Assessment of Patient Privacy and Confidentiality in District Hospital Varanasi, Uttar Pradesh

By

Priyanka Sharma

Dissertation submitted for the partial fulfillment of the

MBA Hospital and Health Management

Academic year, 2015-2017

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INSTITUTE OF HEALTH
MANAGEMENT RESEARCH
(WHO Collaborating Centre for District Health System Based on Primary Health Care)

IIHMR UNIVERSITY

TO WHOMSOEVER MAY CONCERN

This is to certify that Priyanka Sharma student of MBA Hospital and Health Management from The IIHMR University, Jaipur has undergone internship training at National Health Systems Resource Centre, New Delhi from 6-02-2017 to 5-05-2017.

The Candidate has successfully carried out the study designated to her during internship training and her approach to the study has been sincere, scientific and analytical.
The Internship is in fulfillment of the course requirements.

I wish her all success in all her future endeavors.

Dean, Academics and Student Affairs
The IIHMR University, Jaipur

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Technical Support Institution with National Rural Health Mission
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The certificate is awarded to

Dr. Priyanka Sharma

In recognition of having successfully completed her
Internship in the department of

Public Health Administration

and has successfully completed her Project on

ASSESSMENT OF PATIENT PRIVACY AND CONFIDENTIALITY IN DISTRICT HOSPITAL VARANASI, UTTAR PRADESH

Date 5/5/2017

National Health Systems Resource Centre

She is a committed, sincere & diligent person with a strong drive and zeal for learning

I wish her all the best for future endeavors

Dr. Himanshu Bhushan
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THE IIHMR UNIVERSITY, JAIPUR

CERTIFICATE BY SCHOLAR

This is to certify that the dissertation titled **ASSESSMENT OF PATIENT PRIVACY AND CONFIDENTIALITY IN DISTRICT HOSPITAL VARANASI, UTTAR PRADESH** and submitted by **Priyanka Sharma** Enrollment No. iihmr.u/01.2015-2017/0328 under the supervision of **Dr. Nutan Jain** for award of MBA in Health and Hospital Management of the University carried out during the period from 6-02-2017 to 5-05-2017 embodies my original work and has not formed the basis for the award of any degree, diploma associate ship, fellowship, titles in this or any other institute or other similar institution of higher learning.

Priyanka Sharma

Signature

THE IIHMR UNIVERSITY, JAIPUR

CERTIFICATE BY SCHOLAR

This is to certify that all ethical issues have been considered while collecting data for my dissertation titled Assessment of Privacy and confidentiality in District Hospital,Varanasi, Uttar Pradesh.

Priyanka Sharma
Signature of student

ABSTRACT

Title: ASSESSMENT OF PRIVACY AND CONFIDENTIALITY IN DISTRICT HOSPITAL VARANASI, UTTAR PRADESH

Author: Priyanka Sharma

Background:

Privacy and confidentiality are cornerstones of the doctor-patient relationship. Patients must feel comfortable disclosing all relevant information, most of which is highly sensitive in nature

Maintaining the rights of patients, including privacy and confidentiality of medical information is the basis for a successful patient-physician relationship. It is in this regard that the following analysis studies the existing conceptions of privacy in the Healthcare sector. It aims to study the existing mechanisms of privacy protection and their application in everyday practices in a district hospital setting.

Objectives:

The objectives of the study are:

• To review norms and/or guidelines related to privacy and confidentiality in healthcare setting.

• To assess knowledge, attitude and practices of service providers, managers and users of facility-based public health services on privacy and confidentiality in public health facilities.

Methodology:

The study is descriptive in nature. The study was conducted at district hospital, namely Pt. Deen Dayal Upadhyay District Hospital Varanasi, which also caters the need for the adjoining districts during February-April 2017. The first part assesses domestic legislation for the provisions of privacy and confidentiality. For the second part of the study primary data was collected and analyzed regarding knowledge, attitude and practice of the health service providers and users of public health facilities. A total of 196 respondents were interviewed out of which 30 were doctors, 60 were nursing staff and 106 were the users of district hospital health services. Attitudes regarding privacy and confidentiality were measured using a five-point rating scale but middle point "neutral" was not used.

Results and Conclusion:

Review of the present legislature and regulations like Mental Health Act, PCPNDT Act, and MTP Act suggest that the Right to Privacy has been embodied in a multitude of domestic legislations pertaining to the healthcare. A strong foundational framework where the rights are addressed and find mention in a single document is still awaited. The embodied laws and regulation need to seep down to the level of healthcare service delivery

at the facility level and need to be reflected in the knowledge and practice of healthcare providers which is lacking presently.

