

WELL-BEING AND SPIRITUALITY

Talk with the
English Speaking Cancer Association (ESCA)
The Cancer Journey: Caring for the Whole Person

Geneva Switzerland
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duplicated nor quoted.*

INTRODUCTION

First and foremost, I wish to thank Patsy Allen and organizers for the invitation to speak this morning, as we reflect on the importance of spirituality in the process of caring for the whole person. May I commend you heartily for the great strides you have made in being a presence for cancer patients, survivors, families and friends as they participate in a journey. The symbol of the ecumenical boat here in this historic Geneva building, could well be applied to the search for well being ... within the cancer context or any other context. We are on a journey, tossed by tumultuous waves by-times, becalmed and feeling abandoned at critical moments, certainly needing others to row together on the journey, and knowing that each port of call is but one more stop in the accumulation of one's quality of life. The move of "spirituality" to the centre of health care has basic ramifications for medical, nursing and technical procedures - not only for the patients, survivors and caregivers, but for the broader population too - including those in the work place.

CENTERING AND DEVELOPING A "PRESENCE"

- Breathing and welcoming exercises!

SPIRITUALITY & WELL-BEING: SPIRITUALITY AND THE HEALING PROCESS

After the initial shock of a cancer diagnosis, when we become acutely aware of our personal mortality and vulnerability, there is the strong possibility that the person really begins to live when faced with the reality of death - and knowing that cancer is the second leading cause of death in the U.S. of A. - we are in a new situation. My experience

is that many people begin to live when they know they might die. A focused spiritual response is expected when such a threat to your being occurs. A similar affect penetrates the family. The quality of life during that journey is a responsibility shared by all of us.

Joni Walton, writing in the *Nephrology Nursing Journal*, observes that “insight into the spiritual realm of patient care will transform nursing in this millennium. Harnessing the restorative powers of spirituality and caring for the body-mind-spirit of nurses and patients alike are kindling a spirit of renewal within the nursing profession.” [Finding a balance: a grounded theory study of spirituality in hemodialysis patients] , October, 2002.

The importance of spirituality as a central component of well-being is increasingly recognized by doctors and mental-health professionals. Spiritual well-being is important. (“Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients,” *The Lancet*, Vol 361, May 10, 2003, p.1603-7). Many health care professionals are now paying attention to the importance of spiritual health. Growing data have provided empirical support for the hypothesis that spiritual well-being and health are positively correlated, and that consumers of healthcare are increasingly using “spiritual healing” and religious resources to improve health. This is also seen in all models of “well-being”.

Empirical evidence and practice wisdom strongly suggest that the experience of living with cancer, for example, often increases an individual’s awareness of the spiritual part of the self. Individuals with cancer frequently use spiritual resources to cope with their cancer. (*Cancer Nursing*, Vol 26, No 4, 2003, p. 260) Or, put another way: “Patients who are diagnosed with cancer often find that they and their family begin to give more thought than before to spiritual questions.”[Many citations] *Cancer Nursing* Vol 25, No 3, June 2002. P. 210. After physical quality of life, the spiritual QoL ranks second for persons living with cancer.

One of the hallmarks of spirituality is the search for meaning. Victor Frankl’s little book of 50 years ago, *Man’s Search for Meaning*, is still relevant. In a sense, through meaning, healing can take place even while even in the active stages of disease. Frankl suggests that suffering will not destroy humans; rather, suffering without meaning will destroy. How often has that been true in your experience? There are many barriers to healing - from ineffective symptom control to the inability to maintain contact with family and friends. A spiritual sensitivity can aid in keeping the barriers down: “The value of the interventions to break down barriers to healing [even] near the end of life should not be underestimated.” [Gauthier, Donna M. “The Meaning of Healing Near the End of Life,” *Journal of Hospice and Palliative Nursing*, Vol 4, no. 4, October-December, 2002, p.226.]

While we medically “present” patients according to disease, is this where the patient wishes to be? Is it where we wish to be - a label with a function rather than as a team member participating in the whole? “Patients want to be seen and treated as whole persons, not as diseases. A whole person is someone whose being has physical, emotional, and spiritual dimensions. Ignoring any of these aspects of humanity leaves the patient feeling incomplete and may even interfere with healing. For many patients,

spirituality is an important part of wholeness, and when addressing psychosocial aspects in medicine, that part of their personhood cannot be ignored.” JAMA, Oct 4, 2000.

THEN WHAT IS RELIGION?

