

Exploring culturally appropriate care across the cancer trajectory: Are the health beliefs of Aboriginal people incorporated or further suppressed by Western ideologies?

Nicole Helmer, RN, BScN, MN (c)

The implications of oncological incidences among Aboriginal people is frequently misconstrued, as research has demonstrated that cancer incidence rates are significantly lower in Aboriginal people, yet the mortality rates amongst the population are detrimentally high (Marrett & Chaudhry, 2002). Throughout this paper literature will be presented in an attempt to gain a further understanding as to why a nation of people are at such high risk of dying from a disease that society believes they're immune to. The purpose of this paper is to identify the historical aspect of cancer within Aboriginal communities and to determine culturally appropriate means of providing care throughout the cancer trajectory, including prevention, diagnosis, treatment, end-of-life and bereavement.

This assignment is a review paper exploring literature published on traditional healing practices of Aboriginal people of Canada and the existence of cancer amongst the population. As well, the means by which cancer information is distributed and received by Aboriginal communities and its effect on treatment compliance will be explored. In addition, this paper will examine cancer care agencies across Canada to determine the extent of established practice guidelines and standards of care which are specific to cancer care within Aboriginal communities. Furthermore, future implications regarding the development and implementation of culturally appropriate care throughout the cancer trajectory will be introduced and further explored.

Traditional Health Beliefs

Historically, mainstream culture has monopolized the means by which healthcare is provided to all citizens of Canada, especially Aboriginal people. Once patients enter the healthcare setting there is an expectation that they will follow the rules of Western society, as alternative methods of healing, as well as traditional beliefs and health practices are disregarded. This indifference toward traditional health beliefs is replaced with Westernized teaching of paternalistic healthcare in which patients are expected to listen solely to advice of their doctor, who may lack an understanding of culturally sensitivity. The tunnel vision typical of healthcare providers (HCP) further perpetuates the assimilation of Aboriginal people by disregarding their traditional practices, which not only address cultural beliefs but also provide an effective form of healing.

It is recognized by the author that the health beliefs and healing practices of Aboriginal people are diverse and widespread, and it is misleading to generalize all beliefs into an all-encompassing 'Aboriginal' component. However, for the purpose of this paper, the author will generalize practices of Aboriginal people, which consist of First Nations, Métis and Inuit, while indicating specific beliefs where appropriate.

The traditional health beliefs of Aboriginal people incorporate the four dimensions of physical, social, emotional and spiritual health that require an equilibrium in order to attain optimal health. The four dimensions, as represented through the symbolic form of the medicine wheel, demonstrate the importance of being in harmony with the environment in order to achieve holistic healing (Hunter, Logan, Barton & Goulet, 2004). When individuals experience a disconnect from their cultural identity or an imbalance among the dimensions of healing, they may be at risk for depression or substance abuse; thereby requiring a reconnection by the use of

traditional native spirituality, which facilitates the individual's return to a state of feeling complete (Hunter et al, 2004).

Generally, HCP are trained to provide care through the Westernized lens of medicine; therefore, traditional health beliefs of Aboriginal people may affect the HCP ability to provide adequate care. In order for nurses or physicians to engage in culturally appropriate care they must become familiar with the traditional healing practices of Aboriginal people and adapt to a holistic practice which is coherent with Aboriginal beliefs and values. Through this adaptation, the HCP will gain a better understanding of the traditional healing practices of their patients; thereby creating a stronger foundation for building trust and understanding the patients' perspective regarding the disease process (Hunter et al, 2004). Understanding a patient's culture provides the HCP with an insight into how the disease, particularly cancer, is viewed. It is through culture that individuals understand cancer and find ways to explain the disease while gathering an understanding of their attitudes towards it (Dein, 2004). It is particularly important for the HCP to grasp the significance of these healing beliefs as they may affect a patients' willingness to participate in treatment modalities; therefore, cultural sensitivity is required in the development of treatment protocols in order to ensure patient acceptance.

Holistic healthcare practice is imperative in Aboriginal communities, as it is through culturally sensitive care that HCP gain a clearer understanding of Aboriginal cultures and their healing traditions. In a profession where statistical data and quantifiable results are regarded as superlative knowledge, the HCP must recognize the equivalent importance of cultural responses to cancer in the provision of oncological care (Dein, 2004).

Traditional healing practices are viewed as a starting point for the healing of self, as well as the healing of others and are initiated as a result of a presenting illness (Hunter et al, 2004). In

a survey conducted of 10,000 First Nations and Inuit people, over 80% believed that a return to traditional ways of healing was good practice for promoting wellness (Lemchuk-Favel & Jock, 2004). Therefore, it is the responsibility of the HCP and program planner to develop and incorporate traditional healing practices within the care provided across the cancer trajectory.

Healing practices, as presented through chart form in Appendix A, are origins of Aboriginal culture and guide notions of spirituality and the flow of energy required for healing to occur (Hunter et al, 2004). Healing circles are an important symbol of Aboriginal culture and symbolize family and unity. For hundreds of years they have served as a means for people to come together and support one another in times of angst (Campbell, 1999). Within these circles individuals are encompassed in a space of trust, where one expresses their pain and sorrow and becomes empowered as all listen and realizes they are not alone. The circle is therapeutic and healing in nature and appropriate to incorporate throughout stages of the cancer continuum, especially for family and community members during a time of bereavement. The sweat lodge is a healing practice that is beneficial throughout the cancer trajectory but particularly at the time of time of diagnosis and treatment. Through the engagement of a sweat lodge practice, individuals gain a connection with the spirits who bring guidance and healing of the mind, body and spirit.

