas	11	October 22, 2008
6	The Opaswayak Cree Nation	4	October 22, 2008

A mail and email survey was also administered as a supplement to the focus groups. The purpose the additional survey was to offer those individuals who could not attend or be accommodated by the focus groups to share their experiences.

A total of 38 questionnaires to those willing to complete the survey (25 via email address with a return of 9 completed surveys returned and 13 via Canada Post with a return of 5 completed surveys returned in a post paid envelope) for a total of 14 surveys returned.

Individual participant responses have been kept strictly confidential.

2. EXECUTIVE SUMMARY

The following insights have been drawn from participants in the six sessions that comprised this focus group study conducted between September 10th and October 22nd, 2008 and is based on areas of discussion within the groups.

The period between suspicion and confirmation

The period between suspicion and confirmation of cancer is an incredibly stressful time. Many of the participants related stories of waiting for test results, while trying to carry on with daily routines and obligations. For too many patients, results were not reported back to them when they were told they would be. Quite often a one week wait turned into a two or three week wait and in some cases, even more. Some participants reported that they would call and make inquiries after a reasonable period of time, often to no avail, or only to be told by an insensitive clerk that they needed to wait patiently. In the case of one rural resident, the results were actually lost on the general practitioner's desk.

This phase in the cancer journey was clearly described as the most stressful. Patients and caregivers observed that they needed to feel more confidence in the system and belief that the system was aware of their needs and would be responsive to them.

Length of time waited before appointment with oncologist

Most participants experienced short wait times for surgical treatment; however, the wait times for biopsies tended to be longer than expected and was remembered by survivors and caregivers as being extremely stressful. In addition, the experience of waiting for the first visit to an oncologist and entry into the formal cancer system was longer than anticipated and also remembered as a particularly stressful time. Patients with advanced cancer symptoms appear to be processed more expeditiously.

Length of wait within the oncologist's office

The wait time within the oncologist's office for most patients appeared to be satisfactory; however a recurring complaint was that they felt that the oncologist rushed through the appointment.

Several rural participants also complained that appointments with their oncologist and other specialists are not scheduled on the same day. They would then have to make the trip back into Winnipeg or find overnight accommodations adding both an additional financial burden and unnecessary stress. Other rural participants were appreciative that staff was sensitive to the challenges of travel and scheduled their appointments

successively, sometimes one after the other. A few rural participants complained that they made the trip into Winnipeg only to find out that their appointment had been cancelled. Others complained that greater use of Telehealth would be appreciated, and that it seemed to be optional on the part of the physician, with little regard for the cost, stress and inconvenience of those who had to travel to Winnipeg.

Upon confirmation of the diagnosis

For patients and caregivers alike the time of confirmation of cancer was another highly stressful time. Many described how their minds were racing upon hearing what they referred to as the “C” word. For many, the time immediately following the confirmation of cancer was much of a blur. They could not focus on what they were being told during the rest of the appointment. Many said that it was important for someone else to be with them during the appointment, first of all to listen and absorb any information communicated by the physician and secondly for emotional support.

While a few northern participants stated that they preferred to be notified over the phone so that they could save the time, stress and costs of travelling to Winnipeg, they also said that personal requests such as avoiding calls to their place of employment or calling at certain times were not followed by the physician.

Wait times for various services during the confirmation of diagnosis and the start of treatment

Approximately half of the participants in the focus groups experienced a quick diagnosis and were treated within a time frame that they considered appropriate. Those with advanced and aggressive types of cancer were quite often treated the next day or soon after. It seems that for most of the participants, with a few exceptions, their treatment as a cancer patient at CancerCare Manitoba was fairly positive. As well, many others with less aggressive or advanced stages of cancer believed they were treated within a reasonable length of time. Only a few focus group participants felt they waited too long for treatment.

More concerning was the frustration voiced by a surprising number of participants residing in rural Manitoba who reported a misdiagnosis of some other malady when in fact their illness was a cancer. There appears to be a lingering feeling that if the cancer had been diagnosed more quickly, the prognosis would have been much better. This was a particularly pronounced sentiment expressed by some of the caregivers who had lost their loved one.

The misdiagnosis usually occurred at one of two points of contact – either with a General Practitioner or with an Emergency Room physician. In some cases, the patient’s malady was attributed to other ailments such as muscle strain or pneumonia. In the worst cases, the malady was simply written-off as being stress-related or hypochondria. A few patients were sent on their way with minimal examination and little or no treatment. Proper

examination and final confirmation came only after several visits, strong urging or failed treatments for misdiagnosed suspected non-cancerous ailments.

Clarity of explanation of the disease, its effects and treatment pathway

Most of the participants were satisfied that the disease, the treatment plan and its implications were sufficiently explained to them; however, many mentioned that they experienced shock upon confirmation of cancer and were unable to retain much of the information explained to them. Some were thankful that they were given literature on their specific cancer and were able to read up on it once the shock had subsided. Others accessed the internet for more of that information, but still there was significant frustration voiced by those diagnosed with a rare type of cancer. Information on these cancers was not as readily available.

Some patients were clearly dissatisfied with either the initial consultation or the options pursued by their physician. One rural resident, who was offered immediate surgery for his prostate cancer, was uncomfortable with the consultation and sought out the Prostate Centre at CancerCare Manitoba, where he is now undergoing “watchful waiting”. Women with breast cancer complained that they had a lumpectomy followed by mastectomy, since the initial surgery did not provide clean margins and a second and more radical surgery was required. In fact, a surprising number of rural and northern patients complained of poor margins in the initial surgery that resulted in the need for a second surgery. This complaint was not as common among participants in the Winnipeg group.

Communication between primary care and the specialty services of a surgeon or oncologist

While for the most part the patients’ experiences were positive with charts, results and other information being forwarded without any problems, there were a few instances when communications broke down. There were several examples of lost patient information, information not being sent on from regional hospitals and/or physicians to oncologists or other specialists. Several participants complained that they experienced significant frustration having to provide the same personal medical information several times as they went through the system. They voiced concern that electronic transfer of information was not been used sufficiently to ensure efficient and timely transfer of information and to reduce the need for the patient to repeat information over and over with every provider in every part of the system.

Directions and supports offered upon diagnosis

The majority of the participants felt that they were informed of the direction of their treatment and provided with access to required support. Despite being overwhelmed at the time of confirmation of cancer, those provided with packages containing information

on their type of cancer and supports that could be accessed were generally satisfied with what was provided to them.

The support service most often referred to as a “life saver” was the transportation support services of the Canadian Cancer Society and South Central Cancer Resource. A number of patients indicated that they would not have been able to get the care they required without the transportation support service. However, patients that were transported by the CCS service were not necessarily aware of how the ride was provided.

Participants and caregivers who were not supplied with sufficient information and those of lower literacy levels reported feeling “alone” and ill-equipped to handle the diagnosis, treatment and subsequent prognosis of their cancer. In addition, patients and caregivers without adequate family and community support expressed particular feelings of vulnerability and a sense of being lost and alone with nowhere to turn.

Many of these participants were unaware of the services and support networks offered through CancerCare and the Canadian Cancer Society. Many of the caregivers complained they had insufficient support and expressed a wish that there was some type of orientation or resources to help them in caring for their loved one. In a few cases, the patient was sent home despite the inability of their caregiver to provide basic care, properly administer medications or provide mental health support.

Length of time before treatment began

Although most of the patients believed that they received treatment within an acceptable length of time, there were a few cases where access to chemotherapy treatment appeared to be much longer than would seem appropriate for the level or severity of the diagnosed cancer type. Patients want and expect treatment shortly after they are diagnosed. Most are aware that early diagnosis and treatment is crucial in the battle against cancer and their expectations that the system will move aggressively with their care are quite high.

Difficulties experienced during treatment

Overall, the healthcare system does not appear to be sensitive to the emotional, financial and home support needs of cancer patients and their families.

In most cases, the emotional toll on patients and their families is substantial. They feel that they are left alone dealing with a terrifying disease and many unanswered questions. There appeared to be a consensus among most of the participants that there is a pronounced need for stronger emotional supports.

