IMMERSION IN THE FIELD OF CLINICAL ONCOLOGY SOCIAL WORK: A
FIELD PRACTICUM EXPERIENCE AT THE ALLAN BLAIR CANCER CENTRE

A Field Practicum Report
Submitted to the Faculty of Social Work
In Partial Fulfillment of the Requirements
For the Degree of
Master of Social Work

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March 2017

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Abstract

The following paper will reflect on my practicum experience at the Saskatchewan Cancer Agency, Allan Blair Cancer Centre. Utilizing critical self-reflection, review of current literature, and theory, I will highlight my learning goals and use these to focus on the contribution of the oncology social worker while stressing the importance of the multi-disciplinary team, the person centred approach to care, and best practice interventions with cancer patients. I will also describe how systems theory and the strengths perspective help to guide practice. Likewise, as I wanted to evaluate my own effectiveness in this occupation I will use relational theory to explore this in depth. Lastly, I will explain the importance of ethical practice in cancer care and suggest areas of emerging concern.
Acknowledgements

I cannot thank Sandra Goodman-Chartier enough for mentoring and supporting me throughout this process and afterward. Her kind, caring, and knowledgeable approach to oncology social work is exceptional and I believe I was able to learn from one of the best.

I wish to express my thanks to Dr. Garson Hunter for providing guidance and encouragement throughout my MSW experience and taking time out of his busy schedule to be my supervisor. Also, to Dr. Randy Johner for agreeing to be on my academic committee, providing much needed guidance and feedback.

I would also like to thank Dr. Ferguson, Dr. Amjad, and Dayna Desautels, for accepting me onto their team and taking the time to share with me their knowledge and experience in the area of cancer care. To the radiation oncology team for providing much needed humour, and for taking the time out of their busy days to answer my many questions. To the oncology social work team, including manager Joan Morris, for allowing me the opportunity to complete my practicum at the agency and assisting me in learning the social worker role. Special thanks to Grant Rathwell for, not only sharing his office space, but his kind, compassionate, encouragement throughout my practicum.

I would like to thank my family, Clark, Megan & Natasha for believing in me and putting up with me during the process. Lastly, I would like to thank the patients and their families for allowing me to be part of their cancer journey. It was through their openness and willingness to accept me into the process that heightened my learning and has led to my ongoing desire to do this type of work.
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Chapter One: Introduction

A diagnosis of cancer can be life changing, requiring people to make decisions that may impact whether they live or die. Given this fact, it is important for the oncology social worker to unconditionally accept people and their decisions and to provide any necessary supports along the way.

The following paper will outline my experience as a practicum student with the Saskatchewan Cancer Agency at the Allan Blair Cancer Centre. I will utilize my learning goals to delve into, not only the workings of the agency, but also the role of the oncology social worker. To do this I have chosen to highlight the multi-disciplinary team and person centred ideology as these belief systems drive cancer care providers to ensure the patient is at the forefront of all decision making. As you will see, the Saskatchewan Cancer Agency values and policies promote active patient participation in their own care and provides the resources to make this possible.

To understand and evaluate the role of the oncology social worker I will utilize the theoretical models of systems theory and the strengths based perspective as these are helpful in analyzing the patient experience thus providing some direction in how the social worker can support their client throughout their cancer journey.

Lastly, I write this paper from the viewpoint of a student learning the role of the oncology social worker, however four months after completing my practicum I was able to take my passion in this field and turn it into my career. Therefore, I am now in a position where I am able to continue my learning in the area of psychosocial oncology and am thankful for this.
Within this paper, I will utilize different terms to name the people I worked with. I have always referred to individuals who I work with therapeutically as clients, however, in the medical field they are called patients. I decided to explore these terms more to assist myself in deciding which terminology to use and whether it made a difference. I often believed a patient was someone who care was done to, meaning there was a power imbalance with the relationship, with the patient being inferior; whereas client meant someone who was equal to the clinician and entered into a joint process to achieve client goals. According to Shevell (2009), I am not far off. He states that patient means, ‘to suffer’ thus suggesting one who is passive and an object of another’s actions (p. 770). Conversely, client originated in psychology as a term utilized to reinforce the individual was not sick or ill and is an empowering term. Still there seems to be little agreement on which term to use. So, Wing (1997) suggests one ask the individual what they wish to be called. In this study, they sought out the input of individuals and found many wished to be called ‘patient’ due to their belief that such a term would keep their need to receive care at the forefront. He goes on to explain that regardless of the term one uses it remains important to ensure the autonomy of individuals, plus their needs and wishes, are always advocated for. Otherwise, he suggests, more work needs to be done to come up with a better term. I for one have decided to remain neutral to the terms and will therefore refer to those I work with as both clients and patients.

1.1 Rationale for Practicum

Choosing a practicum setting for my Master of Social Work program was difficult as I was uncertain which area to focus on. However, I had often wondered what it might be like to work at the Saskatchewan Cancer Agency. I recalled seeing postings for
positions at the agency but had avoided applying due to my concern that I would not be suited for oncology social work even though I had past experience in this type of setting.

Prior to my early university education, I had the opportunity to complete a placement at McMaster Medical Centre in paediatrics on the paediatric in-patient ward and outpatient clinic. I worked with many families who had a child with cancer and the memories from the placement have stayed with me over the years. It was a very fulfilling experience, even though they were dealing with the terrible fact that their child had cancer, the families were so giving that I felt like I had received as much as I had given. I truly felt that my work was important, helpful, and I loved it.

Still, when it came to applying for the posted job opportunities at the Cancer Agency, I worried that I would be unable to cope emotionally due to having loved ones of my own die from cancer in the past. I worried that in my care of others, I would somehow turn it into something about myself, and this would not be acceptable.

However, one day in my position for Child and Youth Services, I received a call from one of the doctors from the Cancer Agency. She was seeking out mental health care options for a young patient. It was through the follow up calls that I learned a bit more about the role of the oncology social worker and was provided with the name of a worker who would possibly be interested in supervising me. I found that I was excited about the possibility of returning to this type of work and I took the necessary steps to make it happen.

1.2 Practicum Proposal Learning Goal

The main goal for my practicum as outlined in my proposal was to gain knowledge and experience in the area of clinical oncology social work. In particular, I wanted to
focus on the contribution of the oncology social worker and how they fit within the multi-disciplinary team. Similarly, I wanted to gain an understanding of the impact a diagnosis of cancer has on the individual and their loved ones, how this is assessed, and what interventions are implemented throughout the course of the illness.

1.3 Agency Overview

My practicum took place at The Allan Blair Cancer Centre (ABCC) during the months of January to March 2016. The Allan Blair Cancer Centre is part of the larger Saskatchewan Cancer Agency and is located in the Pasqua Hospital in Regina. The setting of this centre is unique, because it occupies two main floors, the upper being outpatient and chemotherapy areas, and the lower floor housing the radiation therapy area. Also included is a ward in the Pasqua Hospital that, although it is part of the Regina Qu’Appelle Health Region, serves those who are receiving cancer care.

At present, there are 840 employees working across Saskatchewan at the Saskatoon Cancer Agency, the Allan Blair Cancer Centre, the sixteen Community Oncology Program centres throughout rural Saskatchewan, the various cancer screening programs, and the Cancer Lodge. The staff are medical and radiation oncologists, nurses, radiation therapists, social workers, physicists, pharmacists, health records, administration, and others, all working together as a multi-disciplinary team. After receiving a diagnosis of cancer, an individual may receive a call or letter from a ‘new patient navigator’. New patient navigators are clinical social workers who contact potential patients and inform them of their referral to the agency, provide them with valuable information about their upcoming visit to the agency, and often will assess if distress is presenting in the patient. This process itself can relieve some of the stress the
patient may be experiencing since they will now have a contact person available to them, gain information on what to expect when they arrive for their first appointment, and it allows them to ask questions that may have been weighing on them since learning they are to attend a ‘cancer’ centre (Adler & Page, 2008; Saskatchewan Cancer Agency, 2015).

During their initial appointment at the centre, patients will see a medical or radiation oncologist, who will outline the possible treatment plans available, suggest further investigation and answer the patients’ questions about the type of cancer they have and how it may impact them. This first visit can be quite overwhelming since individuals may interact with many members of the agency team and receive an abundance of information. This is where social work can be particularly useful, by helping the patient to increase their understanding of the process and to have someone with whom to express their fears and concerns. The overarching goal of the cancer centre is to provide each patient with access to the best care possible, both physically and emotionally. More detail of oncology social work will be provided later in this paper.
2.1 Person Centred Approach

Historically medical care was provided solely by the family physician who saw patients in their office or the patient’s home, with most of the nursing care provided by family members. However, as technology evolved, and with it new ways to doctor, the family physician was less able to carry out their duties on their own. Similarly, the advancement of medical specialties meant referrals to specifically trained physicians to assist patients with increasingly complicated presentations (Mitchell et al., 2012). Still, the well-established medical model, where the physician directs how and what treatment is offered to the patient, remained consistent, even though as previously mentioned, healthcare was evolving from viewing the person as a body with illness to recognition that illness impacts all aspects of the person, body, mind and spirit (Christie, Camp, Cocozza, Cassidy & Taylor, 2012).

