

METASTATIC BREAST CANCER IN CANADA

The lived experience of
patients and caregivers

ACKNOWLEDGEMENTS

THE CANADIAN BREAST CANCER NETWORK (CBCN) AND RETHINK BREAST CANCER (RETHINK) WISH TO ACKNOWLEDGE EVERYONE WHO CONTRIBUTED TO THIS REPORT.

First and foremost, thank you to the exceptional individuals with metastatic breast cancer and their caregivers who participated in this survey for taking time to share their experience, challenges, insights, hopes and concerns about metastatic breast cancer. We are confident your voice will help inform policies and programs to better meet your unique needs in living with breast cancer. Thank you to the many partner organizations and groups across Canada who shared this survey with their membership and helped engage participants.

This report was written by Jenn McNeil and Ashley Mac Isaac-Butler edited by, Diana Ermel, Janis Murray, Sharon Young, & Niya Chari. This design and layout was created by Paulina Perzynska.

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ABOUT

THE CANADIAN BREAST CANCER NETWORK

The Canadian Breast Cancer Network is Canada's leading survivor-directed national network of organizations and individuals concerned about breast cancer. CBCN strives to voice the views and concerns of breast cancer survivors through the promotion of information sharing, education and advocacy activities.

RETHINK BREAST CANCER

Rethink Breast Cancer has developed pioneering programs that speak to the unique needs of young women with breast cancer. Over the past decade, we've helped transform the face of breast cancer and provide much needed resources and community and support for younger women (in their 20s, 30s and early 40s).

EXECUTIVE SUMMARY

This report shares the lived experience of metastatic breast cancer patients and their caregivers. Through an online survey initiated by CBCN and Rethink, 87 individuals either living with metastatic breast cancer or caring for someone with this disease, shared personal experiences and challenges that come with this diagnosis and the impact that it has on their lives. Of the individuals that participated in this survey, 82% were patients living with metastatic breast cancer and 18% were caregivers.

This survey was commissioned to help inform patient group submissions to the pan-Canadian Oncology Drug Review and ensure that the experience of those affected by this disease are accurately represented and considered when recommendations are made with respect to new oncology drug therapies.

This report highlights the following themes related to living with metastatic breast cancer:

- the impact on the quality of life for both the patient and the caregiver;
- the patient experience regarding accessibility to treatment and support resources;
- the importance of access to new therapies; and,
- the financial impact associated with accessing treatment.

METHODOLOGY

Information for this report was gathered through an online survey published in English and circulated through communications from CBCN and Rethink and partner groups in Canada from October 2012 to November 2012. The survey consisted of a combination of multiple choice questions and also allowed for comments from participants. The survey information was limited as no geographic or demographic information was collected. Survey respondents needed only to identify that they had experienced a metastatic breast cancer diagnosis or that they were a caregiver of someone with metastatic breast cancer. The purpose of this survey was to inform patient submissions to the pan-Canadian Oncology Drug Review.

STATISTICS & OVERVIEW

Metastatic breast cancer refers to cancer that has spread from the breast to different parts of the body, most commonly the bones, liver, lungs and brain. It is estimated that 23,800 women will be diagnosed with breast cancer in 2013, representing 26% of new cancer cases in women; an estimated 5,000 women will die from breast cancer in 2013¹. Of those 23,800 people, approximately 10% will have an initial diagnosis of metastatic breast cancer², and approximately 30% of women diagnosed initially with earlier stages of breast cancer will go on to develop metastatic breast cancer³. The 5 year relative survival of women diagnosed with metastatic breast cancer is 20%⁴. While there is no cure for metastatic breast cancer, there are treatment options that focus on slowing the progression of the disease and managing symptoms.

1. Canadian Cancer Society. www.cancer.ca . [Online] 2013. <http://www.cancer.ca/en/cancer-information/cancer-type/breast/statistics/?region=on>.

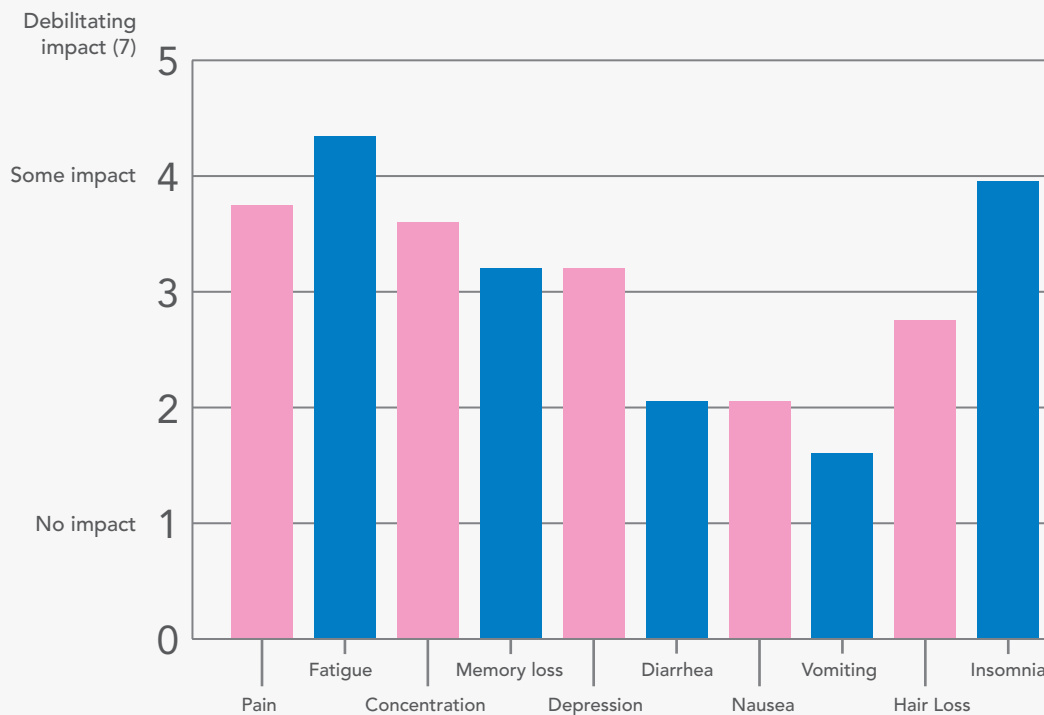
2. Facts and Controversies in Systemic Treatment of Metastatic Breast Cancer. C., Bernard-Marty. s.l. : The Oncologist, 2004, Vols. 9: 617-632.