Knowledge of the privacy and confidentiality was found low among patients. A majority of patients (95 percent) do not know about their right to privacy and confidentiality, which is the reason for their not being empowered enough to seek private and confidential health care.

To ensure that patients' rights are observed it is not sufficient merely to issue guidelines and instructions. It is essential also to provide education for care providers and medical students, as well as patients and their families, so that a joint approach may be adopted by all concerned. A comprehensive strategy is needed to engage with members of the public and the media through educational programs and information campaigns regarding all aspects of patients' rights to privacy and confidentiality and a suitable legal framework for patients' rights needs to be developed and implemented.

Keywords:

Privacy, confidentiality, knowledge, attitude

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Lastly but not least, I would like to express my adoration and regards to my parents and siblings who have been a constant source of support.

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LIST OF ABBREVIATIONS

ASHA: Accredited Social Health Activist

AWW: Anganwadi Worker

CHC: Community Health Centre

CDR: Child Death Review

GoI: Government of India

FP: Family Planning

HBNC: Home Based New born Care

HIV: Human Immunodeficiency Virus

IEC: Information Education Communication

IPD: In Patient Department

IPHS: Indian Public Health Standards

IRDA: Insurance Regulatory and Development Authority

JSSK: Janani Shishu Suraksha Karyakram

MCH: Maternal and Child Health

MCI: Medical Council of India

MDR: Maternal death review

MoHFW: Ministry of Health and Family Welfare

NACO: National AIDS Control Organization

NCD: Non Communicable diseases

NUHM: National Urban Health Mission

OPD: Outpatient Department

PCPNDT: Pre Conception Pre-Natal Diagnostic test

RKS: Rogi Kalyan Samiti

TI: Targeted Intervention

WHO: World Health Organization

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ASSESSMENT OF PRIVACY AND CONFIDENTIALITY IN DISTRICT HOSPITAL VARANASI, UTTAR PRADESH

INTRODUCTION

"There exists no universally definition of the right to privacy and confidentiality. This topic is evolving continuously and its extent as well as nature is context driven largely. Numerous aspects to the right to privacy are there, each of which are different from one another in terms of the circumstance in which they're invoked." (cis-india, 2014) "Bodily privacy however, is to the date, the most guarded facet of this vastly comprehensive right." (cis-india, 2014) "The privacy over one's own body including organs, genetic material and biological functions that make up one's health is an inherent right that does not; as in the case of other forms of privacy such as communication or transactional privacy, emanate from the State." (cis-india, 2014) "This right that has its foundations in the Natural Law conceptions of The Right to Life, which although regulated by the State can at no point be taken away by it except under extreme circumstances of a superseding Right to Life of a larger number of people.[1"] (cis-india, 2014)

"The contemplation over the formation of a universally applicable Right to Privacy until now has only been as an extension of the Fundamental

Right to Life and Liberty (Article 21) and freedom of expression and movement (Articles 19(1) (a) and (b)) of the Constitution of India. A valid interpretation this might be, but it narrows the scope of this right of privacy and confidentiality. However the right to privacy and confidentiality has much larger implications" (cis-india, 2014). "Thus there is an imminent need to create a sound and efficient structure of legislation and policies that would regulate the safeguarding of privacy in Institutions/facilities[1]." (cis-india, 2014)

RATIONALE

"The aim of this study is to chart the amalgamation, body and implementation of privacy provisions in laws within the healthcare sector in India. It reviews the legislation relating to numerous aspects of the healthcare sector and legal provisions that provide for the protection of the privacy and confidentiality of individuals who furnish their personal information and genetic material to facilities of healthcare, either for the purpose of treatment or for research. It is however vital that the information collected be limited by construction of safeguards at an institutional level that trickle down to routine practices of healthcare data collection, management and storage within healthcare institutions.[1"]

"The aim of the study is to review the existing provisions of privacy protection in the form of laws, guidelines and to see the actual practices in government hospital for determining the present status of privacy and confidentiality."

