



Key Informant Interviews

A VIEW FROM THE FRONT LINES

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I. Executive Summary

This report is the second phase of a project undertaken by the Manitoba divisions of the Canadian Cancer Society and Canadian Cancer Action Network. The goal is to develop a five-year action plan to address the financial hardships suffered by a significant minority of people with cancer and their families. This report is rich in examples that expand our understanding of the issue and support the findings of the literature review conducted in phase one. These insights will help point the way to practical solutions involving all segments of society.

The key informants for this report were chosen for their expertise and experience in cancer care, from diagnosis to palliation. They represent a variety of health care providers working in a wide range of disciplines in urban, rural and northern Manitoba. They include professionals from a centralized cancer treatment centre, community-based cancer treatment programs, hospitals and two First Nations communities.

It is important to understand that this report represents a qualitative analysis of the personal views and opinions of these health care providers. They volunteered to be interviewed and their views do not represent the official view of the agencies that employ them. In addition, it should be noted that their perceptions of current policies and practices may not be completely accurate. Where possible, the writer has identified potential misunderstandings of program or system policies, and has made an effort made to research and footnote the official policies and practice of the programs referenced.

The interviews convey the sense of helplessness and frustration that clinicians, families and individuals may feel when faced with an unexpected and devastating diagnosis and the financial circumstances that follow.

Personal Risk Factors

Although not statistically proven, there is general agreement among the key informants that multiple risk factors contribute to the risk of financial hardship due to cancer. These perceptions are supported by the literature review.

Those who may lose more income and experience higher out-of-pocket costs include:

- Young adults
- Parents with young children
- Rural residents

An individual's financial risk may also be affected by:

- Age
- Gender
- Occupation
- Employment status
- Access to benefits
- Treatment modality

- Type of cancer

Also at higher risk are those who are:

- Socially isolated
- Suffering from mental illness or addictions
- Single parents
- Struggling with English as a second language

Cost Drivers

Financial hardship can be significant and, in some cases, devastating when medical worries are compounded by:

- Loss of income for both the person with cancer and the primary caregiver
- The cost of:
 - Transportation and accommodation
 - Chemotherapeutic and supportive medication
 - Medical equipment and supplies

Systemic Factors

When people do not get the right care and assistance at the right time, it is more costly for them and for the system in the long run. The key informants cited many opportunities to ease the financial stress on people with cancer and benefit society as a whole:

- Public programs for income replacement could be more effective if they were more flexible and accommodating of circumstances where people deal with sickness at varying levels over a prolonged period. These assistance programs have not kept pace with the realities of living with cancer today.
- Coverage for drugs and medical supplies could be improved by eliminating inconsistencies and updating the rules to better align with contemporary cancer treatment.
- Better co-ordination could increase efficiencies within the health care system for both people with cancer and those providing services.
- Northern residents, including First Nations, Inuit and Métis communities, face unique financial challenges when they are diagnosed with cancer.

Solutions

The key informants agree that all sectors of society will need to work together to address these issues. They provided a number of creative ideas and recommendations, which are summarized in Section VIII of this document.

Many professionals in Manitoba's cancer care system see the value of a rehabilitation focus involving an interdisciplinary approach to improving quality of life throughout the cancer journey. Further development of this approach to care could help to address many of these issues.

Other possible solutions involve:

- Improvements to income replacement programs
- Better communication of the assistance programs available to people dealing with cancer
- Person-centred co-ordination of services in the health care system
- Increased access to home care and/or hospice and palliative care beds
- Greater awareness of the problem among health care providers, people with cancer, their families and society as a whole.

II. Acknowledgements

Thanks to:

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- *Kim Morrissette*, Aboriginal Services Project Co-ordinator, CancerCare Manitoba, for referral to contacts working with the Aboriginal population.

Sincere appreciation goes out to each of the 25 key informants who took time to do the interviews, read and correct the transcripts and answer my never-ending questions. I was inspired by their dedication to the people they serve in their work and their desire to improve the quality of life of people with cancer.

- *Annie Osada*, Home and Community Care Case Manager, Sandy Bay Health Centre;
- *Barb Hues*, Primary Nurse, Haematology Clinic, CancerCare Manitoba;
- *Bunty Anderson*, Psychosocial Clinician, Patient and Family Support Services, St. Boniface Unit, CancerCare Manitoba;
- *Candace Myers*, Speech and Language Pathologist, Patient and Family Support Services, CancerCare Manitoba;
- *Carol Boscow*, Pharmacist (recently retired), The Pas, Manitoba;
- *Cathy Bourne*, Paediatric Oncology/Haematology Nurse Clinician, CancerCare Manitoba;
- *Cindy Hart*, Director of Health, Fisher River Cree Nation Health Centre;
- *Dr. Cornelius Woelk*, Community Cancer Care Family Physician, Boundary Trails Health Centre, and Regional Director for Palliative Care for the South Central Region;
- *Dr. Brent Schacter*, Oncologist, CancerCare Manitoba;
- *Dr. Mike Harlos*, Medical Director, Winnipeg Regional Health Authority Palliative Care Program;
- *Dr. Sri Navaratnam*, Head of the Department of Medical Oncology and Haematology for CancerCare Manitoba and the University of Manitoba;
- *Garnet Bond*, Home and Community Care Nurse, Sandy Bay Health Centre;
- *Gayle Nickol*, Primary Nurse at the Prostate Centre, CancerCare Manitoba;
- *Joanne Roulette*, Health Director, Sandy Bay Health Centre;

*View from the Front Lines:
A Discussion of Issues Related to the Financial Hardship of Cancer in Manitoba*

- *Jill Taylor-Brown*, Director, Patient and Family Support Services, CancerCare Manitoba;
- *Kim Paradoski*, Primary Nurse for the Brain Tumour Clinic, CancerCare Manitoba;
- *Mandy Armstrong*, Assistant Health Director, Sandy Bay Health Centre;
- *Megan McLeod*, Supportive Care Co-ordinator, Community Cancer Program Network, CancerCare Manitoba;
- *Nadine Volanski*, Manager, Burntwood Health Region, Community Cancer Program;
- *Orit Reuter*, Oncology Social Worker, Health Sciences Centre and CancerCare Manitoba;
- *Sylvia Maytwayashing*, Medical Transportation, Sandy Bay Health Centre;
- *Tracy Robinson*, Clinical Nurse Specialist Blood and Marrow Transplants, CancerCare Manitoba;
- *Venetia Bourrier*, Director of Pharmacy, CancerCare Manitoba, and Director, Provincial Oncology Drug Program;
- *Virginia Kukianchuk*, Home and Community Care Co-ordinator, Sandy Bay Health Centre; and
- *Wanda Murdock*, Community Wellness Worker, Fisher River Cree Nation Health Centre.

A special thank you is extended to *Jill Taylor-Brown*, Director, Patient and Family Support Services, CancerCare Manitoba. Without her extensive knowledge of the issues, unwavering support, patience and encouragement, this report would not have been possible.

III. Introduction and Process

Key informants were initially approached by email in April 2010. This initial contact was followed by a telephone contact and a full interview. The majority of interviews were done in person, with seven being conducted by telephone. All but two of the interviews were recorded on a digital tape recorder as notes were taken. The highlights of each interview were documented and sent to each key informant for approval and editing in August 2010. Only information from the approved documents was analysed to develop the themes in this report.

It is important to understand that this report represents a qualitative analysis of the personal views and opinions of the health care providers interviewed. The information provided by the key informants does not necessarily represent the official view of the agencies that employ them, and may not be completely accurate. Where the writer has identified potential misunderstandings of programs or system policies, an effort was made to research and footnote the official policies and practice of the programs

referenced. However, the information presented by the key informants is their perception of policy and practice as health care providers working in the field.

The interviews paint a picture of the helplessness and frustration clinicians, families and individuals may feel when faced with an unexpected and devastating diagnosis and the financial circumstances that follow. This report is not intended to decisively answer questions of individual responsibility versus system or community responsibility. It is intended to help us recognize the issues as understood by health care providers on the front lines and to seek a range of solutions to these issues.

The findings both support and enhance those found in the literature review. They describe some of the factors that place people at risk for financial burden, the extra costs for individuals and families associated with a diagnosis of cancer, the loss of income that often accompanies the treatment and caregiving of this disease, the systemic issues that contribute to financial hardship and the impact that financial hardship has on these individuals and their families. It helps to identify issues and gaps in the health and social services systems and offers potential solutions for this complex issue.

IV. Risk Factors for Financial Burden

The key informants identified specific groups of people who are at a higher risk of incurring financial burden and several factors that can contribute to that risk. If more than one risk factor exists for an individual, the financial stress is compounded and it may be impossible for the individual to recover their former financial status.

1. Parents with Young Children

Parents at risk fall into two groups: those who have a child with cancer and those where one of the parents has cancer. Both of these situations increase the risk of financial burden.

Parents with young children, particularly lower-income families, are susceptible to financial stress as they incur costs due to cancer, as well as their basic living expenses. They are at an increased risk if they live paycheque to paycheque and have mortgage and/or car payments, a high debt load, no private medical insurance and no savings.

Loss of salary becomes an issue for parents of a child with cancer as one, and sometimes both parents, leave work for an indefinite period of time to care for their child. Single parents are at greater risk if their child develops cancer.

“We have had instances (with children with cancer) where both parents will stay working because they have to. One will work days and the other nights so there is always someone with the child. However, this takes a huge toll on the whole family. We have parents of a little one now who did this – one worked until 4 a.m. and then the other went to work at 8 a.m. Now they have both taken a leave of absence because their child is not doing well.”

Key Informant

The key informants noted other financial pressures that parents of a child with cancer may feel. For example, holiday and birthday presents have a far greater meaning during a difficult time, and the parents may not have the discretionary funds for gifts, vacations or extra-curricular activities. When family budgets are tightened as a result of a cancer diagnosis, activities like dance, gym, hockey or music lessons are no longer deemed essential.

Parents who have cancer may need child care on a short-term basis to attend appointments or until they feel well enough to care for their children. Other than privately, or through existing day cares, there is patchy access to child care. Home care will provide short-term relief for parents caring for their sick child, but will not provide care for children if the parent is the client.¹ In Winnipeg, the Family Centre offers hands-on help with kids, cleaning and counselling services that are provided on a sliding scale based on income. The cost may be reduced or waived if needed. However, there is a three to six month wait list for daily support and the wait for evening/overnight and weekend help is up to a year.²

If long-term child care is needed, due to financial issues or a parent's health, and the parent cannot make adequate provisions for the care of their child/children with other family members, the parent may approach Child and Family Services and enter into a Voluntary Placement Agreement. Guardianship of the child is not transferred with the understanding that, when able, the parent will resume care of the child.³ In the interim, the child is placed in a licensed foster home or child care facility.⁴

A parent with cancer, or parents of a child with cancer, may incur significant costs in the area of child care, housekeeping and respite if:

- One parent is working and the other is ill and unable to take care of the children
- The parent with cancer must attend treatment, monitoring or other medical appointments
- The person who is ill with cancer is a single parent
- Child care is needed for siblings while the parent takes the child with cancer to appointments
- No relatives or friends are available to care for the children.

For those in critical need of help with housework and meals, Homemaker and Parent Aide Services are available through child and family services agencies, according to the provincial government's administrative manual.⁵ For example, Child and Family Services of Western Manitoba has a program that provides in-home care for the children of a family in crisis when other family members or friends are unable to help. The children are kept together in their own home with a qualified caregiver while the family deals with their problem situation.⁶ Agencies such as the Child Protection Agency (Manitoba),

¹ Phone interview with Cindy Shantz at Homecare on Mar. 17, 2011.

² Manitoba Family Services and Community Affairs (<http://www.gov.mb.ca/fs/cfsmanual/1.2.5.html>)

³ Manitoba Family Services and Community Affairs (<http://www.gov.mb.ca/fs/cfsmanual/1.2.5.html>)

⁴ Manitoba Family Services and Community Affairs (<http://www.gov.mb.ca/fs/cfsmanual/1.4.2.html>)

⁵ Manitoba Family Services and Community Affairs (<http://www.gov.mb.ca/fs/cfsmanual/1.2.4.html>)

⁶ Child and Family Services of Western Manitoba (<http://www.cfswestern.mb.ca/>)

Métis Child and Family Services and various First Nations child and family service agencies will provide emergency or short-term child support if a child's safety is at risk.⁷ However, finding information on the delivery of these services may be difficult for parents who are not otherwise involved with the child and family services system.

