Diversity, Oppression, and Social Justice Term Paper:

Examining Diversity and Oppression for Young Adults within Cancer Care

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Examining Diversity and Oppression for Young Adults within Cancer Care

1: Introduction

As described by Mullaly, oppression is perpetuated by the domination of subordinate group by a more politically, economically, socially, or culturally powerful group (Mullaly, 2010). As diversity exists in many forms, this domination of a subordinate group can lead to the “othering” of many diverse subordinate groups. To critically examine this “othering” that exists within a service delivery model this paper will examine the current cancer care system related to the delivery of psychosocial resources. To further examine sources of oppression within the cancer care system this paper will explore a case example of a specific diverse population within cancer care, young adults.

1.1: Organization

Section 2 of this paper will discuss the methodology utilized for this review, while Section 3 will discuss oppression within the cancer care delivery system. Section 4 will then discuss the unique experience a specific diverse population, young adult cancer patients. Finally, Section 5 will conclude with a proposed anti-oppressive framework for use with this population and Section 6 will provide concluding remarks.

2: Methodology and Summary of Sources

To frame the information presented within this review, this section will discuss the methodology to select articles (Section 2.1) and a general summary of sources (Section 2.2).

2.1: Methodology

In January 2012, searches for peer-reviewed journal articles and dissertations were conducted using the University of Calgary online databases in the areas of social work, psychology, medicine, and nursing. In addition to these databases, searches from the Google Scholar database with the same key word searches were conducted to obtain additional background information. Key word search included the following phrases, either singularly or in combination: young adult cancer; young adult oncology; young adult psychosocial; psychosocial oncology; anti-oppression; oppression; marginalization; social justice. A summary of these searches are documented in Table 2.1.
Table 2.1: Summary of literature searches conducted in January 2012.

<table>
<thead>
<tr>
<th>Data Bases Searched</th>
<th>Key Word Searches (Utilized Singularly or in Combination)</th>
<th>Number of Sources Selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology and Behavioural Sciences Collection</td>
<td>young adult cancer; young adult oncology; young adult psychosocial; psychosocial oncology; anti-oppression; oppression; marginalization; social justice</td>
<td>3</td>
</tr>
<tr>
<td>SOCIndex with fulltext</td>
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<tr>
<td>Social Services Abstracts</td>
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<td></td>
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<tr>
<td>Social Work Abstracts</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>PsycINFO</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>CINAHL Plus with full text</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Psychology and Behavioral Sciences Collection</td>
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<tr>
<td>Academic Search Complete (EBSCO)</td>
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<tr>
<td>Expanded Academic ASAP</td>
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<tr>
<td>Journal Citation Reports (JCR)</td>
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<td></td>
</tr>
<tr>
<td>PubMed</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Google Scholar &amp; citations from articles selected above</td>
<td>32</td>
<td></td>
</tr>
</tbody>
</table>

***Note: some databases may have included duplicate search items, therefore exceeds total number of sources in reference list.

Initial inclusion criteria included articles written in English, were North American sources, current within the last ten years, and contained the key word searches within the abstract. Given the limited results obtained from this search, selection of sources were then expanded to include sources current within the last fifteen years, key word searches anywhere in the article, and inclusion of meta-analyses from international sources. Finally, in order to provide a complete picture on the prevalence and emerging areas related to this topic, sources cited within articles previously selected were reviewed and grey literatures sources were also included that were published from national organizations and working groups with psychosocial oncology expertise current within the last five years.

2.2: Summary of Sources

As outlined in Appendix A, 74 total sources were reviewed, with approximately 45% American sources, 50% Canadian Sources and 5% came from international sources. Almost half were current within the last 5 years and nearly 40% were current within the last 10 years. Selected sources included: 55
research-based articles; 2 meta-analyses that reviewed at least 20 sources; 9 theory or review based articles; 1 book; 2 websites; and 5 grey literatures sources such as reports and prepared manuals.