3. Extending Survival with Chemotherapy in Metastatic Breast Cancer. J., O'Shaughnessy. s.l. : The Oncologist, 2005, Vols. 10 (supp13): 20-29.

4. Canadian Cancer Society. www.cancer.ca . [Online] 2012. <http://www.cancer.ca/en/cancer-information/cancer-type/breast/prognosis-and-survival/survival-statistics/?region=nu>.

**PATIENT PERSPECTIVE OF THE
IMPACT OF METASTATIC BREAST CANCER
ON QUALITY OF LIFE**

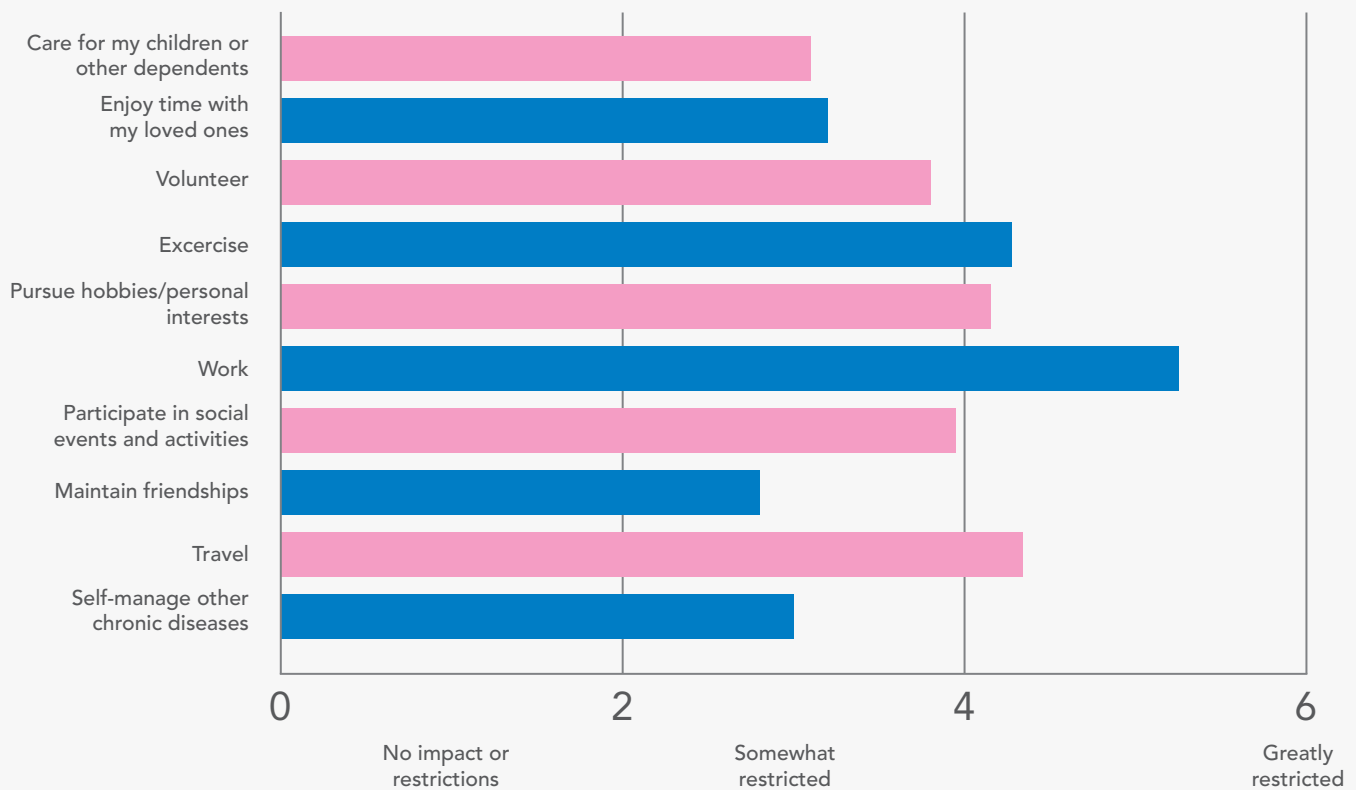
PLEASE RATE HOW THE FOLLOWING SYMPTOMS OF METASTATIC CANCER HAVE AFFECTED YOUR QUALITY OF LIFE