Thus, it took patients becoming vocal, expressing their dissatisfaction with the medical system, along with the request for more personalized care where they would collaborate with the medical team, to instigate the development of multidisciplinary teams who would “interact dynamically, interdependently, and adaptively to achieve a common goal” (Taplin et al., 2015, p. 239). To establish this model of care the medical establishment needed to take on a new belief system where the patient is at the forefront and their wishes become the focus of treatment. This led to person centred care (Christie et al., 2012; Sharma, Bamford & Dodman, 2015).

Person centred practice originates in the field of psychotherapy where there was a movement away from the therapist as the expert toward a belief the client was the expert
of themselves and only required tools to increase their understanding of their problems
and possibly overcome them. According to Carl Rogers (1995) “individuals have in
themselves vast resources for self-understanding and for altering their self-concepts,
basic attitudes, as self-directed behaviour; these resources can be tapped if a definable
climate of facilitative psychological attitudes can be provided” (p. 15). Therefore, person
centred care is based on the belief in unconditional positive regard for the client and their
situation. Thus, clinicians require the capacity to be empathetic and willing to listen and
understand the patient’s concerns and make them the basis of care decisions. When the
client receives this type of care it allows them to take ownership of their own health and
become the key decision maker regarding their outcome (Christie et al., 2012; Ekman et
al., 2011).

Studies suggest the key component of person centred care is establishing a
therapeutic relationship as it sets the stage for the patient and medical professionals to
come together as a team. To do this the new team needs to develop rapport, understand
the beliefs and values of all members, trust and respect each other, and openly
communicate (Adler & Page, 2011). Once the relationship is established the patient
begins to feel they are a major part of the healing process and are empowered to make
their own care decisions. (D’Ambruoso et al., 2016; Mitchell et al., 2013; Sharma et al.,
2015).

For this process to be successful the medical team needs to evaluate the patient’s
capacity to understand the information provided to them, reduce the amount of medical
jargon used, be respectful of cultural differences, and consider the role of
family/caregivers in the decision making. They must also coordinate their services and
advocate for the patient wishes when necessary (Adler & Page, 2011). This approach requires an agency with policies supporting this type of care model, the capacity to establish multi-disciplinary teams to deliver the necessary services, and a process of ongoing evaluation to ensure changes are made when necessary to improve patient outcomes (Sharma et al., 2015).

2.2 The Multidisciplinary Team Approach

For person centred care to be successful it must be carried out by teams, made up of multi-disciplinary professionals who provide their specialized services to meet patient goals, as these types of teams are proven to provide improved patient and system outcomes (Glaser & Suter, 2016). This is accomplished by having a team invested in establishing and carrying out shared goals, based on patient needs and wishes, their history, condition and prognosis. Therefore, effective communication is necessary to provide a consistent message to the patient whether it be verbal or written. Similarly, all team members need to have specific roles while respecting and understanding those of the other team members. This ensures any errors are reduced and patient care is not compromised. Lastly, it is vital to team success to evaluate the services provided, how they worked as a team, and seek out patient feedback regarding these (D’Ambruoso et al., 2016; Mitchell et al., 2013, pp. 6-17).

In cancer care, as mentioned in the agency outline, multidisciplinary teams consist of numerous professional staff. For instance, during the head and neck clinic at ABCC, the patient is seen by a radiation oncologist, registered nurse, plastic surgeon, ear nose and throat specialists/surgeons, speech language pathologist, registered dietitian and oncology social worker. All of these team members come together to review the patient
chart, meet with the patient, discuss a treatment plan, present this to the patient, and
discuss with them how to move forward. Thus, all members coordinate their specialties
to ensure the patient receives the best care possible. Often a result of such care is
improved compliance to treatment and better patient outcomes (D’Ambruoso et al.,
2016).

Social workers provide a unique role in the multi-disciplinary team as they are the
one professional who, based on professional values and beliefs, tends to focus on the
psychological, social and emotional impact of illness. It is the social worker who
continually reminds the team of the ‘person’ they are caring for, advocates for holistic
care, and instigates patient input into the decision-making process (Cannon, 1913; Glaser
& Suter, 2016). Similarly, where the medical professional sees the physical symptoms
present and work to find a cause and solution, the social worker sees a person who is in
distress and seeks to assess how the illness impacts their life with the aim of assisting
them to resume their role in society. Therefore, by working together they are able to
establish a treatment plan considering all aspects of the person (Cannon, 1913).

Still social workers may believe their contribution is not recognized by all team
members and may be hesitant to express their perspective regarding the process or
treatment plan. Glaser and Suter (2016) suggest the social worker who feels this way
need only refer to the professions standard of care which outlines the social worker duty
to ensure other professionals understand their role and to do what they need to
communicate this to the multi-disciplinary team (p. 405).
2.3 Systems Theory

To support and promote the social work role, clinicians require tools to assist them in interpreting client problems and, in turn, develop appropriate interventions to assist them. Systems theory is a framework that is often utilized by social workers as it provides a way of understanding the dynamics in the client’s environment and how they are impacted by them (Friedman & Allen, 2014).

Systems are seen as singular, interconnected organisms, whose whole is more than the sum of its parts. An example would be an individual who is part of a family. If one part of the system is unstable or fluctuates (the individual) it impacts the entire system (the family) (Kriz, 2013). For instance, if the individual experiences a crisis, the whole family system may be affected. The crisis, in turn, may then bring about misunderstanding and mistrust taking the system off balance, leaving it unable to manage the crisis. Therefore, the system must learn to adapt to the fluctuations by implementing small changes to restore balance to the whole. (Kriz, 2013).

When working with family systems, Dore (2008), suggests systems theory can assist a clinician in understanding the “processes that affect the ideal functioning of a family thereby causing disorder” (p. 435). With this in mind, the clinician can assist the family members in exploring their roles in the family unit and how they are impacted by the current problem. Further, a systems approach can be the impetus for clinicians to provide interventions matching the individual’s/family strengths and resources they have in their environment, rather than direct or problem solve for them. By keeping the focus on the individual the clinician can assist with promoting growth, problem solving and,
assist the individual to initiate change. This in turn, promotes balance and control in themselves and the system (Friedman & Allen, 2014).

2.4 Strengths Perspective

To assist the clinician to focus on client strengths, the strengths perspective can be utilized. The strengths perspective was originated by Dennis Saleeby (1996) with the aim of empowering individuals to recognize their ability to take control of their lives, providing them with the impetus to look within to discover solutions to their problems (De Jong & Berg, 2002; Green, Lee & Hoffpauir, 2005). It is a theory grounded in the belief that everyone has strengths and abilities to cope with stressors but may not access them at times of distress. Therefore, when a client presents with problems/concerns they often have poor esteem, feel helpless, and place the blame for problems on external sources. However, once empowered, the hope is they will be able to take ownership of these problems so they can cope with, and manage, similar issues in the future (Green, Lee & Hoffpauir, 2005). In this context, the relationship between clinician and client is collaborative; with the client being the expert of themselves’, and the goal is to assist the client in recognizing their capacity to come up with positive solutions. Likewise, the clinician is enticed to see the client in a new, more positive, way and recognize that everyone has strengths; we just may need to work at helping them to be realized. Similarly, using this perspective allows social workers to maintain our professional values of self-determination, empowerment, and being non-judgemental (De Jong & Berg, 2002; Saleeby, 1996).

Resilience is also a major component of the strengths perspective. This is the ability to carry on despite the hardships one has experienced. It is resilience that can be
the stimulus to reflect on what has, and has not, worked in the past in solving problems (Saleeby, 1996). For example, when I worked with a patient who was struggling to cope with his illness and the cancer treatment, I asked him questions regarding how he had dealt with difficult times in the past, what did he do to get through it? By asking such questions the client was encouraged to think back to skills, strengths and resources he drew on in the past, to come up with possible solutions in the present.

When implementing this theory into practice, Saleeby (1996) warns clinicians to always see the client as an equal, continuing to respect them and their wishes, and refrain from ‘diagnosing’ problems in a way that undermines their innate capacity to thrive.

2.5 Relational Theory

This hesitancy to diagnose or label clients is also supported by the relational approach to social work. By utilizing a Relational theory perspective, the clinician places the focus on the client, their environment, and the meaning the client places on their interactions with others (Segal, 2012). Human interactions are seen to be the main focus of this theoretical approach. These interactions can be at all levels, micro, mezzo, and macro. Thus, to fully understand the client perspective, the clinician must consider the client interactions within themselves and without. For instance, when evaluating the impact of the therapeutic setting on the client, one must consider all aspects from policies to encounters with all employees, from the reception staff to their clinician (Segal, 2012).

This level of understanding can only be obtained by the clinician developing a relationship with the client that is supportive and respectful, allowing them the opportunity to share their experiences without fear of judgement (Segal, 2012, p. 377). Contrary to the strengths perspective, Segal (2012) suggests this may include
accompanying the client through the process of exploring their problems before assisting them to move toward a discussion of more positive solutions. Thus, consistent with social work professional values and ethics, the clinician respects the uniqueness of each client, ensuring they carry out a thorough assessment to understand the client’s perspective and assist them in working toward their goals for change (Segal, 2012).
Chapter Three: Integrating Theory into Practice

3.1 History and Mission of the Saskatchewan Cancer Agency

Learning objective 1: To understand the history, mission, purpose and function of the Allan Blair Cancer Centre.

To learn about the history of the Saskatchewan Cancer Agency I reviewed the annual reports as well as the webpage of the agency. However little information was available. Therefore, I carried out a literature search where I learned a great deal about the history of cancer care in Saskatchewan.

