



## Report of the Professional Issues Forum on **Cancer Survivorship** Saskatoon, SK CAOT Conference 2011

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### **Introduction**

The Cancer Survivorship Professional Issue Forum (PIF) was held at the TCU Place in Saskatoon on June 23rd 2011 from 1:00 pm to 4:00 pm. The Forum was facilitated by Natalie MacLeod Schroeder. There were approximately 30 people in attendance, though attendance varied throughout the Forum. Participants included clinicians, cancer survivors, and staff of cancer-related organizations. The purposes of the cancer survivorship PIF were to:

- Explore the rehabilitative needs of individuals living with and beyond cancer, the competencies required to work in the area of cancer survivorship
- Introduce and make CAOT members aware of practice opportunities in the field of oncology and cancer survivorship and the resources that exist to support these practices.
- Expose CAOT to best practices in cancer survivorship care.
- Formulate a position statement on cancer survivorship and occupational therapy for publication.

This report will summarize the cancer survivorship PIF presentations, discussions and recommendations.

### **Background**

An individual can label him or herself a cancer survivor from the moment of diagnosis and for the balance of life, regardless of whether death was ultimately due to cancer or some unrelated cause or event (National Cancer Coalition for Cancer Survivorship, 2006). “Cancer Survivor” is a term intended to honour people who are living with and beyond cancer. Nearly one million people in Canada count themselves among a growing population of cancer survivors (CPAC, 2010).

At this time there are limited resources, guidelines and support for Canadian occupational therapists working in oncology and cancer survivorship. Cancer survivorship is a growing practice area for occupational therapists in Canada due to the growing population of individuals living with and beyond cancer. This growing population presents a need for collaboration in the development of best practice in occupational therapy for addressing the diverse and unique needs of cancer survivors.

## Facilitators

**Natalie MacLeod Schroeder**, PhD Candidate, MSc, OT Reg (MB) is an occupational therapist from Winnipeg Manitoba. She is currently the Education, Systems and Research Coordinator for Health Sciences Centre, an instructor at the University of Manitoba School of Medical Rehabilitation, and a doctoral candidate in Education. She is the current CAOT Board Director for Manitoba. In recent years, she has been involved in a pilot program in partnership with the University of Manitoba, Health Sciences Centre and CancerCare Manitoba co-supervising Master of Occupational Therapy students in a student led occupational therapy clinic for people with cancer.

**Janet Craik**, MSc., OT (C) holds a Bachelor of Science degree in occupational therapy from Queen's University and a Master's degree in Rehabilitation Science from the University of Toronto. Janet has many years of experience in occupational therapy as a front line clinician, educator and manager. Her knowledge and expertise in project management and her research interests in knowledge translation and professional practice issues help her in her current role as the Director of Professional Practice for the Canadian Association of Occupational Therapists.

## Panelists

**Dr. Margaret Tompson** Since becoming a cancer survivor in 1999, Margaret has had the opportunity of meeting many cancer survivors at varying stages of their cancer journey and has shared stories with them. She has been involved in: support groups, advocacy groups, educational sessions for breast cancer survivors, an advisory group to the local cancer agency, national groups studying cancer survivorship care needs, a conference on cancer survivorship, the Canadian Cancer Society peer counselling program. Finally, though now retired, Margaret was a practicing occupational therapist in Saskatchewan for over 33 years, has a doctoral degree, is a CAOT Fellow and has been one of the past CAOT Presidents.

**Dr. Margaret Fitch** has a Bachelor of Nursing, Dalhousie University (Halifax), a Master's of Science in Nursing (Faculty of Nursing) and Doctorate (Institute of Medical Science), University of Toronto. Dr. Fitch holds the positions of Head of Oncology Nursing and Supportive Care and Co-Director of the Patient and Family Support Program at the Odette Cancer Centre (Sunnybrook Health Sciences Centre). She holds appointment as Associate Professor in the Faculty of Nursing and Professor in the School of Graduate Studies at the University of Toronto. Dr. Fitch is the Chair of the Cancer Journey Portfolio of the Canadian Partnership Against Cancer.

**Stephanie Phan** is an occupational therapist in the Survivorship Program at Princess Margaret Hospital. She is involved in the Fatigue, Function & Mobility, and Lymphedema clinics. She has worked in various areas of cancer care including hematology, solid tumours, palliative care and psychosocial oncology. She has recently presented at national and international conferences on the use of a logic model in developing a cancer-related fatigue clinic at Princess Margaret Hospital, breast cancer and patient education as well as on the role of occupational therapy in

oncology practice. She holds a Status-Only Lecturer appointment within the Department of Occupational Science and Occupational Therapy department at University of Toronto and is a preceptor to occupational therapy students.