The financial burden on the patient and their families is also significant and sometimes results in devastating outcomes such as bankruptcy or the need to draw from retirement savings. Many patients were unable to work during treatment and/or unable to return to work after treatment. Those patients that were self-employed or employed in smaller

workplaces without benefits suffered a loss of employment and therefore of income. Likewise, caregivers would often take time off to provide transportation and support for their loved one during medical visits. The cost of travel, accommodations, meals etc. add up substantially for rural patients and only contribute more to those financial challenges.

The high cost of cancer medications impact substantially on the budgets of families afflicted with cancer. In most cases, these costs exceed personal insurance and many patients report that their Pharmacare deductible is very high. Some oral chemotherapy and anti-nausea medications can incur a staggering expense. Universally, patients commented on the inadequacy of the income tax deduction for health expenses and the fact that costs are incurred immediately.

For those live with low incomes or below the poverty line, the cost of medication is simply unaffordable. Lengthy waiting times for approval of government assistance and the inadequate level of available financial support add only more stress, frustration and devastation to the patient's experience. Some patients told stories of the challenges of meeting the requirements for Employment Insurance, Canada Pension Plan or Income Security and the long wait times for payments when the costs are immediate. Although some patients are fortunate to have strong support by family and friends, there are others that are left with very little support.

The system does not appear to be sensitive to the many challenges of cancer patients and their families, particularly for those who need to travel to Winnipeg for treatment. It does not take into account the compounding effects that occur. Families and their children are left to "make do". The costs are far-reaching and take its toll on relationships and the normal progression of family life. Often children are left on their own, struggling to make sense of the misfortune that has been cast on their lives. Marriages and partnerships fail. Friends and relatives are ill-equipped to comfort the patient and their families at a time when it is needed most.

Compassion and support from direct service staff

While most of the participants were quite complimentary of the sensitivity of physicians and direct service staff, there were several incidents of blatant disregard and disrespect. In one community there was a universal concern about the attitude of the cancer clinic physician. This physician was described as cold and insensitive and often found lacking in his skills of treating the side effects of cancer treatment. The same criticisms were levelled at a few of the nurses at that same hospital. There were a few mentions of other physicians, nursing and clerical staff in other settings who seemed to be indifferent to the stress that cancer patients and their families were experiencing.

Unresolved life style challenges due to the impact of the treatment

Treatments for many of the participants leave substantial personal challenges. Most of the women who underwent mastectomy operations were devastated and had to make

decisions regarding breast reconstruction. One woman expressed outrage at the Manitoba Health provisions for breast prosthesis at \$12.50 compared to the actual cost of prosthesis (approximately \$300.00) or the Manitoba Health expenditure for the cost of reconstructive surgery which is in the tens of thousands. Male prostate cancer survivors had to deal with the impact of the treatment on sexual relations with their partners. A brain tumour cancer patient who experienced misdiagnosis lost sight in one eye and his license to continue driving the truck that he used to earn his livelihood. A survivor of throat cancer had to overcome how others perceive him and his ability to communicate with others.

Life challenges for cancer survivors and their families are affected well beyond treatment and diagnosis. There is always a lingering fear that the cancer will return. Most make lifestyle choices based on that fear. For some it ignites a positive spirit celebrating survival and a desire to enjoy each day as it happens. Others are less positive and simply have to deal with that fear, often alone, sometimes not wanting to drag family or friends into their fear. The outpouring of emotions that occurred during the focus group sessions clearly demonstrated survivors and caregivers have a strong need for ongoing support, someone to talk to and someone to listen to their fears and their story.

In Conclusion

For a small majority of focus group participants, the diagnosis and treatment of cancer was exemplary. However, there are several aspects within the areas of initial diagnosis and treatment that are well below what Manitobans expect and deserve to receive.

Improvements in quantifying how well the system performs in dealing with cancer patients are needed, particularly in communities outside of Winnipeg, where the effects of inadequate service appears to be more pronounced. There appears to be too many cases of misdiagnosis, poor surgical margins, lengthy waiting times for results or treatments and poor or inefficient communication. This only compounds the fear and stress that is cast on cancer patients and their families, not to mention the financial burden of medications, lost time, travel and accommodations.

Several participants in the study felt that the system did not adequately care for the cancer patient. Many of them voiced the need for patients and caregivers to ask questions, demand results and advocate for the best care possible. Many felt that if you did not look out for yourself or you did not look out for your loved one, that the system might not offer the care that each patient should deserve.

Improvements to the care experience could address the following issues:

- Strategies involving family physicians and emergency room physicians to increase their sensitivity to the signs and symptoms of cancer.
- Improvements in the area of diagnostics to reduce wait times shorten the completion and communication of results and improve the efficiency of communicating result information.

- Mechanisms to ensure that surgical treatments for cancer are consistent with best practice in the hopes that poor margins and the need for second surgeries are reduced.
- Improvements to “patient navigation” from the start of the process i.e. suspicion of cancer to completion of treatment, or required rehabilitation and support. Patients and caregivers need to experience an increase in confidence that the health care system is managing their care.
- Strategies to assist patients with all of the information and assurance requirements following the confirmation of diagnosis; including strategies to promote the knowledge of and use of the cancer information and cancer support services of the Canadian Cancer Society.
- Strategies to improve access to psycho-social supports for patients, caregivers and families.
- Strategies to improve communication between the cancer system and the patient’s family doctor.
- Review of Canada’s social safety net with the view of improving financial security during a time of high cost, high stress, and a loss of income.
- Review of transportation needs of all cancer patients to see if more can be done to offer this vital service to more patients around the province

3. DETAILED FINDINGS

The following summary of responses was accumulated from the six focus group sessions.

DIAGNOSIS STAGE

Confirmation of Diagnosis Experiences

About half of the participants from this study reported having good experiences with their cancer diagnosis process. Those participants who had bad experiences at the diagnosis stage with cancer reported concerns regarding dismissive medical professionals, misdiagnoses, lost medical records and miscommunications among physicians. These problems were more evident in the rural and northern groups than they were in the Winnipeg group. The cancer diagnosis stage was where the vast majority of challenges and frustrations occurred for the participants.

The following are some examples of what were relatively positive experiences. It seemed that several of the participants, both survivors and caregivers, were appreciative of the care they received, even though some of those experiences were less than ideal. Some of those who were diagnosed and treated quickly without any problems said that they were grateful. Several also added that they felt in some ways “guilty”, because they had heard of others who were less fortunate.

In one of the rural focus groups, one cancer survivor related his story of bladder cancer which was discovered by his family physician during a routine check-up. The physician promptly referred him to an urologist who in turn arranged for a biopsy. The biopsy showed that he had a very aggressive form of bladder cancer and after visiting CancerCare in Winnipeg he immediately started receiving treatments for his cancer at the regional hospital. In his opinion, he was treated well both in Winnipeg and at the regional hospital and was very pleased that everything progressed so efficiently.

A couple of rural survivors shared how they sought second opinions after their family doctors were initially dismissive of their symptoms.

In one case a female patient found some dark blood in her urine. When her family doctor dismissed the symptom as “just menopause” she thought she would seek a second opinion. The second doctor examined her and called for an emergency ultrasound. Within hours he informed her that he had found a tumour and it was likely cancer. She said the tumour was removed that night, which she was told was “the size of an orange”. She was pleased to announce that she was now cancer free and went on to say that she was thankful that she had switched doctors. She urged others to stand up and ask for a second doctor’s opinion “if things don’t feel right”.

In another case, a prostate cancer survivor sought a second opinion after his PSA levels had started to elevate. His family doctor was not concerned and kept telling him that PSA levels elevate naturally with age. Still concerned, the patient decided to seek the advice of another doctor who immediately ordered a biopsy, which subsequently came back positive and required treatment. Despite the experience he had with his family physician he felt that he had been treated within a reasonable amount of time once cancer had been confirmed.

Another rural prostate survivor also received treatment quickly, but had to wait for some time before his biopsy results were returned.

The survivor's doctor initially discovered that there was something wrong during a regular physical examination. The doctor told him that his PSA count was elevated and referred him to an urologist, who performed a biopsy. Unfortunately he waited about a month for the biopsy results to come back and they tested positive for cancer. Fortunately, he was scheduled and received treatment within a short period of time. Despite the stress and worry it caused the patient while waiting for the biopsy results he still claimed that it was a "very positive experience," mainly because treatment was provided quickly.

