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Role of NGOs in the facilitation of cancer care access in Northeast India

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Abstract---Background: The news of cancer often entails psychological and financial constraints on the patient and their caregivers. In India, the health systems are under tremendous load, with cancer services facing geographical, behavioural, economic and infrastructure challenges. In the backdrop of this, Non-Governmental Organisations (NGOs) master to walk along with those facing a long and tumultuous journey of cancer treatment by facilitating cancer care services. This paper examines the narratives of NGOs on their role and modus operandi in bringing ease of cancer care access. Method: By purposive sampling, four NGOs and six oncologists were interviewed in two cancer institutes in Northeast India, namely (i) Tomo Riba Institute of Health & Medical Sciences (TRIHMS) in Arunachal Pradesh and (ii) Dr B. Borooah Cancer Institute (BBCI) in Assam. A semi-structured interview schedule was used for the study, with data coded and transcribed verbatim on emerging themes. Requisite ethical clearances were received from the respective institutes. Results: Collaboration with the NGOs and cancer institutes has opened an array of ease of access for cancer patients. Such partnerships become indispensable, especially in the study area where socio-cultural diversity, infrastructural or psycho-social barriers could influence the timely treatment of cancer patients. Additionally, NGOs become a complement in providing services the health systems lack, for example, providing financial and logistical support to cancer patients to those who cannot afford it. Conclusion: Facilitation of cancer services in collaboration with NGOs is an excellent means to guide cancer patients to take timely and informed decisions. The existing cancer institutes could address lacunae by exploring teamwork with the NGOs.

Keywords---cancer care access, NGOs role in cancer care, Northeast India.

Introduction

Central to the functioning of the Indian health system is its work in tandem with the Non-Governmental Organisations (NGOs). Health programs in the country have witnessed the participation between the government and NGOs as ever-increasing. NGOs play essential roles in the unfolding plural process of forming global social contracts with international institutions, enhancing the accountability and legitimacy of these institutions [1]. NGOs generally have the advantage of considerable planning and budgetary flexibility. They can therefore focus their support to act as agents to help connect Ministry of Health policies to action and, in so doing, increase the impact of their support to health services in developing countries [2]. Likewise, existing literature documents the ease of access to healthcare services when NGOs are a facilitator for finance, services or general support [3-5], especially when there is a partnership between the government and the NGOs. A vast difference in the scale of successful implementation of programs is seen in Switzerland, Ethiopia, Timor-Leste, South Africa, Bangladesh, Philippines and India [6-9] on successful implementation of programs in TB, vaccination drives, displaced migrant health and cervical cancer screening due to the partnership of the government and NGO sectors.

In India [10], a review study highlights when the tsunami hit Tamil Nadu, to prevent contaminations from causing widespread public health hazards collaborating with the NGOs helped the local bodies. An example of disposing of dead bodies in such collaboration helped reduce the spread of diseases in the state. Globally, it has been witnessed that the gaps filled by the interventions from these organisations are phenomenal but confusing in a few instances. Not discounting the impact of NGOs on the health outcomes experienced by those in dire need, there are situations when their credibility is questioned. A few criticisms on the functioning of these organisations alongside the government identified after the literature search [9,11-12] are overlapping unclear antecedent presence of multiple organisations, power permeating donor institutions and lack of coordination. Illustration of the unclear antecedent is articulated in a finding in West Bengal [10], where larvivores fish were distributed to the NGOs for release in water bodies, but the health department of high endemic areas was not informed on the site of release. As a result, the fish died in the dry season, and the process went waste. Thereby replication of the model was not done. However, the way forward in the healthcare delivery system is likely to strengthen itself in partnership with the NGO sector to fill gaps and support one another for better public health outcomes.

Method

By purposive sampling, ten semi-structured interviews were conducted comprising of four NGOs and six oncologists (radiation – 2, surgical – 1, medical – 2 and gynaecology - 1). Each interview lasted from 30 minutes to an hour. The interviews were conducted at TRIHMS, BBCI and in the offices of the NGOs. Transcription verbatim was done following the codes of syntheses of the findings by MS Word version 16.16.27. A summary of the methodology is given in Fig 1. Ethical clearances were obtained from the study institutes.

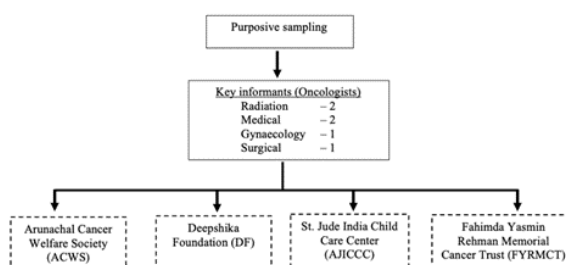


Figure 1. Summary of the study methodology

Result

Participants' characteristics

The key informants comprised six oncologists, while two out of four NGOs interviewed have a national presence, whereas the functioning of the rest is limited to the state, tab 1. In Arunachal Pradesh, there is only one NGO (ACWS) that works in cancer service facilitation, while in Assam, there are numerous, but only three were interviewed for this study.

