

## HELENE HUDSON LECTURESHIP

*Editor's Note: This article was prepared based on the Helene Hudson Lectureship given at the Annual CANO/ACIO Conference in 2016. The lectureship was established in memory of Helene Hudson from Manitoba who provided inspiring leadership for oncology nursing and patient care.*

# Compassion, connection, community: Preserving traditional core values to meet future challenges in oncology nursing practice

By Virginia Lee, Rosemary Reilly, Kate Laux, and Andreeanne Robitaille

## INTRODUCTION

With thanks to CANO/ACIO and Amgen, a memorial lectureship in honour of Helene Hudson was established to continue to promote the spirit and vision of oncology nursing practice. This special plenary lecture provided a welcome opportunity to pause and reflect on oncology nursing practice and the changing world in which we live.

Over the past four decades, owing largely to the interdisciplinary field of psychosocial oncology, there has been significant progress in how we understand and care for the psychological well-being of patients who have been diagnosed with cancer. The more than 600 evidence-based interventions documented to date (Moyer et al., 2009), and the current focus on patient-centred care (Kitson et al., 2013), suggests that attending to a patient's emotional needs and psychosocial well-being is a widely recognized and indisputable part of cancer care. Yet, unmet emotional needs persist across Canada and there remains much room for improvement in terms of providing adequate emotional support at diagnosis and throughout treatment (Carlson et al., 2004; Coronado, et al., 2017).

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Patients live within a certain threshold of emotional distress at any given time by virtue of cancer's threat to life. By extension, it would be justified and appropriate for patients to expect to receive compassionate care and emotional support from healthcare professionals who work in cancer care. The challenge, however, is that meeting these emotional needs in practice is at risk of being overshadowed by rapid advances in medicine and technology, as well as modern-day priorities that focus on efficiency. This paper describes how one Canadian cancer centre cultivated a sense of compassion, connection, and community, individually and collectively, by integrating innovative meaning-making activities into cancer practice.

## TECHNOLOGY AND HEALTH CARE

It is almost impossible to imagine life without the Internet. Only 25 years old, the Internet and the expansion of technology has permeated almost every aspect of our lives. Realistically, we cannot stand in the way of progress, nor would we want to. However, progress comes with a responsibility to evaluate the consequences that come with change.

Technology has changed the way we connect with each other. Technology can efficiently connect us virtually, but it can just as quickly isolate us. Increasingly, improvements to processes of care, such as self-registration at automated check-in stations, are dependent on technology to improve the efficiency of the healthcare system. However, the cancer experience is already an isolating

experience (Hoey, et al., 2008). The further loss of human connections, social cues, and rich conversations can enhance feelings of fragmentation, disconnectedness, and inadvertently lead patients to feel like just a number (Thorne, 2005). The quest for efficiency is essential to absorb increasingly large volumes of patients, but can fall short of acknowledging the emotional personal journeys with cancer.

Technology has changed the way we provide and receive information. The Internet has created a freely accessible open compendium of health information, presumably to empower patients with knowledge and engage in decision-making. Many institutions are converting patient education materials from paper to electronic modalities. Content is shortened to accommodate shorter attention spans and videos are embedded to share personal patient journeys (Barnes, Marateo, & Ferris, 2007). However, not all patients have the capacity to search the web and access information, and not all information is reliable (McMullan, 2006). There is a risk of overlooking individuals who are not net-savvy when there is an over-reliance on electronic modalities for the dissemination of information.

Technology has complicated the dying process. The constant tide of medical breakthroughs, technological advances, and experimental treatments can provide a false sense of security that death can be indefinitely kept at bay. It may have come to the point where it is no longer clear what it means to be living with cancer or dying from cancer. Atul Gawande summarized the debate succinctly:

“All-out treatment, we tell the terminally ill, is a train you can get off at any time—just say when. But for most patients and their families, this is asking too much. They remain riven by doubt and fear and desperation; some are deluded by a fantasy of what medical science can achieve. But our responsibility, in medicine, is to deal with human beings as they are. People only die once. They have no experience to draw upon. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come—and to escape a warehoused oblivion that few really want.” (Gawande, 2010)

Ostensibly, technology has made life easier and more convenient for many of us. But technology is evolving so rapidly that we run the risk of losing sight of the core values that provide a person with a sense of personhood—values that become more accentuated in importance when faced with a life-threatening illness. While not all patients can or wish to be electronically connected, all patients want a human connection and to be treated with compassion and respect. The modern-day challenge is to figure out how to preserve the capacity to care with compassion and to connect, as a community, in a world that is increasingly dependent on technological innovations.