Respondents were asked to rate the impact of different aspects of the disease on a scale of 1 to 7, with 1 being no impact, 4 being some impact and 7 being debilitating impact. When asked to rate how a series of symptoms impacted the respondents' quality of life 27% felt that fatigue has the most impact on their lives rating it a 5 on a scale of 7. Pain (22.6%), concentration (21.3%), memory loss (19.7%), and insomnia (19.7%) were thought to have "some impact on quality of life" rating it a 4 out of 7 while vomiting, although more prevalent, had the least impact on quality of life (73.8%). The four symptoms rated most highly by patients that negatively affected quality of life were fatigue, insomnia, pain and concentration. Additional symptoms that patients indicated impacted their quality of life included loss of appetite, burning feet, burning tongue, hand-foot syndrome, peripheral neuropathy, balance, hemorrhoids, diarrhea, urinary tract

like symptoms, constipation, weight gain, swelling of the feet, easy bruising, dry mouth, weepy eyes, exhaustion, lymphedema and inability to sleep due to pain. Many patients expressed concerns regarding the psychosocial impact on their quality of life including emotional uncertainty regarding the future, dealing with their own mortality and fear of dying, difficulty communicating with family members, inability to manage household responsibilities, the effect of their illness on their children, being overwhelmed with the amount of medical appointments, feelings of anger and mood swings, body image issues, guilt about the burden on caregivers, and the financial impact of their illness. The respondents were asked how living with metastatic cancer has restricted their ability to participate in certain areas of their life. Almost half of the respondents (44.3%) felt that living with metastatic cancer greatly restricted their ability to work and 23% indicated their ability to

PLEASE RATE HOW LIVING WITH METASTATIC CANCER HAS RESTRICTED YOUR ABILITY TO PARTICIPATE IN THE FOLLOWING AREAS:



exercise was greatly restricted. Travelling (25.4%), pursuing hobbies (25%), volunteering (21.3%), and participating in social events (19%) were considered somewhat restricted. Participants indicated that enjoying time with loved ones and maintaining friendships were not impacted as a result of their diagnosis. Caring for their children and self-managing other chronic diseases did not apply to 86.6% of respondents.

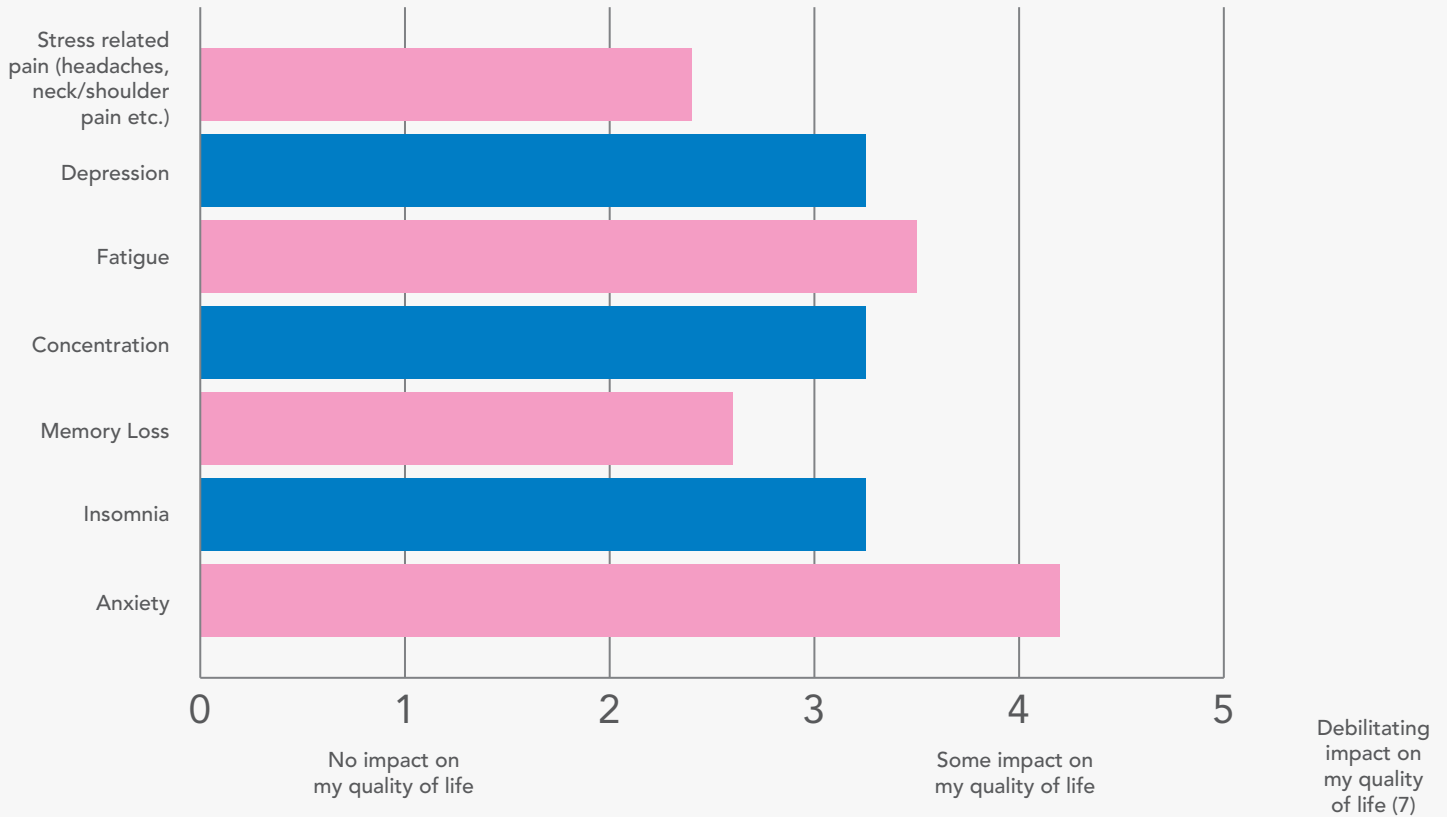
Several of the respondents commented on the additional financial burden they experienced due to their inability to work. Many were not able to maintain the lifestyle they had before cancer. They also provided additional information on how the disease has markedly restricted their ability to participate in certain areas of life related to ascribed roles and daily routines. They described symptoms such as low energy that led to the inability to care for aging parents, additional stress in relationships