Many many definitions exist ... probably from the Latin religio - meaning “to bind together”. It is cultural and community based. Most of us are what we are due to nationality and/or birth. Major religions are well known - Christianity, Islam, Buddhism, Judaism, Sikhism and so on. Religions are usually divided (denominations) - i.e. Christianity has Orthodox, Roman Catholic, Anglicans, Protestants... other religions have similar divisions. Within each part, there are less identifiable distinctions along liberal and conservative lines.

But for us... religion is important for its rituals, symbols and stories. These are important for many members of faith communities. Religion is often the vehicle for spirituality and spiritual journeys. Religious practice is an important comfort for people; ill and well, young and old. This is why we have departments of Pastoral Care in most hospitals.

While spirituality and religion are separate, they are not unrelated. The perennial quest of separating religion and spirituality is faced by both scholars and book store managers. Certainly, most people trained in my own field of clinical pastoral education realize and preserve the distinction. While the tendency of many would be to embrace a “secular view of spirituality”, there is the positive realization that “for many people, both therapists and clients, their primary means of expressing their spirituality is through organized religion... religious participation is a legitimate means of spiritual expression.” (McColl, p. 12) It is certainly not the only means. Religion is quite distinct from spirituality, yet often inter-related. Religion remains an important vehicle for rituals, symbols and stories. It is a vehicle for spirituality for many..... and provides a comfort zone. Again, the notions of religion and spirituality are separate, yet often related.

I borrow from the health field to suggest a general distinction between religion and spirituality:

There is no general agreement on definitions of either spirituality or religion, but there is general agreement on the usefulness of this distinction. Religion can be viewed as a specific set of beliefs and practices associated with a recognized religion or denomination. Spirituality is generally recognized as encompassing experiential aspects, whether related to engaging in these practices, or to a general sense of peace and connectedness. The concept of spirituality is found in all cultures and is often considered to encompass a search for ultimate meaning through religion or other paths. Religion is highly culturally determined; spirituality is considered a universal human capacity, usually - but not necessarily - associated with and expressed in religious practice. Most individuals consider themselves both spiritual and religious; some may consider themselves religious but not spiritual. Others, including some atheists (people who do not believe in the existence of God) or agnostics (people who believe that God cannot be

shown to exist), may consider themselves spiritual but not religious. One effort to characterize individuals by types of spiritual and religious experience identified the following groups, using cluster analytic techniques: religious individuals who highly value religious faith, spiritual well-being, and the meaning of life; existential individuals who highly value spiritual well-being, but not religious faith; nonspiritual individuals who have little value for religiousness, spirituality, or a sense of the meaning of life. The last group 'failed' in all wellness scores.

Allow me to repeat the last line of that study: The last group 'failed' in all wellness scores.

Without making a judgement, many years ago in the academe it seemed to me that there are only two "types" of religion - healthy and unhealthy A healthy religion unites existence, and unhealthy one divides it. On the religious side, frequently it is the religious/ theological framework which supplies the feeling of hope, which as my colleague put it the other day - "hope is the oxygen of the human spirit."

Geneva too is very multi-national. In cancer situations one can only imagine how relevant this sensitivity is. Understanding different cultures is important in that it is sometimes even more difficult to find those who can play a supportive role if they are not of the dominant culture. For example, modesty among certain groups might deter women from performing and receiving breast examinations.

A medical journal article last year listed key words and phrases in spirituality literature:
Meaning - making sense of life situation; deriving purpose from existence;
Existential - searching for personal meaning within one's life, death, and concerns about freedom and isolation;

Value - cherished beliefs and standards of, for example, truth, beauty, behaviour, or thoughts;

Transcendence - appreciation of a dimension beyond self; creating ability to rise above 'here and now' experience;

Connecting - relationships and communication with self, others, environment, higher power, the sacred;

Becoming - links to identity, personal growth, through reflection on life experience;

Coping - means of using or developing strategies in critical life events, achieving inner peace;

Spirituality - the search for existential or ultimate meaning within a life experience, such as illness. (This belief usually refers to a power other than the self, which people may or may not describe as God, higher power, or forces within nature, and with which they communicate. The power helps the person to transcend the here and now, re-establish hope and the ability to cope);

Religion - is an expression of spiritual belief through a framework of rituals, codes, and practices; the sense of otherness or a power being a deity or supreme being;

Philosophical - relates to the same searching, but with a rejection of any influential power external to the self." [P. Speck, I. Higginson & J. Addington-Hall. "Spiritual needs in health care," BMJ July 2004:123-4.]

