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## ABOUT DAKSHAMA HEALTH

Dakshama Health aims to serve the Health and Education Sector, and work on capacity building, awareness generation, and health education for the service providers as well as patients and caregivers. Since 2012 Dakshama Health has successfully conducted several projects in the health space and the work spans around Chronic Non-Communicable and Rare Diseases. Dakshama is committed to empower the community with an accessible, efficient healthcare system that improves the safety and quality of care of patients with diseases, and works on capacity building and awareness in India, through prevention, advocacy, education, and collaboration amongst stakeholders within the community. Dakshama occupies a niche segment in the healthcare space, with an Advisory Board comprising some of the best clinical specialists in India. Dakshama strongly supports the belief that most diseases are preventable through early education and proper health management, the use of technology, and Information provision through IT and modern methods of healthcare.

### 1. Introduction:

Dakshama Health is a prominent patient organization in India that provides quality healthcare services to all. In collaboration with the Delhi State Cancer Institute (DSCI), Dakshama Health provided two Cancer Advocacy & Patient Education (CAPE) counsellors to counsel patients suffering from Head and Neck cancers. The purpose of this report is to provide a comprehensive analysis of the data collected by the CAPE counsellors from March 2023 to January 2024

### 2. Counselling for Cancer Patients:

The estimated number of incident cases of cancer in India for the year 2022 was found to be 14,61,427 (crude rate:100.4 per 100,000). In India, one in nine people is likely to develop cancer in his/her lifetime. With such a high number of cancer patients in India, the need for cancer patient counsellors is apparent. Head and neck cancers are a growing health concern in India, and patients often struggle to access necessary treatment and support due to a lack of awareness and information. Dakshama Health is working to address this issue through patient counselling and education. Indian cancer patients face barriers to seeking counselling, such as limited awareness, stigma, limited access, a shortage of trained counsellors, and high costs. Addressing these issues requires a comprehensive approach that involves raising awareness, reducing stigma, improving access to counselling services, increasing the number of trained counsellors, and lowering the cost of counselling services.

### 3. Analysis:

#### 3.1 Individual Counselling:

From March 2023 to January 2024, data was collected from a total of **435** patients (147 OPD and 288 IPD) and **126** caregivers. The direct beneficiaries of this data collection were the **435** patients themselves, while approximately 126 caregivers and attendants were indirect beneficiaries. The patients and their caregivers received education about their condition and treatment of the patient as well as the lifestyle changes, they needed to make from the patient counsellor. They received information about their diets, and oral hygiene and were given emotional support. 146 were first time visitors. Of the patients seen in March 2023 to January 2024, 95% were referred to the counsellor by the Junior residents working at DSCI and the rest were direct walkins.

All patients coming for counselling receive a booklet on Head and Neck Cancers and their management, which enables patients to have access to accurate and comprehensive information regarding their disease. By arming patients and their attendants with the information and tools they need to properly manage the disease, this strategy promotes patient empowerment. Since the majority of patients are more at ease speaking Hindi than any other language, having all the information written in Hindi helps patients understand it better.

### 3.2 Involvement in IPD:

The counsellors provide emotional and psychological support and information regarding the condition to patients as well as their caregivers in IPD. They discussed cases with doctors to have a better understanding of the patient's condition and ways to help them.

**288 in IPD were counselled (Different cancer patients i.e. head and neck, carcinoma, breast, lungs, cervix, ovary, colon, gallbladder, liver, RCC, Sarcoma and so on.)**

### 3.3 Gender Distribution:

**67** male patients and **10** females were head and neck cancer patients. Men are more prone to engage in various risky behaviours such as tobacco chewing, smoking, drinking etc. In the contrary, Counsellors reflected that women due to hesitation do not prefer to visit the healthcare facility and thus many symptoms go unnoticed due to a lack of awareness and social stigmas. The data reflects that there's a dire need for awareness campaigns which can help in educating as well as providing early intervention resources to people in need. The rest of the patients were from various other cancer therapy areas with breast being most prevalent. The youngest patient was 22 years old and the oldest 84 years. Most patients are over 50 years old.

### 3.4 First-Time Visitors:

Most patients are new visitors. 176 patients returned for repeat counselling sessions 112 patient completed at least six cycles of treatment.

### 3.5 Referral Source:

According to the statistics gathered, **84%** of head and neck cancer patients are referred by government facilities like GTB Hospital, Ram Mohan Lohia Hospital, etc., while the remaining patients are treated at private hospitals like Max and Fortis. According to the data collected, government hospitals are more likely to recommend patients to cancer treatment facilities like DSCI.

### 3.6 Occupational Differences:

**21%** are labourers, 7% were farmers, 2% were homemakers, **30.90%** are unemployed and **40%** have other professions. Patients come from the poorest economic strata and are unable to sustain expenses related to frequent visits, out of pocket for medicines and diagnostics and food and nutritional support to manage the treatment for cancer.

