



Report on One Day Workshop on

### Cancer and Palliative Care: The Scenario in Arunachal Pradesh

#### Date

18thSeptember 2019

#### Organized by:

Counseling Resource Cell (CRC), Centre for Youth Development and Leadership Studies (CYDLS) Under Department of Social Work, Rajiv Gandhi University, Rono Hills, Doimukh, AP-791112 In collaboration with AMG Foundation, Gompa Road, Itanagar, Aruanchal Pradesh

#### Submitted by:

Ms.ChaphiakLowang Coordinator of CRC, CYDLS Department of Social Work, RGU, AP

#### **CONTENTS**

Acknowledgments

Organizing Committee

#### Preface

About the Organizing Institution

Background

Objectives

Resource persons

Target population

Budget

#### **Technical Sessions**

Session Wise Deliberations

Outcome of the Workshop

#### Annexures

- 1. Programme Schedule
- 2. Newspaper Clipping
- 3. List of Participants
- 4. Photo Gallery

The workshop on 'Cancer and Palliative care: The Scenario in Arunachal Pradesh', had been conducted with the support of many personals. It was teamwork that made it happen. May we therefore take the opportunity to thank each and every one of them.

Firstly, we are grateful to our Hon. Vice Chancellor, Prof. Saket Kushwaha for giving us the approval to conduct the workshop. Without his due permission the workshop could have never been implemented. Secondly, we are grateful to Prof. A. Mitra, for being the Chief Guest in the inaugural session. His motivation and guidance inspires us to do more. We also thank Prof. S.K. Singh, Dean Academics for being with us as our Guest of Honour. His support and love for the department in words and actions have always encouraged us. We are grateful to the chairperson cum Head of the Dept. of Social Work, Dr Kaushalendra Pratap Singh for his support and presence in times of need to conduct the workshop. We also extend our heartfelt gratitude to the resource persons of the workshop namely Dr. Sam Tsering, State Nodal officer, Cancer Control Programme, Govt. of Arunachal Pradesh; Dr. Tashi Chotton, incharge of Pain and Palliative Care, TCC TRIHMS; Dr. Hage Sonia, Radiation Oncologist cum pain and Palliative unit, TRIHMS. It has been their willingness and desire to be part of the workshop that benefitted the participants in fulfilling the workshop's objectives.

We extend our gratefulness to the collaborating organization, AMG Foundation for the willingness to work in collaboration with the university. The organization also extended the assistance in felicitation and refreshments for the workshop. We also extend our gratitude to the silent assistance provided by the co-coordinator, Dr Rachel Kabi, Guest Faculty of the Dept. of social Work and Mr. GomarBasar, Member Secretary of CYDLS for their emotional support. Mr. GomarBasar also assisted in reaching out to the media along with AMG member for the same and Dr Rachel Kabi in finalizing the report. We also extend our gratitude to Mr. John G. Gangmei for being with us physically in managing and arranging the physical structure for the workshop.

Lastly, but not the least our heartfelt gratitude to entire MA in Social Work students for their endless efforts and enthusiasm. Their motivation encouraged the organizers. They had raised a fund for the certificates and collaborated with various departments of the university to participate in the workshop. We also thank Ms. ChampaTanga, Assistant professor, Dept. of ECE, RGU for contributing with our students financially and being with us emotionally.

Once Again, We are thankful to all of you.

#### **Organizing Committee**

Programme Task	CYDLS, Dept. Of Social Work,	AMG Foundation,
	RGU	
Chairperson, CYDLS	Dr Kaushalendra Pratap Singh	
Programme Coordinator	Ms Chaphiak Lowang	Likha Sonsi
Co-coordinator	Dr Rachel Kabi	
Member	Mr John Gangmei	
	Mr Gomar Basar	

# **PREFACE**

#### The University

Rajiv Gandhi University (formerly Arunachal University) is the premier institution for higher education in the state of Arunachal Pradesh located at the picturesque tabloid of Rono Hills approximately 25 km away from the state capital Itanagar. Late Smt. Indira Gandhi, the then Prime Minister of India, laid the foundation stone of the University on 4<sup>th</sup> February 1984 at Rono Hills. The University was recognized as a Central University in the year 2007 established under the Act of Parliament. Being the only Central University of the State at present there are Twenty-Six (26) Departments and Two (02) Institutes functioning under Nine (09) Academic Faculties. The University has continuously maintained its premier status among top hundred (100) educational institutions in NIRF ranking across India.