In November 1996 the Royal Commission on Aboriginal Peoples released a report stating that governments, health authorities and traditional practitioners were to co-operate in the protection and extension of traditional healing practices and explore their incorporation within contemporary health problems (Campbell, 1999). Twelve years later the Royal Commission's recommendation has been disregarded and the traditional practices of Aboriginal people continue to be ignored throughout the healthcare system. In a quasi meta-analysis conducted by Hunter et al (2004), 18 studies were reviewed and key themes were identified including the concept of

holistic healing and culturally sensitive care. While the identified themes facilitated in providing a better understanding of Aboriginal issues, minimal data was gathered in regards to the existence of healing traditions in mainstream healthcare and how such practices aid the attainment of health (Hunter et al, 2004).

Throughout history, the traditional beliefs and healing practices of Aboriginal people have been suppressed and assimilated by Western ideologies. While steps have been taken to right this wrong, it is now time for the government and government agents, such as HCP, to fix the mistakes of the past and take a proactive approach in the resurgence of traditional healing practices in the care of Aboriginal people. A proactive approach involves HCP becoming more aware of traditional healing practices and appropriate means of incorporating such practices into healthcare modalities, as well as respecting the rights of all cultures to diversity and equality of care.

Cancer Overview

It is a thought pattern amongst most researchers and HCP that cancer is virtually a non-existent health issue of the Aboriginal population; yet recent studies have indicated that due to the decrease in infectious diseases and accidental deaths, cancer is now ranked third for mortality in Aboriginal populations (Marrett & Chaudhry, 2002). It has always been difficult to obtain accurate figures of cancer cases as Statistics Canada, which is a primary means of gathering quantitative data, does not collect cancer statistics by ethnic status (Waldram, Herring & Young, 2006). Rather, the gathering of data from alternative means, such as through provincial registries, may lead to inaccurate findings, creating a disproportionate number of cancer incidence and mortality reported amongst Aboriginal people.

A cohort study involving Status Indians of Ontario (n=141,290), was conducted by Marrett and Chaudhry (2002) and found 2572 cancer incidences and 1433 cancer deaths to have occurred between 1968-1975 and 1984-1991. The results of the study demonstrated that the Aboriginal population shares similarities with the general Canadian population in that common forms of cancer for both include lung, breast, prostate and colorectal; however, cancers which have a higher incidence rate amongst Aboriginals as compared to non-Aboriginals include cervix, gallbladder and kidney. While the breast, prostate and colorectal cancers have a higher incidence rate in the general population, the study demonstrated that the incidence rates for the three types of cancers have risen significantly in the Aboriginal population, with a dramatic rise in colorectal. In data collected from Cancer Care Ontario, between 1968-1991 gallbladder cancer was found to be more than twice as common in Aboriginal people (Grace, 2003). Possible explanations for the increasing incidence of cancer include a combination of genetics, lifestyle and sociocultural factors, as Aboriginal people have adapted a Euro-Canadian culture of smoking, poor diet and insufficient physical activity (Marrett & Chaudhry, 2002).

Cervical cancer is one of the three most prevalent cancers, occurring 73% more often in Aboriginal women (Grace, 2003). This form of cancer is thought to be caused by initiation of sexual intercourse at a young age, engagement in the act with multiple partners; it is also considered to be highly preventable with routine Papanicolaou (Pap) tests. In a study conducted by Young, Kliewer, Blanchard and Mayer (2000), incident rates of invasive cervical cancer were 1.8-3.6 times higher in Aboriginal women, with a peak incidence in the 20-34 age group, as compared to the general population. In addition, the study found that, with the exception of those aged 15-19 years, 43% of Aboriginal women received routine Pap smears as compared to 60% of the general population. According to Waldram et al (2006), barriers to screening for

cervical cancer include lack of comfort in discussing Pap smears with HCP, friends or family; confusion or lack of knowledge regarding specifications of the test; and feelings of embarrassment and discomfort, both psychologically and physically, when dealing with male physicians (p.93). This revelation demonstrates a need to develop culturally-appropriate screening programs while incorporating psychosocial support in order to address the emotional and mental needs of the patient.

