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Governance and Cancer Care in India: A Drive for Quality Improvement

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ABSTRACT

With the improvement in the life expectancy and the rapid growth of population India is now facing a cancer epidemic. It is now grappling with disparities in the availability of quality care infrastructure and increasing patients. Cancer has a profound social and economic impact on its population. Delivery of affordable and equitable cancer care is one of India's greatest public health challenges. In this context the author attempts to study modalities of service improvement and good governance and its application to the context of healthcare (cancer care) system in India.

Introduction:

The rapid improvement of the primary health care infrastructure along with dissemination of advanced diagnostic modalities has led to a gradual increase of life expectancy in India .This has also led to a shift of the disease burden from communicable diseases to non-communicable and lifestyle diseases including cancer. Cancer is the second cause of death worldwide and accounts for nearly 13% of total global deaths. The prevalence of cancer was conventionally more widely recorded in the developed countries but in the recent years it has increased substantially in the developing countries as well. The Global Burden of Disease (GBD)suggest that about 70 percent of all cancer deaths are now concentrated among low- and middle-income countries.Rajpal et al(2018)

The delivery of affordable and equitable cancer care is one of India's greatest public health challenges. The author explores the cancer care statistics In India along with the complex nature of cancer care systems and attempts to put them in the context of governance to help develop mandate to improve the quality of care on the drive to understand and deliver a high quality and cost effective cancer care program.

The Statistics of Cancer in India

"Although statistical trends are usually not directly applicable to individual patients, they are essential for governments, policy makers, health professionals, and researchers to understand the impact of cancer on the population and to develop strategies to address the challenges that cancer poses to the society at large. Statistical trends are also important for measuring the success of efforts to control and manage cancer." (Cancer.gov)

WHO estimates, by the year 2020 the death toll of cancer will reach to 20 million cases worldwide. As per the recent estimates by India's National Cancer Registry Program (NCRP), 1.45 million cases would occur in 2016 along with 0.74 million fatalities in India. This is expected to further increase to 1.73 million cases and 0.88 million deaths in 2020. Considering a median life expectancy of 74 years, one in 8 men and one in 9 women are expected to suffer from cancer. Gandhi et al(2016)

According to the National Institute of Cancer Prevention and Research (NICPR) around 2.5 million people are estimated to be suffering from cancer along with over 7 lakh new cancer patients registered in India leading to more than 5,56,400 cancer related deaths.

India accounts for the third highest number of cancer cases among women after China and the US, growing annually at 4.5-5%Deyl (2017).

As per data provided by Indian Council of Medical Research (ICMR), there has been a significant rise in various cancer cases and deaths in the country. The rise in the number of cases may be changing life style patterns, diet, and increase in the consumption of tobacco and tobacco products and also improvement in the availability of diagnostic facilities.

Estimated Incidence cancer cases in India - State wise - All sites- (2011-2014) - Both sexes

States	2011	2012	2013	2014
Jammu & Kashmir	10688	11052	11428	11815
Himachal Pradesh	5836	5966	6097	6230
Punjab	23506	24006	24512	25026
Chandigarh	893	915	937	960
Uttaranchal	8633	8899	9173	9455
Haryana	21539	22122	22721	23336
Delhi	14204	14517	14836	15160
Rajasthan	58426	60065	61743	63459
Uttar Pradesh	170013	175404	180945	186638
Bihar	88563	91721	94981	98346
Sikkim	490	513	539	571
Arunachal Pradesh	1108	1134	1160	1187
Nagaland	1579	1595	1612	1630
Manipur	2149	2119	2092	2066
Mizoram	871	885	900	914
Tripura	2944	3036	3141	3259
Meghalaya	2367	2413	2460	2507
Assam	24846	25119	25391	25663
West Bengal	77806	79915	82087	84325
Jharkhand	28135	29067	30026	31012
Odisha	35736	36599	37478	38375
Chattisgarh	21835	22569	23325	24105
Madhya Pradesh	61883	63814	65797	67831
Gujarat	51415	52920	54469	56061
Daman & Diu	209	232	259	288
Dadra & Nagar Haveli	293	310	328	349
Maharashtra	95508	97674	99871	102101
Andhra Pradesh	72395	74900	77543	80334
Karnataka	52099	53476	54886	56330
Goa	1240	1266	1293	1321
Lakshadweep	55	58	60	63
Kerala	28583	29434	30372	31400
Tamil Nadu	61266	62049	62830	63609
Pondicherry	1069	1114	1160	1208
Andaman & Nicobar Islands	321	326	331	335
Total	**1028503**	**1057204**	**1086783**	**1117269**

