

# Public Health Education, Management, System and Practices in the Context of the Indian Subcontinent



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Edited by

Krishnendu Sarkar, Reeti Debnath  
and Pinaki Sensarma

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# SUMMARY OF THE CHAPTERS

## **Chapter 1: Oncology behind science: A holistic approach to patient care**

Ruby Ahluwalia

It delves into the author's journey, culminating in the creation of the 'Satori' program—a multidimensional initiative that addresses the psychosocial dimensions of cancer alongside medical treatment. Backed by research studies, it advocates for a comprehensive paradigm shift in oncology. A must read all those who wants to understand cancer treatment in a holistic manner.

**Key words.** Cancer, Sanjeevini Life, Sartori Program

## **Chapter 2: Health of the people: Interaction of the individual and the aggregate**

Rivu Basu and Lina Bandyopdhay

Around the concept of 'Capability Approach' it introduces a philosophical and economic framework that focuses on the idea of individual well-being and human development. Where there is a blend of 5 key concepts: capabilities, function, agency, endowment and conversion factors signifying an individual's ability to act and demonstrate freedom to achieve set goals.

**Key words.** Capability Approach, Well-being, Human Development

## **Chapter 3: Exploring epidemiology of malnutrition along with water sanitation and health in school going children some methodological issues and observation in West Bengal**

Reeti Debnath and Kamalesh Sarkar

It is based on a case study from West Bengal on nutrition issue involving WASH Nutrition as a cross-cutting determinant, which has both health and development challenges like malnutrition, sanitation and anaemia. The paper calls for a well-designed nutrition surveillance system for the

identification of nutritional deficiencies in children and adolescents at an early stage and necessary intervention.

**Key words.** Development challenge, WASH, children

#### **Chapter 4: Facility based management of severe acute malnutrition (SAM) through NRC- a comprehensive approach to reduce childhood mortality**

Manisha Choudhury, Udpita Hazarika, Sangita Saikia

It deals with SAM as a major concern, especially with more cases of severe wasting. Where Nutrition Rehabilitation Centres (NRCs) challenges were evident in form of long treatment times and slow weight gain. The role of community involvement in programs like Integrated Child Development Services, *POSHAN Abhiyan* etc. are discussed in giving children with SAM a better chance for recovery and a healthier future.

**Key words.** Severe Acute Malnutrition, Nutritional Rehabilitation Centre, Community involvement

#### **Chapter 5: Whispers of wellness: Indian public health and mental well being**

Sukanto Sarkar, Kamini Verma and Sukriti Mukherjee

It unveils the silent battles of millions facing mental health issues, and the escalating menace of substance abuse. A call for action with cutting edge technologies. To understand the dimension of mental health including issues related to neuro chemistry. Where various aspects of groundbreaking solutions are suggested.

**Key words.** Substance abuse, Neuro Chemistry, Health Care professionals

#### **Chapter 6: Demographic factors and its impact on mental health and wellbeing during COVID 19 pandemic**

Moulika Mandal and Chitrani Pandey

It deals with the various aspects of impact due to COVID-19 pandemic on global mental health. How the various determinants affected? How various vulnerable groups were affected? How public health planning and policy can cater to the population's diverse needs, aiming to bolster resilience and mental well-being for better crisis preparedness?

**Key words.** Determinants, Coping mechanism, Health planning



## **Chapter 7: Routine immunization data system in Indian context**

Prabal Mukherjee

It is about how the quality and reliability of routine immunization (RI) data would matter for the success of India's Universal Immunization Program (UIP) involving stakeholders, like Accredited Social Health Activists (ASHA), Auxiliary Nurse Midwives (ANMs), Data Entry Operators, public health Managers among others. And, how U-WIN, a digital platform for UIP, can help in this regard.

**Key words.** Universal immunization program, Healthcare Delivery System, Digital Platform

## **Chapter 8: Adult immunization**

Paramita Sengupta, Satabdi Mitra

Immunization Agenda 2030 is World Health Organization's flagship global strategy aims at curtailing down millions of deaths due to vaccine preventable diseases (VPD) globally. Linked to Sustainable Development Goal 3b (SDG 3b), it covers the promotion of vaccine development in countries like India. Where before vaccination there is a need for screening by HALO strategy.

**Key words.** Immunization Agenda 2030, Adult Vaccine, Preventable Deaths

## **Chapter 9: COVID 19 pandemic and vaccination drive: Experiences of development partners**

Pinaki Sensarma, Jayita Pal, Jitumoni Rajkonwar

It provides a chronological overview on pandemics that happened since human existence with knowledge on microbiology and epidemiology that has grown with time. As a case in context, COVID 19 has been studied as the 1<sup>st</sup> pandemic of 21<sup>st</sup> century and many innovative actions to arrest the pandemic have been highlighted.

**Key words.** Pandemic, Vaccination, Public places

**Chapter 10: One health key to Sustainable Welfare**

Anoop Velayudhan, Amruta B, Aparna KA

Outbreak of COVID 19- led to an integrated approach on wellbeing of human health, animal health and environmental health involving robust surveillance mechanisms. A case study on National Action Plan for Dog Mediated Rabies Elimination (NAPRE), India has been used in this regard.

