

bloom

ISSUE 33 DECEMBER 2021



page
4

Message from Cathy Hirsch: Plans are proceeding for the 20th RRI Breast Cancer Support Conference

page
5

The 411: Sex + Cancer

page
7

Intimacy, sexuality and cancer: tips for patients and physicians to initiate conversations

Reach to Recovery International (RRI)

RRI is committed to improving the quality of life of individuals affected by breast cancer and their families.



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Reach to Recovery International, Inc. is a global non-profit organisation based in Baltimore, Maryland, USA.

Table of contents

04. Message from Cathy Hirsch
05. The 411: Sex + Cancer
07. Intimacy, Sexuality and Cancer
08. Sexuality and breast cancer: a psychological perspective
10. Sexuality and breast cancer in India in social and cultural contexts
12. Sexuality and breast cancer in the clinical context
14. Sexuality and breast cancer: perspectives from Zimbabwe
15. I am not an invalid
16. South East Asia Breast Cancer Symposium 2021
18. Spotlight on Portugal: Life beyond cancer
19. Global Kitchen

Our mission

Reach to Recovery International's mission is to:

- Unite organisations throughout the world which support individuals affected by breast cancer, including their families, in order to share ideas and best practices;
- Disseminate valuable information to support individuals affected by breast cancer throughout the world via bi-annual conferences, our website, our e-newsletter, and other forms of worldwide communications; and
- Assist our Member Organisations in achieving their goals of:
 - Improving the quality of life of individuals affected by breast cancer,
 - Providing psychosocial support to individuals affected by breast cancer, either through group meetings or activities or one-on-one peer support provided by carefully trained survivor volunteers,
 - Advocating on behalf of individuals affected by breast cancer,
 - Providing patient navigation to individuals affected by breast cancer.

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What would you like to read about in the next edition of *bloom*?

Email your theme suggestions to info@reachtorecoveryinternational.org. A theme will be chosen by March 2022. Regardless of whether your suggested theme is chosen this time, it will remain under consideration for future editions.



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Celebrate the work being done by your organisation's volunteers!

Do your organisation's volunteers do outstanding work to support those touched by breast cancer in your community? Bloom wants to hear all about it! Send us articles about the projects your volunteers are working on, and be sure to include high resolution photos. Articles should be 200 - 400 words long and should be sent in Word format to info@reachtorecoveryinternational.org. It's a great way to thank your volunteers for a job well done, and to raise awareness about your organisation!

Upcoming events:

World Cancer Day 2022

4 February 2022

www.worldcancerday.org

20th Reach to Recovery International Breast Cancer Support Conference

22 – 25 September 2022 / Guadalajara, Mexico

[website pending](#)

World Cancer Congress

17 – 20 October 2022 / Hybrid Event / Geneva, Switzerland

www.worldcancercongress.org



“ REACH TO RECOVERY INTERNATIONAL IS COMMITTED TO IMPROVING THE QUALITY OF LIFE OF INDIVIDUALS AFFECTED BY BREAST CANCER AND THEIR FAMILIES THROUGH A WIDE RANGE OF SERVICES OFFERED WORLDWIDE. ”

Message from Cathy Hirsch - President of RRI



Cathy Hirsch

Anyone who has been touched by breast cancer, whether their own or that of a loved one, knows that it is life altering. Months or even years of surgeries and treatments wreak havoc on the body, and the accompanying fear, pain or discomfort, fatigue, and often hormonal changes can affect mental well-being. Increased awareness in many parts of the world has erased some of the stigma attached to a breast cancer diagnosis and allowed patients to openly ask questions of their health care providers and seek practical and emotional support from peers or mental health professionals. Unfortunately, one common by-product remains largely in the shadows, as many patients, loved ones, and even health care providers are reluctant to talk about it. That is, the effect breast cancer has on one's feelings about their own sexuality.

In this edition of Bloom, we shine a light on this hidden issue that is suffered by so many but openly discussed by few. Kimberley Cullen of Canada's Breakthrough Cancer Trust offers tips on dispelling the myths surrounding sexuality and breast cancer. Leonie Young and Janine Porter-Steele of The Wesley Hospital's Choices Cancer Support Centre in Brisbane, Australia stress that it is crucial for those touched by breast cancer to talk about sexuality. They have suggestions for both patients and health professionals to get the conversation started. Katerina Chotzoglou of Greece's Alma Zois describes the psychological changes that breast cancer patients go through and explains how those changes affect their sense of self and sexuality. From India, Rama Sivaram discusses breast cancer and sexuality from both a social and cultural context and a clinical context. Faresi Takawira and Barba Marufu of Zimbabwe offer their perspectives on breast cancer and sexuality, and Poh Choo Chuah of Malaysia's Pink Unity explains how she regained her sense of self after arduous breast cancer treatment affected her appearance and self-esteem.

Also in this edition of Bloom, our spotlight is on South East Asia with a report from Carolyn Taylor on the 5th South East Asia Breast Cancer Symposium. We also have

a spotlight on Portugal with Carolina Negreiros' report on an exhibition of portraits of women who have dealt with breast cancer.

We know you will enjoy trying the healthy recipes from Greece, one of the culinary capitols of the world, which are featured in our Global Kitchen.

Plans are proceeding for the 20th Reach to Recovery International Breast Cancer Support Conference, scheduled to be held in Guadalajara, Mexico from 22 – 25 September 2022. Within the next few weeks you can expect to see an announcement from us in your inbox with a link to the Conference website, through which you can register to attend the Conference and submit your abstract.

For nearly two years now, we have been living with the threat of the COVID-19 pandemic. While we expected the world to be back to "normal" by now, that is not the case. With the development of new variants before vaccinations were made available everywhere, many are now dealing with new restrictions and travel bans. We urge all our members to stay vigilant and safe, in the hope that we will be able to gather in person next September.

“ PLANS ARE PROCEEDING FOR THE 20TH REACH TO RECOVERY INTERNATIONAL BREAST CANCER SUPPORT CONFERENCE, SCHEDULED TO BE HELD IN GUADALAJARA, MEXICO FROM 22 – 25 SEPTEMBER 2022. ”

The 411: Sex + Cancer

Dr. Kimberley Cullen, PhD, C.Psych



Many of the challenges that couples face when trying to navigate a sexual relationship after breast cancer are based on assumptions and expectations about how sex should be. Here are four common myths that can get in the way of reclaiming your sexual relationship, and tips on how to bust them.