According to Shephard (2003) the Saskatchewan cancer agency has roots from cancer care development in North America and Europe. Cancer care came about as a result of statistics gathered in France and Italy, among others, revealing that mortality rates due to cancer were rising and needed to be better managed. In turn, physicians suggested cancer care would be best carried out in cancer clinics with teams of specialists who would dedicate their work to this area.

Shephard (2003) explained that Saskatchewan, having a pre-existing culture of social care, as well as similar mortality rates due to cancer, became the first province in Canada to establish centres for cancer treatment and research. These centres, in Regina (1931) and Saskatoon (1932), provided the services of a pathologist, surgeon, radium therapist, and internist (Shephard, 2003 p. 327). Further, the Health Minister was asked to draft legislation that would provide direction on how the services should be provided; the result was the development of the Saskatchewan Cancer Commission Act in 1930. This Act detailed that cancer care would be a fee for service along with the recognition that some services may need to be provided free of charge to those who could not afford
it. Not only did this act allow for the provision of cancer care but also led to the development of provincial healthcare as municipalities were required to pay for the individuals’ healthcare (Shephard, 2003. p. 328).

The two centres soon became vital in providing cancer care for the people of Saskatchewan regardless of numerous hurdles regarding payment of physicians and location of the clinics. For instance, in 1935 the Regina clinic moved from the General Hospital to the Pasqua Hospital due to complications in the agreements of how the agency would work and the desire to obtain the specialized skills of Dr. Allan Blair who became the director of the Regina centre. Eventually the centres went on to provide a model to the rest of the Canadian provinces on how effective cancer care can be provided (Shephard, 2003).

As seen in the Saskatchewan Cancer Agency General Report for 2015-16 (2015) the overarching mission of the agency is to achieve a healthy population free from cancer by providing “leadership in health promotion, early detection, treatment and research for cancer” (p.3). This mission upholds the original values of courage, integrity, vision, innovation and collaboration, as laid out by the organization founders. Further, it suggests this mission can be achieved by providing better care, value, health, and teams, to the residents of Saskatchewan.

Developing service models that improve access to and quality of cancer treatment can provide better care. For example, the agency has begun to use telehealth (video conferencing) to provide medical follow up care near to the patient’s home reducing the burden of travel to many rural communities in Saskatchewan (Saskatchewan Cancer Agency, 2015). In addition, the agency hopes to provide better value to patients by
improving challenges such as wait times for blood work and access to services (Saskatchewan Cancer Agency, 2015).

Better health can be achieved by reducing the incidence of cancer in Saskatchewan. Therefore, emphasis is placed on continually promotion of cancer screening, for example breast and colorectal screening programs, with the aim of engaging more citizens to participate. Placing emphasis on employee skill development via activities such as, goal setting, coaching by the leadership team, and increasing employee engagement; care by better teams is achieved. The aim is to keep and attract competent medical staff (Saskatchewan Cancer Agency, 2015).

3.2 Social Policies and Cancer Care

Learning Objective 2: To become familiar with social policies regarding the care of cancer patients in Saskatchewan and how these impact the health services offered at the Allan Blair Cancer Centre.

To become familiar with the social policies of Saskatchewan and the cancer agency I reviewed the legislation that guides the services the cancer agency provides as well as the various policies surrounding supportive care services, since these are particularly aimed at meeting the needs of patients. The following information has been gained by completion of these activities.

The Saskatchewan Cancer Agency is a not for profit provincial healthcare organization. The Cancer Agency Act (2010) mandates that the agency is responsible to provide “the detection, diagnosis, testing, treatment and monitoring of individuals, including follow-up care, provide performance outcome analysis and provide assessment of treatment outcomes” for individuals in Saskatchewan who present with cancer. Also,
included in the mandate is the education of health care providers and individuals regarding cancer prevention and attributes of a healthy lifestyle. All of these activities are carried out with a budget that is provided by the provincial government and monitored as outlined in The Regional Health Services Act (1997). This Act ensures that the cancer agency provides the government with an operational report and plan for how they will provide the services they are mandated to provide and the associated budget. Also, this Act guarantees that the public has access to this information.

All health information is governed by The Health Information Protection Act 1999). This legislation is designed to protect the personal health information of all individuals in Saskatchewan who receive healthcare services. It applies to both paper and electronic information. The Cancer Agency has made it a priority for all staff to be well versed in the requirements laid out in the act and thus provides extensive training to all staff.

As previously stated, the Saskatchewan Cancer Agency has developed policies regarding the cancer care provided to people accessing the services offered. As one can imagine there are numerous policies required to ensure the agency provides the highest quality of service and considers the vast needs of individuals. Subsequently, I will focus on a few of the policies that may impact the patient and their cancer care.

One policy for discussion deals specifically with the type of supportive care that each patient is entitled to. Care that meets the psychological, social, spiritual, physical, informational, emotional, and practical needs of patients is considered supportive care (Saskatchewan Cancer Agency, 2004, p.2). These needs are met by referral from the responsible staff member (or self-referral by patient) to the service/services required
throughout the individuals’ cancer journey, diagnosis to survivorship. Services include psychosocial support to the patient and/or family members that is provided by clinical oncology social workers, such as pain and symptom management, nutritional support, etc. Similarly, outside referrals to services such as home care, would also be considered here and require the consent of the patient (Saskatchewan Cancer Agency, 2001).

3.3 The Oncology Social Worker

Learning Objective 3: To gain professional experience working in the area of oncology social work.

Practicum activities related to this goal were to critically review the best practice guidelines for oncology social work, shadow and observe the role of clinical social worker within the multi-disciplinary team at the Allan Blair Cancer Centre, and participate in case management and counselling with clients and their loved ones.

The review of best practices led me to delve further into the development of oncology social work, what makes it unique, and how the profession fits into the cancer care multi-disciplinary team. The following information has been obtained via literature review and will incorporate experiences gained throughout my practicum.

3.3.1 History of Cancer Care

To better understand the role of the clinical oncology social worker it is helpful to review the history of cancer care, the impact of the disease on the individual and their loved ones, and how social work can assist individuals dealing with it.

The word ‘cancer’ is one of the most dreaded words when it comes to our own or a loved one’s health. Cancer, according to Rosenthal (2001) is “the presence of an uncontrolled proliferation of a certain cell in the body” (p.1). This malignancy can take
over the body and lead to death. Hence, the basis of dread when hearing the word is understandable and has remained so for many years. For instance, in the 1800’s a diagnosis of cancer often meant a person would not only die but also suffer a painful death (Watson et al, 2014). As a result, according to Holland (2004), the topic of cancer was taboo and physicians rarely told their patient of their diagnosis. Furthermore, they would instead tell their family members who, fearing being stigmatized by their community or even that they could catch it, often kept it secret as well. In addition, the treatments offered by the medical community were geared at treating the body but not the person who was suffering. Consequently, cancer care was limited and rarely successful (Watson et al., 2014).

Fortunately, in the mid 1900’s, with research findings revealing the link between certain behaviours such as smoking and cancer, the medical community began to openly talk about cancer with their patients. This included providing information regarding warning signs of cancer and encouragement to seek out screening (Fobair et al, 2009). Similarly, there was renewed hope for increased survival rates with new developments in surgical techniques, chemotherapy, and radiation therapy (Fobair et al., 2009; Holland, 2004). All of these developments led to a new perception that cancer was something that may be avoided or successfully treated, rather than a death sentence (Holland, 2004; Fobair et al., 2009; Watson et al., 2014).

By the 1980’s researchers began to explore the impact of a cancer diagnosis on the individual revealing the distress a diagnosis has on the individual, and their loved ones, throughout their cancer journey diagnosis, as well as, during and after treatment (Fobair et al., 2009; Holland, 2004). Results showed, of those diagnosed with cancer,
approximately 35 percent would experience psychosocial distress, 70 percent symptoms of heightened anxiety and depression, and 50 to 75 percent would require some sort of psychosocial care (Adler & Page, 2008; CAPO, 2010; Raingruber, 2011). Much of the distress was related to their diagnosis, impending diagnostic procedures and treatment, reduced capacity to carry out daily tasks at work and home, loss of independence/jobs, social problems including financial, emotional, and relationship difficulties, to name a few (Adler & Page, 2008; Zabora et al., 2001). The impacts of such distress are poor coping, decreased quality of life, poor treatment compliance, and poorer outcomes (Adler & Page, 2008; Grassi, Nanni & Caruso, 2010).

Family members were also shown to experience the same distress, as it was a shared crisis. Given that cancer treatment was increasingly provided in the home, caregiver burnout became an increasing problem (Adler & Page, 2008; Blum et al., 2001). Northouse et al (2012) suggest family members provide more than half of the care to the patient and in turn lack the needed knowledge or skills to do this. Similarly, family members may experience emotional, physical, and financial distress. Not only do they fear for the life of their loved one but also are faced with the possibility of risk to their own health, or being unable to pay bills (Northouse et al, 2010; Northouse et al, 2012). Therefore, Zwahlen et al. (2008) suggest cancer care providers need to be aware of the impact on caregivers and advise their distress should be assessed just as a patient’s is.

Likewise, cancer survivors also appear to experience distress as they are often left with physical symptoms, have difficulty returning to their normal lives, and without ongoing supports are at continued risk of developing depression and anxiety (CAPO,
Consequently, these social concerns along with the physical impact of the disease influence how an individual will cope with a diagnosis of cancer.

