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Review Article

Comprehensive value-based cancer care in India: Opportunities for systems strengthening

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Cancer has been one of the leading causes of death in India in the past decade. The growing cancer burden has generated an unmet need to identify and address gaps in the healthcare system to enable access to affordable and quality cancer care for all in a manner that enhances the value of care. This paper provides an overview of the value-based care approach, identifies areas for enhancing the objectives of value-based care through multi-characteristic and multidimensional consideration of patient centricity and proposes health system strategies to improve comprehensive value-based care in India within the current context, focusing on implications for women's cancers. The core characteristics of patient centricity – heterogeneity and complexity – are detailed to complement and expand on previously defined aspects of value-based care. Comprehensive value-based cancer care can serve as a test case and proof of concept for the rest of the health system in India and focusing on women's cancers as a starting point can mandate attention to gender-responsive and transformative design and implementation.

Key words Cancer care - health system strengthening - health reform - patient-centeredness - value-based care - women's cancers

Introduction

India ranked 145th out of 195 countries and territories in the healthcare access and quality index (HAQI) in 2016, trailing behind neighbouring China (48th), Sri Lanka (71st) and Bangladesh (132nd)[1]. The HAQI placement of India indicates that almost a fifth of the global population which resided in the country in 2016[2] did not have access to high-quality healthcare, if any access at all. Both access and quality are key components of achieving universal health coverage (UHC)[3], a sustainable development goal for 2030[4]. However, progress towards UHC in India is hampered by the staggering level of out-of-pocket expenditure (OOPE) on health (over 62% in 2018)[2], with cancer causing the highest OOPE[5], leading millions overall into impoverishment[6].

Cancer was the fourth leading cause of death in India in 2017[7], and there were 1.15 million new cases in 2018 with an expected doubling of incidence by 2040 based on accounting of demographic changes[8]. Cancer care in India is concentrated at tertiary hospitals and major cancer centres in urban areas with gaps in infrastructure and human resources that, among other factors, hinder delivery of high-quality cancer care[9]. Further, there is a 'north–south divide' between northern and better-resourced southern States, though intra-State differences also exist[9]. The COVID-19 pandemic has only worsened prospects for cancer patients with

infection control measures delaying presentation for diagnosis and treatment, shifting patients from curative to palliative care, as well as causing worse COVID-19 outcomes for individuals with cancer who are infected with SARS-CoV-2[10]. Specifically, in 2020, oncology services in India witnessed a 54 per cent decline in new patient registrations, 37 per cent reduction in outpatient chemotherapy and screening activities at 25 per cent of normal levels[11]. Between 18,159 and 53,626 life-years are estimated to have been lost due to delayed diagnosis and treatment of cervical cancer alone so far[12].

India is presently at an opportune moment to reset and revise its healthcare system to truly meet the needs of its populace by prioritizing what is valued by its primary beneficiaries – patients. The 2018 launch of the Ayushman Bharat (Healthy India) reform has set India on an ambitious and contentious path to improve the health system[13-15]. The Ayushman Bharat has two arms – Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB-PMJAY) (National Health Protection Scheme), which seeks to provide financial protection for the poor through publicly funded health insurance coverage of nearly 500 million people, and the Comprehensive Primary Health Care Programme[13,14]. The former is focussed on secondary and tertiary hospital-based care, while the latter serves as a restructuring of the Indian primary healthcare system. Various foundational shortcomings have been cited, including inadequate budgetary allocations to practically strengthen primary care beyond the creation of health and wellness centres (HWCs)[15,16]. The AB-PMJAY, as presently structured, serves to fund the private health sector without adequate regulatory mechanisms in place instead of investing in the public healthcare delivery[16-19]. Policy capacity analysis of the Government of India reveals deficits in both operational and analytical capabilities to implement and realize the goals of the AB-PMJAY[20]. Redirecting the trajectory of the Ayushman Bharat through value-enhancing changes could help avoid pitfalls of previous efforts, including earlier stages of the Ayushman Bharat itself.