Table 1
Participants profile

SN	Name of NGO	Year of inception	State presence	Institute collaboration
1	ACWS	2018	Arunachal Pradesh	TRIHMS, District Administration, IMA**-state branch & PRIs
2	FYRMCT	2018	Assam	BBCI
3	DF*	2004	Assam and Maharashtra	BBCI & TMH***
4	SJICCC*	2018	Assam, Delhi, Karnataka, Maharashtra, Rajasthan, Tamil Nadu, Telangana, Uttar Pradesh and West Bengal	BBCI & TMH

*Guwahati centre, ** IMA – Indian Medical Association, *** TMH - Tata Memorial Cancer Hospital

The funding source of these NGOs is mainly donors driven, followed by funding from a government departments, public sector undertakings, corporate companies, banks, individuals, family, friends, relatives and personal donations.

Themes

The key themes emerging in the study are (i) partnership engagement, (ii) facilitation during COVID-19 lockdowns and (iii) challenges in operation. Fig 2 illustrates the word cloud from the transcription.



Figure 2. Word cloud – Transcription

Partnership engagement

The NGOs interviewed in the study facilitate cancer services to the patients in coordination with the cancer institutes. Each organisation has a unique model of operation with a varying mission statement. Logistical support is the mainstay of its functioning process. However, when a patient who cannot afford it requires monetary support, these organisations mobilise personal and donation drives. Since cancer patients come from all over the districts and the neighbouring states in the study area, there is a dire need for accommodation. Two NGOs, SJICCC and DF, provide food and lodging facilities to cancer patients free of cost to cater to this need. At the same time, ACWS guide the patients in identifying accommodation at a nominal fee near the cancer institute. While BBCI has a dedicated medical social work department, TRIHMS does not have one. However, both institutes have a rigorous outreach program of cancer screening, cancer awareness and blood donation drives. The doctors in the study area identify patients who require assistance from these NGOs and refer them accordingly. The social worker in BBCI ensures patients avail timely cancer treatment moderates between the doctors, patients and NGOs. Fig 3 illustrates the path taken by a cancer patient to avail of services from the NGOs.

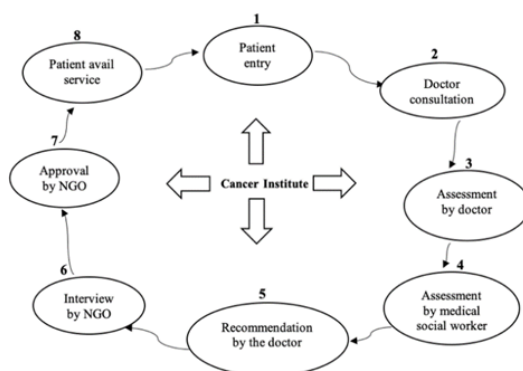


Figure 3. Interaction of cancer patients for availing services through the NGOs

All the key informants acknowledged that collaborating with NGOs has helped save the lives of cancer patients. One key informant describes this collaboration as a necessity.

"ACWS facilitates the needs of the cancer patients in the State in terms of monetary and logistic support. It is trying to arrange an ambulance by organizing a lottery draw for fund raise".

Since 2015, ACWS has provided logistical support to around 30 cancer patients taking treatment outside Arunachal. To date, ACWS has provided financial support up to Rs. 15,00,000 to 15 cancer patients. This NGO collaborates with TRIHMS to identify cancer patients requiring assistance with a dedicated Facebook page for people to reach out to them. The chairman of ACWS echoed his organization's support as:

"We usually aid in our capacity to the patients such as logistical support, accompanying patients when they travel outside Arunachal for treatment or in certain cases raise funds for those facing financial crunch. Our assistance comprises of helping find a reasonable accommodation and speaking to the doctors in the hospital where they are taking treatment outside Arunachal".

Many NGOs collaborate with BBCI, which works in tandem to identify and coordinate patient services. However, the services catered by each of these NGOs are diverse. The patients are referred by the social work department of BBCI in discussion with the doctors to these NGOs. A key informant recognizing the importance of the role of NGOs in cancer care said:

"Patient compliance is a huge factor. Staying in Guwahati for a long period is expensive. So, arranging accommodation at a subsidized rate may solve the problem. In fact, in the case of paediatric patients, we have a home nearby operated by St. Jude India Child Care Centre. A total of 24 families can stay there as long as they want. Lodging and food are free for these patients in SJICCC. Deepshika Foundation also provides on similar lines. In some centres, the patient stays for years in St. Jude's".

The Member Secretary of Deepshika Foundation shares how services are provided to cancer patients.

"We try to provide logistical support to the cancer patients. So far, in this centre (Sishu Ashray Sthal), we have accommodated 1879 paediatric cancer patients. Food and transportation are accessible for patients in the centre. We don't charge a penny here. Even in our Hospice centre, we give them free ambulance services within a range of 40 Km, travel from the hospital to the Hospice centre. This facility is for patients from all over the country".

