

Dra. Christine Maheu: “An average of 30% to 50% of the cancer survivors will require professional support”

- 1. The number of cancer survivors increases every year, which is very good news, but then the return to a normal life is not easy for these survivors. What are the main effects of cancer in patients’ personal and social life?**

The main effects of cancer and treatment on individuals’ work ability and return to work include dealing with the late and long term effects such as cancer-related fatigue, cognitive changes such as difficulty with multitasking and concentration. How the late and long-term effects of cancer and its treatment will impact the individuals’ personal and social life, and overall quality of life depends on their severity and how they are being addressed.

The psychosocial impact of a cancer diagnosis is increasingly recognized as a significant clinical issue. The most extensively assessed constructs in psycho-oncology are Fear of Cancer Recurrence (FCR), Health Anxiety (HA), worry, and uncertainty in illness (1–4).

Most of these effects remained under-recognized and under-treated in oncology practice (5), causing lots of distress to people. Patient-reported outcome measures (PROMs) are advocated for use in routine cancer clinical practice for early detection of distress and for evaluating the quality of care on health outcomes (5).

Work and distress: SEE IN CANCER NURSING MODULE.

- 2. How about the return to work? What does the studies and your experience say about the challenges these people face after recovering? Which are the most difficult to face? And which the most hidden or unnoticed? (self-esteem, cancer recurrence...)**

Following the end of treatment, individuals can feel abandoned and alone for no longer having that safety net around them from their regular visits with the oncology team. Fear of cancer recurrence (FCR) is a common emotion affecting the majority. While this emotion is normal, it can reach levels requiring professional clinical support. Approximately 55% of all individuals with cancer will experience clinical levels of FCR.

Cancer diagnoses are associated with a reduced HRQOL and work ability: While most CSs who were employed before their cancer diagnoses continue to work after treatment, recent systematic reviews report that one in five CSs will experience cancer-related disabilities that reduce overall HRQOL and work ability (6,7). Longitudinal studies also demonstrate that reduced work ability among CSs is associated with an increased incidence of depression, financial difficulty, cancer-related fatigue, neuropathy, and ultimately a poorer global health status (8,9). Consequently, the risk of unemployment among CSs is 40% greater than that of healthy individuals (10). *Collectively, cancer represents a major public health issue that reduces HRQOL among CSs and is a leading cause of economic burden from diminished work ability, delayed RTW, job loss, and early retirement (10–12).*

Reduced HRQOL and work ability among CSs have consequences at the individual and societal level: As the majority of CSs are in the prime of their working lives, reduced work ability and the inability to

RTW in a timely manner imposes significant personal, social, and financial strain at the individual, familial, and societal level (13–16). Recent reports estimate that the indirect cost of cancer among Canadian CSs (e.g. through loss in work hours) was \$3.18 billion annually and that survivors' annual household income was 26.5% lower (~5K) than the general population (17,18). A recent review highlights the economic burden of cancer, and advocates for the government to ensure support is in place to help buffer the impact of cancer and its treatment so that CSs can continue to engage in productive lives (19). As shown, delays in RTW negatively impact HRQOL, while re-employment is associated with increased HRQOL scores among CSs (8,20). *Taken together, these findings demonstrate that work ability and RTW are essential to improve HRQOL in CSs and ultimately to their overall health and economic recovery to assume a fulfilling and productive life (21).*

3. Can we find significant differences between men and women or depending on the age (or other parameters)?

Yes, literature shows that women delay RTW in comparison to men, and older individuals return later. They also tend to return to work with work changes such as fewer hours. Some go to early retirement when they get a diagnosis.

Breast cancer is the largest population with cancer and ends up being women. Depending on the intensity of treatment, like with chemotherapy, there is a greater risk of delayed RTW.

We notice that women have a more challenging time with RTW related to side effects and economic factors.

We know that the duration of absence from work after diagnosis for early-stage breast cancer was 11.4 month plus or minus 5.5 months and significantly longer for those who had chemotherapy and multimodal therapy delayed return to work (22).

Receiving chemotherapy is a determining factor in work ability and return to work:

- Receiving adjuvant chemotherapy shows that the full-time employment rate tends to decrease from pre- to post-adjuvant chemotherapy (**54% to 32%**) (23).
- chemotherapy (alone and with other treatments decelerated return to work (24) (Marino et al 2013)
- Women who were treated for breast cancer with chemotherapy had longer return to work absence than those who did not (9.5 months versus 5.4 since diagnosis (25)
- Breast cancer survivors with higher symptom burden and lower function are associated with lower work retention.