including marriage and friendships, loss of career, and impairment of cognitive functions.

One patient shared *“I live with elderly parents. As their health deteriorates I find I cannot cope with being a caregiver for them in addition to caring for myself. **The community support services do not seem to understand my limitations.** I live with parents because of my health and financial situation ... I live with them so they can look after me, as well as me help look after them. I fear for the future when my parents become more severely ill, and when my cancer will progress ... From my experience the community supports will not be there to help us live out our lives in dignity.”*

Another patient shared the impact on her career *“**The biggest change was that I had to give up my career as a family physician**”.*

PLEASE RATE HOW CARING FOR SOMEONE WITH CANCER HAS LED TO THE FOLLOWING EXPERIENCES:



THE IMPACT OF METASTATIC CANCER ON CAREGIVER QUALITY OF LIFE

Caregivers were asked to rate how caring for an individual with metastatic breast cancer has impacted their quality of life. Out of the nine caregivers who answered the question six people rated anxiety as the greatest impact on their lives. Fatigue (44.4%) also greatly impacted their quality of life and depression (55.5%) had some impact on quality of life. One caregiver stated that there was a **“definite negative impact on my ability to carry out all of my job responsibilities in a timely manner.”**

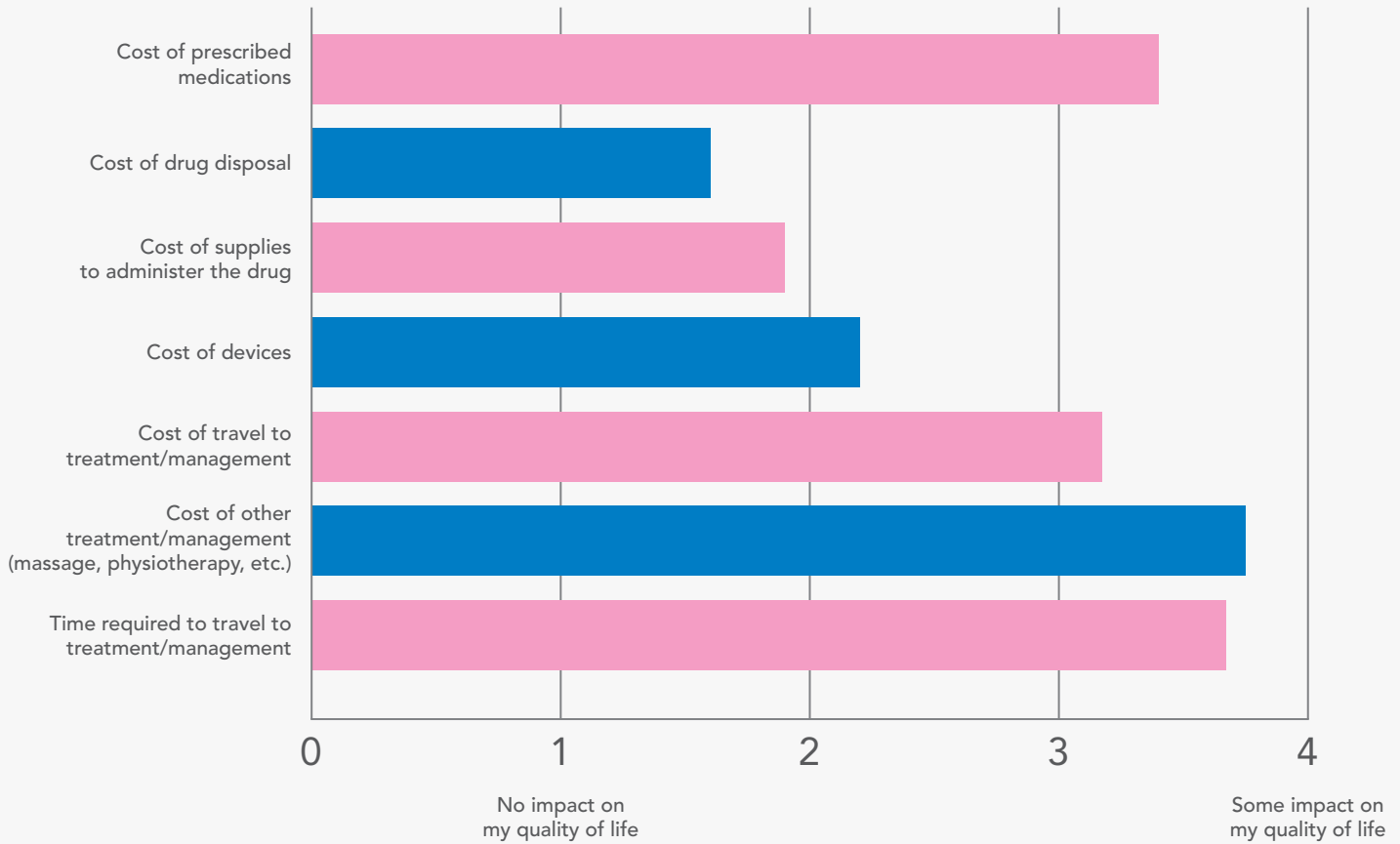
While work is heavily impacted (33.3%) by caring for an individual with metastatic breast cancer, it is not the only aspect of life that a caregiver found affected. The inability to pursue hobbies and interests (44.4%), travel (22.2%),

