Medicine and Society

Patients' awareness of their rights: A cross-sectional study exploring the Indian perspective

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INTRODUCTION

Countries across the world believe that all patients irrespective of their race, gender, caste, creed, religion or belief and nationality are entitled to certain basic rights[1] while availing medical facilities, resulting in a consensus that physicians, healthcare providers and governments should safeguard patients' rights. The developed world strives proactively to enlighten their citizens about their rights as patients owing to their commitment to the WHO's declaration[2] on the promotion of patients' rights. Health being a universally acknowledged parameter to measure human development, raising quality of health through increasing awareness of patients' rights becomes inevitable in many developing countries.[3] There is growing concern for patients' rights in India, but the challenge is that health is still on lower priority for the majority of its population wherein the public may get less chance to know their rights as patients.[4]

The efforts to increase awareness of patients' rights by hospitals and governments are solely based on their expected contributions to medical efficiency,[5] medical practices and to improve understanding between medical staff and patients.[6] No government can ignore its duty to protect the patients' rights because its implementation is primarily a matter of national concern[2] and a constitutional commitment in case of India as per Article 21 of the Constitution of India.[7]

Considerable efforts have been made to get patients aware about their rights either through laws or guidelines or discussions by professional bodies and the Government of India. The Constitution of India sets the tone for patients' rights by scripting 'protection of life and personal liberty'.[7] A Code of Ethics Regulations published in 2002 by the Medical Council of India (MCA) deals with the duties and responsibilities of physicians in addition to certain rights of patients.[8] The Indian Medical Association (IMA) Code of Conduct for respecting patients' rights urges doctors to take a pledge on both informed consent and informed refusal from the patient towards any medical or surgical treatment.[9] Jan Swasthya Abhiyan, started in 2001, emphasized the Right to Health and Healthcare as basic human rights, which are set out as the major objectives in its document called People's Health Charter.[10]

Under the right to information, the people have the right to know their fundamental rights conferred by the Constitution of India[7] and the court of law.[11] In Paschim Banga Khet Mazdoor and others versus State of West Bengal and others,[12] the Supreme Court, referring to Article 21, held that it is the primary duty of a welfare State to ensure that medical facilities are adequate and available to provide treatment. Many rulings by the Court have strengthened the provisions to protect patients' right as in another case, Re T (Adult Refusal of Medical Treatment) case,[13] where the Court found that patients have a right to refuse treatment. Awareness of rights makes the service providers professionally competent and diligent. It can also be argued that medical studies should be open not only to future physicians, but also to laypersons, who through this scientific education could 'form a just estimate of the physician's knowledge'. Medicine, it is argued, would progress much more rapidly, if physicians were to practise 'under the inspection and patronage of men qualified to judge their merit, and who were under no temptation, from sinister motives, to depreciate it'.[14]

There have been a few studies on the status of patients' rights in India,[15–17] but none of them cover the entire aspects of patients' rights across different demographic variables of patients. The studies can be augmented by the reason that variables such as gender, age, education level, place of residency and entitlement also explain the variations in awareness of patients' rights as discussed in the studies of a few researchers.[18,19] In India, there are various legal provisions and norms such as the Constitution, MCI Regulations, IMA Code of Conduct, Jan Swasthya Abhiyan People's Health Charter and Indian Council of Medical Research,[7–10,20] which contribute to the evolution and existence of patients' rights. The draft of Charters of Patients' rights[21] is a compilation of patients' rights guided by the national and international level provisions. The objective of the draft was to make them publicly known in a coherent manner.[10] Whether or not these measures have reached the patients is, however, a question due to several impediments such as low physician–population ratio, illiteracy, indifferent attitude of healthcare providers, poor empowerment of patients[22] and lack of systemic mechanisms to make patients aware of their rights.We examined the awareness level of patients' rights among patients and assessed the association between patients' demographic characteristics and their awareness.