Nearly all of the sources reviewed identified multifaceted sources of oppression within the cancer care delivery system, and over three quarters of the sources identified the unique needs of the diverse demographic of young adults within cancer care. While over half of the sources reviewed provided suggestions for inclusion within an anti-oppressive framework, none of the sources actually utilized terminology related to oppression, diversity, marginalization, or anti-oppression. In addition, the sources that did propose elements for inclusion within an anti-oppressive framework primarily came from within psychology and medicine and only a handful came from within the social work literature.

3: Oppression within Cancer Care Delivery System: Biomedical Model

Mullaly suggests that oppression is dynamic, multidimensional, and relational concept. He also suggests that it can be encapsulated as being the domination of subordinate groups through power-over dynamics, leading to marginalization of the subordinate group (Mullaly, 2010). Within the cancer care delivery system, there exists many opportunities for the domination of subordinate groups such as: those that live significant distances from a major cancer center; those with multiple co-morbidities; those with a more advanced stage of disease at diagnosis; and those with limited access to clinical trials. While each of these sources of oppression are worthy of being examined within the cancer care delivery system, the scope of this paper will examine cancer care delivery model by viewing the oppression generated by the delivery of psychosocial resources within the larger biomedical model of general cancer care. Within this model biomedical interventions, supports, and resources are seen as being the dominant group, while psychosocial supports are categorized as “the Other” with limited and resources being allocated to addressing the psychosocial aspects of the cancer journey.

Despite this “othering” that has been developed within the cancer care delivery system, evidence within the literature provides strong supports that psychosocial resources are a vitally necessary part of the cancer care delivery system. In fact, literature suggests that in North America, between 35%-45% of cancer patients can expect to experience significant distress during their cancer journey (Breitbart, 2002; Bultz & Carlson, 2006; Carlson & Bultz, 2003; Carlson & Bultz, 2004; Carlson et al., 2004; Jacobson & Ransom, 2007; Jacobson & Jim, 2008; McMurty & Bultz, 2005; Zabora, et al., 2001). This high level of distress for cancer patients is in line with reported levels in the literature at a global level, including:
PSYCHOSOCIAL SUPPORTS FOR YOUNG ADULTS

Europe (Dolbeault et al., 2003; Gil et al., 2003; Mehnert, 2004); Asia (Fielding et al., 2004; Shimizu et al., 2004); South America (Santos, 2004); and the Middle East (Isikhan et al., 2001; Sadeh-Tassa et al, 2004; Montazeri et al, 2004). Given this high rate of distress seen in cancer patients, the National Comprehensive Cancer Network Distress Management (NCCN) Panel has created a definition for this multifaceted distress that states it to be:

“...a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis.” (National Comprehensive Cancer Network, 2002, v.1)

However, despite the strong evidence for the levels of distress and need for psychosocial supports for cancer patients, these supports are continually being delivered within the larger biomedical context of service delivery for cancer care. This biomedical context perpetually marginalizes those experiencing distress along their cancer journey by continually favoring biomedical interventions over psychosocial interventions. This can been seen by the astonishing finding that in a publically funded health care system such as Canada, less than 3% of operating dollars were allocated to psychosocial funding within cancer centers. Yet, that same budget allocated 5% of funds to the cleaning of the cancer centers (Asbury et al., 1998). As best stated by McMurtry and Bultz:

“...despite evidence-based research demonstrating the high prevalence rates of emotional distress, [the cancer care system] continues to focus attention on biomedical aspects of treatment leaving a significant gap in patient care...psychosocial elements are not being acknowledged in day-to-day decisions surrounding care and treatment.” (McMurtry & Bultz, 2005, p. 697).

This lack of attention to the day-to-day psychosocial elements of cancer care requires psychosocial professionals to confront both privilege and oppression on a daily basis to best provide supports for their clients. This involves continual advocacy efforts across multidisciplinary teams of health professionals to raise awareness that while psychosocial supports may be “the Other” within the cancer care delivery model, these supports are as important for cancer patients as the dominant biomedical aspect of the cancer journey. Given the profound psychosocial impact of the cancer journey, patients
require equal attention to the biomedical and emotional/psychological aspects of cancer care. Studies have shown that through providing appropriate psychosocial supports within cancer care provides the following positive outcomes:

1. **Increased quality of life for patients**: When sources of distress for patients are recognized and addressed, quality of life increases (Carlson et al., 2004; Carlson et al, 2011; Detmar et al., 2002; Velikova et al., 2004).