On the other hand, social and emotional supports, improved coping skills and optimism have been found to help improve overall health. Therefore, by assessing distress, identifying those at risk of psychosocial concerns, and implementing supports, patients may present with improved psychological adjustment to their disease, higher overall functioning, increased treatment compliance and more satisfied with their care (Adler & Page, 2008; CAPO, 2010; Hutchison, Steginga & Dunn, 2006). Similarly, increased social supports led to better overall outcomes, decreased burden on caregivers and an increase of care (Zabora et al, 2001). Distress screening will be reflected on further in this paper.

Given this knowledge, the medical community responded, as per Fobair et al. (2009), when Ida Cannon, who was one of the first medical social workers, stressed the need for patient concerns to be brought forward to the physician. She explained how social work could advocate for advancing the understanding that patients were individuals who had families, jobs, communities, lives outside of the cancer that were impacted by disease and it’s treatments. This forward thinking led to the eventual development of psychosocial oncology with the aim of reducing the patients’ distress (Watson et al, 2014; Holland, 2004; Fobair et al, 2009; NAOSW, 1983).
3.3.2 Oncology Social Work

CAPO (2010) defines psychosocial oncology (PSO) as:

a specialty in…cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional (practical) aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs. (p. 2)

Further, the principles of psychosocial care support the belief that all patients have the right to understand their diagnosis and the implications of it. With this knowledge in place, the patient will be more equipped to care for him or herself and make decisions regarding their care based on their own goals and values (Adler & Page, 2008).

Therefore, services need to be based on person/family centred care, be ethical and respectful of culture and diversity, involve inter-professional collaboration and be evidence based (CAPO, 2010, p. 7-8). When services are person centred, service providers should: recognize the importance of each patient’s point of view, seek to understand their values and beliefs, treat them with dignity, and respect their right to self-determination (CAPO, 2010). Given this ideology, psychosocial services need to be easy to access and offered to all patients. Research results also reveal the importance of screening patients regarding need or benefit of psychosocial services as few will seek out supports on their own (Blum et al., 2001).

The Institute of Medicine’s ‘Cancer Care for the Whole Patient’ (Adler & Page, 2008) outlines a model of care delivery established to ensure all patient needs are met. The model is as follows; ‘identify patients with psychosocial health needs that are likely to affect their health or health care, develop with patients appropriate plans for linking
them to appropriate psychosocial health services, support patients in managing their illness, coordinate psychosocial with biomedical health care, and provide follow up on care delivery to monitor the effectiveness of services and determine whether any changes are needed.’ (p. 159).

Like the values and beliefs of the social work profession, psychosocial oncology services follow the ethical principles of autonomy, beneficence, honesty and confidentiality (CAPO, 2010, p. 8). Following these values ensures that teams respect each individual regardless of their gender, sexual orientation, socioeconomic status, etc. (CAPO, 2010). Also, to ensure best care is provided to each patient, teams need to participate in ongoing inter-professional collaboration so that all team members are aware of the patients’ wishes and challenges. Lastly, all services are based on evidence based best practice and presented to each patient so they are able to understand and provide informed consent, thus receiving the best care options available to them at the time (CAPO, 2010).

Along with the above principles, CAPO (2010) guidelines suggest providing the services via a tiered care model. Level one would include opportunities to provide education to the patient and families. This would include providing information, through patient navigators or information sessions, to educate the patient on the health care system and what they can expect upon attending the cancer agency. Level two would include supportive care offering emotional support via peers and printed materials. Level three would be for patients who, upon assessment/screening, require assistance to manage any practical, functional and emotional concerns related to their physical and mental
health, and finally, level four would be for patients who are deemed to need specialist care and require referral to appropriate resources to obtain this (CAPO, 2010).

To provide such services in the level three and four categories the clinician would be required to provide interventions to help reduce the patient’s distress (Holland, 2004). Therefore, they would require an understanding of cancer, types and stages, risks and benefits of treatment, and prognosis (Stearns, 2001). Although all cancer team professionals could offer such services, and many nurses have and continue to do so, social work clinicians who were already present in the hospital appeared an excellent fit for this role. This led to the creation of oncology social work (Fobair et al., 2009).

According to the Association of Oncology Social Workers (AOSW) standards of practice (2012) oncology social work is defined as “a humanizing influence felt throughout the hospital or cancer center... a profession designed to promote the patient’s best utilization of the health care system, the optimal development of coping strategies and the mobilization of community resources to support maximum functioning” (p.1). With the aim to empower individuals, their families and caregivers, as they go through their cancer journey, social workers clearly embrace the aforementioned principles of psychosocial care. Also, by providing interventions that are proven to be best practice, adhere to social work values and ethics, and are available to all patients at all stages of the illness trajectory, from diagnosis to death or survivorship, social workers are able to assist patients in coping and adapting to life with cancer (AOSW, 2012). Some of the activities utilized to accomplish these goals are, assessment, case management, education, advocacy, patient navigation, mobilize resources, program development, and treatment planning (AOSW, 2012, p.1).
The standards of practice also outline the qualifications required for the position and the scope of practice (AOSW, 2012; CAPO, 2010). The oncology social worker, as previously mentioned, requires extensive knowledge of cancer diseases and treatment, the psychosocial impact the disease has on the individual and their loved ones, knowledge of best practice interventions, community resources, as well as, clinical expertise. Similarly, training in adult education, communication skills, interdisciplinary practice, and person centred philosophy would be beneficial (Adler & Page, 2008; Blum et al., 2001). It is suggested that a Master of Social Work degree be required as this level of education can best provide the theoretical knowledge and clinical skills needed. The AOSW also suggests clinicians receive supervision, opportunities for continuing education, and on the job experience, to raise their competency level (AOSW, 2012).

3.4 Screening for Distress Model

Learning Objective 6: To learn about and utilize the Screening for Distress Model, in order to explore the impact a cancer diagnosis has on the patient and their loved ones, to help to decide appropriate interventions.

The discussion regarding when to refer leads perfectly into the area of distress screening, as it is often the result of this screening that patients are referred to oncology social work. The following is a discussion of the origins of distress screening, what it entails and best practice related to it.

The NCCN clinical practice guidelines (2009) suggest all patients will experience some form of distress during their cancer journey and approximately 35 percent will benefit from further assessment and psychosocial supports, as a result (Zabora, Brintzenhofeszoc, Curbow, Hooker & Piantadosi, 2001). Likewise, research has shown
benefits of routine distress screening in increasing patient adherence to treatment, improving communication between the patient and care team, and decreased symptoms of anxiety and depression in patients (NCCN, 2009). It was also recognized that screening alone was insufficient without referral to appropriate psychosocial care. Therefore, recommendations were given for distress screening and, if needed, referral to psychosocial care, for cancer centres to receive accreditation in oncology care (NCCN, 2009; Watson et al., 2014). As a result, it became important to assess distress and its’ impact on the patient diagnosed with cancer.

Distress, as defined by Holland (2004) is “…unpleasant emotional experience of psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (p. 453). Similarly, Bultz and Holland (2009) refer to distress as the ‘sixth vital sign’ that needs to be assessed as equally as pulse, respirations, blood pressure, temperature and pain. This in turn suggests that cancer impacts the person as a ‘whole’, mind and body. This person-centred perspective moves a medical model service into one where individuals are recognized as unique, their input regarding their needs and challenges is sought out, and services are easily accessible (CPAC, 2016).

This distress often begins upon receiving a diagnosis of cancer and can be experienced at various levels from normal to debilitating. One’s distress response is dependent on many factors including, their temperament, the type, stage and prognosis of the cancer, the degree of disability resulting from the cancer and/or treatment, the patients’ age, stage in life, their past experiences with cancer and the amount of supports available (Wells & Turney, 2001). For instance, a poor prognosis would most definitely
lead to increased distress however if the individual has many supports, friends, family, and a good relationship with their medical team, these could be protective factors and help to diminish the distress the patient feels. Similarly, a patient who has past experience dealing with adversity and has strong problem solving skills or spirituality may be able to draw upon these strengths to help them to manage their distress (Wells & Turney, 2001).

On the other hand, a patient who was living pay check to pay check to pay their bills may be put into a position where they need to give up their home and rely on social assistance, or has a history of mental health concerns, may experience increased distress (Zabora et al., 2001). Unfortunately, the latter was a reality for a patient I worked with and resulted in his having to move in with family to be capable of following through with treatment. Understandably the distress accompanying a cancer diagnosis can change the trajectory of one’s life and this alone can add to the level of distress (Wells & Turney, 2001).

3.4.1 Tools for Screening Distress

Compared to the negative connotation for distress, distress screening is “proactive rapid identification of key indicators that allow for further assessment and appropriate referral” (Bultz et al., 2011, p. 464). Distress screening is carried out on paper or electronic tablet, with preference given to the latter as research has indicated patients find it easy to use and the results are easily accessed (Canadian Partnership Against Cancer, 2009). In Canada, the Edmonton Symptom Assessment System (ESAS) is a validated tool and considered best practice when accompanied with the Canadian Problem Checklist (Adler & Page, 2008; CPAC, 2009). Both of these tools are brief, easy to
understand, and assess the physical, practical and psychosocial concerns of the patient. Also, the ESAS is free to use and available in a variety of languages (CPAC, 2009). (An example of both of these tools is available at https://www.cpd-umanitoba.com/wp-content/uploads/2016/12/ESAS-Canadian-Problem-Checklist.pdf) Another suggested tool is the Distress Thermometer developed by NCCN (2016) which measures emotional distress however is not the preferred tool as answers are limited to yes or no rather than scaled from 1-10 as found in the ESAS (CPAC, 2009).