Child care, house cleaning and meal preparation are available to people willing and able to pay for it privately. But those already experiencing a financial burden as the result of a cancer diagnosis are unlikely to have any money for non-essentials. Some people receive child care and housekeeping from friends and relatives. However, key informants tell us that often those most at risk of financial burden are individuals who do not have a circle of family and friends to fill these gaps.

According to key informants, it is common for families to rely on credit cards during financially stressful times. If the family is only able to make the minimum monthly payments, the use of credit cards may contribute to long-term debt.

"I know of a young woman with cancer. She has four children (10 years and younger) and gets a number of her treatments in the community. She and her husband have faced a number of challenges. In this case, we have pushed the envelope in terms of providing the care that this woman needs in the community. We see her frequently in our centre and she doesn't have to come to Winnipeg very often. We were really not aware of the financial struggle of this family until a nurse visiting the home just prior to Christmas asked one of the children, 'Are you waiting for Santa?' This patient's husband then said, 'Shhh – don't talk about that. There isn't going to be a Santa this year.' This was one that really slipped under our radar. This family was just plugging along, doing the best that they could, getting some disability support but not able to express the degree of financial difficulty that the family was in."

"Siblings have activities at school and otherwise, and often the family can no longer afford these extras because the money has to be divvied up differently."

Key Informants

It was pointed out by one key informant that children who are dying of cancer have access to things like the "Make a Wish Foundation" that will support them and their family to take a special trip. However, there is no such program available for children where one parent may be dying of cancer.

2. Rural Residents

Rural residents face a number of challenges. All the key informants recognize transportation and accommodation for rural Manitobans as a significant cost that Winnipeg residents do not incur. And, because there is no limit on this cost (e.g. no deductible as with Pharmacare), it may not take long for these costs to exceed the costs of

⁷ Manitoba Family Services and Community Affairs (<http://www.gov.mb.ca/fs/about/org/csd/wcfs.html>)

medications.⁸ The health care system needs to be cognizant of the toll travel and accommodation takes on rural people.

For rural residents living in northern Manitoba, there is the Northern Patient Transportation Program (NPTP). The subsidy for travel is based on the bus rate from communities served by roads and may include costs for an essential escort (as required for an infant or disabled person).⁹

According to NPTP guidelines, participants should use public transportation (bus, train, or airplane) as their method of transport. However, if an individual is unable to travel by bus due to discomfort or a compromised immune system, they may need to travel by car, which is listed as a secondary option by the NPTP. The participant will be reimbursed for travel using their own vehicle, at a rate equivalent to the cheapest available public transportation.¹⁰ This funding is provided only after the individual has made the trip and does not take into account the wear and tear on the vehicle. Some individuals have difficulty paying for gas or necessary car repairs before reimbursement.

“There is a mindset around this (transportation costs for rural residents) that needs to be changed. It is a system change that is needed. There needs to be more awareness of the increased costs and accompanying loss of income faced by rural patients.”

Key Informant

Rural residents often need to relocate to Winnipeg at some point during their cancer journey. If so, they incur an array of additional expenses including gas, wear and tear on the vehicle, the cost of bus or air transportation, accommodation and food. These costs are exacerbated by the loss of salary if the person with cancer (and their caregiver) has to take time off work to travel.

“I don’t think that rural Manitobans should be punished for living there when they get cancer. There should be some grant money provided. Perhaps not everything covered but the Manitoba government does provide assistance for people who have to go out of province for treatment. In the same way, they could provide assistance for people in the rural area to get to Winnipeg.”

Key Informant

Efforts are being made to make the cancer journey a less literal kind of journey. Cancer Care Manitoba has 16 active Community Cancer Care sites across Manitoba, enabling people in rural areas to be diagnosed and treated closer to home. As well, Telehealth (a video network set up to facilitate communication between rural and urban health sites) is

⁸ Two studies found that for people with cancer, travel was a significant categorical cost and exceeded all other costs. Longo, C., Deber, R., Fitch, M., Williams, A.P. and D’Souza, D. (2007) and Mathews, M., West, R. and Buehler, S. (2009)

In an effort to reduce travel-related costs, people with cancer may choose a radical form of treatment, such as women with breast cancer choosing mastectomy over breast-conserving surgery. Longo, C., Fitch, M., Deber, R., Williams, A.P. (2007)

⁹ Manitoba Health Emergency Medical Services (<http://www.gov.mb.ca/health/ems/nptp.html>)

¹⁰ Employment and Income Assistance Administrative Manual (<http://www.gov.mb.ca/fs/manuals/eia/22/>)

used by some providers to reduce travel for people with cancer. CancerCare Manitoba also tries to cluster tests and appointments for people from rural areas in order to minimize the length of stay in Winnipeg or Brandon.

In Manitoba, at the time of the interviews, radiation therapy was offered only in Winnipeg. Treatment is still solely available in Winnipeg for children with cancer, most people with acute haematological cancers and those undergoing intensive treatment (e.g. a bone marrow transplant) or multiple treatment modalities. In such cases, relocating to Winnipeg for the duration of the treatment is necessary. Unfortunately, there is limited affordable accommodation in Winnipeg for people with cancer, especially adults. Some people are not well enough to stay in Lennox Bell (for adults) or Ronald McDonald House (for children). They may be too immune-compromised or feel ill when they smell food cooking.

Certain types of cancer incur more financial hardship than others due to relocation costs. For example, an individual who undergoes a bone marrow transplant will have to relocate to Winnipeg for at least 100 days¹¹ and there may be frequent trips to the city afterwards. The individual will need a caregiver and must pay for food, laundry, accommodation, phone bills and other provisions needed for a three-month stay in the city for themselves and their caregiver.

“I know of an older patient from Swan River who can’t drive. So every time he needs to come into Winnipeg for an appointment, his daughter has to take time off work to drive him...plus their travel expenses. Even if you can claim your mileage, there are still expenses that you can never recover.”

“I know of a family from the North whose child had leukemia. They spent three years travelling back and forth to Winnipeg. The child subsequently died. The costs associated with their child’s illness were financially devastating to the family. Their net family income was virtually nil. They had to look to their community to fundraise. After their child’s death, the family set up a trust fund to help other local families in similar situations with their expenses. They fundraise on an annual basis to keep this fund going. With children, the parents or at least one parent must be at every appointment and every treatment and everything is a trip. This takes a huge toll on families.”

Key Informants

¹¹ The 100-day mark, which is 100 days post-transplant, is generally considered a milestone. By this time, the individual is considered past the worst of the procedure and on the path to recovery. Bone marrow transplant recipients need physician supervision until the 100-day mark for an optimal chance at recovery. Paediatric Oncology Resource Center. (<http://www.ped-onc.org/treatment/BMT/BMT.html>)

“More bed and breakfasts and reasonable accommodations are needed in the areas around the teaching hospitals. We need to look at this need in terms of the percentage of beds at the Health Sciences Centre and St. Boniface hospitals that are used by rural people. You can’t just have one Lennox Bell – you need to have more than that. It would be good to have apartments that are available for rent on a monthly basis, much like a Holiday Towers.”

“There is an apartment in the Harry Medovy Apartments called Will’s Place that is completely furnished and was given in memory of a child by their family. However, this is not free. The cost is more than \$1000/month and it is mainly used for families whose child is having a bone marrow transplant. However, it often sits empty. The paediatric oncology social worker expends a significant amount of time assisting families in trying to obtain funds. We have about five to seven patients per year who require a bone marrow transplant. These children are six to eight weeks in hospital and may be seen at clinic daily for an extended period of time after their transplant.”
Key Informants

One key informant noted that seven or eight years ago, when radiation therapy resources were extremely stressed, the Manitoba government paid to send patients to Grand Forks or Fargo. In addition to paying for the treatment, travel and accommodation costs were paid for the individual and one family member. Most of the patients willing to travel to Grand Forks or Fargo for treatment were from areas outside of Winnipeg. Rural people perceived this as an opportunity to get the treatment they needed and also to have their travel and accommodation expenses covered, which would not happen if they traveled to Winnipeg.

Manitoba is one of only a few provinces in Canada that offers assistance to help cover transportation costs related to receiving medical care outside of the province. The Manitoba Out-of-Province Transportation Subsidy Program offers financial assistance to help reduce costs, but is not designed to cover 100 per cent of an individual’s expenses.¹²

For example, people with carcinoid tumours are sent to London, Ontario, where a special type of radiation treatment is used. Some sarcomas that require limb-saving surgery are routinely sent to London or Toronto for care, and there are certain radioactive treatments that are only done in Edmonton. With prior approval, Manitoba Health will pay for the airfare and the medical cost of the treatment and may help with accommodation, but the individual must pay up-front and wait to be reimbursed. There are also food and ground transportation expenses. The cost of an escort may be covered if the escort is needed for the individual’s safety and well-being. However, due to the potential costs incurred, it may mean that the individual will travel without any supports.¹³

¹² Manitoba Health (<http://www.gov.mb.ca/health/mhsip/travel.html>)

¹³ Manitoba Health (<http://www.gov.mb.ca/health/mhsip/ooop.html>)

“People living in urban areas, which includes most if not all the cancer specialists across the health provider spectrum, do not really understand the challenges faced by people in the rural area. If you told most urban people that they would have to drive 100 kilometres to get treatment, twice a month for the next six months, they would be outraged. However, rural people seem to accept it as part of the way of life. This is an added burden of cost. The further away you get, the harder it is.”

Key Informant

3. Adolescents and Young Adults

Young adults are perceived to be at greater risk of financial burden when they receive a cancer diagnosis, as many are still in school or have jobs that do not provide adequate health benefits, disability insurance or extra medical coverage. They may be new to the workforce and ineligible for Employment Insurance sickness benefits or Canada Pension Plan Disability. Young adults, not yet in an established career, have no assets and may not have a partner able to support them financially. Their parents may be unable to provide assistance if they have other children or are retired, on a fixed income or planning their own retirement.

The ability of adolescents and young adults to get an education is affected by their illness. An individual who has been unable to continue their education may have difficulty finding a job that offers more flexibility and a higher income. This can have a long-lasting impact on the financial future of this group.

4. Other Contributing Risk Factors

Age

As noted previously, adolescents and young adults are a group with increased risk. Similarly, the elderly who live on fixed incomes and/or have minimal or no social resources are also at increased risk.

Gender

Both men and women face increased risks, depending on their circumstances. The key informants noted that there are traditional and ethnic communities in Manitoba where women do not work outside of the home. If the man becomes ill, there is a greater possibility that there will be no income during the period that he is off work. In the North, males tend to make the higher incomes, so if the man is unable to work the loss of income is greater.

Women are more likely than men to work in part-time or home-based jobs that do not provide adequate sick leave benefits or return to work policies.

Women also tend to be the caregivers even when they are the person with cancer.

“[One example that I recall is] an older woman in her sixties living in a rural area who was working right up until her diagnosis. She was diagnosed with cancer and undergoing treatment. At the same time, she was trying to look after her husband who had just had a stroke. She doesn’t qualify for anything. Her costs have increased as a result of increased transportation costs to attend frequent medical appointments in Winnipeg. This woman is challenged with the home care needs of her husband while she is extremely weakened with her own condition. The family was relying on income from these years to help them in their retirement. They are now trying to sell their house to cover the expenses that they have incurred.”

Key Informant

Occupation

Key informants observed that there are certain occupations and types of work where people are more likely to have few, if any, extended health care and sick leave benefits. They mentioned:

- Garment factory workers
- Trade workers
- Farmers
- Small business owners
- Contract workers
- Lower-paid and/or entry level jobs of any kind

Those who are in non-professional positions may have less flexibility in their work schedules while they are undergoing treatment and may be forced to take more time off. For those who have been employed in physically demanding work or where their cancer and subsequent treatment have resulted in disability and/or disfigurement, returning to their previous work may not be an option, placing them at risk of long-term financial stress.

“I know a financial consultant whose diagnosis and treatment resulted in huge speech difficulties. He used to do a lot of presentations and although he can still technically do them, he feels that he is unable to be as effective in this job as he was previously.”