Myth #1: Eventually sex will and MUST go back to “normal”

This common myth puts a lot of pressure on couples. This added pressure makes the discomfort and distress associated with sexual changes feel even worse, and can lead to feelings of frustration and resentment. Hanging on to this myth also gets in the way of discovering new experiences. Sexual relationships are constantly evolving, who we are sexually changes over the years, the definition of “normal” also evolves.

Myth Buster: Accepting that things are different

- Acceptance means assessing the situation and developing realistic

expectations about your current and future sexual relationship

- Acceptance opens the door to new and exciting ways of being sexual
- Acceptance also means acknowledging the grief and how you feel about the loss of your old sexual relationship (this can include loss of breasts, loss of certain sexual activities). It’s ok to be sad and miss these things.

Myth #2: Different means worse

Remember that you are in new territory here. The landscape is different, your body is different, emotionally you are both different, and sex might never be **exactly** the way was before. It’s important to acknowledge that yes, things will be different, but this doesn’t mean they can’t be as good – including sex! A first step to busting this myth is to shift your thinking from “I will never be the same again” to “life will be different, **and** I have the resources I need to find new ways of satisfaction.”

Myth Buster: Flexibility and Persistence

- Get creative! Be flexible and open to new experiences
- Experiment with new sexual/sensual activities and ways of being physical
- Try things a few times even when they feel new, awkward, or uncomfortable, and don’t give up because something didn’t work the first time

Myth #3: Sex will spontaneously and effortlessly resume

Going through breast cancer and treatment takes a lot of physical and mental energy. It should come as no surprise that sex can take a back seat as your focus on your treatment and recovery. Many couples assume that with time they will seamlessly fall back into their natural sexual rhythm. Time is often not enough; it’s what we do with this time that counts. Think about it: If you are an avid runner who breaks an ankle, you will likely be out of commission for a while. Time alone will not magically fix your ankle; you need to work at it and

gradually build up to running the way you were before. Sex after breast cancer is no different.

Myth Buster: Back to Basics

- Find new ways to connect and feel close...date, start a new activity together, make an active effort to spend more time together, learn new things about other
- Ease back into sex. Communicate about expectations and comfort levels.
- Take pleasure in getting reacquainted each other's' bodies

Myth Buster: Scheduling Sex

- There will always be something keeping you busy, and it may seem like there is no room/time for your relationship. This is why scheduling is so important!
- Think of scheduling as PRIORITIZING your relationship
- The short- and long-term benefits of scheduling quality time together are worth this extra effort
- Sex doesn't need to be spontaneous to be great!!!

Myth #4: If we aren't having sex, physical affection is also off limits

Don't assume that stopping sexual activity means stopping physical affection. By the

same token, don't assume that physical affection always leads to sex. Physical expressions of affection can be especially important when you aren't having sex because it enhances feelings of closeness and intimacy

Myth Buster: Express Affection

- Expressing affection is an important step towards finding your way back to sex
- Physical expressions of affection can include kissing, cuddling, massages, holding hands, making out, heavy petting, prolonged foreplay, and engaging in non-penetrative sex
- ALL expressions of affection count: Do the things that increase closeness and intimacy
- What can you and your partner do to make each other feel good and/or attractive?
- What are some day to day things that make you feel closer to your partner? (e.g when my partner brings me coffee in the morning, when my partner sends me a text in the middle of the day)

[For more expert advice on The 411 click HERE!](#)



Dr. Kimberley Cullen, PhD, C.Psych, is a Clinical and Health Psychologist whose research and clinical work has been dedicated to enhancing the sexual health and well being of women with cancer. Through her work and public appearances, she hopes to empower women to openly discuss the impact of breast cancer on their sexual quality of life and is an advocate for the development of available resources to address these issues.

Intimacy, Sexuality and Cancer

Leonie Young, *DUniv*, and Janine Porter-Steele, RN, PhD
Brisbane, Australia



Leonie Young (left) and Janine Porter-Steele, RN, PhD, Choices Manager

Cancer can have an impact on just about every aspect of a person's life, but one of the more common, long-lasting effects of cancer, especially breast cancer, is issues relating to body image, intimacy, and sexual function. Such concerns need to be focused on and the opportunity created to discuss them at any stage of the treatment pathway. There are many definitions for human sexuality,^{*} and how we feel about intimacy, sex, sexuality, and sexual relationships depends on a range of issues. It's important to remember that it's not unusual to have sexual difficulties, even in times of good health and well-being. There are numerous reasons for this, and often it can come down to inadequate information and education concerning sexual or reproductive health.

Why is it important to talk about sexuality and intimacy when diagnosed with cancer? It's important because this topic is very often overlooked and not discussed. This can be because it is often felt there are more important things to think about and discuss at this time, such as treatments and treatment schedules. Of course, it's not going to be the first question someone asks their doctor, but it commonly is an issue that comes to the forefront at some point during, or at the end of, treatment. Understanding this will help you feel more confident to talk about it with someone who can help.

Living with cancer can affect a person's sexual functioning in various ways, and some of these effects may be due to the cancer itself, the treatments, or a person's sense of self and/or their emotions at the time. Some of the sexual issues people with cancer must deal with can be relatively minor, but sometimes they are ongoing and can be more serious and importantly, these questions change from the time of diagnosis, through treatment, and then into recovery.

In addition to the cancer diagnosis, patients may have other conditions such as depression or hypertension, or they may be trying to manage menopause symptoms. Along with all this, their partners may be dealing with their own medical, psychological, or sexual issues. In fact, one of the best predictors of sexual concerns after a cancer diagnosis is what the person's intimate life was like before their diagnosis. Sometimes, cancer can intensify pre-existing issues, and while people may have managed different levels of desire before, cancer can complicate things

and it can have an impact on both patients and their partners. People often say they experience loss of libido and, interestingly, partners can, too, during this stressful time.