**Key words.** Covid-19, Rabies, Robot Surveillance

**Chapter 11: Revolutionizing public health in India: The transformative impact of artificial intelligence**

Anjan Adhikary, Nipanjana Saha, Reeti Debnath

Evolution of AI in Health care and specifically in Public Health utilized expert system utilizing human specialists. Progressively over the years, through the 1980s to the present day the endless list of useful technology has been made possible. Where caution must be exercised in the use of Medical Diagnostic algorithms and digital health records.

**Key words.** Artificial intelligence, Public Health Expert System, Diagnostic algorithm

**Chapter 12: Mobile based health technology**

Prakash Kumar

Use of mobile devices such as smartphones and tablets, along with associated applications and services, has shown potential to improve healthcare access and delivery in remote or underserved areas. During COVI 19 pandemic m-Health was effectively implemented. Mobile Health technology empowers individuals to actively manage their health while improving healthcare access, delivery, and outcomes. Notwithstanding, issues related to privacy and security concerns, infrastructure requirements, and user acceptance.

**Key words.** Mobile Health, Remote Healthcare, Data Privacy and Security

### **Chapter 13: Environmental health challenges in Indian context: Case studies from Delhi**

Pallavi Tiwari and Mayank Thakur

Environmental health risks pose serious threats to people all over the world. Poor health has far-reaching and devastating consequences. Addressing health challenges requires a multi-faceted approach that includes identifying the risk through risk assessments, increasing access to healthcare and promoting healthy lifestyle choices. Social determinants of health have to be addressed, and investment needed in preventative measure. Present study tries to investigate quantitatively association-based studies published in India, specifically in the context of environmental health risks.

**Key words.** Environmental Risk, Health Challenges, Association based studies

### **Chapter 14: Built environment and health: human-machine interactions**

Krishnendu Sarkar, Anna Laura Petrucci

This chapter offers three interlinked insights, i) Introduction of built environment, public health, and human-machine interactions as disjoint and joint sets, ii) Approach for change with stakeholder participation right from assumptions to impact, and iii) Thinking for the future for ensuring more of well-care than sick care. Put together, it attempts to provoke novel inquiries and solution approaches for sustainable living.

**Key words.** Built Environment, Public Health, Human-Machine Interactions

## CONTRIBUTOR BIOGRAPHIES

### **Doctor Anjan Adhikari**

He is a medical doctor and senior Professor of Pharmacology. He is currently working in Calcutta Medical College as Medical Superintendent and Vice Principal (MSVP). An ethicist and member of many Institution ethics committees, he is an author of multiple articles in journals of international repute. His last publication is “Stimulus-Responsive Hydrogels for Ophthalmic Drug Delivery”.

### **Doctor Amrutha B**

Doctor Amrutha is Project Coordinator at National Ayush Mission Kottayam, Kerala. She has worked as Junior Consultant (Monitoring & Evaluation) at National Health Mission Idukki, Kerala and also as Research Assistant in IIHMR Bangalore - TATA Trust study. She did MPH from Global Institute of Public Health Thiruvananthapuram, Kerala.

### **Dr. Anna Laura Petrucci**

Prof. Arch. Petrucci, is an Associate Professor (adjunct) of Architecture and Urban Design at the King Saud University College of Architecture and Urban Planning. She has been extensively engaged in the teaching and practice of Architecture and built-environment systems. Besides, she has wide experience in procedures, accreditations and funded research programs in the various roles as Co-Founder, Art Director, Senior Consultant, and Professional Practice for Architecture – Design – Communication. Her engagements are also with La Sapienza University of Rome Department of Architecture and Design and Higher School of Architecture Paris Val de Seine among others.

### **Doctor Anoop Velayudhan**

Doctor Velayudhan, is a practicing physician and presently, a PhD scholar with the Indian Institute of Health Management and Research, Jaipur. His doctoral thesis is on clinical manifestation of COVID among children.

### **Doctor Aparna K A**

Doctor Aparna is doctor with interest in one health and zoonotic research. A student of St. Stephens Hospital where she did her DNB, she currently practices at Mission Hospital Bahadurgarh.

### **Ms. Chitrani Pandey**

Ms. Pandey has completed her BA with psychology majors from FLAME University and is pursuing her master's in Neuropsychology at the University of Bristol, UK. She has actively participated in research since she was an undergraduate student.

### **Doctor Jayita Pal**

Doctor Pal is an enthusiastic Public Health Professional with more than 10 years of working experience in various domains of Public Health including Maternal & Child Health and Immunization. She had worked with UNICEF and other international bodies like Royal College of General Practitioners (RCGP), and Health Education England-National Health Service (HEE-NHS, UK) under various academic projects. She has been monitoring the recent advances in patient care including Management of COVID-19.

### **Mr. Jitumoni Rajkonwar**

Mr Rajkonwar has worked in institutional and community eye health programs among various other public health programs. He was involved in the Covid Vaccination program in the state of Meghalaya and had dealt with vaccine hesitancy and resistant groups through community mobilization and demand generation activities and he is committed on leveraging those lessons learnt for the successful implementation of other public health programs.

### **Doctor Kamallesh Sarkar**

Doctor Sarkar is a senior Medical Doctor and alumnus of Medical College, Kolkata and AIIMS, New Delhi. He superannuated from the National Institute of Occupational Health Ahmedabad and had served as a Director, ICMR and Scientist G, at NICED, Kolkata. He has authored multiple articles published in reputed Medical Journals and widely acknowledged as an international expert in Silicosis and other occupational diseases. Besides, he is an inventor and biomedical researcher as evidenced by more than 80

original publications in various national and international journals of repute in various research areas of Epidemiology.