“In the North, most of our employed population work for either the mine or Manitoba Hydro. With the mine, they are not able to accumulate sick leave, which definitely creates problems for them.”

“A lot of people in the rural area are farmers so their net worth may be significant but their cash flow often is not, making it difficult for them to qualify for support programs.”

Key Informants

Employment Status

The self-employed may not have additional health benefits or disability insurance, and depending on their income level, may find it cost-prohibitive to purchase these products. The key informants observed that self-employed people might delay seeking treatment because of their financial situation. It has only been within the last year that the self-employed have been able to pay into Employment Insurance so that they can be eligible (once they have been enrolled for a full year) for the Employment Insurance Sickness Benefit and the Compassionate Care Benefit.¹⁴

Seasonal or casual workers often do not qualify for Employment Insurance benefits because they have not accumulated enough hours of insurable employment during the qualifying period to be entitled to receive EI regular benefits.¹⁵

Access to Benefits

Individuals and families with no private insurance are clearly at greater risk of financial burden than those who do have insurance. Some private insurance plans offer more support than others. For example, drug coverage varies widely depending on the plan.

Individuals who have not filed their income tax in the previous year may not have access to a number of government programs providing financial support to those in need. It may be difficult and time-consuming to sort out these financial matters while dealing with a cancer diagnosis. Meanwhile, further debt may accrue.

Key informants pointed out that even people with access to benefits sometimes find themselves in dire predicaments due to cracks in their long-term disability coverage. An example would be a person with cancer who relies on long-term disability benefits provided by her employer during an initial bout with cancer, and later moves to a new job. Even if her new employer also provides long-term disability benefits, she may be ineligible for long-term disability coverage if she becomes sick again – either because she hasn't worked there long enough or because the plan contains a clause that eliminates coverage for a 'previously existing condition'. The end result is an individual who is unable to work, receiving no benefits and facing the financial burden of her illness.

Treatment Modality

Certain types of cancer treatment – such as surgery, radiation therapy, complex chemotherapy, multiple treatment modalities or a bone marrow transplant – place individuals and families at a greater risk for financial burden. Most people undergoing these types of therapies must take some time off work during recovery. As has been noted previously, rural residents often relocate to the city during treatment, which means the individual and their caregiver are unable to work, while at the same time incurring significant relocation costs. Anyone who develops complications as a result of their treatment is also at increased risk for incurring financial burden. Complications add to the cost of care in a number of ways and often mean that more salary will be lost as the treatment is extended or delayed.

¹⁴ Service Canada (<http://www.servicecanada.gc.ca/eng/sc/ei/sew/index.shtml>)

¹⁵ Service Canada (<http://www.servicecanada.gc.ca/eng/ei/types/regular.shtml#section2>)

Type of Cancer

Each person's experience with cancer is different and varies widely depending on the type diagnosed. Persons whose disease/treatment has resulted in significant pain management issues or severe morbidity often have poor and slow recoveries.

The key informants provided a number of examples of types of cancer that may place individuals at risk of financial hardship. People with head and neck cancers often require radical surgery, which can result in speech problems and facial disfiguration that make a return to their previous employment impossible. People with lung cancer often have significant and lasting respiratory problems that affect mobility and their ability to work in a physically demanding job. Individuals with brain tumours have an immediate change in the quality and scope of their life. The diagnosis immediately impacts their employment as the individual experiences cognitive and physical changes. The diagnosis typically follows a dramatic medical event, such as a seizure, right or left sided weakness, ataxia or aphasia. Persons with leukemia can suddenly find themselves acutely ill and unable to work for several months.

Other Factors

There are other factors that increase the risk of financial burden to people with cancer. People facing additional challenges include those who are socially isolated or dealing from mental illness or addictions. Unique challenges are also faced by people who are struggling with English is a second language, or do not speak English and do not understand the system, and who possibly have a different understanding and attitude toward authority.

V. The Cost Drivers

When an individual receives a diagnosis of cancer, there are a number of unexpected costs associated with the illness. Regardless of where an individual or family is on the economic scale, and whether they are able to continue working, have a disability plan and have extra health insurance, their expenses will increase in one or more of the following areas:

- Chemotherapeutic and supportive medications
- Transportation, parking and accommodation
- Medical equipment and supplies
- The basics – food, clothing and shelter

1. Chemotherapeutic and Supportive Medications

People with cancer require different types of medications: chemotherapeutic agents and biologicals that attack the cancer itself, supportive care medications that address the side effects that deal with the effects of chemotherapy, anti-nausea drugs, pain medications, antibiotics, antivirals, antifungals and others. However, not all of these drugs are used within the hospital setting. Outside hospitals, the provinces and territories provide varied

coverage of drugs through provincial/territorial drug benefit plans.¹⁶ With the exception of British Columbia, Alberta and Saskatchewan, persons with cancer will have to pay for a portion, or all, of the cost of certain essential medications as part of internationally accepted treatment protocols for their type of cancer.¹⁷

For example, in Manitoba, all intravenous chemotherapeutic agents are covered through the Provincial Oncology Drug Program since they are administered in hospital. However, almost none of the oral agents, which can be taken at home, are covered – nor are the medications used to control the symptoms caused by the chemotherapy unless they are administered in a health facility.¹⁸ As more cancers are treated by oral medications, the burden of drug costs will increasingly shift to the individual.

“The biggest issue that we face is the fact that about five per cent of our drugs are oral agents. About 20 to 25 per cent of the drugs currently in development are oral drugs and this is increasing exponentially. These drugs are the best that we have to offer in terms of the science but they are expensive and the financial burden for paying for them rests with the patient.”

“There are second and third line oral drugs coming on stream now that are even more expensive.”
Key Informants

Eligible Manitobans, regardless of disease or age, are covered by Pharmacare, which is a drug benefit program designed to assist those whose income is seriously affected by high prescription drug costs.¹⁹ A Manitoba resident who has filed her income taxes within the last two years will be required to pay a Pharmacare deductible based on her adjusted family income in the calendar year two years previous to the current government fiscal year. For example, if her medication expenses occur in the 2010/2011 fiscal years, her deductible will be based on what she earned in the 2008 calendar year. To calculate the deductible, Pharmacare will deduct \$3,000 from line 150 (total income) of the tax return for her spouse and each dependent under the age of 18 years. The minimum deductible for Pharmacare is \$100 and the percentage of adjusted family income to calculate the deductible rises from 2.71 per cent (if the adjusted income is \$1,000 or less) to 6.12 per cent (if the adjusted income is \$100,000 or more). If she and her spouse elected to split pension income, the line 150 amount is reduced by the split pension amount indicated on line 210 to ensure the pension income transferred is not included twice in a family's total income.²⁰

The following table provides some examples of the cost of the deductible in Manitoba in 2010/2011 based on a sample of family incomes.

¹⁶ Drug Coverage.ca: A guide to re-imburement (http://www.drugcoverage.ca/p_cancercover_mb.asp)

¹⁷ In Manitoba, medications administered in hospital are covered by Manitoba Health. Manitoba Health (<http://www.gov.mb.ca/health/mhsip/index.html#insuredmedicalbenefits>)

¹⁸ Drug Coverage.ca: A guide to re-imburement (http://www.drugcoverage.ca/p_cancercover_mb.asp)

¹⁹ Manitoba Health (<http://www.gov.mb.ca/health/pharmacare/index.html>)

²⁰ Manitoba Health (<http://www.gov.mb.ca/health/pharmacare/estimator.html>)

*View from the Front Lines:
A Discussion of Issues Related to the Financial Hardship of Cancer in Manitoba*

Family Income (Line 150 of both spouses' tax returns)	Deductible – 0 Dependents	Deductible – 2 Dependents
\$25,000	\$1,010	\$730
\$35,000	\$1,487	\$1,224
\$45,000	\$2,128	\$1,657
\$55,000	\$2,689	\$2,396
\$65,000	\$3,178	\$2,885
\$75,000	\$3,667	\$3,374
\$85,000	\$5,202	\$4,835
\$95,000	\$5,814	\$5,447
\$100,000	\$6,120	\$5,753

Medication expenses must meet the deductible every year before Pharmacare will start to pick up the cost of medication. The Manitoba government fiscal year must also be taken into account. Because the fiscal year runs from April 1 to March 31, an individual diagnosed with a cancer in March 2010 may have to pay the full cost of his monthly medication for that month, and again in April 2010.

In Manitoba, Pharmacare offers two options to help people pay for their deductible. The first option is to apply for a reduction in the deductible based on future income. This is helpful if the family income will be reduced by more than 10 per cent because either the person with cancer and/or the person's partner must be off work for an extended period of time. The second option is to apply to Pharmacare to pay for the deductible on an annual instalment plan. In order to qualify for this program, the monthly cost of the drugs must represent 25 per cent of the average monthly adjusted family income, as of the date of application, the person must have reached or exceeded any private coverage and they must be willing and able to pre-authorize payments through Manitoba Hydro.²¹

Key informants pointed out that some cancers are almost exclusively treated with oral medication, which can cost up to one hundred dollars a day. As soon as an individual is prescribed medication, they become immediately financially responsible for the costs up to their Pharmacare deductible. Some of these drugs must be taken for the entire life of the person with the disease and the deductible must be paid annually. While key informants celebrate the scientific success of drugs to change a life-threatening cancer into a chronic long-term condition, the individual with cancer's standard of living may be compromised due to the expense of the drug.

²¹ Manitoba Pharmacare Program (<http://www.gov.mb.ca/health/pharmacare/index.html>)

“Many people with cancer have never applied to Pharmacare before because they have never needed the service. They generally do not understand the program. We do a lot of counselling on this.”

“Many people have deductibles of \$2,000 and \$3,000. Lots of people do not have that amount of money to dish out.”

“People are shocked at the cost of the drug and the fact that they have to pay for it, especially at a time when their life expectancy is decreased and they already have a number of other stressors. To add financial stress to this often seems just too much.”

Key Informants

Another issue that came up in key informant interviews in relation to the Pharmacare system was the cost of adjunctive drugs, such as anti-nauseants used to control the side effects of chemotherapy. They are expensive and only covered by provincial health plans if taken in hospital. In order to function while undergoing chemotherapeutic treatment, people with cancer need these additional medications despite the high cost.

If people have private health insurance, some drug companies will pay for a portion, or all, of the cost of these drugs up to the Pharmacare deductible. One key informant stated that “more recently, she has seen some private insurance plans doing this, but not often.” And The Canadian Cancer Society notes, that “private insurers have increased the maximum payouts for claims to reflect the new drug cost realities. However, some private plans have an annual or lifetime cap on costs, many of which are below the costs of newer cancer drugs.”²²

There are some safety nets provided for certain groups in need. Individuals off all active chemotherapeutic drugs and within six months of death can qualify for the Provincial Palliative Care Drug Program in Manitoba (PPCDP)²³ where all medications are covered.

“People not on palliative care who are relying on Pharmacare to cover their drugs and have had a high income in the previous year but are earning almost nothing in the current year can apply for special consideration based on projected future income. Not everyone avails himself or herself of this. There is a certain degree of advocacy required and often the person is too sick and family too preoccupied to apply for special consideration. Some other government programs are also context adaptable but you need to be able to state your case.”

Key Informant

²² Canadian Cancer Society (http://www.cancer.ca/Canada-wide/About%20us/Media%20centre/CW-Media%20releases/CW-2010/Backgrounder%20Cancer%20Drug%20Access.aspx?sc_lang=en#ixzz1Ei54E6ix)

²³ Manitoba Health (<http://www.gov.mb.ca/health/pcdap/index.html>)

Drug costs will be paid, for the most part, if an individual with cancer is on Employment and Income Assistance for sick individuals (EIA) or is eligible for the Non-Insured Health Benefits (registered status First Nations or Inuit).²⁴

The pharmaceutical industry plays a huge role in setting and controlling the prices for new medications. The provinces negotiate separately with the pharmaceutical companies and reach agreements that cannot be shared; the larger the province, the bigger their negotiating power. Pharmaceutical companies cover the cost of drugs that are part of clinical trials and they will sometimes continue to cover the costs for individuals who were in the trials and have benefited from the medication. In certain circumstances, the pharmaceutical companies will consider covering the costs for certain individuals if there is proper documentation from CancerCare Manitoba pharmacists.