Source – ICMR, Based on cancer incidence report (2009-2011) and the Report on Time Trends in Cancer incidence Rates (1982-2010).

(Press Information Bureau Government of India, Ministry of Health and Family Welfare, 2014)

NCRP (ICMR), Bangalore, published a report on Time Trends in Cancer Incidence Rates in India. Takiar et al 2010 conducted a study on the same to project cancer cases for India by sex, age and cancer groups. It estimates rise in the total number of cancer cases from 979,786 cases in the year 2010 to 1,148,757 cases in the year 2020. Tobacco related cancers are expected to go up from 190,244 in the year 2010 to 225,241 in the year 2020 and from 75,289 in year 2010 to

93,563 for males and females respectively. Prevalence of Gynecological related cancers is estimated to rise from 153,850 in 2010 to 182,602 in 2020. Incidence of breast cancer alone is expected to cross the figure of 100,000 by the year 2020.

Despite of such figures the cancer care infrastructure of India is inadequate. India has a dismal availability of Radiotherapy centers at 314 per million inhabitants the number of radiation oncologists stand at 353 per million. WHO (2014). The country is facing a severe shortage of qualified medical personnel with mere 2000 oncologists to look after 10 million patients. The country will need minimum 600 cancer care centers by the end of the decade to deal with this challenge. Dey (2016).

The financial burden for the treatment of a disease, especially Cancer can be a major source of stress for patients and families. Out of pocket expenses incurred for the diagnostic tests and cancer treatment can consume a significant part of the family budget. Lansky et al (1983). However, patients and their families do not have a good estimate of the expenses involved. This has been a universal challenge in developed and developing countries alike and has emerged as a cause for health policy concern. (Mohanti et al (2011) Quoting Meropol et al 2009; Sikora and James 2009; Steinberg 2008.

Healthcare delivery systems in India are undergoing rapid transition. For tertiary specialty of chronic diseases more than 80% patients are seeking treatment from private or corporate health centers and more than 90% of these patients end up bearing the costs by themselves. The advancement of medical technology and faster dissemination of advanced diagnostic and treatment modalities and newer drugs hasled to a drastic increase in the overheads borne by the patient or the family.Public healthcare facilities and teaching hospitals still provide specialty care at low costs but the waiting times can be prohibitively long and the patients still have to pay for the medicines and indirect costs of treatment which jeopardize the family budget.In the perspective of these disparities of demand and availability of resources, it is imperative to focus on equitable distribution of these resources through enhanced governance strategies.

Governance and cancer care in India: The gaps

There is a considerable disparity in the service delivery in the treatment of cancers between hospitals in India and the west. Given the quality of medical education in India and emergence of India as a medical tourism destination there are no insuperable barriers to for the healthcare systems to move towards good governance in health service delivery. Bhaidkar (2014). The rapid mushrooming of private health centers across the country has seen a remarkable rise in cancer diagnostics and centers but the lack of core guidelines to define a cancer center is a matter of concern. To deal with the rising number of cancer cases and to meet the needs of the population it is of essence that the government recognizes cancer care as a priority area and creates systematic guidelines to form national standards to define cancer care.