## EMOTIONAL SUPPORT IS A HIGHER ORDER NEED

In 1943, Abraham Maslow proposed a psychological theory of human motivation that was based on a hierarchical five-tier model of fundamental human needs (Maslow, 1943). The theory states that human beings are motivated to first satisfy two of the most basic needs for human survival: i.e., food, water, warmth, rest, and security (physiological and safety needs). Once these lower order needs for survival are met, individuals are motivated to meet other higher level psychosocial needs such as the need for friendships and intimate relationships (love and belonging needs), to feel a sense of accomplishment (self-esteem needs), and to feel that one has achieved one's full potential, as a developing human being (self-actualization

needs). Theoretically, the task of self-actualization is achieved after individuals have lived a long and full life, at the end of which, one can look back, and take stock of one's productivity, contributions to society, and legacy left to future generations (Erikson, 1950).

Conducting an untimely life review often forces a confrontation with one's mortality. At any age, contemplating one's finiteness poses a daunting task. When cancer is involved, it gets more complicated with variations determined by stage of illness, phase of treatment, and readiness to face one's illness situation (Lee & Loiselle, 2012). Contemplating one's mortality has been likened to staring at the sun—one can only do so for short amounts of time, the effects of which can be blinding (Yalom, 1980). In the context of cancer, when personal goals and aspirations are temporarily disrupted or permanently halted and the future is uncertain, psychological needs become magnified and the need to reach a sense of self-actualization may accelerate and become more urgent. While healthcare has found a way to benefit from the technological advances to fulfil some of the basic physiological needs for survival, the healthcare system has lagged behind in fairly distributing sufficient attention and resources to support the fundamental higher order needs for belonging, self-esteem, and self-actualization.

## SELF-ACTUALIZATION THROUGH MEANING-MAKING ACTIVITIES

Meaning-making approaches within the context of cancer care have been identified as promising approaches to effectively buffer the psychological burden of cancer (LeMay & Wilson, 1992; Lee, et al., 2004; Henoeh & Danielson, 2009). The term meaning-making refers to the cognitive and emotional efforts that are directed at revisiting, reviewing, and reframing parts of a stressful life situation until a new framework of beliefs can be reconstructed to make sense of the traumatic event and provide a renewed sense of peace and purpose (Frankl, 1984; Park, 2010). Having a sense of meaning in life refers to the

perception that one's life experiences are orderly and purposeful (Thompson & Janigian, 1988), and that recovery from extremely stressful life events can even potentiate the ability for self-actualization (Tedeschi & Calhoun, 2013).

The challenge inherent to modern hospital settings is finding the time, space, and resources for patients to engage in the search for meaning. While meaning-oriented psychosocial interventions are highly salient and desired by cancer patients (Moadel, et al., 1999; Kvåle, 2007), the wider dissemination of traditional meaning-oriented interventions has been limited by the stigma surrounding mental health and illness (Holland, Kelly, & Weinberger, 2010), practical inconveniences such as travel time, long waiting lists, an inability to commit to extensive treatment sessions, and the tendency to predominantly offer meaning-oriented interventions to patients with advanced or terminal cancer (Hack, et al., 2011; Kissane, 2009).

To address these limitations, the opportunity arose to implement and explore the impact of two meaning-making approaches at the Cedars Cancer Centre at the McGill University Health Centre in Montreal, Quebec. One study adapted the original face-to-face version of the Meaning Making Intervention (Henry, et al., 2010, Lee et al., 2006a, b, 2008.) into a self-administered patient workbook and a group psychoeducational workshop that was delivered monthly within the hospital's non-profit cancer resource centre. Six workshops were conducted over seven months in the cancer centre. Each workshop ranged between three to 10 participants per group. Thirty-nine participants completed self-report questionnaires measuring health-related quality of life, spiritual well-being, and self-efficacy, before, immediately after, and one month after the workshop. Although no significant differences were found for self-efficacy, functional well-being and physical well-being, study participants showed significantly improved scores for social well-being, and increased faith and spiritual well-being immediately after the workshop, as well as one month following completion of both the workshop and workbook.

A second qualitative study (manuscript in preparation) sought to explore how group art therapy facilitated the process of meaning-making among women receiving treatment for breast cancer in a tertiary care cancer centre. Ten women, aged 41 to 67 years, consented to attend eight two-hour group art therapy sessions and participate in an audiotaped interview about their experience and the impact of art-making. Thematic analysis revealed that the art therapist's guided exposure to a wide range of art media provided a release of conscious or unconscious emotional states related to the breast cancer, and facilitated an insightful connection to past relationships with significant others. For all participants, this deep introspection ultimately led to a redefinition of their identity. Art-making provided individuals with the opportunity for self-discovery, empowerment, and new ways to express emotions, reduce anxiety, and communicate with others. A strong theme of existential growth emerged when the participants faced, rather than denied, their mortality. As a result of the art therapy experience, participants reported feeling a deep sense of satisfaction when engaged in art-making, felt a deeper compassion for others, an emergence of new opportunities and possibilities, feeling able to meet future challenges, and a fuller appreciation of life.

