

# Evolving Role of Psychosocial Oncology in Regional Canadian Cancer Center

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## Abstract

Everyone's cancer experience is different and adjusting to life after treatment can also vary among survivors. A diagnosis of cancer in itself, raises many questions which impact the patient and their families. In addition to treatment patients receive under their oncologists there is a team of knowledgeable professionals available to help patients and families cope with the physical and emotional aspect of dealing with cancer. We evaluated the role of such individuals in our regional cancer center and found that they play a significant role in making the lives of our patients and their families better. Social workers provide a wide range of services including psychosocial assessment with action plan, education and counseling intervention. Information and referral linkage to resources and services in the community, along with transition planning are an important aspects of their responsibility. All services are provided from a psychosocial perspective to maximize a patient's potential for treatment while enhancing

## INTRODUCTION

In literature, it is noted between 35-45% of all cancer patients experience significant emotional distress. The number reaches 70% for palliative care patients<sup>1</sup>. Several studies have found that family members experience as much, if not more distress as the patient's.<sup>2</sup> The word psychosocial may seem intimidating but it may help to break down what it means. The root of "psycho" relates to the mind and "social" reflects the relationships people have with family and society<sup>3</sup>. For the people diagnosed with cancer, a psychosocial oncology worker is an important member of the health-care team as he or she provides services such as counseling, education, information, support group and referrals to community resources. Patients are also provided assistance in order to seek financial help. An oncology social worker often acts as a liaison between people with cancer and the medical team and helps people find ways to navigate the health-care system. Social work is an important part of the treatment process for oncology and hematology patients and their families in any cancer clinic. These services are focused on assisting patients and their families in coping with stresses associated with their diagnosis of any kind of malignancy. Social workers assist with a variety of physical, psychological and social adjustments, as well as planning and implementing appropriate and timely discharges. The Social Worker's role is to enhance the patients/families

ability to cope, and their adaptation to the stresses associated with diagnosis, treatment, hospitalization and discharge. Social Workers provide a wide range of services and all services are provided from a psychosocial perspective to maximize a patient's potential for treatment while enhancing the integrity of the patient-family system.

## MATERIAL AND METHODS

We reviewed the role of the Clinical Oncology Social Workers at our regional cancer center from 1st Jan 08 till 31st December 2008. In the Allan Blair Cancer Center, Regina in the year 2008, the total number of new patients seen were 1141. This does not include pediatric oncology patient case load and patients from our other provincial treatment center located at Saskatoon. The computerized data base and social workers personal data sheet were reviewed.

## RESULTS

In Allan Blair Cancer Center, Regina in 2008, a total of 1141 new patients diagnosed with histology proven malignancy, were registered. Referrals can come from general practitioners or any specialists. Contact is initiated within 5 days of receiving the referral at patient's referral center by a social worker called Patient Access Coordinator (PAC) prior to their first appointment. PAC will attempt telephone contact with each patient. Each attempted contact is documented in our computerized medical system

(CMS). Three phone contact attempts without completion is considered sufficient. In the year 2008, PAC completed a total of 949 calls. During this interaction, the patient is provided with emotional support and information designed to assist them as they await their initial appointment with an Oncologist. Patients are being provided with contact information should they require further previsit as support. At the same time, a letter is sent to the referring physician as notification we received the referral and their patient has received PAC services. PAC was not able to contact 192 patients due to various reasons documented in CMS system. The most common reasons were: patient request, language barrier, deceased patient and hospitalization. We made notification to 976 referring physicians. Twenty eight patients were contacted but were not seen at clinic by the oncologist. The PAC will follow the patient after the initial call if psychosocial concerns have been identified, until such time as they have been given an appointment with their oncologist. At that point, PAC will refer to that oncologist's assigned social worker for ongoing psychosocial care. Further assessment will be done by the regular social worker. If at any point while patient remains on the wait list and PAC thinks patient needs more support then they will be referred to a clinical oncology worker. Patients receive their social worker's card with all relevant information (about clinical oncology worker) in their orientation package on the first appointment day when they present at the Cancer Center Admitting Office. Social workers made 1592 support calls in year 2008 to patients on the waiting list in addition to the regular initial PAC call. These calls are result of PAC wanting to follow up or due to calls coming in to the Clinic from the patient with concerns or questions prior to their first appointment. The PAC position is covered at all time, when the assigned social worker is absent due to holiday or sickness; she is replaced by another member of the social work team.

At the present time, patients are required to wait until they receive a appointment to see a oncologist and receive their definitive treatment. Referral Centre's and health care workers often receive calls from distressed patients and families during this waiting period. With introduction of the PAC program the anxiety is reduced and services are improved. PAC at our center does the initial psychosocial assessment, provides support for psychosocial needs including: financial concerns, health system concerns, family issues, attitude/reaction to diagnosis and capacity to cope issues. More specifically the areas where patients need increased support are in providing information about the

referral process and why they are waiting, their first visit, who the members of their team are. They also introduce them to links with necessary community resources. PAC will give a description of what to expect at initial visit, what things are associated with travel, transportation, and lodging. PAC's major role is to reduce anxiety in waiting period and provide support to make patient and their family members comfortable. At our center both with recent accreditation survey and operational review recognized that patients and families desire to have this service available prior to their first appointment with an oncologist.