The Ministry of Health and Family Welfare along with its nodal bodies (department of health, department of family welfare and directorate of health services) need to put up a coordinated effort to deal with this challenge. A central body must be formed to coordinate with these bodies to help achieve the common objective of increasing 5-year survival from cancer which currently stands at 30% in India, compared to 60% in the West. WHO (2014)

Governance in Organizations

Governance plays a critical role in regulation and delivery of quality healthcare. In low income countries with poor governance, as incomes rise, increasing number of people are choosing the private sector over the public hospitals for their healthcare needs. Even the less well to do individuals choose private healthcare providers and pay significant amounts of their disposable income for their healthcare needs even when the public services remain poor and underutilized. This is because public hospitals can be perceived as poorly governed and the assumption that the quality of care is better in the private centers.

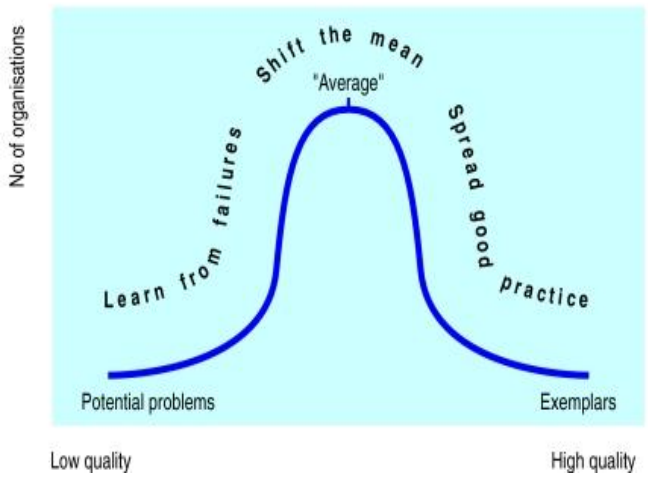
Healthcare effectiveness: Bodolica et al (2014) In the past decade there has been a significant makeover of the healthcare landscape owing to the rapidly changing economic, social, politico-legal and technological realities of the external environment along with rapidly growing emphasis on overall system effectiveness. The stakeholders in healthcare delivery share a complex relationship with involvement of multiple players including medical regulators, clinicians, paramedical personnel, third party players like health insurance companies, and patients the consumers of care. A well-functioning healthcare system necessitates that all the stakeholders in the organization have a close synchronization towards the improvement of processes and practices.

With the escalating costs of care and the inability of the governments to secure accountability for clinical choices and allocation of resources the question of healthcare effectiveness finds itself under increasing scrutiny. (Chiozza and Plebani 2006). Discussion on governance in healthcare organizations becomes of utmost importance in the context of inadequate coverage for cancer care, suboptimal functioning of public hospitals, rise of consumerism in healthcare and failure to provide adequate prompt and high quality healthcare services to the consumers.

Quality improvement Philosophy

Whilst delivering upon the healthcare needs, large organizations (tertiary care hospitals) show a variation in performance against the quality criteria. Quality improvement is a continuous process which must address the whole range of performances. Deficiencies in the

standards of service delivery weather detected through clinical audits, complaints, incident reports or through routine surveillance represent one end of the spectrum. The organizations which are exemplars represent another end of the spectrum. A significant shift towards improved healthcare quality will occur only when there is a transformational shift in the quality of service delivery in the organizations which are at the middle of this spectrum. The good practices of these organizations must be standardized into process maps and must be incorporated into the local and national guidelines.



Source: Scally, G., & Donaldson, L. J. (1998). Clinical governance and the drive for quality improvement in the new NHS in England. BMJ : British Medical Journal, 317(7150), 61–65.

Through leadership and commitment from the top brass of the organization, documentation and team work protocols must be created to promote an organization wide approach to improve quality improvement, making the delivery of service more responsive to the patients' needs and preventing adverse outcomes.