There are many solutions, and often a first step is knowing how to bring the topic up and ask for guidance. All patients should receive information about the possible side effects of the disease and its treatments on sexuality and intimacy, such as altered physical function and libido, problems regarding fertility, and menopause symptoms. It is, however, a difficult topic to bring up, not only for women but also for health care professionals who are also hesitant to initiate discussion and wait for the patient to voice their concerns. Consequently, it often becomes an endless circle of inaction, frustration, and sadness.

It is also very important to acknowledge that these worries are valid regardless of a person's age, whether or not they are in a relationship, the stage of their disease, and the type of cancer and surgery they are dealing with.

Here are some words you could use to help you bring the topic up with your health care provider:

Is it safe to have sex / continue with our normal intimate relationship?

I have heard this treatment may affect my relationship with my partner. Can you tell me what might happen?

My partner is worried he may hurt me if we have intercourse. Is this something I should be worried about?

I don't feel attractive because of my scars and I'm worried my partner may not find me desirable any more. Can you recommend someone I can talk with about this?

I have developed vaginal dryness and it's very painful and uncomfortable especially during intercourse - what can you suggest?

Here are some helpful phrases that health care professionals can use to raise the subject with their patients:

I always ask how things are going with sexual relationships because it's really very common to have difficulties after treatment. Is that something you would like to talk about?

I'm really pleased to hear the treatment side-effects are settling down. I find for most people at this stage another area of concern may be about intimacy and sexual function. Are there any issues you would like to discuss?

If connection with a physiotherapist is available to you, their expertise can assist with advice relating to positioning and exercises to help improve pelvic floor strength. A breast care nurse or general practitioner may also be able to provide information regarding the appropriate use of gels and creams – and this is a topic we can provide more information about at another time!

Importantly, be kind to yourself and have realistic expectations.

^{*}W.H.O. Gender and reproductive rights: sexual health. 2002. who.int/reproductive-Health/gender/sexual_health.html. Accessed May 2007

Sexuality and breast cancer: a psychological perspective

Katerina Chotzoglou, Board Member of Hellenic Association of Women with Breast Cancer (Alma Zois), Alma Zois volunteer, and breast cancer survivor

Greece



Katerina Chotzoglou

The diagnosis of breast cancer is always a huge shock for both the patient and her partner. The announcement brings us closer to fear and reveals our fragile status and the temporality of life. For the patient, it may also mean an eventual impairment of her femininity and a fear of mutilation. For younger patients, this comes with the fear of fertility issues. Even if recent treatment methods bring hope, fighting breast cancer remains a difficult battle with long-lasting consequences on the couple's life. Sexuality is not just the intercourse but the way we understand our bodies along with desires, values, beliefs, orientation, and thoughts. Since sexuality is experienced through all of the above, we could say that it is unique to each one of us. But sexuality is also dynamic, changing according to life changes. And cancer is a life-distressing situation.

We already know that breast cancer can affect sexuality in a temporary or more permanent way, depending on treatment, the disease stage, and also on the couple's sexual history. Fatigue, decreased sexual desire, pain, anxiety, changes in body image, fertility problems, or early menopause are the most commonly expressed issues.

In this article, I will try to approach the effects of breast cancer on sexuality from another point of view by discussing the psychological impact of the disease and its treatments. The announcement of the diagnosis, the period of treatments, the end of treatments, and the return to normal daily life considerably modify the couple's emotional state. Often, previous issues that the couple experienced re-emerge and resonate with the diagnosis, which can lead patients to psychic distress.

The announcement of the diagnosis leads to shock. In breast cancer, for example, the body, once a "well-known land," becomes an unknown, hostile, and as such, an out-of-control place. The body has betrayed her! "Am I still a real woman? Will I be capable to have sex again? Do I have to live from now on in a situation of uncertainty, a nightmare?"

The mastectomy is experienced as a mutilation, a loss. There is a trauma behind the woman's reactions of distress, a blocking of thought in the face of mutilation. Female identity is affected. Women no longer recognize themselves. They see something missing in their body and in the eyes of others. In this context, some of them will feel they need a period of mourning for their loss, others will not.

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A mastectomy may revisit issues from past separations, abandonments, and losses. Mourning the loss of femininity may

reactivate other real or symbolic deaths. If mourning occurs, the patient is on the safe path; if she does not, she hides her trauma as if it does not exist but it is still there, bleeding and festering.

Breast reconstruction without a previous recognition of the loss may be dangerous since mourning, negotiation of the new self, and moving ahead is a long process. In other words, avoiding the fear of what some patients often refer to as a "hole" in their bodies does not cancel the mutilation she has experienced. This asymmetry between the real body part and the one added reflects another asymmetry or even a psychic dispute that prevents acceptance. The reconstructed breast (or breasts) feels absent during intercourse and as such cuts the body in two parts; the one that reminds her of her sexually healthy self and the other that leads her to death.

In the case of immediate breast reconstruction, the patient may feel less anxious or depressed about the loss the day after the surgery, femininity not being disputed, but still pain and discomfort will remind her of the missing part and its representations.

Chemotherapy and its side effects of hair loss, intense fatigue, sexual disorders, and nausea shake up all the landmarks known

up to diagnosis and upsets the patient's psychological, mental and body image balance. The body continues to be an uncontrollable stranger, an "Other." The same way the chemotherapy destroys the malignant cells together with the benign ones, the paradox destroys the balance.

Finally, after treatments the patient must resume a normal life. Or not? At the announcement of the diagnosis, the goal for both patients and their families is healing, while the period of treatment and post-treatment is the chance for them to re-shape, re-think and re-organize their life within a fragile emotional, social and family context. The diagnosis of breast cancer cuts the woman's life and her context into two phases—the pre-cancer period characterized by the control of self and good self-esteem, and the post-cancer period which leads patients to live a situation of precariousness with fears of recurrence.

Despite medical advances, psychotherapeutic care for the sexuality issues brought on by breast cancer may not be provided by the medical and nursing team. Doctors focus on treatments, while a woman needs more than a cure to adjust to post-cancer life. She also needs a desire to live fully, rediscover her self-confidence, and enjoy her second chance at life.

Medical professionals, oncologists, and nurses play an important role in supporting the patient and her partner throughout this journey. Apart from the treatment plan, supporting sexuality as part of the woman's entire self, should be discussed openly. To do so, the medical community should implement a training for oncologists and nursing staff, with theoretical and practical courses to address the issue of sexuality among cancer patients in a more effective, yet less stereotyped way.