**92%** patients do not have any associated conditions whereas **8%** patients have various comorbidities such as TB, high blood pressure etc.

### 3.7 Demographic Differences:

The data provides information that **40%** of the patients are from Uttar Pradesh, **36%** are from Delhi and **24%** are from different states.

### 3.8 Patient Counselling Satisfaction:

The data collected reveals that all 91% patients gave an average rating of **4** out of **5** for the counselling satisfaction being provided by the CAPE Counsellors. This data suggests that DakshamA Health and DSCI are providing satisfactory services to patients and their families.

### 3.9 Events & Therapy Sessions:

Apart from one-on-one counselling sessions, DakshamA Health organised group counselling sessions for patient in IPD and the counsellors were allocated five wards each to conduct 2 -3 hour sessions for patients everyday for around three months. Two events were organised in partnership with the hospital- a wellness day on 9<sup>th</sup> November and a music and therapy session on 5<sup>th</sup> January 2024

**The Wellness Day** was an innovative initiative with an aim to enhance the well-being of cancer patients at DSCI. It is well-established that cancer treatment can be physically and emotionally taxing for patients. In line with our commitment to providing holistic care, a program that involved a team of experts in Yoga, Meditation, and Energy healing were brought together to provide holistic healing. The program's aim was to improve the overall quality of life for cancer patients by providing them with access to holistic services. This program consisted of a team of professionals, including a certified Yoga Trainer Mr. Debangshu Chaudhary and Ms. Ruchi Arora, Ms. Namrta Amar, Meditation Instructor- Mr. Aditya Amar; and an Energy Healer- Ms. Pooja Chandra. This team was coordinated by Ms. Chinki Gautam - CAPE Counsellor at DSCI.

The primary objectives of this program were as follows:

- **Pain Management:** Yoga and meditation techniques can help patients manage pain and discomfort associated with cancer and its treatments. The practices promote relaxation and alleviate stress, leading to enhanced pain control.
- **Emotional Support:** The emotional well-being of cancer patients is crucial. Meditation and energy healing can provide patients with tools to manage anxiety, depression and stress leading to improved mental health.
- **Increased Resilience:** Yoga, meditation, and energy healing can help patients build resilience, cope with the side effects of treatment and maintain a more positive outlook on their journey to recovery.
- **Enhanced Quality of Life:** By integrating these holistic services- we aim to offer a more comprehensive and patient-centric approach to cancer care, ultimately improving the overall quality of life for our patients.

#### **Wellness Day (Integrating Holistic Services for Cancer Patients).**

Conducted: - 9<sup>th</sup> November 2023

Organised By: - Ms. Chinki Gautam- CAPE COUNSELLOR

Notable Guests: -

- Dr. Vatsala Aggarwal (Director of DSCI)
- Dr. Pragya Shukla (HOD of Oncology)

Number of Attendees – 150 Persons.

#### **The second Event was- Music Therapy Session and Gifting Initiative at DSCI Hospital, Dilshad Garden**

Conducted: -5<sup>TH</sup> January 2024

Organised By: - Ms Amita Singh Chauhan

Notable Guests: - Dr. Pankaj [HOD - GASTRO]

Number of Attendees: - 150 Persons.

The event aimed to propose a unique method that involves organising a **Music Fest [ Music Therapy Session]** for cancer patients and their Caregivers, Doctors; and other Hospital Staff at DSCI Hospital. This event's purpose was to introduce **Therapeutic Music Sessions** as well as to distribute greetings Cards with flowers to uplift the spirits of the patients.

**Mr. Aditya Sharma** who conducted that Music Therapy Session is a professional Singer and wanted to tribute a Music session in memory of his mother who was a cancer patient in DSCI hospital just a few months back she took her last breath in the hospital. This event was concluded with a smooth and peaceful environment in the Hospital.

#### **4 Challenges Faced:**

There are some setbacks that the counsellors faced. The lack of doctors in the hospital, especially in head and neck unit made it difficult for the patients as well as the counsellors. Oncologists are on frequent leave and shortages in other human resources often leaves the patients with no choice but to seek treatment in other hospitals. Lab tests are often unavailable, and patients are referred to other hospitals for lab workouts. Surgeries are not offered due to fear of infections as there is severe shortage of staff and maintenance of infection prevention is a challenge. A dedicated private space for counselling is unavailable reducing the effectiveness of the counselling services. The administrative head of the hospital changed bringing in a lot of new developments. The head of Oncology is on medical leave having suffered a stroke herself.

#### **5 Recommendations:**

The CAPE Counsellors can organise workshops and programs in DSCI to spread awareness and educate the patient and caregivers about the ways to deal with cancer effectively. They can involve the doctors and hospital staff in these workshops and programs for a more comprehensive and collaborative effort. A dedicated space can be identified that is covered and provides a private and dignified area for counselling.

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Photo Gallery