Suggested implementation of distress screening is to have patients complete the distress screen at various stages of the cancer journey (CPAC, 2016) as it is important to know the extent of the patients’ psychosocial distress and whether referral to further supports is warranted (Grassi et al., 2010). Wells and Turney (2001) explain there are different stages during this process and the level of distress can be impacted at each one. These stages are diagnosis, treatment, post treatment, recurrence and terminal illness (p.28). At diagnosis, a patient may experience feelings of shock, disbelief, fear, denial, guilt etc. These feelings, although understandable, may lead to unhealthy levels of distress. For instance, a natural reaction might be to present with shock and deny the diagnosis; however, once an individual has had time to process the news, they will begin to accept it as reality and move forward. On the other hand, one who continues to deny the diagnosis may be unable to make decisions regarding their own care or cope with the disease. I had one patient I worked with who did not wish to know anything about her cancer but rather wished for all information to be presented to her friend, but at the same time agreed to any treatment suggested by the physician. She told me she did not want to deal with it and her belief was if she didn’t listen to anything she would be fine. The
result was she did not present with distress; however, she was also not participating in her own care and any complications that might arise in the future would likely end up causing her distress.

Fears of dying or pain are often accompanied by feelings of guilt. A family provider may feel guilty they will die and leave their family dealing with the consequences of debt or inability to pay their bills. Other guilt feelings may result from regret of past behaviours, such as smoking, that have led to the cancer diagnosis (Wells & Turney, 2001). I witnessed both of these scenarios during my practicum as well as expressions of disbelief to having a cancer diagnosis. Some patients were shocked as they had lived healthy lives, ‘did everything right’ with their diet and exercise and were angry they were put into this position. One patient in particular struggled with this to an extent where anxiety and depression became comorbid concerns that negatively impacted her distress level and her capacity to manage her illness.

Distress can also be present when a patient struggles or has strong beliefs around whether or not they should tell their loved ones they have cancer. In particular, whether to tell children about the cancer diagnosis can be very difficult. The decision regarding the amount of information and when to share the information can lead to a great deal of distress for a parent. Still the reality is children will require some information eventually as they may witness their parent managing the many side effects of treatment, many of them quite visible (Wells & Turney, 2001).

The end of treatment can lead to a number of different responses. Some individuals may experience reduced distress as they see this as a time of victory and their life getting back to normal (Wells & Turney, 2001). In the radiation department at the Allan Blair
Cancer Centre there is a bell individuals ring at the end of treatment. Often it is a celebration as patients congratulate themselves for making it through the treatment. Often their family, loved ones, and the staff at the agency gather around to join in the celebration. However, some patients may see the end of treatment as a scary time as it often means they will have infrequent follow up at the centre. The fear of having to manage the illness on their own can lead to ongoing distress and difficulty getting back to their life as before (Wells & Turney, 2001). A good example of this is with head and neck cancers. Patients attend the centre for seven weeks for daily treatment (week days) and at the end they go home and manage the lingering side effects of treatment with no knowledge of whether or not the treatment was successful. Many report a great deal of distress until they are able to attend a follow up appointment six weeks later.

Patients also report missing the daily interaction with staff, as they are a large part of their support system. This loss of support, as well as a fear of recurrence, can lead to significant distress for the cancer patient. Wells & Turney (2001) report this can be debilitating, negatively impacting the individual’s ability to move on in life. Similarly, recurrence of the disease can lead to new levels of distress, as the patient may have to start the entire process over again.

Lastly, realization the disease is leading to one’s death can lead to extensive distress. Accompanied with the pain and discomfort of a disease taking over one’s body is the reality life is coming to an end. Some individuals are capable of taking this time and making the most of it, however many struggle. Fortunately, there are supports available, such as hospice and spiritual care, to help to reduce the distress an individual and their loved ones feel (Wells & Turney, 2001).
3.4.2 Limitations of Distress Screening

As distress screening is a newer concept its’ implementation can be met with some hesitancy on the part of the care team. Some professionals may not see it as necessary or avoid reviewing it with the patient so they are not being put in a situation to deal with emotional concerns of patients. Similarly, studies have revealed approximately 20 percent of cancer centres do not implement the screening as per NCCN guidelines and when they do patients may not complete the tool, have family complete it for them, feel rushed, or deny referral to psychosocial care (Blum et al., 2001; NCCN, 2016; Oktay, Nedjat-Haiem, Davis & Kern, 2012). Some patients may prefer to deal with their concerns on their own, refuse to discuss with the physician due to believing medical symptoms are more important, may perceive themselves as weak if assessed as needing further support, or have negative views of mental health as related to their cultural beliefs (NCCN, 2016; Mackenzie, Carey, Sanson-Fisher, D’Este & Lin Yoong, 2015). Conversely, screening may result in too many referrals to a psychosocial team that may lack the resources to meet the demand (Oktay et al., 2012).

Due to the above concerns Blum, et al. (2011) suggest the importance of establishing agency policies ensuring the implementation of screening along with processes attached to it. Therefore, agency professionals need to be trained in implementation and evaluating results (NCCN, 2016). Upon completion, there must be a process where the clinical team is informed of the results and in turn contact the patient to complete further assessment and provide interventions as needed. Similarly, the implementation processes should be monitored for effectiveness and improvement strategies be applied when warranted (Bultz et al., 2011).
3.5 Best Practice Psychosocial Care

Referral to psychosocial supports is based on the scores obtained from the screening for distress tool. The NCCN (2016) suggests best practice is to screen every patient at the points previously mentioned and refer to psychosocial services when warranted. Based on research results, referrals are made where there is a score of 4.5 or higher (Grassi et al., 2010). Results below this would present expected levels of distress whereas higher scores suggest the patient may benefit from further supports and require further screening (NCCN, 2016). Some areas shown to be of particular concern are activities of daily living, mental health (anxiety, fear), need for information (about their diagnosis and treatment side effects) and physical symptoms (Harrison, Young, Price, Butow & Solomon, 2009).

Upon referral, the oncology social worker takes on the case management role including assessment, treatment planning, advocacy, education, coordination of care, linking patients with services or supports, provide best practice interventions, and ongoing monitoring of care plan to ensure client needs are being met (Adler & Page, 2008; SASW, 2012).

A thorough assessment consists of obtaining information regarding the patient and family response to the cancer diagnosis. Importance is placed on gaining insight to their understanding of the diagnosis and treatment options, goals of care, adaptive skills to manage the illness, the extent of social and practical supports available to them, barriers to accessing care, psychosocial history including mental health history, and any cultural concerns that may impact their care (AOSW, 2012; Blum et al., 2001; NCCN, 2016). Also, as the cancer journey can last for some time and can be unpredictable, it is
important that the assessment process be ongoing throughout the patient’s cancer journey (CAPO, 2010).

The next step in the process is for the oncology social worker to review the assessment results to formulate a treatment plan aimed at reducing the level of patient and/or family distress and increasing their capacity to cope with the illness and its’ consequences (NCCN, 2016). During my practicum, I had the opportunity to shadow my supervisor while she completed assessment of client and family needs. It became clear this was a difficult task as the initial appointments a patient attends can be extremely overwhelming leaving it somewhat unclear what they understand and do not understand.

I have to admit I was unsure what I understood during the initial appointments for a number of reasons. Not only did I find the medical terms overwhelming, but also the sheer volume of information patients received during their appointments. The details provided regarding their cancer, the available treatments, their side effects, and the success rates of it, all come so fast it is difficult to attend to them let alone process the information. I could barely imagine how the patient could internalize all of this information and grasp the reality of their situation.

This uncertainty helped me to see the importance of social work presence in this setting. For instance, during one meeting with a new patient and oncologist, information was presented on the type of cancer and the treatment options available. The patient experienced difficulty in understanding the options and appeared to be having difficulty explaining this. At this time my supervisor, having assessed that this was occurring, utilized active listening skills to ask the physician for further explanation that would be easier for the patient to understand. In turn, the patient was able to make their decision.
Further, the social worker, having knowledge in cancer care, was also able to anticipate other areas requiring further elaboration and went on to ask questions to assist the patient to have a thorough picture of the situation. Thus, she carried out the task of advocacy ensuring they had the required information from the medical team to make the best possible decisions regarding their own cancer care (Adler & Page, 2008). These actions not only supported the patient, but also the physicians, allowing them to work together to best meet the needs of the patient.

Education and coaching may be offered to patients to assist in managing the illness and treatment side effects. These often include the expertise of the nursing team as these issues are often related to the patients’ physical health or the dietician when related to diet and weight management. Similarly, some interventions are aimed at behaviour change, such as smoking cessation and increasing physical activity (Adler & Page, 2008).

Where the oncology social worker often becomes involved is assisting patients with their practical needs and linking them with appropriate services. A diagnosis of cancer is often accompanied with a disruption in the trajectory of one’s life. This includes time away from work and possibly financial crisis. Unfortunately, many people do not have the types of disability insurance that provide them with financial security; rather many have to rely on employment insurance and possibly funding available from charitable organizations. For example, a patient with breast cancer may need to undergo chemotherapy for a period of four months followed by a three-month recovery and three weeks of radiation treatment and therefore could theoretically miss eight months of work. Without disability insurance, the patient would likely wait for a month or so and receive
15 weeks of employment insurance and need to apply for long term disability or access social assistance.

