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Reach to Recovery International (RRI)
RRI is committed to improving the quality of life of individuals affected by breast cancer and their families.

REACH TO RECOVERY INTERNATIONAL

Satori by sun and candlelight:
Changing roles and responsibilities in breast cancer care for patients, caregivers, and health care providers

Rama Sivaram

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Background

Ruby Ahluwalia, a stage 3 breast cancer survivor, says, "I saw people sitting on the floor of the hospital with no hope in their eyes . . . . Those eyes would haunt me."

3 years after her own treatment, Ruby conceived Sanjeevani Life Beyond Cancer (SLBC) in collaboration with Tata Memorial Cancer Hospital, Mumbai. Her first program was called Can-Sahyogi (cancer companion/ helper) and involved hand holding, supporting and working with underprivileged cancer patients in the hospital outpatient department. There was no looking back. Today, there are 17 centers across 15 cities in India, all managed by SLBC-trained caregivers. Caregivers undergo the caregiver's course called Can-Saarthi (cancer-charioteers, who drive patient care), a skill-development program with the objective of raising the bar for cancer care in India and providing employment to cancer survivors and their relatives with rigorous training in cancer caregiving.

The need for awareness programs to rebuild the quality of life, health and immunity of cancer patients called for a supportive holistic healing initiative and so SLBC created Satori (awakening to the self) along with Can-Chetna and Can-Varta (meaning cancer-consciousness and cancer-talk). The program model equips patients and survivors with skills to strengthen immunity by working on factors like diet, pranayama (breathing techniques), yoga, tapping, sound and music healing, counseling and rewriting constructive scripts for enhanced living. The initiative addresses both body and health-related physical issues and their primary mental constructs, which play a vital role in wellness.

In the wake of the COVID-19 pandemic, there are distress calls from patients who have very little or no recourse for treatment due to multiple factors. The founder, Ruby, asked me online, "What can we do, that extra something special for patients with recurrence, denied care due to this pandemic, how can we lift them from feeling left out?"

Satori 2 for patients *with recurrence* was then born.

The cries lost in the pandemic 2020-2021

"*My cancer has come back. I am told there is no more treatment, so I need not come back, maybe try something called palliation.*" Many voices, many women, some lucky to get and complete treatment and others lost in the pandemic. Voices of women with recurrence began surfacing and something had to be done. While all activities of SLBC continued online, in hospitals and at the 17 centres, it was not prepared for patients with recurrence who could not reach cancer care centres due to lockdowns, fear, risks of COVID-19 and co-morbidities, shortfall in cancer services and logistic issues. Team Sanjeevani recognized that optimism, optimal treatment and emerging supportive care for a first diagnosis does not always hold true for a recurrence because how the disease takes its course and affects the patient can only be surmised.

What could we do for patients devastated by a second diagnosis or recurrence? As patient needs grow and change, caregiving too must adapt accordingly. The tools and roles of caregiving cannot be static nor can they always be evidence based; as long as they intend promotive, relative well-being and quality of life, they should be available to patients. COVID-19 in every neighbourhood and almost every home, along with nationwide sporadic lockdowns, have brought life to a standstill and impacted cancer care across India. The need to prepare, plan and execute that extra special supportive care is a clarion call.

Need for Satori 2 for patients with recurrence

Satori 1, the original holistic healing package, is complete in itself to optimize quality of life for those in active treatment and post treatment-survivors, helping them adopt and adapt to a new normal by rebuilding their health and immunity. However, it does not suffice for patients with recurrence and needs to be more robust. Recurrence brings dramatic changes in the patients and their caregivers; their needs become more specific, personal, clinical, physical, emotional and spiritual. The levels of each component differ from patient to patient, sex-gender, age, type of and stage of disease, clinical treatment available and a prognosis of long or short survival outcomes.