REVIEW OF LITERATURE

"The right to privacy and confidentiality is cardinal human right that is vouched for by international standards. It is legally protected, cannot be waived or taken away, and is universally applicable (WHO 2002).The **Universal Declaration of Human Rights** (Article 12, 1948) states that no one shall be subjected to arbitrary interference with his/her privacy, family, home, or correspondence, nor to attacks on his/her honor and reputation.[2"] (Program for Appropriate Technology in Health (PATH), 2003)

"Privacy and confidentiality have long been identified as two important elements of high quality, client-centered reproductive health programs (Bruce 1990; Huezo and Diaz 1993; Murphy 2002). In 1994, The Programme of Action resulting from the International Conference on Population and Development (ICPD) held in Cairo, urged governments "to secure conformity to human rights and ethical standards in the delivery of family planning and related reproductive health services.[2"] (Program for Appropriate Technology in Health (PATH), 2003)

"The World Health Organization (WHO) defines **privacy as a personal right** and **confidentiality as a duty**, in this case, on the part of providers." (Program for Appropriate Technology in Health (PATH), 2003)

"Privacy is "the right and power to control the information (about oneself) that others possess". (Program for Appropriate Technology in Health (PATH), 2003) "Privacy also commonly refers to the privacy of a person and the rights of individuals not to be physically exposed against their will." (Program for Appropriate Technology in Health (PATH), 2003)

"Confidentiality is "the duty of those who receive private information not to disclose it without the patient's consent". (Program for Appropriate Technology in Health (PATH), 2003) "Confidentiality is the mechanism through which the client's right to privacy is protected." (Program for Appropriate Technology in Health (PATH), 2003)

Abidance to privacy and confidentiality norms translate into high quality health service delivery. Healthcare quality has two aspects. "Technical quality deals with accuracy of diagnosis, procedures and clinical protocols while service quality deals with the manner in which services are given to the patients. As patients are not the best judge of technical quality of care, service quality is usually the main determining factor of patient's quality perception." (cis-india, 2014)

Privacy and confidentiality is pivotal in delivering quality care and maintaining patients' dignity is critical to their recovery. "Measures to maintain dignity in patients' care in western countries include maintaining bodily privacy, spatial privacy, donating sufficient time, treating patients as an individual, giving them autonomy and maintaining confidentiality of medical records and information." (cis-india, 2014) "However, this is still an unrecognized issue in Asian countries. Compared to international standards Indian Healthcare sector is still embryonic in the extent of its interaction with the law regarding privacy and confidentiality." (cis-india, 2014)

"The term '**Privacy'** is used in number of legislations primarily **referring to as the foundation of the fiduciary relationship between a doctor and a patient.** This fiduciary relationship finds roots in a reasonable presumption of mutual trust between the doctor and patients which is recognized through the Indian Medical Council Act of 1952" (cis-india, 2014)(section 20(A) .This section lays down the code of ethics which a doctor must follow at all times.

"Privacy in the healthcare sector refers to a number of aspects including

Informational privacy, **physical privacy, associational privacy, proprietary privacy and decisional privacy."** (cis-india, 2014)

"Health information disclosure can be sought for in the following situations:

Referral to other facility, can be demanded by the court or by the police on a written application, can be demanded by insurance companies when the patient has relinquished his rights on taking the insurance (as per insurance act), and required for some provisions of consumer protection cases and by income tax authorities[5], for disease registration, in case of communicable disease investigations, drug adverse event reporting." (cis-india, 2014)

LEGISLATION REVIEWED

"Laws are enterprising since they reflect the attitude of the society at particular point in time and are decreed to control the behavior and practice of the society[6]." (Vaz, 2012) "For example the ratification of *The Persons with Disabilities Act* for emancipation, equality and participation promotion in persons with disabilities, *The Pre-Natal Diagnostic Techniques Act* to check female feticide and *The Medical Council of India, Code of Ethics Regulations* which provide for the professional standards for medical practice." (Vaz, 2012)

"In India there is no uniform regulation specifically protecting medical privacy and confidentiality[7]." (Vaz, 2012) "Healthcare legislation in the country is only specific to certain health conditions which include physical and mental illness, disability, certain communicable diseases and HIV/AIDS. The existent legal framework is weak." (Vaz, 2012) "Furthermore, recurring themes are lacking requisite safeguards, ineffective implementation, and inadequate compensatory mechanisms stemming from judicial inactivity." (Vaz, 2012)

Mental Health Act, 1987[8]

"Privacy protection provisions under this act include oversight by concerned authorities over collection of information and the restrictions imposed on the disclosure of the collected data[1]." (cis-india, 2014)

"Medical records inspection in the psychiatric hospitals and nursing homes can only be carried out by officers who are authorized by the State Government[9]." (cis-india, 2014)

"On a monthly basis, two social workers along with a psychiatrist will analyze the living condition of every patient and the administrative processes of the psychiatric hospital or psychiatric nursing home[10]." (cis-india, 2014) "A doctor may issue medical certificates containing information pertaining to the nature and degree of the mental disorder as reasons for the detention of a person in a psychiatric hospital or psychiatric nursing home[12]. Lastly, under the provisions of this act the disclosure of personal records of any facility by inspecting officers is prohibited[13]" (cis-india, 2014).