This is a bleak financial picture for a patient to accept along with a cancer diagnosis. Therefore, it is important that the oncology social worker is first, aware of these financial burdens, and secondly can refer the patient to the correct community resources to ensure they receive all of the supports available to them. Fortunately, there are non-profit organizations that assist individuals in this situation. However, this illustrates the significant impact a cancer diagnosis can have on an individual. Other resources that can be accessed include home care services and lodging during treatment.

Coordination of care is an important task of oncology social work. Cancer care is provided by a multi-disciplinary team involving many different professions to ensure the patient receives an accurate diagnosis, receives any needed medical interventions, is treated for any co-morbidity, and support for their psychosocial needs. The presence of so many professionals can not only be daunting to the patient but also confusing. In addition, there may be communication gaps between the caregivers that heighten this. Therefore, the oncology social worker’s capacity to coordinate the patients care can help to reduce the patient’s level of distress.

This can be accomplished by the social worker being aware of all aspects of the patient’s care. This may include attending multi-disciplinary rounds where the patient’s case is discussed, attending new patient consults and follow up appointments with the oncologist, and attending education sessions on specific types of cancer and its’ treatment (Adler & Page, 2008). Research has shown that co-ordination of care aids in improving patient functional status, satisfaction with care, and reduces hospitalizations (p. 197).
I would like to add to this that attending the appointments and rounds also helps the social worker to improve their own knowledge and skills and in turn better support the patient. Just as stated in the Saskatchewan Association of Social Workers (SASW) standards of care (2012), social workers are responsible for increasing their knowledge in their area of service to ensure they are able to provide the best quality care to their client. The education one receives during these opportunities certainly accomplishes this. For instance, ABCC has a head and neck cancer clinic. Part of this clinic includes attending multi-disciplinary rounds where there is discussion regarding patients and their disease. Often diagnostic tools are reviewed as well as discussion regarding available treatment options. By attending the social worker increases their knowledge and their capacity to aid in translating complicated information for the patient (Adler & Page, 2008).

Program development or promotion of psychosocial services is important to ensure all patients have access as suggested in the aforementioned principles. This however can be difficult to achieve. During my practicum, I was fortunate to attend a presentation by supportive care to the oncology nursing department. My supervisor gave a presentation on when to refer to social work. At ABCC each nurse works with specific physicians and social workers. Thus, they would refer to the social worker based on the distress screening results, as well as their own and the doctor’s belief that the patient could benefit from psychosocial care. There was a great deal of discussion at this presentation and it appeared unclear when a referral should take place in part due to the evaluation of the screening for distress tool and to the inconsistency in the practice of the social work team. Some social workers like to attend the new patient consult along with the physician so they can present themselves as a team member and provide supports at the
beginning of the patient’s cancer journey. Where others preferred to contact the patient at a later date and set up a meeting to complete an assessment and begin to set treatment goals. Both of these approaches are valid but it was the inconsistent approach that seemed to add to the confusion of when to refer.

I have a tendency to see both sides of a situation and could see the benefit to both approaches however one encounter with a patient led me to believe that early intervention might be the most effective. I was asked to sit in on a new patient consult with a young lady and her mother. Both appeared overwhelmed during the appointment and upon my explaining the social work role and offering supports both denied any need at the time. Still I provided them with my contact information and let them know where they could find me if needed. Approximately one week later they knocked at my office door and asked to meet. They had further questions about the treatment options thus I contacted the nurse and was able to set up another appointment with the physician to allow them to get further clarification. We continued to meet throughout my practicum with my providing ongoing supports around emotions, finances, work etc. I believe that had I not been in that initial appointment they might not have accessed services that turned out to be beneficial in assisting her with her cancer treatment.

3.5.1 Best Practice Interventions

Adler and Page (2008) explain that cancer can lead to poor outcomes for patients due to the psychological and social impacts of the disease. Therefore, patients require interventions proven to assist them in increasing their capacity to cope. Coping behaviours include seeking social supports, information seeking, emotional expression, problem solving and positive reframing (Adler & Page, 2008, p. 60). When patients
receive such support, they tend to experience less psychological distress, experience increased optimism, and report improved quality of life.

Best practice interventions, as basic as, transportation to and from appointments, assistance in paying for medications, access to detailed information on their illness and treatment, as well as peer support, can all help to diminish worries and fears (Adler & Page, 2008). For example, the Canadian Cancer Association funds a volunteer driver program where individuals can be transported to and from appointments and treatment at the cancer centre. This service not only assures patients attend their appointments but also can remove the burden from strained family members who need to continue to work and support the family. Similarly, funding sources such as the Kinsmen Foundation provide much needed funding to allow patients to travel long distances and pay for lodging, allowing patients to stay close to the centre and obtain the care they need.

Other strategies include counselling to assist the patient who is struggling in managing the psychological impact of the disease (Blum et al., 2001). Cognitive behavioural therapy (CBT) is recognized as a best practice counselling intervention to assist with stress reduction and improved coping (Raingruber, 2011). CBT has been shown to be effective during all stages of the cancer journey, in particular during the initial and treatment phases of cancer care, as it provides strategies to reduce symptoms of anxiety or depression, can aid in problem solving, teaches relaxation and mindfulness, and has been shown to reduce cancer related pain (Adler & Page, 2008; Tatrow & Montgomery, 2006).

CBT is evidence based psychological treatment grounded on the principle that one’s feelings are directly related to what they are thinking and doing. Thus, negative
thoughts may result in negative behaviours and feelings. Conversely, positive or balanced thoughts may improve feelings and coping behaviours (Daniels, 2015; Somers & Queree, 2007). With this in mind, individuals are provided with strategies aimed at assisting them to attend to and alter their thinking in such a way they are able to minimize distressful feelings and carry out adaptive behaviours (Somers & Queree, 2007).

There are many strategies utilized in CBT, such as, establishing a therapeutic relationship, goal setting, cognitive restructuring, relaxation, and mindfulness (Daniels, 2015; Somers & Queree, 2007; Tatrow & Montgomery, 2005).

A positive therapeutic relationship is one that includes effective communication where both individuals are willing and able to give and receive information. For this to happen the relationship must be one where trust is established and earned. As in the CASW (2005) guidelines, social workers have a duty to care, to respect privacy and maintain confidentiality. To do this one must utilize their skills and knowledge in developing relationships where the patient feels safe to share their beliefs and values. Similarly, the clinician needs to be mindful of client self-determination and be aware of any pre-conceived goals they may have and not place these on the patient. When this is done, the patient is more likely to engage in the therapeutic process and participate fully in addressing their concerns (CASW, 2005).

Once a therapeutic relationship is established with the patient it is important to obtain consent from them to share information with their family or include them in the counselling process. Family involvement is often encouraged as their support can be vital to patient outcomes, however, the patient must be willing to accept them as part of the care team (Adler & Page, 2008). From my many years’ experience in mental health I
know family members can assist the patient to follow through with strategies and reinforce coping skills in their everyday life. Correspondingly, family members may also benefit from strategies to help them manage the impact of their loved one’s illness.

It is important to note, this art of establishing a relationship can be a quick process in a cancer centre as patients may attend their first appointment and immediately become quite distressed. The oncology social worker must utilize their skills of engaging with patients to gain their trust (Blum et al., 2001). I had an opportunity to experience this when called in to meet with a distressed patient who was informed she required treatment differing from that advised by her surgeon. By introducing my role and myself in a calm manner, I was able to offer some assistance by teaching deep breathing with the aim of helping the patient to relax enough to attend to the information being provided to her. The result being, her increased capacity to share her fears and worries, as well as, discuss her treatment options.

Once a therapeutic relationship is established it is important to assist the patient to discuss their concerns and set goals to deal with them. Once it is clear what the patient’s goals are the clinician can educate them on helpful strategies to reduce their distress (Adler & Page, 2008). For instance, a patient who is struggling to be calm during radiation treatment, making it impossible to receive the treatment, may benefit from practicing progressive muscle relaxation (a technique where the individual contracts and releases their muscle groups one at a time) so they are able to calm their body, think calming positive thoughts, and cope with the treatment (Golden & Gersh, 1990).

Cognitive restructuring is a key CBT strategy. It is a tool designed to assist the patient to focus on their thinking and how it may impact them in negative ways. In the
previous example, for instance, once calmed down, the patient could use thought stopping to halt any negative or worried thoughts. This is where one says ‘stop’ to make the thought go away. Or they could challenge their thinking, changing thoughts of being afraid of the treatment to ones that reinforce the treatment is helping to make my tumour shrink. Similarly, they could use positive imagery, thinking of being in a pleasant setting to take their mind off of their worried thoughts. Such strategies help the patient to take control of their negative and worried thoughts which in turn increases their capacity to cope with the situation. By building on these skills the aim is for the patient to cope better, and in turn, complete the course of their treatment (Golden & Gersh, 1990).

Mindfulness is an emerging strategy gaining a great deal of recognition as a beneficial tool to reduce distress and improve outcomes. When the individual focuses on the ‘here and now’, utilizing relaxation strategies to help calm themselves, they are better able to pay attention to what is going on at the present time and push away any thoughts. According to Carlson (2016) mindfulness strategies have been shown to be beneficial at all stages of the cancer journey in helping patients to cope with treatment and worries of recurrence.