### **Doctor Kamini Verma**

Doctor Verma graduated from the prestigious AIIMS, New Delhi. She also completed MD Psychiatry and did DM in Addiction psychiatry from there. Her area of interest includes Tobacco use disorders, neuro psychiatry, Stigma and gender differences in substance use. Currently she is working as an Assistant professor in the department of psychiatry at AIIMS Kalyani.

### **Dr. Krishnendu Sarkar**

Dr Sarkar is the Chief of Academics, NSHM Knowledge Campus, Kolkata. He had served as Scientist, CSIR, India around informatics. Besides, he worked in process automation areas and is involved with social development. He was accorded the title of ‘Master Educator’ by Dr. Edward de Bono of Lateral Thinking fame among other recognitions. He has contributed policy briefs for G20 India 2023.

### **Doctor Lina Bandyopadhyay**

Doctor Bandyopadhyay, DPH, MD (SPM), WHO-Fellow, Advisor Public Health (SAG) is currently working as Professor (Eq), Department of PSM at the prestigious All India Institute of Hygiene and Public Health, Kolkata under the Ministry of Health and Family Welfare, Govt of India. She has been working as a physician serving in rural and urban areas and attending Emergency Medical Response duties in various parts of India. Her area of interest has been Maternal and Child Health and Epidemiology.

### **Dr. Manisha Choudhury**

Dr. Choudhury is currently Assistant Professor at the Dept. of Food Science and Nutrition, College of Community Science, Assam Agricultural University, Jorhat. A PhD in Medical Science and MSc in Food & Nutrition, her areas of research are -- Public Health Nutrition, Food Security, and Community Nutrition. She had served in both government and non-government sectors in India providing technical guidance and staff management for different programs and interventions.

**Dr. Mayank Mathur**

Dr. Mayank is a Professor of Physical Planning and Dean, Student Affairs at the School of Planning Architecture New Delhi with three decades of teaching experience, research and consultancy. His area of research has been in the field of housing, micro-environment and urban design. He has presented several papers at international and national conferences. He is a member of various professional committees relating to the field of Planning and has published papers in international and national journals.

**Dr. Moulika Mandal**

Dr. Mandal is an Assistant Professor of Psychology at FLAME University, India. She holds a PhD in Psychology from the Indian Institute of Technology, Bombay. Her research focuses on cognitive psychology, public health, behavioural sciences and applied neuropsychology.

**Ms. Nipanjana Saha**

Ms.Saha, holds a BSc degree in Nursing with a Master of Public Health. As a public health enthusiast and a faculty member in the Department of Public Health at NSHM Knowledge Campus, Kolkata, she is driven by a passion for advancing public health. Her research delves into maternal and child health, advancing AI technologies in healthcare, and the prevention of non-communicable diseases

**Ms. Pallavi Tiwari**

Ms.Tiwari is an architect with a Master of Planning in Urban Planning from the School of Planning and Architecture (SPA), Delhi, India. She is presently an Assistant Professor in the Department of Physical Planning, SPA, Delhi while also completing her PhD in public health and city land use planning at the same institute. She has worked on innovative projects pertaining to the informal sector and local area planning at the Design Innovation Center at the SPA. Her research interests include climate change, city planning, vulnerability studies, public health and education.

**Doctor Paramita Sengupta**

Doctor Sengupta is Professor and Head in the Department of Community Medicine and Family Medicine at the All-India Institute of Medical Sciences (AIIMS), Kalyani and the first Dean of AIIMS Kalyani. She has been a professor for the last 14 years. She is a founder member of Indian

Society for Adult Immunization and has started the Immunization Centre of AIIMS Kalyani.

### **Doctor Pinaki Sensarma**

Doctor Sensarma is an MBBS under Calcutta University. Did his post-graduation in maternal and child welfare from reputed All India Institute of Hygiene and Public Health, Calcutta University. Besides, MPH from SCTIMST, an Institute of National Importance, he has a Management Degree. Had worked with UNICEF for about 10 years and has vast expertise in RCH, Covid Vaccination monitoring and evaluation, Gender Studies and RCH. He has notable work on immunization matters.

### **Mr. Prabal Mukherjee**

Mr. Mukherjee is researcher in cervical cancer and HPV vaccines at the Jodhpur School of Public Health and presently serves as a Public Health Consultant at the World Bank Group, India. He has held pivotal roles with renowned organizations such as Jhpiego, Clinton Health Access Initiatives, UNICEF, and the National Health Mission, contributing significantly to maternal-child health, routine immunization, and COVID-19 response efforts.

### **Dr. Prakash Kumar**

Dr. Kumar is currently posted as Assistant Professor, in the Department of Computer Science at the Central University of South Bihar (CUSB). He has years of research and development work around informatics for social development.

### **Dr. Reeti Debnath**

Dr. Debnath, Associate Professor & Program Coordinator (Public Health), NSHM Institute of Health Sciences, NSHM Knowledge Campus, Kolkata, is also the Foreign Research Advisor at Kazakhstan Medical University, and guiding PhD students at national and international level. She has published numerous articles in national and international journals and contributed book chapters in edited books. Her research interests include Disease Epidemiology, Migration Studies & Quality in Healthcare.

