

Tending the Spirit and Living with Cancer

Shane Sinclair PhD

Postdoctoral CIHR Fellow
Manitoba Palliative Care Research Unit
University of Manitoba
Tom Baker Cancer Centre
Spiritual Care Coordinator



“In the midst of dealing with profound loss in our lives, the ability to reascribe meaning to a changed world through spiritual transformation, religious conversion, or existential change may be more significant than the specific content by which that need is filled”

(Marrone, 1999)

What is Spirituality?



- “An animating or vital principle held to give life to physical organisms”
- Webster’s Dictionary
- “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or the sacred”
-Puchalski,et al. J Pall Med, 2009
- “An individual's sense of peace, purpose, and connection to others, and beliefs about the meaning of life”.
- National Cancer Institute
- “the feelings, thoughts, experiences, and behaviors that arise from a search for the sacred”
- Larson, Swyers & McCullough
- “A connection between the essence of one’s self, others, or Other, affecting ones sense of wholeness both within themselves and within an ultimate reality”
- Sinclair, CMAJ, 2011
- Spirituality is not synonymous with religion but may be interrelated for many.

Underneath your outer form, you are connected
with something so vast, so immeasurable and
sacred, that it cannot be spoken of

- Eckhart Tolle

Sometimes seeing is believing and
sometimes the most real things in the
world are the things we can't see.

- The Polar Express

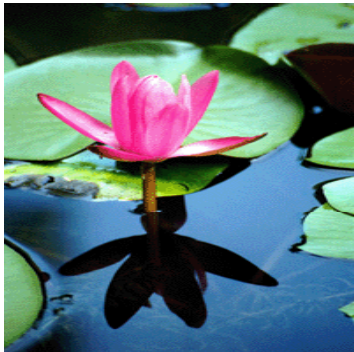
Why is Spirituality Important?



- “Psychosocial health services are psychological, social and *spiritual* care services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioural, social and *spiritual* aspects of illness and its consequences so as to promote better health”.
 - Canadian Association of Psychosocial Oncology Standards of Psychosocial Health Services 2010



- Spirituality has been formally recognized in guidelines and standards for cancer survivorship
 - Canadian Partnership Against Cancer Survivorship Guidelines (forth coming)
- “Spiritual, emotional, and physical well-being are often inextricably linked” - Romanow Report
- Alberta’s health system recognizes that health encompasses a person’s physical, spiritual and mental health, from birth to the end of life
 - Alberta Health Act, 2010 **not declared*



- A recent consensus project recommended that spiritual distress be adopted as patient vital sign that should be routinely screened for.
 - National Consensus Project for Quality Palliative Care, 2009

Is spirituality a universal domain of human health?

- Do you believe God or a Higher Power exists?
 - 49% - Yes, I definitely do
 - 33% - Yes, I think so
 - 11% - No, I don't think so
 - 7% - No, I definitely don't

Is spirituality a universal domain of human health?

- Do you believe God or a Higher Power exists?
 - 49% - Yes, I definitely do
 - 33% - Yes, I think so
 - 11% - No, I don't think so
 - 7% - No, I definitely don't
 - 25% of Canadians who responded 'No, I definitely don't', identified having spiritual needs
- A increasing number of North Americans identify themselves as spiritual, including those whose spirituality is expressed religiously and those for whom it is independent of religion.
 - Gallup 1999, Zinnbauer 1995, Corrigan 2003
- When spirituality was defined as a connection to others and finding meaning in life, it is a terms that Atheists except.-Smith-Stoner, 2007

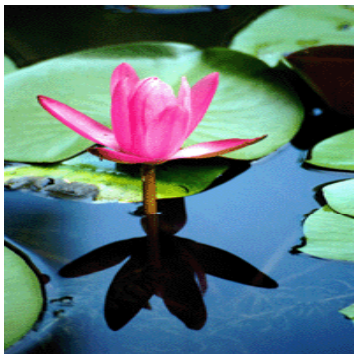
Why is Spirituality Important?