3.6 Evaluating Personal Effectiveness utilizing Relational Social Work Theory

Learning Objective 7: To evaluate personal effectiveness/impact in working with individuals and families facing a terminal illness

As stated previously, my desire to participate in the role of clinical oncology social work was impacted by my past experiences with cancer, both professionally and personally. Yet I was also concerned with my capacity to work with people who were facing death. I was concerned that my past experience with my own fear of death, being
a parent, and experiencing the death of those close to me, might weaken my capacity to cope with a client’s sadness, fear, and despair of having a terminal illness, or leave me incapable of carrying out the role in a manner the position requires. Similarly, I was uncertain if my education and work experience would prepare me to work in this area. Given these concerns, my responsibility to be self-aware (SASW, 2012), and the statement that “professional self-awareness is widely considered a necessary condition for competent social work practice” (Kondrat, 1999, p. 451), I aimed to carry out a thoughtful assessment of my suitability and capacity to be an effective oncology social worker.

To be self-aware we need to gain an understanding of how we know what we know, how we use this knowledge, and how it impacts the work we do. Heron (2007) suggests the act of being reflective assists us to understand how our thoughts, beliefs, and actions, impact how we respond to others and is necessary to integrate the ‘self’ into ones’ practice (p. 342). Thus, in order to be competent, knowledgeable, professionals, we need to understand what influences our actions and reflect on how these impact the clients we work with (McCoyd & Kerson, 2013).

Establishing strong, trustworthy, relationships with our clients is one of the cornerstones of social work practice (McCoyd & Kerson, 2013). Standards of practice suggest the worker must establish a relationship with our clients that is accepting of the person for who they are, compassionate, non-judgemental, and responsive to the clients’ feelings and concerns (SASW, 2001). By utilizing relational theory, which is according to Folgheraiter (2007), “… a close partnership and reciprocity between expert systems and the society” (p.266) one can critically analyze the process and quality of the relationship.
To do this, Rosenberger (2013) proposes the social worker must use “empathic attunement and engagement” (p.19) which is the ability to understand and accept all feelings and experiences of both the client and themselves. This is accomplished by asking questions to understand the client’s experiences in the past and present, while reflecting on our own experiences and how they may impact our interactions with the client (p.19). Similarly, by asking for clarification or expressing concerns, when uncertain of the client point of view, we show the client they are being listened to (Rosenberger, 2013). Together, these actions result in improved relationships with our clients.

Feeling nervous was a constant during this practicum as everything was new and, when called into an unknown situation, I found myself going over possible scenarios to minimize showing this to the patient. For example, I recall meeting with a female patient and her son, only knowing he was upset. Going into the meeting I was wondering what the main concerns would be; could she be upset with her health, worried about her family, etc. During our discussion, I soon realized she appeared to be upset that her family tended to speak for her with health practitioners. For example, during our meeting another professional attended the room to check on how she was doing. The patient stated she was doing fine however her son disagreed. When the clinician left she angrily suggested she did not need her family to answer questions on her behalf, as she believed this brought more negativity to an already difficult situation.

At this moment, using a family systems approach, I began to wonder if the patient’s illness had, in her mind, diminished her family role as caregiver, leaving her powerless. Or whether her illness had taken the family off balance and, by initiating an argument,
she was attempting to bring things into a new balance, making the situation about their relationship rather than her illness (Sutphin, McDonough & Schrenkel, 2013; Haefner, 2014). However, I did not know if my perceptions were accurate and needed to explore what the patient’s statements meant. Therefore, with a little prompting, in the form of acknowledging that often people feel a lack of control in these situations, listening reflectively, and letting her be the expert, she was able to express many concerns. It turned out she was frustrated with her health and how it was impacting her physically and emotionally and how little control she felt in managing the interference of well-meaning friends and family. She denied being mad at her son and affirmed her continued need of his support. Thus, she went from being very angry to very emotional.

As a clinician, I was pleased she had come to these realizations. I believe it was my capacity to remain neutral, by prompting myself to listen, keeping focused on the relational inquiry stance, by being present and walking alongside the patient, rather than pushing or directing, that facilitated this (Rosenberger, 2013). Since having this interaction I learned that I must continue with this reflective approach to be an effective clinician.

Still, a career in oncology social work may lead to a unique set of professional challenges for me as working with individuals who are dealing with their imminent death may lead to worker emotional distress (Rasmussen et al., 2016; Rohan & Bausch, 2009), compassion fatigue (Holland & Neimeyer, 2005; Stearns, 2001), and professional grief (Stearns, 2001; Rohan & Bausch, 2009). All of which may affect one’s capacity to establish quality therapeutic relationships.
Emotional distress can take many forms; one is related to our attitudes surrounding death. Peck (2009) suggests, as clinicians, our attitudes of death are related to our previous experiences. Some may have death anxiety where they fear or worry when thinking about or confronted with death and dying (Jonasen & O’Beirne, 2015) while others may change their attitudes as a result of work experience. Regardless, as per the relational perspective, it is important to gain an understanding of our own beliefs should we choose to work with the dying.

My earlier experiences with death were varied and began at around the age of 15 when a young neighbour was tragically killed in a car accident. I remember not going to the funeral as my parents thought it would be too upsetting for me. My family often saw me as a sensitive person and protected me from negative experiences. Still I remember being shown pictures of the open casket, as this was a customary practice of his family. I remember feeling somewhat haunted by the picture of him and tried to remember him alive instead. Similarly, when my grandmother died I clearly remember feeling panicked that she was still alive in the coffin. Hence when attending funerals to this day, I will not observe the open casket.

I share these experiences to explain that I have not had a good relationship with death, even feared it for many years. Thus, one of my main concerns with working in oncology social work was that this fear would diminish my capacity to provide the best service to my clients. Results from studies show this may be true. Peck (2009) reports that increased death anxiety, on the part of the clinician, may have a negative impact on clients, as the clinician may not be as responsive to client needs or may hesitate having
the necessary conversations to assist clients in reaching their goals regarding their end of life wishes (Stearns, 2001).

Other concerns regarding distress can be related to ongoing witness to death and dying. Clinicians who work in oncology are exposed to death more in one year than others do in a lifetime and bear witness to intense responses by the patient and family that are often also felt by the clinician (Rohan & Bausch, 2009, p. 88; Stearns, 2001). During my practicum experience I met patients who were told they only had one year to live or even less if there was no curative treatment available for them, as well as those who died during the short time I was at the agency. It got to the point that I lost count of the number of deaths I was exposed to. One patient in particular was told that there was no treatment available and she only had a few months to live. I remember being struck by her strength as she confronted the physician asking him to clarify that every option had been explored. She went from crying to advocating for herself. It was at this time she explained what her goals were moving forward and asked for assistance from the medical team in completing them. In my mind at the time I recall thinking how this must be overwhelming for her to comprehend and I felt helpless. My supervisor said “I’m sorry” and I realized there was nothing else to say at that moment. Unfortunately, there are many such conversations that happen when working in oncology.

The exposure to death as well as the accompanying pain and discomfort of clients may impact clinicians and lead to reduced emotional, cognitive and physical capacity in the form of compassion fatigue or burnout (Holland & Neimeyer, 2005; Rohan & Bausch, 2009). Witnessing intense emotions from family members and loved ones may leave a clinician feeling unable to meet their needs appropriately and in turn believe they
are inadequate in their professional role (Chow, 2013). Moreover, the clinician may not perform as well as expected due to extreme emotional investment into their client’s needs or conversely avoid them removing needed supports, or feel less satisfaction from their profession (Holland & Neimeyer, 2005; Strom-Gotfried & Mowbray, 2006). Early in my practicum I recall feeling exhausted, overwhelmed, and concerned, as I did not respond to situations as I had anticipated. I noticed that I did not have an outward reaction to the patients’ expression of grief and despair upon receiving a poor prognosis. I was uncertain if this was my pulling away from the situation or my capacity to remain calming at such a time. In retrospect, it was most likely both as one of my strengths is to provide a sense of calm when needed yet my inexperience in the area may also have led me to put up a barrier to protect myself from the intensity of the situation.

This too may be strength since the oncology social worker is exposed to repeated losses of clients, which when accumulate over time, may lead to professional grief. Clinicians’ respond to these losses both as a professional and as a human being and the grieving process does not appear to differ regardless of the viewpoint taken. The impact of this grief is dependent on one’s own experiences with loss, the extent of their relationship with the client and the culture found in the workplace to assist them to deal with the losses (Strom-Gotfried & Mowbray, 2006). Should the resources be minimal the clinician may experience feelings of regret, anger, sadness and anxiety (Holland & Neimeyer, 2005; Rohan & Bausch, 2009; Stearns, 2001; Strom-Gotfried & Mowbray, 2006) leading them to possibly avoid clients, become apathetic, experience negative physical symptoms, or even leave the position.
Fortunately, I did not experience these negative outcomes, as my experience was over a short duration. However, as this is a major concern of mine, it is important to learn what would be helpful in keeping them at bay. Stearns (2001) suggests clinicians require supervision by experienced oncology social workers, ongoing educational in the areas of death and dying, and opportunities for self-reflection. Similarly, Chow (2013) adds the competencies needed to excel in this field are good communication skills, effective self-care practices (exercise, spirituality, adaptive coping strategies), and opportunities to reflect and debrief with colleagues. The presence of these protective factors often results in improved coping as the clinician becomes more informed on the field of oncology, increased balance of work/life roles, decreased distress, and personal growth needed to remain committed to and satisfied with their work (Chow, 2013; Holland & Neimeyer, 2005; Rasmussen et al., 2016; Rohan & Bausch, 2009).