#### About the Department of Social Work

The Department of Social Work (DSW) at Rajiv Gandhi University (RGU) was established in 2015 with the vision of providing quality Social Work Education in the state of Arunachal Pradesh. DSW at RGU is the first full-fledged Department of Social Work offering face-to-face Master of Arts in Social Work (MASW) Program in the state with a total of four regular faculty members and sixteen students in the first batch which has now been increased to thirty-five (35) including three seats for Economically Weaker Section (EWS). The Doctoral Program in Social Work (PhDSW) was introduced with July 2018 to focus on strengthening the research component in the region

#### **About the Organizing Institution**

The AMG Foundation and the CYDLS merged with a mutual goal to achieve in the workshop.

The AMG Foundation is a non-profit organization founded by Lt. AmungTaduLollen. She was diagnosed with stage III cancer in the year 2016 which succumbed her in the year 2018. During her short span of treatment, she met many individuals and families with cancer and her heart melt to pain imagining the hurdles they might be going through financially, psychologically and physically. Her empathy for the individuals and families living with cancer surrounded by unbearable problems encouraged her to initiate the AMG Accessories, paving its way to AMG Foundation. The AMG Accessories are handmade and all it's earning goes to the individual living with cancer. The AMG Foundation besides financial assistance aims to create awareness on cancer and provide skill training for accessories infusing traditional and modern styles. The foundation is now carried on by her like-minded friends emphasizing to reach her dreams to the people in need.

The 'Centre for Youth Development and Leadership studies' was established in 2016 by the Department of Social Work at Rajiv Gandhi University, Doimukh Arunachal Pradesh. The centre is divided into four cells namely, Training and Leadership Research Cell, Youth and Community Engagement Cell, NSS programmes and Engagement, and Counselling Resource Cell. Each cell has its specific defined objectives to achieve. For effective functioning of the centre, each cell has a coordinator. The coordinator in collaboration with other coordinators of the cell conducts programmes and activities and aims to achieve the mutual goal of the centre. Until now various programme had been conducted by the centre. The centre strives to bring in change in the society through youth development.

#### Background

Globally about 1 in 6 deaths is due to cancer. It is the second leading cause of death and in the year 2018, 9.6 million deaths were due to cancer. It is alarming to note that approximately 70% of deaths from cancer occur in low- and middle-income countries (WHO, 2018). The National Cancer Prevention and Research Institute report that by 2020, more than 17 lakh new patients in India can get cancerous. An aspect of concern is that the North-east India is now India's 'Cancer Capital'.

In the North East India of 'Cancer Capital', the Papumpare district of Arunachal Pradesh along with Aizawl district in Mizoram has reported the highest age-adjusted cancer incidence rates. The state also records the highest number of cases of stomach and liver cancers in the country mostly diagnosed in late stage, making it difficult to save lives through treatment (Arunachal Times, 2018 December 10). With the alarming number and people of the state conditioned to high risk factors like consumption of tobacco, dietary habits of consuming spices, hot beverages, unsanitary food and water like smoked meat calls for immediate attention. Acknowledging the magnitude and severity of the issue, the AMG (Amung) Foundation at Itanagarand Counselling Resource Cell (CRC) of Centre for Youth development and Leadership Studies (CYDLS), Rajiv Gandhi University emerged collectively and organized a one day workshop on 'Cancer and Palliative Care: The scenario in Arunachal Pradesh', on 18<sup>th</sup> September 2019 at the university for the students and teachers. The brief elaborations of these organizations are provided in the annexure.

