**Patient empowerment and patient centered care in India & in GCC**

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**Abstract**

**Purpose**: The purpose of this article amidst Covid19 is to critically evaluate, assess the level of and possibly contribute to empower patients’ for a patient centered care in Indian context. Within the literature, the subtle and intangible aspects with regards to patient empowerment and patient centered care have not been fully elucidated though regulatory systems for better care of patients has been elaborated sufficiently. The inherent pandemic deficiency in implementation of available regulatory provisions for patient empowerment and patient centered care, primarily due to lack of ethics is addressed in this article with an objective to kindle ground breaking decisions and ethical behavior of agencies in pursuit of empowering patients and thus a healthy society in terms of at least physical health.

**Design/methodology/approach**: To ascertain the study gap (subtle and intangible lacuna in patient empowerment and patient centered care in existing literatures) a detailed, systematic literature review undertaken. A broad comparison of patient centered care prevailing in GCC (Gulf Cooperation Council) is taken as a benchmark. Ethical concepts are applied to assess the prevailing situation. This is a qualitative study based on the author’s working experience and informal discussions with health care professionals/ administrators both in India and in GCC.

**Findings**: The deficiency in execution pertaining to patient empowerment and patient care as brought out in this explorative study basically due lack of ethical congruence may be of significance in offering health security to Indian citizens if addressed appropriately. The identified inherent loop holes in the health care administration system can be a seed for detailed research study and or of use in decision making with regards to patient empowerment and patient centered care in India (about which there is always serious persistent doubt).

**Originality/Value**: This study in this pandemic period, based on the nuances of prevailing health care practices in India is first hand critical assessment on patient empowerment and patient centered care which can prompt revisiting ethical standards and may offer some progress by way of better health to the large segment of Indian society.

**Societal implication**: This article is a prologue to find a solution to the persistent pathetic most elusive research question; how to offer “health security” (at least minimum as enshrined in constitution) to Indian population? This overwhelmed Covid19 surge in India is the last penultimate chance for correction of haphazard health care offerings via ethical behavior. The intention is to acclimatize health authorities to imminent positive provocation, though scripted for academic journal with fond hope academia is not water tight.

**Limitations**: This article is one of the initial steps towards amelioration of mammoth pan India malady (lack of patient empowerment and patient centered care emanating due to ethical paucity), and hence views of all stakeholder /agencies though vital could not be included in this article. Since aim of the article is to prime the mind of regulators and not to ascertain full reality, prevailing health care situation is captured with only keen observation, informal discussion with some of health care stakeholders and not through/based on primary/secondary data generated from either agencies or public. Medical aspects’ pertaining to patient empowerment and patient centered care is beyond the reach/scope of this article. A thin ray of ethical vision is only considered for assessment of patient empowerment as per the limited span of the study.

**Keywords**

Patient empowerment, patient centered care, GCC (Gulf Cooperation Council), health care, regulatory authority, ethics

**Type of study**: Critical analysis prelude to social construction of reality case study research design

**Introduction**

The option to choose, to know and get redressed if need be, as an extension of fundamental right under Article 21 as enshrined in constitution in pursuit of health (Jhawar, 2018) can be termed as patient empowerment, though this may not be exhaustive. Patient empowerment is a multidimensional process that increases the ability of the patient to act on their health issues and thus take control of their lives (Luttrell., 2009). All those designed, executed by health care system around the wellbeing / rehabilitation of the patient may be termed as the patient centered care. Precisely patient centered care may be termed as an essential process towards patient centered system that can improve treatment outcomes (Robbins, 2013). However, it is difficult to define/confine patient empowerment and patient centered care easily. While attempts to appease agitating medical fraternity over odd rude anti social behavior by very sad odd stray incident or applaud health care workers for their yeoman services in particular during Covid19 is instantaneous by law makers, there has never been an appropriate attempt to either empower patients or ensure patient centric care in India whole heartedly without which the term “health care for all citizens” is inconclusive. Possibly, complete callous attitude of the health service provider to the needs of the customer provokes odd rude patient behavior. The genesis of the problem of “apathy to patient” may be in the way most prevalent Allopathic system of health is administered and or the demography and size/shape of population in India. Somewhere in the recent past, medical ethics started eroding and today it is at most deplorable state in India, where most ethical form of medicine was once practiced by the decedents (by profession) of Jivaka and Sushruta (Singh, 2012). Jargons like patient empowerment and patient centered care started emanating as the nobility & humility in offering good health and alleviating pain became rarity. Now in India, health service is commodity and when noble service is brought to the level of commodity sans value, consumers need to be empowered and protected. More than ninety percent of population of India is at the mercy of public or private/ corporate health care system. Rest seeks medical support outside India in either USA, UK or in EU where patient centered care is general norm and top priority in achieving equitable care to all by health services (Cynthia Bonsignore, 2017). News flashes of deplorable conditions/plights of Covid19 stricken patients, service related corruptions all around India though not sporadic is an indicator of India’s health care system.