A breast cancer survivor wrote in response to the mail-out survey:

"I felt the lump one morning when showering. I went to a walk-in clinic that evening. At that point the doctor made arrangements you have a biopsy within a few days. Two weeks from that point I received the final diagnosis. The same day I talked to both a cancer doctor and a surgeon. Arrangements were made for surgery 4 days later. This took about two and a half to three weeks."

"The information I was given was good. I knew what was going to happen and the outcome. I received most of the information about the disease before surgery. My treatment options were limited."

"If everyone received the care and concern I did improvements would be minimal I couldn't have asked for better care or concern. I can't think of anything else the health care system could have done to make my situation any better."

In the case of one rural prostate patient, the use of Telehealth and efficient processing of this survivor's case resulted in a rather positive experience.

One of the rural caregivers shared how her husband's prostate cancer was initially discovered through a regular blood test. Within a couple weeks he was sent to the local cancer clinic who utilized Telehealth for his appointments with doctors in Winnipeg. The Telehealth technology saved them many trips to Winnipeg. According to this caregiver, "the staff at the cancer clinic was great, and my husband never had to wait longer than 5-10 minutes before seeing his doctor".

Unfortunately one rural caregiver lost her husband to pancreatic cancer, but was grateful for the support they received.

Her husband had been sick for quite a while prior to diagnosis, but stayed in denial (he blamed being sick with the flu, “eating something”, being overweight, etc.). One night, as she described it, he became “pure yellow”. She took him to the hospital and he saw a doctor that night. Three days later they conducted a CT scan and that same day he was diagnosed with pancreatic cancer. The following day he and his wife were on their way to Winnipeg for treatment. Although she eventually lost her husband, she described their experience at St. Boniface as “fabulous from the nurses and doctors to the palliative care ward”. Even though everyone at St. Boniface knew what was happening (that her husband was terminal), no one once said “give up”.

A Winnipeg breast cancer survivor said that she had a relatively positive experience during diagnosis despite having to wait for some time for a biopsy.

After discovering a lump in her breast she made an appointment with her family doctor, who promptly referred her for both a mammogram and ultrasound. The ultrasound was performed within days and confirmed a growth. Her doctor booked her for a biopsy for which she had to wait about a month. Even though she had to wait almost a month for the biopsy, she was grateful that it was no longer because of the waiting and worrying.

A Winnipeg prostate cancer survivor also maintained that his experience was relatively positive despite what he described as “being bounced around from doctor to doctor and some other mistakes along the way”.

His cancer was picked up on PSA tests over a period of 3-4 years. He was scheduled within a short period of time for an operation, which went well. He said that he thought that the medical profession was working “125%” in his case, although he did add, “They were doing the job . . . but with stupid little mistakes . . . for example, they had my phone number wrong, causing a delay of about 3 weeks for a colonoscopy”.

There were also some very disturbing stories of misdiagnosis and other breakdowns in the system. One rural cancer survivor had to wait five months to be diagnosed with cancer and to have surgery, but was treated quickly once he was diagnosed with cancer.

He originally walked into the local emergency ward with a heavy nosebleed. The nurse looked at him and said: “It’s the weather outside. Lots of people have nose bleeds this time of year”. The patient continued to experience severe nosebleeds and saw four other doctors over the next three months on numerous flare-ups and was always told that he was fine. He finally went to another hospital where they suspected that there was the possibility of cancer and immediately referred him for tests. It was eventually confirmed that the root of his problem was cancer. An MRI was arranged for him in Winnipeg within hours of his diagnosis, and he underwent surgery the next day. According to this survivor, it was “all a very bad experience, especially with the

rural medical clinic and emergency department . . . once the cancer was diagnosed and confirmed, everything was very quick.” He added, “There is no better hospital than the Health Sciences Centre”. Unfortunately he lost sight in one eye and was unable to continue his business as a truck driver/owner.

There were a couple of cases where rural doctors did not seem to be equipped to recognize the possibility of cancer.

A caregiver in rural Manitoba shared her story of how difficult a time their family had getting her five-year-old granddaughter properly assessed. The doctors kept telling the family that there was nothing wrong with the girl, and that they were just being overly protective. It took several visits and strong urging by the family that something was wrong, to finally have the girl thoroughly assessed with a diagnosis. She had leukemia.

Another rural caregiver shared a story of misdiagnosis of her mother’s lung cancer by local medical staff. Even though the rural medical professionals reviewed the identical medical file and test results as doctors in Winnipeg, they were unable to correctly diagnose her mother with the disease.

Another rural caregiver offered an example of misdiagnosis that almost cost her brother his life not once, but three times.

When her brother started feeling sick, (symptoms included indigestion and troubles with bowel movement), he was told that he had an ulcer. He began getting treated for ulcer, but the symptoms persisted. It wasn’t until months later when he suffered a slight stroke and was taken to Winnipeg that he was diagnosed with liver and stomach cancer.

A rural caregiver, who lost her husband, experienced a lack of urgency and sensitivity to her concerns during his diagnosis.

Her husband had been diagnosed with pneumonia after seeing a doctor for his first symptoms. The symptoms persisted so he was sent for a CT scan, when the doctors found something of concern. At the time the couple didn’t have a regular doctor, and were using a walk-in clinic. The doctor at that clinic didn’t know what to do with him after the CT scan results came back, and suggested that the couple “find themselves a doctor”. They insisted that the clinic’s doctor do something for them, so he arranged to have a biopsy in Winnipeg.

About a week after the biopsy, the gentleman’s wife phoned CancerCare for results and was told that they had no information on him from the doctor’s office yet. After waiting for days and hearing nothing, she called CancerCare again, only to be told by the secretary to back off and leave CancerCare alone. The secretary told her that they couldn’t do anything until they had the written report from the doctor. Nobody seemed to know where the report was or care to track the results down.

Winnipeg was short of pathologists at the time and her husband didn’t get diagnosed

until about a week before he died. She felt that the system never gave her husband a chance (to live). She said it took 52 days from the day of his diagnosis of cancer to the day he died. She wrote a letter to the Minister of Health, but was only told that they are sorry about the shortage of pathologists in Manitoba, because a number have left the province.

Another survivor in one of the rural groups spoke of his experience with a dismissive family doctor.

He said that he started finding blood in his urine, but the doctor dismissed it. He waited another month, but the problem became worse. He went back to his doctor, got the same reaction and was told that there is nothing to worry about.

He thought he had to do something to prove to the doctor that he really had a problem, so he boiled a jar and deposited a sample in it. He took it to his doctor, and only then did the physician finally agree that something was wrong. He was sent to an urologist in Winnipeg who gave him a biopsy and finally confirmed that he had cancer and he was subsequently treated.

A different example of the dismissive attitude towards cancer symptoms by some Manitoba medical professionals came from one rural caregiver. Her thirteen year old daughter was diagnosed with a brain tumour.

She initially took her child to their family doctor after about two weeks of headaches. The doctor dismissed the symptom as stress-related, telling them to come back in a couple of weeks if the headaches didn't get better. A week later her daughter's headaches became worse, so the doctor prescribed her Tylenol 3. It didn't work. The following week she started vomiting. The caregiver went back to the doctor and insisted that he "do something for this kid". Her daughter then underwent an emergency CT scan in a rural medical centre. Four hours later they received the news that her daughter had a brain tumour.

Another example of dismissive experiences with local physicians came from a rural cancer survivor.

He visited the doctor repeatedly about problems he was having with his throat. He then began to complain to his doctor about regularly losing his voice. He said that it took three years before finally being taken seriously. He had to switch doctors, in order to get diagnosed with cancer of the throat and undergo a tracheotomy.

One Winnipeg survivor's negative experiences with cancer diagnosis had to do with a reluctant surgeon that performed the biopsy.

When she went for the ultrasound at the Health Sciences Centre, the biopsy physician was clearly reluctant to perform the procedure. He even asked her: "Have you ever had trauma to your chest? It looks like scar tissue to me. Are you sure you want me

to biopsy it?” As it turned out, she had a very large breast cancer that eventually resulted in a mastectomy.

A second Winnipeg survivor (aged 74) shared her story about how her family physician suspected seeing “something” on her ovary from an internal examination and immediately sent her to a gynaecologist.

