



# Newsletter

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## EDITORIAL

### WHAT IF PATIENTS DON'T STICK TO CANCER TREATMENT?

Nonadherence with medication is a complex and multidimensional health care problem. The cause may be related to the patient, treatment, and/or health care provider. As a consequence, substantial number of patients do not benefit optimally from pharmacotherapy, resulting in increased morbidity and mortality as well as increased societal costs. There is not just one solution for the nonadherence problem that fits all patients. To improve adherence effectively, there is a need for a tailored approach based on the type and cause of nonadherence and the specific needs of the patient.

Adherence is defined as the extent of which patients are able to follow the recommendations for prescribed treatment. Patient may be nonadherent during different stages of treatment. They may also discontinue treatment prematurely. Patient's reasons for deviating from the (agreed) treatment plan are diverse and may be intentional or unintentional. A meta-analysis of 569 studies of medication adherence revealed an average nonadherence rate of 25%.

Nonadherence could be intentional or unintentional. Intentional nonadherence can be considered as a process in which the patient actively does not follow treatment recommendations. The patient weighs the pros and cons of the treatment. Patient beliefs and the level of cognition are important factors in this process. Unintentional nonadherence may be the result of forgetfulness and not knowing exactly how to use medicines. It is a passive process that is specifically associated with the complexity of a medication regimen and the patient's memory. Use of multiple medications (polypharmacy) is associated with increased risk of complex dosing scheme. Factors that may predict nonadherence include forgetfulness, illiteracy, inability to understand the purpose of treatment, not perceiving the treatment as necessary, a lack of trust in the treatment, and a lack of knowledge about the effect of treatment. In addition, psychiatric problems, including depression, cognitive limitations, missing visits, and a poor relationship with the health care provider have also been found to contribute to nonadherence.

Interventions directed towards unintentional nonadherence include simplification of dosing regimens, reminders, improved communication between patient and physician, and introduction or improvement of patient counseling. Adherence can be improved by using specific form of drug packaging. Reminding patients to take their medication by Short Message Services (SMS) is increasingly being used. Dialog between patient and provider is of utmost importance. Questioning the patient about habits of medication use is also recommended. The interventions are aimed at all patients regardless of whether adherent or not, and tailored to the specific needs of the patients.

**Impact of Nonadherence to Cancer Therapy:** Nonadherence to chemotherapy has been associated with worse outcomes in a number of disease states and with increased physician visits, higher hospitalization rates, longer hospital stay, disease worsening, and increased mortality. The most robust body of literature on adherence to cancer treatment involves adjuvant hormonal treatment (AHT) of early-stage, estrogen receptor-positive breast cancer. After surgical resection, with or without adjuvant

chemotherapy, hormonal therapy for 5 years decreases the risk of death by about 30%. Adherence rates are alarmingly low, ranging from 50% to 73%. Age  $\geq 70$  years (vs  $< 50$  years) is consistently associated with an increased likelihood of treatment gaps.

An acute lymphoblastic leukemia (ALL), is a curable cancer. The nonadherence rates have been observed in small studies to range from 10% to over 50%. Retrospective analyses have found adherence rates with imatinib for CML or gastrointestinal stromal cell tumors to be about 80%.

**Risk factors for Nonadherence:** A number of barriers and risk factors have been associated with poor adherence. Adverse events of chemotherapy are the most obvious cause. Other barriers include forgetfulness, competing priorities, decisions to omit doses, lack of information, higher out-of-pocket costs, duration of treatment, a poor relationship with the healthcare provider, and emotional factors. Adherence is 1.5 times lower in patients from families in conflict. The elderly have exhibited lower adherence rates in some studies. Lack of direct communication about the importance of long-term orally administered cancer therapy can result in nonadherence. Nonadherence is associated with worse outcomes.

The literature available from our country regarding noncompliance of patients of RT is sparse, with available data focusing on specific tumor types. Illiteracy and poor socioeconomic status are associated with poor compliance (TMH Study). Around one third of noncompliant patients are illiterate (33%), and almost half are unemployed (53.3%). Barely one tenth (9.6%) of noncompliant patients have health insurance. Comprehensive support (Socioeconomic, accommodation, logistic, nutrition, transfusion, education, etc.) along with prospective tracking of noncompliant patients has reduced the rates of noncompliance from  $> 20\%$  to  $< 5\%$  in the paediatric oncology department of TMH. Rigorous patient counselling while planning for RT is imperative in ensuring confidence in the efficacy of a treatment modality.