**Design, Conceptual framework & methodology**

The research inquisitiveness/ questions arising out of broad conceptual framework are: what is the present level of patient empowerment in India, which of the stakeholders of health care system hamper (questionable ethical behaviour) patient empowerment most, what is the level of patient empowerment in India compared to that of GCC and where is deficiency in patient empowerment in India? It is a view point article based on the outcome of informal discussion with persons with expertise in management of health care system both in India and in GCC and that of the author.

**Theoretical framework**

This study is based on the social construction of reality (Stake, 1995,2000,2005) case study research design though this study does not qualify to be a full research study due to primary data collection constraints. The direction of this case study as per (Stake, 2005), is shaped by the interest in the case. This being an intrinsic case study (GCC selected as sample because all the six nations of GCC are rated within 50 in health care rating by (Health Care Ranking, 2019)), the case itself is of interest and the purpose of the study is not theory building but curiosity in the case itself. Thick description with the opportunity to learn & kindle further action is the objective of this study as per theoretical model of this study. Patients’ plight in India is of very curious nature and a social reality issue as again precipitated in this Covid19 pandemic. Observation and description by the author and opinion of experts through informal discussions on the prevailing health care situation in India and GCC region countries related to patient empowerment and patient centered care is the study strategy. Ethics is a kind of normative investigation, hence is applied to evaluate patient empowerment and patient centered care.

**Review of literature and Gap analysis**

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| --- | --- | --- | --- |
| S**.** N**o** | **Year** | **Author** | **Finding** |
| 1 | 2001 | Paterson B | Patient empowerment as myth in chronic illness (Paterson, 2001) |
| 2 | 2002 | **David H Peters et al.,** | On policy choices in public health service delivery, ambulatory curative care, and inpatient care (together with health insurance) to offer better health care in India (Peters, 2002) |
| 3 | 2006 | Grethe Fochsen, Kirt D et al., | On imbalance in doctor patient relationship in rural India (Grethe, Kirti, & Anna, 2006) |
| 4 | 2006 | **Krishna D Rao, et al.,** | On perception of quality measurement scale and aspects of perceived quality by patients (Rao, Peters, & Bandeen-Roche, 2006) |
| 5 | 2010 | Ronald M Epstein et al., | On patient centered care definition and its implication on health care offering to the nation (Epstein, 2010) |
| 6 | 2015 | Abhay Bang | On health insurance and empowerment in India (Bang, 2015) |
| 7 | 2015 | **AP Pandit; M Kulkarni; S Sonik** | On importance of quality primary health care to society (Pandit, Kulkarni, & Sonik, 2015) |
| 8 | 2016 | [Rangeel Singh Raina](https://www.ncbi.nlm.nih.gov/pubmed/?term=Raina%20RS%5BAuthor%5D&cauthor=true&cauthor_uid=27504307) &[Vijay Thawani](https://www.ncbi.nlm.nih.gov/pubmed/?term=Thawani%20V%5BAuthor%5D&cauthor=true&cauthor_uid=27504307) | On need patient empowerment and training aspects for participative health care (Rangeel Singh Raina, 2016) |
| 9 | 2017 | **Sanjay K, Manash P B & Unnikrishnan A G** | On the basics in patient centered care & physicians’ role (Kalr, Baruah, & Unnikrishnan, 2017) |
| 10 | 2018 | Wasserman et al., | On complicated patient clinician relationship (Wasserman & Perez-Stable, 2018) |
| 11 | 2019 | **DR.R Kumar** | On health literacy in universal health coverage (Kumar, 2019) |
| 12 | 2019 | Geoff Walsham | On health information system with suggestion for action (Walsham, 2019) |