Accountability is the most important factor to improve healthcare delivery. Continuous training and supervision of all staff at all levels, focus on records and record keeping leading to easy availability of systematic data to managers, development of procedures to promote user friendly and patient centric service delivery and promoting professionalism amongst staff are the key areas to improve the standard of care delivered by an organization. Running of public hospitals like business would lead to discipline amongst the hierarchies. Mamdani (2007).The need to be accountable will incentivize improvement in productivity, patient satisfaction and performance.

Clinical Governance : The name clinical governance emerged in the United Kingdom where the National Health Service defined clinical governance as a framework through which organizations are accountable for continually improving the quality of services and safe guarding the high standards of patient care by creating an environment in which excellence in clinical care will prevail. Rogers (2014)

Clinical governance both in the private and the public sector is the desperate need of the hour.It comprises of five key components

- Patient education
- Risk management
- Clinical audit
- Evidence based care
- Effectiveness

According to Scally et al, 1998, The development of clinical governance is designed to consolidate, codify, and universalize often fragmented and far from clear policies and approaches, to create organizations in which the final accountability for clinical governance rests with the chief executive of the health organization—with regular reports to board meetings (equally as important as monthly financial reports)—and daily responsibility rests with a senior clinician. Each organization will have to work out these accountability arrangements in detail and ensure that they are communicated throughout the organization. (Scally, Donalsson 1998)

The above factors ensure that there is a systematic approach to maintain and improve the quality of patient care and promotes accountability. Accountability of the organization is the principal factor in clinical governance. Sirohi (2014).

Improving health through an evidence-based implementation program

Life for those who have had a cancer across India can be improved through continues assessment of their healthcare needs after the diagnosis, followed up with support to ensure that those needs are met.

Researchers in the University of Manchester developed an assessment tool using knowledge from applied research into knowledge translation and service improvement, which emphasized the need for tailored, context-sensitive approaches to implementation of evidence. This flexible assessment tool was designed to evaluate and measure the implementation of services to patients suffering from stroke.(Harvey G et al 2013). This tool (GM-SAT) could be applied in the context of evaluating the quality of cancer care delivered to patients in India enabling the fulfillment of national strategy and improved care for these patients.

Performance Measurement

Need of Performance Measurement in Cancer Care

Inappropriate or unnecessary care or poor service delivery in cancer care wastes precious resources and increases costs and can also affect the prognosis of the patient. Performance measurement can be a tool to identify these gaps in the delivery of care with the use of administrative data sets. Performance measurement can enable users to choose providers on the basis of quality of their performance. It can also help minimize variations of practice and help identify areas that require improvement.

Creation of datasets to quantify service delivery will help enhance clinical performance. Lazar (1998)

Specifically, purchasers should require the following from payers: 1) Staging information of cancer.

2) Coding for international classification of diseases and other important (comorbid conditions)

3) Incentives or requirements for proper data collection if the payer is using a reimbursement strategy that places the risk on the provider;

4) Readiness to collect and report information to care providers so as to help improve the quality and reduce the costs of cancer care.

Demanding better clinical performance can lead to better outcomes. Once good data is presented to patients and providers, better clinical behavior and improved cancer care systems will quickly follow.Lazar (1998)

Clinical Databases

Collection and evaluation of routine patient data is a central part of any health services planning and administration. It is important that the policy makers demonstrate a strong commitment to the accuracy, appropriateness, completeness, and analysis of healthcare data. This information is critical if the clinical quality is to be evaluated and the impact of the clinical governance initiatives is to be assessed. Scally (1998).Toevaluate the data dealing with cancer patients, the key factors considered are incidence, prevalence, mortality, and survival. There is a deficiency of precise data pertaining to the latter two form Indian cancer centers. Meticulous maintenance of this data will ensure that the key outcome measures are available to the policy makers and appropriate interventions can be made. Sirohi(2014).