The workshop aimed to work at different levels of prevention: primordial, primary, secondary and tertiary. There is something for each one. The workshop through awareness aimed to de-condition the risk factors like dietary habits and alcohol and tobacco consumption. It also reaches out to encourage early diagnosis for timely and effective treatment. And above all, reach out to the individuals and families living with cancer that the department of Pain and Palliative care at TRIHMS, Naharlagun offer care for quality of life after cancer. It also focused on knowing the provisions envisioned for the cancer treatment by the state.

These objectives were aimed to be achieved through the interaction and discussions with the professional speakers of the field. The contents of the sessions with the experts are elaborated in the report. Lastly the report evaluates the outcome of the workshop by mentioning some outcomes. But before elaboration of the sessions let us highlight the objectives of the workshop.

#### **Objectives**

The workshop aimed to obtain the following objectives:

- 1. To know the magnitude and severity of cancer prevalence in the state of Arunachal Pradesh.
- 2. To identify the types of cancer mostly prevalent among male and female in the state of Arunachal Pradesh.
- 3. To understand the Pain and Palliative care as a significant intervention in working with the individuals/families living with cancer.
- 4. To mediate the participants to the resources of treatment and rehabilitation in the state and neighboring state.
- 5. To understand the role of a social workers in working with individuals with cancer and their family members.

Dr Sam Tsering, State Nodal Officer, Cancer Control Programme, GoAP, TRIHMS

Dr Tashi Chotten, MD Anesthesia, incharge of Pain and Palliative Care, TCC, TRIHMS

Dr Hage Sonia, Radiation Oncologist, TCC, TRIHMS, Naharlagun-AP

Dr Rachel Kabi, Guest Assistant Professor, Department of Social Work, RGU-AP

#### **Target Population**

The participants could be the entire MA in Social Work students enrolled currently comprising a total of 56 (fifty-six). Interested teachers, students and staffs from other department of the university are also invited. The expected target population was approximately 113. But the total number of participants that took part in the workshop was 84. The lists of participants are provided in the annexure.

#### **Budget**

The proposed workshop was through voluntary sponsored programme. It is a collective effort of all the organizations involved to achieve the mutual goal of cancer awareness and prevention.

Sl.No.	Particulars	Sponsors
1	Felicitation	AMG Foundation
2	Refreshments	AMG Foundation
3	Certificates	CYDLS

## **TECHNICAL SESSIONS**

#### **Sessions Wise Deliberations**

The workshop was divided into inaugural, technical and concluding sessions. The report here mainly focuses on the technical sessions which emphasis on how the objectives were achieved. The sessions were divided among four speakers with distinctive themes and topics. Let us highlight the contents of the sessions as per the speakers.

#### 1. 'Magnitude and Severity of Cancer in Arunachal Pradesh' by Dr. Sam Tsering.

The session emphasized on magnitude of cancer in the state. It highlights Papumpare District as the most affected of all. In discussion it was acknowledged that maybeit's because of the provisions of detection like hospitals easily available to the people of the district as compared to the other districts. Therefore the cancer incidence might be also equally prevalent in other districts but due to unavailability of services like the capital of the state; it might fail in detecting the cancer incidence. Hence, the magnitude of cancer might be much higher than it's depicted. The following are the cancer incidence in Arunachal Pradesh year wise and district wise.

Tear	PBCR West, TRIHMS, Naharlagun	PBCR East, BPGH, Pasighat	Total
2011	421	171	592
2012	471	198	669
2013	512	247	716
2014	448	205	653
2015	439	326	765
2016	462	348	810
2017	474	340	814
	Grand Total		5029

Table 1: Registered New Cases Per Year in last years

Source: Population Based Cancer Registry (PBCR), Arunachal Pradesh

The table above indicates that cancer registration has improved every year from 2011 to 2017; highlighting its increase in incidence in the state. The table below shows that Papumpare district is most affected of all by cancer.