The gynaecologist, however, did not think there was anything to worry about, as didn't any of the physicians at the Winnipeg Cancer Clinic. She was told to wait six months, that there was “probably a 20% chance of cancer” in their opinion. On her continued urging that something was wrong, they acted quite quickly. It was only then determined that it was cancer. She was very happy that she did not wait any longer, as the doctors were suggesting and commented, “I am just disappointed that the doctors are so reluctant to acknowledge that there might be a problem. With ovarian cancer, the symptoms are so vague that you don't feel sick; you are not debilitated in any form, except you feel this odd feeling in your stomach... Ovarian cancer is ‘not a silent killer’; it is an ‘ignorance killer’.”

Still in the Winnipeg focus group, a leukemia cancer survivor, who at the time of her diagnosis lived in northern Manitoba, shared how her local family doctor initially misdiagnosed her (telling her that her extreme tiredness was merely a symptom of being overstressed).

The doctor suggested that she take a vacation to relax and so she decided to visit her family in the U.S. where her symptoms persisted. There, she arranged for a bone marrow test and she was diagnosed with leukemia. She wondered how the northern Manitoba doctors could have missed the diagnosis; “Is it that they are not doing their job, not looking well enough, or that they haven't got the equipment up there? Would I even be here today if I hadn't gone on vacation to the U.S.?”

A breast cancer survivor wrote:

“For three months my breast was draining and I was told it was hormonal by four doctors. I had to fight to get into CancerCare. It did not show up on a mammogram or ultra-sound, but I knew something was wrong.”

Another breast cancer survivor wrote;

“I discovered a lump under my arm pit and when I went to the doctor, he told me it was nothing and sent me home. The pain continued and so after I had gone back for the third time, he finally said that he would send me to a surgeon in Winnipeg just to shut me up. Because of the placement, he couldn't remove it. I went to Winnipeg to the surgeon and she also assured me there was nothing wrong, but said she would do the biopsy anyway. Two days later my arm went numb and two weeks later I was scheduled for a biopsy. I went into the hospital for the biopsy and came out with a radical mastectomy.”

Numerous participants across all groups pointed to the appointment scheduling inefficiencies in the system. For example, oncologists often sent participants back to their family doctors to arrange certain appointments for their tests. Many of the survivors and caregivers felt that this only added to their wait times because now they had to make an extra appointment with their family physician just so he/she could arrange for an appointment recommended by the oncologist. This led to a broad sentiment that doctors are just too busy, or that they don't seem to care enough for their patients.

Average Time to Diagnosis

The reported length of time from initial suspicions to formal diagnoses ranged widely among participants across all groups, from months to years. However for the majority the wait time was several months.

Many participants were of the opinion that, the two main reasons for some of the long wait times were dismissive medical professionals and initial misdiagnoses. However, in the vast majority of cases, once the individuals were diagnosed with cancer, the next steps in the process occurred relatively quickly (surgery and subsequent treatments such as chemotherapy and radiation therapy occurring within days and weeks respectively).

Stress Experienced During the Confirmation of Diagnosis

All participants agreed that the initial stress upon confirmation of cancer diagnosis is significant: "When it happens, there is so much you have to deal with... just trying to get through day to day . . . to do all the paperwork, language barriers for clear communications, which medications to give their loved ones, etc." According to one survivor, once the diagnosis of cancer is made, "you just look at it in the face, that's all you can do. You look at it in the face, and you face it down. And it works".

By far one of the greatest causes of stress at the onset of cancer for both cancer survivors and caregivers across all groups was the wait for doctors' appointments and test results. In one Winnipeg breast cancer survivor's words: "The waiting is unbelievable stress."

Many of the participants complained of unfortunate lapses in information sharing among the different medical centres and facilities, and patient records getting lost or misplaced in the system. For example, one rural cancer survivor's pathology report never made it to her local General Practitioner from Winnipeg, and she ended up having to track it down herself. Another survivor shared the story of trying to schedule a CT scan appointment. She said she called up the doctor's office, and the nurse (after shuffling some papers for a moment) told her on the phone "Oh, that was an emergency two weeks ago".

A few patients didn't experience any breakdowns in communications, attributing their positive experiences to their assertiveness. They said that they continued to ask questions until they were satisfied with the answers. In addition, some requested copies of any reports and communications between their family doctors and specialists from their files. Many others throughout the study agreed that one has to advocate for oneself in the

system at all times for peace of mind. As one Winnipeg group participant offered, “You have to know what to ask. You must always fight for yourself to get certain tests done.”

Other causes of stress during cancer diagnosis include not knowing what questions to ask during the diagnosis stage. On top of that, many said that there was the immediate added stress of worrying about how their families will cope. As one survivor put it, “There is absolutely nothing you can think of more than looking after your kids and what they are going to do. Everything you do, washing clothes, you wonder: Do I have cancer? Do I have to say good-bye to my family?” One rural caregiver said that for her daughter (who had brain cancer) the most stressful thing was being away from her family and friends over the full course of her treatment, as paediatric cancers are only treated in Winnipeg.

Being alone and away from home for months during treatments (which typically had to be done in Winnipeg) was a stressful experience shared by many. In one rural case, a survivor felt better by having a supportive friend there to help her through the process. She also found it surprising, and stressful, to have some friends walk away from her once they learned that she was battling with cancer. Having a helpful doctor and supportive people around her, however, was a huge help.

Another rural caregiver’s source of stress stemmed from having to drive her mother who had bowel cancer to Winnipeg for various appointments thirteen times, of which three times their appointment was cancelled without their knowledge.

Participants in all groups also identified as their sources of stress during their cancer experience not hearing everything they were told by medical professionals. Some admitted that this may have been largely due to the initial shock of learning and accepting that they had cancer.

Cancer Support Services Experiences during the Diagnosis Stage

Some participants’ experiences with cancer support services were generally very good, particularly with CancerCare Manitoba, which many agreed is fantastic. Many also felt that cancer support services provided them with added mental strength to combat their disease. Numerous examples were provided about participants’ positive and negative experiences with the cancer support services.

One survivor mentioned being given a folder full of business cards of individuals available to help him. Another example was that of a councillor at CancerCare who sat with one of the survivor’s entire family during his surgery. The councillor was always available to him whenever he needed to talk. “There is so much support coming from the Central Region. I get phone calls from people all the time checking to see how I am doing,” shared the participant.

Other survivors reported having had hospital visits from CancerCare with information, pamphlets, etc. in the days following their surgery. As one survivor put it, “It was good to have someone to talk to.” A few felt, however, that the information given to them was a little too much for them at the time.

One rural survivor mentioned how much she appreciated being set up with rides to and from Winnipeg for medical appointments. “I can’t say enough about the support I am getting now”, she added.

Many in the Winnipeg group also echoed how satisfied they were with CancerCare. One survivor shared how the staff would provide her with coffee and snacks while she waited for her treatments. Another added that she finds the support groups very good. There are local support groups in Steinbach that she attends about once per month, and finds them very supportive.

One survivor in a rural group was happy when she was matched up with people who had similar experiences (through the Breast Cancer Center of Hope). She had a nurse that walked her through everything. The survivor also made really good use of what people told her, which made a great difference in her ability to make better decisions for herself.

Another survivor in one of the rural groups mentioned an information support group located across from the HSC that also has Cree staff. It’s a very nice environment, and as one caregiver added, “They calmed my mother down first and then they explained the situation to her in a way that she could understand”.

Some added that cancer clinics in both rural communities and Winnipeg are always on call, and that patients could call them anytime with any problems, such as in getting their appointments pushed ahead. Many other participants also agreed that CancerCare has been wonderful. One rural survivor mentioned that CancerCare had bought her a wig after she lost her hair from treatments, adding that “such considerate actions save a person’s dignity”.

Positive support services experiences also extended to some rural medical staff. One rural caregiver spoke highly of a nurse in the local hospital who was able to speak to her dying husband in a way that she didn’t have the strength to - “It’s up to you. Whatever you decide we are going to support you. And nobody is going to think anything of it. We just want you to be happy with the decision you make”.