Examining the case of cancer as a test case for enhancing value-based care can provide lessons for a broader health systems reform, including consideration of gender-related challenges that are of inherent value to patients[21]. For example, the burden of informal caregiving for children, elderly and sick often falls on women and has only worsened with the COVID-19 pandemic[22]. Women also face stigma associated with cancer, particularly cancers perceived to have links with reproduction (*e.g*. breast cancer), or are socially assigned to sexual transgressions (*e.g*. cervical cancer)[23]. India is primed for improving cancer care, including and especially for women, for example, given existing capacities of the health workforce. A recent study on cervical cancer screening demonstrated that the knowledge of healthcare professionals regarding symptoms and risk factors is over 75 per cent[24]. This review provides an overview of the value-based healthcare approach, identifies areas for enhancing the objectives of value-based care and proposes health system strategies to improve comprehensive value-based care in India within the current context, focusing on implications for women's cancers.

Value integration

Value-based care is premised on using value generated for the user – patients – as central to health system performance assessment and improvement[25,26]. It shifts the focus of health systems strengthening from maximizing the volume of services delivered to optimizing the outcomes achieved according to patient need[25,26]. Albeit important, outcomes are prioritized over input considerations of structure and process by employing financial incentives, *eg*. outcome-based payment structures, that target clinical outcomes and require meeting specific performance criteria. Through this approach, the value-evaluative equation incorporates non-monetary (outcomes) and monetary (costs) components. As per the model developed by Porter (2010)[26], the results express outcomes of each patient group [condition(s)-specific] with a similar set of needs relative to costs of the full cycle of care for that patient group. Patient value can be further enhanced through the value-based geography of care model and leveraging its three domains: location of care (with the highest effectiveness, efficiency and convenience to patient), integration across time and optimal combination of healthcare personnel[27]. In practical terms, this approach to value integration is principally focussed on clinical outcome achieved per dollar expended, and while centred on the patient, it does not fully incorporate the foundational characteristics of patient-centeredness or its multidimensionality, including patient experience and preferences[28]. A systematic review of value-based initiatives implemented to-date demonstrates the limited application of the value-based approach – over a third of initiatives focus on financial outcomes and cost-savings. Further, out of the 47 studies included in the review, only 16 used patient-reported outcome surveys[29].

The pathway to an expanded definition of value-based care will require synergy with different aspects of patient-centeredness and reconsideration of including process- and structure-oriented indicators in performance evaluation. The WHO-integrated people-centred health services approach highlights this need[30]. Both value-based care and patient-centered care provide a compatible[28] and quality-oriented[31-33] health systems goal to further. The use of value-based payments to enhance equity[34] demonstrates this compatibility of value generation for the system and the patient-centeredness of addressing equity concerns. Efforts to generate high-quality cancer care and health systems[33], in turn, require holistic and comprehensive value-based care that effectively reflects patient centricity with its various characteristics and dimensions. The 'triple-value model'[35], for example, incorporates personal, technical and allocative value. It was designed to enhance patient safety and, in turn, healthcare value in a manner accounting for patient centricity. The model promotes patient engagement in ensuring the safety of care, which has a direct impact on patient experience, while simultaneously considering resource allocation issues at the systems level[35].

Patient centricity

There is growing research to not only understand patient centricity but also identify strategies to achieve it at the systems level. This requires, at its foundation, recognizing the core characteristics of patient centricity – heterogeneity[36] and 'patient complexity'[37].

There is heterogeneity across individuals, including in the same patient group, and over different contexts and circumstances that should be considered while simultaneously seeking to understand commonalities to develop a blueprint for value-based care. Sources of patient heterogeneity that demands examination are demographics, preferences and clinical factors (*e.g.* severity of disease, disease history and genetic profile)[38].