From a systematic review by van Muijen et al. (2013), they found:

- Heavy work and chemotherapy were negatively associated with return to work.
- Less invasive surgery was positively associated with return to work.
- Breast cancer survivors had the greatest chance of return to work.
- Old age, low education and low income were negatively associated with employment.
- Moderate evidence was found for extensive disease being negatively associated with both return to work and employment, and for female gender being negatively associated with return to work.

4. Do you consider that all cancer survivors need help from mental health professionals? Even when their main problems are mostly related to work?

An average of 30% to 50% will experience distress and anxiety that will require professional support such as group work. A smaller percentage 10% to 15% will likely require one-to-one support from intense psychological therapy. The others could benefit from community support. Hence, it is always best first to screen, then to determine what is the best approach for that individual. Definitely, all cancer survivors should receive distress screening and this being done for all follow-up visits. Distress can occur at any time during the cancer journey.

5. What is the most necessary kind of help these specialized professionals can provide in these cases?

Depending on the intensity, can be for mild, using community resources, directing them to self-management support like MoodfX, to more intense psychological support.

6. In your opinion, when is the best moment to these professionals to start their intervention with these patients? Why?

Ideally, communication with cancer survivors about work starts at diagnosis and continues on at least a year after they have returned to work. Initially, cancer survivors need to know how their cancer and its treatment will affect their work abilities, to help decide whether they can continue or need to temporarily stop working, knowing when they can eventually return to their former job, or if they need to consider at alternative work or apply for disability or sick leave (if these are available to them) (26).

After treatment, ongoing assessment and communication are needed to determine if waiting for recovery of symptoms (such as neuropathy, cognitive challenges, bowel and bladder problems) may have plateaued to move into a more active return to work planning.

For FCR, it tends to rise after the end of treatment. So definitely when the person nears the end of the treatment, discussion and assessment to see if they are suffering from FCR should be done.

Advance planning for a return to work is often needed for those who will need to have work modification, alternative work at the work site or need to find other work at another worksite and out of their field as this takes considerable time to plan. PCP can also help survivors obtain realistic expectations of functional limitations to help them come to terms with the changes they may need to take to allow them to return to work (26).

7. Can you explain to us some successful cases you have had or known which can be representative of the importance of this kind of treatments after cancer?

My co-lead with Cancer and Work is a vocational rehabilitation counsellor with 25 years of experience and shared that, what she often encounters are cancer survivors dealing with psychological issues that have not been addressed until they come to her. Following her counselling sessions, she often sees that these individuals had been sitting with depression until they discuss returning to work not noticing that depression had not been treated and was impacting their ability to return to work. As

psychological issues are common following cancer, and that these can reduce an individual's ability to return to work in a timely manner, individuals should be screened and assessed at each follow-up and be asked, if they are delaying return to work for fears and anxiety. There are those who feel that work increases their stress and by increasing their stress level, they increase their risk of recurrence. However, the evidence is not there to support this link. What we do know is that people have more stress and weaker immune systems, making them more prone to illness.

8. Why have you dedicated your career to this particular subject? What makes it so interesting or important for you?

Because cancer does not end with the end of treatment. Individuals continue to have lingering issues following cancer and end of treatment such as high levels of fear of cancer recurrence that affect their overall health-related quality of life which has an impact on their work ability and return to work.

What we are seeing is that there are major issues with the economic burden of cancer.

Economic Impact on cancer survivors from reduced work ability

- At least two-thirds of all cancer survivors are expected to report cancer-related financial difficulties as a result of loss of work (27).
- Reduced productivity, missed time from work, and job loss can lead to loss of benefits, income, and important social connections, leading to financial hardship for survivors and their families (28).

Financial hardship as a result of cancer and job loss:

- is increasingly being documented among cancer survivors(29,30).
- Estimation from 2009 indicates that new cancers in Canada generated a wage loss of \$3.18 billion yearly and that for those facing cancer, their annual household income was 26.5% lower (~\$5K) than the general population(17).

Considering the economic impact of cancer treatment, attention is warranted as part of Cancer Survivorship Care.

9. Now you are the co-director of Cancer and Work. What do you do, what kind of experts are working in it, which are your mean goals...