Likewise, an official from SJICCC shares the mechanism of providing services to cancer patients.

"We cater to only paediatric cancer patients. We try our best that no family should have to put up on the street during their cancer treatment. So, we prefer those of lower socioeconomic conditions, but that is not always the case. There are instances when people who face fund shortage or are struggling financially during the cancer treatment of their children or their parents have lost their jobs, then such patients have also been accommodated".

The founder of FYRMCT shares the partnership with BBCI to provide cancer patient services.

"We usually try to provide financial support or transportation of the deceased cancer patients from the hospital to their homes under the palliative scheme. This scheme started in 2019. Social workers other than the ones in BBCI also reach out to us for support. We also get phone calls from public leaders, community workers, and people who reach out through Facebook. For example, there was a patient 18 years old boy with lymphoma in GMCH, the doctors of the hospital contacted us to help this patient".

Table 2
Summary of area of operation of the NGOs

SN	NGO name	Area of work
1	ACWS	• Logistic assistance. • Patient transportation. • Fund raising. • Blood donation drive. • District cancer awareness campaign. • Deceased cancer patient transportation. • Donation to TRIHMS – RO water filter in cancer OPD, wheel chairs and 50 percent coupons for tests in private laboratories.
2	FYRMCT	• Pain & palliative scheme. • Deceased cancer patient transportation. Food and clothing distribution.
SN	NGO name	Area of work
3	DF	• Cancer patients all age groups. • Help-desk at BBCI & TMH. • Free accommodation, food and transportation. • Skill development. • Out-reach campaign. • Financial assistance.
4	SJICCC	• Cancer patients (0-15 years). • Free accommodation, food and transportation. • Skill development of the care providers of cancer patient. • Counselling.

Facilitation during COVID-19 lockdowns

All the NGOs in the study usually had patients coming through word of mouth. During the COVID nationwide lockdown, these organizations arranged accommodation, transportation for patient treatment, deceased transfer and outreach campaigns with the district administration. Another key informant added to the vital role ACWS played in saving lives of cancer patients in the State.

“During the lockdown, a six-year-old child with leukaemia needed financial support. ACWS organized a donation drive and helped the child financially for their treatment”.

Challenges in operation

A homogenous recognition amongst all key informants is the need cancer patients face in terms of lodging and financing constraints. The significant challenges faced by all the NGOs were lost to follow-up of patients, no awareness of the cancer institutes of State, preferring alternative therapies to conservative cancer therapy, infrastructure shortage in one of the study areas and funding support for the NGO.

Table 3
Summary of challenges faced in operation by the NGOs

SN	NGO name	Challenges
1	ACWS	• Lack of awareness of state cancer facilities. • Convincing patients to get correct and timely cancer treatment. • Fund crunch. • Patient preference of alternative medicines. • Treatment adherence – lost to follow-ups.
2	FYRMCT	• Lack of awareness of state cancer facilities. • Fund crunch.
3	DF	• Convincing patients to get correct and timely cancer treatment. • Patient preference of alternative medicines. • Treatment adherence – lost to follow-ups.
4	SJICCC	• Lack of awareness of state cancer facilities. • Finding blood donors • Treatment adherence – lost to follow-ups.

Discussion

Paramount to the efficient delivery of cancer services is the patient uptake of timely, correct treatment adherence. These study findings illustrate that the NGO's role as the binder between the patient and provider can make a difference in the overall treatment outcome. The key informants' experience with the NGOs entails a way forward collaboration perspective. NGOs generally have the advantage of considerable planning and budgetary flexibility [2]. NGOs have the potential to act as agents to help connect MOH policies to action and, in so doing, increase the impact of their support to health services in developing countries [2]. Similar to other studies in NGO collaboration for health systems delivery [11,13-14], it is possible to have efficiency when smooth transitioning is allowed for functioning. Likewise, the NGO's role was not limited to facilitation in this study. Instead, services include arranging accommodation, food, transportation or, at times, financial aid for laboratory investigations or surgery and livelihood training are few services catered by them. Further, few NGOs reported a fund crunch to run the organization while convincing patients for timely treatment and loss of follow-up as challenges. The lack of awareness of the availability of state cancer institutes acts as a determining factor for travel outside the domicile state, resulting in loss of time and money. Hence, further exploration on strengthening the collaboration of the cancer institutes with the NGOs could enhance the overall patient experience on cancer services.

Conclusion

A collaboration of the NGOs with the cancer institutes is a bridge to fill gaps in which the health systems lag. Mobilizing or facilitating the patients for timely and correct cancer treatment will influence the control of morbidity or mortality due to cancer. Saving lives through the wing of community outreach of the NGOs could

further strengthen the health systems enhancing the overall patient experience to avail of cancer services in the region.

Limitation

These study findings are limited only to the study area. Hence, it cannot be generalized to the country. Future research could explore the impact of NGOs on patient experiences to avail of cancer care services.

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