- “Psychosocial health services are psychological, social and *spiritual* care services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioural, social and *spiritual* aspects of illness and its consequences so as to promote better health”.
 - Canadian Association of Psychosocial Oncology Standards of Psychosocial Health Services 2010



- Spirituality has been formally recognized in guidelines and standards for cancer survivorship
 - Canadian Partnership Against Cancer Survivorship Guidelines (forth coming)
- “Spiritual, emotional, and physical well-being are often inextricably linked” - Romanow Report
- Alberta’s health system recognizes that health encompasses a person’s physical, spiritual and mental health, from birth to the end of life
 - Alberta Health Act, 2010 **not declared*



- A recent consensus project recommended that spiritual distress be adopted as patient vital sign that should be routinely screened for.
 - National Consensus Project for Quality Palliative Care, 2009

- Do you consider yourself to be a spiritual person? If so how would you describe this part of yourself?
- Where do you presently find meaning in life? Would this change if you were diagnosed with cancer?
- What importance do you believe spirituality can play when living with cancer (personally or as you have witnessed in others)?

The Importance of Meaning and Spiritual Needs in Cancer Patients

- 41-94% of patients in various studies expressed a desire to have their spiritual needs addressed by their health care professionals
- Sulmasy, JAMA, 2006
- 75% of advanced cancer patients felt that their spiritual needs were not met during a recent hospital admission
- Balboni, JCO, 2007
- The McGill Quality of Life Questionnaire's existential/spiritual subscales have been repeatedly shown to be at least as important as any of the other subscales in measuring overall quality of life among palliative care patients
- Cohen, Pall Med., 1996
- One study of 95 cancer patients diagnosed within the past 5 years found that spirituality was associated with less distress and better quality of life regardless of perceived life threat, with existential well-being but not religious well-being as the major contributor
- Laubmeier, 2004
- An extensive qualitative study exploring what domains of end-of-life care were most important to cancer patients.
 - 1) receiving adequate pain and symptom management;
 - 2) avoiding inappropriate prolongation of dying;
 - 3) achieving a sense of spiritual peace;
 - 4) relieving burden; and
 - 5) strengthening relationships with loved ones
- Singer, JAMA, 1999

“The person feels “healed” but not “cured,” and may experience a profound sense of psychological and spiritual well-being and wholeness, even if disease persists”.

Shimon Waldfogel

The importance of spirituality when living
with cancer at the end-of-life?

Sinclair S. (2011). Impact of death and dying on the personal lives and practices of palliative and hospice care professionals. *CMAJ*

RESEARCH

CMAJ

Impact of death and dying on the personal lives and practices of palliative and hospice care professionals

Shane Sinclair PhD

See related commentary by McGrath and Kearsley, page 169

Competing interests: None declared.

This article has been peer reviewed.

Correspondence to:
Dr. Shane Sinclair,
shane.sinclair
@albertahealthservices.ca

CMAJ 2011. DOI:10.1503/
cmaj.100511

ABSTRACT

Background: Working within the landscape of death and dying, professionals in palliative and hospice care provide insight into the nature of mortality that may be of benefit to individuals facing the end of life. Much less is known about how these professionals incorporate these experiences into their personal lives and clinical practices.

Methods: This ethnographic inquiry used semi-structured interviews and participant observation to elicit an in-depth understanding of the impact of death and dying on the personal lives of national key leaders ($n = 6$) and frontline clinicians ($n = 24$) involved in

Results: Eleven specific themes, organized under three overarching categories (past, present and future), were discovered. Early life experiences with death were a common and prominent feature, serving as a major motivator in participants' career path of end-of-life care. Clinical exposure to death and dying taught participants to live in the present, cultivate a spiritual life, reflect on their own mortality and reflect deeply on the continuity of life.

Interpretation: Participants reported that their work provided a unique opportunity for them to discover meaning in life through the lessons of their patients, and an opportunity to incorporate these teachings in their own lives. Although

The importance of spirituality when living with cancer at the end-of-life?

- Religious beliefs were negatively correlated with requests for Physician Assisted Suicide (PAS) in Palliative Cancer Care
- Wilson et al., Health Psychology, 2007
- Belief in an afterlife was associated with lower levels of hopelessness; desire for death and suicidal ideation
- McClain-Jacobson et al., General Hospital Psychiatry, 2004
- Terminally ill patients in Oregon requested PAS for several reasons including: loss of autonomy, loss of dignity, an inability to participate in activities that make life enjoyable and a determination to control the manner of death.
Sullivan, NEJM, 2000
- The construct of dignity in particular, has been identified as the greatest factor in decisions for hastened death
- Chochinov
- Spirituality positively effected palliative care patients sense of dignity
Chochinov, JPSM, 2009
- A systematic review found that 94% of studies show some positive effects of spiritual beliefs on bereavement and grief
- Becker et al., Pall. Medicine, 2007

- How has your own experience with cancer or that of a family member or friend taught you about what was important in life?
- When has the presence of another brought you healing?
- Who do you consider to be a spiritual person in your life? Why?