### **Doctor Rivu Basu**

Doctor Basu, MD (CM), MBA, FAIMER has been a Public Health Activist, who sincerely believes that managerial sciences and Digital health hold the key to increasing efficiency in the health sector. Working on these missions,



he has worked with people, Government and other stakeholders towards betterment of health systems, published handsomely in National and International journals, and facilitated numerous students and trainees. Currently, he is working as a Faculty in the All-India Institute of Hygiene and Public Health, Kolkata.

### **Ms. Ruby Ahluwalia**

Ms. Ahluwalia is the Founder & Chairperson of Sanjeevani Life Beyond Cancer. She has been a senior bureaucrat, accomplished author, nutritionist, yoga practitioner, finance professional alongside a wealth of experience in Public Private Partnerships in her long 35-year stint with civil services. Among her many laurels include the prestigious Business World social impact and change makers award by BW business world, the social world Excellence award by the esteemed university of science and technology Meghalaya and the esteemed Global women leader award by the World Women Leadership Congress.

### **Ms. Sangita Saikia**

Ms. Saikia is currently working as a Clinical Dietician at Tezpur Institute of Medical Sciences PVT-LTD, Tezpur, Assam. She has wide experience in planning, management, implementation, capacity building, monitoring and evaluation of high impact nutrition interventions in NHM, govt. of Assam mostly looking at the Nutrition Rehabilitation Centers in the State. Where her expertise in clinical nutrition in assessing and dietary management of different critically ill patients has been appreciated.

### **Doctor Satabdi Mitra**

Doctor Mitra is presently working as a medical doctor in the department of Community Medicine at KPC Medical College, Kolkata. She has 22 book publications to her credit. She is presently handling research projects on STS ICMR project, tobacco control project, and listed in the editorial board of PLUS one, Journal of comprehensive health. She has been presenting in National and International conferences and is an expert on adult immunization.

### **Doctor Sukanto Sarkar**

Doctor Sarkar is a Medical Doctor who had served as Professor of Psychiatry at MGMCRI Pondicherry before taking charge as Head of Psychiatry Department at AIIMS Kalyani. He has published over 40 articles in national and international peer reviewed journals. Besides, has been the

principal investigator of extramural funded projects under ICMR, DHR and Multidisciplinary Research Unit, and has guided various MD, PhD and ICMR STS Projects. He is a member of Indian Psychiatric Society and Indian Association of Geriatric Mental Health. Areas of interest include epidemiological research, neuromodulation and neuropsychiatry.

### **Doctor Sukriti Mukherjee**

Doctor Mukherjee is a Medical Doctor in Mental Health. He has worked as a Senior Resident at NIMHANS on a community psychiatry research project and was involved in training the medical officers in PHCs. He has co-authored chapters in Point of Care Guide for Tele MANAS Counsellors & Facilitators Manual for Trainers of Tele MANAS Counsellors. Now, he is a Senior Resident at AIIMS, Kalyani, with special interest in Neuromodulation and training medical residents.

### **Mr. Udipta Hazarika**

Mr. Hazarika is currently pursuing his post-graduation studies in Innovation, Nutrition and Health (FINH) from the Asian Institute of Technology, Bangkok, Thailand. He has a keen interest in food product development, waste valorisation, sustainable packaging systems, and food security. Currently, he is working on the development of gluten-free food products.

# CHAPTER 1

## ONCOLOGY BEYOND SCIENCE: A HOLISTIC APPROACH TO CANCER CARE<sup>1</sup>

RUBY AHLUWALIA

### **Introduction**

In the depths of adversity, where hope and despair converged, my journey into the unknown realms of my existence began. This is my story.

### **My Journey with Cancer**

The story of a woman who started her life like most others, as a young girl with dreams in her heart and joy in her being. Dreams do come true, I was told, but they come true at their own time, their own cost, on their own terms - I knew. Just the way you know certain things, from the inside of you.

That is probably why most of my friends call me a “hard-core optimist”.

Anyway, the story I am sharing with you today and the dream which was fulfilled through it, had a strange trajectory. Its pathways were so rubbled that even I, the so-called ‘hardcore optimist’, almost reached the edge of giving up. But the power of the dream made me stand firm, even if it was on the edge only. Stand I did, experience I gained, learnings I gathered from it, and then destiny threw me off - towards life.

It was a normal weekend in the life of a full-time professional in the year 2009, when, after breakfast, I sat down to look at the school work of my daughter. The sudden visit of “Shanta” who used to massage my children when they were young, brought a smile to my face as my shoulders cried for her comforting hands.

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<sup>1</sup> Holistic Approach to Cancer Care

A few strokes by her skilled hands were starting to bring relief to my shoulders when she decided to take a pull from the front and felt a lump in my breast. With that lump started a journey which completely overturned my life!

The diagnosis of cancer in my breast brought numbness initially, leading to confusion as none of the textbook causes of breast cancer applied to me. A lumpectomy surgery, then mastectomy and finally chemotherapy for the triple-negative Stage 3 cancer made me explore my body and my mind like never before.