2. **Improvements in mental health and role functioning**: Overall patient distress is decreased when psychosocial functioning is seen as a priority and appropriate supports are provided to patients (Bultz & Carlson, 2006; Carlson et al., 2004; Carlson et al, 2011; Detmar et al., 2002; Velikova et al., 2004).

3. **Reduction in consultation time with biomedical health care providers**: When patients are better able to communicate all sources of concern and distress to their health care team consultation times are significantly reduced (Homsi, 2006; Pruyn et al., 2004).

4. **Creates economic savings with the cancer care delivery model**: When the underlying causes of distress are both acknowledged and appropriately addressed patients are then provided with the most effective biomedical interventions. This saves costs within the cancer care delivery model because it avoids patients receiving unnecessary or inappropriate biomedical supports (Canadian Journey Action Group, 2009; Chiles et al., 1999; Koocher et al., 2001; Newell et al, 2002; Simpson et al., 2001).

In summary, by avoiding “othering” psychosocial supports within the cancer care delivery model it provides appropriate supports for distressed cancer patients, saves time, and makes economic sense. As best described by Carlson and Bultz:

“...reducing the emotional burden of cancer care will reduce the economic burden...putting patient needs squarely at the center of the [cancer care delivery model] involves a fundamental shift in not only spending allocations, but also in the overall approach to patient care. Full recognition that the ‘people part’ of cancer care is vital to a well-managed and compassionate care system makes ethical, emotional, and economic sense (Carlson & Bultz, 2006, p.95).

Therefore, addressing the oppression generated by the biomedical context within cancer care involves looking at the many areas of diversity within cancer care and advocating with multidisciplinary professionals for appropriate psychosocial supports. To examine a case example of how this may be
done, Section 4 and 5 will address diversity in cancer care in young adult patients.

4: Diversity in Cancer Care: Young Adult Cancer Patients

As Carter-Black and Kayama note, despite common circumstances, there often exists much diversity even within a particular marginalized group (Carter-Black & Kayama, 2011). This is certainly the case within cancer care. While patients may all have a diagnosis of cancer, much diversity exists within their experience. This diversity can be seen on many levels such as race, gender, age, socioeconomic standing, tumour group, and many more factors. While each of these are important diversity considerations, given the scope of this paper, this review will focus on diversity related to age and young adults within cancer care. This is a demographic that has many unique needs within the cancer care delivery system, yet experiences oppression on many levels and is often marginalized within the current cancer care delivery model.

This section will discuss the current prevalence cancer in young adults, who can be categorized to be between the ages of 15-35 years old (Section 4.1), and then will explore the young adult cancer experience within the current cancer care service delivery model (Section 4.2).

4.1: Current Prevalence and State of Young Adult Cancer Care

Young adults account for 2% of all patients with new diagnosis of invasive cancer in Canada. (Bleyer, 2007; De et al., 2011; Kent et al., 2011; SYAA, 2011; Zebrack, 2010b). Within North America, nearly 69,200 young adult patients are diagnosed with cancer each year, yet survival rates for young adult cancers have not increased within the last four decades (National Cancer Institute, 2011). The National Cancer Institute suggests that poor survival rates that are not improving within this age group can be attributed to: delayed diagnosis of primary cancers; inadequate treatment practices and settings, including inconsistent treatment and follow-up care guidelines; poor understanding of the biology and etiology of cancers in young adults; inadequate collection of patients and patient data; low number of available clinical trials and poor participation; unique psychosocial and supportive care needs; limited emphasis on prevention and early detection (National Cancer Institute, 2011). Therefore, an in-depth understanding of the needs and experience of this demographic is vitally important to reduce the marginalization experience by young adults and will be explored in Section 4.2.
4.2: The Young Adult Experience within Cancer Care

While there exists much diversity even within the young adult cancer experience, several general trends exist within the lived experienced for this demographic. The Young Adult Oncology Program through McGill University describes this period as being:

“...marked by many developmental changes and social milestones as people in that age group graduate high school, attend college or university, secure a job, start a career, establish financial independence, form long-term and intimate relationships, have children and raise a family. Developing cancer at this stage in life presents unique challenges as the patient grapples not only with the realities of the disease but also with its impact on the pursuit of those social milestones... [young adults] are left to deal with the far-reaching effects of living with the disease, such as delays to future plans, financial hardship and social isolation as a result of losing time from school, work, and social engagements.” (McGill, 2012, p.1).