**Leila Amin** graduated from the MScOT program at McMaster University in August 2009. She is currently a graduate student in the School of Rehabilitation Science at McMaster with research interests in the area of paediatric oncology. As part of Leila's thesis project she is working on a team to develop a questionnaire that can be used to measure "transition readiness" in childhood cancer survivors. Once complete, the questionnaire will serve as a tool to flag survivors who may be more likely to discontinue attending follow-up appointments into adulthood. Leila plans to use evidence generated from her thesis to participate in setting the direction of a research program that further develops the role of occupational therapist on paediatric oncology teams and that reflects provision of cancer care in a family- and client-centred fashion. Her other research interests include evaluation of outcomes such as quality of life in childhood cancer survivors as well as developing adequate supports for siblings and parents of bereaved cancer patients. Leila has dedicated much of her spare time to engaging in extra-curricular activities that involve working with children who have cancer and their families. She has been a volunteer at The Hospital for Sick Children as well as Camp Trillium Childhood Cancer Support Centre for over five years. She has also been involved in the creation of a documentary entitled Kids Care, designed to assist families deal with the death of a loved one due to cancer. Leila's career goal is to become an occupational therapy clinician scientist at one of the 17 paediatric cancer centres in Canada, working to improve the quality of care, quality of life and long term outcomes of children living with cancer and their families.

### **Summary of Issues Raised During Panel Presentations**

**Dr. Margaret Tompson:** Dr. Margaret Tompson spoke to the forum not as an occupational therapist, but as a 12 year cancer survivor. She shared her personal story of learning a new language of cancer which included chemotherapy drugs, radiation protocols, blood counts and staging of tumours. She related her experiences adjusting to the "new normal" following cancer treatments including fatigue, residual impairments, adapting to a new body image, coping with "brain fog", and changed work capacities. She further shared her change in focus on the cancer journey from the focus on survival in the treatment of cancer, to identifying priorities in surviving and thriving following a cancer diagnosis.

**Dr. Margaret Fitch:** Dr. Margaret Fitch presented the issues of survivorship within Canada and initiatives of the Canadian Partnership Against Cancer. She summarized the issues of cancer survivorship as being a neglected phase of the cancer journey.

<http://www.caot.ca/pdfs/PIF/P2%20PIF.pdf>

Cancer recurrence, second cancers, and treatment late effects concern survivors and there are few guidelines on follow-up care. Further complicating the issues of survivorship is the fact that there is a lack education and training for health care professionals in this area.

Cancer survivorship in Canada: More people are living as cancer survivors in Canada due to increasing incidence and prevalence of cancers, scientific advancements and new treatment protocols. With the increasing number of cancer survivors, there is a need for care that balances health and illness care. Cancer treatments can result in serious complications which impact quality of life. These include physical, psychological and cognitive symptoms such as loss of comfort, decreased mobility and physical functioning, decreased self-esteem and self-image, altered cognition, and fear; changes in roles, employment and recreation; difficulties accessing on-going health care; and increased risk for further cancers (Aziz & Rowland, 2003; Denmark-Wahnefried et al, 2005; Ganz, 2001). Care for cancer survivors is further complicated by a number of barriers such as a lack of knowledge on the part of health care professionals, lack of role clarity in the follow-up of cancer survivors, lack of knowledge on the part of survivors themselves as to needs and expectations, poor public awareness, and a lack of research to inform practice, education and policy.

Canadian Survivorship Initiatives: An environmental scan regarding survivorship (2007-8) identified a number of issues: 1) different definitions of cancer survivorship, 2) cancer survivors are not a homogeneous group with respect to risk and needs and a better understanding of needs is imperative, 3) care of the cancer survivor needs to focus on prevention of cancers, surveillance, intervention and coordination, 4) cancer survivorship care in Canada was believed to be patchy and, overall, not of high quality and 5) models of care, guidelines and care plans are needed. These findings were supported by two Provincial workshops which identified a range of physical, psychosocial and practical needs on the part of cancer survivors and an overall lack of follow-up care and support.