and participation in social events (22.2%) also negatively impacted a caregiver’s quality of life. One respondent shared that the role of a caregiver had a **“negative impact on career progression and family finances”**.

PATIENT CONCERNS REGARDING FINANCIAL IMPACT AND ACCESSIBILITY OF TREATMENT

Respondents were asked to rate how issues regarding the costs associated with prescribed medications, travel, drug disposal and complementary therapies have affected their quality of life. While the majority of respondents indicated the cost of devices (50%), drug disposal (51.6%) and supplies (51.6%) affected their quality of life with “No Impact,” their written and rated responses showed that, on average, the cost of prescribed medication (32%) and travel (33%) did have a large impact on their life. Common

PLEASE RATE HOW THE FOLLOWING ISSUES ASSOCIATED WITH TREATING CANCER HAVE AFFECTED YOUR QUALITY OF LIFE:



concerns were around the cost and stress of travel and parking for treatment/management as well as the cost of drugs that were not covered through insurance. Some individuals expressed concern about the cost of certain drugs they were taking and how managing the disease affected their work and leisure.

Several respondents elaborated on the financial impact that this diagnosis had for them. Their concerns related to access to drugs that they might need in the future, lack of insurance, or costs associated with complementary therapies.

“I have the good fortune of having drug insurance through my old employer (I am on medical leave); however, this has meant I cannot seek other employment because then I’ll

lose my insurance. Also, I am worried because the next set of drugs are not currently covered by insurance (private or provincial)...apparently the cost could be \$7500/month.”

“Up until now my drugs are covered by Trillium (Ontario provincial drug benefits) but I worry that down the road as my disease progresses that I may not be able to afford treatment, particularly if drugs are not covered by Trillium program. As far as I know massage is not covered by Ontario provincial programs so I don’t access these resources as much as I would like... But I believe regular massage therapy would greatly enhance my quality of life.”

“I do not have private health insurance. The cost of medications has caused me to be less mobile & active.

I am no longer able to participate in most of my regular social functions due to financial restrictions.”

*“Since I was not even a year in the company I work with when my cancer recurred, it was decided **I will not receive any benefits** ie. health plans, coverage for my medications, short/long term disability. As a result I have to pay from my personal pocket all my medications. In addition, I have to take time off without pay every time I will have doctors follow-up and/or medical appointments.”*

Respondents were also asked to rate accessibility of treatment and support resources. When asked to rate whether cancer treatment was close to or in the patient’s community 58.1% responded that it was fully accessible. Mental health support (50%) and symptom management options (57.4%) were also considered fully accessible by the majority of the respondents. This does, however, conflict slightly with some written comments. Several patients expressed how difficult it is when treatment is not offered in their community and also wished for more accessibility to mental health supports. Patients shared the following:

Challenges related to travel

*“I wish that **cancer treatments were available in my own community**; it would make it much easier on me physically I would not be so fatigued and exhausted all the time.”*

“I can still drive myself- but am on a trial so have to travel from my city to another city to be in that trial (400 km return trip)”

Access to complimentary therapies

“If my secondary health care providers (acupuncture, massage, physio, working out, nutritionist and social

worker) were in one place it would be much easier for me both time-wise and energy-wise.”

