

Patient empowerment in cancer management healing the whole person

Robert L. Stevenson wrote, "Life is like a card game. It is not about being dealt a good hand; but how you play a bad hand well". To me this statement encompasses all that we are aiming to achieve in supportive and complementary healthcare. My life has been devoted to how best can we help people with cancer to play a bad hand well. We need to acknowledge the four aspects of healing and pay attention to body, mind, emotion and spirit as separate yet integrated aspects of the whole; this will take us to a place of true restorative healing. By this I mean that our task as responsible holistic healthcare providers should involve a respectful approach; an approach that *restores the person to a rightful place of personal empowerment*. In this state, people can make decisions using their psychological, emotional and spiritual intelligence because they are empowered; therefore they can make conscious, informed, considered choices about any treatment they wish to have. It can all be done with an easeful attitude without the desperation of trying to do too many therapies that so often negate the inner peace that people with cancer are trying to find. By supporting them in this manner, they can heal their life by improving the quantity and the quality. Importantly, this is a win-win situation. My experience asserts that those who are confronted by death can

embrace the opportunity to heal their life and move into a state of empowerment, a state that offers them a quality of death both in process and experience. It is also imperative for the family, the carers and the supporters to be involved in this experience. Not only is the wellbeing of patients enhanced but also the ongoing wellbeing of their carers, an area often neglected in practice. There is ample research material available on issues of the bereaved.¹

Basically what I am proposing, as a model for complementary therapy for people with cancer, is a shift in the emphasis from what we do *to* patients as therapists to what we do *for* patients in terms of re-empowering them as a first line therapy approach.

As healthcare providers, we need to be conscious of the minefield -the dangers of providing too many options, confusions, alternatives and complementary additions to people with cancer today. Twenty years ago, lack of information was the issue; but now, particularly with the use of the internet, people with cancer and their close carers are commonly overwhelmed by information overload. There is so much it seems that a person with cancer and their family is required *to do* within the alternative and complementary systems of care. Lifestyle changes seem monumental at a time when the trauma of the diagnosis alone is still being internalised, recognised and processed. How to do it all whilst juggling their medical interventions? We find that people already traumatised can become very stressed and pressured by trying too hard to de-stress! Why is this such an important issue in holistic healing? The following Australian study² addresses some of these very important issues surrounding the diagnosis of cancer.

David Kissane et al. (*Medical Journal Australia*, vol. 169, 17 August 1998) led a study of 303 women with early stage breast cancer who participated in a randomised trial of adjuvant psychological group therapy. The objective of the study was to determine the prevalence of psychological

Table 1

RESULTS OF THE 303 WOMEN IN THE STUDY.
45% (135/303) HAD A PSYCHIATRIC DISORDER.
42% (127) HAD DEPRESSION, ANXIETY OR BOTH.
27.1% (82) HAD MINOR DEPRESSION.
8.6% (26) SUFFERED AN ANXIETY DISORDER.
9.6% (29) HAD MAJOR DEPRESSION.
6.9% (21) HAD A PHOBIC DISORDER.
20% (61) HAD MORE THAN ONE DISORDER.
QUALITY OF LIFE MEASURES NEARLY ONE-THIRD OF THE WOMEN FELT LESS ATTRACTIVE.
MOST HAD LOST INTEREST IN SEXUAL ACTIVITY
THERE WAS SUBSTANTIAL DISTRESS ABOUT HAIR LOSS.
4.3% (13) SYMPTOMS OF LYMPHOEDEMA WERE DESCRIBED.
BREAST CONSERVATION SURGERY WAS ASSOCIATED WITH A BETTER BODY IMAGE (P<0.01).

morbidity and to describe the quality of life in women with early stage breast cancer. The results verified my 27 years of anecdotal experience in that there are high degrees of psychological and psychiatric disturbances evident even in women with early stage breast cancer. My work with women has identified this issue at all stages of cancer; recognition of this factor is vitally important in improving ongoing life quality and disease management (Table 1).

The conclusion states "Women recently diagnosed with early stage breast cancer have high rates of psychiatric and psychological disturbance. Quality of life is substantially affected. Clinicians should actively explore their patient's psychological adjustment to enable early recognition and treatment of these disorders". It is later cited in the article: "We believe this profile is of interest to clinicians in assessing the women's probable prognosis". This area is one that definitely warrants continuing research. In 1994 I authored a book called *Women of Silence: The Emotional Healing of Breast Cancer*,¹ as a consequence of listening to the life stories of thousands of women affected by breast cancer. In my own anecdotal experience in dealing with more than 10,000 people affected by cancer in general, the issue of post-traumatic stress disorder associated with diagnosis is of genuine concern. Further, previously unaddressed life crises have added fuel to the fire and increased personal suffering. Psychological and re-empowerment interventions can be enormously helpful here. In only a few percent of my breast cancer clients, psychological intervention has been insufficient to deal with trauma and depression and they have been referred to a psychiatrist for further assessment and anti-depressant drugs. I suspect that there could be a greater role for the use of antidepressants in cancer management. I have

recognised that women in difficult socioeconomic circumstances have great difficulty in managing lifestyle change. This group, in particular, experiences hopelessness, helplessness and denial that can lead to greater levels of depression and substance abuse including alcohol. In addition, the lack of finance prevents the use of complementary and alternative therapies even though this group endures a high rate of suffering from their diagnosis, treatments, side effects and so on.