Given the profound impact of a cancer diagnosis at this developmental stage, this section will explore the lived experience and psychosocial issues of the young adult cancer patient within six areas reported within the literature surveyed that include: social isolation and impacts to relationships (Section 4.2.1); delayed diagnosis and limited research (Section 4.2.2.); body image and fertility concerns (Section 4.2.3); Impacts to independence, financial situations, and careers (Section 4.3.4); unique survivorship issues (Section 4.3.5); and effects of facing mortality in young adulthood (Section 4.3.6).

4.2.1: Social Isolation & Impacts to Relationships

As outlined in Appendix A, nearly all of the literature surveyed suggests that impacts to relationships and the resulting social isolation for young adults begins from the point of diagnosis onwards. This is due to the fact that young adults receive cancer care within biomedical system that is geared towards the needs of much older adults (Buckland, 2011; Evans & Zelter, 2006; Levine et al, 2010; NCI Cancer Bulletin, 2011; National Institute of Health, 2011; YACC, 2012; Zebrack et al., 2007; Zebrack, 2008; Zebrack, 2010b;). In fact, within this system, less than 5% of the cancer centers in Canada provide appropriate peer support for young adults. This lack of support tailored to young adults serves to compounds difficulties, leading to further isolation for these patients as they are forced into services geared towards issues for much older adults, creating further “othering” for this group (Buckland, 2011; Brock & Perry, 1995; Morgan et al., 2010; Snobobm et al., 2010).
Another aspect is that this model that fails to take into consideration the unique developmental milestones of young adults and ignores the important role of social supports and networks for this demographic. As Treadgold and Kuperberg describe:

“social acceptance by the peer group play a central role in [young adult] development. Peer relationships help a young person to individuate, formulate an identity, and foster independence. For [young adults], peer support is invaluable in helping them cope with their illness. However, cancer and its treatments may diminish the size of existing social networks, with potential development and emotional consequences....the wish for normalcy often results in profound isolation for [young adults], who keep their cancer experience encapsulated and away from their healthy peers.” (Treadgold & Kuperberg, 2010, p.4843).

Therefore, young adults may require assistance with how to seek support from family and friends as well as how to communicate about the effects of their cancer within both social and workplace relationships (Corey et al., 2011; Grinyer, 2005; Zebrack, 2006a). They may also need encouragement that, despite their cancer diagnosis, they should be encouraged to pursue social activities and relationships such as dating, going out with friends, sustaining friendships, and finding a mate (Subbiah, 2010; Thomas et al, 2006; YACC, 2012; Zebrack, 2006a; Zebrack, 2008). This may become difficult for the young adult cancer patient as the impact of both the physical appearance and physical function of the patient changes over time with each stage of the cancer journey (McGill, 2012).

4.2.2: Delayed Diagnosis & Limited Research

Delayed diagnosis and limited research specific to young adult cancer patients is a trend that is confirmed throughout the North American literature for young adults (Bleyer, 2002; Bleyer et al., 2006; Buckland, 2011; National Institute of Health, 2011; Treadgold & Kuperberg, 2010; YACC, 2012; Zebrack, 2006a; Zebrack, 2006b). In fact, a study conducted by Mitchell and colleagues reviewed the treatment options for young adult cancer patients diagnosed over a four year period and found that “young adults are less likely to enrolled in clinical trials than younger children.” (Mitchell et al., 2004, p. 62). These lack of clinical trials highlight that not only are young adults failing to be seen as unique subgroup with unique needs, but that their survival rates are being compromised because of lack of specific research for all types of young adult cancers. This lack of trials is then leads to little research and literature being
mobilized around all aspects of young adult cancers.