Despite the generally high level of satisfaction for cancer support services, the services clearly did not reach everybody. Many rural survivors and caregivers complained that they did not receive any help outside of their family and community supports. They felt that they were left all alone to deal with their problems. There were no phone calls from anyone offering help, and many were not told about any support services available to them. A number of participants were also not provided any literature or pamphlets at the time. Some ended up having to do a lot of research on their own because they could not get enough help at the onset of their or their loved one’s illness.

Many rural participants felt that there are virtually no cancer support services provided locally, with an apparent disconnect existing between Winnipeg and surrounding rural communities. According to some rural participants, support services were available in Winnipeg only, which was unfortunately not an accessible option to many. Furthermore,

support groups in Winnipeg were perceived by a number of rural participants to be of a much higher quality than those in rural communities (e.g. Winnipeg support groups frequently have guest speakers, whereas rural area groups do not).

Not all rural areas appeared to have limited support services, however. For example, volunteers in one of the rural community's cancer departments were reportedly very good. Many are survivors themselves and therefore understand what patients are going through.

Other negative experiences with cancer support services included one rural caregiver's encounter with a phone support service where patients are linked by phone with another individual of similar experience. She tried accessing the service twice, but couldn't get matched with anyone. She also tried the CancerCare Manitoba psycho-social oncology twice, but was told both times that there weren't enough rural participants to run the group. She said she also has not heard any positive comments from others about this service

Some participants said that they weren't interested in joining cancer support groups where they would have to hear about others' heart wrenching experiences. One Winnipeg participant described her view as: "... you are no longer just dealing with your situation, but theirs as well."

One rural caregiver was very upset with care at a hospital in Winnipeg for their lack of sensitivity towards her dying mother: "Not once did they ever have good care from CancerCare, their oncologist, or the doctor that does the chemo. They are all useless with no heart." She felt that they didn't show any emotion and therefore did not care.

Adequate Explanation of the Disease, Treatment Options, and Sequence of Events by the Oncologist or Surgeon

Many participants across the groups felt that the oncologists and surgeons were very good, very informative, and told them exactly what had to be done and what to expect for side effects from the proposed treatments.

In response to the mail-out survey, a rural breast cancer survivor wrote about her very positive experience with the system:

"The explanations by each of the medical professionals that I dealt with were very complete and answered my questions. They were also very good about not overwhelming me with information about what was ahead. They gave me information about the current stage, the options I needed to consider, and the pros and cons for each. Then as we got to the next stage, once again they provided the information that I needed."

"The medical team was compassionate, supportive, and provided the information that I needed. I felt that throughout the time I was provided with excellent care and treatment."

“My family physician is also the physician responsible to the local cancer care clinic. So he always had access to the computer records of my treatment. We also had a teleconference meeting with the oncologist in Winnipeg. My family physician was present for that.”

Despite the explanations provided to patients by the oncologists and surgeons, many caregivers and cancer survivors agreed that: “being assertive is very, very important in the system and knowing what questions to ask”. They also felt that if they didn’t ask all of the right questions, they would not always get complete answers from medical professionals. One rural survivor felt that she had to push for literature on her condition. She added that in her view the most important thing with cancer is to be open about it, “Talk about it with your family and friends. You get the support and it helps you.”

In one example, a Winnipeg survivor with Stage 1 prostate cancer was very happy with the explanation of the disease and treatment options by his doctors. The doctors thoroughly explained all of the alternatives to him and then told him that he had to make a decision on what he wanted to do with the situation. They also suggested that he could go to a prostate support group, and informed him of literature about his disease. According to this participant; “Ultimately it’s up to you what you want to do.”

Some unsatisfactory experiences regarding the explanation of cancer and the implications of the disease and/or treatment were shared as well.

In Winnipeg a female survivor said that she told to her doctor that she was no longer having regular periods after ovarian cancer surgery. She asked her oncologist if perhaps she was postmenopausal and rather than explaining her situation in an understandable way, the doctor kept repeating that she was “pare-menopausal”. She was uncertain what that meant and was offered no further explanation. She felt that perhaps the doctor was rushed, or just assumed that she knew the implications of a pare-menopausal condition. Further, the oncologist avoided answering any questions that she had about whether she could have more children.

Another Winnipeg cancer survivor said that her doctors never told her about how ovarian cancer manifests itself. She felt alone, unaware of what to expect or how she might be effected. This lack of explanation by physicians was echoed by several survivors in the other groups who said that their doctors would not say anything to them or explain how they might be affected. They all wished that they could be further informed of the implications of their cancer and subsequent to their treatment. Intrinsicly, they trusted their doctor to inform them more fully of their prognosis.

English and medical language barriers widen the gap in doctor-patient relations and were evident in a few cases. In one case a rural caregiver mentioned how she didn’t think her mother really understood what her doctors were telling her about her condition and next steps going forward. The doctors spoke to her mother (a Cree-speaking woman) in technical terms that she couldn’t understand, without attempting to bring the explanations down to a more understandable level. The caregiver added that when some people “hear

all the technical terms, they will agree with them, but they won't tell them (doctors) that they don't understand".

Quality of Communication between Family Physicians and the Surgeons or Oncologists

The quality of information sharing and communication between local family doctors and Winnipeg-based medical specialists is in dire need of improvement. Participants from all groups, especially rural groups, cited numerous examples of information breakdowns between local and Winnipeg physicians and staff.

For example, one rural survivor said that his Winnipeg haematologist arranged for him to have treatments at the cancer centre in his rural community every three months. When he didn't hear back from anyone for some time after the treatments were scheduled to begin, he inquired locally. He was told that while his treatments were in their system, but the clinic had never received a confirmation from Winnipeg to begin the treatments.

In another case, a rural patient called the local cancer centre to inquire about her prescribed medication and was told that it hadn't arrived from Winnipeg yet. She never was actually informed about how much longer it would be or what the hold-up was.

There were also examples of medical professionals "passing the buck" among themselves, causing great stress and frustration among rural cancer patients. One rural cancer survivor said that because she didn't have a family doctor in her community she kept being sent to her rural cancer doctor by Winnipeg cancer specialists. The rural cancer doctor, however, would in turn tell her that he only deals with her chemotherapy, and to find a local family doctor. She was frustrated by the system.

A rural caregiver in response to the mail-out survey said she was satisfied with communications with her mother's family doctor and the surgeon, but found it almost impossible to reach or talk to her oncologist.

"Oncologists are the main line of defence. The patient and the family need to feel that there is an open line of communication. It is very difficult to get to see a doctor and it is not acceptable that when you do you have to spend hours chasing after a specialist. This time is difficult enough without all of that added to it."

Many patients and caregivers literally took matters into their own hands as a result of communicational breakdowns. As one rural caregiver shared, "You always have to make sure that the information is at the doctor that you are going to see." She added that "if not for her attending doctor to check with the oncologist, who knows how much longer her biopsy results could have been sitting on his desk and how long they had sat there already".

A rural caregiver wrote:

“My mother was hypertensive for approximately 25 years and found she was very dizzy even after having a physical exam by a local physician. She took herself off of her antihypertensives in an effort to resolve the problem. Following this she started noticing she was constantly struggling for air. Her physician sent her to Winnipeg for tests and found that her chest X-ray she had done 8 months previous showed a mass which was still present. She was not aware of the initial mass. They physicians wondered why she was not followed up sooner especially given the fact she had symptoms. It was a struggle to get her physician to listen to her concerns.”

“The physician seemed to be aware of what had happened in Winnipeg during surgery and was aware of the necessary follow up. Unfortunately there was to be a letter sent by her surgeon in Winnipeg to the Oncology department so that they could arrange for follow up chemotherapy or radiation therapy if possible. This letter was not sent and was not followed up by the family physician or the surgeon. The family called the surgeon’s office repeatedly and was reassured repeatedly that it would just take time to organize as every department was busy. When the family insisted that it be looked into it was found that the letter had never been sent due to an oversight by the surgeon.”

In another case, the apparent lack of understanding of one rural cancer survivor’s medical needs by a local hospital on call physician almost resulted in a life-threatening situation. When she developed an infection and needed IV antibiotics as a result of low immunity status, the rural physician refused and insisted instead on oral antibiotic treatment. Only on her insistence to call her oncologist in Winnipeg did they do what she was requesting.