2. Transportation, Parking and Accommodation

The challenges in this area faced by rural residents have been outlined in detail under 'Rural Residents' in Section IV. However, according to the key informants, transportation in the city is a challenge – particularly for people without a car or who cannot drive a car. While Canadian Cancer Society (CSS) provides a subsidized volunteer driving program²⁵, some individuals may be unable to access it because the individual:

- Has an oxygen tank or a disability requiring a wheelchair accessible vehicle,
- Has an appointment that is before 8 a.m. or after 4 p.m.,
- Perceives that the \$6 charge for this CCS program is not affordable and is not aware that it can be waived, or
- Is unable to provide two days notice to book the ride.

The CCS volunteer driving program is available in Winnipeg, Brandon, Flin Flon and The Pas; as well, some CCS-supported service is provided to seniors groups in the Interlake, South Eastman, North Eastman and NorMan regions of the province. The South Central part of Manitoba has services from two community-organized groups funded through individual and local fundraising efforts. However, there are still parts of the province with no programs in place to help people who are unable to drive themselves to appointments.

For persons requiring a wheelchair accessible vehicle, Handy-Transit is not always available and they must take a more expensive private cab. Many able-bodied individuals are advised not to take a bus because of their low immune status and the risk of exposure to infections. When a child is immune-compromised, parents are always advised not to use public transit.

The key informants universally report that the cost of parking is a problem for many of the people that they see with cancer.

²⁴ Health Canada (<http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/index-eng.php>)

²⁵ Canadian Cancer Society (http://www.cancer.ca/Manitoba/Support%20Services/MB-Driver%20program.aspx?sc_lang=en)

“Something needs to be done about the cost of parking. This is a huge expense for families.”

“Parking costs are a huge issue for our patients. It seems like a little thing but some people are going to be coming here once a week for the rest of their life and with a minimum \$6 parking fee every time, it adds up. I had a patient the other day who was an urgent add-on to our clinic and of course everything got delayed and the patient’s car was towed at a cost of \$150.”

“The cost of parking is astronomical. (Children’s) clinic visits are long and can be unpredictable. You can have a 9 a.m. appointment and still be at the clinic at 3 p.m. We tell our families not to use the metered parking for this reason.”

Key Informants

The Rainbow Society has committed to donating four or five parking passes to the Paediatric Unit annually. The Parent Support Group has donated a parking pass, which is on a year-to-year basis. The staff tries to rotate these passes among the families who have children in the hospital. However, there is nothing for the outpatient clinic where a parent may spend \$10 to \$15 on parking for one visit.

One key informant laughingly suggested a drive-through phlebotomy window, where people could drive up to a window and have their blood taken to save on parking costs. Another option would be arrange to have blood taken by a variety of laboratories across the city and province. For rural residents, some physicians at CancerCare Manitoba do accept the results of blood work from other health regions but others do not. Timely communication of the results is not well supported by computerized systems across the province.

3. Medical Equipment and Supplies

Supplies needed for persons with particular cancers are not always covered, unless the individual with cancer has extended health benefits or is on the palliative care program. Examples given by the key informants of supplies needed by some people with cancer and not covered in Manitoba are:

- Supplies for gastric feedings
- Digital thermometers, which are needed by all children with cancer and adults whose immune status is low due to treatment
- Electric razors, which are needed by all adults who are predisposed to bleeding, either as a result of their disease or a result of their treatment
- Home care supplies such as bath stools, walkers and canes

- Supplies for tracheoesophageal puncture (TEP)²⁶

People often delay replacement of items not covered by the provincial health plan, due to the cost. For example, a TEP prosthesis must be replaced when it leaks (an average of three to six times per year). Some private health insurance plans will reimburse the cost, however, there is usually a one-time provision allowance or a yearly maximum.

4. The Basics – Food, Clothing, Shelter

Key informants stated that there are several food-related issues. All people with cancer are encouraged to eat healthy foods and to maintain a good level of nutrition as part of the healing process. There is no coverage for expensive food supplements if they are required. When adults, adolescents and children are required to take steroid medications as part of their treatment, they develop voracious appetites and cravings, which increase the cost of food for the family.

“The cost of food is an issue for many of our families. In the outpatient department, you not only have to feed the child but you also have to feed the parent and very often the siblings. Some children are here five days a week. CancerCare Manitoba does provide soup and cookies but this is often not enough. Children that have leukemia (approximately a third of the patients that we treat) are on steroids and this causes a huge increase in their appetite. They eat more than the average teenager. They often crave things and the cost of food, even at home, can become a huge expense. We watch parents not eat so their children can eat.”

People/organizations often donate toys or books to our department but I wish that they would donate gift cards to different grocery stores or a coupon to get a pizza after a long day at the clinic.”
Key Informant

Clothing for growing children can be a challenge under normal circumstances. For a child gaining weight due to the use of steroids, or losing weight while undergoing treatment, the expense of new clothes can become an issue for parents.

For those whose illness results in the need for a wheelchair, there are the costs of building a ramp and making modifications to the home to accommodate the wheelchair. In some cases, a home’s hallways are too narrow for a wheelchair. While the Residential Rehabilitation Assistance Program (RRAP)²⁷ offers financial assistance to allow homeowners and landlords to pay for modifications to make their property more

²⁶There is no universal coverage for the supplies associated with a tracheoesophageal puncture (TEP). Some people with head and neck cancers must have their larynx (voice box) surgically removed. Many of these people can be fitted with prosthesis. With a TEP, the prosthesis allows a much more rapid attainment of intelligible speech, more natural-sounding speech and the possibility of speech that does not require the use of one hand (which is the case for those using an artificial larynx). Various supplies are required in order to maintain the tracheoesophageal puncture site, the prosthesis and resultant speech. Recently, CancerCare Manitoba has decided to cover replacement TEPs if the person has no insurance coverage for it and cannot afford to pay.

²⁷ Canada Housing and Mortgage Corporation (http://www.cmhc-schl.gc.ca/en/co/prfinas/prfinas_003.cfm)

accessible to persons with disabilities, the program has some limitations. It is geared towards low-income individuals and the home must have a low valuation, the work must not be started until the RRAP loan has been approved and homeowners must agree to continue to own the house during the loan forgiveness period, which could be up to five years.

All families with children who have cancer and adults with certain types of cancers are required to have a phone. There are families who do not have phones. Those relocating to Winnipeg from a rural area will also need to pay for telephone service in their temporary accommodation.

For the working poor, all of these added costs may mean that mortgage or rent payments fall behind. Sometimes, families of moderate means have financial commitments that leave them with very little disposable income. People in this situation may increase their level of debt trying to stay in their homes, or they may lose their homes. For some, the only choice may be to go on Employment and Income Assistance.

“It has become clear to me how many people live paycheque to paycheque. Children are a constant drain on one’s income and those with dependent children often fall into this category.”

“There is no help for missed mortgage payments or missed payments of any kind. There is nothing to help tide people over the time that their child is having treatment. There is no back-up in the system for things such as everyday bills, mortgages, rent etc.”
Key Informants

5. Other Costs

There are a number of other cost drivers that are related to specific types of cancer. For example, individuals who have head and neck cancers or major head and neck surgery may be extremely disfigured and require dental rehabilitation. However, Manitoba Health will cover only dental surgery performed in hospital.²⁸ If dentures are necessary, or existing dentures need to be refitted, they may not be covered by health plans.

Many people who have had surgery in the lower arch of the jaw cannot get dentures to fit and require dental implants for appearance and for eating. Implants are very expensive and not covered by public health plans. Even most private dental plans only cover a small portion of the cost of implants.²⁹

“Your face is your first contact with the world and when your jaw and face are receded and you can’t wear dentures, you don’t really have any other options except for implants, which most people cannot afford.”
Key Informant

²⁸ Manitoba Health (<http://www.gov.mb.ca/health/mhsip/#hospital>)

²⁹ Vancouver Center for Cosmetic and Implant Dentistry (<http://www.vccid.com/content/implants/faq.php#q20>)

Individuals who need radiation to treat their cancer may experience bone death in the jaw and are at risk for serious infection that can affect the heart. Without good ongoing dental care, this type of infection will require hospitalization and may be life-threatening. Fortunately, the population in Manitoba requiring dental care related to bone death is relatively small – between 50 and 200 people per year, according to key informants.

Another area of cost is physiotherapy related to prostate and other urinary and pelvic cancers. Pelvic floor physiotherapy is often recommended, but is not covered by Manitoba Health unless received in hospital.³⁰ Private insurance plans will cover physiotherapy services to a certain amount and then the individual is responsible for further payments.³¹ Having access to this therapy pre- and post-operatively may help people with this type of cancer regain urinary control.

An often-overlooked expense is fertility preservation for young adults. Cancer treatments may leave an individual infertile, but banking eggs or sperm for the future is not covered by health insurance plans.³² According to a local fertility clinic's website, banking, freezing and storing sperm for a year costs about \$1,650, while harvesting, freezing, storing and hatching an embryo costs about \$2,800.³³ Since young adults are often at risk of financial hardship due to their age and employment situation (as discussed in Section IV), paying for fertility preservation may be unrealistic.

Another gap in health coverage is the costs incurred by donors. Canadian Blood Services will cover all expenses for unrelated donors³⁴, but there is no coverage for related donors since the physician, not Canadian Blood Services, is responsible for finding potential matches and arranging for testing with family members.³⁵ Unfortunately, in the case of bone marrow transplants, related donors are often the best match. The costs incurred due to travel, accommodation and loss of salary for each extraction may bring financial hardship upon a donor who is already making a selfless contribution.

³⁰ Manitoba Health (<http://www.gov.mb.ca/health/mhsip/index.html#hsni>)

³¹ Blue Cross Health and Life Insurance will cover \$450/calendar year for physiotherapy on their Medi-Blue plan. The monthly subscription rate for this plan is \$55.05 (\$660.06 annually) for a family between the ages of 65-74. Blue Cross (http://www.mb.bluecross.ca/products/individual_plans/health_dental_plans/medi_blue_basic/benefits)

³² In Manitoba, a tax credit equal to 40 per cent of the costs of fertility treatments up to \$8,000 and received within the province is available. Manitoba Finance (http://www.gov.mb.ca/finance/tao/fttc_faq.html#question1)

³³ Heartland Fertility Clinic (<http://www.heartlandfertility.mb.ca/fees.html>)

³⁴ Canadian Blood Services operates a stem cell/marrow match bank called OneMatch and will reimburse expenses a donor incurs as a result of donating stem cells. If the donor has to go to another city for the procedure, Canadian Blood Services will cover travel and accommodation costs for the donor and a companion. Canadian Blood Services (http://www.bloodservices.ca/centreapps/internet/uw_v502_mainengine.nsf/page/E_ubmdrPKG-intro?opendocument&CloseMenu)

³⁵ One match will not test a specific donor for a specific patient; only donors in their data bank will be reimbursed for travel. A family member who is found to be a match by the physician-directed testing will be responsible for any travel expenses incurred. Canadian Blood Services (http://www.bloodservices.ca/CentreApps/Internet/UW_V502_MainEngine.nsf/page/The_Matching_Process_for_Patients?OpenDocument)

“Recently, we had a patient from Saskatchewan and the Kinsmen helped with the expenses to have his brother flown back and forth.”
Key Informant

Funeral costs are expensive and come at a time when a family may be in a precarious financial position after the added expenses of a cancer journey. The costs for the funeral will be covered if the person is on Employment and Income Assistance.³⁶ There is also a one-time death benefit through CPP³⁷, and Veterans Affairs Canada provides assistance for funeral, burial and grave-marking costs for Canadian military.³⁸ Other Canadian charities, such as Childhood Cancer Canada, will help financially struggling families pay for a funeral with a donation from their Benevolent Fund.³⁹ Hospital staff play a vital role in sourcing charities available to grieving family members since they may be unable to do it themselves during such a distressing time.

“We used to have access to a small fund (to assist families with funeral costs) that was donated to us by a family whose child died, but that fund only has a small amount of money left in it now.”
Key Informant

VI. Systemic Issues Contributing to Financial Hardship

There are a number of systemic issues that contribute to financial hardship. These include loss of income for the person with cancer and sometimes for the caregiver as well; shortages of home care resources, hospice and palliative care beds; a lack of awareness among health care providers and people with cancer; a lack of rehabilitation programs to support people with cancer in their recovery phase; and a lack of resources to help people with cancer return to meaningful work. In addition, there are several unique challenges facing people who live in northern Manitoba and First Nations, Inuit and Métis communities that contribute to the financial burden. Each of these issues will be discussed separately, but for individuals with cancer and their families, they often develop cumulatively.