*“Complementary services are accessible, but **I’ve had to look extensively to find practitioners who really understand the physical issues associated with metastatic disease** and in particular bone mets (sic). Complementary services attached to/affiliated with cancer treatment centres to ensure that they are fully educated around metastatic disease.”*

Access to mental health services

*“I would like **more frequent access to mental health supports**. Once per month (at most) is not enough to help me cope with challenges of day to day living with elderly parents and living with metastatic cancer and the social isolation which results from both situations. I would use massage therapy if it were covered by provincial health benefits. Currently cannot afford, even though I understand it can be partially covered a tax deductible expense. I don’t believe the tax benefit is sufficient to make use of this type of service affordable.”*

*“I wish there were more programs for the mental health part of it. After two years I was finally able to connect with a therapist that was of no cost to me but I can only see her once a month. **The emotional turmoil that a metastatic cancer patient goes through are phenomenal!** More access, more programs for free or little cost need to be created!”*

Access to support programs and information

*“I would like some kind of **support group or communication with other young women with metastatic disease in my city**. I would also like to see a complementary health centre for cancer patients, so we don’t have to be searching all over the city for supportive care.”*

*“Being this is my second time in treatment, I feel the staff at the Cancer Centre assume that we know it all. **There are a lot of services available now that I know nothing about** and it is only by talking to another patient that I’m learning about some of these services. I do believe that the **Cancer Centre can do a better job of getting the word out.** Working in health care I find we can do a much better job of promoting what is available.”*

*“I have been lucky to be living with stable metastatic breast cancer for nine years. As I continue to beat the odds for survival I find that there is a **gap in supports available to meet my needs.** Supports in place are for newly diagnosed or people severely ill at end stage. As treatments are developed that continue to extend life without offering a cure the needs of people like me will become more apparent and programs and services will need to be developed to fill this gap. Meanwhile I persevere.”*

*“I still **would like to see a support group for breast cancer patients with mets** (sic), our needs are quite different from someone who is a Stage 1 patient.”*

*“Programming for metastatic breast cancer from a support perspective is not easily available. This is needed. We live in Toronto and it is **difficult to find support groups dedicated solely for metastatic disease.** I can’t imagine if you were in a smaller community.”*

ASSESSING THE RISKS AND VALUE OF NEW TREATMENT OPTIONS

When asked whether choice in deciding which drug to take when building a treatment plan was important or not important the majority of respondents (59.3%)

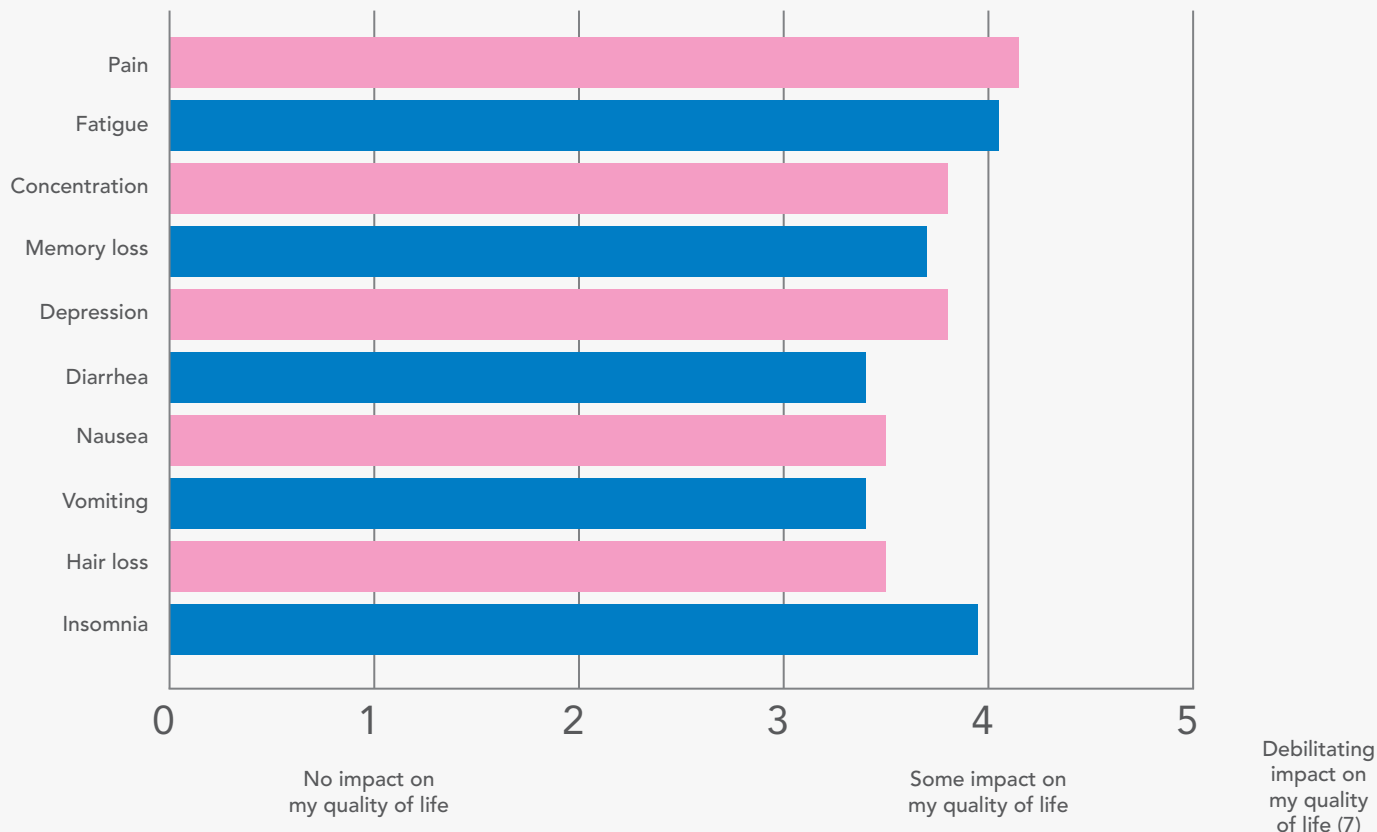
believed it was very important. Only two participants thought it was “not very important as long as there is treatment available.” Clearly there was a need to take some control in these circumstances.