Since the physical and psychological pain after the first chemotherapy became unbearable, I turned to painting. I decided to paint a canvas reflecting my mental state after each chemo. Not only did this activity give me a tool to vent my pain, but it also helped me understand my emotions in a better way. Dealing with the side effects became much easier. I painted eight canvasses during my treatment and named the series Towards Satori.... (Satori is the Japanese word for Samadhi).

Looking back at this series, I realised that this whole journey of treatment for cancer became a spiritual journey for me.

When I completed all my sessions of chemotherapy and regained my senses, I visited the doctor to find out what next.

“What medicines do I need to take now?” I asked my doctor.

“No medicines, you are now cancer-free.”

“I am so grateful to you for that but what medicines do I need to take to keep myself free of cancer?” I still pestered him.

After all, I had heard about people having recurrences and that fear was uppermost on my mind now. “There are no medicines to keep the recurrence under check.

You just have to be careful with your timely check-ups,” the doctor said.

I was happy, very happy, that I was cured of a life-threatening disease and that I no longer needed to go through that gruesome treatment protocol. However, the same question persisted in my mind - what efforts should I make to keep myself cancer-free or at least reduce its chances of recurrence in times to come, and the unavailability of a clear answer was bothering me.

“Looks like becoming cancer-free is one thing and remaining cancer-free is another,’ I thought to myself.

## The Need for Holistic Cancer Care

In my quest to remain cancer-free, I started my journey of self-exploration. My biggest question to myself was

“What led me to have cancer in my body? Why and how I had compromised my immunity to this extent that a life-threatening disease took over my body?”

I explored the answer to this question in the book that I ended up writing called ‘Fragrance of a Wild Soul’.<sup>2</sup>

In this book chapter, I sought answers and a pattern of questioning the self-appeared:

- How did my urge to nurture others lead me to get undernourished to the extent that I created a hollow inside me?
- How do I understand that my suppressed self led me to abuse my body, soul, and mind?
- How a catastrophic experience like cancer made me see the splits in my soul and also gave me an opportunity to mend it for myself.

The blossoming of the pure self, then losing it and finally mending it-sewing it back, bit by bit, by self-analysis towards an even stronger self and a free spirit, is the ride of this story.

We all have our own cancers, even if they have not become tumours as yet.

How we can heal ourselves and come out of our self-created pits and discover our infinite potential is the purpose of telling this story?

This journey also made me realise the meaning of life, the purpose of my existence and that it is possible to overcome any life crisis, provided you deal with it with the right attitude.

Also, while going through my treatment I would see thousands of poor people going through a similar journey as mine and I would always ponder as to how they go through this challenging experience without any of the resources that I had.

Holding their hand and providing them with everything that they would need to win the battle with cancer became my dream. Helping them come out of this experience scar-free to operate at a much higher level in life than ever before and lead a fulfilled life became my purpose.

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<sup>2</sup> The story about triumph, hope, and will. This book explores the author’s journey and battle with cancer that helped her to decode her wellness.

## Sanjeevani Life Beyond Cancer

With this determination in me “Sanjeevani Life Beyond Cancer” was born in 2012, a Non-Profit Organisation, which provides comprehensive cancer care services throughout India. Initiating from one city, Mumbai, Sanjeevani currently operates from 26 centres spread across 14 states in India. Sanjeevani has worked with more than seven lakh fifty thousand cancer patients and has provided them support through its various patient-centric flagship programs. In the future, Sanjeevani plans to operate from at least one city in every state in India.<sup>3</sup>

Sanjeevani believes that a disease like cancer opens multiple fronts for a cancer patient. All of them need to be addressed for the prognosis of a patient to become positive. No patient should feel left alone in his journey of cancer and no survivor should live a sub-optimal life. Sanjeevani is the only organisation which works across India on the complete spectrum of cancer care space through long-term innovative solutions. The flagship programs currently in operation are **Can-Chetana** for Prevention, **Can-Sahyogi** for in-hospital patient assistance, **Can-Saarthi** for skill development of cancer survivors and their relatives, Satori for strengthening the immunity of the patients through nutrition, breath and mental constructs to be able to manage the side effects of the treatment and reduce their chances of recurrence, and **Can-Ahaar** for nutritional supplements for the poorest of the poor patients. The impact studies done on the various flagship programs show encouraging and positive outcomes. Sanjeevani continues with their research work with patients to help build robust models for comprehensive cancer care in the country.

## Exit From My Civil Services Career

Considering the magnitude of effort that would be required in the field of integrated cancer care and the rate at which cancer cases are rising, I resigned from my work and took an early exit from my career in the Civil Services of India, so that I could fully concentrate all my energies on working on cancer care through Sanjeevani Life Beyond Cancer.

In the same pursuit of enriching the cancer care space, I have authored two books ‘Fragrance of a Wild Soul’ and ‘Mann Baawra’.<sup>4</sup>

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<sup>3</sup> <https://www.sanjeevani-lifebeyondcancer.com>

<sup>4</sup> The blossoming of the pure self, then losing it and finally mending it – sewing it back, bit by bit, by self-analysis towards an even stronger self and a free spirit is the ride of this story.

While I was writing my books, I maintained regular interactions with a multitude of cancer patients. It was disheartening to witness the ongoing struggles faced by these individuals regarding their physical, emotional, and spiritual dimensions of the disease, despite receiving optimal medical care. This realisation ignited a strong conviction within me that a more comprehensive and holistic approach to cancer care was necessary. It became evident that we must address the entirety of a person's being, rather than solely focusing on the disease itself. And thus, my journey of exploring oncology beyond science began, with the aim of bridging the gaps and offering a more integrated approach to cancer care.