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Sexuality and breast cancer in India in social and cultural contexts

Rama Sivaram, Consultant KEM Hospital Research Centre, Pune; Faculty, Sanjeevani Life Beyond Cancer; Member, Nag Foundation Pune, India



Rama Sivaram

In my 25 years in health care with a focus on the reproductive health of women in India, I have come to realize that intimate health issues faced by women need finer and more sensitive tuning. When a woman presents herself to a health care professional, she is presenting more than disease. Knowingly or unknowingly, she exposes her whole vulnerable self in the context of her beliefs and institutions, such as family, society, community, religion, and social norms. Natural biological identity plays a dominant role in a woman's life.

Yet, in many support group conferences, the seemingly simple question “What is sexuality?” stumps almost every woman. This is not surprising, because in common parlance a word starting with “sex” immediately brings to mind the sexual act. In many of our adolescent workshops when we ask “What is sex?” there are giggles and sniggers until we hand out a questionnaire where, after name and age, comes “SEX – M or F.” It is difficult to grasp that sexuality begins when life begins and is an innate part of us and our personalities.

Sexuality as a concept can be confusing because sex and sexuality are similar and yet different. Sex is seen as an act performed for procreation, pleasure, power, communication, etc. Sexuality is harder to define because of complex body/mind connections. The brain and body work together, influencing our physical and emotional functioning. Defining sexuality requires a deep understanding of the complex biological, physical, emotional, psychological, social, spiritual and ethical reaction to being male or female.

It takes time, patience, and respect to create the desired safe space for every woman to deal with issues concerning herself because she is conditionally wired to respond or react in unquestioning ways as expected of her in her socio-cultural milieu. Sexuality and breast cancer have to be understood in socio-cultural, individual, and clinical (physical symptoms) contexts. Indian women by and large unquestioningly imbibe and adopt culture-specific rules; however, in

the present-day context of semi- or-mixed tradition, how they look at themselves is closely connected to what they learn from parents, community, religion, media, schools, etc. They are programmed to behave in a certain and appropriate manner, even while their instincts may tell them something else. In a stressful circumstance such as cancer, these overarching social norms affect the woman in many ways at her individual level.

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IT TAKES TIME, PATIENCE, AND RESPECT TO CREATE THE DESIRED SAFE SPACE FOR EVERY WOMAN TO DEAL WITH ISSUES CONCERNING HERSELF BECAUSE SHE IS CONDITIONALLY WIRED TO RESPOND OR REACT IN UNQUESTIONING WAYS AS EXPECTED OF HER IN HER SOCIO-CULTURAL MILIEU.

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Indian culture draws widely from centuries old religious texts and sutra-rules. Prescriptions for rites and duties of women, especially married women, rest heavily on patriarchy. A good woman means one

without a blemish who serves her husband dutifully and bears and rears progeny. It is not surprising that when the Big C rears its ugly head it releases despair, learnt memories, myths, and misconceptions. By and large, even today women are heavily influenced by the male members of their families and their handed-down social beliefs. Cancer means a setback in body image – a stigma. When the norm of being the perfect woman who serves her husband and family breaks down it can be devastating to the woman and her relationships. It is a perceived loss of procreative and feminine power. A woman feels flawed.

Most oriental cultures are shame societies, with guilt as a hidden icon. Both shame and guilt are self-worth issues. In matters of sexuality, intimacy with a spouse in privacy is sanctioned and not shameful. The disclosure of breast cancer or another women's cancer, with the accompanying loss of a breast or womb, represents a woman's failure within her micro environment. The woman views it as a matter of shame, incompetency, and incompleteness as a woman that makes her no longer suitable for a man. Indian women are programmed not to talk much about their needs, pain, or discomfort, even when sexually active within private confines. The subject becomes even more taboo when a woman is afflicted with breast cancer. We are women caught in the culture of silence, since our “belongingness” with our group is based on adopting group norms. One may ask, can this and does

this still happen in the 21st century? Yes, it does in a complex, covert way that is further exacerbated by the women's own existing and evolving thought processes, lack of awareness, and unpreparedness.

So where do we begin? Advocate, advocate, advocate and create awareness and more awareness. In every educational session on cancer prevention and in every support group meeting, we make time to debunk the myths and misconceptions of the feminine archetype. When a woman builds the rapport needed to share intimate issues of herself and sexuality, her physical symptoms, and her overwhelming positive or negative emotions she is ready to resolve her problems. Cognitive Behavioural Therapy (CBT) approaches combined with guiding the woman to seek treatment for specific physical symptoms can be very helpful. The closer a woman gets to her individual self rather than group identity, the more her self-awareness dawns or increases manifold.

Society is not static. The undercurrents of our culture continue. In addition to our "belongingness to group" identity, women in the 21st century try to succeed in finding their own self-identities as individual entities. While this process of modernisation is continuing to happen, it has not completely displaced the age-old traditions and beliefs. Modernisation is still in infancy when it comes to addressing sexuality. The diagnosis of a breast or reproductive cancer sends women across the world into the same cycle of grief, insecurity, and fear. These are inborn, universal, conscious human feelings that are necessary safety valves for survival. There is no difference in emotional response and reaction. However, what women learn in their societies affects their coping mechanisms.

It is always good to know what a woman talks to herself about before and after breast cancer. Most often before cancer it is not about her sexuality or sexual being; it is about her family, her children, her home and, for a woman working outside the home, her work. The post-cancer monologue of a woman includes, "What am I afraid of losing and what am I defending – my lack of breast or womb, my cancer status, my new normal, my relationship, my gender, my identity, my sexuality, my guilt of being cursed with disease, my ability to perform, or

my infertility." Some women blame cancer for their own or their husband's lack of sexual desire. Some feel that cancer means the end of conjugal life and compatibility. Returning to normal conjugal life is a major issue. With much older, post-menopausal women, sexuality is often replaced by spirituality or other senior activities because there is a belief that sexuality no longer matters for women once their reproductive life cycle has ended. Hormonal changes do cause physical symptoms and decrease libido and arousal. These are limited to bodily functions, and women going through these changes must know that, with a little help and nurturing, sexual intimacy can be restored. Women need to write a dialogue with their present selves and potential selves, contesting and challenging their negative thoughts, feelings, and beliefs.