While the increase of cancer incidence rates is a problem within Aboriginal communities, the number of Aboriginals dying from cancer is astoundingly high. The elevated number of deaths in association with cancer is thought to be a result of late-stage diagnosis and lack of use or accessibility of available health services. According to Marrett and Chaudhry (2002), the rise of oncological mortality cases is indicative of an epidemiological transitional shift in the pattern of illness, which results from a cluster of social problems, including lack of knowledge. Barriers to seeking out cancer information include fear, lack of communication with HCP, stigmatization, low socioeconomic status and preference for traditional healing practices (Friedman & Hoffman-Goetz, 2006)

Communication of Cancer to Aboriginal People

Research has shown television and community newspapers to be the primary means of distributing cancer information to rural and remote communities; therefore, it is important to ensure disseminated messages are culturally-appropriate and contain sound content relevant to the target population. According to Friedman and Hoffman-Goetz (2006), the framing of cancer prevention information presented in newspapers has the potential of profoundly affecting the health behaviours of its readers. The reliance only on mass media for obtaining cancer

information is not preferable, as the data presented is rarely evidence-based on proven research; as well, the mass media may fail to capture health disparities amongst minority groups. In addition, this informational sort most often fails to provide the follow-up or mobilizing information required to enable behavioural actions (Hoffman-Goetz, Shannon & Clarke, 2003). Furthermore, mainstream media neglects to report on the incidence and mortality rates of specific cancers, thereby creating lack of knowledge regarding risk factors and prevention matters. This deficiency in reporting may be a result of powerful advocacy groups influencing the research agenda or a spill-over from non-Aboriginal media. However, when sound information is distributed through culturally-appropriate messages, mass media may be seen as beneficial and its coverage of cancer issues an important means of gaining health information when health service interaction is infrequent. In regards to facilitating mammography utilization, mass media has been considered complementary with physician advice (Hoffman-Goetz et al, 2003).

In a study conducted by Friedman and Hoffman-Goetz (2006), 27 cancer articles, which were published in ethnic community newspapers, were assessed for cultural sensitivity using the CSAT measurement tool. Three aspects of printed material measured by the CSAT tool includes i) format – organization, font and print size; ii) written message – comprehension of familiarity with cancer terminology and ethnic-specific expressions; and iii) visual presentation – photographs, illustrations, customs, symbols, and setting used to convey message (Friedman & Hoffman-Goetz, 2006). Out of the 27 articles, nine were derived from First Nation newspapers and received the highest CSAT score, indicating the utmost cultural sensitivity. The articles published in the First Nation newspapers received the highest CSAT score of 3.28 (95% CI=2.99-3.56) for written messages, as well as high scores in visual and written description

categories with a CSAT score of 2.99 (95% CI=2.69-3.68). While the majority of the articles were scientific in content, some were anecdotal and contained stories of individual experiences, while others were comprised of both scientific and anecdotal content. In addition, the First Nation articles were the only ethnic articles to address issues of racism and discrimination. In further reviewing the content of the nine First Nation articles, the true cultural sensitivity came into question. Already recognizing the most prevalent cancers among Aboriginal people being breast, colorectal, prostate, cervix, lung, gallbladder and kidney, only three articles presented breast cancer information, one article focused on prostate and one was directed towards cervical cancer. There were no articles regarding colorectal cancer, which is dramatically increasing in Aboriginal populations; neither was there any mention of lung, gallbladder or kidney cancers. Rather, the primary cancer mentioned in the articles was leukemia/lymphoma, which has a significantly lower incidence rate within this culture as comparative to the pre-mentioned cancers. In addition, throughout the nine identified articles, there was no mention of traditional healing practices or deviation from the Westernized ideologies present throughout healthcare. The results from this study demonstrated that cancer information distributed to Aboriginal communities is greatly lacking in appropriate cancer content specific to the target population. As well, there is a clear deficiency in culturally-appropriate messages that are attuned to the health beliefs and values of the target readers. Therefore, it is imperative that strategies be put in place that ensure the literature presented to Aboriginal communities is relevant to the common health issues of the population and demonstrates support for traditional healing practices in conjunction with conventional treatment options.

In a similar study conducted by Hoffman-Goetz et al (2003), 31 Aboriginal newspapers published in Canada were explored in an attempt to identify the volume and focus of articles

regarding chronic diseases of First Nations, Métis and Inuit peoples. Approximately 400 articles were selected from the Aboriginal newspapers, with 56 focusing solely on cancer in Aboriginal communities within Canada. The highly targeted cancers of discussion included breast (23), leukemia (9) and melanoma (5), with only one article on cervical cancer and one on prostate cancer. There were no articles regarding colorectal or lung cancer and no mention of gallbladder and kidney cancer throughout the 56 oncology articles. The limited number of cancer articles failed to address the cancers significant in Aboriginal populations, nor did they address the issue of the high prevalence of smoking amongst Canadian Aboriginal people, which is the number one cause of cancer.

The deficiency of appropriate common cancer coverage in First Nation newspapers strongly suggests a need to develop strategies in reducing health information disparities among Aboriginal communities and improve the content of information distributed in relation to oncological care. The cancer information distributed to Aboriginal communities requires cultural appropriateness in hopes of attaining higher rates of cancer screening; thereby increasing the probability of early diagnosis, leading to lower mortality rates amongst Aboriginal people. A checklist developed by Friedman and Hoffman-Goetz (2006) is useful in assessing the cultural sensitivity of cancer information (Appendix B).