### **The Satori Program: A Multi-Pronged Approach**

While interacting with numerous cancer patients during my treatment, I would often think as to why people remain so distressed during the journey of cancer. I would go through huge bouts of depression and dejection. It would always bother me to see patients without any hope in their eyes despite the best medical treatment that they were getting.

The above compelled me to seek answers and look within. I then figured out that, though the doctors are trying their best, the scope of their involvement with the patient is limited to medical intervention only, while the patient is craving care and answers which go beyond medical care.

Cancer is a life-threatening disease. It is undoubtedly associated with a lot of anxiety, fear, and depression (Radhakrishnan, Selvaraj, and Chidambaram et al., 2023). The diagnosis of the disease and thereafter the subsequent treatment process can also be emotionally distressing for the patient (Linden, Vodermaier, and MacKenzie et al., 2012). It is often considered synonymous with death, pain and suffering (Powe and Finnie, 2003).

Cancer-related stigma is one potential barrier to care and support (Maechem, Orem and Nakigudde et al., 2016). Consequently, it is critical to understand cancer stigma in India better and the degree to which it is perceived, experienced, and internalised. Stigma is increasingly recognised as a fundamental determinant of health and health inequity, whether it is disease-specific or targeted towards marginalised groups. Disease- or health-specific stigma is defined as a social process or related personal experience characterised by exclusion, rejection or blame that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem. The judgment is medically unwarranted concerning the health problem itself. Stigma has been linked to lower uptake of screening for disease, linkage to

care once diagnosed, retention in care, adherence to medication, social support, mental health, and overall poorer health outcomes for multiple conditions, including cancer.

This seemingly terminal illness brings with itself loads of critical problems and miseries more so for the underprivileged society. Once this dreadful illness gets detected, families get caught up in vicious cycles of debts and deprivation taking a toll not only on the financial status of the household but severely affecting even the psycho-social level. However, its psychological impact on patients, though important, has been a highly neglected aspect for health professionals involved in the treatment process. Studies reflect that psychological and social aspects of the patient and family experience are somehow not yet fully integrated into overall cancer care (Johansen and Rosberger, 2012). Myths and misconceptions about this chronic illness are also not uncommon. A review of the literature indicates that psycho-social and emotional problems occur frequently, not only at the detection stage but also during the advanced and terminal stages of cancer, and they need to be appropriately identified and managed (Chaturvedi, 1994). Inadequately equipped healthcare facilities and an insufficient number of medical experts add up to the patient's miseries. After facing a lot of struggles, even if the patient lands up in a hospital to get medical treatment, their psychological need to cope and survive with this traumatic and distressing illness often becomes the lowest priority. These physical and mental concerns need to be alleviated by providing them with some psycho-social support, to improve the coping ability of the patient and his/her overall quality of life (Payne et al., 1999).

In terms of the psychological effects of cancer, anxiety and depression are at the forefront. Depression in cancer care is highly prevalent at the time of diagnosis, treatment, and even post-treatment. Prevalence rates in the range of 25 to 38% have been reported for major depressive disorder, while the same for depression spectrum symptoms has been reported to the extent of 58% (Massie, 2004). The intensity of signs and symptoms of depression may change with the course of the illness trajectory, but its impact on cancer treatment is highly detrimental. It is linked to slow recovery, low medical adherence, a sense of helplessness, and an elevated risk of suicide. With specific reference to cancer, the maladaptive cancer cognitions (fear of dying), and specific manifestations (anticipatory anxiety and nausea), specific phobia (fear of MRI or the blood-injection-injury subtype) may occur. Other unique manifestations of anxiety in cancer care could include fear of recurrence (FOR).



Keeping in view the above studies, and the ‘Patient-Centric Care’ as defined by the Institute of Medicine (IOM)<sup>5</sup>, a Program called ‘Satori’ was designed at Sanjeevani. Though it is easy to preach that patients should remain positive during their treatment, they can do so only if all their fronts are closed, and their concerns are addressed. Thus, what is required is psychosocial support in various forms.

- Family, friends, neighbours, support groups of patients, and to top it all, interactions with survivors go a long way.
- Counselling and psychological assistance.
- Nutritional guidance.
- Expressive therapies to release tension and frustration.

To address such a vast spectrum of effects, a management model must be comprehensive and grounded in the phenomenological and socio-cultural realities of the context.

## **Need for Psychosocial Support in Cancer: A Research Study**

With increasing incidences of cancer all over the world, the role of counsellors in providing psychosocial and emotional support to patients and encouraging them to adhere to the treatment protocols after treatment becomes crucial. Consequently, it becomes imperative to assess the role of psycho-social caregivers from the point of view of creating awareness amongst the beneficiaries, judging their satisfaction levels and understanding the set of challenges faced by the psycho-social caregivers themselves in dealing with the patients who are passing through difficult traumatic conditions.