As Indians, we love the word karma (the sum of our good deeds and bad deeds) and fate (the power beyond our control). Both karma and fatalism are cultural beliefs drawn from primitive religions to meet psychological needs when there is no answer to "why?" and when cause and effect cannot be established. Also, to question disturbs familial and social hierarchy. There would be no Indian who has never used karma and fate at some point of good fortune and in adversity. So, there are women who think the loss of a breast, infertility, loss of libido, and perceived loss of status are attributable to bad karma or fate. Women react or respond to these situations depending on their own micro environment and cultural beliefs.

So, what can we do and what can she do?

Women who summon the courage to seek help with or without being part of support groups are the best champions of their own cause. Support groups play a major role in creating a sisterhood, allowing for sharing and learning and boosting participants' confidence in themselves. They show the women that they are not alone. Similarly, women who seek professional help take charge of their solution. Healthy sexuality requires empowering women to acquire self-awareness, personhood, self-identity self-esteem, and a positive body image. It requires effective communication between spouses which allows both parties to vocalize their needs, fears, and anxieties without shame or guilt.

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Sexuality and breast cancer in the clinical context

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Sexuality is a part of human life. Internally it is controlled by our hormones and externally it is influenced by culture, religion, and society. In this article, “clinical context” means body-related physical symptoms and problems which are outcomes of breast and other women’s cancers and cancer treatments, and which need to be dealt with via clinical interventions, preferably by a gynecologist. Mental health issues due to bodily changes, sexual dysfunction, and, most importantly, fear of potential pain or trauma with sex also fall into the clinical context and need to be addressed by mental health specialists. Even though we talk of the continuum of care in cancer from the moment of diagnosis into palliation and survivorship, the primary concern of every oncologist is to treat the cancer and manage the collateral damages of surgery, chemotherapy, and radiation until treatment is complete. While oncologists know of short-term and long-term side effects, many patients do not until faced with a problem. Women seek recourse for non-sex-related problems quickly but postpone seeking care for intimate issues like sex and sexuality issues

The role of medications, surgery, reconstruction, and radiation therapies:

Women with breast and reproductive cancers often face altered menstrual functions, and fertility issues, especially with chemotherapy, hormone therapy, and other medications. For menopausal women the problem may be exacerbated. There is also the connection between endocrine and neurochemical functions that add fatigue, insomnia, lack of motivation, feeling unappreciated, palpitations, anxiety, etc. Surgery, reconstruction, and radiation therapy often leave their own marks as lymphedema of the breast and arm, loss of nerve supply, breast asymmetries, chest wall deformities, etc. which, besides leading to less arousal due to pain or fear, lead to self-esteem and body image issues. Women with modified radical mastectomy face greater body image and self-esteem issues.

For many, these problems evolve over time into withdrawal, disinterest, indifference to self, lowered and unfulfilled sexuality, negative feelings and emotions, and relationship issues with partners. Were these problems simply age or lifestyle related they would be taken in their course, but as a result of breast or women’s

cancers they are perceived in a poor light. A three-member team consisting of a gynecologist, a counselling therapist, and the woman herself is necessary to properly address sex and sexuality issues brought on by cancer. Women need to be made aware that they can contribute to their own sexuality and well-being, and the gynecologist and therapist can be brought in for bigger and more complex problems which only an expert can handle.

Self-care for common sex- and sexuality-related problems: Women can address some of their problems by learning simple home remedies such as maintaining a healthy diet, exercising regularly, learning more about types of sexual activity, positions and postures, and adjusting their daily activity clock for optimal well-being in general and specifically for improving desire, libido, and shared fulfilment. This is possible if there is already intimacy between the couple and there is also overall satisfaction in the relationship and the desire to get the best out of it. Marital or relationship problems and resentment that existed before the cancer can be stumbling blocks and may require professional help. Unfortunately, in

India it is common for women in unhappy situations to suffer in silence.

Some of the problems that women themselves can handle are vaginal dryness, lack of lubrication, and dyspareunia (pain during intercourse or any other penetration). Lubricants to ease vaginal dryness and lack of lubrication are available over the counter in forms like creams, gels, and tablets. (Petroleum jelly (Vaseline) and douches are not recommended.) If approved by the oncologist and gynecologist, estrogen supplements that can be taken orally or via an estrogen-releasing vaginal ring may be prescribed. For dyspareunia, women can use a local topical anaesthetic cream. There is also desensitization therapy that teaches women to stimulate better circulation and vaginal relaxation to reduce pain. However, if pain and dryness persist a gynecologist should be consulted. He or she may recommend changing medications that may be contributing to vaginal dryness and pain.

Urinary tract infection (UTI) and vaginitis: Women who are prone to UTI must stay well hydrated with water and cranberry juice and should take probiotics.

Traditional Indian women in the southern part of rural India drink plenty of water, sour butter milk, boiled cumin, and ghee (clarified butter) concoction. They visit the restroom frequently and use sour buttermilk to wash away the infection. There are very scant studies on these practices and those that do speak only of the possible merits of probiotics and cranberry. But the practice is still continued in some rural parts of India and seems to work for simple yeast infections.

If a woman does develop a UTI, medical attention is required. In addition to the discomfort brought on by these conditions, they can contribute to lack of sexual drive.

Hot flashes and fatigue: These symptoms can be induced by hormone therapy and lowered estrogen levels and require a visit to the gynecologist and medical oncologist, who may want to change or add prescribed medications. Certain medications in the antidepressant category can be used to alleviate hot flashes when they are severe. Some medications are known to affect sexual drive so must be used with caution. Other options are wearing cotton clothes and loose-fitting clothes in warmer climates and adjusting room temperatures. Walking, exercises such as tai chi and gentle yoga, and affirmations are known to help

Osteoporosis and risk of fractures: Another side effect from cancer treatment can be osteoporosis and increased risk of fractures. Discomfort from this can contribute to avoidance of sex. Calcium and Vitamin D3 are recommended to improve bone health. Couples can experiment with positions that are more comfortable for the woman but still satisfying for both.