While there are innumerable number of articles/ reports pertaining to patient empowerment and patient centered care in India, very little work is done (except lay press sporadic reporting) to highlight the undercurrent of nexus/ ethical lapses amidst most stakeholders (other than consumer/customer) and on apathy in implementing regulatory norms related to ethics. Comparison with medically less advanced region like GCC to bench mark level of patient empowerment and patient centered care in India is not cited in any of the study. This article is to bring out partially hitherto not addressed (research gap) above delicate but pernicious malady of health care system prevailing in India which is blatant by Covid19 pandemic fury.

**Objective of study**

The inherent pandemic deficiency in India due to lack of ethical behavior in implementation of available regulatory provisions for patient empowerment and patient centered care is addressed in this article with an objective to kindle ground breaking decisions by constitutional agencies to ensure patient empowerment and patient centered care and thus a healthy society in terms of at least physical health. GCC health care system is cited to drive the point that it is not the level of technology/ medical advancement but the commitment (to ethical behavior) of the regulatory/ constitutional agencies that matter in offering patient centered care.

**Brief on prevailing medical practice and patients’ precarious plight**

In India other than one’s health, all other aspects having link to either vote bank or government income are partially linked by way of multitude of cards (like Aadhar, PAN, DL, BTL card, Ration card, Voter ID). None of the above has even the simplest data relating to health of the individual citizen/population. Only knee jerk action could be possible (as had been in Covid19 management) in mass health emergencies by health administration in India for want of Health Information System (HIS). Lack of sufficient health care professional coupled with their callous attitude & work ethics, insufficient equipments at all levels of governmental health institutions (PHC, ESI, District and Tertiary) are nowhere near rudimentary need for patient centered care or patient empowerment (Dr. Rattan R, personal communication, July2020). With profiteering as only philosophy, both corporate hospitals and health insurance compete with each other in fleeing hapless patients along with ubiquitous stand alone health clinics (as evident from the frequent news flashes on the dubious ways by which corporate hospitals were either avoiding treating economically downtrodden or stashing huge treatment charges from mildly mannered middle class Covid19 afflicted citizens) . In India almost all stakeholders of health care system in one way or other seek to diminish the patent empowerment and the role of pharmaceutical, medical equipment industry is substantially contributory (incidences of exorbitant cost of stents, anti cancer medications and sub standard medication in connivance with medical fraternity are many). Transparency is least in health communication to patient due to ignorance (which is inherent because medical information is highly specialized and hitherto guarded) and resultant exploitation (Prabhan D, personal communication, May 2011). Medical negligence and unethical practice (corruption not included) in health service is rampant but seldom brought to light and or redressed (Bhandari A, personal scholarly discussion, June 2018). Outbreak of Dengue fever and fear of Dengue among population of Bengaluru had at least to some hospitals offered unethical opportunity to treat most of other than Dengue fever as *per se* Dengue fever (Dr Sylvia, 2019). Most hospitals do not apply fool proof ELISA test to identify Dengue and relay on less sensitive NS1 (Non Structural Protein1) laboratory investigation for profit reasons. Non traceability and delay to patient care center of Covid19 positive patients is couple of the reasons for the pandemic going out of control in India. Needless to mention most Physicians are laboratory oriented than clinical oriented as laboratory orientation demands less expertise and copious kick backs. Probably the term patient empowerment is alien to most of the medical practitioners (as observed by the author) because medical schools in India do not give due importance to both patient empowerment and patient centric care. Laws pertaining to patient rights protection are lackluster (Nayantara, 2019). In India, patient empowerment still continues to be a neglected area because not many are willing to take a stand in favor of the patients (Rangeel S R, 2016). Although laws have been enacted in the US for patient empowerment, in India there is no clear cut strategy on this issue yet (Rangeel S R, 2016).