This lack of knowledge mobilization regarding young adult cancers often then leads to delayed diagnosis for these patients. In addition to lack of available literature and research, Rabin and colleagues suggest that this delay may be caused by any one of the following:

1. Feelings of invulnerability and reluctance to seek care on the part of the young adult;
2. Limited access to health care/drugs because of lack of insurance; and/or
3. Reluctance on the part of the treating physician to suspect cancer (Rabin et al., 2011).

Therefore, it is clear that further research, awareness, and appropriate knowledge mobilization is required to reduce delayed diagnosis for young adult cancer patients.

4.2.3: Body Image & Fertility Concerns

The literature suggests that body image concerns for young adults can include loss of hair, gain/loss of weight, impairment of sexuality, mutilating surgery (De et al., 2011; Snobobm et al., 2010; Zebrack, 2008). This is seen in several studies and meta-analysis that suggest that a priority concern for young adult cancer patients was obtaining information about sexuality, fertility, and reproductive risks/implications. Given that young adults are either thinking about starting their own families or have already begun to start their own families these concerns many include: pregnancy safety, options for having a family, early menopausal symptoms, genetic susceptibility, and inheritability of cancer for offspring (Bolte & Zebrack, 2008; Hall et al., 2010; Levine et al, 2010; Rabin et al., 2011; YACC, 2012; Zebrack, 2006a).

4.2.4: Impacts to Independence, Financial Situations & Careers

Young adult’s lives are inherently transitional in relation to developing careers, families, and relationships. The diagnosis of cancer often creates a trajectory that causes great discordance with this stage of life which has the potential to cause great disruption to independence (Buckland, 2011; Levine et al, 2010; National Cancer Institute, 2011; Thomas et al., 2006; YACC, 2012). As stated by Treadgold & Kuperberg:

“Cancer often involves intensive and lengthy treatment which has the potential to put [young adults] at risk for disruption of these demanding yet normal maturational processes. Therefore, special attention must be paid to the establishment of unique supportive services to help [young adults] navigate challenging developmental tasks in the context of the cancer experience.” (Treadgold & Kuperberg, 2010, p. 4842).
Thus, the need for unique supports to balance the need for independence with that of financial stability is of paramount importance. This was seen in a study by Roberts and colleagues who found that a significant concern for patients was the impact the illness had on their careers and the subsequent impact on their financial situation. As most young adults are beginning their careers, their independence related the stability of their career and thus their finances. At a time when young adults are attempting to establish their independence from parents and family support systems, many young adults are often forced to rely more heavily on these systems (Roberts et al., 1997).

In addition to financial considerations, young adulthood is a time where patients are attempting to balance their own independence with the need to seek appropriate supports. Traditional biomedical models rely on the patient to raise issues. In effort to seek independence, young adults may not want to raise their concerns or have appropriate tools to raise them in an appropriate manner given their limited experience within the health care system for a life threatening illness (Buckland, 2011; Hall et al., 2010; NCI Cancer Bulletin, 2011; National Cancer Institute, 2011; National Institute of Health, 2011; Snobobm et al., 2010; YACC, 2012; Zebrack et al., 2007; Zebrack, 2010a). Therefore, it is appropriate that the cancer care delivery system recognize these limitations and work towards providing opportunities for specific, concrete, and detailed information for young adult patients. This removes the onus from the young adult patients to the cancer care delivery system.

4.2.5: Unique Survivorship Issues

Since young adults have most of their entire adult lives ahead of them, survivorship issues can be long lasting and compounded and integrated at each development milestone in adult life (Buckland, 2011; National Cancer Institute, 2011; YACC, 2012). Figure 1 depicts some of the integrated survivorship issues a young adult cancer patient may face post-treatment.
Figure 1: Depiction of integrated survivorship issues for young adult cancer patients.

While each of these issues depicted in Figure 1 have the potential for profound effects on the survivor, a shocking less than 1% of cancer research is devoted to survivorship issues for this demographic (Rabin et al., 2011).