Sl. No.	Districts	No. of Incidence
1	Papumpare	802
2	East Siang	326
3	West Sinag	307
4	Lower Subansiri	215
5	Upper Subansiri	164
6	West Kameng	133
7	East kameng	132
8	Kurung Kumey	127
9	Upper Siang	83
10	Tawang	61

 Table 2: District Wise Cancer Incidence Case of Arunachal Pradesh

Source: Population Based Cancer Registry (PBCR), Arunachal Pradesh

The other alarming situation of cancer is also depicted in the state, as Dr. Sam Tsering presented the report of the PBCRs in Arunachal Pradesh. Some of these facts are as follows:

- Papumpare District records highest incidence of stomach cancer among both male and females in India.
- It is also the largest district recorded of liver cancer in males and cervical and ovarian cancer among women in India.
- It also records highest incidence for Thyroid cancer in India.

With these incidences, Dr. Sam Tsering also highlighted the risk factors like indulgence in tobacco products actively and passively. He stated that presence of nicotine in tobacco products make a person addictive and difficult to abstain. He also reported that the number of early deaths due to tobacco use in Arunachal Pradesh is 1,94,950. His presentation on the incidence was supported by pictorial representation of cancerous organs in a human body. The other risk factors highlighted were alcohol consumption, hepatitis B and C infection etc.

Dr. Sam Tsering also highlighted that cancer is treatable if detected early and chances of survival is 80 percent. And it is the other round if detected at late stage, where survival chances are only 20 percent. Hence, he warned the participants to look for warning signals such as: change in bowel or bladder habits, a sore that does not heal, unusual bleeding or discharge, thickening or lump in the breast or elsewhere, indigestion or difficulty in swallowing, obvious change in wart or mole, nagging cough or hoarseness. The identification of the symptomsshould be directly followed by consulting the doctor. He also suggested that it is essential to go forevidence based medicine than any superstitious or alternative medicine with lack of evidence of the treatment. Such practice by the patients and families delays in early treatment causing death of the person even though diagnosed in early stage. Lastly, Dr. Sam Tsering mentioned that the state hospital, TRIHMS do provide treatment services like Surgery, Radiotherapy and Chemotherapy.

#### 2. 'Introduction to Palliative Care' by Dr. Tashi Chotton

The speaker acknowledged the participants on concept of palliative care, its beneficiaries, history, dimensions of interventions, places of palliative care, why do the state need palliative care and lastly the challenges in palliative care. The concept was assisted to understand by the definition of palliative care as per World Health Organization (WHO) as "It is an approach that improves the quality of life of patients and their families, facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identifications and impeccable assessment and treatment of pain and other problem i.e, physical, psychosocial and spiritual".

She also said that palliative care treats, prevents, relieves symptoms of a serious or progressive illness but does not cure it. It works along with curative care and also alone when curative care is no longer helpful. Dr. Tashi also stated that palliative care is provided to chronically and incurably ill individuals as well as for family and friends at any point of time. For example, palliative care for the patient with incurable cancer after discharge from hospitals, the patient with AIDS, with a major CVA, with Alzheimer's, MS and MND. It is also offered to patients with advanced cancer, neurological disease like dementia and motor neuron disease, end stage renal failure, end stage respiratory, heart and liver failure.

She said that Arunachal Pradesh with alarming number of cancer incidence is in need of palliative care. She also statedthat the patients in India in need of palliative careare about 3 million patients with cancer at any point of time and 2.08 million living with HIV/AIDS. With

such demand in the country, the speaker identified that at present more than 1000 pallitive care centres are available across India; from which more than 800 are in Kerala. Hence excluding Kerala, only 1 percent of the population of the country is covered.

Dr. Tashi also stated that patients with terminally ill and living with incurable diseases usually come across various problems like social problems, emotional, psychological and spiritual problems besides physical problems. Hence the approach of palliative care is multidisciplinary approach. And such approach need only be in hospital settings, rather it could be anywhere and better at home or hospice and OPD. Hence palliative care emphasizes on maximizing quality of life, management of pain and symptoms, communication among the treating physicians, coordination of medical and supporting services, assistance with patient decision-making about care, support for care-givers, delivery by the team.