The Importance of Meaning and Spiritual Needs in Cancer Patients

In a sample of 248 cancer patients the following rates of endorsement were found for questions regarding needs:

- Overcoming fears - 51%
- Finding hope - 42%
- Finding meaning in life - 40%
- Finding peace of mind - 43%
- Finding spiritual resources - 39%

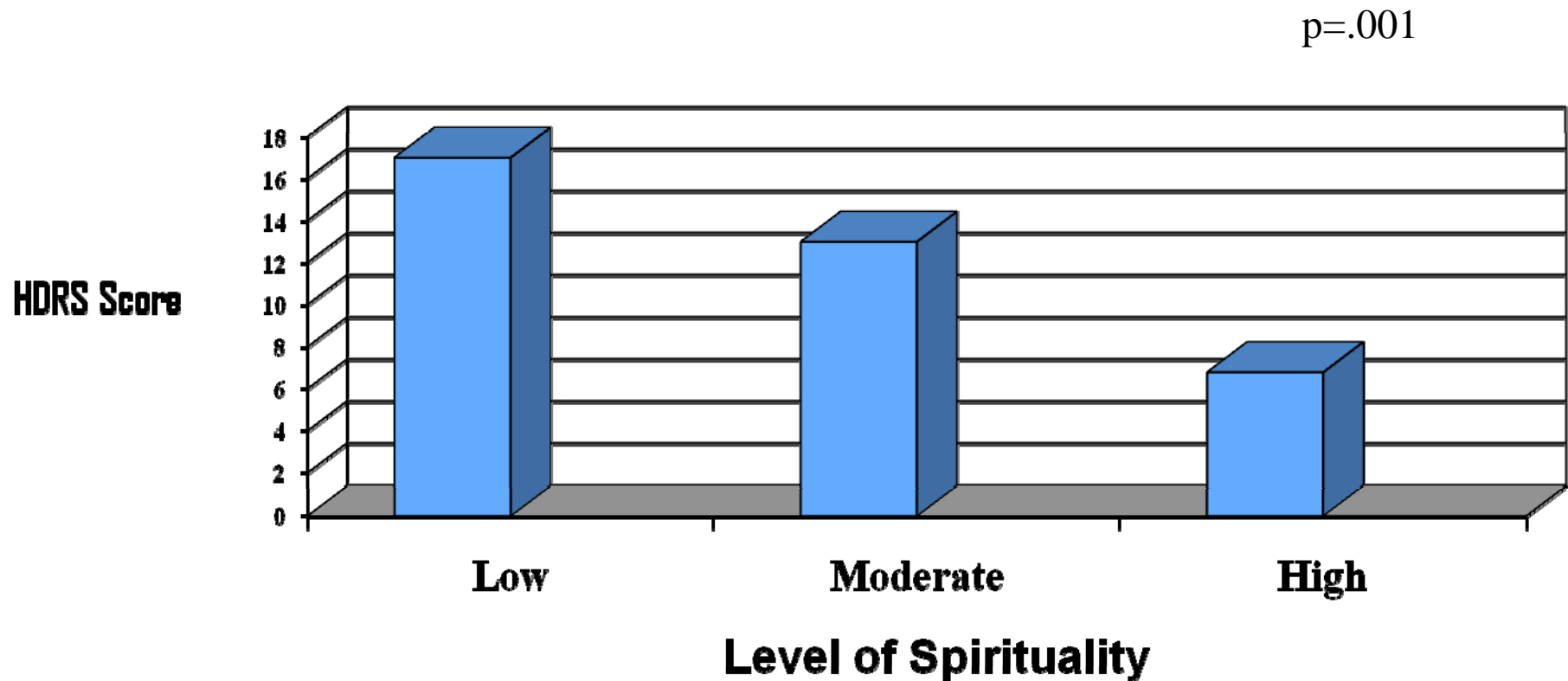
Higher rate of spiritual/existential needs in ethnic minorities, unmarried patients, more recent diagnosis