I'm working with the co-director who is a vocational rehabilitation counsellor of 25 years. We have been working together for over 8 years and together have drawn many disciplines to contribute to Cancer and Work such as health professionals occupational therapist, physiotherapist, neuropsychologist, work wellness institute, cancer survivors. Such as, now we have a study with self-employed cancer survivors to hear of their experience with remaining at work during treatment. From the results of this study, we will produce testimonial videos to teach others strategies to manage work while being self-employed and receiving treatments for cancer. We are also developing an e-course to train primary care providers on how to support the return to work process of cancer survivors. This course is an accredited course and will be freely available this summer.

In Canada, the indirect cost of work-related cancer impairments is estimated at \$3.18 billion annually. Although delays in RTW negatively impact overall HRQOL, re-employment is associated with increased HRQOL scores among CSs. Evidence suggests that a multidisciplinary approach that includes physical, psychological, with a strong work-focused vocational rehabilitation (VR) component improves RTW rates in CSs. *Despite these recommendations, cancer survivorship care models have yet to integrate VR components in RTW interventions as means to HRQOL, work ability, and RTW rates among CSs.*

Our research plan is to conduct a pragmatic preference trial with a 2-year follow-up to compare the effectiveness between the two study treatment arms, *iCanWork*, a VR led work-focused cancer care web-based intervention, and usual care on the study outcomes HRQOL, work ability, and RTW rates, and assess treatment satisfaction, and *iCanWork*' cost-effectiveness. Our trial will include consenting CSs from 4 participating cancer centers and open to all eligible interested CSs in Canada.

10. As a researcher, can you bring to us some of the last findings from researchers in this field of study? Any good news?

For both FCR and RTW the fields are moving faster now since recognizing the health and economic impacts of these two issues for cancer survivors. What we are seeing are research moving from just descriptive, longitudinal studies to intervention studies. Hence moving from what is wrong to what can be done about it. Such as, for RTW, the latest systematic reviews recommend a multidisciplinary approach with strong vocational components. Thus, this is the approach we are proposing to test in our coming *iCanWork* interventions.

For FRC, I have just completed a randomized clinical trial showing the effectiveness of cognitive-existential group therapy for its efficacy to reduce FCR immediately after the 6-weekly sessions and up to 6 months after. Our paper is currently under review.

11. Do you consider that the society increasingly understands the importance of mental health care in general and Psycho-oncology in particular? Does the governments?

In general practice, not so much. Psycho-oncology issues still remain under-addressed and cancer survivors are uncomfortable bringing up the topic as they think they should be grateful that their cancer is in remission. There needs to be greater understanding and awareness by general practice on the late and long term effect of cancer and its treatment with FCR, cancer distress, depression, and work ability impairments being some of the top unmet, debilitating needs. Still remains underaddressed. More screening needs to be done. In Canada, psychological support is not covered by the province. A major barrier to raising these possible issues with patients is the lack of services to provide if a need is identified. There is the idea that if you cannot offer support for a possible problem, you don't screen for it. Yet, there are many options that could be thought of to counter this barrier such as knowing what are the available studies that could support these needs for free as done with a research project.

12. In April, you will be talking in this conference for Catalan College of Psychologist called “After cancer: return to life, return to work”. What is the most important idea that you would like listeners (most of them psychologist) to learn from it?

We are noticing that psychological issues need to be addressed sooner than later because, when left undressed, they become barriers to RTW. We know from the literature that work ability at 6 months post-diagnosis predicts RTW at 18 months. Hence, if a person is suffering from FCR, and has for example neuropathy, her work ability is reduced and she is at risk for delayed RTW if she does not get the counselling she needs. The counselling needed would be both from a psychologist to help deal with FCR and a vocational rehabilitation counsellor or social worker to help address the neuropathy and to provide for work accommodation ideas.

Professionals should be asking their patients about what is their concern with returning to work. They should provide patients with self-management options to deal with anxiety, and having in mind, their work site. Hence, how to manage anxiety while at work. This could be as simple as guiding them to assess what brings them relief such as walking. They could be recommended to take shorter breaks during the day but increasing the amount so that they could go out many times during the day to take some fresh air and brisk walk.

When psychologists assess their patients for mental issues, they need to contextualize this issue of mental health challenges, and work, and money issues. Need to learn to get at the economic burden of cancer that can cause anxiety and difficult situations with work. Such as, returning to work too soon when not physically or mentally fit because of money problems.

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