From bits and pieces of conversations, the angst of these women highlights two major themes: one when they did not think about and address their needs before cancer and then when cancer opened them to themselves and they take an active stance to address those needs. So, we hear stories of how cancer changed them. Yet, when some women make changes and come to terms with their new normal, carefully rebuilding their lives and gaining control, they are suddenly undermined by recurrence. Recurrence switches on an avalanche of feelings, implying threat, life limitations, a sense of que sera sera, fear of pain and death, and a sense of betrayal of some x factor. Change again is a challenge when hope, belief and relief are displaced. In the existing models of patient care, the focus for patients with recurrence is medical management. Goals of care are active treatment, passive treatment or palliation. Addressing physical, psychological, existential, social, spiritual, etc components only happen within institutional setting and in clinical context. In the cultural context of India, a hospital is for cure; so, palliation, recurrence and the dreaded cancer together mean no cure, painful death, losses and a hopeless situation. The added burden of the pandemic and resulting isolation continues to cast doom and fatality on lives, livelihoods, and mental health.

Self-care model of chronic illness

Self- Care is the practice of taking an active role or action to preserve or improve one's own health, protecting own well-being and happiness, in particular during periods of stress.

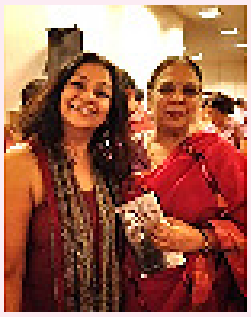
– Oxford Languages

Satori 2 draws on and has adapted from the Middle-Range Theory of Self-Care of Chronic Illness in cardiac patients. It is stated that, "self-care influences both clinical and person-centered outcomes in patients with chronic conditions. Those who engage more effectively in self-care have better quality of life, lower hospitalization rates and less mortality than those who report poor self-care." So, women who reach out to us are being taught to take care of self and maintain quality of life through a set of health promoting practices to manage illness, cancer recurrence in our case.

Since every cancer is different and breast cancer has its own types, subtypes and treatment approaches, our program is unique and different in that it serves the group as well as the individual, it is designed to address both common and individual needs with respect to both complementary or alternate therapies and medical information-based guidance. It is in response to the dearth of medical information and management of conditions otherwise requiring hospital or home care services. Goals of care in Satori 2 are the new introduction of a medical information module, where women learn self-care skills based on their current health condition and stay engaged in their own self-care. The main two objectives are wellness or complementary therapies and the medical information module.

Wellness or complementary therapies

On a common faculty consensus, the number of participants is limited to between 10-15 so that women get more time to share, talk and learn. On demand are restorative and healing therapies, like specialized medical yogasana (physical postures and stretches), pranayama, and yoganidra (a powerful meditation technique involving a self-body scan, visualization and breath awareness); tapping-emotional freedom technique (tapping specific points on the head, face and torso in a particular sequence). It combines a little of psychology where the person identifies and focusses on an issue, gauges their feelings using a scale of 1-10, creates their own reminder phrase which acknowledges the problem and acknowledges self-acceptance in spite of and along with it. This is followed by a specific sequence of tapping and feelings are again gauged on a scale of 1-10. Counselling therapies are facilitated for emotional well-being and healthy coping skills. Dietary and nutrition intervention addresses specific and special needs for improved immunity and optimal well being during and after treatment.



Ruby Ahluwalia, founder of Sanjeevani Life Beyond Cancer, and Rama Sivaram

The medical information module

Complementary therapies play a significant role in connecting women to themselves by helping them recognize their needs and deficits and overcome them through acceptance, commitment and adherence. It is a promise they make to themselves. This is making the self-care model a doable intervention model. The term medical information in this context implies that, with the consent of the women, we have access to their medical file and history and current treatments and treatment protocol. Based on this, we educate them on their disease, side effects and their management, how to practice self-care and when to seek medical care. A very important and often unaddressed aspect that the module focusses on is a close watch on alternative medicine or therapies, drop-out patients and status of diagnostic and laboratory parameters and panels. This is done as the management aspect of self-care after self-maintenance and monitoring of symptoms when women follow naturopathy, ayurveda and other Oriental systems of medicine, where some macro and micro nutrients are eliminated from the diet and some medication could contain lead and mercury with potential toxic effects. Classic examples include protein free diets and edema, saltless diets and altered mood changes, lack of adequate calcium in vegetarianism and banned dairy products combined with aromatase inhibitors like Letrozole, Femara and skeletal metastasis, further exacerbating increased risk of osteoporosis and fractures. Medicines containing heavy metals and dietary do's and don'ts may cause further damage to organ systems or biochemical parameters. One-to-one and group discussions enable the team to connect with one another. The medical information module immediately asks the women to get their blood panels and diagnostics and to connect with the nutritionist, psychologist and professional caregiver. Be it a clinical or mental health issue the faculty meets online periodically and discusses cases. This is done specifically because the goals of the program are improving and maintaining well-being, monitoring symptoms and seeking management indicators that can be self-managed or need medical /clinical oncologist management. Because they are still living and may continue to live with their disease for a long time, and because they are following different therapies, it is important to be updated and make choices.