Standards of Care and Practice Guidelines

Culturally-appropriate communication on a broad level is imperative for creating a large scale effect; however, communication on an individual level is equally as important in order to provide culturally sensitive care to patients and family members. In a narrative presented by Ellerby, McKenzie, McKay, Gariepy and Kaufert (2000), a 70-year-old Elder who only speaks Ojibway

is admitted into the healthcare setting and diagnosed with prostate cancer. In the presence of Mr. F's son and male interpreter, the physician explains that Mr. F has advanced cancer which has metastasized to his bones. The son refuses to allow the interpreter to translate the diagnosis to his father because cancer is a cultural metaphor for 'being eaten within' and will only cause fear and pain. Rather than make direct reference to death and dying, which may bring death closer, Mr. F's son requests time to communicate with his father through a more indirect and gradual process. The physician works together with the son to meet his cultural and spiritual care needs and arranges a time to hold a 'sharing circle' with the patient and family members in order to discuss palliative care planning. This introduction of Aboriginal bioethics addresses ethical values which may be held by Aboriginal people that are applicable to all dimensions of living, which includes respecting the individual, practising conscious communication and non-interference, involving family and allowing for Aboriginal medicine (Ellerby et al, 2000). To further facilitate HCP in providing culturally-appropriate care, standards of care and practice guidelines must be developed to illustrate means of doing so.

The practice of oncology care in the general population is guided by standards and guidelines. Cancer care agencies throughout the world develop guidelines to provide optimal oncological care based on empirical evidence. There are hundreds of guidelines that address all areas of the cancer continuum and provide support to the HCP in the provision on oncological care. Guidelines range from communicating diagnosis, providing supportive care for the bereaving family, initiating treatment and enacting symptom management. The guidelines are essential elements in the provision of effective, patient-centered care; and are currently developed primarily for the general population through a Westernized lens. In 1998 the Canadian clinical practice guidelines made recommendations related specifically to the Aboriginal

population, involving community-based screening and primary prevention guidelines (Young, Reading, Elias & O'Neill, 2000). However, searching throughout the literature it became evident that within Canada there are no existing or detectable in-progress guidelines related to oncological care for Aboriginal people. In an attempt to delve further into Aboriginal cancer care standards, alternative resources were investigated. In a search of Australian and New Zealand literature a number of practice standards and guidelines were uncovered, including a health standard based on empirical evidence regarding best practice of interventions for chronic conditions in Aboriginal people. The practice standard was designed to assist HCP to enhance the current services provided by utilizing the principles of i) self-management and self-determination; ii) promoting Aboriginal community participation; iii) placing individuals and community at the centre of care; iv) emphasising a primary health care approach; v) encouraging an integrated, coordinated approach across the continuum of care; and vi) fostering multidisciplinary care (NSW Health, 2005).

An additional guideline found from the Australian/New Zealand literature was practice standards for melanoma, highlighting the need for awareness in non-Caucasian groups. Through this guideline, means of examining and managing melanoma were introduced to the HCP in an attempt to provide comprehensive care to Aboriginal patients (N.A, 2008). Additional Australian/New Zealand literature presented guidelines for providing cancer health and Cancer Control services for Indigenous Australians. In a search of the American literature, guidelines were found addressing main cancer survivorship topics such as i) access to quality care and services; ii) education, training and communication; iii) infrastructure, programs and policies; and iv) applied research and surveillance (Kaur, 2007).

Clearly, Canada is lagging behind in the establishment of practice guidelines associated with the cancer care provided to Aboriginal people; however, some steps forward have been taken. The Assembly of First Nation's mission statement on health includes the need to develop national strategies in regards to health promotion, prevention, intervention and aftercare (Adelson, 2005). This recognition is a step towards the development and implementation of such strategies.

A strategy introduced by Cancer Care Ontario (CCO) which aims to address and promote the awareness of the cultural needs of Aboriginal patients is the Aboriginal Patient Navigator (APN) program. The results of a 2002 Aboriginal cancer care needs assessment strongly recommended the establishment of APN positions at all cancer care centres in Ontario (Faries, 2005). The role of the APN was to provide support and advocate for Aboriginal patients and family members. The APN role is beneficial in the healthcare setting, as it creates cultural sensitization among cancer center and hospital service providers, as well as establishing links with Aboriginal health agencies while providing a means for addressing the unique needs of Aboriginal people (Faries, 2005).

Following the implementation of the pilot study at the highly-Aboriginal populated Thunder Bay Regional Health Science Centre, successes were achieved and lessons were learned. The pilot project was successful in strengthening translation services for patients, as well as raising awareness within the cancer centre through various strategies, such as cultural awareness sessions and outreach programs. The project was also successful in assisting patients and family with arranging accommodations and seeking financial assistance through the First Nations Inuit Health Branch (Faries, 2005). Lessons learned from the pilot project include i) the need to develop policies regarding traditional ceremonies and means of accommodating large

extended families; ii) a team effort is required to bridge the cultural gap between the hospital and Aboriginal culture; iii) the APN scope of practice must be clearly defined, as there is constant pressure to expand beyond the cancer system; and iv) appropriate training and orientation for the APN is essential for the success of the program.

In 2006, the Juravinski Cancer Centre in Hamilton adapted the CCO strategy and implemented the APN role to meet the needs of the more than 25,000 Aboriginal people serviced through the centre. The role is seen by the organization as a means of helping Aboriginal patients through their cancer journeys and increasing their access to cancer services (Banning, 2007)

The introduction of APN positions within Thunder Bay and Hamilton health services has proven to increase the degree of adequate culturally-based services for Aboriginal patients and families and would be a beneficial component of provided cancer care on a national level.