A national workshop in March 2008 worked toward creating an agenda for cancer survivorship. At this workshop, priorities for cancer survivorship were identified:

- Establish national standards and guidelines for survivorship care
- Identifying appropriate models of care delivery to meet the long-term needs of survivors
- Development and implementing survivorship care plans
- Promoting survivorship research
- Ensuring effective knowledge translation
- Facilitating a comprehensive communications plan
- Promoting a consortium of national cancer advocacy groups

This work has resulted in the Survivorship Project for the Cancer Journey Action Group which has a focus on managing cancer transitions, developing online support groups and has established 11 recommendations related to the structure and delivery of care to cancer survivors and 8 recommendations related to psychosocial and supportive care of cancer survivors.

Recommendation 1 (Structure of care): Access to survivorship services to meet a broad range of needs - It is recommended that survivorship services be recognized as a distinct component and standard of cancer care with service arrangements to meet a broad range of psychosocial,

supportive (information, psychological, social, physical and spiritual) and rehabilitative needs of survivors.

Recommendation 1 (psychosocial/supportive care): Supporting healthy lifestyle behaviours - It is recommended that survivors have access to self-management focused education and support to facilitate tailored adoption of healthy lifestyle behaviours inclusive of: daily physical activity; balanced nutrition; and smoking cessation programs to improve health related quality-of-life and physiological outcomes, reduce distress and risk of recurrence.

Implications for research: A number of research initiatives are currently underway across Canada and cancer survivorship has been identified as a priority by a number of funders. There remain a number of research needs related to cancer survivorship including a focus on survivorship treatments, creation of interdisciplinary teams (clinician and research) which includes primary care, oncology, nursing and allied health.

Stephanie Phan: Stephanie discussed her experience creating a role for occupational therapy in a cancer survivorship clinic. This role is the direct result of a strong advocacy effort on the part of the occupation therapists at Princess Margaret Hospital. To develop the role, a funding proposal was developed to fund a pilot project on the role of occupational therapy in breast cancer survivorship. As a result of this pilot project, a permanent position for occupational therapy was established which Stephanie now holds. In this position, Stephanie acts not only as a clinician providing occupational therapy services, but as an advocate for both the client and occupational therapy but also as an educator, researcher and program developer.

<http://www.caot.ca/pdfs/PIF/P3%20cancer%20PIF.pdf>

In order for occupational therapists (or any health care provider) to work in the area of cancer survivorship there are a large number of learning needs. These include: a general understanding of the issues of survivorship and issues of quality of life; knowledge of prevention, detection and treatment of recurrent and secondary cancers; an understanding of health care systems and models of care in cancer treatment and survivorship; knowledge of rehabilitation services; knowledge of pain management; and knowledge of palliative and end-of-life care (Ferrell et al., 2003). A program in survivorship care needs to address the prevention and detection of new and recurrent cancers and side effects of treatment and access to effective interventions for ongoing symptoms and issues. The focus should be on healthy behaviours which improve quality of life and ensuring that survivors are able to direct their care with an organized plan for services and follow-up.

Stephanie identified that barriers to survivorship care continue to exist. The fragmented delivery system for oncology services often results in poor coordination. There is often no centralized responsibility for coordinating care which can result in difficulties in communication. The lack of standards of care for this population also affects service delivery. Health care providers (as well as the system) often lack the knowledge and capacity to deliver survivorship care. Finally, there is a lack of guidance provided to survivors in methods to maximize their own health outcomes. Stephanie provided a review of a number of resources available related to

cancer survivorship including clinical practice guidelines, cancer societies and networks, journals, websites and specialty certifications in cancer rehabilitation for clinicians working in the area of cancer which would assist clinicians and clients.

Survivorship Program at Princess Margaret Hospital: The goals of the Survivorship Program include:

- Empower and prepare survivors to manage their health with appropriate self-management support
- Recruit and train cancer survivors as a human resource
- Reallocate health care human resources through changing scopes of practice
- Apply e-health technologies to engage survivors by providing information and support at point of need
- Organize patient and population data to facilitate education, survivorship research and efficient and effective survivorship care

The survivorship program includes a number of initiatives including clinics which lymphedema, fatigue, function and mobility, neurocognitive and healthy bones. In response to an unmet need of cancer survivors for ongoing psychosocial support, the program developed a web-based patient portal which can provide information and virtual support to clients.

Leila Amin: Leila Amin presented on the barriers to occupational therapy in a cancer setting and potential methods to integrate occupational therapy into cancer care teams, based on her research into the transition from childhood cancer survivor to adulthood and the experiences she gathered. This research led her to identify a number of gaps to this population such as the need to prepare children and parents for the transition to adult care and address self-advocacy and self-management skills of the children; a need for increased coordination of services between paediatric and adult oncology teams; and the need to educate parents and children about the late effects of cancer treatments and risks for further cancers.