Over the years, I have adopted a pro-bono approach in my practice to assist those who would like to follow this approach but genuinely cannot afford it.

I strongly emphasize that complementary supportive care must be the essential first point of call for anyone with cancer with particular attention being paid to the psychological, emotional and spiritual aspects of that person's life. It is particularly important as well that any suggested life changes are simple, attainable and that they modify the patient's life in a compatible way rather than a radical change that can lead to more stress and distress. As hospitals are the first port of call for people with cancer, they could also be the first port of call for the introduction of the above concepts. Nurses particularly can be great sources of information, care and compassion as can patient advocates within the hospital. In Australia I was a member of The Ministerial Advisory Committee for Women's Health for the Victorian Government where my charter was to advise on the integration of complementary therapies into mainstream medicine. This was to be achieved in two main streams by the development of a comprehensive brochure with information and resources on complementary therapies with the aim of it being available in every hospital and doctors' rooms in the state. There was also to be established a Centre for Excellence

which specifically addressed integrative and complementary medical approaches. Unfortunately, after nearly 3 years of dedicated work by our committee of 18 women, the government was voted out of office and the work not implemented!

Complementary supportive care with the active intervention of empowerment methods can do much to alleviate human suffering. Pain and suffering go far beyond the physical. Many patients have told me that unrelenting emotional pain is debilitating and dis-empowering and worsens any physical pain being experienced.

Eric J. Cassel's article (*NEJM*, March 18 1982), *The Nature of Suffering and the Goals of Medicine*, although published in 1982, is a highly recommended article that addresses many of these issues and sadly, is as pertinent today as it was then even though we are in the year 2003! If we fundamentally examine the nature of suffering, Cassel goes on to say ... "we can also realise how much someone devoid of physical pain, even devoid of symptoms, may suffer. People suffer from what they have lost of themselves in relation to the world of objects, events and relationships. We realise, too, that although medical care can reduce the impact of sickness, inattentive care can increase the disruption caused by illness."³

So, to what extent are we prepared to open our minds to new ideas and models of care and are we prepared to do what it takes to implement them? To what extent are we able to open our hearts to empathise with the needs of people with cancer? And, more importantly, dare we open up our souls to listen, acknowledge and encompass the whole experience of the cancer patient as a person who has body, mind, emotion and spirit? Indeed, all aspects are in need of attention. All are in need of healing.

The following story serves to highlight, from very personal experience, how my ideas and life have been opened up to the many important factors involved in healing the whole person. My credibility in this work has evolved from a trilogy of experience as a carer, healthcare provider and patient. My partner and I began our journey on the long road of healing, typical of many patients and carers; confused, naïve, challenged and getting stressed while trying hard to de-stress. We soon developed a much more measured and rational approach which emphasized support, love, care, hope and the need to pursue options in an intelligent and considered manner rather than in desperation. It is important to relate this story in the context of this article.

My experience with cancer began in Australia when my boyfriend of just a few months was

diagnosed with osteogenic sarcoma (cancer of the bone). I was 21, a surgical nurse in his veterinary practice and soon discovered myself in the role of full-time carer when he underwent a full leg amputation in January 1975. Rapid and uninvited change had entered my life. However, the one event that impacted at that particular time 4 days post-amputation was the timely intervention of a Canadian nurse. Severe post-surgical pain, coupled with fear of the unknown, made it a very difficult situation for effective pain management. The interventions of this nurse, her calm authority and expertise with progressive muscle relaxation proved to be effective in alleviating the pain and inducing a deep and restful sleep. How simple, yet effective, this was and how welcome to experience a healing art in those days within the hospital setting. However, once he was well enough, this exercise was dropped from the daily routine. It was only put into practice again when, in November 1975, he developed secondary tumours in his lung, inguinal lymph node and sternum. The prognosis was poor and a life expectancy of 3 to 6 months was given.

At that time, relaxation and nutrition was offered as an alternative approach. With no other options, we embraced the hope that these therapies presented. However, the stringency of the diet and lifestyle change caused a too rapid weight loss and the relaxation therapy was not helping as we had hoped, particularly with the ever-increasing intensity of pain. We sought the help of acupuncture; however, an incorrect X-ray report indicated tumour spread to the spine. This was later proved to be a hospital error. High-dose radiotherapy, guaranteed to relieve the pain, was recommended including a recommendation to cease the acupuncture. He was given a prognosis of 2 weeks when we decided to marry. But the situation deteriorated even more when an obstructed ureter caused hydronephrosis. It was at this point that we decided to go to the Philippines in March of 1976 amidst much anxiety and fear from all concerned. Being the eternal optimist, I felt it could be a good place for a honeymoon ...not a view shared by many! He went to the Philippines as a man *dying* with cancer. He returned 1 month later as a person *living* with cancer. The healers paid great attention to his state of mind and spirit. Through hope in action and wise counsel, it was as if his spirit and will to live were rekindled. Interestingly, there was no change in the tumours; in fact they slowly increased in size while weight returned, pain diminished and in general, here was a person living very well with a usually fatal, painful and very debilitating condition.