Future Implications

While the establishment of APN roles in cancer centres throughout Ontario is a step in the right direction, more needs to be done by the Canadian government in order to ensure cancer care provided for Aboriginal people includes a cultural component and is not solely practiced through Western ideologies. The need for culturally-appropriate guideline development is recognized across the cancer continuum, with additional future implications including i) development of Aboriginal health systems; ii) educating HCP on the theoretical aspects of incorporating cultural care; iii) introducing a stress-coping paradigm; and iv) providing culturally appropriate care.

Aboriginal Health Systems

Historically, healthcare for Aboriginal people has been provided under the terms of the provincial and federal governments. Through the Health Transfer process of the late 1980's some

communities, such as Kahnawake and Eskasoni First Nations, have transitioned away from the Western model and built the capacity and infrastructure to govern their own health systems (Lemchuk-Favel & Jock, 2004). Initiating Aboriginal governed health systems has been shown to be beneficial in developing unique Aboriginal approaches to healthcare delivery, incorporating a synergy of traditional and western philosophies and improving access to healthcare through a culturally supportive environment.

Barriers that prevent the provision of healthcare services to Aboriginal people in urban settings involve language, cultural appropriateness, fear of stigmatization, and heightened mobility. One means of addressing such barriers involves the development of Friendship centres which have played significant roles as providing meeting places for Aboriginal people in urban settings. Friendship centres have been key locations in which Aboriginal programs have started, including the urban Aboriginal Head Start and diabetes health promotion (Lemchuk-Favel & Jock, 2004).

Whether located in urban settings or in rural, remote environments, Aboriginal communities possess inherent resources, which are valuable in the development and implementation of effective and cost-efficient health services. Relinquishing control of health systems to the community not only creates a climate of self-empowerment but it also enables community members to direct attention to health needs specific to their population (Kirmayer, Brass & Tait, 2000).

Leininger's Cultural Care Model

In today's healthcare setting patients are treated through a Westernized lens regardless of their ethnicity or culture, which has perpetuated a system of assimilation and cultural suppression. An

existing issue in healthcare is the ethnocentrism of HCP, further forcing the dominant society's monocultural values and beliefs onto Aboriginal patients (Weaver, 1999). Cultural insensitivity is a recognized barrier to care for many HCP, which leads one to question; why, as HCP are we so culturally blind and insensitive to the needs of others? Future research would be beneficial in determining whether it is the university programs, healthcare system or society in general that conditions HCP to provide ethnocentric care. In order to change this outdated way of thinking, HCP must be trained to bridge cultural differences, and the healthcare system should incorporate a model of transcultural care, as pioneered by Leininger in the 1960's.

It is through transcultural care that the HCP adopts a holistic approach to medicine, exploring the patients' lifestyle, values, norms and expectations through a cultural assessment (Weaver, 1999). HCP attempting to transform their practice into a transcultural one must ensure that they appreciate and accept human and cultural differences, demonstrate concern and are free of prejudice and bias, as well as recognize how stereotyping negatively impacts healthcare delivery (Weaver, 1999). While this model was developed specifically to nursing, the principles are transferrable to all healthcare workers. Leininger believes that healthcare practices that include a cultural component improve patient compliance and respect, and decrease racism while increasing understanding and knowledge of different cultures (Weaver, 1999). A study conducted by Weaver (1999), sought to determine appropriate means of providing transcultural care to Aboriginal people. Through the completion of 40 surveys by Indigenous nurses, essential aspects of knowledge, skill and values required for providing culturally-appropriate care were identified. The results demonstrated the importance of the HCP understanding of cultural history and factors, specific health beliefs and practices, and diversity amongst Indigenous nations. In order for the HCP to be proficient in practising transcultural care they must possess the skills of

working in a non-Western cultural context, and communicating with additional containment skills of listening and patience (Weaver, 1999). Finally, in order to practice proficient transcultural care, the HCP must be open-minded, non-judgmental and non-ethnocentric, as well as respectful of diversity and cultural traditions.

In providing transcultural care, the HCP must alter their practice to work in a non-Western context and acquire the necessary knowledge and skills. The inclusion of transcultural care into mainstream healthcare would be a large step forward in changing the paternalistic approach of healthcare to one which is all-encompassing and supportive of diversity and traditional healing.

Stress-Coping Paradigm

A cancer diagnosis creates a great deal of stress for those diagnosed as well as their loved ones. While most stress-coping models are developed in Western ideologies, an Indigenous stress-coping paradigm developed by Walters, Simoni and Evans-Campbell (2002), incorporates the impact of historical trauma, as well as protective factors of family, community, spirituality and traditional healing practices. The stress-coping paradigm (Appendix C) provides a framework for understanding how Aboriginal people deal with traumatic life experiences in the face of colonization (Walters et al, 2002). Through this model it is also understood that traumatic life stressors and health outcomes are moderated by cultural factors that buffer and strengthen psychological and emotional health.

The incorporation of a stress-coping model, specifically addressing the psychosocial needs of the Aboriginal population throughout the cancer continuum, will utilize the protective

factors valued by Aboriginal people and may augment their psychological and emotional wellbeing following a cancer diagnosis.