The total new referrals to social work, once oncologists assess the patients, were 899. In 2008 we had 4 full time social workers who handled a total of 805 new patients, averaging 201 patients per social worker and an other 94 referrals handled by the department manager or staff working on a temporary basis. The number of average ongoing total case loads (new and review patient) seen on a monthly basis by a social worker is 100. Frequency of these contacts varies from daily to bi weekly to monthly contact depending on an individuals needs. These figures are outside of any PAC caseload statistics. After the first meeting with oncologist the treatment management plan is discussed. The social worker works with patients and families to develop a plan for living with the treatment by identifying their coping abilities, physical needs, family and spiritual needs, and providing support. Individuals make decisions that may not be the choice of family members or even health care team so this support helps them through the cancer journey. All cancer patients need emotional support which ranges from orientation to in depth counseling. The majority of families (80%) need counseling especially in context of life style adjustments, sexuality, fears and denial. Thirty percent of patients in first few weeks of consultation are provided with palliative care counselling and referral because of advanced stage of their disease. They receive support, assistance and guidance regarding end of life issues. Family members receive reassurance and comfort while experiencing grief and are offered bereavement counselling as well. The majority of out of town patients seek information on accommodation, especially if they have to receive radiation for 6-7 weeks. Each SW enter their daily work load in an excel spread sheet. Each 10 minutes they spend with patient or related affairs is equivalent to 1 unit. An audit of social worker time spent in their social work practice is done twice yearly, for the months of May and November which reflects the overall counseling/care work load. At the end of the year total units are calculated .In 2008, the full time 4 social

workers spent around 40 % of their time directly with the patient, either on treatment or in follow up, 12% with the family members, 11% with other health team members organizing and planning for patients, 7% with community workers, 20% in case conferences' and 10% in personal assistance. The time spent with patients varies depending on the severity of patient need and concerns. Usually patients will discuss their diagnosis and concerns that they think they will face during treatment and the impact on their spouses and children. Patients feel loved and cared once they form a bond with their Social worker. It is amazing that all the Social Workers know the patient's immediate family member by name which makes the patient feel loved and cared for. In the oncology field, most of the patients need help to cope with mental turmoil and seek attention from family, friends and health care workers. Very few meet specialist in the psychosocial field. The majority (> 80%) of patients want to have insight into the cancer diagnosis, treatment and survival. Very few (<10%) patients do not directly ask for help in dealing with overt anxiety or worries concerning themselves or relationship problem, other 5% wanted to talk about well defined problem. The remaining 5% were not motivated enough to see Social Worker. Some kind of financial aid and help was provided to 240 patients. Most of the patients and families are satisfied with services offered by our psychosocial department. All the goodies and flowers received by our radiation department always mention SW name and patients always thank them for what they did for them. In our setting we work as Doctor/Nurse/Social Worker team which is not done in many cancer centers. It provides for much quicker response time and the patient becomes familiar with "their team".

### **DISCUSSION**

Social work and human history go together. Social work was always in human societies although it began to be a defined pursuit and profession in the 19th century. This definition was in response to societal problems that resulted from the industrial revolution. .Eventually, an increasing number of educational institutions began to offer social work programmes. The settlement movement's emphasis on advocacy and case work became part of social work practice. During the 20th century, the profession began to rely more on research and evidenced-based practice as it attempted to improve its professionalism. Today social workers are employed in a myriad of pursuits and settings<sup>4</sup>.

The burden of cancer in Canada is significant and growing. The Canadian Cancer Society estimates 166,400 cases of

new cancer and 73,800 deaths from cancer will occur in Canada in 2008<sup>5</sup>. While the physical symptoms of cancer are addressed with medical treatment, the emotional impact of the disease frequently goes unattended leaving patients, families, and friends alone to cope, often ill-equipped to deal with the illness and unfamiliar with assistance and resources. Psychosocial oncology is a specialty in cancer care concerned with the understanding and treatment of the social, psychological, emotional, spiritual, and functional aspects of cancer, at all stages of the disease trajectory from prevention through to bereavement<sup>6</sup>. Cancer has a direct impact on the lives of millions of Canadians. Current incidence rates show that 39% of Canadian women and 45% of men will develop cancer. On average, 3,200 Canadians will be diagnosed with cancer every week and 1,419 Canadians will die of cancer every week<sup>7</sup>. A significant proportion of cancer patients at all stages of the disease will suffer social, emotional and psychological distress and challenges as a result of the disease and its treatment. Research demonstrates that psychosocial and emotional distress, which is often experienced in the form of depression or other adjustment difficulties, is a significant problem for up to half of all cancer patients<sup>8</sup>. The Canadian Association of Psychosocial Oncology's ( CAPO) national standards requires a process to be in place to identify the learning needs of psychosocial oncology professional and provide resources to achieve them<sup>9</sup>.