Various systematic reviews have sought to define the dimensions of patient-centeredness and develop a taxonomy of patient values and preferences. One such review found the core dimensions of patient-centeredness as 'patient as a unique person, patient involvement in care, patient information, clinician–patient communication and patient empowerment'[39]. Another identified that value information garnered in the literature pertained mainly to patients themselves, expectations of health professionals and interactions between the patients and healthcare professionals[40]. Further, the main themes identified were autonomy, compassion, empowerment, partnership, professionalism, responsiveness and patient uniqueness[40]. Taking a heterogeneity perspective, each of these should be assumed to not have a singular and standard value or preference 'setting'.

Moreover, understanding values and preferences according to treatment burden[41] and from a 'patient complexity' perspective, accounting for the workload on patients from the demands of care and patient capacity to respond to these demands[37] is essential to promote patient-centeredness with the overall aim of improving quality of care and quality of life at the end of life. The workload aspect comprises the patient's time and energy to undertake activities of daily living and manage care demands. The capacity aspect relates to factors that impact the patient's ability to engage in activities and demands, such as functional status and socioeconomic or sociodemographic standing[37].

Patient complexity assessment does not currently extend to comprehensively incorporate the triple burden faced by patients – the experience of the disease itself, navigation of the health system to access care and administration of the actual care. These burdens can negatively reinforce each other and accumulate over time to generate adverse effects[37]. There can be an additional workload due to multi-morbidities[41] and complexities based on the social, cultural and health systems contexts in which patients experience disease and death which have yet to be understood. Furthermore, demographic variables and their influence also bear consideration. For example, the informal caregiver burden on women can overstretch their workload when they fall ill in terms of both their own care and that of others[42-44]. Efforts to apply a complexity model should seek to fully acknowledge the workload on patients and value the capacities that patients possess as this can improve the people-centeredness of care.

Taken together, patient heterogeneity and complexity are the features of a generative process that can facilitate a transition from patient centeredness to patient empowerment[45]. This can in turn lead to the co-production of healthcare, which is a valued patient goal and can help effectively achieve comprehensive value-based care[46,47].

Landscape of cancer care in India

The 2012 convening of the National Cancer Grid (NCG) in India was a major step towards standardizing and delivering high-quality cancer care[48,49]. The

NCG is a consortium of over 230 cancer centres (to-date) within the country and functions as a platform for exchange of evidence and expertise, such as the production of evidence-based management guidelines, training and research[11,48,49]. The AB-PMJAY has linked with the NCG to expand cancer care and to implement the inclusion of cancer treatment under its Health Benefits Package 2.0 in 2019, specifically for secondary and tertiary care hospitalization[50]. The operational framework of a national cancer screening programme for breast, cervical and oral cancers was outlined in 2016[51,52] in line with the Comprehensive Primary Health Care Programme of Ayushman Bharat[53] and the National Programme for Prevention and Control of Cardiovascular Disease, Diabetes, Cancer and Stroke[54], and screening has also been integrated into the AB-PMJAY. While these strides are promising, they have yet to be translated into access to screening and treatment for most in the country[55]. Nevertheless and despite its shortcomings, a renewed national commitment to health and large-scale government financing of care across the cancer continuum through the AB-PMJAY have set the stage for the pursuit of value-based and patient-centered cancer care.

The NCG introduced the Choosing Wisely India (CWI) initiative to identify 'low-value or potentially harmful practices' within the national cancer care system, guided by a task force of diverse stakeholders that included patient and patient advocacy representation[48,56]. The CWI was initiated to drive performance improvements for the delivery of high-value cancer care[48]. A list of 10 recommendations was developed to avoid common medical practices with evidence of causing unnecessary harm. The list is intended to serve as a launch point for review and shared decision-making by patients and providers[56].

Actionable strategies for comprehensive value-based cancer care

Comprehensive value enhancement of cancer care in India requires compliance with the core characteristics of patient-centeredness – heterogeneity and complexity – as these are not adequately captured in the traditional designation of value-based care. The Table outlines each of these characteristics alongside examples of strategies that can be implemented for value-enhancement of cancer care in India and the potential impact on women's cancer care.