1. Loss of Income

Loss of income is almost always associated with a diagnosis of cancer, particularly if the treatment for the disease is lengthy and involves multiple modalities (chemotherapy, radiation therapy, surgery, bone marrow transplant, etc.). The majority of those who cannot work during the treatment and/or rehabilitation phases of their illness must take several months off work. Many do not have short- or long-term disability plans. The sickness benefit associated with Employment Insurance is only 15 weeks in length.⁴⁰

³⁶ Manitoba Family Services and Consumer Affairs (<http://www.gov.mb.ca/fs/manuals/eia/23/>)

³⁷ Service Canada (<http://www.servicecanada.gc.ca/eng/sc/cpp/deathpension.shtml>)

³⁸ Veterans Affairs Canada (<http://www.veterans.gc.ca/eng/sub.cfm?source=bereavement/gravevac>)

³⁹ Childhood Cancer Foundation (http://www.candlelighters.ca/prog_serv/benevolent_fnd/index.html)

⁴⁰ Service Canada (<http://www.servicecanada.gc.ca/eng/ei/types/special.shtml#Sickness3>)

An individual seeking sickness benefits must have worked at least 600 hours in the last 52 weeks before their claim. Part-time or seasonal workers may not accrue enough hours to be able to apply for EI sickness benefits. EI benefits pay 55 per cent of an individual's salary up to a maximum of \$468/week. At a time when cost for drugs, transportation, medical equipment, food, clothing, child care and home care may be rising, a cut in salary may put the family in a precarious financial position.

A problem arises when an individual takes the 15 weeks off work offered by the EI sickness benefit, but is unable to return to his job when the 15-week leave is up. The person does not want to quit their job, and has intentions of returning when healthy. A sickness benefit of 52 weeks would be more consistent with the time frame for treatment and recovery from some cancers.

Key informants also expressed the need for flexibility within all income replacement programs. There are individuals who can work part-time during their treatments but not full-time. However, most programs do not accommodate that flexibility.

“Some of my patients would benefit from a system that would allow them to work in between their chemotherapy treatments and not lose their benefits, or to work part-time but still get the disability benefit from their plan up to the maximum. Some of my patients on chemotherapy seem to be able to work through it but many others are not able to do this. In the current system, if you try to go back to work and then need more time off, many plans will penalize you and you have to start over with a two week waiting period before you get any benefits. Being back at work helps people emotionally. If there were a way to encourage people to work as they can, it would be helpful. Some programs limit the amount you can earn before they begin to take away the benefit.”

Key Informant

In Canada, contributions paid into the CPP by employees, their employers and self-employed people provide coverage for those whose disability prevents them from working at any job on a regular basis. The disability must be long lasting or likely to result in death. People who qualify for disability benefits from other programs may not qualify for the CPP disability benefit. To be eligible for a CPP disability benefit, an individual must have made enough CPP contributions in at least four of the last six years, or he must have made valid CPP contributions for at least 25 years, including three of the last six years, prior to becoming disabled. The application process for the CPP disability benefit may take as long as three months, although the time frame is much shorter for terminally ill applicants.⁴¹

These rules mean that it can be very difficult to qualify for the CPP disability benefit, even if an individual is unable to work for many months and has no other disability plan. A person may not qualify because they have not contributed enough to CPP or because their illness may not be considered “severe and prolonged.” If a person with cancer

⁴¹ Service Canada (<http://www.servicecanada.gc.ca/eng/isp/cpp/summary.shtml>)

anticipates returning to any job on a regular basis over the long term, they will not be able to receive CPP disability benefits.⁴²

In some cases, loss of salary may become a permanent situation. Some individuals are not able to return to work even after their treatment. They may have a permanent disability as the result of their illness or treatment, or they may not regain their former strength and stamina.

“A man in his sixties who had head and neck cancer, is now three years post treatment and considered ‘cured.’ This gentleman was working prior to his diagnosis and treatment but is now on Employment and Income Assistance, which is an extremely limited income. He would like to return to work but faces several barriers to this including lack of energy and arm and shoulder dysfunction limiting his ability to do any lifting.”

“A young woman who had always done reception had a tongue resection, so her speech is intelligible but not perfect. She has experienced significant complications, major dental and huge pain management issues. She has done everything that she can to help herself. She has applied for over 40 jobs with interviews and has not been successful in finding one. She continues to apply and to look for work. Return to work issues for some people are huge and we have not had great success with the return to work program run by the Society for Manitobans with Disabilities. In many ways, it is up to employers. In addition to problems with speech, swallowing and facial disfigurement, many employers are not willing to take a risk on a person with cancer. They think about the potential need for sick and medical appointments. There can be a big stigma (about cancer) for some employers.”

Key Informants

The sad result of the gaps in disability benefits for people with cancer is that some individuals may choose less optimal treatments or delay treatment because of the loss of income associated with the recommended treatment.

“Farmers will sometimes delay their treatment because they are seeding or harvesting and can’t get in without losing their crops”

“One patient has delayed his treatment because he didn’t have enough time in on his job to get his sick time.”

“One of the positives of the Canadian system is that for the most part, everyone has access to the medical treatment that they need. If people are not using radiation for palliation because of cost considerations, something should be done about that because it is a basic right.”

Key Informants

⁴² Service Canada (<http://www.servicecanada.gc.ca/eng/isp/cpp/review.shtml>)

With some cancers, the individual will first present as a medical emergency. For example, with leukemia, an individual can be feeling fine, become acutely ill and be admitted to hospital resulting in an immediate loss of income.

“Your sick time, if you have any, is gone in a minute. You still have to pay rent and feed yourself even if you don’t feel like eating – and you still have basic living costs.”

“A young woman was diagnosed with cancer in her late twenties. She was self-employed, lived in the city and had a client base as part of her occupation. She was unable to work or live alone during her treatment and moved in with her mother who lives in a small community. Her clients had to go elsewhere for service while she was unable to work. She is now off treatment and is able to return to work. She finds herself in a position where she has expectations of the same income and a thirties lifestyle. However, in many ways, she has to start over to build up her client base. She is now in a position of having to borrow from her mother. Her parent is now supporting her instead of putting money into her RRSPs.”

“I know of a young man who is now dying of his cancer but has been through several rounds of chemotherapy and other intensive treatment options. His job is in construction and he is self-employed and married with two young children. His wife does not work outside of the home. He has trouble paying for his bills. It has been a real challenge for this individual to make the many trips that he has had to make for his treatments. The program at the community level can help with blood work but not the type of treatment that he has needed. As soon as possible after each round of chemotherapy, this young man has returned to his construction job. In the last little while, he has given that up. But prior to this, he was back at work as soon as he was functional, trying to make ends meet. I don’t know for sure but I don’t think he has much disability coverage, if any. When he is off, nobody is making any money and his wife is home with very young children.”

Key Informants

The only choice, for some, is to go on Employment and Income Assistance Benefits (EIA). The Employment and Income Assistance Regulation sets out assistance rates that will cover basic living expenses. In order to receive the benefits, an individual with cancer must acquire medical documentation from a physician indicating a physical or mental incapacity or disorder that is likely to continue for more than 90 days. An EIA medical panel reviews the case to determine eligibility.⁴³ EIA will pay for medications, most devices and medical transportation, but the monthly payments may represent a drop in income.

A single person with a disability living in private rental accommodation will receive \$616 in EIA, \$105 for IAPD (Income Assistance for Persons with Disabilities), \$50 for RentAid (formerly known as Manitoba Shelter Benefit) and a GST credit of \$22. The

⁴³ Email correspondence from Nathan Watson, Policy Analyst at Manitoba Family Services and Consumer Affairs. April 26, 2011.

total benefit amount due to an individual with a disability is \$793.⁴⁴ A single parent with one child under 18 will receive a monthly payment of \$1,425.⁴⁵ An additional shelter allowance and coverage for the cost of utilities are available for people on EIA who meet the financial needs test. Depending on the type and severity of the disability, the individual may also be eligible for benefits to assist their daily living, such as basic telephone and coin laundry costs. EIA also assists with uninsured health benefits for dental, optical and drug costs. Going on EIA may represent a huge reduction in salary and a drastic change in the family's standard of living, but it may be the only option.

Advocates for recipients point out that the EIA funds are insufficient to provide adequate food and shelter and do not alleviate the hardship experienced by many people with cancer who need this funding to support themselves. In Manitoba, if an individual goes on EIA, he can have up to \$2,000 in liquid assets but must deplete all of his registered retirement savings, GICs, etc., before he is eligible to receive any funding. If he owns a house or car he does not need to sell them, but a lien will be put on the home. Rent payments must not exceed the allotment for shelter, and if they do, the recipient must find cheaper accommodations.⁴⁶ One benefit of receiving EIA is that recipients have access to Manitoba Housing. However, by forcing people to use up all of their registered retirement savings to be eligible for EIA, this program potentially turns a temporary situation into a permanent reliance on social assistance.

“The demoralizing experience of EIA is an impediment to access. The barriers that exist for people who own homes or have RRSPs make it difficult to access EIA.”

“I have been an advocate in the social assistance system. My experience is that how responsive it will be to special requests is very dependent on whom you connect with. I always ask to be put through to the supervisor and plead my case there. Trying to get through is very difficult. There is always a busy signal and you can't get through to a live person. You most often end up leaving a message on voice mail, which may or may not be returned. People who are forced to rely on SA must feel very marginalized and devalued within the system. The other reality is that SA is simply not enough money to live on.”
Key Informants

⁴⁴ Email correspondence from Nathan Watson, Policy Analyst at Manitoba Family Services and Consumer Affairs. April 26, 2011

⁴⁵ Email correspondence from Nathan Watson, Policy Analyst at Manitoba Family Services and Consumer Affairs. April 26, 2011.

⁴⁶ Aniceto, Leo. Welfare: A Guide to Employment and Income Assistance in Manitoba. (2000, revised 2005). Community Legal Education Association. http://www.communitylegal.mb.ca/pdf/pub_Welfare.pdf

2. Caregiving and its Cost

There are times during cancer treatment when individuals require a caregiver. Most caregivers are family members or close friends of the person with cancer. With certain types of cancers (e.g. brain tumours) and certain types of treatments (e.g. bone marrow transplants), the person with cancer requires a full-time caregiver. For parents of children with cancer, one parent almost always must quit work while the child is undergoing treatment and both parents may need to take time off work when the child is very ill or in the palliative care stage of their disease. Except in very unique circumstances, all persons with cancer who choose to die at home require at least one caregiver. Sometimes partners or relatives are forced to take shift work so that they can care for the person with cancer during the day and work at night.

In the experience of the key informants, for single people, it is often a sister or friend who will care for the individual. When the caregiver is someone who is working, they are forced to take unpaid leave to provide this care.

Canadian caregivers have virtually no access to income assistance. “Currently at the national level in Canada, caregivers only have access to tax relief and a short-term paid work leave to provide palliative care. In Australia and the U.K. caregivers are directly paid a certain amount of money, based on need. The U.K. also recently introduced a state pension for low or no-income caregivers. Such initiatives recognize the important role of caregivers in our society.”⁴⁷ Unless the caregiver can show that he or she is mentally unable to work as a result of their relative’s disease, they are not eligible for private disability insurance or income replacement plans such as EI or for Employment and Income Assistance sickness benefits.

All income replacement plans need to recognize that there are circumstances where caregivers cannot work – not because they are mentally unwell, but because of the physical, emotional and psychological impact of caring for a loved one.

“For parents who have access to long term disability plans at work, they often do not qualify for it because they are not sick, it is their child who is sick. They must say and prove that they are having mental health problems. We are working with one family whose ill child has died, but they have three other children and are still fighting for back payments from their long-term disability plan. This family has one source of income and nearly lost their home because of the impact of their child’s illness. They do not need this kind of stress on top of all that they have been through.”