Some points that can be incorporated in adherence protocols, especially those with high patient throughput in hospitals are mentioned below:

1. Holistic approach toward treatment, which includes all aspects of care; oncologic, social, financial, personal, and mental.
2. Optimum counselling by the clinicians and support staff, social workers, dieticians, support groups.
3. Red flagging of patients at high risk for noncompliance (poor social support, financial issues, advanced-stage patient planned for multimodality treatment, etc).
4. Adherence to the RT time points.
5. Systematic review of patients on treatment for assessment of toxicities and review of socioeconomic factors that may lead to noncompliance.
6. Making patients aware of financial models to assure financial assistance (Ayushman Bharat).
7. One fifth of patients desire RT at native place. You may facilitate this provision.
8. Rehabilitation for post-treatment to improve self-sustenance.

to be continued on 4<sup>th</sup> Page

## What is Breast Cancer (BC)?

Breast cancer starts when cells in the breast begin to grow out of control. These cells usually form a tumor that can often be seen on an x-ray or felt as a lump. The tumor is malignant (cancer) if the cells can grow into (invade) surrounding tissues or spread (metastasize) to distant areas of the body. Breast cancer occurs almost entirely in women, but men can get breast cancer, too.

How breast cancer spreads

Breast cancer can spread when the cancer cells get into the blood or lymph system and are carried to other parts of the body.

## How does breast cancer start?

Changes or mutations in DNA can cause normal breast cells to convert into cancer. Certain DNA changes are passed on from parents (inherited) and can greatly increase your risk for breast cancer. Other lifestyle-related risk factors, such as what you eat and how much you exercise, can increase your chance of developing breast cancer, but it's not yet known exactly how some of these risk factors cause normal cells to become cancer. Hormones seem to play a role in many cases of breast cancer, but just how this happens is not fully understood.

## How common is breast cancer?

Breast cancer is the most frequently encountered cancer in females worldwide and in India. In 2020, there were 2.3 million women diagnosed with breast cancer and 685 000 deaths globally. As of the end of 2020, there were 7.8 million women alive who were diagnosed with breast cancer in the past 5 years, making it the world's most prevalent cancer. Women from less developed countries have more number of cases when compared to more developed regions. Although the incidence of breast cancer has increased globally over the last several decades, the greatest increase has been in Asian countries. In Asia, breast cancer incidence peaks among women in their forties, whereas in the United States and Europe, it peaks among women in their sixties. Breast Cancer is the most common cancer, combined, in cities and rural areas of India as well. As per the Globocan 2020 data, in India, breast cancer accounted for 13.5% (178361) of all cancer cases and 10.6% (90408) of all deaths. In India, premenopausal patients constitute about 50% of all patients. When it comes to the 5-year overall survival, it is reported to be 95% for stage I patients, 92% for stage II, 70% for stage III and only 21% for stage IV patients. The survival rate of patients with breast cancer is poor in India as compared to Western countries due to earlier age at onset, late stage of disease at presentation, delayed initiation of definitive management and inadequate/fragmented treatment

## Breast cancer signs and symptoms

The most common symptom of breast cancer is a new lump or mass. A painless, hard mass that has irregular edges is more likely to be cancer, but breast cancers can be tender, soft, or rounded. They can even be painful. For this reason, it is important to have any new breast mass, lump, or breast change checked by a health care professional experienced in diagnosing breast diseases.

Other possible symptoms of breast cancer include:

- Swelling of all or part of a breast (even if no distinct lump is felt)
- Skin irritation or dimpling (sometimes looking like an orange peel)
- Breast or nipple pain
- Nipple retraction (turning inward)
- Redness, scaliness, or thickening of the nipple or breast skin
- Nipple discharge (other than breast milk)

Although any of these symptoms can be caused by things other than breast cancer, if you have them, they should be reported to a health care professional so that the cause can be found.