As India proceeds in its healthcare evolution, care should be tailored from its onset to identified sources of patient heterogeneity. These can help carefully adjust care modalities, for example, adjust therapeutics to patient health status, response to treatment and existence of side effects or complications and life expectancy[57]. Porter (2010)[26] outlined a hierarchy of outcome measurement with three tiers, the health status achieved (*e.g*. survival and disease control), process of recovery (*e.g*. treatment time and access) and sustainability of health (long-term consequences of therapy), which has been applied to breast cancer[61]. Patient-reported metrics are necessary across these tiers of outcome measurement as well as in terms of process and structure, which require reintegration into the healthcare value equation. Individualization of care should therefore be measured through patient-centered metrics (*e.g*. patient-reported experience and outcomes measures) that span the full journey to assess the patients' experience throughout their care pathway. Such metrics need to also be included in value-based evaluations to effectively monitor an expanded definition of value-based care[38]. An example of such a metric may be the value of individualized care (expected value of individualized care)[62]. Moreover, development of the National Cancer Database for Cost and Quality of Life in India holds promise as it is intended to serve as a country-specific open-source repository of data on OOPE associated with cancer alongside health-related quality of life scores[63]. This platform could be expanded to incorporate comprehensive value-based care criteria as well.

Similarly, addressing patient complexity requires new and revamped strategies such as the creation of an integrated national patient navigation system that follows care pathways. There is extensive evidence on the efficacy and relevance of well-designed patient navigation on improving participation in cancer screening and adherence to follow up diagnostics[64,65], including related to cancer care in India[66]. Patient navigators need to be trained in case management to offer patients guidance through the cancer care system and to address structural and cultural barriers to care (*e.g*. stressful interactions such as management of health claims, coordination of care, as well as identifying and understanding resources to administer self-care to adhere to clinical advice). Tata Memorial Centre and Tata Institute of Social Sciences have already launched the Advanced Diploma in Patient Navigation (KEVAT)[67], the first of its kind in India, to provide "structured patient support system for cancer care that will form a bridge between patients and access to

Table. Examples of action-oriented strategies for comprehensive value-based care and relevance to women's cancers

Core characteristic of patient centricity	Examples of actionable strategies for comprehensive value-based care	Implications for women's cancers
Heterogeneity (in demographics, preferences and clinical factors)[36]	• Practice explicit consideration of sources of patient heterogeneity across the care continuum, including gender diversity • Define and deliver individualized therapeutic strategies[57] based on patient participation and shared decision-making • Assess patient experience and outcomes throughout their care pathway with patient-reported metrics • Include patient reported as mandatory in RCTs[58] and as part of value-based evaluations (*e.g.* EVIC)[38] • Ensure patient and public participation in refining comprehensive value-based through deliberative democracy efforts[59]	• Promote gender-responsiveness to women's specific health needs, including to address stigma related to women's cancers (*e.g.* breast and cervical cancer) • Improve care for impoverished women based on their specific needs to address gender inequities • Provide opportunity to adapt care to gender-specific social determinants of health at the individual level • Advance patient participation and empowerment to define value based care within their lived experience with disease
Complexity (related to experience of disease and navigation and administration of care)[22]	• Develop an effective, accessible and integrated national patient navigation system through Ayushman Bharat and linked with the NCG • Incorporate mandatory competence-based training for healthcare professionals on patient-centered approach and avenues for tailoring care • Study patient navigation pathways through rigorous implementation science to understand barriers and facilitators to accessible, effective, affordable and comprehensive value-based cancer care • Foster and engage community-based patient support groups to assist patients in trouble-shooting day-to-day challenges, including specific messaging and assistance for women • Invest in development of low-cost technological solutions to demanding administrative tasks of care, building on any digital technology and telemedicine platforms adopted during the COVID-19 pandemic • Promote knowledge-sharing between patient communities, their caretakers, providers and researchers[59,60] • Prioritize community-based primary care as the closest point-of-care to deliver on the demands of complexity	• Promote gender-responsiveness to recognize and address additional challenges faced by women in terms of their workload (*e.g.* burden of informal caregiving), particularly the impact of such challenges on each individual patient's ability to access and utilize healthcare • Permit focus on natural history of cancers experienced by women and need to customize delivery of care accordingly to each patient • Recognize the challenges that women face in healthcare utilization due to time and geographic constraints and bring comprehensive value-based care close to the patient