Collaborative research was undertaken by Sanjeevani and the College of Social Work, Nirmala Niketan, Mumbai to understand the “Impact study of ‘CanSahyogi’ Program”, an initiative of Sanjeevani, through which they provide psychosocial support to patients in the hospitals. The study involved 342 respondents, including 250 cancer patients and support providers across various states. Both quantitative and qualitative research methods were used in data collection<sup>6</sup>. Information from patients from Mumbai and Ahmedabad cancer hospitals was obtained through In-Depth Interviews (IDIs) and Focus Group Discussions (FGDs).

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<sup>5</sup> IOM defines patient-centered care as “providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”.

<sup>6</sup> <https://www.sanjeevani-lifebeyondcancer.com/research-report>

## Brief Profile of Respondents

- For quantitative analysis, only cancer patients were interviewed from across India, by telephonic interactions.
- IDIs were conducted with 11 cancer patients, who were selected randomly from the two hospitals, one in Mumbai and the other in Ahmedabad.
- Ten doctors in the field of oncology and fifteen psycho-social caregivers were also selected for the in-depth interviews over the phone and in person.
- For qualitative analysis, six FGDs were conducted with a total of 56 cancer patients from Mumbai and Ahmedabad.

A summary of some major outcomes is listed below in Table 1-1 and Table 1-2.

**Table 1-1. Likely Problems as Perceived by the Cancer Patients**

| Problems  | Frequency<br>(N=222) | Percent<br>(%) |
|---|----------------------|----------------|
| <b>Psychological Problems</b>                           |                      |                |
| Anger/frustration/guilty feeling/pain/agony             | 25                   | 11.3           |
| Irritability/mood swings/suicidal thoughts or behaviour | 8                    | 3.6            |
| Excessive stress/depression distress                    | 25                   | 11.3           |
| Loss of self-esteem/confidence                          | 9                    | 4.1            |
| <b>Social Issues</b>                                    |                      |                |
| Discrimination/stigmatisation                           | 17                   | 7.7            |
| Education hampered                                      | 11                   | 5.0            |
| Difficulties in marriage                                | 2                    | 0.9            |
| Other problems at the societal level                    | 4                    | 1.8            |
| <b>Physical Problems</b>                                |                      |                |
| Change in appearance (hair loss/eyebrow loss etc.)      | 78                   | 35.1           |
| Pain due to chemo/radiotherapy and other treatment      | 50                   | 22.5           |
| Vomiting and uneasiness                                 | 45                   | 20.3           |
| Excessive fatigue and tiredness                         | 52                   | 23.4           |
| Loss of appetite  | 17                   | 7.7            |
| Loss of freedom of movement at home/work                | 27                   | 12.2           |
| Other physical problems                                 | 12                   | 5.4            |
| <b>Financial Problems</b>                               |                      |                |
| Fund crisis to undertake treatment                      | 27                   | 12.2           |
| Unemployment/loss of job                                | 42                   | 18.9           |
| Travelling & accommodation during treatment             | 21                   | 9.5            |

*Multiple Response: Percentage and totals are based on respondents.*

**Table 1-2. Support areas needed to cope with Cancer**

| <b>Support areas</b>  | <b>Frequency<br/>(N=246)</b> | <b>Percent<br/>(%)</b> |
|---|------------------------------|------------------------|
| Emotional support and counselling   | 190                          | 77.2                   |
| Financial assistance  | 164                          | 66.7                   |
| Spiritual coping mechanisms<br>(yoga, meditation)   | 143                          | 58.1                   |
| Counselling to family members and caregivers  | 134                          | 54.5                   |
| Help with therapeutic treatments (reflexology,<br>naturopathy etc.)   | 120                          | 48.8                   |
| Help in sorting out social issues like misconceptions<br>about cancer, social abuse, stigmatisation,<br>discrimination etc. | 93                           | 37.8                   |
| Help with nutrition and diet-related queries  | 92                           | 37.4                   |
| Employment opportunities  | 48                           | 19.5                   |
| Any other assistance  | 11                           | 4.5                    |

*Multiple Response: Percentage and totals are based on respondents*

In the next section, the author discusses the findings of the above-mentioned study.

#### **Through the patient's lens:**

- The study revealed that more than three-fourths of patients (77.2%) expressed the prime need for provision of **emotional and psychological support** during the entire course of illness to deal with traumatic situations.
- In spite of family support, patients **felt the need for someone who is familiar with the disease** and has the knowledge to guide them correctly. 54.5% of patients voiced a **strong need for counselling of family members** and caretakers for coping with the distress.
- Despite painful treatment, **strong psycho-social support** emerges as one of the crucial factors that **encourage patients to cope with the disease and continue their treatment**.

#### **Through the lens of medical experts:**

- The experts identified that the **lack of adequate personnel** to address the information needs of patients often leads to elevated anxiety and stress among cancer patients.
- Unanimously expressed a **strong need to integrate psychosocial care** in cancer care hospitals along with the regular medical line of treatment.

- Strongly recognised the **need to encourage para-professionals (like Sanjeevani)** to support the interaction between doctors and patients.
- Increasing influx of patients in hospitals leads to **inadequate time and interaction with doctors**. This emerges as one of the important reasons for engaging para-professionals to provide psychosocial support to the patients.

## **A Multipronged Approach to Deal with Cancer**

Apart from the above, a comprehensive management model has been devised by Sanjeevani and has been operational since 2016 called ‘Satori’- a wellness initiative of Sanjeevani. This flagship program consists of sessions on - psychotherapy, nutritional guidance, emotional freedom techniques, yoga and pranayama, meditation, reflexology, art-based therapy, and dance.