4.2.6: Effects of Facing Mortality During Young Adulthood

Much of the literature surveyed found that an impactful psychosocial concern for young adult cancer patients involves the ability to face a life-threatening illness at such a young age. In fact, a study by Roberts and colleagues with 46 young adult cancer patients found that time-limited support groups targeted to young adults were most effective in addressing the psychosocial effects of facing mortality of young adulthood as they were adequately address fear of recurrence, end of life issues, advanced planning, and unique dynamics for young adults. (Roberts et al., 1997).
Young adult patients are faced with a balance of addressing existential issues and an unpredictable future with the ability to keep hopes and dreams for the future alive (Grinyer & Thomas, 2004; YACC, 2012; Zebrack, 2006a; Zebrack, 2010a). As the McGill Young Adult Cancer Program identifies, young adults are at a point in their life where there are endless possibilities for them to pursue, and the notion of their own mortality is not something that is first and foremost in their mind (McGill, 2012). Therefore, a cancer diagnosis suddenly changes everything as it forces them to confront their own mortality. While young adults may have increased cognitive abilities that allows them to understand the gravity of their illness and possible mortality; yet, they do not have the life experiences necessary to have developed a coterie of positive coping skills necessary to face their own mortality from a life threatening illness (Roberts et al., 1997; Treadgold & Kuperberg, 2010). Therefore, as Treadgold & Kuperberg note:

“A death of [another young adult cancer patient] brings up not only sadness caused by the loss of a friend, but also the fear about one’s own mortality. For cancer patients, mortality holds a particular meaning because each member feels vulnerable in the face of his or her own life-threatening illness and may also feel guilty about being a survivor. For this age group, the high disease burden and low survival rates associated with [young adult] cancers can cause significant distress” (Treadgold & Kuperberg, 2010, p. 4846).

5: Proposed Anti-Oppressive Framework for Social Workers

Young adults are a largely understudied population with treatment and care issues that include delays in diagnosis, low participation in clinical trials, lack of age-appropriate care, concerns around social support during cancer treatment, as well as late effects of treatment, secondary cancers, and long-term psychosocial requirements for cancer survivors (YACC, 2012). As Treadgold & Kuperberg note:

“The realization that this is a group with unique psychosocial needs is not a new one, but with the increasing calls for dedicated services, there has also been an acknowledgement that age-specific psychosocial support should be an intrinsic part of the treatment plan for any [young adult] patient with cancer” (Treadgold & Kuperberg, 2010, p.4842).

Therefore, of paramount importance when working with this population is an anti-oppressive framework that recognizes the diversity of young adults within cancer care. Over the next three pages, Table 5.1 outlines suggested elements for an anti-oppressive framework when working with young adults in cancer care. This table also outlines how each of these proposed elements challenge the
oppression young adults face and how each element seeks to enhance social justice for this demographic.

Table 5.1 (Page 1/3): Suggested Elements for an Anti-Oppressive Framework for Young Adults within Cancer Care and the link to Challenging Oppression and Enhancing Social Justice.