RCTs, randomized control trials; EVIC, expected value of individualized care; NCG, National Cancer Grid

care" [68]. Nationwide scale-up of a training model such as KEVAT through the Ayushman Bharat, specifically of healthcare personnel at its Comprehensive Primary Health Care Programme with Health and Wellness Centres, could be the first step to offering extensive support, guidance and relief for overburdened patients. Advanced training could help tailor such support to patient-specific needs, and availability of navigators in both clinical and community settings could then expand their reach and impact. This would need to be coupled with relevant financing and infrastructural developments to build a complete national patient navigation system. Community-based patient support groups are a necessary complement to the navigation system as trusted informal spaces to promote shared understanding and reciprocity. Moreover, technological innovations for improved patient self-management, especially affordable options for administering such care, are critical to upgrade healthcare in India. Use of deliberative democracy approaches[59], such as through public reasoning, can produce a culture of public debate in health decision-making for continual assessment and reassessment of value-based care, how it is defined and how this definition can translate through the health system, including the cancer care system.

The strategies outlined in Table have important implications for women's cancer care. Notably, each provides an opportunity for furthering gender-responsiveness in the Indian health system through more personalized care. Currently, there is substantial

room for consideration of biological, social, cultural, demographic and economic factors and the interaction of these in impacting women's health access, utilization and outcomes. Investigating patient navigation pathways can help identify specific systemic weak spots in delivering comprehensive value-based care for each patient, irrespective of condition(s), to address gender-related disparities in patient-centeredness of care. This could not only improve women's cancer care but also bring attention to gender diversity in cancer care and recognition of heterogeneity across the spectrum of gender identities. Moreover, value-enhancing strategies such as expanded use of patient-centered metrics has high acceptance among patients, including breast cancer patients[69,70], and their use in randomized control trials of health interventions, which remains low[58], should be made mandatory.

Given the current state of healthcare in India, value-enhancing policies and translational actions should be grounded by re-prioritization of primary healthcare. Primary care is principled on being person-focussed[60] and can best deliver on the demands of patient-centeredness[71]. Comprehensive value-based integration would therefore occur from the promoted entry point into the health system.

Overall, this review provides a rationale on and proposes strategies for comprehensive value-based care. Specifically, it advocates for multi-characteristic and multidimensional consideration of patient centricity and promotes consideration of structural and process inputs alongside outcomes as part of performance assessment of the new generation of health reform in India through the Ayushman Bharat platform. Implementation of proposed strategies may be considered with state level variations in cancer in mind[72]. In the case of cancer, healthcare delivery innovations can effectively bring even complicated care closer to home. For example, follow up after chemotherapy can occur at the primary care level through use of optimal tasking and telemedicine[73]. The argument for including other characteristics of patient centricity, *i.e*., heterogeneity and complexity, and taking account of the full patient journey does not preclude or replace previously defined elements of value-based care. Indeed, the main premise of expanding value-based care is to make it more comprehensive as countries apply different policy and practice levers[56,59] for value-enhancement in healthcare. Given the extensive investment in the cancer care system in India, the development of comprehensive value-based cancer care can serve as a test case and proof of concept for the rest of the health system. Furthermore, focusing on women's cancer can mandate overall attention to gender transformative design and implementation within the health system.

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