It's not about the artistic talent. It's about the images, the things you create and what they mean to you.

[By making art], you are documenting something you have gone through. It changes how you understand where you are. It changes how you could be next.

Every time I explore my "innerscape" [using art] I learn a little bit more about my true self, inner peace, the beauty and the joy of being myself, and feeling connected as a whole being.

The methodological limitations inherent to these two small, uncontrolled studies are acknowledged. However, they offer compelling insight into the human need for meaningful reflection following adverse life events, and the potential for meaning-making approaches that may give

rise to unexpected stories of personal growth and transformation. Engaging in art-making provided a safe context to reflect on profound personal changes and to re-story the losses following traumatic events.

## CULTIVATING COMPASSION THROUGH CONNECTIONS AND COMMUNITY

Considering the pivotal role that meaning-making activities hold for patients coping with cancer (LeMay & Wilson, 2008; Park, 2010), there can be more investment at the organizational level devoted to activities to nurture the search for meaning and attain the fundamental needs for belonging, self-esteem, and self-actualization following adversity. The absence of such support may translate into a perceived lack of compassion and diminution of the psychosocial needs in cancer care. There is an important need to identify opportunities to elevate the importance of psychosocial cancer care in increasingly complex clinical care.

Recently, compassion training for healthcare professionals has been proposed to address the rise in concerns about the lack of compassion and sub-optimal patient care in modern-day healthcare environments (Sinclair, et al., 2016a). This has stirred up an epistemological debate as to whether compassion is an innate dispositional quality or whether it can be taught and developed (Sinclair, et al., 2016b). However, we know from neurocognitive research that human beings are physiologically equipped to respond with compassion (Marsh, 2011). We also know that compassion can be evoked more readily when the well-being of those with whom we have a connection are at stake (e.g., our children, husband, wife, friends, and colleagues). It is less instinctive to show compassion to total strangers. Yet this is what oncology nurses do. Everyday. Initially, all patients are strangers. Some, over time, we get to know and develop a deeper connection. Other clinical encounters are shorter and more challenging. Yet oncology nurses have demonstrated the capacity at the individual level to convey a sense of acknowledgement and

understanding of the patient's situation through non-verbal cues, attentive listening and respectful communication. Thus, the value of compassion training may lie, not so much to develop, but in nurturing an innate capacity for compassion.

The introduction of "third spaces" into healthcare settings is proposed as another approach to consider when facing a future that is sure to include more technological advances and institutional priorities driven by efficiency, economics, and other factors that can overshadow compassionate care. "Third spaces" are dedicated environments that can simultaneously attend to individual and group psychosocial needs (Keenan & Miehl, 2008; Oldenburg & Brissett, 1982). These are characterized as open, neutral, accommodating environments that provide a common meeting ground for people with diverse backgrounds and experiences. In healthcare settings, this space would be open to patients, family members, as well as healthcare professionals; it is a place of levelling where hierarchical status is non-existent. There is no obligation to be there and individuals are free to drift in and out, as they please. While some individuals will eventually become regulars to this dedicated space, newcomers are made to feel welcome and invited to stay. Participants feel warm and nourished and gain spiritual regeneration by spending time there. Third spaces provide a dedicated space to promote growth and healing during adversity.

At the McGill University Health Centre, in Montreal, QC, the opportunity to create permanent "third spaces" in the cancer centre arose with the dissemination of the research results of the art therapy study describe earlier. Impersonal waiting rooms in the cancer centre were transformed by exhibiting artwork made by patients with cancer on the walls. Every six months, a call for new artwork is issued based on a theme related to concepts that mediate psychological growth following adversity (e.g., hope, love, peace, beauty, resilience, and belonging). Public lectures are regularly scheduled to increase access to research evidence about the psychosocial benefits of art-making

among non-academic audiences, clinicians, representatives from community organizations and the general public. Temporary spaces to make art (called art hives) are coordinated in various locations across the hospital and mini art packages are distributed to the inpatient units to provide patients, family members, and healthcare professionals the opportunity to experience the benefits of making art themselves. Through this multi-pronged approach, individuals were able to learn (by attending the public lectures), witness (by seeing the patient art exhibition), and experience (by making art individually or in a group setting) the potential for self-discovery

and personal growth even when receiving treatment in large, ultra-modern tertiary care cancer centre. The implications of “third spaces” in healthcare settings provide a hopeful and feasible approach to cultivate compassion, connect individuals, and create a sense of community to meet future challenges in oncology nursing practice.

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