METHODS

We did a cross-sectional descriptive study on awareness of patients' rights in five selected multispecialty hospitals in Tamil Nadu including two teaching hospitals, two 100-bedded hospitals and one corporate hospital. We included inpatients of private hospitals. Convenience sampling method was used to choose the patients from the general and private wards of general medicine, general surgery, orthopaedics, obstetrics

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and gynaecology, dermatology, ENT and ophthalmology departments. The sampling method was adopted because (i) inpatients recruited for this study needed to be fully conscious, willing and able to give consent and (ii) there incidents of patients were few transferred to critical departments at any point of time. Patients admitted to acute care and paediatrics units were excluded from the study. Hospitals of small to large size were included to capture patients with diverse backgrounds. With a 50% prevalence of variability and 5% level of significance, the sample size was calculated at 384 patients. As the selected hospitals differ in terms of bed occupancy, the samples were distributed across the hospitals proportionate to their bed occupancy. The quota was calculated by the number of admissions in the study month in each hospital divided by the overall admissions of that particular period as estimated in previous studies.[5,23]

Data were collected using a structured questionnaire, divided into two sections; the first section comprised demographic information containing gender category (inclusive of transgender), age, level of education, income, residential status and entitlement (insured or not). Relating the level of patient rights awareness to the demographic characteristics of patients is considered relevant as patients' rights vary in different countries and are determined by the patient's status, income and other related characteristics.[12] The second section of the questionnaire consisted of 73 measurable items (MIs) taken from 17 patients' rights (Table I). The patients' rights, which are the constructs of this study, are based on the source documents such as UN's Universal Declaration of Human Rights,[24] WHO's Declaration on the Promotion of Patients' Rights in Europe[25] and mostly from the Patient Charter declared by India.[21]

The level of awareness of patients' rights was gauged by means of Likert scale ranging from 5 (high degree of awareness) to 1 (zero awareness). By abstracting the arithmetic mean of each of the 17 patients' rights, the mean between 1 and 2 was contemplated as zero awareness, 2.01–4 as moderate and 4.01–5 as high degree of awareness. The MIs in the questionnaire were checked for their reliability using alpha-Cronbach test, the coefficient of which was 0.98. The alpha coefficient for 17 rights (each patient right has MIs ranging between 3 and 6) was 0.95 to 0.99. The questionnaire was also validated by seeking advice from healthcare experts and teaching faculty of Sri Ramachandra Institute of Higher Education and Research (SRIHER), the affiliating university of the authors.

The questionnaire was administered among inpatients after apprising them of the intents of the study; subsequently, their consent was received in writing. Data were analysed using chi-square to determine the relationship of patients' rights awareness with gender, age, educational level, income, place of residence, entitlement of patients, history of previous hospitalization and income. Calculations were made using SPSS software (SPSS version 22); $p<0.05$ was adopted as the level of statistical significance.

Ethical compliance

Ethical approval was obtained from the Institutional Ethics Committee of SRIHER, Chennai, before data collection. Written informed consent was obtained from all respondents after providing them written information about the study.

RESULTS

The majority of respondents were women (63.5%) and the educational level of 45.6% of patients was below high school (Table II). Most of the patients were uninsured (66.2%) and 90.4% of patients had an annual income <₹500 000, whereas 52.1% of patients were hospitalized for the first time.

Among 17 patients' rights, 1, 3, 4, 5, 7–9, 11, 12, 16 and 17 were well known to the patients while there was moderate level for 2, 6, 10 and 13–15. Right number 3 had the highest degree of awareness with a mean (SD) score of 4.36 (0.86) and 15 had the lowest (3.77 [1.20]; Table I). Awareness (high and moderate) about patients' rights did not vary much across all rights and ranged between 85.2% and 96.4% (Appendix 1).

We found no significant relationship between patients' demographic characteristics and their awareness of rights (Table III). Insurance and history of previous hospitalization were not associated with awareness of any patients' rights among patients, whereas age, gender, education, occupation, rural and urban residence and income showed some relationship with awareness of few patients' rights.