TREATMENT STAGE

Length of Wait before First Cancer Treatment Following Diagnosis

The majority of the participants across all six focus groups appeared to have relatively positive experiences during the treatment stage and for the most part reported that the doctors and the system served them well. In some rural communities, local doctors gave patients their cell numbers and said to call anytime. For most, once the cancer was diagnosed and confirmed, everything went relatively well.

The reported wait time between diagnosis and surgery for advanced cancers was typically only days, compared to months when diagnosis was delayed or incorrect. Actual wait time for first cancer treatment tended to depend on individual situation and the type of cancer.

For example, in the case of the rural caregiver’s granddaughter who was diagnosed with leukemia, the child was put into the hospital the same day she saw an oncologist. She ended up receiving treatments for 26 months. In the caregiver’s opinion, the support was “just phenomenal” and the staff always had time to talk.

Another rural survivor reported that it took about two weeks from her first doctor's visit to surgery. She had surgery at the beginning of August, saw the radiation oncologist at the beginning of September, and the medical oncologist at the beginning of October. She also experienced no wait time at all for the oncologist visits.

One other example of relatively quick turnaround times between diagnosis and treatment included one survivor who had been diagnosed with breast cancer in May and had her surgery that same month. She also ended up doing all the radiation treatments between August and September of that year.

There were a few cases reported among the groups of unacceptably long wait times for treatments following diagnosis. For example, one prostate cancer survivor from Winnipeg had his surgery within a couple of months of being diagnosed, but because his was a "slow moving" cancer, he was told not to worry (about starting the chemo treatments quickly). As a result, chemo treatments took "weeks and weeks and weeks" of waiting for a call. His general practitioner eventually helped him schedule those appointments. Interestingly, this participant also observed that his chemo treatments could have been scheduled much sooner by the system, "When you go have your treatments every day (32 in total), you realize that they have spots that are unfilled. But they just don't bother to do it (fill them with appointments)."

A rural female patient whose oncologist's careless misidentification of the location of a breast tumour experienced severe hardship by having to undergo her five weeks of radiation treatments twice, because the first time they missed the tumour. This same patient informed the radiation oncologist and the radiation therapists that they were treating the wrong spot, but her concerns were ignored. Thanks to the staff at the local hospital, they confirmed the mistake through an ultrasound, initiated by the patient after completion of her first course of radiation. She ended up getting a different oncologist with a team of three other doctors who spent four days setting her up for new radiation treatments. The new oncologist was extremely supportive. In the end "all went well" however, she was disappointed to see that there were "absolutely no apologies offered whatsoever by either CancerCare or the College of Physicians and Surgeons. She said that the local hospital "was her sanctuary". In her own words she said, "Go with your gut, whatever you have to do. If you as a patient don't know the system, and don't know what you need to do for yourself, unfortunately, it's not going to happen."

Compassion and Support from Direct Services Staff (CancerCare Volunteers, Receptionists, Pharmacists, other Non-Medical Staff)

As mentioned earlier, the vast majority of participants felt that the direct service staff were usually pleasant and compassionate. Many said that they had nothing but positive experiences with all staff, both at their local hospital and at CancerCare.

One rural patient mentioned how wonderful the local hospital pharmacist has been for them (others from the group agreed) - "You have any questions, day or night, just phone him and he will tell you what to do. And if he is concerned about something, he will

phone you at home.” Some added that the pharmacist would come to their hospital bed after surgery to tell them what they needed to do if they were in pain.

A rural caregiver wrote regarding her mom’s experience with ovarian cancer:

“I called Health Links who directed me to Cancer Care. They were wonderful with a wealth of information and really helped out with stress. Many thanks to CancerCare for the information they sent to me. The people at CancerCare really took the time to talk and their compassion was wonderful. Always having someone there to talk to was the best.”

A few participants mentioned inconveniences experienced with the direct services staff, such as appointment scheduling (e.g. time of day; multiple appointments with other physicians scheduled over 3 days rather than one day). Such appointment scheduling was particularly hard on participants undergoing radiation treatments, who were forced to make extra trips to the hospital while “feeling awful”, or drive half way across the city for two appointments in one day.

Several participants in the rural groups also complained about their specialist appointment scheduling, where some used to have their appointments scheduled in Winnipeg every second day, rather than on the same day, without consideration of where they lived.

One caregiver wrote about her and her husband’s experience:

“The length of time between the actual first visit to the doctor and by the time the actual diagnosis was made took 4 months. Because of my husband’s age, they viewed him as an overweight male with a sore back and I feel they did not take his illness seriously.”

“I was totally disgusted in the way both me and my husband were treated. As mentioned, he was not taken seriously and we were both scared as he gradually got sicker and sicker yet at no time was anyone willing to help us.”

“The surgeon did not explain anything except that my husband was terminal and had 6-9 months to live. We both did not understand his cancer or its effects or symptoms. The oncologist did advise that there was a chemo treatment available; however it would not cure his cancer and could make him sicker. I do not believe we received an explanation.”

“We were given no information. In fact, I personally went to Cancer Care Manitoba to try getting information on my husband’s cancer and any treatment information and the woman at the desk was rude, demeaning and absolutely heartless. Any information I got was from friends and family. Not once did any cancer organization or the hospital contact us or give us any information on his condition.”

“He was not taken seriously and we were both scared as he gradually got sicker and sicker yet at no time was anyone willing to help us.”

Another rural caregiver wrote:

“My husband was then sent to recovery. When meeting the Doctor in the hallway he had asked if I had told my husband the results. My answer was, “You did it, you better tell him”. When he did there was little compassion. Neither my husband nor myself was given any information and I personally did not have a clue what pancreatic cancer was. I took it upon myself to go to Cancer Care Manitoba to try getting information. Imagine my surprise when I am greeted by a very unpleasant lady who would not provide me with any information on cancer, treatment or anything until such time as my doctor requested it. The way I was treated brought me to tears. My sister, at the time I was dealing with this, was down the hall trying to arrange for a counsellor to come and meet with both of us. She was told someone would be by later today. I am still waiting for the phone call as no one ever did contact us.”

“You will have to excuse my sarcasm however I am totally in disbelief. Our stay at Health Science center was almost a week. We were basically told go home and die and enjoy what you have left. We arrived home and were happy to see that home care had been arranged to change bandages etc. We were assigned an older lady who complained of having to walk upstairs to treat a patient. *HELLOOOO*, who is the sick one? I think that we need to start being a bit more careful of the caregivers who are tending to terminal patients.”

Level of Sensitivity of Medical Professionals (Physicians and Nurses)

Overall, the level of sensitivity of medical professionals (family physicians, specialists, nurses, etc.) tended to vary widely among participants’ experiences, with most doctors being especially supportive in getting participants scheduled as quickly and conveniently as possible after diagnosis.

With some exceptions, rural participants had a lot of praise for their physicians and nurses. Some said that their local physicians would phone them at home in the evening to see how they were doing. Nurses would also come over by the house to give needles so they wouldn’t have to come to the hospital. One participant said that her oncologist came to see her at the HSC twice after her liver surgery. In her view, “The support there (at HSC) was exceptional through it all.”

Many participants across all groups praised their family doctors for acting swiftly once they were diagnosed with cancer, helping to arrange all necessary appointments with specialists, and often speeding up the wait time for such appointments and test results.

For many of the study’s participants, however, the level of sensitivity by physicians was perceived to be significantly lower during the confirmation of diagnosis stage. Several thought that some doctors would talk down to them, instead of to them. As one Winnipeg survivor put it: “When asked a question, sometimes they just sit there looking at you like - why are you asking that question? You should know it already.” In another example, a Winnipeg caregiver’s doctor seemed to be angry when she wanted to see the test results for her sick mother.

Among participants, there seemed to be a general sentiment of being at the doctor's mercy during the process. Consequently, some participants didn't want to upset their physicians with too many questions or requests out of fear of having to wait even longer for their appointments, test results, etc.

In one example, a Winnipeg survivor observed a potentially serious lapse in medical judgement and/or ethics on the part of one Winnipeg physician. According to him, a doctor who wanted to add him to his prostate cancer research database told him that he could only do so if he (the participant) stopped carrying his nitro (the participant had also suffered two heart attacks in addition to his bout with prostate cancer). This doctor went on to tell him that he did not need his nitro anymore, without having ever seen any of the participant's medical records.