An initial activity clock (clocking their daily routine) to assess how much time, care, sleep, rest, exercise they give to themselves is organized for self-assessment. This is to enable them to stay in control of their life and illness. Intended outcomes are adherence, personal responsibility, overall well-being and quality of life, minimizing symptoms and pain, minimizing emergency hospitalization, recognizing when some laboratory procedures and a doctor's attention is necessary and cannot be ignored, whatever choice of treatment one may choose. Women are educated on the three components of self-care so that they can put it to best practice. These are:

Self-care maintenance: Health promoting practices/behaviors like nutritionist-guided eating, managing timing for each activity like sleep, physical exercise and activity, taking medications and committing and adhering to treatment.

Self-care monitoring: Mindful awareness, self vigilance and surveillance, paying attention to symptoms and changes in the body and mind. Tracking physical and mental status in order to respond/act on them.

Self-care management: Responding to a symptom, event or any other change in the body and mind with appropriate and acceptable medication which has been prescribed or alternate approaches for relief from any distressing symptoms. Evaluating physical, cognitive, emotional change, signs and symptoms, progressive pain, change in activities, diet and environment, etc. are part of the discipline in self-care. This means taking action by seeking information and online or telephonic medical consultations when needed in the form of medication or advice.

Satori 2 has emerged as a program for patients with recurrence of any cancers. This article highlights women with breast cancer and ovarian cancer recurrence. Dealing with recurrence in halted services and lockdown,

the vaccine not recommended for women undergoing treatment, less than 45 years of age, and stamped with co-morbidities, it is a trying circumstance. Women wear their Big C like the scarlet letter; they blame themselves and feel guilty, betrayed, anxious and angry. Satori 2 continually works on busting these gender-driven myths, misguided information and beliefs, and over-worked mental processes, which are fed by the self-scripted, depressing thoughts and increase a vicious cycle of body-mind reactions and responses. As caregivers, we are trying to adapt and go beyond hand-holding into training patients in self-care skills and putting them in control. We teach them that the choices they make can be kindnesses to themselves, and it works. We clarify at the outset that they are major partners and contributors in Satori 2 because they will teach us what is useful and what we need to change or add. So, we seek out every opinion and response, putting aside all platitudes. The response is gratifying. It is truly motivating that the women are overwhelmed with a sense of gratitude for being listened to and heard with empathy. They express motivation to recharge themselves and take control. Acceptance and understanding their circumstances, acting on them and feeling more positive, physically and mentally, is because of the positive actions they are taking and the skills they are learning and putting into practice. Satori 2 is confident that in this journey through cancer there is an oasis — a safe place to grieve, heal and move on in their passage to recovery or another space.

I would like to end with a voice which is bubbling with the joy of self-discovery,

"*I learnt to live for the first time in 56 years for myself after Satori 1 and 2. I am alive and I am aware that I am here and now with or without breast cancer.*"

I would like to thank Ruby Ahluwalia, the Founder of SLBC, and the very young and dynamic team of administrators and interns: Priyasha, Ghousia, Abida, Arpita, Mouli and Roopika for collating all patient data and keeping in constant touch with every patient, following up, building bridges and keeping us connected.

https://www.sanjeevani-lifebeyondcancer.com/

To explain the title of the article – Satori by sun and candlelight – "Satori" is a Japanese Zen Buddhits tradition that means the path to self-awakening or understanding the nature of self. "By sun and candlelight" is borrowed from *How do I love thee?*, Sonnets from the Portuguese, No. 43 by Elizabeth Barrett Browning.

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