Lastly, Dr. TashiChotton acknowledged that the Palliative Care Centre is established at TRIHMS in November 2018. The centre has two doctors and a nurse. And the challenges it is facing are that least staff, lack of awareness among the medical staff as well as the common people and the lack of social workers.

#### 3. Role of a Social Worker in Palliative Care - Dr. Hage Sonia

Dr. Sonia shared on the role of social workers in providing palliative care services to the patient and the family. Social workers need to be registered social workers who can work predominantly or exclusively with people living with terminal illnesses and they are specialized in working with people living with terminal illnesses, specialized in working with adults and children who are at the end of their life, their families, those they are close to and their communities.

She further said that social workers provide care coordination services, emotional support and resource navigation guidance to patients and their families. They need to work with a team of other allied professionals and care givers, such as physicians, nurses, medical assistants, hospital chaplains etc. psycho-social assessment, care coordination, counseling and psychotherapy, psycho education, care even after death etc. The importance of developing a treatment plan that includes all the needs of the patients is also one of the important role they can play in addition to connecting with other support services in the area for the benefit of the patient. Further, being an advocate for the patient and family and leading community education workshops are some of the diverse ways of helping that can be provided in the palliative care centre.

#### 4. Scope and Challenges of a Social Worker in Palliative Care - Dr Rachel Kabi

The last session began with the emphasis on the demand for social workers in the state of Arunachal to be involved in providing palliative care services, especially the psycho-social and emotional support to the patient and their families. The taboo of addressing the issue of death or openly talking about it prohibits many terminally ill patients to discuss this with the family. The social worker is therefore the medium that connects the family to the patient and enables them to address these issues in an acceptable way. The session focused on the challenges of this task as it is an emotionally draining aspect that leads to burn out of the care provider. The area of working with terminally ill children was also an important issue of concern as children are just born and not even knowing the meaning of life they are facing death. The death sentence or warrant hanging before the face of a terminally ill person can be so traumatizing and daunting. Therefore, social workers play a major role over here in enabling patients handle this. The speaker also said that this profession has its own rewards as social workers get the time to listen to patients, their life stories, their joys, pain and come up with a life review which can be so meaningful in their lives. The unfinished business in people's lives can also be handled as part of this exercise. Many examples of services provided in palliative care centres and how the social workers have been with the patient and the family preparing them for the last moments of life on the earth, and also being with the family even after death and providing them the support to navigate through the difficult times was shared to throw some light on the crucial role that social workers can play at the palliative care centre. The importance of developing a positive relationship with patient and family and becoming advocates to mobilise resources essential was emphasized. Lastly, she shared about how the primary and secondary methods of social work can be practiced and how even research is so very important to be undertaken so that facts are shared and disseminated in the field.

#### **Outcome of the Workshop**

From the sessions held and the objectives framed, if evaluated it could be observed that the objectives of the workshop are fulfilled. Hence, some of these outcomes from the workshop are as follows:

- 1. The participants had been sensitized that
  - a. The prevalence of cancer incidence in the state is high with Papumpare district the highest affected of all districts in India.
  - b. Secondly, the most prevalent cancers are stomach, liver, thyroid for both male and female in the state with ovarian and cervical cancer among women.
- The participants also had been acknowledged on the concepts of 'Pain and Palliative Care'. And that these treatments are available at TRIHMS in the Department of Pain and Palliative Care, which is newly established in November 2018.
- 3. The social work student participants were also highlighted on the scope, the challenges in working with individuals and family members living with chronic and terminal illness.
- 4. The speakers also highlighted the importance of multidisciplinary approach in working with cancer patients and his/her families.
- 5. The audiences were also acknowledged on the financial assistance of Rs. 10 lakhs available for the treatment of the individual with cancer. The criteria, requirements and the procedures are easy and can be availed from TRIHMS, Naharlagun.