However, patients' age was associated with awareness of right numbers 9, 14, 16 and 17. The patients' gender influenced awareness of right numbers 2 and 6, while level of education of patients effected awareness of right number 3. Occupation had

TABLE I. Awareness about patients' rights

S.No.	Patients' rights	Mean (SD)
1	Right to information	4.10 (0.86)
2	Right to records and reports	3.96 (1.12)
3	Right to emergency medical care	4.36 (0.86)
4	Right to informed consent	4.13 (0.95)
5	Right to confidentiality, human dignity and privacy	4.15 (0.81)
6	Right to second opinion	3.95 (1.00)
7	Right to transparency in rates, and care	4.05 (0.90)
8	Right to non-discrimination	4.32 (0.91)
9	Right to safety and quality care according to standards	4.33 (0.82)
10	Right to choose alternative treatment options	3.99 (0.94)
11	Right to choose source for obtaining medicines/tests	4.10 (1.00)
12	Right to proper referral and transfer	4.01 (1.05)
13	Right to protection for patients involved in clinical trials	3.91 (1.04)
14	Right to protection of participants involved in biomedical and health research	3.79 (1.16)
15	Right to take discharge of patient, or receive body of deceased from hospital	3.77 (1.20)
16	Right to patient education	4.05 (1.05)
17	Right to be heard and seek redressal	4.01 (1.00)

a robust relationship with awareness of right numbers 10, 13 and 14. Patients' location of residence was associated with right numbers 11 and 17. A statistically significant association was found between income of patients and awareness of right numbers 2, 5, 11, 12 and 17.

TABLE II. Demographic characteristics of samples

Characteristic	Frequency (%)
Gender	
Men	140 (36.5)
Women	244 (63.5)
Transgender	0
Age (years)	
18–30	107 (27.9)
31–45	127 (33.1)
46–60	83 (21.6)
>60	67 (17.4)
Educational level	
Below high school (<10th grade)	175 (45.6)
High school graduate (10th–12th grade)	70 (18.2)
Graduate	101 (26.3)
Postgraduate	34 (8.9)
Doctorate and above	4 (1.0)
Occupation	
Employed	96 (25.0)
Unemployed	168 (43.8)
Self-employed	100 (26.0)
Retired	20 (5.2)
Entitlement status	
Insured	130 (33.9)
Non-insured	254 (66.2)
Residential status	
Urban	201 (52.3)
Rural	183 (47.7)
History of previous hospitalization	
Yes	184 (47.9)
No	200 (52.1)
Income (per annum in ₹)	
<500 000	347 (90.4)
500 001–1 500 000	30 (7.8)
1 500 001–5 000 000	5 (1.3)
>5 000 000	2 (0.5)

DISCUSSION

Our survey of inpatients showed that the awareness level of all the rights was ≥3.77 on a scale of 5. The awareness ranged between 3.77 and 4.36 indicating a robust level of awareness. Patients admitted for the first time were no exception to this. High awareness of patients' rights was largely independent of the demographic variables. These findings are in agreement with the notion that patients are keen to know their rights. The findings also reverse a myth that the doctor in India is the authoritative person who prevents patients from enjoying the benefit of knowing the details of treatment.[26] India being the fastest growing technology hub in the world is one reason why there is an increase in awareness of patients' rights whereas the findings of similar studies in other countries show a moderate-to-low level of awareness.[5,23,27]

The rights such as informed consent (4) may not require much effort to keep patients informed because in many instances, consent may be implied by the conduct of the patient. A patient who voluntarily seeks treatment or presents himself or herself at a hospital for a routine procedure implies his or her consent to treatment.[28] A study revealed the important deficiencies in research participants' understanding of core elements of informed consent,[29] which can be rectified through counselling of patients.

Law of the State may also determine the degree of awareness. The highest awareness of rights to emergency medical care may be attributed to the fact that the Clinical Establishments Act was enacted to provide free emergency care, and its misuse led to enactment of the 'Tamil Nadu Medicare Service Persons and Medicare Service Institutions (Prevention of Violence and Damage or Loss to Property) Act, 2008'.[30] Accreditation plays a vital role, and may be a strong predictor of patients' rights awareness since accreditation has proved a determining factor for hospitals to implement standards and measures protecting patients.[31] A survey[32] provided evidence that public reporting may be substantially impacting hospital quality improvements and reporting efforts.