## Breast cancer risk factors you cannot change

- Being a woman
- Getting older
- Certain inherited genes (BRCA1 and BRCA2)
- Having a family/personal history of breast cancer
- Starting menstruation (periods) early
- Going through menopause after age 55

## Lifestyle-related breast cancer risk factors

- Drinking alcohol
- Being overweight or obese
- Not being physically active
- Not having children
- Not breastfeeding
- Hormonal birth control methods
- Hormone therapy after menopause
- Breast implants
- Early detection and screening

Mammography sensitivity has been reported to vary from 64% to 90% and specificity from 82% to 93%. However there is a lack of adequate mammography machines and trained manpower. Digital mammography uses computer-aided detection software but remains costly. It is due to these reasons that mass-scale routine mammography screening is not a favored option for a transitioning country like India.

Ultrasonography has an overall sensitivity of 53% to 67% and specificity of 89% to 99% and might be particularly helpful in younger women (aged 40 to 49 years). Though breast self-examination is not accepted as an early detection method for BC, this technique, if used diligently and skillfully, can serve as a useful adjunct to making the woman aware of her normal breast.

## Breast cancer treatment

Management of BC is multidisciplinary and has come a long way. In the past, the widely used treatment option was mastectomy followed by adjuvant chemotherapy for locally advanced BC, triple-negative breast cancer and HER2neu expressing tumours (human epidermal growth factor receptor 2). At present, it includes a loco-regional approach (targeting only the tumour with the help of surgery and radiation therapy) and a systemic therapy approach that targets the entire body.

## Chemotherapy

The systemic therapy includes endocrine therapy for hormone receptor-positive disease, chemotherapy, anti-HER2 therapy for HER2 positive disease, bone stabilizing agents, polymerase inhibitors for BRCA (breast cancer gene) mutation carriers and, recently, immunotherapy. However, the majority of patients still undergo primary surgical procedures. Gene expression profiling in hormone receptor-positive disease is also a promising option but has financial implications.

## Surgery

Breast-conserving surgery (lumpectomy or partial mastectomy) can often be used for early-stage breast cancers. But for some women, it can result in breasts of different sizes and/or shapes. For larger tumors, it might not even be possible, and a mastectomy might be needed instead. Some doctors are addressing this problem by combining cancer surgery and plastic surgery techniques, known as oncoplastic surgery. This typically involves reshaping the breast at the time of the initial surgery, such as doing a partial breast reconstruction after breast-conserving surgery or a full reconstruction after mastectomy. Oncoplastic surgery may mean operating on the other breast as well to make the breasts more alike.



### Radiation Therapy

Radiation therapy (also called radiotherapy) uses high-energy rays to kill cancer cells. It affects cells only in the part of the body that is treated with the radiation. Breast cancer radiation therapy may be used to destroy any remaining mutated cells that remain in the breast or armpit area after surgery.

### Targeted therapy drugs

Targeted therapies are a group of drugs that specifically target gene changes in cancer cells that help the cells grow or spread i.e. PARP inhibitors. These

drugs are most likely to be helpful against cancers caused by BRCA gene mutations, and have shown some promise in treating some types of breast cancers.

Early Detection is the key to fight against Breast Cancer

- Perform Breast self-examination periodically
- Know your body & communicate any changes to your doctor

**Dr. Ajay Sharma**

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## PEDIATRIC ONCOLOGY DIWALI CELEBRATION



Diwali celebration was organized in the Department of Pediatric Hematology & Oncology by Ms. Kajal Jaiswal, Play Room Teacher for children undergoing cancer treatment under the guidance of Dr. Gauri Kapoor, Director, Department of Pediatric Hematology & Oncology on Saturday, 22<sup>nd</sup> October 2022 at Indraprastha Hall, RGCIRC, Rohini, Delhi.

Activities like hanging decoration making, clay modeling, quiz, and fun games were organized. Several children gave cultural performances like

singing, dancing, poetry recitation, speech, etc. Overall it was an enjoyable afternoon attended by 53 participants wishing everyone a Happy Diwali. This was followed by refreshments and gifts distribution to all children by Shri D. S. Negi, Chief Executive Officer and Dr. Pinky Yadav, Chief of Operations cum Medical Superintendent.