Key Informant

According to the key informants, there are numerous issues with the CCB. It is too short. It is difficult for physicians to determine the length of an individual’s life when they are being treated for cancer. The benefit is only available once during an illness and to only one person at a time. If three people want to split the caregiving responsibilities, they

⁴⁷ *Canada Lags Behind in Caregiver Support*, May 2005. Medical News Today (<http://www.medicalnewstoday.com/articles/24808.php>)

⁴⁸ Service Canada (<http://www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml>)

must each take a two-week portion of the leave at separate times. Additionally, the CCB is limited to family members and not available to friends who may be caring for someone in the dying phase of their illness. Finally, access to the benefit needs to be made time-sensitive.

“We had this situation with one of our children where it must have been five years ago that they were told that their child had a week to live. The child did extremely well but the family had taken the benefit and when the time came that the child was dying, they were not able to take it again when they really needed it.

Some of our families have applied for the Compassionate Care Benefit. I am unsure as to the success of receiving payments from this benefit. It is very difficult to predict when a child will die. It is very dicey to approach this subject with a newly diagnosed child. They don’t even want to go there. The problem is that you have to say that the child will die within six months. Could they die? Yes. But we are hoping that they will be the one that survives the disease.”
Key Informant

Currently, bone marrow transplant programs are debating the establishment of a policy that post-transplant individuals must have a caregiver. This policy is not practical if the bone marrow recipient is single or does not have family. It may add to the financial hardship of the situation if they have to hire a caregiver.

“There are huge cost implications for requiring that all our patients have a caregiver 24/7 post transplant. I know of a man right now whose wife has a number of health problems. He has a brother who has a cab and has given him an account so he can get back and forth from the hospital but if I were to say to this gentleman now that he needs a caregiver 24/7, he would not be able to do it.

I know of a young girl who is coming from Saskatchewan and she could never afford a caregiver.”
Key Informant

The bone marrow transplant policy debate exemplifies how dependent the health care system has become on unpaid caregivers. Caregivers’ work is barely acknowledged in legislation, policies and practices of all levels of government, regional health and social services bureaucracies, yet it saves the Canadian health care system millions of dollars each year. In Manitoba, the only recognition of the financial impact a caregiver faces is the \$1,020 primary caregiver tax credit.⁴⁹

2. Insufficient Home Care Resources

In Manitoba, individuals who choose to die at home and are in the last six months of their life are eligible for the Regional Palliative Care Program. Under this program, resources needed in the home can be increased significantly and most supportive medications are

⁴⁹ Manitoba Finance (<http://www.gov.mb.ca/finance/tao/caregiver.html>)

provided free of charge.⁵⁰ In some other provinces, families must pay for these services based on their income.

However, even in Manitoba, there are inconsistencies. For people with certain brain tumours, death may be inevitable but some quality of life can be maintained, and symptoms improved for periods of two years or more, with active oral treatment. Younger people with certain cancers may also be treated aggressively up until almost the end of their lives. In Manitoba, if you live within the Winnipeg Health Region and are on chemotherapeutic agents that require monitoring for adverse effects (specifically blood counts), you are not eligible for the Palliative Care Program.⁵¹ Individuals on active treatment in rural areas, depending upon their location and access to resources, are admitted to their Regional Palliative Care Program. This inconsistency exists because home care resources are extremely limited.

The maximum number of hours of care per week that one can qualify for is 50⁵² and in many rural areas, a lack of staff makes it difficult to provide this amount of care to all individuals in the palliative stage.

“Two thirds of the acute palliative care beds in the WRHA are in Riverview Health Centre, which has no labs or X-rays after hours. It would be very inappropriate to admit a patient receiving aggressive chemotherapeutic agents to let him/her die from neutropenia sepsis (a possible complication of aggressive chemotherapy) in a palliative bed over a weekend. If the chemotherapeutic drug does not have that profile of adverse effects (e.g. some of the newer oral agents), then they are accepted. It is also generally incongruent to be undergoing toxic chemotherapeutic treatments with potentially life-threatening adverse effects, and yet have a comfort-focused approach to care.

In rural settings, the palliative beds (if any) are in the hospital, and the same physician who is giving the chemotherapy is doing the palliative care – i.e. the clinical team takes responsibility for their patients and are expected to address side effects of the treatments administered by the oncologists.”

Key Informant

⁵⁰ Hospice and Palliative Care Manitoba (<http://www.manitobahospice.ca/index.php?categoryID=1>)

⁵¹ Is no longer receiving aggressive disease-focused treatment (most often this is chemotherapy) requiring monitoring for and treatment of potentially serious complications Winnipeg Regional Health Authority (<http://www.wrha.mb.ca/prog/palliative/professionals.php>)

⁵² Manitoba's Home Care Policy states that the cost of home care should not exceed the average costs of a personal care home bed, which is currently calculated at 50 hours per week.

“The WRHA Palliative Care Program does offer consultative services for any patient with a life-limiting illness, regardless of the treatments they are receiving or their care setting; in fact, the WRHA (rather than CCMB) fund the physician staffing of CCMB’s St. Boniface site symptom management clinic. Through this, we ensure that all oncology patients have access to expertise in pain and symptom management regardless of where they are in their illness.”

We will see patients in consult anywhere, anytime. The symptom needs of such patients are usually not complicated and should be easily managed by the attending services; if not, we will provide consultative support. It is a common assertion that when we don’t transfer a patient to a palliative care unit, they don’t get palliative care. This is completely inaccurate. Palliative care is not a place, but an approach to care.”
Key Informant

In some cases, the primary caregiver will try to return to work during the day when home care is available and then care for the person with cancer when they get home. Many people with brain tumours can be difficult to care for; they often don’t sleep and are disruptive. A caregiver cannot be expected to function properly at work the next day if he has been awake during the night to tend to his loved one.

“I know of a mother who has a brain tumour and her son, who is in his late twenties, has been caring for her and trying to do his job. However, it has gotten to be too much for the son and now his mother has to go into a personal care home.”

“Home care resources are stretched to the limit in the North. There is not enough home care and it can only be offered within the town limits. The home care staff never go on reserve (even when it is across the river) and the Métis community across the highway has no services at all. We can’t lend them equipment; we can’t get a nurse in there. There are all these barriers to providing care (to people who need it).”

Key Informants

4. Availability of Hospice and Palliative Care Beds

Hospice care is provided at two not-for-profit centres in Winnipeg: Jocelyn House has four beds⁵³ and Grace Hospice has 12 beds⁵⁴. There are also palliative care beds at the St. Boniface Hospital and Riverview in Winnipeg. A number of smaller hospitals in rural areas provide palliative care but the availability and level of care and services provided are inconsistent across the regions.

⁵³ Jocelyn House (<http://www.jocelynhouse.ca/jh/>)

⁵⁴ Grace Hospital (<http://www.gracehospital.ca/hospice/about.html>)

If someone on a palliative care program has several months to live but cannot be cared for at home, and is not appropriate for a hospice setting, they may be transferred to a personal care home, where the per diem rate is based on their previous year's income.⁵⁵

The lack of hospice and palliative care beds is a complex issue. More palliative care beds are needed to manage people with cancer who are in the palliative care program (i.e. those within six months of death). The palliative care beds in the Winnipeg Region are a back up for people who are being cared for in their homes. It is rare for someone in an acute care bed in a hospital to be transferred from that bed to a palliative care bed in the Winnipeg Region.

“Approximately 30 per cent of the caseload of our palliative community nurses consists of patients receiving chemotherapy who are not eligible for admission to our palliative units. With the support of our community nurses, there is a higher degree of skill than with the regular home care pool to attend to pain, nausea, etc. This is an initiative of palliative care. This issue is a reflection of our need for more long-term palliative beds. This is the critical issue, and we have a working group meeting monthly on this, with a report coming shortly. It would be that group that would determine how public the document is. We are trying to put together a tangible plan for increasing hospice beds in the city. In the rural area, the program is managed a little differently depending on the medical and hospital resources that are available in each region.”

More hospice care beds are needed for individuals who experience a long palliative stage, cannot be cared for at home and do not require the services of an acute care hospital. There are people with brain tumours who could benefit from the right type of hospice care bed. Hospice beds at Jocelyn House and the Grace House have long waiting lists.

“We need more palliative care beds and hospice beds where people who are cognitively impaired can be when they are dying and get the 24/7 care that they need. There may need to be a daily cost but it needs to be a cost appropriate to the family's circumstances.

“The cost of this fractured care (our current system) to the patient and family is that on top of their loss of income, their out of pocket costs, and the fact that many of these families also have mortgages and other living expenses to pay, they are charged a per diem from the moment they are assessed for a nursing home bed in the hospital that can be between \$30 and \$70 per day based on the family's income and assets.”

Key Informant

⁵⁵ Eligibility for the Personal Care Home Program is based on a comprehensive multidisciplinary assessment conducted through our Long Term Care Access Centre and the Panel Review Board. The residential charge for Personal Care Home services is based on the income of the resident and ranges from \$29.70 to \$69.70 per day. Winnipeg Regional Health Authority (<http://www.wrha.mb.ca/ltc/pch/index.php>)

5. Lack of Awareness among Health Care Providers and People with Cancer

Many health care providers and persons newly diagnosed with cancer are not aware of the financial hardships associated with the cancer journey. Because Canada has a universal health care legislation, it is assumed that the majority of costs related to health care will be paid for by the system. The focus within the health care system among providers is naturally on the medical aspects of a person's care – on treating and curing the illness wherever possible, alleviating unwanted side effects, preventing complications and basically looking after the individual's needs while they are in the presence of the provider. Often people with a life-threatening illness, like cancer, are reluctant to complain about the cost of something that has the potential to extend their life or make them more comfortable, especially to the very people who are working so hard to care for them. Most, if not all, major cancer centres in Canada offer psychosocial services. However, according to key informants, only a small percentage of people with cancer actually have contact with these services.

There is little public understanding of the financial hardship associated with this disease. Families who have experienced cancer often never recover financially to their pre-cancer level. Although rare, the overwhelming devastation of going bankrupt, losing a home or being unable to return to work after surviving cancer is a reality for some.

This general lack of awareness, combined with the reluctance of people who are in financial difficulty to seek help, leads to a situation where people often do not get access to the financial help that is available.

“Lack of awareness of the problem is a barrier to accessing what is available. Patients don't know and health care providers don't know.”

“A lot of patients are very reticent to discuss their financial concerns with the doctor or the nurse. They are embarrassed by it. There is an expectation that everyone is covered for their care when in fact there is a huge gap.”

“You can't avail yourself of something that you don't know about. We need to increase patients' awareness that it is OK to talk about this. I put things up in my room that support this. We need to outline the issues for the patients: medication costs, loss of work, etc. One problem is that when you are first diagnosed, everything is such a whirlwind and you remember close to nothing at all in the first part of your illness.”

“(There is a big problem with) health care providers who don't get it but don't know that they don't get it. Providers must become more educated about the burden that cancer can have on both patients and caregivers.”

Key Informants

“In the rush of the clinic, financial need often becomes a lower priority – you are cramming so much information in. Maybe it needs to be a higher priority than it is.”

“It doesn’t take a lot of time and effort to demonstrate caring and sensitivity to these issues. It can be as simple as a few sentence exchange where the provider says, ‘I’m sorry I’m so short of time but I’m concerned about this for you. Would it be all right if we talked about this again or if I give you some information about it?’ I think that this is a very practical way in which health care providers, including physicians, can demonstrate caring.”
Key Informants

6. Lack of Rehabilitation Programs

Lack of rehabilitation programs available to people with cancer was mentioned by a number of key informants, but expressed differently by each. It was pointed out that we have cardiac rehabilitation programs but limited rehabilitation programs for people with cancer.

“We need this type of culture in cancer care. We need studies to show us in the long term: How many people have long- term survival? And of those how many are able to return to work?”
Key Informant

The key informants feel that more effective support to help cancer survivors get back to work is needed, especially for those who have significant disability due to their illness – for example, speech impairment and/or facial disfigurement. There may be better ways to help these individuals to be more employable and to find a meaningful occupation – even one that might be part-time with flexible hours. The key informants agree that from an economic perspective, these programs pay for themselves. If people are able to work, they will be financially independent. Current programs for people with head and neck cancers and transfusion-dependent people focus only on managing the illness. Physical changes take a toll on self-esteem, making re-entry into the work force more difficult and elusive. Education, work retraining and support for gradual work re-entry could be one of the main goals of a cancer rehabilitation program that would make a significant difference in peoples’ lives.