Provision of Culturally Appropriate Care

In relation to oncology, the provision of culturally-appropriate care should occur across the cancer trajectory; however when HCP and patients are of different cultural backgrounds, communication and decision-making create challenges (Kelly & Minty, 2007).

Throughout the cancer trajectory, a deficiency of culturally-appropriate care has been greatly acknowledged, as screening programs, communication of diagnosis and treatment modalities continue to be presented through a westernized lens, lacking flexibility for cultural incorporation. However, the end-of-life spectrum of the cancer continuum is starting to make progress in the provision of culturally-appropriate care to Aboriginal people. In a literature review conducted by Kelly and Minty (2007), published literature was explored to determine how end-of-life care was provided to Aboriginal patients. Following the application of inclusion/exclusion criteria, 39 articles, which focused on end-of-life care, were selected and reviewed. Common themes noted throughout the literature reflected end-of-life issues, such as respect for personal independence in decision-making, free from persuasion from the HCP; as well as respect for the inclusion of Elders in the decision-making process, as they are valued for their wisdom and experience. Another noted theme was the incorporation of traditional healing practices in conjunction with Western practices. It was suggested that Aboriginal patients should have the same access to a traditional healer in the healthcare setting as they do to a hospital chaplain. Other areas addressing appropriate end-of-life care for Aboriginal patients included family involvement with the death of a patient and recognition of the HCP in regards to the

belief in an afterlife and the importance of maintaining relationships with loved ones upon entering the spirit world (Kelly & Minty, 2007).

Through the literature review, insight was provided on what constitutes a good death amongst Aboriginal people, such as preparing themselves physically and spiritually. This is done by dressing in particular clothing which is to be worn in preparation for their journey and saying good bye to their loved ones, thereby maintaining positive relationships. Through this insight it is also recognized that dying is a unique individual process and the HCP must ensure sensitivity for the specific patient's wishes (Kelly & Minty, 2007). The final issue discussed in the literature review is organ donation, which rarely occurs amongst this population, as it is the belief that when Aboriginal people die they are to be buried with a complete body and soul in order to prepare them for their next life. This creates an issue in healthcare as there are a large number of Aboriginal patients awaiting transplants but a low donation rate. As found in the United States, an increased rate of organ donation has occurred over a 17-year period, as a result of generating awareness through culturally-sensitive messages (Kelly & Minty, 2007).

This movement forward in palliative/end of life care is encouraging for the healthcare provided to Aboriginal people, as it appears that some aspect of the oncology world is starting to recognize the unique needs of this population and incorporating them into the care provided.

Conclusion

Historically, the Canadian healthcare system has ignored the unique needs of Aboriginal people, and the oncology world continues to do so today. The intent of this paper was to explore the cultural appropriateness of care provided to Aboriginal people across the cancer trajectory and identify whether the health beliefs of Aboriginal people were incorporated or further suppressed

by Western ideologies. As proven throughout this paper, in the oncology world the health beliefs and traditional healing practices of Aboriginal people continue to be disregarded. The lack of culturally-appropriate standards of care or practice guidelines demonstrates the healthcare system's intention of continuing to assimilate Aboriginal people into Western society.

Neglecting to develop appropriate means of providing care to correlate with the values and beliefs of Aboriginal people will only further perpetuate Aboriginals' resistance to attaining necessary care throughout the cancer trajectory. Late diagnosis and high mortality rates will continue to triumph over screening and survivorship; however, the development of culturally-appropriate programs may increase participation in screening practices and treatment modalities. Incorporating traditional healers, promoting Aboriginal health systems and embarking on holistic care practices are key strategies in improving the health of Aboriginal people. In order to improve the health of the original people of our homeland, healthcare must remove the focus from their own agenda and start concentrating on the needs of the Aboriginal people.

References

- Adelson, N. (2005). The embodiment of inequity. *Canadian Journal of Public Health (96)*, S45-S60.
- Banning, L. (2007). *Aboriginal patient navigator role supports Aboriginal patients*. Hamilton Health Sciences & Foundation.
- Campbell, C. (1999). Aboriginal healing circle 'powerful'. *Family & Health (4)*, 1-7.
- Dein, S. (2004). Explanatory models of and attitudes towards cancer in different cultures. *The Lancet (5)*, 119-124.