Ensuring delivery of High Quality patient care

Transparency and accountability are the two main indicators to evaluate the quality of care delivered to cancer patients. Development of a systemic culture promoting timely audit process to document and report critical, never and sentinel events in a transparent manner and creating a mechanism to learn from such events. If such events are not reported no lesions can be learnt. Increased rates of reporting errors or near misses within the healthcare setup lead to better patient care and safety. Reporting these events regularly (on a monthly and quarterly) manner leads to improved institutional awareness and implementation of subsequent corrective measures leads to improved quality of care and safety. Sirohi(2014).

Multidisciplinary care

A protocol to form a multidisciplinary care team to treat cancer patients includes a medical oncologist, radiologist, onco surgeon, palliative care physician, pathologist and nurse must be created. All newly diagnosed cases must be evaluated by the MDT or the tumor board. The patient or the family representative must also be involved to ensure better representation. In case of remote hospitals where all the concerned stake holders are not available, the telemedicine options may be used. Such protocols must be standardized nationally which will ensure evidence based and unbiased care to the patient. MDT will also eliminate the possibility of misdiagnosis and will help deliver quality cancer care to the patients. Sirohi(2014).

A study conducted by Gabel et al (1997) found that the MDT increased patient satisfaction by encouraging involvement of patients' families and friends and by helping patients make treatment decisions. The time between diagnosis and the initiation of treatment was also significantly decreased.

Dealing with poor performance

Poorly performing medical and support staff can be a risk to the patients and the organization they work for. Though the incidence of such problems is relatively low, the acknowledgement of its existence and the resolve to deal with the problem is very important to the repute of the organization. A small percentage of the hospital based medical staff may have subpar performance records and may warrant consideration of a disciplinary intervention. It is imperative that the organizational ethos moves from a situation where doctors are reluctant to make any intervention which might be perceived as a criticism of a fellow doctor's clinical approach. A multi-tiered approach is required beginning from the regulations from the medical councils, internal organizational norms and local bodies of doctors so that satisfactory and timely solutions can be found to what can be seen as a wicked problem. The test will be whether such cases can be dealt with in a sympathetic manner which, while correctly putting the protection of patients first, will also deal fairly with experienced and highly trained professionals. Scally et al (1997)

Professional development

The staff of any healthcare organization is the most vital factor to determine how an organization rises to meet the challenges of a new agenda. Good recruitment practices, employee engagement, retention and continuing professional development of the staff will be the major determining factors of a healthy work culture. It is important that the staff is engaged in the decision making process and their inputs are valued and incorporated into any major service redesign. Through systemic processes the staff must be encouraged to help develop new strategy and must help evaluate the existing process by their critical analysis and service improvement strategies. Valuing the staff and engaging them more thoroughly in the decision making processes is a common feature of organizations that demonstrate sustained excellence. (McGregor 1960)

Conclusion

Traditionally management meetings have been dominated with activity targets and financial issues. Many healthcare systems across the world are now coming up with strategies to shift this focus towards service improvement and clinical governance. There is recognition that a commitment to high quality clinical care should be the corner stone of any healthcare organization. There is an understanding that well managed organizations will be those in which financial control, service performance, and clinical quality are fully integrated at every level. (Scally et al 1998)Realigning the focus of health service delivery to be more in line with the complex experience of patients is central to developing solutions that work. Vogeli (2007).

Service improvement is only possible when baseline outcomes are clearly defined related to morbidity, mortality, survival and patient satisfaction. Developments like the National Cancer Grid of India which is a partnership of all the major regional cancer centers and the initiative to improve quality across the public sector is major step in that direction.(Sirohi 1997) Healthcare organizations and its staff must take up more accountability and responsibility in the entire cancer journey of each patient. Standardized protocols across the country along with the drive to provide optimum care to the patients within the available resources will be a step in the right direction. Clinical governance and service improvement interventions are big ideas that can inspire and enthuse. It is now for the policy makers and the service providers to turn it into reality. This will require a systematic endeavor across all the stake holders discussed above. If this challenge is met the benefits will pass on to every practice, hospital and patient in the country. With the rapidly increasing cancer patients in India and its booming population it is the need of the hour to bring this transformational shift in the governance discourse in the country.

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