**Abnormal apathy; pathetic patients**: Too frequent health care negligence exposés and rarity on remedy signify the apathy towards patients and enormity of the impending health crisis in India. It will be superfluous to cite examples of health care negligence since its candid to both literate and illiterate in India. Nexus cannot be ruled out between health care professionals, allied health care professionals and their professional bodies, allied health care industry and the governing agencies. Professional medical nongovernmental organizations with sole aim of insulating its members from the onslaught of patient empowerment efforts impede health welfare legislations like National Health Commission Bill 2017 (Protest by IMA on NBC Bill 2017, 2019). The disparity between the money value spent by a patient and value in terms of health achieved in return is huge. This is exemplified by the fact that there has never been a recession in corporate health care business (strategic divestiture/merger/acquisition are primarily for performance enhancement). The least capital intensive industry in terms of sunken cost recovery is health care service where individual professional targets are mostly overshot as health care service selling is haggle free and the tactics of selling relay on increasing the level of ignorance of the patients/customer and or consumer which in a way is supported by invisible concocted medical research inferences propagated by pharmaceutical industry mostly. None of the nodal agencies till date could bring in any semblance of standardization in the corporate/ private health care system offerings to patients though there are more than few regulations in this regard. Infinitesimal segment of society (of government, corporate staff) benefit from copious health care support while majority are left to lurk in ill health prevalent in government health institutions. It’s known to all that almost all of central or state ministers of India sought government institutions when they contacted Covid19. Instances of squandermania in Covid19 emergency medical supplies purchases amplify unethical behavior. India would have achieved quantum leap in harnessing numbers of bank accounts, income tax PAN cards, dazzle of digitalization but is at rock bottom when it comes to digitalized health information (Aadhar card fails to offer basic health information of the individual needed in health emergency of an individual). India may have superior digital knowledge but benefit from it to health care needs of Indian society is stupendously low. Unregulated devious ways of health insurance has only added misery to the hapless patients while colluding in profiteering with health care professional institutions. All the above are only a glimpse of tip of the iceberg of abnormal apathy and plight of pathetic majority Indian patients. Above and more similar not cited due to limitations of this article will testify for lack of ethical behavior among all stakeholders (other than patients)

**Patient empowerment & patient centered care: one speck of GCC & Indian scenario**

Gulf Cooperation Council (GCC), cluster of six Arab countries sandwiched between Persian Gulf and Red Sea with less than one fifth population of India (World population review GCC countries, 2019). GCC is nowhere near India in terms of technology, human power and in digitalization (other factors/aspects of development not considered). Majority of the health care professionals in GCC are either from India, Egypt from oriental Asian and or EU/ American origin (Hassan, 2015). With no more than twenty pharmaceutical manufacturing units, GCC imports most of the medications and medical equipments. In spite of slip in petro economy, GCC nations have been offering value added health care service to its citizens and to the expatriate population (more than half of the total population). Happiness is synonymous with health; probably UAE in GCC is one of the few nations to have an exclusive minister of state to work towards happiness of her residents (National programme for happiness and wellbeing UAE, 2016). What was a semblance of health care regulatory activity in early twenties is now state of art regulatory system in all GCC nations so the quality of imported medicines, equipments and personnel are fool proof. Stringent enforcement of quality system by respective Ministry of Health authorities, in spite of burgeoning mini, medium corporate health care institutions in recent past in GCC, has only enhanced quality of health care service unlike in India. One unique observation about GCC health care system is; adherence to legal compliance in health care system is uncompromised (Saudi food and drug administration, 2019). To cite an example of health care development, Kingdom of Bahrain had just two corporate and two government health care institutions in early twenties, can now boast of state of art cardiac center and three world class medical teaching school with most stringent service quality, health information system (Central Population Registry card, the equivalent of Aadhar, unlike Aadhar is linked to health information of the individual). Most of the GCC airports are a bridge to travelers from east to west and to African nations but pandemic like Dengue is least or unheard of due to stringent control and pre emptive measures by the authorities. While Indian pharmaceutical industry has harnessed the top slot as a supplier of generic drugs to the world, it is nowhere in reaching essential drugs to the society at affordable price. An undocumented fact is that most of Indian expatriates including menial manual laborers cling to GCC for the sake of quality health care service apart from avoiding day to day hassles of existence in India. GCC nations still lack advanced medical and technological service but what they have is well regulated corruption free ethical quality health care system which is spread across all its population uniformly. Needless to cite, innumerable incidences of death for want of basic medical amenities in India is a bitter pill to ingest. Over the years India has only created great void in health care services between haves and have not’s. Below is a dose of reality with regards to child mortality in GCC nations and in India to amplify the Indian apathy to compliance and ethics in health care system.