- Ellerby, J., McKenize, J., McKay, S., Gariepy, G., Kaufert, J. (2000). Bioethics for clinicians: Aboriginal cultures. *Canadian Medical Association Journal* (163)7, 845-850.
- Faries, E. (2005). *Aboriginal patient navigator pilot project evaluation report*. Cancer Care Ontario Aboriginal Cancer Care Unit.
- Friedman, D. & Hoffman-Goetz. (2006). Assessment of cultural sensitivity of cancer information in ethnic print media. *Journal of Health Communication* (11), 425-447.
- Grace, S. (2003) A review of Aboriginal women's physical and mental health status in Ontario. *Canadian Journal of Public Health* (94)3, 173-175.
- Hoffman-Goetz, L., Shannon, C. & Clarke, J. (2003). Chronic disease coverage in Canadian Aboriginal newspapers. *Journal of Health Communication* (8), 475-488.
- Hunter, L., Logan, J., Barton, S., Goulet, J. (2004). Linking Aboriginal healing traditions to holistic nursing practice. *Journal of Holistic Nursing* (22)3, 267-285.
- Kaur, J. (2007). *A national action plan for cancer survivorship: Native American priorities*. Centre for Disease Control and Prevention.
- Kelly, L. & Minty, A. (2007). End-of-life issues for Aboriginal patients. *Canadian Family Physician* (53), 1459-1465.
- Kirmayer, L., Brass, G. & Tait, C. (2000). The mental health of Aboriginal peoples: Transformations of identity and community. *Canadian Journal of Psychiatry* (45), 607-616.
- Lemchuk-Favel, L. & Jock, R. (2004). Aboriginal health systems in Canada: Nine case studies. *Journal of Aboriginal Health*, 28-51.
- Marrett, L. & Chaudhry, M. (2003). Cancer incidence and mortality in Ontario First Nations, 1968-1991 (Canada). *Cancer Causes and Control* (14), 259-268.

- No author. (2008). Melanoma in specific populations in Australia. *Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand*.
- NSW Health. (2005). *Aboriginal Chronic Conditions Area Health Service Standards*.
Department of Health: North Sydney.
- Walters, K., Simoni, J. & Evans-Campbell, T. (2002). Substance use among American Indians and Alaska Natives: Incorporating culture in an 'Indigenous' stress-coping paradigm. *Public Health Reports (117) Supplement 1*, S104-S117.
- Weaver, H. (1999). Transcultural nursing with Native Americans: Critical knowledge, skills and attitudes. *Journal of Transcultural Nursing (10)3*, 197-202.
- Young, T., Kliewer, E., Blanchard, J. & Mayer, T. (2000). Monitoring disease burden and preventive behaviour with data linkage: Cervical cancer among Aboriginal people in Manitoba, Canada. *American Journal of Public Health (90)9*, 1466-1468.
- Young, T., Reading, J., Elias, B. & O'Neill, J. (2000). Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. *Canadian Medical Association Journal (163)5*, 561-565.

Appendices

Appendix A

Talking circle: Is a place of trust and confidentiality. Opened by prayer and a song sung by an elder. Whoever holds the eagle feather may speak of what they wish. All are heard, and no one has to speak if they do not desire to. Circles can be very emotional as well as therapeutic and healing in nature.

Drum circle: Like a talking circle but with powerful music and the ancient songs. The drum represents the mother's heartbeat heard in the womb and is very comforting as well as powerful.

Eagle feather: Represents vision, strength, and courage. The eagle feather is a very sacred object. The eagle can see the furthest and fly the highest. Whoever holds the eagle feather can speak freely and no one can interrupt.

Medicine wheel: Divided into four quadrants representing a color, gift, sacred object, a stage of life, and a race. The number four and the circle are symbolic of unity in diversity. The circle within the circle represents a whole person. Teachings allow a person to move from denial to awakening, through fear, and on to acceptance and healing at one's own pace. North represents European, winter, and the age of elder. Fire and mental health are represented. Sweetgrass gives balance and kindness, and the gifts are wisdom and strength. The color is white, and the teaching is acceptance and healing. East is represented by the Asian race. The season is spring and the age is infancy. The earth and spiritual health are represented. Tobacco gives strength and the gift is vision. The color is yellow and the teaching is fear. South is represented by the Aboriginal race. The season is summer and the age is youth. Wind, air, and emotional health are important. Cedar gives purity and honesty, and the gifts are love, trust, and discipline. The color represented is red, and the teaching is denial. West is represented by the African race. The season is autumn, and the age is adulthood. Water and physical health are represented. Sage offers sharing, and the gift is introspection. The color represented is black or blue, and the teaching is awakening.

Smudging: Sweetgrass or tobacco is burned in a small bowl, and the smoke from the burning is brushed gently over the face, heart, and body to cleanse and purify. This is done silently in a circle while standing. Prayers are said before and after a smudging.

Sweat lodge: A purification ceremony and healing of mind, body, and spirit. It may be held in preparation of an undertaking such as a fast, or it may be a healing ceremony in itself. It is important to connect oneself to the spirits when seeking guidance and healing. This ceremony is held in a lodge and conducted by an elder and consists of burning tobacco, sage, or cedar and maintenance of the fire. A talking circle may occur within a sweat lodge.

(Hunter et al, 2004)