TABLE III. Association of patients' rights with their demographic characteristics

S.No.	Age	Gender	Education level	Occupation	Insurance	Residence	Previous hospitalization	Income
1	0.901	0.205	0.772	0.836	0.166	0.253	0.145	0.668
2	0.114	0.025*	0.704	0.309	0.701	0.248	0.576	0.031*
3	0.161	0.397	0.043*	0.182	0.38	0.725	0.379	0.902
4	0.127	0.744	0.439	0.41	0.868	0.362	0.006*	0.881
5	0.264	0.062	0.166	0.775	0.866	0.473	0.126	0.039*
6	0.117	0.044*	0.426	0.676	0.983	0.128	0.409	0.096
7	0.763	0.268	0.527	0.81	0.432	0.718	0.24	0.394
8	0.734	0.224	0.446	0.529	0.453	0.427	0.044*	0.533
9	0.027*	0.074	0.205	0.758	0.714	0.379	0.786	0.728
10	0.138	0.306	0.079	0.008*	0.516	0.779	0.893	0.385
11	0.145	0.85	0.522	0.173	0.053*	0.041*	0.472	0.023*
12	0.133	0.126	0.216	0.361	0.709	0.635	0.734	0.046*
13	0.267	0.763	0.282	0.025*	0.993	0.623	0.022*	0.885
14	0.005*	0.309	0.182	0.029*	0.766	0.876	0.865	0.176
15	0.051*	0.138	0.119	0.526	0.889	0.139	0.297	0.506
16	0.023*	0.53	0.163	0.377	0.353	0.249	0.602	0.255
17	0.025*	0.531	0.325	0.377	0.157	0.015*	0.074	0.000*

All figures are p values * statistically significant

The benefits of a high awareness level are arguable. A researcher[15] found a high awareness but felt that this may not be true in practice in hospitals. Although the level of awareness was satisfied, the level of outcomes should not be converse. Such phenomenon is common in developing countries due to a discrepancy between 'being aware of rights' and 'being practised'. A study[33] states that right number 13 was abstract in India due to widespread illiteracy making it easy for pharmaceutical companies to ignore obtaining informed consent.

Limitations

Our survey was administered only among inpatients. Hence, it may not reflect the awareness of outpatients, other patients going to clinics and the public at large. As it was done in private hospitals it is less likely to represent similar patients in government hospitals with a highly divergent patient population in terms of patients' education level and income. Our findings, showing overall awareness level of patients' rights, argue for broad representation from the community in future investigations.

Conclusions

Most patients were aware of their rights. The awareness level was not significantly associated with their demographic characteristics indicating that the patients irrespective of their diverse backgrounds were aware of their rights. Nevertheless, awareness of patients' rights may not necessarily guarantee the enforcement of rights in hospitals in many developing and least-developed economies. There is not much respect for patients' rights in these countries, and in case of violations, the only recourse for patients is to approach consumer courts. Laws, charters, amendments and enactments will be of use if governments strengthen the monitoring and enforcement wings that guard the rights of patients and protect them from exploitations. Public reporting of quality indicators, quality improvement initiatives of hospitals and compliance with standards have a positive impact on the performance of hospitals whereby the protection of patients' rights may get highlighted.

Hospitals should have committees to ensure protection of patients' rights. These committees should review all complaints from patients through efficient procedures and direct physicians to take proper care to protect patients' rights. The findings of this study may help the various stakeholders of hospitals to evolve a framework of education, training and communication that raise the level of awareness of patients' rights. Furthermore, the outcomes may help the government to take policy decisions for hospitals and accreditation agencies to ensure an increasing level of practices and enforcement of patients' rights in their routine working mechanisms. Future research should investigate whether and how patients' rights are seen as practice and extent of impact of patients' rights awareness on quality of medical treatment.