Pre-Conception and Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act,1994[14]

The Act was instituted for prevention of female feticide. "Key features of the act pertaining to privacy include:

Maintenance of records for a two year period of all the pregnant women who have undergone ultrasonography." (cis-india, 2014) "The concerned person should have in his possession a printed copy of the computer record should be maintained after authentication." (cis-india, 2014) "It is binding for a mother to furnish consent of age, abortion history and family history before availing pre-natal diagnostic testing." (cis-india, 2014) "Specific sensitive information relating to family history of mental retardation or physical deformities also needs to be disclosed." (cis-india, 2014)" "Care should be exercised to maintain privacy and confidentiality of the woman with regards to disclosure of family history especially, genetic information as any inadvertent data leak could sabotage the privacy and confidentiality of the woman concerned." (cis-india, 2014)

Medical Termination of Pregnancy Act, 1971[15]

"The right to an abortion is a woman's inherent right to bodily and decisional privacy but is not afforded to patients and their families for determination of the sex of the baby.

"The act is supplemented by Medical Termination of Pregnancy Regulations (2003) which provide for relevant restrictions within every day practices of data collection use and storage in order to protect the privacy of patients." (cis-india, 2014) "The Act necessitates written consent of the patient in order to undergo an abortion which infers that the patient is mindful of all her options, has been counselled about the procedure, risks and post-abortion care[16]." (cis-india, 2014)

There is also prohibition of disclosure of information related to treatment for termination of pregnancy to anyone other than the Chief Medical Officer of the State[17]. "The hospital maintains the record of pregnancy termination in a register which must be destroyed on the expiry of five years period from the date of the last entry[18]." (cis-india, 2014) "The medical practitioner assigns a serial number for the woman terminating her pregnancy[19]." (cis-india, 2014) In addition to this, the admission register is kept safe in custody of the head of the hospital[20].

Indian Medical Council (Professional conduct, Etiquette and Ethics) Regulations, 2002 (Code of Ethics Regulations, 2002)

"The Medical Council of India (**MCI**) Code of Ethics Regulations[21] lays down the professional standards for medical practice which govern the nature and extent of doctor patient confidentiality. It also sets up universally recognized standards relating to consent to a particular medical procedure and acceptable limit collecting highly personal information when it is not requisite for the given procedure.

"The provisions under these regulations are related to the security of the collected information by medical practitioners and the characteristics of doctor patient confidentiality." (cis-india, 2014) Physicians are mandated to safeguard the confidentiality of patients during the entire procedure and maintain security of the information provided by the patient including information relating to their personal and domestic lives[22]. "The only exception is

related to the revelation of certain information, where here is a serious and identifiable risk to a specific person or community of a notifiable disease." (cis-india, 2014)

Ethical Guidelines for Biomedical Research on Human Subjects[23]

"The conditions for the regulation of privacy and confidentiality pertaining to biomedical research comprises of aspects of consent as well as a constraint on the information that may be collected followed by its subsequent usage." (cis-india, 2014)

"The principal of informed consent is a structural part of this set of guidelines." (cis-india, 2014) The information related to privacy included in the participant/ patient information sheet is composed of: the choice to prevent the use of their biological sample, the outcome of breach of confidentiality, the present and future uses of the biological material if it is likely to be used for secondary purposes, the risk of revelation of biologically sensitive information and publications inclusive of photographs and pedigree charts[24].

"The Guidelines warrant special concern for privacy and confidentiality when conducting genetic family studies[25].Privacy and confidentiality, specifically surrounding the identity and records, is maintained when using the information or genetic material provided by participants for research purposes[26]." (cis-india, 2014)

Investigators are required to maintain confidentiality of epidemiological data due to its implications on issues like national security or public safety[27]. "Data of individual participants can be revealed in a court of law under the orders of the presiding judge, in case there is a threat to a person's life, to the drug registration authority regarding cases of severe adverse reaction and if there is risk to public health[28]." (cis-india, 2014)

Insurance Regulatory and Development Authority (Third Party Administrators) Health Services Regulations, 2001

"The provisions under the Act regulate the practices of third party administrators within the healthcare sector so that compliance to the basic principles of privacy and confidentiality is ensured companies from giving details of their customers without prior consent[30]." (cis-india, 2014) The Insurance Regulatory and Development Authority Regulations[29]restrict referral