Sensitivity of breasts: Some women feel anxious that their breasts have less sensation when touched. Some complain that the slightest pressure to the area, where the skin may have been stretched tight by surgery, is painful so they lack desire for sex. The woman herself can perform gentle massage to reduce the taut feeling and should let her partner know which type of touch causes discomfort and which type does not.

Younger women with fertility issues and menstrual disorders: Being unable to conceive or having to postpone conception can affect sexuality adversely. There is often performance anxiety and the question, "Will I conceive this time?" Women can seek counselling to address this deep sense of incompleteness. I recall a young survivor at a conference saying with a smile on her lips and unshed tears in her eyes, "They stole the crib and left the playpen."

Senior women: Some women may experience stress incontinence or

incontinence that can affect how they feel about their sexuality. Women can help themselves by doing pelvic and vaginal exercise to strengthen the pelvic floor and the muscles in the lower part of the body. The most common are Kegel exercises, pelvic thrusts, squats, frog and hinge pose exercises for flexibility and staying power, strengthening the inner thighs, stretching the hip and groin region, and preventing tension and locking. Yoga postures such as chakravakasana (cat/cow posture) can also be helpful. Women who experience these problems should also use the restroom frequently, wash with water and gently dry afterwards, and wear breathable underwear. There are also surgical options that can achieve good results.

Conclusion: Even women who have never experienced cancer go through phases during which they have less energy, lowered libido, altered mood, decreased immunity, etc. This is normal and acceptable as long as these conditions do not become chronic. It is important that the lines of communication about sexuality and other issues between partners remain open. The joy and satisfaction of intimacy is not always about sex alone; it can be about a fond look, an affectionate hug, or simply sitting together without a word. Losing a breast or womb to cancer does not mean losing your sexuality, femininity, or personhood. Sexuality encompasses many aspects of ourselves and is capable of renewing and rejuvenating itself with infinite possibilities and in infinite ways. This brief, meaningful verse in Amaru Shataka, Hundred Poems of Amaru, is as applicable today as it was when written in India in the mid 8th century:

*Each turned aside
On the bed
Silently suffering
Secretly hoping to reconcile but
Afraid to lose face
At some point their furtive eyes met
There was a quick
Unintentional laugh and the
quarrel broke in one wild embrace*



Krishna painting, Radha's breast, Kangra Paintings, Gita Govinda

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Sexuality and breast cancer: perspectives from Zimbabwe

Faresi Takawira and Barbra Marufu

Zimbabwe



Faresi Takawira and Barbra Marufu

“EVEN NOW, 18 YEARS LATER, THE ADVICE FROM MY DOCTOR RINGS IN MY EARS. I WISH EVERY HUSBAND WOULD HEAR THAT ADVICE; THE BRAIN IS THE GREATEST SEX ORGAN.

”

Faresi's perspective:

The sexual changes and adjustments one goes through following a breast cancer diagnosis and treatment can be enormous to an individual, couple, or family. Some form of sexual dysfunction is common in most women suffering from breast cancer. The effects of treatment, lowered self-esteem, changed body image, anxiety, fear, as well as fatigue kill the libido in most women. Some women who have had a mastectomy feel a sense of disconnection with their body and see themselves as being deformed and unsexy.

The issue of sexuality is not commonly or publicly discussed in my community. This causes many women to suffer in silence. A short survey within my community revealed different challenges for women diagnosed with breast cancer. Some younger patients fear that, if they follow the process of mastectomy, chemotherapy, and radiotherapy, they will never be able to have children. Some women won't go for the prescribed treatment, opting instead for traditional methods due to fear of mastectomy. Some refuse to undergo mastectomy for fear of rejection by their partners, and this fear has some basis in reality as some men have left their wives because they had their breast removed. Another concern uncovered by the survey

was the effects of chemotherapy on one's sexuality. Estrogen levels are compromised, thereby causing lowered sex drive and vaginal dryness. These side effects come as a surprise to most patients, who are not made aware of them prior to treatment – they only find out about them once they experience them. Communication and counselling should play a vital role in helping couples and individuals deal with these issues. If the issues are not addressed, they can cause marriages to break down.

With the rising numbers of women diagnosed with breast cancer, awareness campaigns must be a top priority and all people should be educated about breast cancer. A breast cancer diagnosis and the resulting treatment should not change one's status as a woman, lover, wife, mother, and more. I want to encourage women diagnosed with breast cancer to talk freely about their sexuality and how they feel about themselves, to discover themselves again, and to enjoy their God-given lives. There is life after mastectomy; do not lose hope.

Barbra's perspective:

I grew up not fond of having my breast touched. I remember fist fighting with a boy in high school for rubbing against my

breast intentionally. Looking back, I don't think I ever developed a positive sexual relationship with my breast. When I lost a breast to cancer, my husband was more concerned than I was. I had more serious issues to worry about. My husband's fear of losing a sexually active wife was allayed by the advice of my doctor. My husband wanted to know how the mastectomy would affect our sexual life. The doctor answered in one sentence only: "Your greatest sexual organ is your brain." It was so helpful as we travelled through our post-surgery journey.

I consider myself blessed when it comes to having a caring husband. Some women are not so lucky and are divorced after mastectomy. I have heard of situations where husbands would have nothing to do with a woman with a "part missing." A friend of mine told me that for ten years her husband would not touch her. Even now, 18 years later, the advice from my doctor rings in my ears. I wish every husband would hear that advice; the brain is the greatest sex organ.

I am not an invalid

Poh Choo Chuah, *Pink Unity, National Cancer Society of Malaysia*
Kuala Lumpur, Malaysia



Poh Choo Chuah

I was diagnosed with breast cancer ten years ago. To many people ten years is a long time, but to me it was like two shakes of a lamb's tail. Being afflicted by cancer, such a deadly disease, of course shook me right to left, up and down. The treatment process was like a rollercoaster ride in a theme park. From the day I was diagnosed it involved not only my doctors but also my family, my colleagues, my friends and even my neighbours.