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Conflicts of interest. None declared

REFERENCES

1 WHO. *The Constitution of WHO*. Geneva:WHO; 1986. Available at *www.who.int/governance/eb/who_constitution_en.pdf* (accessed on 3 Mar 2020).
2 Abbing HD. Twenty year WHO principles of patients' rights in Europe, a common framework: Looking back to the future. *Eur J Health Law* 2014;**21:**323–37.
3 Rahman RM. Human rights, health and the state in Bangladesh. *BMC Int Health Hum Rights* 2006;**6:**4.
4 Kasthuri A. Challenges to healthcare in India—The five A's. *Indian J Community Med* 2018;**43:**141–3.
5 Mastaneh Z, Mouseli L. Patients' awareness of their rights: Insight from a developing country. *Int J Health Policy Manag* 2013;**1:**143–6.
6 Danute D, Vladickiene J, Kalediene R, Haapala I. Awareness and practice of patient's rights law in Lithuania. *BMC Int Health Hum Rights* 2006;**6:**10.
7 The Constitution of India as on 9th December, 2020. Available at *https://legislative.gov.in/sites/default/files/COI_1.pdf* (accessed on 28 Apr 2021).
8 Medical Council of India (Professional Conduct, Etiquette & Ethics) Regulations; 2002. Available at *www.nmc.org.in/rules-regulations/code-of-medical-ethics-regulations-2002* (accessed on 28 Apr 2021).
9 Indian Medical Association Code of Conduct. Available at *www.ima-india.org/ima/left-side-bar.php?pid=462* (accessed on 28 Apr 2021).
10 Jan Swasthya Abhiyan's Peoples Health Charter; 2015. Available at *https://phmindia.org/about-us* (accessed on 28 Apr 2021).
11 Dresser R. Research information for reasonable people. *Hastings Cent Rep* 2018; **48:**3–4.
12 Supreme Court Judgment; 1996. Available at *https://indiankanoon.org/doc/1743022/* (accessed on 29 Apr 2021).
13 Supreme Court Judgment; 1992. Available at *www.globalhealthrights.org/wp-content/uploads/2013/03/EWCA-1992-In-re-T-adult-refusal-of-medical-treatment.pdf* (accessed on 29 Apr 2021).
14 Haakonssen L. Medicine and morals in the enlightenment: John Gregory, Thomas Percival and Benjamin Rush. *Clio Med* 1997;**44:**i–x, 1–247.
15 Fernandes AB, D'Cunha S, Suresh S. Patient rights: Awareness and practice in a tertiary care Indian hospital. *Int J Res Found Hosp Healthc Adm* 2014;**2:**25–30.
16 Agrawal U, D'Souza BC, Seetharam AM. Awareness of patients' rights among inpatients of a tertiary care teaching hospital—A cross-sectional study. *J Clin Diagn Res* 2017;**11:**C01–C06.
17 Ramnika A, Sumita S, Renu G, Rajesh K. Study of awareness of patients' rights among under-graduate medical students. *J Clin Diagn Res* 2018;**12:**1–4.
18 Abedi G, Askarian M. Awareness and observance of patient rights from the perspective of Iranian patients: A systematic review and meta-analysis. *Iran J Med Sci* 2017;**42:**227–34.
19 Massod S, Rahman M, Humaria M, Shazia N, Shamila M. Awareness among hospitalized patients of their rights: A cross sectional survey from tertiary care hospital of Rawalpindi. *Pak Armed Forces Med J* 2016;**66:**651–6.
20 The Indian Council of Medical Research Ethical Guidelines; 2017. Available at *https://main.icmr.nic.in/sites/default/files/guidelines/ICMR_Ethical_Guidelines_2017.pdf* (accessed on 28 Apr 2021).
21 Government of India. Charter of Patients' Rights for Adoption by NHRC. National Council Secretariat. Ministry of Health and Family Welfare. Govt. of India; 2018. Available at *http://clinicalestablishments.gov.in/WriteReadData/8431.pdf* (accessed on 29 Aug 2019).
22 Ghooi RB, Deshpande SR. Patients rights in India: An ethical perspective. *Indian J Med Ethics* 2012;**9:**277–81.
23 Yaghobian M, Kaheni S, Danesh M, Rezayi Abhari F. Association between awareness of patient rights and patient's education, seeing bill, and age: A cross-sectional study. *Glob J Health Sci* 2014;**6:**55–64.
24 UN. Declaration of Human Rights. 50th Anniversary of the Universal Declaration of Human Rights; 1948–1998. Available at *https://digitallibrary.un.org/record/252125?ln=en#record-files-collapse-header* (accessed on 29 Aug 2020).
25 WHO. Declaration on the promotion of patients' rights in Europe, European consultation on the rights of patients; April 1994. Available at *www.who.int/genomics/public/eu_declaration1994.pdf* (accessed on 29 Sep 2020).
26 Yousuf RM, Fauzi AR, How SH, Akter SF, Shah A. Hospitalised patients' awareness of their rights: A cross-sectional survey from a tertiary care hospital on the east coast of Peninsular Malaysia. *Singapore Med J* 2009;**50:**494–9.
27 Al Qahtani NA, Sattam MA, Fisal AA, Meshari AA, Amer SA, Marwan AA, *et al*. Assessment of the patients' awareness regarding their rights and responsibilities in the major governmental hospitals in Riyadh, Saudi Arabia. *Int J Med Dev Ctries* 2019;**3:**198–203.
28 Mathiharan K. Law on consent and confidentiality in India: A need for clarity. *Natl Med J India* 2014;**27:**39–42.
29 Gota V, Nookala M, Yadav A, Menezes SR, Kannan S, Ali R. Quality of informed