<table>
<thead>
<tr>
<th>Proposed Anti-Oppressive Framework for Young Adults within Cancer Care</th>
<th>Explanation of Proposed Anti-Oppressive Framework for Young Adults within Cancer Care</th>
<th>How Proposed Framework for Young Adults Challenges Oppression and Enhances Social Justice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide Education/Awareness of Human Development Theories for Young Adults Across all Health Care Disciplines</td>
<td>• Resources and education should be devoted to educating the public, health professionals, insurers, and policy administrators about the special needs and lived experiences of young adult cancer patients (Bleyer, 2002, Buckland, 2011; Hayes-Lattin, 2010; Hall et al., 2011; Kent et al., 2011; LYSAA, 2011; McGill, 2012; Zebrack, 2006a).</td>
<td>• Assists in structural transformation by recognizing both the oppression and diversity that exists within cancer care for young adults and strives towards consciousness raising for key differences for the lived experiences of this demographic (Mullaly, 2010).</td>
</tr>
<tr>
<td>Advocate for Flexibility in Treatment Schedules</td>
<td>• Assist in advocacy and education with both patient and other health care professionals to determine a flexible treatment schedule that meets the biomedical needs while simultaneously taking into account: the patients school/ work schedule; family commitments; and social network supports (Buckland, 2011; Zebrack, 2006a).</td>
<td>• Increases patient empowerment by acknowledging important social systems within their lives outside of the context of cancer (Bleyer, 2002; Buckland, 2011).</td>
</tr>
<tr>
<td>Advocate for and Assist in the Creation of Specific Young Adult Peer Support Programs (Individual, Group, &amp; Retreat Programs)</td>
<td>• Young adults may find themselves isolated from peer groups and family support systems who just want them to be cheerful and optimistic. Unable to express fears and concerns with those closest to them, young patients often find refuge in those who understand a similar journey, therefore the development of specific programs is vitally important (Hall et al, 2011; Treadgold &amp; Kuperbuerg, 2010; Zebrack, 2006a). Such support groups are able to identify and target issues specifically related to the young adult population that include: anxiety about health and physical well-being; worry about fertility and raising children; problems in relationships; financial concerns; body image; diet; exercise; and complementary and alternative medicines (Rabin et al., 2011; Roberts et al., 1997). • Providing peer-based, age specific, therapeutic activities and programs has been proven to be effective in addressing the psychosocial needs of young adults. They can address issues of survivorship, provide cancer education and tools for self-advocacy, and build bridges among young adult cancer survivors with similar journeys, and provide hope (Haase &amp; Phillips, 2004; Treadgold &amp; Kuperberg, 2010; Zebrack et al., 2006b).</td>
<td>• Within the biomedical system often places the patient in a passive role. Participation in a peer group requires active participation that can be empowering by encouraging the patient to take on more decision making responsibility in relation to their treatment and the impacts of cancer on all aspects of life (Treadgold &amp; Kuperberg, 2010). • Inclusion of groups that are traditionally marginalized such as young adult cancer patients in program development assists in empowerment (Van der Plaat &amp; Barrett, 2005). • By creating, developing, and delivering alternative programs specific to young adults, it assists to develop a base to which larger social change can eventually be affected (Mullaly, 2010). • Assists in narrowing the dichotomy of power between patients and medical staff through effective collaboration with young adult cancer patients (Mullaly, 2010).</td>
</tr>
</tbody>
</table>
### Table 5.1 (CONTINUED: Page 2/3): Suggested Elements for an Anti-Oppressive Framework for Young Adults within Cancer Care and the link to Challenging Oppression and Enhancing Social Justice.

<table>
<thead>
<tr>
<th>Ensure Patient Input in Decision Making Process &amp; Providing Detailed, Specific, Developmentally Appropriate Information</th>
<th>Ensure Connections with Other Young Adult Cancer Patients</th>
<th>Use of Technology Advances Where Available and Appropriate</th>
<th>Advocate for Coordination of Care and Specialized Screening Tools for Distress for Young Adults</th>
</tr>
</thead>
</table>
| - Seeking patient’s input through each stage of the treatment process and avoid assumptions regarding decisions based on the patient’s age/developmental stage. In addition, seeking input from the patient regarding the level and type of information they would like shared along their journey (Zebrack et al., 2006a).  
- Written and verbal information should be provided post-treatment that include individualize information such as: history of treatment; type of cancer; surgeries; chemotherapies and dosages; radiation sites and dosages; potential late effects; risks for recurrence or secondary cancers; and other survivorship issues (McGill, 2012; Zebrack, 2006a) | - Appropriate connections with other young adults post-treatment are vitally important to assist in reducing isolation and addressing unique survivorship challenges (Buckland, 2011). | - Creation of support groups and peer resources through the use of online support groups, social media, blogs, digital storytelling, music, and photovoice specific to the young adult experience (Treadgold & Kuperberg, 2010; O’Callaghan et al., 2011; Yi & Zebrack, 2010). | - Specific cancer care with professionals who have an in-depth understanding of young adult oncology will assist in providing the most coordinated care for this demographic. It will assist in helping to facilitate quicker diagnosis, development of additional clinical trials to enhance survival, as well as appropriate psychosocial supports. (Cooke et al., 2011; De et al., 2011; Ferrari et al., 2010; LYSAA, 2011).  
- Specialized screening for distress tools are required to adequately address the unique lived experiences for young adults. Current national and international screening for distress tools have poor reliability and validity for young adults and many have not been tested at all with this demographic (Corey et al., 2011; Canadian Partnership Against Cancer, 2011; LYSAA, 2011). |
| - Ensures that further empowerment is experienced for this population by seeking input in a variety of creative ways from those whose lived experiences provide valuable insights (Mullaly, 2010). | - Creates coalition-building between young adult patients that allows for mutual support while at the same time providing an opportunity for the creation of a collective voice for a marginalized population (Mullaly, 2010). | - Given the limited number of young adults with cancer, the use of technology allows for those patients isolated by distance to connect with their peers to reduce isolation. It provides a less expensive option to allow patients to connect with patients with a similar cancer (Treadgold & Kuperberg, 2010).  
- Allows for the participation of patients that may not otherwise be well enough to come to a face-to-face support group (Rabin et al., 2011; Treadgold & Kuperberg, 2010).  
- Reduces barriers of attending for those young adults with families and demanding careers (LYSAA, 2011; Rabin et al., 2011). | - Coordinated care and specialized screening tools assist in challenging oppression for this population by recognizing their lived experience and providing appropriate supports along their cancer journey (Corey et al., 2011; Canadian Partnership Against Cancer; LYSAA, 2011). |
Table 5.1 (CONTINUED: Page 3/3): Suggested Elements for an Anti-Oppressive Framework for Young Adults within Cancer Care and the link to Challenging Oppression and Enhancing Social Justice.