The rollercoaster ride evoked many emotional highs and lows alternating good times with difficult ones. It covered the elated feeling of knowing that the cancer was caught at an early stage and the pain of losing one breast and going through the process of becoming totally bald. The reality is that we can control our thoughts and our thoughts can control our emotions and feelings. That made me look at myself long and hard in the mirror. A dull, pale face with sagging skin and sunken cheeks stared back at me! That image was forever etched in my mind. It made me feel insecure and dull. How would my husband think of me? I did not want my children to see me as a frumpy mess; neither did I want my friends to show sympathy and remorse to me. I did not want to look like an invalid!

It was a day of revelation. From that day onwards a new "ME" emerged, thanks to countless hydrating face masks and creams, pretty and cute headgear to cover my baldness, and chic trendy clothes. I was elated to be able to fit into clothes that

I had kept since my marriage. My beautiful gowns and expensive cheongsams would be seeing the light of day. Every time I walked out of my house, I was immaculately made up and elegantly dressed strutting with my head held high. It brought back my self-esteem and my confidence. My family members noticed the difference and I could sense the smiles and looks that meant everything was going to be alright. It was true—I had cancer—but after the correct treatment I was no longer a patient. I love to call myself a survivor.

There are numerous writeups in brochures about possible physical, emotional and mental disorders among cancer patients and how to overcome them. I am sharing my thoughts and reflections here, however, because I feel that every cancer survivor has the right to stand up and pick up the pieces. I came back with a bang and ready to face the world. Did cancer give me a beating? Yes it did, but it did not defeat me.

“

THE TREATMENT PROCESS WAS LIKE A ROLLERCOASTER RIDE IN A THEME PARK. FROM THE DAY I WAS DIAGNOSED IT INVOLVED NOT ONLY MY DOCTORS BUT ALSO MY FAMILY, MY COLLEAGUES, MY FRIENDS AND EVEN MY NEIGHBOURS.

”

South East Asia Breast Cancer Symposium 2021:

Strengthening Regional Collaboration to Achieve Better Outcome of Breast Cancer Control in SEA Countries

Carolyn Taylor, *Global Focus on Cancer USA*

Spotlight on:
South East Asia
SEABCS summary report



Carolyn Taylor

The Indonesian Breast Cancer Foundation (IBCF), in partnership with the National Cancer Center Dharmais Hospital, the Indonesia Women Imaging Society, the Indonesia Society of Surgical Oncology and The Global Focus on Cancer hosted the virtual 5th Southeast Asia Breast Cancer Symposium (SEABCS) 2021 on July 31 – August 01. The theme for this year was “Putting Patients at the Heart of Breast Cancer Control” and it, as the first virtual SEABCS, proved to be the most successful symposium in the event’s 5-year history. SEABCS is a global forum and is attended by medical professionals and experts in breast cancer, breast cancer communities, patients, survivors, midwives, and government officials. The symposium serves the objective of continuing dialog to improve breast cancer control and address its challenges in the region.

Access was free for all cancer survivors, care partners and advocates and, as no travel costs were required, a virtual platform offered more equitable access to the meeting. This increased participation from previous years by more than 70%. The same held true for clinician participation: for a small fee of between \$10 - \$30 USD, clinicians could join in the two-day event and receive a CME certificate. Again, we saw a substantial increase in clinician attendees from past meetings. We also had a record number of countries participating with a total of 22. This year saw the first symposium endorsed by the American Society of Clinical Oncology (ASCO) and the first ASCO joint session. The 70 presentations made by clinicians, government representatives, policy

makers, and patient advocates covered: *effective policy shaping, key regional learnings from COVID-19, communications, multidisciplinary care and management, improving early detection and timely treatment, and equitable and sustainable approaches to achieve impact, along with clinical presentations in the areas of radiology and surgery.*

Conclusions from the Conference:

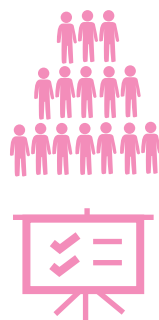
Equity, integrity, and improvement of healthcare quality should be something everyone in the region should be striving for. Sustainable programs promoting breast health awareness, breast cancer early detection and early diagnosis, breast cancer comprehensive and timely treatments, along with supportive care throughout the continuum should be implemented in all levels of health care centers by health care professionals in coordination with advocacy groups. Multidisciplinary care should be the standard.

Many studies have demonstrated cost-

saving in the treatment of cancer through the implementation of early detection and screening methods. In that regard, breast cancer screening and treatment services should be decentralized to improve access to and use of these services.

What is rarely acknowledged is the disproportionate impact of cancer on the lives and livelihoods of women, and the downstream impacts this creates for societies. More studies are needed to assess the financial burden of both medical and non-medical costs of a cancer diagnosis. Additionally, studies similar to the ACTION studies should be undertaken periodically, at least every 10 years to provide comprehensive data for the region. Countries should mobilize resources for such “evaluation” studies on the perspectives of health care and the patients.

Mutual commitment and responsibility from all stakeholders is important to ensuring the success of breast cancer prevention and control through health promotion, screening, early detection and standardized treatment.



TOTAL # OF PARTICIPANTS	1,248
TOTAL # OF ADVOCATS	706
TOTAL # OF CLINICIANS	542
PRESENTATIONS DELIVERED	70

These efforts will significantly decrease new cancer incidents while increasing the survival rate of breast cancer patients. The success of breast cancer prevention and control are closely related to the participation of the community, including the role of advocacy organizations. A strong collaboration among breast cancer organizations in SE Asian Countries may help to strengthen the effort to reduce the prevalence of advanced breast cancer cases in the region, with the hopes of reaching the 2040 WHO target goal.

The establishment of a regional South East Asian Breast Cancer Coalition or Task Force of clinicians, advocates, patients, care partners, advocates, policy makers, academics could be a valuable tool in building capacity across the region.

“

SUSTAINABLE PROGRAMS PROMOTING BREAST HEALTH AWARENESS, BREAST CANCER EARLY DETECTION AND EARLY DIAGNOSIS, BREAST CANCER COMPREHENSIVE AND TIMELY TREATMENTS, ALONG WITH SUPPORTIVE CARE THROUGHOUT THE CONTINUUM SHOULD BE IMPLEMENTED IN ALL LEVELS OF HEALTH CARE CENTERS BY HEALTH CARE PROFESSIONALS IN COORDINATION WITH ADVOCACY GROUPS.