From my practicum experience I would have to agree with the above for had these not been present I believe I would have struggled with the emotional impact of social work in oncology. I was part of meetings where patients were given news of their impending death thus having a supervisor present who could model appropriate responses helped to provide learning in dealing with these difficult conversations. Likewise, the support of fellow social workers provided opportunities to express how these interactions impacted me as well as advice on how to manage the intense feelings that were present. This debriefing reinforced the importance of keeping grounded and not getting caught up in the patient’s grief so I could continue to support them. My colleagues also reinforced the need to take care of myself and enjoy life which was important as I often reflected that I needed to exercise more and set myself up to get better quality sleep.
In the end, I began to realize that my fears were unfounded. I experienced successful interactions with patients and their loved ones, as well as others that were not successful. However, the same could be said about my role in mental health which I consider myself successful in and well suited to. What remains important is my ability to continue to assess my interactions with clients, evaluate my role in the relationship, and continue to learn new ways to be an effective social worker (McCoyd & Kerson, 2013).
Chapter Four: Values and Ethics

4.1 Ethical Issues in Oncology Social Work

Learning Objective 4: To understand and reflect on ethical issues facing clinical oncology social workers.

It was not long after starting my practicum that I came to realize ethical issues were at the forefront of every interaction between the patient and the care team due to the nature of the patient/doctor relationship and the number of decisions that take place. The Saskatchewan Cancer Agency promotes ethical decision making as an important aspect in clinical care due to the impact medical decisions can have on the patient. Therefore, they have joined with the Saskatoon Health Region to provide regular opportunities for staff to learn about ethics and become champions in instilling ethical care to patients. I was fortunate to attend the IDEA (Identify, Determine, Explore, Act) ethics facilitator program. This training aims to educate participants on the components of ethical practice and in turn have them take on the role of a champion of ethical awareness within the agency (Fahim, 2014).

An ethical dilemma is defined as competing values or duties that pull us in different directions (Fahim, 2014). When this happens, we will often feel a sense of discomfort, be unclear regarding which action is the best choice, may disagree with others regarding what should be done, and be concerned that someone is being treated unfairly. As you can see in figure 1 and 2, the IDEA ethical decision making process is compatible with the ethics screen used in social work. In the IDEA model (Figure 1), one is directed to identify the facts, determine the relevant ethical principle, explore the options, and act.
Figure 1

Ethical Rules Screen

Figure 2
Also, the five conditions of, empowerment, publicity, relevance, revisions and appeals, and compliance, must be considered to ensure power differences are minimized and that decisions are transparent and made based on evidence (Fahim, 2014, p.3). Similarly, the ethical rules screen (Figure 2) directs one to review our professional code of ethics to guide us in decision making and to then move onto the screen where we would utilize the following principles used in ‘bioethics’.

Bioethics is the field of medical ethics. The principles of bioethics are respect for autonomy, non-maleficence, beneficence, and justice. Autonomy supports the belief that individuals have the right to live at risk. As long as they are deemed capable of understanding and appreciate the consequences of their decision, they have the right to make it. For instance, a patient decision to refuse treatment must be based on receiving the necessary information to make the decision, be voluntary with no sign of coercion, and can always be changed. Autonomy is also an important value of the social work profession and a key part of our code of ethics (CASW, 2005). When we support autonomy, we are promoting the inherent dignity and worth of each client and trust they are the experts of themselves, and have the right to determine their fate. As a clinician, I have a duty to ensure this right is upheld in the treatment of others (CASW, 2005).

Non-maleficence is the minimum risk of harm along with the maximum benefit. When looking at a dilemma with this perspective one must do a harm versus benefit analysis, and proceed in such a way that the harms must never outweigh the benefits. In cancer care this may mean that a treatment is not offered as it will do more harm than good. Further, when it appears the harm and risks are equal the decision must be in favour of the benefit.
Beneficence is when a decision is made based on the utilitarian concept of the greatest good for the greatest number. This is driven by values of common good and the belief in protecting the rights of others. In medicine this is supported by ‘fiduciary duties’ which are the “legal or ethical relationship of confidence or trust between two or more parties” (Fahim, 2014, p.22). Therefore, the physician’s decision to treat or not treat is based on the assumption the patient trusts their capacity to make the decision. These duties however must be carried out in good faith and never place the interests of the physician above those of the patient.

Justice is a decision based on the belief that distribution of resources must be equitable among all who need it. Should there be insufficient resources available the decision returns to one of non-maleficence, thus ensuring those who get the resource are the ones who will benefit the most. The values attached to this decision process are equality and social justice.

Social justice is a key value and responsibility of social workers (CASW, 2005). Since the beginning of the profession, workers have been advocating for the rights of all. In cancer care, social workers take on the social justice role to ensure that barriers to treatment are removed. It is our duty to ensure treatment decisions are not impacted by discrimination of any kind (CASW, 2005; Otis-Green, Jones, Zebrack, et al., 2014). So, when I found myself questioning the treatment offered to a patient with mental illness, it was my duty to look into the situation further. I was uncertain during an appointment with a patient why the physician made the decision to provide a palliative dose of treatment; a shorter course aimed at symptom management rather than having the intent to cure. When asked, the physician explained that more aggressive treatment may cause
more harm than good to the patient, thus acting on the concept of non-maleficence. Still, as I was concerned his rights were not being met I went on to ask more questions to gain further understanding of the patients’ situation. Through asking questions of the physician and peers I learned treatment options are offered based on the stage of the disease and results of studies regarding best practice treatment. Therefore, the decision was also supported by rigorous data and unfortunately, in this situation, there was no curative option. In the end, I realized the care decisions were based on providing the best quality of life for the patient given the circumstances and that the physician, on any given day, carries out the heavy responsibility of these types of decisions on a daily basis. Still, I believe the role of the social worker in this situation, to ask questions and challenge decisions, is extremely important to ensure all options are available to all patients.

4.2 Emerging Concerns

The field of oncology social work is one that continues to evolve based on the increasing numbers of individuals who are diagnosed with, and survive, cancer. As previously stated, the impact of cancer continues from pre-diagnosis through treatment and into survivorship. Much of the care we provide is given to those who are going through treatment yet research has shown that survivors can experience long term effects. As Recklitis & Syrjala (2017) suggest, many cancer survivors spend many years dealing with the long-term effects of cancer and its’ treatment, yet few receive the needed supports to manage this. Thus, they suggest long term distress screening and service implementation. Currently the Saskatchewan Cancer Agency provides an in-house group as well as online support groups however in the age of economic uncertainty social
workers may need to work extra hard to advocate for these and more services to provide the best care possible to patients.

Similarly, as there may be some inconsistency and misunderstanding regarding the role of the oncology social worker, it is important to continue to promote and educate all team members of the role we have in assisting patients to achieve a positive cancer journey. Educating patients is also important to assist them in understanding that accepting assistance is not a sign of weakness but rather merely utilizing all the supports available to them.

Another emerging area is related to new legislation around medical assistance in dying (MAID). As a society moving toward embracing the idea that individuals have a right to die with dignity, social workers may be called upon to be involved in discussions with patients, their families and physicians, regarding ending their life voluntarily. As a profession, we will need to not only understand the legislation, but our role in the process. Being part of this process may require further training to build expertise in how to identify the psychosocial impact of such a decision and how to support patients to talk with others regarding their wishes related death and dying (Adler & Page, 2008). In addition, these societal changes will also highlight the importance of advocating for improved processes or new initiatives to ensure patients receive the type of care they desire and deserve.
Chapter Five: Conclusion

I have learned that a diagnosis of cancer can be life changing to the individual and their loved ones. The diagnosis often comes out of the blue, knocking them off balance and leaving them feeling overwhelmed and vulnerable. Thankfully, the multi-disciplinary team at the Saskatchewan Cancer Agency consists of numerous health care professionals who are knowledgeable, work together, and provide well thought out best treatment options to attempt to treat and cure the cancer.

The role of the oncology social worker is unique within this team as it was created to provide the assessment, supports and interventions to help cancer patients manage the psychosocial stressors that often accompany the diagnosis. As part of a multi-disciplinary team the social worker ensures patient care is also based on patient values and needs, continually advocating on their behalf.

Throughout this paper I have utilized examples from my practicum experience, theory, and literature, to understand and evaluate the role of the oncology social worker and the impact cancer has on the patient. Lastly, I drew from relational theory to evaluate my personal suitability for the field of oncology social work.

This practicum experience has meant a great deal to me. The opportunity to work in the field of oncology rekindled my love for this type of work. I also know it is an area I am suited for and am thankful to all of the patients who, by allowing me to be part of their journey, aided me in realizing this.

Moving forward I know there will be much more to learn as well as many more challenges. I still find it difficult to participate in conversations around a patient’s impending death, and am saddened when a patient dies. I understand that the role of the
medical oncology social worker is important in cancer care but also that it is one that needs to be promoted so all team members realize the contribution we can offer. Regardless of the challenge, I am thankful I will have the opportunity to take them on.
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