| Seek Feedback From Patient Regarding Desire for Level of Communication with Parents/Additional Family Members in Support System. | • As there is much diversity within the young adult group, it is vitally important to seek feedback from the patient as to the level of involvement and to what extent they wish to include family members and additional supports with the medical team. This assists in recognizing the struggles for patients in finding a balance between independence and autonomy during their journey (Buckland, 2011; LYSSA, 2011). | • Assists in additional empowerment for the young adult as it reduces the assumption that the patient either does or does not want additional family members involved in communications about their care. (Buckland, 2011; LYSSA, 2011). |
| Ensure Input in the Development of Research Agendas and Knowledge Mobilization Regarding the Young Adult Cancer Experience. | • Include, as a regular part of practice, connections with those who have influence over the development of research agendas. This includes all multidisciplinary professionals within cancer care (Buckland, 2011). | • Advocate with multidisciplinary teams what current evidence supports regarding the young adult cancer experience and integrate this knowledge into conversations with the health care team (Buckland, 2011). | • Allows for the rejection of the idea that inequalities are an inherent part of the system. Rather, it creates an opportunity to analyze the patterns of injustice and provide an opportunity to create an evidence base that challenges these inequalities (Mullaly, 2010). | • Ensures that oppression for this population is not perpetuated by utilizing outdated and ineffective frameworks with this particular population (Mullaly, 2010). |

6: Concluding Remarks

Diversity within any service delivery system is inevitable. Social work is uniquely positioned to examine this diversity to identify areas of oppression within the systems we work in; social workers can not only critically examine this oppression, but strive to affect these systems through ensuring front line practices that fit within an anti-oppressive framework. As stated by Mullaly:

“One way for anti-oppressive social workers to contribute to social transformation is to create, develop, and/or support alternative social service [delivery systems] that serve members of particular oppressed groups....alternative systems and programs are counter-systems to mainstream [service delivery systems] and can be used to ultimately establish a base from which larger social changes can be eventually affected” (Mullaly, 2010, p. 260).

This paper has provided an example of such a delivery system that marginalizes young adults within the cancer care system. Using Mullaly’s suggestion of working towards anti-oppressive practice through social transformation, this paper has highlighted the unique experience of young adult cancer patients. It has then provided a suggestion for an anti-oppressive framework that seeks to empower young adults...
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within cancer care through honouring their lived experience, connecting them with other young adult patients, and seeking to provide and deliver services that best meet their psychosocial needs. As with any group, there is obviously much diversity even within the young adult cancer experience and this paper is not meant to provide an exhaustive list of possibilities. Rather, as Mullaly suggests, it provides a beginning framework that can form the foundation for areas where larger social changes have the potential to be affected within the cancer care delivery system.
References


Treadgold, C., & Kuperberg, A. (2010). Been there, done that, wrote the blog: The choices and challenges of supporting adolescents and young adults with cancer. *Journal of Clinical Oncology, 28*(32), 4842-4849.