I heartily encourage the latest (6th) edition of the huge resource text, Cancer Nursing, which has just been published. The new edition has a fine section on Spirituality, and one appreciates the centrality given to this area in critical nursing. Does it surprise you that spirituality stands so central in the application of nursing principles?

WHAT IS SPIRITUALITY?

There are scores, perhaps hundreds of definitions of spirituality. At my own Cancer Treatment Centre, we use a brochure which is descriptive, and which has been distributed to you today. It may or may not fit in with your usage or understanding...

Spirituality is an integral component of healing. It is a source of strength in the presence of distress. It is at the heart of our well-being. It enriches all aspects of our life: physical, mental, emotional and community.

Spirituality is a life force that promotes hope, encourages healing, helps us to embrace ourselves and others. Spirituality is expressed in the attitudes, beliefs, and practices that influence people's lives. Spirituality enables us to experience the transcendent or higher power.

Spirituality involves family and friends. It embraces fullness, meaning, love and hope in the journey.

What are Spiritual Needs?:

MEANING - Who am I? Why is this happening?

PURPOSE - When do I feel most alive?

COMMUNICATION - With whom and how can I be open and honest?

BELONGING - Who cares for me? HOPE - Where does my hope lie?

VALUES - What are my guiding principles?

CREATIVITY - Do I feel free to shape my own path?

RELATIONSHIPS - How do I see myself now in relationship to myself and others?

FORGIVENESS - Am I forgiving and forgiven?

What are Symptoms of Spiritual Distress?

* fear * pain * anxiety * confusion * depression * anger * hopelessness * loss * apathy * shame * guilt * grief * withdrawal * isolation * resentment * disbelief * conflict * regret * loneliness * powerlessness

Regardless of whether people with cancer experience spiritual stress or eustress, spiritual needs are an inherent part of living. (Taylor, EJ. "Spiritual Care: Nursing Theory, Research, and Practice." NJ: Prentice Hall, 2002. One could also refer to Sparks & Taylor, Nursing Diagnosis Reference Manual, 2000, "Spiritual Distress," pp. 308 - 311.

SPIRITUAL CARE

You know well that anxiety and denial are common in the early phases of cancer diagnosis. Doubts about the future and emotional instability are a normal reaction during the early months... and you probably can attest that sadness, disappointment, anger, and regret are common feelings following diagnosis. We do know that newly diagnosed patients with cancer exhibit psychosocial distress, including anxiety and depression.

Attendance to spiritual care has salutary effects. Spiritual well-being and meaning serve as a buffer zone against depression, hopelessness and desire for hastened death.

Spiritual care has been shown to:

- reduce the demand for pain medication
- shorten hospital stays
- ease conflict situations
- help bridge gap between hospital experience and the rest of a person's life

Apart from these functional benefits of greater compliance with health care, research reports that acutely and chronically ill people reporting higher levels of spiritual health (and religious commitment) also report higher levels of physical and mental well-being, more hope, less depression, less loneliness, and improved coping and quality of life.

At a very basic level, Spiritual Care can be anything which touches the Spirit of another.

- It can be shared laughter or tears, or remembering a patient's birthday.
- It can be keeping vigil with a family as a loved one struggles to recover.
- It can be crying with that same family when that patient dies,
- It can be supporting a chronically ill individual as she struggles to redefine her worth and personal meaning in the light of illness and its demands.
- It can be a gentle back rub coupled with soothing words that allow the patient to sleep.
- It can be a shared prayer or religious reading that has special meaning for the patient.

How do we best offer spiritual care? As we enter the world of the cancer patient it gives them an opportunity to reflect on what is happening to them and how they feel about the ultimate changes they face. I found the following in the U.K. in a booklet on spiritual aspects of nursing care, but it applies to all of us:

- a willingness to leave our preoccupations aside.
- giving focused time and attention, even for a short while.
- being sensitive to whether the person wants to make use of us; maybe for them it's not the right time or we're not the right person. (Saying 'No' can be a very empowering experience.)
- helping to create the space for people to connect with their own reality.
- non-judgmental listening, in which our own 'stuff' does not get in the way.
- active listening, in which our concern is on what is being said or not being said rather than how we can respond.
- 'staying with' strong feelings rather than trying to close them down.