During the next 2 years, 31 different approaches were put into practice at various times until remission day arrived carrying with it the good news and the bad news. The good news was that all the bony secondary tumours had cleared from the chest and lung. The bad news was that he had systemic TB, which had developed into osteopulmonary arthropathy. The TB had been active for some two and a half years. It seemed that all our efforts had kept him alive long enough for the two diseases to battle for survival. TB, it seems, won the battle. Mainstream treatment dealt with the remission of the TB. His remission was published in the MJA in a paper written by the late Ainslie Meares under the title *Regression of Osteogenic Sarcoma Associated with Intensive Meditation*.⁴ Although this article brought us public attention, from my point of view and experience, it was a scanty and, in parts, not completely accurate summation of the extraordinary ordeal that we had been through.

Our experience formed the basis for a Cancer Support Foundation that swiftly grew into a large organisation employing 30 people and based in the Yarra Valley, Australia. People came from all around the globe to learn how to empower themselves using self-help techniques and to help them find meaning and purpose in their lives. They came to learn how to use supportive, complementary care alongside their mainstream medical treatment. Our work has assisted more than 10,000 people with cancer. This experience taught me that life, with all its boundless possibilities and opportunities, should really be taken by the scruff of the neck and that illness can be used as a profound instigator for change and for finding meaning in life. In a way, it can be the possibility of saving your life in order to find your life that is the key! Patients clearly experienced *living well* and in some cases *dying well*. But my greatest learning was yet to come in 1997 when I had the very personal experience of becoming a patient.

After a sudden marriage separation and a total uterine prolapse that followed soon after, my world was to radically change again. A routine hysterectomy left me with paralysis of my lower colon and rectum necessitating various ileostomies and colostomies, many bowel obstructions and eventual removal of the majority of my large colon. I was very ill and I have now had 12 major surgical procedures over the last 5 years. Recently I underwent a ground-breaking surgical technique in The Netherlands that has restored my rectal function. Knowing how to methodically search for options has been a great advantage. Walking in the shoes of the patient has provided me with a deeper empathy

and understanding of the human experience and has reinforced my belief of the importance of treating and caring for the whole person in *body, mind, emotion and spirit*.

The Chinese symbol for crisis and opportunity are inextricably bound together in the one character. What makes the difference is our attitude and how we approach each situation. The Gawler story is one example of how the experience of just two people can make an incredible difference.

Over the last 20 years, there has been a changing pattern of disease. Many cancers are diagnosed sooner and surgical procedures and oncology protocols for diagnosis and treatment have been greatly refined and improved. Inevitably, the mainstream view of 'the cancer experience' has evolved into one of learning to 'live with cancer'. The complementary view, which evolved concurrently as a result of patient experience, has always placed an emphasis on continuing to develop patients' life skills; thus enabling them to 'live WELL with cancer'. Cancer patients are our greatest resource and we can learn much from them.

Their needs are all consuming—not only do they have to grapple with the trauma of diagnosis, but then they have to focus upon the treatments, the side effects, the lifestyle changes, the family issues and more importantly, meeting the challenges of adapting to living with not only a *life-threatening illness*, but also a *life-altering one*.

Although enormous effort has been expended in the development of medical treatment for cancer patients, it is also becoming increasingly accepted that complementary and alternative healthcare services play a vital role. Indeed, it is the increasing patient swell who are demanding reliable information, who want self-help techniques, who are critically assessing their nutritional intake, who want psychological assistance and who want to be empowered to help themselves as active participants in their own healing. They want it all—who are we to deny them? How can we create a model of best practice that acknowledges our greatest resource and teachers; the ones who live with cancer every day—our patients.

In conclusion, I would like to leave you with a story as told by a surgeon friend of mine in Sydney Australia.

One evening, very late, he left his hospital and headed for the car park. It was close to midnight and he was very tired; but he could not help noticing a man on the ground on his hands and knees. He was tired and dressed in a nice suit; however, his heart went out to the man. He asked: "Have you lost something?" The man replied: "Yes, my keys and it is so late." As the story goes, my

friend got down on his hands and knees and after some time he asked the obvious question. "Are you sure you lost your keys here?"

"Well actually no" the man replied. "I think I lost them over there; but this is the only place where the light is!"

Maybe we need to venture outside the square, outside where the light is in order to shift the paradigm towards care and healing of body, mind, emotion and spirit and thus develop a model addressing the humanity in care approach and the alleviation of suffering. Just imagine what the possibilities are for integrated healing approaches in 2003 and beyond. Healthcare providers, through awareness and education, are beginning to understand and acknowledge the practice of supportive, complementary therapies. New models of how to implement and fund these practices making them accessible to the whole community, is the next important step.

References

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