Several participants in the rural groups expressed even stronger negative feelings towards some local physicians, labelling them as "very indifferent". One caregiver even said that it was hard not to feel that they were being treated so indifferently because of their ethnic background (aboriginal). When this caregiver's brother was released from the hospital despite having a low white cell count and fluid in his lungs, she wondered: "Would another person have been treated differently?"

In another extreme case of insensitivity, one rural caregiver's husband who suffered from an inoperable and terminal pancreatic cancer returned to the hospital in their rural community was told by the medical staff on a daily basis, "Do you realize you are dying?" Furthermore, because he was dying, the staff at the local hospital would leave all care for him up to his wife (e.g. leaving his false teeth in his cornflakes, with her husband laying half out of his bed). In the caregiver's experience the rural community hospital where her husband spent his last days was the most horrid, and she doesn't wish it on anybody else. "There wasn't a single person that had anything positive to say to him. To them, he was just a dying man."

Another rural survivor summed up her experience through the mail-out survey:

"The most frustrating aspect has been transportation to and from Winnipeg as I live in northern Manitoba. The RHA has criteria that you must meet before you qualify for an escort or air travel and I must say it is a well kept secret and in the end you rely on your doctors judgment call...For myself personally I have a husband who has MS and can't drive for long periods of time; therefore he has been unable to accompany me on my trips to Winnipeg (as we weren't given the flying option). I have had to rely on other family and friends for companionship. This in itself has been hard because you need your partner with you at these times."

"The other frustration has been the lack of concern from staff in the local clinic and the Patient Office at the hospital. They forget that you are flesh and blood with a beating heart, they lack the sense that you are afraid, sick, confused, overwhelmed and yet they act like you are bothering them. On two occasions I have left the clinic and the Patient office and cried."

“The Breast Health Centre in Winnipeg should be the mould that all clinics, hospitals, health care professionals, etc try to emulate. From the moment that you walk in the door you are treated with compassion, respect and at no time do you feel like you are wasting their time!”

Challenges / Inconveniences Faced

A wide variety of different challenges were identified across the six focus groups. The main challenges faced by both cancer survivors and caregivers included stress on other family members, financial burdens, the feeling of loneliness from lack of available support services in some rural communities, and of having no choices.

A rural breast cancer survivor wrote;

“I had three young children at home and the stress of worrying about them was as bad as the cancer. I had no support from family or friends and so had nobody to take care of my children. I had to place them with CFS and that just about did me in. I was placed with them for five year when I was small and it was not a good experience, so placing my children there was terribly hard. I had no choice though.”

In terms of stress on other family members, many of the cancer survivor participants agreed that their families worried much more about them than they did. As a result, the stress of dealing with cancer is often much greater with the caregivers than the patients. In one Winnipeg participant’s view, cancer diagnoses are much harder on spouses than one realizes: “Talking helps, rather than keeping things inside.”

In addition, a challenge widely identified across all groups was the financial burden of living with cancer, adding to the stress and other uncertainties of being diagnosed or having a loved one diagnosed with cancer. A few felt that their doctors changed their treatment medications without much regard for their high costs. From one Winnipeg caregiver’s perspective, the government is just horrible with their financial support. Her mother went 3-4 months without any income at all after being diagnosed. She was cut off from employment security and then had to wait, filling out a mountain of forms before being finally approved for disability. She is still waiting to be reassessed for PharmaCare for eligibility.

A rural breast cancer survivor wrote:

“I found it extremely hard emotionally being away from home. My mother was elderly and not able to be with me. She came for the surgery, but I was left alone to deal with the remainder of the treatment. It was very lonely and difficult at times. I had to stay at Lennox Bell for six weeks for my radiation and even though it was expensive I flew home every weekend as I felt I needed to be with family, friends and familiar surroundings. That was what kept me going.”

“It was stressful and difficult as I was pretty much on my own and I worried about my elderly mother who had to deal with things at home.”

“I truly believe we need to have more mammogram machines in the province. We need one in our community. There are enough people in the area to more than justify it. I am finding it difficult travelling to the Winnipeg for my annual test (I have rheumatoid arthritis). All women, no matter what age should be able to have a mammogram. The earlier the cancer is detected the better.”

For one rural patient, during the time of her diagnosis, there were no support services available locally at the time. When they moved to Winnipeg after diagnosis, they didn't know anyone. This was extremely hard particularly on her children and husband. She had a social worker helping her out until she learned that the social worker was misinforming her children about her illness and what she could/could not do as a result of her condition. She felt that some of the support services staff was insufficiently trained to handle certain medical situations.

In response to the mail-out questions regarding supports, one rural survivor wrote:

“No stranger could understand the emotional pain I was experiencing. I did not need platitudes. Friends who cared personally and knew my story were a more comfortable choice. I have however used the social services after the trauma of treatment was completed.”

“I did not work for a year while taking cancer treatment. I think I have had a general drop in energy. Now my job is almost extinct due to business failure and it is difficult to sell one self when one knows the full energy isn't there.”

“Concerns about depressed immune system and having to go into public places for groceries, social connections, hospitals and clinics were sick people gather. I was more relaxed going to get an oil change than going to medical places.”

For survivors one of the biggest challenges when faced with a life-altering situation like cancer is the feeling of complete loss of control over one's life. One Winnipeg survivor felt like she had no choice in anything, from being unable to see an oncologist closer to her home, failing to qualify for EI, to being unable to keep her special needs children in the *Kids Can Cope* program during her treatments. She added that the system would not even let her switch to another oncologist in the future given that she was almost six years past her diagnosis.

In addition, a challenge that kept being discussed throughout the sessions was the need for: “... having somebody there to fight for the patient, when the patient can't do it.” As one rural group participant put it: “Really chase your doctor, and really get him on to things”.

One northern female survivor wrote in response to the mail-out survey, “The pills I got gave me blisters all over my hands and feet so I had to stop taking them. My family and I

suffer financially, which causes more emotional problems and stress. My children and grandchildren are so worried about me. My sisters though, have already given up on me and are just waiting for me to die. I would like to see better planning and treatment options and more assistance with all the travelling and the hardships associated with it.”

Other challenges mentioned by participants in the study included:

- Being looked at or treated differently by peers and friends during and after cancer treatments;
- Being away from family and friends for extended periods of time during treatments;
- Local family doctors not understanding cancer patients’ unique medical situations and wanting to treat them in ways potentially dangerous to their health.

Some participants reported no significant challenges or inconveniences during their battles with cancer. For these individuals, having overwhelming support from their families and especially spouses, friends and in some cases the local community was key to their overall well-being. Some were also satisfied that they received good all-round support from the health care system.

Financial Impacts

The vast majority of participants reported having been effected financially to some degree by their illness, both during and after treatment. While many were able to get some of their “out-of-pocket expenses” back from income tax exemptions, some incurred costs that could not be recovered. Major financial out-of-pocket costs incurred by both caregivers and cancer survivors were:

- Travel costs to and from Winnipeg for tests and treatments.

One rural caregiver counted a total of 32 trips to Winnipeg for her husband’s treatments. Another rural survivor had over seventy chemo treatments and as many radiation treatments, all of which were in Winnipeg. One female survivor reported having to drive five hours every day to get her 15-minute radiation treatment. She underwent twenty-eight treatments in all, with no reimbursements for any of her travel costs. Other rural participants said that they had “lots” of trips, sometimes too numerous to count.

Anyone that used the transportation services provided by the Canadian Cancer Society or the South Central Cancer Resource Center is forever grateful to receive the service. In fact, some said that without this service they would not have been able to get the care that they needed.

- Prescriptions drugs and treatments not covered by the province, but recommended by cancer specialists.

According to many of the rural participants, drug costs are astronomical (e.g. \$413/week for one participant, \$4,000/month for another). While chemo and hormone replacement therapy (if injectable) is covered by the province, oral chemo costs are not and can “bankrupt you quickly”. Some of the anti-nausea drugs are also not covered by the province.

Some of the participants also reported requiring drugs not yet approved by the Manitoba government (e.g. Avastin). As a result, their drug costs were not covered by the province and had to be purchased from personal sources. While some of these drugs can be made available through research programs, they are typically available to patients only for a limited time.