Appendix B

Questions for Assessing Cultural Sensitivity of Cancer Information

1. Is the intended ethnic group mentioned? Directly? Indirectly? (Individuals are more likely to process information and take health action if it is perceived to be relevant to them [Kreuter et al., 1999; Skinner, Strecher, & Hospers, 1994]. When articles do not reference the intended target audience, minority groups may not be aware that the cancer risk information pertains to them and may not seek preventive cancer care.)
2. Is the ethnic group described as a high-risk group for cancer or as the intended readers of the cancer information? (Tailored risk information results in greater attention to the message and a higher probability of health action [Kreuter et al., 1999].)
3. Does the article address cancer risk perceptions of the intended ethnic group? (Misconceptions about an ethnic group's specific risk of cancer may discourage individuals from seeking out cancer prevention resources [Bottorf et al., 1998; Hoffman-Goetz, 1999; Johnson et al., 1999].)
4. Are complementary and alternative medicines presented as acceptable methods of cancer prevention or treatment? (Hotson and colleagues [2004] affirm that culturally sensitive health care should include family support systems as well as traditional healing services.) 442 D. B. Friedman and L. Hoffman-Goetz Downloaded By: [Canadian Research Knowledge Network] At: 12:19 29 September 2008
5. Are these cancer treatment options presented in a manner that is understandable and appropriate for the intended readers? (The CSAT tool contains this question as it pertains to disease signs and symptoms only.)
6. Does the article provide mobilizing information? (Cues for action can lead to positive changes in health behavior [Miller & Millar, 1998].)
7. Is the contact person or organization identified for mobilizing information of the same ethnic group as the intended readership? (Culturally appropriate resources are important for minority groups who may prefer to obtain cancer information from ethnic-specific sources [Chan et al., 2003; Odedina et al., 2004].)
8. Is the cancer message linked to credible and accessible sources? (Although the CSAT asks about the credibility of organizations, these organizations may be considered credible but inaccessible to ethnic groups living in remote locations.)

(Friedman & Hoffman-Goetz, 2006)

Appendix C

WALTERS

factors that function as buffers, strengthening psychological and emotional health, decreasing substance use, and mitigating the effects of the traumatic stressors (figure 1). Although a vast literature considers the interrelationships among stress, coping, and health, little empirical research has addressed either the particular culture-specific stressors of AIs or the coping strategies and protective aspects of indigenous culture.

Our model builds on the work of Dinges and Joos and Krieger.^{15,16} Dinges and Joos expanded a model of stress and coping by including stressful and traumatic life events. They identified environmental contexts and “person” factors as potential mediators or moderators of stressful life events. Their vulnerability hypothesis posits that associations between life events and adverse health outcomes are moderated by preexisting internal and external factors that function as buffers. Positive, negative, or neutral health outcomes thus depend on the interaction of internal processes with the state of stress. Dinges and Joos found this model to be the most effective for depicting stress, coping, and health relationships for AI populations. We expect that the model can be generalized to substance-related health outcomes as well.

Krieger’s work incorporates the health consequences of discrimination and ecosocial theory.¹⁶

She underscores the importance of including identity processes and expressions of self as moderators of the relationship between discrimination and health outcomes. Our model delineates the pathways between social experiences and substance use and health-related outcomes, thus providing a coherent means of integrating social, psychological, and cultural reasoning about discrimination and other forms of trauma as determinants of substance use and health-related outcomes.

SOCIODEMOGRAPHICS OF AMERICAN INDIANS AND ALASKA NATIVES

The 2.4 million AIs in the United States constitute about 1% of the total population, and the number of AIs is expected to grow more than 44% to 3.5 million by 2020.¹⁷ Including individuals who also identify as Hispanic or multiracial, there are an estimated 4.1 million AIs in the United States, representing 1.5% of the U.S. population.¹⁸

AIs are not a homogeneous group but members of distinct and diverse tribal nations. The Bureau of Indian Affairs Federal Registry now recognizes 562 tribes at the federal level, and individual states recognize another 200 tribes. Tribal communities are diverse, with members speaking more than 200 languages.

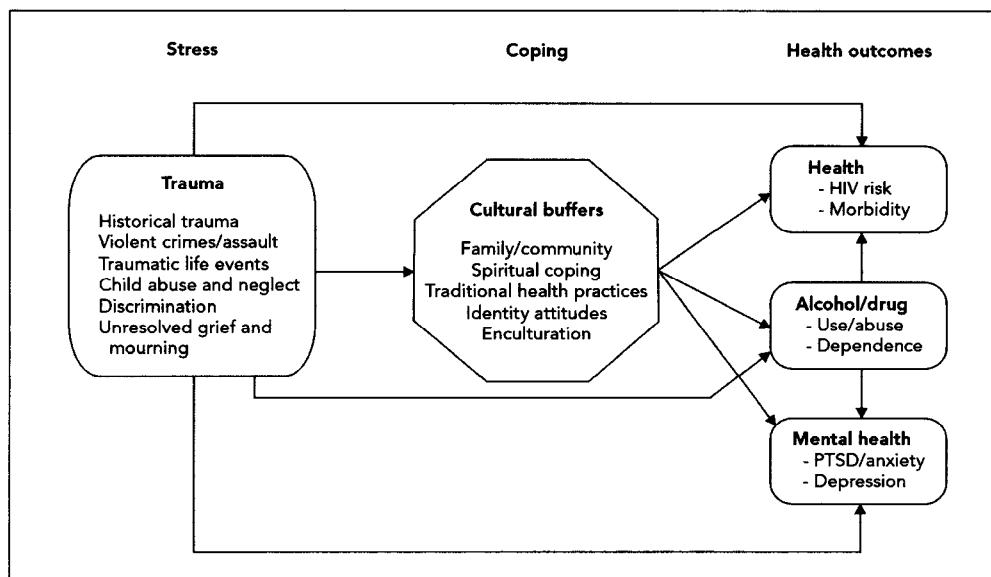


Figure 1. Indigenist stress-coping model