People diagnosed with cancer see so many health professionals along their journey from their family doctor, surgeon, lab technologists, diagnostic technicians, specialists, nurses, and radiation and medical oncologists. The Social Worker is most likely to be the constant in their care. As stated, the social worker is "the pivotal person in facilitating continuity of care in a system where so many professionals provide that care"<sup>10</sup>. They become the familiar face in a sea of so many and in an environment where information overload is often so overwhelming. This is why it is so valuable to all concerned if social work can be involved from the very first appointment with the oncologist. If social work can be involved with the patient/family right from the very beginning, anxiety is lessened which may alleviate many questions for the oncologists and nurses therefore freeing up more of their time for the medical aspect of the patient's care<sup>11</sup>. With the social worker being present she/he can be knowledgeable of the conversation that took place and can assess for comprehension of the information presented to the patient. If puzzlement is detected or if terms used are more of a medical nature the social worker is able

to provide immediate clarification using layman's terms or even asking for clarification for them to facilitate understanding for the patient. Sometimes patients won't ask if they don't understand something and then will leave without fully understanding. With Social Work being a part of the team from the initial visit and beginning to build a rapport with the new patient, everyone involved may benefit. In some cases, the services of the psychosocial department may not be needed at the time but at least the family is aware of the support available if they should require assistance at later date.

The oncology social worker's expertise is a comprehensive view of the person living with cancer that is respectful of each individual's ethnicity, spirituality, family situation, unique strengths and challenges and it is his or her job to represent a person's interests and needs to the medical team. In literature the role of a psychosocial oncology professional are enumerated below:

1. Psychosocial needs assessments to help the person with cancer and his/her family members identify what their potential emotional, spiritual, and practical needs are and plan interventions accordingly.
2. Counseling for patients and family members to promote optimal emotional health and coping. Counseling can address issues such as depression, anxiety, stress, and effects on family and relationships.
3. Support and education for parents who are supporting children with cancer.
4. Teaching patients how to work with the mind/body/spirit connection. For example, teaching stress management/relaxation techniques, guided imagery, meditation, etc.
5. Clinical issues often addressed in social work intervention include such things as a feeling of loss of control during diagnosis and treatment; difficulties coping with physical changes--as well as change and impairment of thought process and mood--resulting from disease and treatment; the need for social support both within the family and the community as this relates to a patient's psychosocial adjustment; the impact and consequences of role changes within the family and the need for internal and external resources for

adjustment and interpersonal issues of communication with loved ones and feelings which emerge from these relationships.

6. Social work research addresses the cancer experience across the lifespan, focusing on psychosocial interventions (e.g., support groups, educational groups, family groups, case management, telephone outreach, computer-mediated support groups); assessment of psychosocial stressors; community-based health promotion and cancer prevention strategies; outreach to high-risk communities to assist with screening, early detection, response to diagnosis, access to services and adherence; transitions between cancer stages and treatments as well as between the cancer experience and the "other" life; dealing with end of life and grief; long-term survivorship issues; mental health screening and services; and caregiver support and resources. Social workers study the impact of spirituality and cultural and ethnic heritage on the cancer experience and develop interventions that have real-world applicability<sup>12</sup>.

There is abundant data regarding the presence of psychosocial distress in cancer patients and its impact on their quality of life. In symptom cluster analysis, depression explained 26% of the variance in quality of life and 56% of the variance in functional status in cancer patients<sup>13</sup>. Pelletier et al found depression was a significant predictor of QOL in a sample of brain tumor patients<sup>14</sup>. Physical symptoms and side effects of treatment are identified by patients as their number one unmet supportive care need. With the help of proper assessment and early identification of these needs our patient population can be served better. Since Oncologists are quite busy with their clinical practice, the role of psychosocial oncology workers becomes more and more important. They can connect with these patients and focus on their different needs which vary from acute counselling to an interpretive psychotherapeutic relationship. MacCormack et al found that patients, irrespective of which treatment they had received, all talked about a unique conversational space to explore and discuss thoughts and feelings with an experienced and understanding professional who cares<sup>15</sup>. In our study we found that they are a valuable and integral part of the oncology team who really makes a difference in our patient's lives.

## **CONCLUSION**

In modern oncology the role of psychosocial worker is immense. They not only play a significant role in patient's life but contribute significantly in making the life of a busy oncologist easier and less stressful. By providing valuable support whether spiritual or family concerns, information on services available to them helps the patient come to terms with their diagnosis and related treatment. They help to alleviate anxiety which makes the life of patient and family member's much more peaceful. I would like to thank all the psychosocial workers around globe in the challenging field of oncology, whose dedication and hard work makes a difference in somebody's life.

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