CancerCare Manitoba offers some rehabilitation programs, such as Speech-Language Pathology, Cancer Management Exercise Program and Psychosocial Oncology counselling⁵⁶ that help to promote and support financial independence throughout the course of this illness. However, with the risk of financial burden looming in the lives of

⁵⁶ CancerCare Manitoba
(http://www.cancercare.mb.ca/home/patients_and_family/patient_and_family_support_services/getting_help/)

people with cancer, the development of an increased focus on a person-centred approach to rehabilitation throughout the cancer journey is essential.

In the bigger picture, cancer rehabilitation involves an interdisciplinary approach that is tailored to the individual's rehabilitative needs and will improve the person's quality of life through a continuum of care⁵⁷. The focus is on maximizing the patient's functional ability for optimal independence from the point of diagnosis to ambulatory care and follow-up.

Key informants explained that this approach to care might be operationalized by increasing opportunities for individuals to get appointments outside of working hours, providing internet access during treatment or inpatient stays, ensuring adequate pain and symptom management, including work goals in the overall treatment plan and then providing support for the actualization of those goals.

According to recent studies, "Active engagement of oncologists, palliative medicine, general practitioners and rehabilitation specialists can be useful to assist in the rehabilitation needs of patients."⁵⁸ And in another study researchers observed significant functional gains in hospitalized cancer patients who received interdisciplinary rehabilitation services.⁵⁹ However, the key informants agreed that most cancer centres in Canada offer portions of a rehabilitation program throughout the continuum of care but very few offer these components of care together in a team-focused inter-disciplinary setting. To a certain extent, cancer rehabilitation, like palliative care, is an approach to care, rather than a specific program. However, cancer rehabilitation programs may offer increased opportunities to extend this philosophy into the continuum of care.

More research is needed to determine the effectiveness of these programs but it makes sense that supporting people with cancer and their families to regain financial independence would go a long way to address the long-term financial burden that certain Canadians face on the cancer journey.

7. Role of Charitable Organizations and Communities

The key informants frequently mentioned the valuable role that charities and community support play in assisting individuals with cancer and their families. Community support in terms of fundraising was particularly prevalent in rural areas.

⁵⁷ Roanne Segal, MD, William Evans, MD, Darren Johnson, MSc, Julie Smith, BSc, Salvatore P. Colletta, PhD, Linda Corsini, MSW and Robert Reid, PhD, MBA. Oncology Rehabilitation Program at the Ottawa Regional Cancer Centre. *CMAJ*. August 10, 1999; 161

⁵⁸ Gupta AD, Lewis S, Shute R. Patients living with cancer – the role of rehabilitation. *Australian Family Physician*. 2010 Nov;39(11):844-6

⁵⁹ Sabers SR, Kokal JE, Girardi JC, Philpott CL, Basford JR, Therneau TM, Schmidt KD, Gamble GL. Evaluation of consultation-based rehabilitation for hospitalized cancer patients with functional impairment. *Mayo Clin Proc*. 1999 Sep;74(9):855-61

Service clubs will lend a helping hand financially to individuals and families who are struggling, but asking for money from a local service organization, especially in a small community, can be very difficult for some people.

Charitable organizations could play a significant role in supporting the development of discretionary flexible funding to support special and emergent needs as they arise. Some key informants have noticed a lack of flexibility in the programs provided by the charitable sector and that some families do not fit the criteria to enable them to apply for funding.

“You can’t bend the rules anymore. The public is quite taken back when you tell them that there is nothing out there to help these families because they assume that all of the money that is donated to CCS and other charities would be there to help people when they need it.”

“I strongly suggest that CCS should be the advocates for these things (access to free chemotherapy and supportive drugs).”
Key Informants

In recent years, there has been a proliferation of charities collecting money to support individuals with cancer and their families. However, the fragmentation of the groups may be counterproductive. There may be more effective ways for these groups to work together with the health care system to address the population in greatest need, rather than to fundraise for specific cancers.

7. Challenges for those Living in Northern Manitoba

Key informants working in the North helped describe the challenges faced by those diagnosed with cancer living in northern Manitoba. Young families in the North are often transient. They come to the North to earn money and only intend on staying a year or two and do not have a support network in place. If someone in the family gets cancer, they have no family to lean on or friends to ask for favours. Without child care for children, travel and accommodation costs increase because the whole family must go to Winnipeg for appointments. The emotional and psychological impact of a cancer diagnosis affects the everyday life of a family. Tasks like grocery shopping are no longer done thoughtfully or economically because there is a bigger issue at hand. The result is financial burden, which can be devastating for a young family living in the North.

The cost of living is higher in the North.⁶⁰ Housing and food are more expensive and the higher incomes in the North reflect this fact. However, if the person cannot work because

⁶⁰ Government of Manitoba News Release. *Province to Increase Northern Allowance* December 16, 2010 <http://news.gov.mb.ca/news/index.html?item=10423> As a comparison, four litres of milk cost \$8.35 in 2008 versus \$4.09 in Winnipeg CBC News (<http://www.cbc.ca/news/canada/manitoba/story/2008/08/05/gas-churchill.html> *Northern Community seeks help as gas soars to \$1.99 a litre* August 5, 2008 CBC News)

of cancer and must rely on EI sick benefits, even the maximum EI payments will not be sufficient to maintain a reasonable standard of living in the North.⁶¹

Key informants have noticed that women from the North are less likely to drive in the city, which is problematic if their spouse is ill and unable to drive. They must rely on the volunteer driving program, but often choose to take a cab, which adds to the expense of travel.

“The Northern Patient Transportation Program (NPTP) is always over budget millions of dollars every year.”

“We do our best to see that people are seen by Telehealth and we deal with as much as we can through the Community Cancer Program. However, people still need to travel. The NPTP requires that the individual using it must apply for every trip individually. The program will pay for the bus fare from the person’s town to the city or give the equivalent of the bus fare if the person is driving. The person must provide proof that they have a medically necessary appointment that cannot be managed in their area of residence and that they have actually gone to the appointment (a signature from the doctor’s office is required). This is very time-consuming. For the most part, people are reimbursed retroactively rather than in advance. Some people from the rural area are not used to the city, may be upset about some news that they have received that day and often forget to get the signatures. Some do not bother to apply because of the hassle and because very often, they are made to feel that it is their fault when the program is over budget.”

Key Informants

Key informants connected to the Burntwood Health Region point out that the area has suffered from a nurse shortage since 1994. There are times when the region is unable to provide needed health care – for example when a nurse goes on holiday and there is no staff to cover her absence. At times, the region is forced to close down the Community Cancer Program and must send some people to Winnipeg or The Pas for treatment. Every effort is made by the regional health authority to provide additional supports to patients and their families. They will provide an accommodation subsidy per night for a hotel and ensure access to the Northern Patient Transportation Program. However, it is an inconvenience for the person and additional costs are incurred, which are not reimbursed.

⁶¹ To illustrate this point, the Service Canada website (www.servicecanada.ca) gives the basic rate for calculating EI benefits as 55 per cent of an individual’s average insurable weekly earnings. As of January 1, 2011, the maximum yearly insurable amount is \$44,200, or a maximum amount of \$468 per week. A nurse practitioner with four years of experience in northern Manitoba makes \$102,271 a year, while a nurse with the same qualifications in the south makes \$97,622 annually. Manitoba Nurses (www.manitobanurses.ca). If the Northern nurse makes \$1966.75 a week, the maximum EI benefit amounts to only 23 per cent of her annual salary.

9. Challenges for First Nations, Métis and Inuit People

Six key informants from two Manitoba Nations (both within driving distance of Winnipeg) were interviewed together to gather as much information as possible on the special financial challenges faced by First Nations people with cancer and their families.

A number of attempts were made to connect with representatives of the Métis community but these were not successful for a variety of reasons. There is definitely concern in the Métis community about this issue and it is expected that there will be other opportunities to work more closely with a broader representation of First Nations, Inuit and Métis people. For this report, no contact was made with representatives of Inuit groups.

Status members of First Nations and Inuit communities have access to a Federal program called the Non-Insured Health Benefits (NIHB). This program is part of the First Nations and Inuit Health Branch of Health Canada. An eligible recipient must be identified as a resident of Canada and one of the following:

- A registered Indian according to *The Indian Act*;
- An Inuk recognized by one of the Inuit Land Claim organizations; or
- An infant less than one year of age, whose parent is an eligible recipient.⁶²

The program provides a range of health benefits: drugs, medical transportation, medical supplies and equipment, vision and crisis intervention counselling to meet medical or dental needs not covered by provincial, territorial or other third-party health plans. Third-party health plans are ones usually provided by insurance companies. Key informants pointed out that it is uncommon for First Nations and Inuit people to have access to third-party health plans, but if they do, they must access the third-party plan before accessing the NIHB.

According to these key informants, over the years disparities have developed between provinces and territories in the way the NIHB program was administered and in the per capita amounts of money spent. In latter years, efforts have been made by Health Canada to standardize the program across Canada. There is a national drug formulary and pharmacists, with input from the prescribing physician, must communicate directly with Ottawa regarding any exceptions to the formulary. Regional officers manage the dental program, which provides a very similar level of coverage across Canada. The medical transportation program has the same guidelines across Canada but is administered at the level of the First Nation for members living on reserve. Members living off reserve must access medical transportation through their Regional First Nations and Inuit Health Branch.⁶³ But, access to the medical transportation program for those members living off reserve varies depending on the policy of their First Nation and where the individual

⁶² The NIHB is a national health benefit program. It pays for some or all of the costs of medical, dental and pharmacy services that eligible First Nations and Inuit may need. The program policies and practices follow the 1979 Indian Health Policy and the 1997 NIHB Renewed Mandate.

Health Canada (<http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/index-eng.php>)

⁶³ Health Canada (<http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/benefit-prestation/medtransport/index-eng.php>)

resides. The finer points of the medical transportation program (e.g. the amount of back-up documentation required) can and does vary between Nations and regional branches.

Any items that are medically required but not covered under the NIHB (e.g. must have a telephone, the need for a digital thermometer, food supplements, etc.) are usually managed at the First Nation level through their Social Development or Social Services Department for members living on reserve. Each Nation can establish its own policies with regard to these items. The differences can be confusing for persons with cancer and health care providers.

Employed First Nations people are subject to the same risk of loss of income as other Canadians. As previously discussed, they may not have access to private disability plans or may experience some of the shortcomings or the current federal employment assistance programs. For years, individuals with status working for First Nations organizations did not pay into the Canada Pension Plan. This has now changed.⁶⁴ But the majority of First Nations and Inuit people working on reserve or in their own territory would have only paid into CPP for a very short period of time, so minimal benefits would be available to them.

Outside of the services provided at the local level, the Non-Insured Health Benefits (NIHB) is for the most part perceived by First Nations as a large, often faceless bureaucracy that continues to make decisions affecting their lives for better or worse. In many First Nations, health care providers spend a great deal of time chasing down back-up documentation for medical transportation (e.g. letters of authorization for escorts, documentation of the need for a member to get private mileage rather than use the Nation's medical van service, forms or letters from physicians proving that members have attended their appointments). Physicians may be uncooperative about filling out forms if they are unaware of the NIHB program requirements. When appointments are made quickly, obtaining the necessary paper work in advance of travel is difficult. In Nations where food vouchers are issued instead of cheques, problems can occur for people in terms of being in the right location to be able to use the voucher once they get to the city or the closest community cancer program.

Physicians often prescribe dietary supplements for persons with cancer. Because these supplements are not covered through the NIHB, each Nation's Social Services establishes their own policy. In one Nation, social services will only cover the least expensive supplement, despite the brand prescribed. In another Nation, the process of receiving coverage for the supplement requires both a prescription and a cost quote be submitted before approval is given.

One key informant stressed the importance of traditional healing for First Nations people. Although traditionally there is no fee charged by the healer, there are costs associated with the various healing ceremonies – for example, wood, food or token gifts. While each First Nation's traditions are different, and healing is not an area where outside

⁶⁴ In 2009, changes were made to the CPP. First Nations now have the option to pay into CPP. Service Canada (<http://www.servicecanada.gc.ca/eng/sc/cpp/retirement/canadapension.shtml>)

intervention is appropriate, it should be noted that the cost of traditional healing could be an added financial stress for some First Nations people with cancer.