## NURSICON 2022

Nurses have emerged as active contributors and innovators in the healthcare sector. For a long time, nursing meant bed-side care but in the changed scenario, nursing is not just about bed-side care but a lot more.

RGCIRC Nursing fraternity lead by Lt. Col. Madhumita Dhall, Director of Nursing organized 1<sup>st</sup> International and 9<sup>th</sup> National Nursing Conference on 11<sup>th</sup> and 12<sup>th</sup> November 2022 based on the theme “**Many Voices, One Mission: Unfolding New Horizons in Cancer Care**”.

NURSICON stands out in the country as one of the largest conferences dedicated to nursing care for oncology patients. Lt. Col. Madhumita Dhall welcomed the gathering and the conference was inaugurated by Ms Anjana Dhall, President Delhi Nursing Council in the presence of Mr. D.S. Negi, CEO, RGCIRC, Dr. Gauri Kapoor, Medical Director, RGCIRC, Niti Bagh and Dr. Pinky Yadav, COO & MS.

Guest of honour Mrs. Anjana Dhall emphasised the importance of “**Post Basic Diploma in Oncology Nursing**” which will help to deliver high quality safe nursing care for oncology settings.

Foreign faculty drawn US, Singapore & Malaysia, besides representatives from all the leading hospitals in India including Tata Memorial (Kolkata &

Mumbai), AIIMS and RML attended the conference. Nearly 300 nurses from all over India and abroad actively participated in all activities of the event.

Different aspects of nursing related scientific sessions were covered by the faculties of national and international level by direct interaction and virtual session. There were also activities like Panel discussion by experts on “**Current Trends, Challenges and Opportunities in Oncology Nursing**” and Nurse lead workstations on Line care and stoma care, which added more value to the event.

There were also competitions on abstract presentation and posters which made the conference more fruitful. The winners were awarded in the conference.

**NURSICON 2022** acted as a platform for knowledge dissimulation amongst the nursing community and motivate them to build a career in Oncology Nursing. There was a cultural program organised on 2<sup>nd</sup> day of the conference by RGCIRC nurses, showcasing their extracurricular talents.



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## EDITORIAL

Communication is crucial in establishing trust with patients, gathering information, addressing patients emotions, and assisting patients in decisions about care. The quality of communication in cancer care has been shown to affect patient satisfaction, decision making, patient distress and well-being, compliance, and even malpractice litigation. Even if patients have declined oncologic care, they may continue to see their primary care providers and family physician. Patients need to feel that they are not being permanently excluded from the health care system even if they make choices that are contrary to the recommendations of their medical team. Poor doctor-patient communication, the emotional impact of the cancer diagnosis, perceived severity of conventional treatment side effects, a high need for decision-making control, and strong beliefs in CAM are some of the reasons for not sticking to the conventional cancer treatment.

Although some patients decline all conventional treatment and use CAM as an alternative, others decline only some conventional treatments and complement the treatment they accept with CAM. Beliefs about conventional medicine (for example, "Western medicine treats the tumor, not the whole person"), CAM (for example, "holistic medicine treats the whole person"), and causes of cancer also play a very important role in the decision by the patients to decline treatment. Patients who perceive that their cancer specialist was threatening them with a "death sentence," pressuring them into accepting treatment, or making disparaging comments about CAM are more likely to drop of the conventional cancer system.

**"Problem patients,"** are a unique group of self-directed, confident, and active patients who have thought deeply about the meaning of cancer and about their cancer treatment options. It may not always be easy for clinicians to deal with these patients as they deviate from the norm and challenge current evidence, but in the end, relationships with these patients can be rewarding and insightful. These patients spend much time researching their treatment options, they are **window shoppers** and **googlers**. The decision to decline treatment is not necessarily an indicator of distrust of the medical system and the care received to date, but can be a reflection of intensely personal factors. Accepting the challenge and recognizing and honouring the uniqueness of patients who decline conventional treatments will create opportunities for rich patient doctor relationships that will transform **"problem" patients into partners in care.**



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