consent in cancer clinical trials in India: A cross-sectional survey. *Natl Med J India* 2018;**31:**334–8.
30 Government of Tamil Nadu. No. 48 of 2008—Tamil Nadu Medicare Service Persons and Medicare Service Institutions (Prevention of Violence and Damage or Loss to Property) Act, Tamil Nadu Government Gazette Extraordinary 2 December; 2008. Available at *www.stationeryprinting.tn.gov.in/extraordinary/2008/364-Ex-IV-2.pdf* (accessed on 9 Sep 2020).
31 Longo DR, Hewett JE, Ge B, Schubert S. Hospital patient safety: Characteristics of best-performing hospitals. *J Healthc Manag* 2007;**52:**188–205.
32 Laschober M, Maxfield M, Felt-Lisk S, Miranda DJ. Hospital response to public reporting of quality indicators. *Health Care Financ Rev* 2007;**28:**61–76.
33 Nundy S, Gulhati CM. A new colonialism? Conducting clinical trials in India. *N Engl J Med* 2005;**352:**1633–6.

Appendix 1.
Distribution of frequency of awareness of patients' rights

S.No.	Patients aware, *n* (%)	Patients moderately aware, *n* (%)	Patients not aware, *n* (%)
1	296 (77.08)	74 (19.27)	14 (3.65)
2	280 (72.92)	61 (15.88)	43 (11.20)
3	327 (85.16)	41 (10.67)	16 (4.17)
4	305 (79.43)	56 (14.58)	23 (5.99)
5	312 (81.25)	60 (15.62)	12 (3.13)
6	269 (70.05)	87 (22.66)	28 (7.29)
7	307 (79.95)	50 (13.02)	27 (7.03)
8	321 (83.59)	43 (11.19)	20 (5.21)
9	338 (88.02)	29 (7.55)	17 (4.43)
10	290 (75.52)	68 (17.7)	26 (6.77)
11	300 (78.13)	53 (13.8)	31 (8.07)
12	285 (74.22)	66 (17.19)	33 (8.59)
13	270 (70.32)	80 (20.83)	34 (8.85)
14	252 (65.63)	78 (20.31)	54 (14.06)
15	257 (66.93)	70 (18.23)	57 (14.84)
16	285 (74.22)	63 (16.40)	36 (9.38)
17	293 (76.30)	59 (15.37)	32 (8.33)