”

Key Takeaways

- Build capacity for Patient Support Groups to operate effectively
- Early detection must be connected to timely treatment
- Early detection services should be coupled with funding and a clear treatment pathway
- Ensure access to effective and quality breast cancer care and treatment, via multi-disciplinary teams and improvement of communication skills
- Guidelines and clinical pathways for multidisciplinary cancer management should be implemented
- We must leverage the work of global initiatives for local benefit
- The use of telemedicine, social media and eBooks should be linked with access to services
- Some breast cancer services could be decentralized to increase access, as shown with chemotherapy units in Vietnam during COVID
- Service users should be incorporated into development/deployment of services
- Coordinated collaboration is needed across all stakeholders
- Countries should mobilize resources for evaluation studies
- Strong collaboration among breast cancer organizations in South East Asian Countries is needed



Minister of Health RI



Mrs Linda A Gumelar, Chairperson IBCF

Spotlight on:
Portugal!

Life beyond cancer

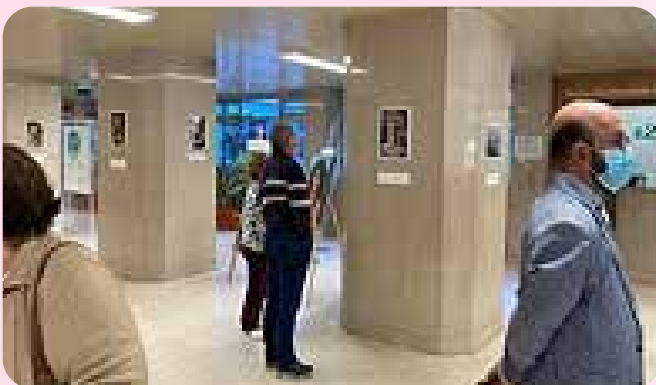
Carolina Negreiros, *Coordinator of Movimento Vencer e Viver NRN Portugal*

The exhibition “Life beyond Cancer” brings together photography and painting with portraits of women who suffered breast cancer, being an initiative of the Win and Live Movement of the Portuguese League Against Cancer – Northern Region.

It is integrated in the events of “Pink October”, which is the month of breast cancer prevention.

The Win and Live Movement is a group of women who have already suffered breast cancer and joined the group to give support to women who are facing the same pathology.

The face-to-face, eye-to-eye meeting between two women (patient and volunteer) who have experienced the same problem enables the patient to feel safely understood, to be able to share her fears and even learn another way to deal with the disease. The shared experience provides not only emotional support but also a social identity.



These art pieces were kindly created and offered by Isabelle Neri (photographer) and Ari Vicentini (plastic artist) who experienced close cancer situations with their patients. In Isabelle Neri's words,

The photograph records the image in thousands of seconds. It can be revisited and recalled by memory and enables the knowledge of situations and social events.

Photographing women who suffered breast cancer has two great meanings for me:

- To praise the strength of these women who suffered the disease and make women aware of the importance of Prevention and Early Diagnosis.
- Awareness saves other women's lives, taking care of the body is a gesture of love for ourselves.

Beetroot and apple salad with yoghurt dressing

Global
Kitchen

Winter recipes
from Greece

Recipe submitted by Marilla Giakoumi, survivor, ALMA ZOIS

Ingredients for salad:

- 1 large beetroot, raw
- 2 Granny Smith apples
- 1 garlic clove (well pressed)
- 1 ½ tblsp of red vinegar
- 3 tblsp of chopped nuts of your choice
- Salt and pepper to taste

Ingredients for dressing:

- 175gr (6 oz) of plain yoghurt
- 175gr (6 oz) of plain Greek yoghurt (denser than plain)
- 4 tablespoons of olive oil

SERVINGS: 2-4

Directions:

1. Chop the beetroot roughly and place in a salad bowl. Add the vinegar and salt, mix together, and set aside for 30 minutes
2. In a second bowl, mix the 2 yoghurts, garlic, and oil
3. Press the beetroot with your hands to extract the juice, then add the juice to the yoghurt mixture
4. Peel the apples, cut them into small cubes, press the cubes a little, then add them to the salad bowl with the beetroot mixture.
5. Add the nuts, some pepper, to the salad bowl and mix together.
6. Refrigerate both salad and dressing for 2-3 hours. Mix each again, then toss salad with dressing before serving.



Mushrooms fricassee

Global
Kitchen

*Winter recipes
from Greece*

Recipe submitted by Vassiliki Frantzi, survivor, ALMA ZOIS



SERVINGS: 2-4

Ingredients:

2 bunches of fresh scallions
500 gr (1 lb) of spinach leaves
1 bunch of Myronia (a Greek aromatic herb in parsley family)
1 bunch of parsley
1 bunch of dill weed
1 kg (2 lbs) of portabellio mushrooms (cut into pieces if too large)
Salt and pepper to taste

Directions:

1. Wipe the mushrooms clean (do not wash because they absorb water)
2. Heat 120 ml (4 oz) of olive oil, then add the mushrooms and cook slowly on low until they change colour and soften
3. Add the onions and cook until they soften, then the remaining herbs, salt, and pepper. Do NOT add water
4. If desired, add add lemon juice to taste before serving

Galatopita (milk pie)

Global
Kitchen

Winter recipes
from Greece

Recipe submitted by Nana Tsapela, survivor, ALMA ZOIS

Ingredients:

1 egg
1 L (1 qt) fresh milk
300 ml (1 ¼ cups) fine semolina
(flour made from durum wheat)
300 ml (1 ¼ cups) sugar, or
equivalent stevia
Zest of 1 orange
1 cinnamon stick
Cinnamon powder garnish

Directions:

1. Preheat oven to 180 C (350 F)
2. Heat milk, sugar, cinnamon stick, and semolina in a medium pot on low heat. Stir until the creamy mixture becomes almost solid (this takes time – be patient!)
3. Beat the egg, then add it to the pot and continue to stir (If you wish you can remove the cinnamon stick at this point)
4. Once all is mixed, pour the cream into a well-buttered oven dish
5. Bake for 45 minutes, until the surface turns pink
6. Remove from oven and sprinkle with cinnamon powder while still hot