When these patients were asked if potential risks associated with treatment affected their decision to take new medication 15.5% were willing to accept serious risks to control the progression of the disease. Of the respondents who answered this question, 13.8% were very concerned about the risk of drugs and 22.4% were less concerned but not entirely willing to accept risk.

When asked which symptoms would be acceptable while undergoing treatment the majority of respondents felt that most symptoms would impact their lives only somewhat. The symptoms included pain, fatigue, concentration, memory loss, depression, diarrhea, nausea, vomiting and insomnia. Hair loss was considered to have no impact on the quality of a person’s life for 16 respondents. This suggests an adaptation to living with metastatic breast cancer. The patients felt it was worth dealing with the symptoms and chose to pursue living life despite the side effects of medication.

Patients were then asked the degree to which they were willing to tolerate restrictions in certain areas of their lives due to treatment from metastatic breast cancer. These areas included: enjoying time with loved ones, exercise, pursuing hobbies/personal interests, participating in social events and activities, maintaining friendships and travel. It seems that family (caring for children), friendships and the work domains were valued most by the people who participated in the study. The graph shows the motivation by assessing what was tolerable. This issue is key if women with metastatic breast cancer are able to adapt and function within these restrictions. Respondents shared several additional comments and

WHAT LEVEL OF SYMPTOMS RELATED TO METASTATIC CANCER TREATMENT WOULD BE ACCEPTABLE TO YOU IF THE BENEFITS OF THE TREATMENT WERE SHORT TERM (FOR EXAMPLE EXTENDING PROGRESSION-FREE DISEASE BY SIX MONTHS)?



thoughts around what side effects and impact on their quality of life they would be willing to consider for progression free survival. This feedback demonstrates that the approach to treatment needs to be personalized as each patients perspective differs based on a wide range of factors as well as at what point they are at in their cancer journey. Some respondents were willing to endure several side effects and impacts if it would extend progression free survival:

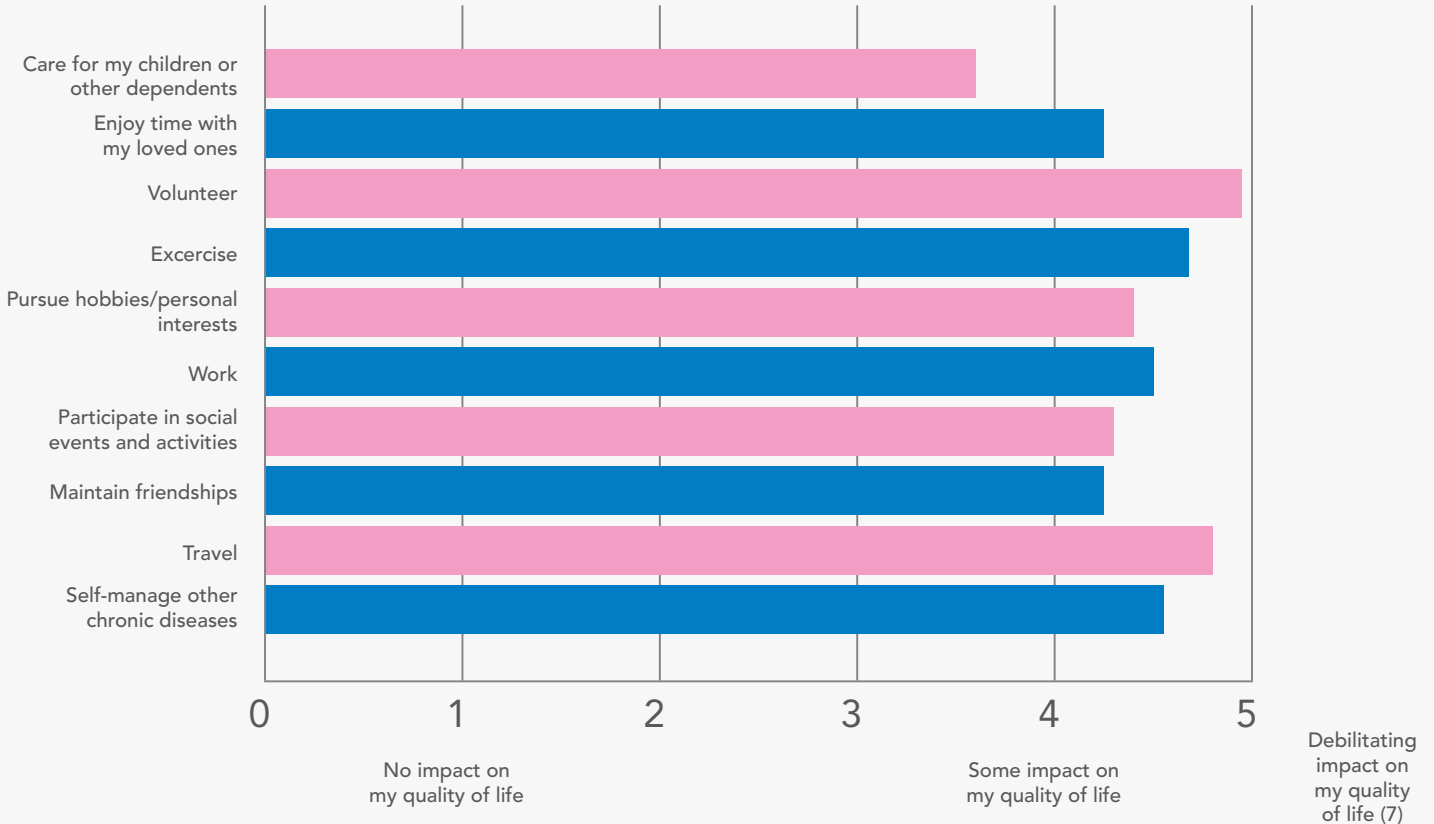
*“Had you asked me some of these questions four years ago, the answers would have been different. **My oncologist tells me that I am running out of***

