

## Survivorship and Palliative Care

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Cancer has joined the ranks of chronic disease, along with diabetes, heart, neurologic and lung disease. One in four people in the USA will have had a cancer diagnosis this year. Two-thirds of those people will live for at least 5 years [1]. This makes for a large number of people who will be suffering from the therapy of cancer treatment. Many of these survivors are going to need encouragement to continue their odyssey by complying with ongoing treatments and nutrition, in order to maintain the status quo.

### Considerations of Palliative Care

Many of those who survive the cancer treatment may be fortunate enough to continue to receive treatment and palliative services, but find the disability following the surgery or medical therapy debilitating and disheartening. The depression that results from an ongoing patient status, together with lack of energy, can affect the patient and family to different extents. My own experience as a patient who survived leukemia treatment and three bone marrow transplants, with intervening neutropenia and infections, and the beneficial impact of coordinated palliative care during that long process, forms the basis for this discussion.

Following diagnosis, during the acute process of cancer therapy, there needs to be a complete assessment of the person's ability to cope with the treatment, his/her will to survive, and the grief levels of the patient and family. In many places, Palliative Care Teams are brought in to accompany the Oncology Teams in the care of the patient [2]. The consideration of the physical, mental and spiritual dimensions of patient and family are addressed at some leisure. "Optimal oncology care requires the provision of both state-of-art cancer therapy and impeccable palliative care. Many people think of palliative care only as end-of-life care, but it also focuses on the relief of patient and family suffering through the skilled prevention, assessment, and treatment of cancer- and therapy-related symptoms to provide the best possible care, whether the cancer is curable or not" [2].

Each step of treatment needs its own encouragement in order to maintain recovery. Caregivers and family must also be considered within the recovery experience [3]. Where appropriate, Palliative Care Services can help with grief and recovery as well as bereavement.

Many hospitals in the USA have Medical Arts programming linked to the Palliative Care Services. These Medical Arts programs, begun in Children's Oncology units and generally funded by grants and donations, are usually attached to Cancer Centers. They can include Dance, Art, Writing and Poetry [4].

### Palliative Care and Nutrition

Nutritional recovery can be very difficult, due to the nausea and loss of appetite that accompany treatments and disease processes [5]. Nutrition, however, is essential for survival, and wellbeing is mandatory for an effective reentry into a life that was almost lost. Nutrition following harsh cancer treatments may need specialized food with supplements to restore cellular, mitochondrial and emotional wellbeing [6].

The Medical Arts have a particular place within Palliative Services, because they can teach the patient and family members to create meaningful Art as a form of personal expression that can first

mitigate the horror of the situation, then secondly venture into a sustaining practice of self encouragement. The initial desire to eat can be a challenge. Encouragement to eat, and then to eat food that heals the cells and mitochondria, can be a result of the expressive process. First, the patient must be in the right mood to accept food that may smell and taste disgusting. The recovery of mood, following an assault on the body and brain, requires an input of neurotransmitters like dopamine. Dopamine is created by serotonin. Serotonin has a large production potential in the GI tract [7]. The right food in the GI tract can affect mood, leading to the action of more eating, and can promote a sustained recovery [8].

An alternative way to encourage the production of the right mood (possibly dopamine) to eat can be by expressing oneself through writing or other art forms. I personally was given art, music and poetry writing, as part of the Palliative Care package at the hospital where I received care [9]. The Poet was in residence at the hospital and gave me one hour of undivided teaching time and encouragement in the skill of writing poetry, every other week. He set up projects and encouraged me to record in poetry all aspects of my experience.

I was too weak mostly to even toilet myself alone, but found pencil and paper (often my meal menu) to be accessible and helpful. During my neutropenia, I had an acute sense of smell. I had no white cells and no nasal mucous to block the odors. The food and the smell of the drains, outside, where I had to take my exercise, smelled the same. Food was repellant. To wake in the morning, I pinched my nose and drank the coffee, the same way I took the foul-smelling cyclosporin capsules for marrow suppression. I was schooled in the basics of nutrition, but found that even the tidbits of food brought from our home garden and cooked in the Cancer Unit were unpalatable. I refused medication to alter my mood or my sleep patterns and was fairly exhausted by the daily routine. Little by little I built up a compendium of poems that addressed what I was suffering. I shared these with the poet and eventually my family. The feedback was enchanting and encouraged another round of verse. The quality of the poetry was no measure of its remedial effectiveness,

but the effect of writing resulted in my being able to eat, because the act of expressing myself left me feeling better at mealtimes.

While expressive writing in long-hand prose, such as describing daily routines, can be tedious and tiring, anxiety can be managed by hand-writing, since it involves using muscles (using up adrenaline maybe) tactile recording. It appears that the right-brain control of language communicates with the left-brain control of writing and withdraws the unpleasant feeling from the amygdala to the frontal

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Received October 15, 2013; Accepted November 15, 2013; Published November 20, 2013

Citation: Wilmot C (2013) Survivorship and Palliative Care. J Palliat Care Med 3: 166. doi:10.4172/2165-7386.1000166

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cortices, where it is more abstract and manageable [10]. The discrete and precise way poetry can work with thoughts and language are less exhausting and help fathom one's process. Being too reflective on the unnatural state of being confined to bed, with the small possibility of survival, heightened by the possibility of not surviving or never seeing children and grandchildren again, can be very disheartening and make one want to give up the effort. Instead, the writing of poetry made me want to live and try harder.