- Accommodation costs in Winnipeg for rural cancer caregivers and survivors.

Accommodation costs in Winnipeg were widely cited by rural cancer survivors and caregivers as being very expensive during periods of treatment (which can last weeks). Commuting long distances during treatments is not an option for rural cancer patients because the treatments make the patient too weak and ill physically to travel home even on weekends. Some participants reportedly tried staying at Lennox Bell for a while, but the facility is very small and patients have to cook their own meals and go shopping on their own. This is fine when patients are feeling well, but is very difficult to do when feeling sick. The only other option for those with no family or friends to stay with in Winnipeg is to stay in higher-end hotels with room service. The minimum rates, however, tend to be around \$100/night. When you have to stay there for eight weeks, the costs really add up.

Other financial impacts mentioned by many included lost income and wages from personal businesses (which had to be shut down in some cases) and participants’ places of employment. In a number of cancer survivor participants’ cases, patients were unable to resume full-time work following their treatments. Others weren’t able to perform their previous job anymore and had to look for work elsewhere.

A rural caregiver wrote:

“Financial impact, emotional impact and side effects for drugs were very dramatic. The cost of the drugs initially was phenomenal. I had group insurance; however once I went over the limit they made me fight with Manitoba Health. Fighting over money during such a time is not acceptable. The financial impact was great due to special diet, travel etc. The side effects of the drugs were horrible and expensive. It seemed we were constantly getting prescriptions to counter act medications to keep reducing side effects.”

“Transportation cost and distance were a major issue. We were 6 hours from the city. I had to take time off work to be a care giver and was very fortunate that I had banked vacation leave. Obviously money was an issue for drugs, travel, normal living expenses as we were now only living off of one income.”

Another rural caregiver wrote:

“Extra expenses included my Father staying in Winnipeg in a hotel while my Mother was in hospital having her surgery and recovery. This included hotel costs, meals, cab rides (as my Father was not comfortable with city driving), parking for his vehicle at the hotel. There were also many long distance calls as my Father did not feel he would understand the medical staff’s explanation of my Mother’s progress so therefore I called the hospital for a report every morning and called my Father to give him progress updates before he went to the hospital.”

“It is expensive to travel and stay in a community (such as Winnipeg) when you are from rural Manitoba. Hotels, meals, travel and time off work all add up to be cost prohibitive to provide support. Even if you live in a community close to Winnipeg it is expensive to drive back and forth to provide support for your family member. Providing assistance or more inexpensive lodging for family members would be a start. This could be in the form of income tax deductions for medical expenses incurred for family members who do not live in your home.”

Several participants also reported having to dip into their personal savings and RRSP’s to pay for some of the out-of-pocket expenses, especially for much needed drugs. One rural cancer survivor participant personally incurred \$36,000 over three years for his treatments. His community also rallied behind him and offered tremendous financial support to alleviate some of the burden.

A colorectal cancer survivor wrote in response to the mail-out questionnaire:

“I have been very fortunate to have had great support from family & friends as well as a reasonable knowledge of Cancer because of 20 yrs as a volunteer with the Canadian Cancer Society. My side effects where not too severe and I quickly got involved in a Colorectal Cancer support group that provided information and was very helpful.”

“Financially, the treatments have been extremely difficult, because Manitoba Health refuses to pay for the Drug, AVASTIN, which was prescribed by my Oncologist, February 2007, and approved also in Feb. 2007 by CancerCare Manitoba, subject to budgeting approval. To date I have paid out approximately \$24,000 for the drug and am faced with further costs of between ten and twenty-four thousand dollars as I now start a new series of treatments. I have written numerous letters to the Provincial Health Minister and CancerCare Manitoba and although results across Canada and throughout the medical world suggest Avastin helps prolong the life of Colorectal Cancer patients, they refuse to support the use when requested by their Oncologists. I feel that I am being treated as a second class citizen, because I live in Manitoba.”

A rural breast cancer survivor wrote:

“I had met a man and he had tried to help me. It was really hard for me because he had a sister dying from the disease as well. He was a farmer and sold his land to help me. When the income tax came along and we claimed my expenses, \$14,000, they refused them. I had to get the receipts, list where I had gone, what time of day it was, where it was, how long the appointment was and who took me. After five years, we won and got the income tax back. The point is we had to pay it first at a time when there was nothing to pay it with. I still am unable to deal with the fact that someone lost their land because they were helping me.”

“Living four hours from Winnipeg made it very hard for me to manage financially to get there. Sometimes my appointments were within a day or two, but mostly three or four. If I had to stay overnight, that added even more stress trying to afford a place. When someone had to go with me, I would ask if they knew someone we could stay with so that I didn’t have to pay a room. It was one thing for me to sleep in a vehicle, but I couldn’t ask someone else to do that. I had enumerable problems trying to find someone to look after my children, especially when it came to paying them, it was overnight, involving school, homework, meals and behavioral issues. Money was at a point where I often thought of going to bed and never getting up. This extra stress place a pile of extra stress on our relationship.”

A number of Winnipeg organizations and services, such as HSC shuttle, the Lennox Bell Lodge, and the Ronald MacDonald House offer subsidized rates to cancer patients who have nowhere to stay in town. As mentioned, however, there are limitations to some of these albeit generous gestures.

In general, participants from across all groups felt that no provisions really exist to regain many of the cancer-related out-of-pocket costs incurred. The tax deduction benefit is highly inadequate and does not address the fact that many cancer-related expenses must be incurred immediately. The financial supports that do exist are nowhere near sufficient to cover all of these expenses. In some cases, the financial burden placed on cancer patients and caregivers resulted in personal bankruptcies and even the need to go on social assistance.

SURVIVORSHIP STAGE

Long-Term Impacts of Cancer Diagnosis and Treatment

Cancer experience tended to affect everyone’s entire life following treatment. In addition to always wondering if the cancer is back, survivor family members also had to deal with the after affects in their own ways. According to many, the tolls on families are “heart-wrenching”.

One Winnipeg caregiver participant said that she can't imagine what it must be like for her dad losing the love of his life after being with her mom for 43 years. In tears while holding her nursing child, she added, "My mom will never know my daughter. To those working at CancerCare, they forget this. You are just another number on the board. They have to remember that you are a person, you have a heart, you have feelings, and it's OK to show that you have a heart too (staff at CC)."

Fatigue and huge strains on family relationships were frequently mentioned. Many participants across the groups agreed that the experience is ultimately much harder on the family than the patient. The emotional roller coaster seems to be much worse than the treatments. Many of the caregivers would end up feeling guilty after a while that they should be doing more for their loved ones. Meanwhile, the patients often feel like they are being a nuisance to their families.

Several participants felt anger and frustration over their experience with the system, stemming, for example, from their disfigurements, in particular among breast cancer survivors. One breast cancer survivor added that because she was over sixty, the surgeons decided against giving her an implant after surgery.

There was also the worry among some participants that after a number of years of survival, they will be dropped out of the system. Closely tied to this worry of abandonment by the system was the belief that as cancer survivors the participants must continue to be assertive with the system, literally demanding to have certain tests done as part of their routine check-ups (e.g. mammograms and pap smears). There was a general sentiment that cancer survivors should not have to constantly remind their health providers to monitor their remission if they had had cancer in the past.

Impacts on Caregivers

Many rural caregivers complained about the high cost of transportation. Both urban and rural caregivers alike reported a partial loss of income, either due directly to their care for their loved ones, or through a fall of productivity by being unable to focus on their work.

Emotional impacts were also significant. As one caregiver put it, "Everybody handles these situations differently, but you have to get through it." Many caregivers mentioned how their community rallied behind them, for example by bringing meals to their house. Among rural participants, community support was seen as a huge benefit to being in a small town, especially when being far away from any cancer support services.

All caregivers across the six groups also suggested that strong moral support was important. As part of their community support, one rural caregiver mentioned that a nurse would come to their house once per day to see her husband and help with his care. Another rural group participant said that they have established their own palliative care group in their town, important especially to those without family support. This comment highlighted a significant need among rural cancer caregivers for professional support services designed specifically for caregiver needs.

For many caregivers, the focus group sessions seemed to be difficult as they told their stories and wept openly remembering their losses, yet therapeutic with the support of others in the room that had also lived through similar experiences.