- ‘staying with’ the hard questions rather than resorting to easy answers

Spiritual care cannot be boxed in nor narrowly defined. Spiritual care is provided not only for those who believe in a certain way. Spiritual care is for everyone. Spiritual care includes whatever gives a person meaning, worth and value. People may express their spirituality in unique ways, but everyone has a spiritual nature that can be touched through the ministrations of another. (This insight reaches back several years and is adapted from the Preface of *Spiritual Dimensions of Nursing Practice*, ed. by Verna Benner Carson. W.B. Saunders Co. USA, 1989) Spiritual care involves other mediums, such as the healing power of music, tai chi, yoga, painting and therapeutic touch.

Practical suggestions for how to discuss spiritual needs are available in nursing literature. (*Cancer Nursing*, Vol 26, No 4, 2003. P. 266). We do know that the hesitancy of entering into the spiritual or religious realm of patients is certainly shown by a very high percentage of physicians. It may be exacerbated with insensitive words, body language and cultural hesitancies. This has serious ramifications for the promotion of well-being.

We know that care givers have spiritual needs similar to those of with cancer. Yet, in contrast with the importance patients attach to spirituality, clinical care and clinical research often omit attention to this area. The patient is usually not reluctant to enter this search for meaning. Appropriate and sensitive discussions with (seriously ill) patients regarding medical, psychosocial, and spiritual needs are both an obligation of and privilege for every caregiver - lay or professional. Sometimes you have noticed that physicians are reluctant or unable to tell patients that they are likely to be approaching the end of their lives ... tending to be overly optimistic. Many of us can be guilty of participating in a conspiracy of silence - and not adding quality to a life which may be at its most important stage. The hands-on practitioner or caregiver has an absolutely critical role.

The growth pattern of the patient or survivor is not simply neutral. He or she (and also the caregiver I would surmise), is not only better able to face the critical moments of the health/illness journey through spiritual care, but goes beyond that to a positive growth: “Spirituality initially serves as a support mechanism to help the person cope with the many challenges of being ill. Gradually, however, the person discovers that their illness is a vehicle which promotes their spiritual growth. This was an unexpected but very rewarding finding for the subjects themselves.” [Samson, Andre & Zerter, Barbara, “The Experience of Spirituality in the Psycho-social Adaptation of Cancer Survivors,” *The Journal of Pastoral Care & Counseling*, Fall 2003, Vol 57, No. 3, p 343.]

SPIRIT - AND BODY

May I insert here a comment about the spirituality and body connection. You may wish to come back to this during question period. We have alluded to tai chi, yoga and other salutary exercise programmes. Four weeks ago I visited a major cancer treatment hospital

which had its own fitness/ rehab centre. Cancer patients, survivors and spouses were specially tested and given appropriate exercise regimes. The menu is as vigorous as any fitness club! The benefits are not only physical, but social-psychological.

This in turn was a reminder that ten years ago breast cancer patients were told to be extremely gentle with their upper torsos. Until a Canadian medical fitness expert challenged that and of course we know the results - that upper body exercises are extremely important... and hence began in Vancouver Canada the women's breast cancer dragon boat races. The program has spread world-wide. Lac Lehman would be a terrific place for a future international regatta. I can see your swan logo superimposed over one of those dragon-boats! Not to linger on a good thought, the point is that physical activity enhances quality of life for all cancer patients, and has a preventative quotient. From the American Medical Association journal - "Physical activity after a breast cancer diagnosis has been strongly linked to improved quality of life. There is reason to believe that physical activity might extend survival in women with breast cancer. Physical activity also has been linked to a lower risk for breast cancer." [Michelle D. Holmes et al, JAMA, May 25, 2005. V 293, No 20 2479.]

SPIRITUAL ASSESSMENT

You might be surprised to know that many medical schools now teach how to make spiritual assessments. There are several models for spiritual assessments. Most are time consuming and cumbersome. We are currently developing a simple self-assessment instrument for emotional and spiritual measurements. Certainly, many caregivers do assessments without being aware of the technical format. But, there is a need to be aware of what is in the self during the encounter with the other. All "... need to learn how to become aware of their spiritual language, assumptions, and experience, so they can recognize how these affect interactions with clients.... also need to learn sensitive and effective ways to discuss spiritual needs with clients. Practical suggestions for how to discuss spiritual needs with clients are available in nursing literature." Cancer Nursing, Vol 26, No 4, 2003. P. 266

Many are shy about raising spiritual issues, confusing these with religious practices, with which we are also to be sensitive. We do know that the hesitancy of entering into the spiritual or religious realm of patients is certainly shown by a very high percentage of physicians. This has serious ramifications for the promotion of well-being. At the same time, in an article in the American J of OT, (Mar/Ap 2003) Lili Liu et al report that occupational therapists (in the study) "believed that spirituality became more meaningful as a result of their experiences in palliative care practice." (P.200) In other words, once we enter the world of the other, we become more sensitive to and comfortable with life and death issues ourselves.