<http://www.caot.ca/pdfs/PIF/P4%20cancer%20PIF.pdf>

During her experience, Leila identified a number of barriers to occupational therapy's participation in oncology teams. In many cases, hospital policies and historical practices prevented occupational therapy from participating in these teams because of the restricted role of occupational therapy in these environments. There was a general lack of awareness of the role of occupational therapy among healthcare providers working in oncology. Finally, Leila noted a lack of representation of occupational therapy at national meetings and conferences related to cancer.

In order for occupational therapy to be included in existing or developing cancer care teams there is a strong need to educate other healthcare providers about the role of occupational therapy. She identified the need to promote the unique contribution of occupational therapy not only within the hospital context, but by participating in conferences and workshops which address cancer and cancer survivorship issues to build awareness. She suggests that

occupational therapists advocate filling the gaps in the services provided to cancer survivors. Occupational therapists also need to look beyond the hospital environment and seek opportunities to participate in collaborations and coalitions which address cancer care such as the Canadian Cancer Institute and the Canadian Partnership Against Cancer. Finally, given the lack of research in this area, there is a strong need for therapists to be engaging in research to demonstrate the role of occupational therapy in this population.

### Small Group Discussion

Powerpoint presentation: <http://www.caot.ca/pdfs/PIF/cancer%20pif%20closing.pdf>

Following the panel presentations and question and answer period, the forum participants divided into small groups to address two questions. The combined responses to these are below.

1. What are the possible roles of occupational therapists working to meet the needs of individuals living with and beyond a cancer diagnosis?

- Functional assessment
- Life goals/roles, beliefs, values, allow clients to assume risks
- Working with clients to thrive versus survive
- Work readiness
- Ability to address environment
- Prepare client to resume life roles and insight into changes following cancer
- Advocate for services
- A holistic approach (physical, psychosocial, cognitive, spiritual, etc.)
- Energy conservation
- Assistive devices
- Collaborate
- Assist in transitions
- Quality of life
- Model of delivery- Occupational therapists can be in acute care, rehab in community setting, telehealth

2. What is needed for promoting involvement of occupational therapists to achieve best client outcomes in cancer survivorship? (actions/conditions/structures/other)

- Research, evidence base
- Advocacy
- Education: for ourselves, inter-professional colleagues, insurance providers, other stakeholders
- Funding for services, resources
- Knowledge of the cancer experience, client and family input

- Student placements focusing on cancer care and survivorship
- Curricula in the academic program which address the issues related to oncology and cancer survivorship
- Pilot projects in clinics to demonstrate the role of occupational therapy
- Need to 'break into' cancer care offices; currently these are mostly physicians and nurses and not interprofessional teams.

## Themes

Throughout the panel presentation and the group discussions a number of themes emerged:

1. Occupational therapy is not well understood among health professionals working in cancer survivorship or by groups representing and supporting cancer survivors.
2. There is a general lack of knowledge and awareness among occupational therapists and other health care providers as to the issues of cancer survivorship and effective interventions.
3. The issues facing cancer survivors are consistent with the scope of practice and expertise of occupational therapists.
4. There is a need for CAOT to participate in coalitions, action groups and other collaborations and alliances related to cancer survivorship in order to further the role of occupational therapy in this population.
5. There is a need for research to develop and support the role of occupational therapy in cancer survivorship.

Following the presentations and the discussions at the 2011 cancer survivorship PIF, it is clear that the role of occupational therapy in cancer survivorship remains in its infancy. While the needs of the cancer survivors are consistent with the knowledge base and scope of practice of occupational therapists, there is a lack of awareness among occupational therapists, other health care providers and stakeholders as to the potential for this role.

## Final Recommendations

At the present time, there is insufficient knowledge and evidence to generate a position statement outlining the role of occupational therapy in cancer survivorship. There are great opportunities to develop this role within Canada given the increased interest nationally in cancer survivorship, and the fit between the issues facing cancer survivors and the gaps in service, and the role of occupational therapy. It is recommended that the Board explore further actions to develop the skill and evidence base for occupational therapy's role, as well as develop partnerships and representation with existing coalitions and alliances addressing cancer survivorship. It is recommended that educational institutions explore the integration of cancer survivorship issues and interventions within their curricula. Occupational therapists and occupational therapy programs/departments are encouraged to advocate on behalf of clients for increased funding and occupational therapy services for cancer survivors.

**(Nos excuses. Les ressources ne sont pas disponibles présentement pour traduction.)**