## Annexure

#### I. PROGRAMME SCHEDULE

A One Day Workshop on 'Cancer and Palliative Care: The Scenario in Arunachal Pradesh'
Date: 18th September 2019, Venue: Mini Auditorium, RGU, Rono Hills, Doimukh-AP

Time	Programme	Resource Person/Incharge
8.45 am to 9.45 am	Registration	Mr.Tadar Talar and Ms. Alisha
		Arangham
10.00 am to 11.00 am	Inauguration	
	Lighting of the lamp	Dignitaries on the dais
	Introduction to the Workshop	Ms.LikhaSonsi
	Welcome Address	Dr. KaushalendraPratap Singh Head, Dept. of Social Work and Chairperson, CYDLS
	Address by Guest of Honour	Prof. S.K. Singh, Dean Academics
	Address by the Chief Guest	Prof. A.Mitra i/c Vice Chancellor Rajiv Gandhi University
	Vote of thanks of the Inaugural Session	Mr. John G. Gangmei
11.00 am to 11.15 am	Tea Break	
11.15 am to 11.45 am	Magnitude and Severity of Cancer in Arunachal Pradesh	Dr. Sam Tsering
11.45 am to 11.55 am	Questions and Discussions	
12.00 pm to 12.30 pm	Pain and Palliative care	Dr.Tasi Chodden
12.30 pm to 12.40 pm	Questions and Answers	DI. Lasi Chouden
12.45 pm to 01.15 pm	Role of a Social Worker in Palliative care	Dr.Hage Sonia
01.15 pm to 01.25 pm	Questions and Discussions	
1.30 pm to 2.00 pm	Scope and Challenges of a Social Worker in Palliative Care	Dr. Rachel Kabi
2.00 pm to 2.10 pm	Questions and Discussions	
2.10 pm to 2.15 pm	Vote of Thanks	Ms.ChaphiakLowang
2.15 onwards	Lunch/Certificate Distribution	

#### II. **NEWSPAPER CLIPPING**

https://arunachaltimes.in/index.php/2019/09/21/rgu-hosts-workshop-on-cancer-and-palliativecare

#### 49 dl 62% = 9:57 pm P RGU hosts workshop on cancer and palliative care

September 21, 2019



RONO HILLS, Sep 20: A workshop themed 'Cancer and palliative care: The scenario in Arunachal Pradesh' was jointly organized by Rajiv Gandhi University's (RGU) Centre for Youth Development and Leadership Studies and Itanagar-based AMG Foundation here on Friday.

The workshop, which was attended by 84 participants, stressed on "the need for psychosocial interventions as part of palliative care approach where social workers can provide quality of life and care during death to a terminally ill person," according to a release from the university.

Addressing the participants, an oncologist from the TRIHMS said, "Papum Pare district being the first in the country in incidences of stomach, cervical, ovarian and thyroid cancer is a (matter of) great concern."

AMG Foundation president Likha Sonsi highlighted the organisation's goals and activities.

The speakers at the workshop were cancer control programme state nodal officer Dr Sam Tsering, TRIHMS pain and palliative care in-charge Dr Tashi Chotton, TRIHMS Radio Oncologist Dr Hage Sonia, and RGU's social work department's guest faculty member Dr Rachel Kabi.

The workshop was attended by, among others, RGU Vice Chancellor (incharge) Prof A Mitra, Academic Dean Prof SK Singh, and Social Work HoD Dr Kaushalendra Pratap Singh.



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#### **III. LIST OF PARTICIPANTS**

#### REGISTRATION FORM A One Day Workshop on 'Cancer and Palliative Cancer: A Scenario in Arunachal Pradesh' Dated: 18<sup>th</sup> September 2019

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#### REGISTRATION FORM

#### A One Day Workshop on 'Cancer and Palliative Cancer: A Scenario in Arunachal Pradesh' Dated: 18th September 2019

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#### REGISTRATION FORM A One Day Workshop on 'Cancer and Palliative Cancer: A Scenario in Arunachal Pradesh' Dated: 18<sup>th</sup> September 2019

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#### IV. PHOTO GALLERY