When death appears on the horizon, immediate discussion is essential. Frequently death has been predictably approaching for some time and discussion already has been delayed

too long. Many of us can be guilty of participating in a conspiracy of silence - and not adding quality to a life which may be at its most important stage. The hands-on practitioner or caregiver or friend will have an absolutely critical role. The point is that in the final pathway of life there can be a well-being, even as the body crumbles.

DIGNITY and SPIRITUALITY

“Dignity” undergirds all aspects of spirituality, well-being and quality of life goals. My own involvement in international human rights is rooted in the notion underlying international human rights Conventions - the inherent dignity of all human beings. It is not a juridical term; lawyers refer to it as “pre-judicial.” In the question period following a speech on human rights and religion, an Archbishop of the Anglican Church asked: “Dr. Morrison, would you place international human rights instruments above any religious doctrine?” As you know, there aren’t any questions. When care targeting dignity becomes the model, care options may expand beyond a symptom management paradigm, and encompass the physical, psychological, social, spiritual, and existential aspects of the patient’s experience. The inherent dignity of every human being is the framework for well-being and spirituality.

HEALING THE HEALERS

Meaninglessness in most structures results in low self-esteem, and even alienation. The structure may be a complicated international organization, but it may also be the family - your family. The opposite is equally true. A great deal of research and writing over the past two decades attests to the link between spirituality and health. Medically, there is a positive correlation between self-esteem and health. [Michael Marmot, *British Medical Journal* (Sept. 13/2003)]. We know from research and hard data [see Jeff Levin's *God, Faith and Health: Exploring the spirituality-healing Connection* (2001)] that there is a strong data based correlation between spirituality and wellness. The statistics for those who are on sick leave, even from our healing institutions, is profound. Amidst the medication, there is room for meditation. The bottom line: we can heal each other in the journey. There is no other, it is all us.

The first stage of healing is one of recognition. Spiritual distress has similar characteristics to work stress and ethical conflict. In my cancer clinic, we tend to avoid the cumulative impact of cancer treatment, and I am often asked to intervene in our caregivers lives. The same principles have to be applied to me. If the issues concerning stress are not addressed properly, we will become disillusioned with everything around us. None of us in this room can escape what others would call “the human grief” which surrounds us. Those of you who have been around a while know that it can have a cumulative effect. Often it is not recognized, even or especially by ourselves. Perhaps the worst offenders are the places of special care like where I work - which can have tragic

consequences for us, and therefore for our patients: “Hospitals and other medical centres are beginning to address the need to recognize grief experienced by staff.... There is a consensus that patient death and the subsequent grief experienced by health professionals is a significant issue and the importance of addressing it is increasingly being recognized.” [“When Patients Die: Grief Amongst Health Care Professionals,” Jill Macaulay, The Canadian Journal of Medical Radiation Technology, Vol 36 Number 1, Spring, 2005, P 17.] Glen Hurst, quoted in the same article, emphasized the importance of a spiritual relationship, in whatever context you feel that to mean.

Finally, I ask that we consider ways in which a team approach can accelerate best practice in quality of life care. I am very excited about the Integrated Palliative Care Team at our Cancer Treatment Centre, which is the model I know. It’s impact is tremendous. With membership drawn from home-care nursing, grief counselor, palliative care worker, nurse practitioner, social worker, pharmacist, physician, spiritual care provider, there is a very real sense in which a whole spiritual dimension is present in our weekly rounds, as we work together as a team for the well-being of those patients under our care. While this fact may not be important for those here this morning, the principle of coming together and each having a piece of the spiritual healing is applicable!

Spirituality is becoming front and centre, and we are learning that while spirituality may become sharper when faced with ultimate moments - ours or our partners, friends, family, colleagues or patients, its development begins and belongs in our work, home life and play.

We are engaged in best practices - the best practices in life. We are called to give and live life in its fulness - to put meaning into living, hope into a future, life into dying, love into caring, and Spirit into all that we do and are!

Thank you.

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