***treatment options,** so the quest for newer, stronger and more debilitating chemo is important to me. It is very scary to face the day (soon) when I will have no treatment and the cancer will be allowed to run its course.”*

*“**I would take a treatment that offered six months progression free survival** even if that treatment somewhat restricted my ability to pursue hobbies/interest.”*

“I believe that I would prefer to tolerate severe restrictions in the quality of my life, if it meant that

TO WHAT DEGREE WOULD YOU BE WILLING TO TOLERATE A METASTATIC CANCER TREATMENT THAT HAD A NEGATIVE IMPACT ON YOUR ABILITY TO PARTICIPATE IN THE FOLLOWING AREAS, IF THE RESULT WERE SHORT TERM (FOR EXAMPLE, EXTENDING PROGRESSION-FREE DISEASE BY 6 MONTHS)?



*I would be able to have a longer period without progression. When I was diagnosed with metastatic breast cancer (four years after my initial diagnoses and treatment for stage 1), **I was given 6 to 9 months to live.** In 3 months, I will have had metastatic disease for four years. I would have tolerated (and still would tolerate) anything to extend the progression-free period.”*

*“**Any new treatment** options that become available that would extend life for even one day is beneficial to me and my family.”*

*“**Six extra months of progression-free disease, wow,** I don’t think I could properly explain the elation sense of hope and relief; especially when that comes after a previous treatment has been discontinued because the disease has progressed.”*

Others indicated the importance and need to balance both progression free survival and quality of life:

*“Having suffered from pain and fatigue, I know that **maintaining some quality of life is important.** But I*

want to balance that with my desire to be around for my young children, as long as possible.”

“If it would give me more time to be with my kids, it would be worth it...but not if I am in excruciating pain and was totally incapacitated.”

“In my wife’s case the use of anti-inflammatory steroids as a pre-treatment for chemotherapy or radiation definitely seems to contribute to the onset of severe anxiety / depression symptoms. **Any new treatment options that extend progression free disease significantly and do not involve debilitating side effects would be extremely welcome.**”

“If there wasn’t a hope that the treatment would extend progression (sic) free disease more meaningfully (one year plus), **I don’t think I would be willing to make significant sacrifices in quality of life.**”

Finally, respondents were asked to elaborate on what access to new treatment options for metastatic cancer would mean even if results were short term (progression free survival for 6 months). They shared many perspectives including the importance of having multiple options and the ability to choose and decide what risks they, as patients, are willing to take or tolerate:

“Access to new treatment options would give me the liberty and dignity of choosing how I live with the disease and choosing my quality of life as I near the end of my life. **It is most undignified that I must fight so hard** and inevitably lose gaining access to certain treatments/drugs that exist but one who is already dying must be ‘approved’ in some way to receive - and be denied!”

“The most important sense of hope for me, when my wife was diagnosed with metastatic breast cancer, was that

there were a number of treatment options available and **as one fails it is replaced by another** but that hope turns to despair and heartbreak as she nears the last treatment option available to her.”

“It has been just over 1 year since diagnosed with metastatic breast cancer. I am just learning the way around the medical field and the attitude towards metastatic patients. **I feel that ANY treatment should be offered to us regardless of side effects.** Depending on where I am in my cancer journey, then I could decide if the side effects are worth the results.”

“The patient should be the one to decide if the side effects are too bad. Let us try a drug if we are willing after hearing all the possible side effects.”

“I think patients (ESPECIALLY young patients) should be given **more decision making power in terms of access to radical treatments to control disease...** with two small children, I am determined to access any treatment that can extend my life and I hate struggling with doctors for this access.”

CONCLUSION

Attempting to understand and seek out help and resources needed to cope with a breast cancer diagnosis is daunting for anyone. For women who have a diagnosis of metastatic breast cancer who have additional fears such as, access to treatments, support and financial burdens, the experience can be incredibly overwhelming.

CBCN and Rethink are hopeful that the results of this survey will promote a better understanding of the unique needs and challenges of women living with metastatic breast cancer and their caregivers.



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