A study was conducted by Monk Prayogshala on this 36-session program through a mixed-methods approach on this program (Karandikar, Parekh, and Chakrawarty, 2018). The study evaluated the overall impact of the wellness program for beneficiaries through survey responses and interviews conducted with 70 previous and 34 present women respondents. Participants were interviewed and assessed on parameters related to life satisfaction, affective states, behavioural changes, nutrition, quality of life, and quality of care.

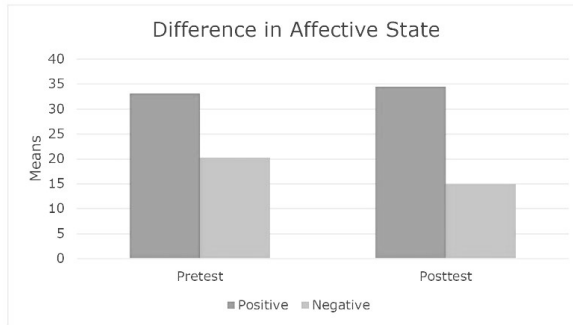
**Quantitative Measures** - The Overall Life Satisfaction Question, Cantril’s Ladder of Life Scale, Positive and Negative Affective Scale (PANAS), Quality of Life Questionnaire (QLQ-30) and EORTC IN-PATSAT32.

**Qualitative Measures** - Interview questions assessed dietary habits, satisfaction with the program, the overall impact of the program on the participants, as well as the impact of the wellness program.

Participants' positive and negative effects before starting and after completion of the program were measured via the Positive and Negative Affect Scale (PANAS). T-tests indicated that there was a significant decrease in participants’ negative affective conditions such as being upset, scared, irritable, nervous, or feeling guilty, after completion of the program.

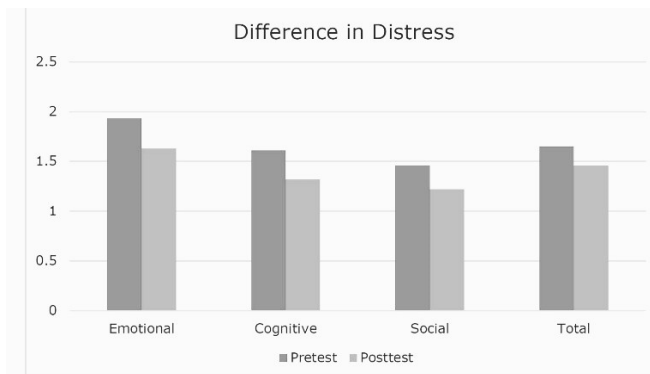
Although there was no significant difference in positive affect before and after the program, the mean positive affect scores were slightly higher

after the participants had completed the program, indicating a positive trend for that component of the program (Figure 1-1).



**Fig 1-1. Pre & Post Test Comparison of Affective States**

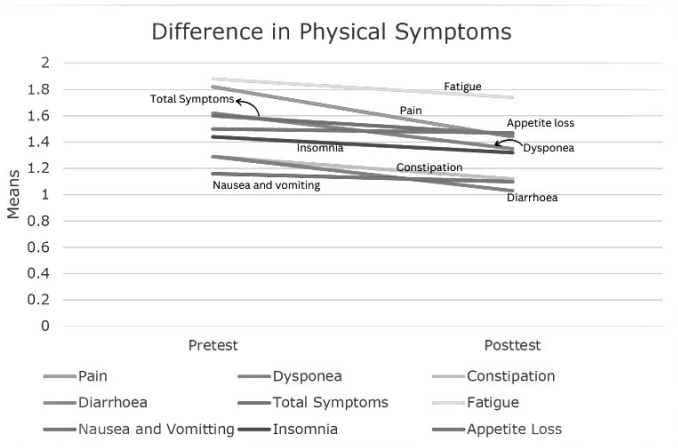
Overall high positive affect indicates that even though the ex-participants exhibited some negative emotions, they were also able to manage them effectively.



**Fig 1-2. Pre- and Post-Test Comparisons of Emotional, Cognitive, and Social Functioning**

Participants (N=34) emotional and cognitive functioning and their quality of life were also measured via the QLQ-30. Participants reported improvement in their cognitive, emotional, and social functioning, which

indicated an improved ability to perform routine tasks, and a more positive frame of mind (Figure 1-2). The Wellness Program, therefore, equipped the participants to accept their condition better, through a greater understanding of their thought processes and encouragement to freely express their feelings about their illness.



**Fig 1-3. Pre- and Post-Test Comparisons of Positive and Negative Effects for Concurrent Batches**

The physical toll that cancer takes is associated with the physiological symptoms of the illness itself, as well as the side effects of its treatment modalities. After completion of the program, the participants reported lower overall pain and other symptoms of physical discomfort. Specifically, there was a significant reduction in symptoms of dyspnea, constipation, and diarrhoea among the participants (Figure 1-3).

The results indicated that the wellness programs are very effective in helping the participants reduce their negative outcomes and cope with physical symptoms of cancer, increasing their overall social, cognitive, and emotional functioning in a better way. These findings pave the way for designing similar interventions within cancer, to cope with the ever-increasing demand of dealing with the physical and mental repercussions of cancer, and not just the illness itself.