Table 1

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Nation | KSA | Qatar | Kuwait | UAE | Oman | Bahrain | India | Remarks |
| Population in million | 34.32 | 2.64 | 4.22 | 9.12 | 4.56 | 1.425 | 1324 |  |
| Population growth in % | 1.68 | 1.81 | 1.69 | 1.45 | 3.01 | 4.6 | 1.19 |  |
| % Paediatric population | 31.2 | 12.6 | 41 | 19.5 | 42.6 | 36.6 | 28.6 |  |
| % of cancer survival in paediatric population | NA | NA | NA | NA | NA | NA | 35 | Global survival rate 80 as per Global Burden of Disease (Global burden of disease, 2019) |
| Probability of dying under 5 years | 7 in 1000 | 8 in 1000 | 8 in 1000 | 9 in 1000 | 11 in 1000 | 7 in 1000 | 39 in 1000 |  |
| Stringent Health regulatory agency | Yes | Yes | Yes | Yes | Yes | Yes | ? |  |
| Digitalized patient health data availability | Yes | Yes | Yes | Yes | Yes | Yes | ? |  |
| Rehabilitation for chronic / genetic disorder patients | Yes | Yes | Yes | Yes | Yes | Yes | ? |  |

Source of information in Table 1 are from World Bank, World Population Review, UNESCO & from author’s data on file

**Analysis/ Inference**

There is no iota of patient empowerment and patient centered care in India as can be inferred from this study for majority of population, while most privileged class of society enjoy benefits out of enormous patient empowerment and patient centered care on demand. Deplorable disparity is due to public health policy without ethical standards. Nevertheless all the stakeholders are equally responsible for diminishing patient empowerment and for deficient patient centered care in India. GCC health care service is far better in empowering patients and in offering patient centered care. Repeated serious harm to majority of victims at too soon frequency is some of the criteria to frame a situation as an unethical one calling for ethical reasoning (Velasquez, 2016). Opinion of experts, ground reality as seen and reported in media point to imminent need to revisit and or redo health policy based on ethical principles

**Conclusion**

Patient empowerment and patient centered care in word and spirit may be utopian, very vague and vexing to determine or define in Indian context. Nevertheless, strides in the direction of adherence to ethical standards by all stakeholders can to large extent empower and offer patient centered care. India has the wherewithal, it only lacks strong will and vision in terms of offering health security by way of patient empowerment and patient centered care. For patient centeredness and empowerment, information on/to patients, patient involvement, and relationship between healthcare stakeholders and patients are essentials (Cynthia Bonsignore, 2017). Information on patient being the initial first step towards patient cantered care and empowerment, basic health data of citizens need to be included in the Aadhar card and linked to mobile contact (for want of which has lead to uncontrolled explosion of Covid19 due lack / impossibility of contact tracing (Kadidal, 2020)). Recent introduction of Bhartiya Jan Aushdhi Yojana and Jan Arogya Yojana schemes with lofty objectives of reaching affordable medicines and health care service to majority population will have double benefit if linked to Aadhar, registered Mobile phone and PAN income tax data. Contribution of all related health care regulatory authorities are vital for patient empowerment and patient centered care. Digitally linking all the primary, secondary and tertiary health care centre and creating a national/ state health information system to be the foremost step, followed by linking all corporate hospital with national/ state health information system need be the objectives as one of the essentials in offering patient empowerment and patient centered care apart from stringent pro patient legal provisions, and elimination of ubiquitous corruption deep rooted in medical service in India. Like in many countries, periodic (at least ones in two years) validation to practice as a health care professional through evaluation by competent licensing authority will to large extent reduce medical negligence and improve quality of service and accountability. Other than legal compliance, ethical compliance need to be in place as they are the foundation for patient empowerment and patient centered care. According to the World Health Organization, a well-functioning healthcare system requires a steady financing mechanism, a properly-trained and adequately-paid workforce, well-maintained facilities, and access to reliable information to base decisions on (Best helthcare in the world, 2019); which is apt for present Indian healthcare scenario. High levels of patient empowerment and centeredness require a total shift in mindset of stakeholders on ethical behaviour, health care design and delivery. Patient empowerment and patient centered care at least as in GCC nations is possible, but not in near future in India at the present level…

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