One First Nation's community had difficulty receiving transportation coverage for cancer therapy in any center other than Winnipeg, even though there was a community cancer program closer to this Nation. Regional Medical Transportation officials dealing with this Nation questioned why private mileage was allowed for trips to service locations other than Winnipeg.

Additionally, when this Nation provided private mileage to clients going into Winnipeg instead of putting them on the regular medical van, the NIHB questioned the travel claim. For many persons with cancer, riding for long periods of time on the medical van with other people is uncomfortable and poses a risk to their compromised immunity.

Another issue for one First Nation was palliative care. The First Nations and Inuit Health Branch provide funding for home and community care programs. Although the provision of palliative care services comes under this umbrella, it is rare that First Nations communities will have sufficient resources to provide appropriate palliative care. In particular, they are often not able to respond immediately when someone in the palliative stage of illness is discharged. When a member with cancer requires short-term palliative care, until the local arrangements can be made, the situation often evolves into a discussion about "who is responsible for this client in waiting?" This is a real challenge at the community level.

In order to provide proper palliative care, remote First Nations communities often transport people in the palliative stage to a more urban hospital. The rules of the Non-Insured Health Benefits Program are complex and can be culturally insensitive to the needs of First Nations people. In many First Nations cultures, the community is the family, but the NIHB only pays for one family member to accompany the person seeking treatment. Additional family members must pay for their own transportation to the city and their accommodation.

If a drug or particular piece of equipment is not covered by the NIHB, the First Nation's member risks not receiving it. Registered First Nations and Inuit people are considered to be "covered" by federal programs, which means they are not eligible for many programs/services available to the rest of the population. Health care providers and First Nations/Inuit persons with cancer struggle with jurisdictional problems like these on a regular basis. These are system issues that need to be addressed by the system, not the person with cancer.

VII. The Impact of Financial Hardship on Individuals and Families

Examples of individuals with cancer who have suffered financial hardship as a result of their diagnosis are scattered throughout this document. This section is an attempt to summarize the impact of financial hardship on individuals and families as witnessed by the key informants.

The previous sections demonstrate the cost associated with a diagnosis of cancer and how it is compounded by a loss of income for the person with cancer and sometimes for the primary caregiver as well. They also demonstrate the inadequacy of formal income replacement programs for the cancer treatment trajectory. For some, there is the added cost of a hospice or personal care home bed. A lack of awareness about the problem among health care providers and persons with cancer, a lack of home care resources, hospice and palliative care beds and rehabilitation programs can all contribute to financial hardship for individuals with cancer and their families. Individuals and families living in the North and First Nations, Inuit and Métis people face unique challenges.

There is some financial impact for everyone who gets cancer but not all suffer the same level of financial hardship. The impacts are varied and can be severe. There are individuals and families who:

- May not take their medications as prescribed because of cost
- Make treatment choices based on cost, not optimal care, which have the potential to increase costs to the emergency and acute care sectors of the health care system
- Go into significant debt as a result of their financial circumstances
- Are forced to sell their homes
- Spend all of their retirement savings
- Never fully recover from the financial burden of this disease

“Financial hardship does have an impact on my patients. Patients have told me that they are not doing something (that has been clinically recommended) because they can’t afford it or can’t take time off work. I do see that people do not always take their drugs because they can’t afford it. Those who have mental health issues are at higher risk of not taking their medication. In my area, 90 per cent of individuals I work with do want treatment. Families will do what they have to do to get the money; they borrow money and sell property if needed.”

“I know of one patient who considered not having consolidation therapy because of the up-front costs of accommodation. There were delays in his treatment because of this and he actually relapsed. It is hard to say whether or not the relapse was related to the delay.”

“It has impact. Finances are just ‘one more thing’ to deal with...and, at a time when your energy may be low, and your sense of vulnerability high.”

Key Informants

“We have one person who is keeping his haemoglobin in the high sixties (as opposed to the eighties, which is optimal) because of the cost of parking. He reduces the number of times that he comes in for a transfusion. If he were to keep it in the eighties, it would mean that the number of his visits would need to increase by a third.”

“I know of one gentleman and his wife who were both employed in the North but because of his illness were forced to relocate to Winnipeg for two years. This man decided to cut his treatment shorter than recommended so that they could return to the North sooner. It was financially very difficult for this family as the wife had to quit her employment as well. The community held many fundraisers to try and help them out.”

“One of the things that happens to families where cancer causes severe financial hardship is that they must completely change their lifestyle. All of their lives, they have done the right thing, they may have put away for a rainy day (savings, RRSPs) and everything is taken away because of cancer.”
Key Informants

VIII. Issues and Solutions Raised by the Key Informants

1. To address loss of income for both persons with cancer and their caregivers:

- a. Increase the length of time available for Employment Insurance sick benefits from the current 15 weeks to a minimum of 52 weeks.
- b. More flexibility is needed in all income replacement programs to support people who can continue to work during treatment.
- c. Make changes to the Compassionate Care Benefit of Employment Insurance by:
 - i. increasing the number of weeks of the benefit;
 - ii. building more flexibility into the program;
 - iii. allowing partial weeks over a longer period;
 - iv. allowing more than one family member to share the benefit, either simultaneously or at different times; and
 - v. softening the eligibility criteria from “significant risk of death” to “significant need for caregiving due to a life threatening illness.”
- d. Support primary caregivers through the establishment of a Canadian Caregiving Strategy that includes access to income programs for caregivers such as Employment Insurance benefits and private disability plans.
- e. Make changes to Employment and Income Assistance (EIA) for people who are ill by increasing the amount of money available to them and changing the requirement that any beneficiaries of this program must use up all of their registered retirement savings before becoming eligible for assistance.
- f. To better support persons who are able to work during treatment, increase efficiencies in terms of scheduling for diagnostic testing, chemotherapy,

radiation therapy and follow-up that fit within the rehabilitation plan for each person.

- g. Continue to build upon the Survivorship Program currently being developed at CancerCare Manitoba with an emphasis on rehabilitation. A program involving an interdisciplinary, case management approach that is tailored to each person's individual rehabilitative needs would improve the person's quality of life through the entire continuum of care. The focus is on maximizing the patient's functional ability for optimal independence, including financial independence, from the point of diagnosis to ambulatory care and follow-up. Inherent in this approach is the "person-centered cancer care" now being proposed and developed by the Canadian Partnership Against Cancer. For more information see http://www.partnershipagainstcancer.ca/cjag_toolkit.

2. To address the high cost of chemotherapeutic and supportive medications:

- a. Continue discussions with the Federal and Provincial government for a national drug program. In the meantime, in Manitoba: make all cancer treatment and support drugs (IV, oral and self-injectable) available at no cost to cancer patients in Manitoba. There are two options to accomplish this:
 - i. Bring all cancer treatment and support drugs under the umbrella of the Provincial Oncology Drug Program.
 - ii. Eliminate the provincial Pharmacare deductible for oral cancer treatment and support drugs.
- b. Work with the large pharmaceutical companies to:
 - i. Reduce the high costs of the drugs used to treat cancer;
 - ii. Control the side effects of treatment; and
 - iii. Develop strategies for the introduction of new drugs in a more cost-effective manner.

3. To address travel, accommodation and parking costs:

- a. Advocate for the development of a transportation and accommodation strategy that would cover travel expenses required for treatment to ensure equal access to care for all Manitobans regardless of their location of residence.
- b. Continue to support the development and expansion of the CCPN (Community Cancer Program Network) as far as this is safely possible.
- c. Support the use of Tele-health services within CancerCare Manitoba.
- d. Increase efficiencies in terms of scheduling for diagnostic testing, chemotherapy, radiation therapy and follow-up to decrease travel for rural residents.
- e. Arrange to have blood drawn/tested at various locations in Winnipeg and Brandon and across all of the health regions to reduce parking costs for all. and transportation and accommodation costs for rural residents.

- 4. To address the availability of home care, hospice and palliative care beds:**
 - a. Increase resources for home care and palliative care delivered at home.
 - b. Increase access to a wide range of care options for people in the palliative care phase of their disease by increasing the number of beds available for people in the palliative care period, from hospice to hospital.

- 5. To address the lack of awareness of the problem of financial burden for persons with cancer in all jurisdictions:**
 - a. Support the introduction of the issue of financial burden and cancer into the education curricula for all health care providers.
 - b. Introduce the issue of financial burden and how to address it into the orientation programs for all staff in all health care institutions working with persons with cancer.
 - c. Increase awareness among all staff working with people with cancer about the financial burden that can be caused by cancer.
 - d. Adopt key knowledge translation strategies to inform various stakeholders about this issue, including the public, persons with cancer and their families, members of Parliament and the Manitoba legislature, local governments, regional health authorities, labour unions, professional associations, industry, private enterprise and charitable organizations.

- 6. To better support persons with cancer in addressing their financial burden:**
 - a. Adopt policies to ensure adequate financial education services to care recipients
 - b. Include assessment for financial screening early on in the process of care and make it an ongoing process that includes clear directions for all staff on what actions they need to take based on the results of this assessment. The Patient and Family Support Services Department of CancerCare Manitoba is currently piloting a screening tool that is intended to address this issue.
 - c. Have dedicated financial support personnel who get involved with those individuals/families at high risk for financial burden early in the process to proactively support applications for resources, navigation through the resource system and financial planning at the individual and family level.
 - d. Increase the availability of information about financial resources throughout facilities where persons with cancer are seen.
 - e. Outline the issues for the patients: medication costs, loss of work, etc. to increase patients' awareness of the costs.
 - f. Create an environment that encourages patients to talk about finances.
 - g. Advocate for better co-ordination and advertising of the direct services/resources available to persons with cancer and their families. For

example, review the Canadian Cancer Society's Manitoba Transportation Program to determine why it is under-utilized. (Key informants' comments suggest that it may not be utilized due to the cost, lack of awareness that the cost can be waived, or inflexibility of the service's hours of operation.)

- h. Create strategies to get resources to the people who really need them. For example, charitable organizations and others could:
 - i. Donate parking passes for those who cannot afford the parking fees.
 - ii. Fund educational resources for families regarding financial burden. For example, families of children with cancer currently receive an educational binder and a book that corresponds to their child's diagnosis. These are provided by the CancerCare Manitoba Foundation through an annual grant application. Information on how to access financial help could be added to these binders and this program could be expanded to include adults.

7. Build partnerships with First Nations, Inuit and Métis organizations in order to support them in engaging the government in the cost challenges specific to these population groups, for example:

- a. Inadequate support for medical transportation (travel and accommodation for status individuals and no travel programs for the Métis).
- b. Gaps in coverage for drugs and supplies (no NIHB for the Métis).
- c. Long wait times for approval under the NIHB program.
- d. Bureaucratic processes that are obstacles to access.
- e. Lack of community-based palliative care.
- f. The need for more research into the financial burden of cancer in these populations and the impact of this burden on timely access to health services.

8. To address other issues:

- a. Include related donors in the Canadian Blood Services program that provides funds to cover the costs of travel and accommodation for unrelated donors.
- b. Increase access to affordable child care across the province.
- c. Be more attentive to the research in terms of financial burden and look at campaigns to raise money for practical forms of assistance that will have a direct financial impact on persons with cancer, such as parking passes, food vouchers, restaurant gift cards or small funds for emergent issues.
- d. Provide home care services for parents with cancer that include supportive care of their children in-home.

IX. Conclusion

The key informants were pleased to learn that this initiative was underway. They recognize that financial hardship is a problem for a significant number of people with cancer and their families. They understand that the health care system can do better but also recognize that intervention from outside of the health care system is needed to produce change.

“It is good that this is being done, if it is taken seriously enough to get off the shelf. We have to learn to do things differently. We have an aging population and a lot of people out there who need assistance. We can’t just continue to talk about dignity; we have to act it out.”

“A lot of money does go to research BUT we need money for more tangible things. Something does need to change. I hope that this will be the impetus for this change. I hope that this is not just a paper making process and somebody says, “Well we looked at it” but nothing changes. I know that it is not instantaneous but if you know that it is not just going to drop away a year or two from now (that gives you hope).”

Key Informants

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