Spirituality and QOL in Cancer

$p=.001$

Spirituality and Depression in Cancer

Severity of Depressive Symptoms (HDRS score)



Nelson, Rosenfeld, Breitbart. Psychosomatics 2002

The Prevalence of Spiritual Suffering

- 44% of advanced cancer patients identified spiritual distress as a frequent and significant issue - Hui et al., Am J Hosp Pall Care, 2010
- 96% of advanced cancer patients experienced spiritual pain in their lives, including 61% reporting such pain at the time of the study - Mako, J Pall Med, 2006

Treating Spiritual Suffering

- Controlling physical symptoms
- Providing a supportive presence
- Encouraging life review to assist in recognizing purpose, value and meaning
- Exploring guilt, remorse, forgiveness, reconciliation
- Facilitating religious expression
- Reframing goals
- Encourage meditative practices - focus on healing rather than cure

Rousseau P. J Clin Oncology, 18:2000-2002, 2000

Spiritual Assessment Tool

F - Faith or Beliefs

- What things do you believe give meaning to your life?
- Do you consider yourself a spiritual and/or religious person?

I - Importance and Influence of Beliefs

- How important is your faith or belief in your life?
- What influence does your faith and belief have on your illness?

C - Community

- Are you a part of a spiritual or religious community?
- Does the community provide support for you? If so, how?

A - Address Care Issues

- How would like me to address these spiritual issues while caring for you?

What is Spiritual Care?

- An interaction that has a capacity to “heal” by virtue of its impact on the persons total lived experience. (Mount, Annals RCPSC, 2002)
- Attends to fundamental issues of existential awareness; relatedness, meaning, purpose and wholeness (NHPCO)
- “Care of the soul is not solving the puzzle of life; quite the opposite, it is an appreciation of the paradoxical mysteries that blend light and darkness into the grandeur of what human life and culture can be”. (Moore, Care of the Soul, p. xix)
- A service that is offered but not imposed. (Rumbold, MJA, 2003)
- The art of attuning one’s own presence to the presence of an other in order to promote connection and wholeness (Sinclair, 2009)
- Falls within the ambit of all health care professionals (Byrne, Progress in Palliative Care, 2001)

Presence...

The outward radiance of one's inner essence or soul (Sinclair, 2009).

'All real living is meeting'. Healing emerges between two people who are fully present to each other" (Buber, 1958)

Presence, the clear and obvious presence of self exists within the realm of the mystical and spiritual (Carl Rogers, 1979, 1980, 1986)

Iatrogenic Suffering – the suffering that is experienced by patients that is rooted in the attitudes, behaviors and beliefs of the health care provider (Kuhl, 2002)

- Listening / being a witness...
- Open your heart and your mind.
- Be human. Be real. Be honest.
- Be present, avoid the urge to make it better.
- Be "with"-- "Watch with me" --not simply doing.
- Acknowledge the reality of spiritual pain -out loud.

Presence...

The outward radiance of one's inner essence or soul (Sinclair, 2009).

'All real living is meeting'. Healing emerges between two people who are fully present to each other" (Buber, 1958)

Presence, the clear and obvious presence of self exists within the realm of the mystical and spiritual (Carl Rogers, 1979, 1980, 1986)

Iatrogenic Suffering – the suffering that is experienced by patients that is rooted in the attitudes, behaviors and beliefs of the health care provider (Kuhl, 2002)

- Listening / being a witness...
- Open your heart and your mind.
- Be human. Be real. Be honest.
- Be present, avoid the urge to make it better.
- Be “with”-- “Watch with me” --not simply doing.
- Acknowledge the reality of spiritual pain -out loud.



We never know what we might find until we are forced to look

John Dewey

Man lives in three dimensions: the somatic, the mental, and the spiritual. The spiritual dimension cannot be ignored, for it is what makes us human

Victor Frankl

Perhaps ultimately, spiritual simply means experiencing wholeness and interconnectedness directly, a seeing that individuality and the totality are interwoven, that nothing is separate or extraneous. If you see in this way, then everything becomes spiritual in its deepest sense.

Jon Kabat-Zinn