The obvious source of energy was food, and so I did eat better and thus did better. The encouragement built on itself. The poetry seemed to make me open to it. The process continued, and finally I went home. There were opportunities to meet and write and read our writings together with other survivors, by phone, after I left. This was sustaining and continued the feedback loop of a flush of remembered pleasure when recalling someone's response to my expressive poetry. I did get back to eating and became very sensitive to correct eating [paleo - type diet]. Much of the disability, initially experienced, has become easy to manage, due to recovery energy and, mostly, sustained hope. I ascribe the active participation in building a renewable way (writing expressive poetry), to manage the situational and physical depression, without medication, as key.

### Expressive Writing Literature

The Literature is quite helpful in the use of Art in Medicine [11]. People react well to experiencing Art in its many forms. This is an emotional response. The physical activity of composing one's feelings into expressive writing and using the poem to both describe how one feels has therapeutic effect in the long term. The fear of the bear becomes the memory of the bear, without the gut wrenching, paralyzing feeling of fear.

James Pennebaker wrote of the help it provided patients with trauma [12]. Karen and Kay work made this summary [13]:

Longer-term benefits of expressive writing

Health outcomes:

- Fewer stress-related visits to the doctor,
- Improved immune system functioning
- Reduced blood pressure
- Improved lung function
- Improved liver function
- Fewer days in hospital
- Improved mood/affect
- Feeling of greater psychological well-being
- Reduced depressive symptoms before examinations
- Fewer post-traumatic intrusion and avoidance symptoms
- Social and behavioural outcomes
- Reduced absenteeism from work
- Quicker re-employment after job loss
- Improved working memory
- Improved sporting performance
- Higher students' grade point average

- Altered social and linguistic behaviour

### The Essentials of Survival

Surviving must lead to thriving in the post-cancer patient. The thought of going through the same disease again has one scrambling for clues as to how to avoid it. Of course, exercise is very important for the cardiovascular and musculoskeletal sustenance, and yoga and tai chi are excellent means of retraining the damaged sense of balance and subsequent stiffness. Memory and mood are well served by all of these activities and input, as well as the ability to put thoughts to paper in the form of poetry. The diet, however, is an essential part of recovery. Quick fixes of energy, through sugar and carbohydrates, even whole grain, can ultimately return one to the original cancerous state. The whole foods paleo diet [14], has an evidence-based effect on restoring the mitochondria in one's neurological system. One can see that in the Functional Medicine results of Dr Wahl's video on Ted Talks [15].

### Improving Care for the Cancer Survivor

Survivors often suffer from a lack of understanding between their PCP and Oncologist. In addition, when the Palliative Care Team moves on to acute care again, patients may be left in the lurch in a psychosocial way. When a person does not die from the critical illness that brought them into the hospital, the hospital's Palliative Care team could merge with Functional Medicine in the community [1,16]. Palliation, as a consulting hospital service, meant to improve the quality of care, has seen some dramatic improvements in survival, due to attention to mood and spirit to address the recovering patient's attitude. In contrast, the role of Functional Medicine is to optimize health at the time of meeting the patient. These specialties should not be so far apart for the general population. Many citizens are survivors of some health disaster. Palliative care instruction, at the time of the acute illness, can help ease them back to society, alongside their primary treatment specialists.

All facets of survival can be boosted through compliance with eating and treatment, such as taking medications appropriately, maintaining physical health with available energy, and learning to self-manage emotions. Expressive art forms can go a long way to help a person through the long dark days of being a patient and regaining some optimism as one recovers physical and mental health [17].

Poetry is succinct and requires less physical effort. The meaning can be the same as writing a longer piece. The emotional response can be managed by the troubled person. Using a poetry therapist at the hospital can set the survivor up for the future [18,19].

Intermittent sessions may be added to offer continuing support [1].

### Conclusion

In summary, compliance reduces recidivism. Medical recidivism is expensive. Palliative Care sows the seeds for sustained self care in the aftermath/survival of Cancer Therapy and can potentially reduce waste in the medical system to the benefit of all concerned. The depth of care that a survivor requires can be provided by the Arts in Palliative Care. Writing poetry expressively is immediately available at the moment of stress. It can alter the mood and therefore the actions. In a time, when medical care is expensive and difficult to arrange, self care, as expressive writing, singing, humming, sharing all of these, taught at a time of intense need, has a very necessary place to prevent distress, anorexia, nausea and some pain [17]. These preventions can lead to appropriate appetite, taking medications and sleep. These are what a survivor needs. Palliative Care methods can help people through

a crisis, as they can help one to die. The skills learned will be used repeatedly to improve the quality of life as a survivor.

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