"TPAs are obliged to maintain the confidentiality of the data collected and maintain proper records of all transactions carried out by it on behalf of an insurance company." (cis-india,

2014) "They are required to abstain from trading information and the records of its business[31]." (cis-india, 2014) "The records for must be kept for a period of not less than three years[32]." (cis-india, 2014)

"A departure to the maintenance of information confidentiality in the code of conduct, requires them to provide pledge information to any Court of Law, the Government in the event of any investigation carried out by the authority against the insurance company, TPA or any other person[33]." (cis-india, 2014)

National Policy for Persons with Disabilities, 2006[34]

The following provisions of the Act provide for the incorporation of privacy considerations in practices pertaining to persons with disabilities. "The National Sample Survey Organization gathers the following data on persons with disabilities**:** cultural and socioeconomic data, cause of disabilities and all matters related to disabilities, once in every five years[35]." (cis-india, 2014) "This data is collected by nonmedical investigators[36]. There is an inherent limit imposed on the information collected." (cis-india, 2014) "Additionally, this information can be used only for the purpose for which it has been collected." (cis-india, 2014) "The Special Employment Exchange which is established under The Persons with Disabilities Act, collects and furnishes information in registers, regarding provisions for employment." (cis-india, 2014) "The retrieval of such data is limited to any person who is authorized by the Special Employment Exchange or persons authorized by Governments' special order, to access, investigate, debate and duplicate any relevant record/document or information in the guardianship of any establishment[37]. Proper consent is required from the individual or their family members/caregivers before conducting any research on disabled persons[38]." (cis-india, 2014)

HIV Interventions

"The Government of India established the National AIDS Control Organization (NACO) for the prevention and control of AIDS in 1992." (cis-india, 2014) "It endeavors to check HIV spread in the country through the implementation of Targeted Interventions (TIs) for most at risk populations (MARPs) especially sex workers, men having sex with men and drug abusers[39]." (cis-india, 2014) "The Targeted Interventions (TIs) has raised numerous concerns about policy gaps in the upkeep of privacy and confidentiality of people living with HIV/ AIDS." (cis-india, 2014)

The shortcomings in framework include: The absence of limitation on the amount of information collected. "Project staff under targeted intervention record the name, address and contact information of MARPs and share this data with Technical Support Unit and State AIDS Control Societies[40]." (cis-india, 2014) "Identity documents and address proof are prerequisites to get enrolled in government ART programs[41]." (cis-india, 2014)"Peer-educators operating under a system known as line-listing, make referrals and conduct follow-ups." (cis-india, 2014) "Peer educators have to follow-up with those who have not gone at regular intervals for testing[42]." (cis-india, 2014) "This can lead to peer-educators noticing and concluding that the names missing are those who have tested positive[43]." (cis-india, 2014) "Although voluntary in nature, the policy presses only on the fulfilling numerical targets, and thereby supporting unethical ways of testing[44]." (cis-india, 2014)

"Owing to the potential stigmatizing and discriminatory impact of the revelation of this sensitive information, right to privacy is an essential requirement for persons living with HIV/AIDS[45]." (cis-india, 2014) "The ramifications of such disclosure include lowered self-esteem, alienation from family/peers, loss of earnings, and fear of incrimination for illicit sex/drug use[46]." (cis-india, 2014) "Thus infringement of confidentiality and gaps in privacy provisions, specifically with respect to diseases such as HIV also deter people from soliciting treatment[47]." (cis-india, 2014)

EXCEPTIONS TO THE PROTECTION OF PRIVACY

In wake of public interest considerations, the legal provisions of privacy and confidentiality are often superseded The right to privacy, even though acknowledged in the course of Indian subpoena and incorporated within domestic legislation is often revoked when faced with situations that demand larger interest of a greater number of people.

Epidemic Diseases Act, 1897[48]

"Under this act, in the case of infectious diseases, the right to privacy, of infected individuals must yield to the supreme interest of protecting public health[49]." (cis-india, 2014) "Thus, in the absolute positivist as well as a more liberal interpretation, at the nucleus of the legislation lies the undebatable rime covenant of the maintenance of public health, even at the loss of the privacy of a few individuals[50]." (cis-india, 2014)

METHODOLOGY

This research study is done in two major parts. The first part assesses domestic legislation in the context of privacy and confidentiality. This is done through the discernment of privacy and confidentiality provisions within various acts. It is based on secondary data sources.

For the second part of the study, primary data was collected and analyzed regarding knowledge, attitude and practice of the health service providers and users of public health facilities. A total of 196 respondents were interviewed out of which 30 were doctors, 60 were nursing staff and 106 were the users of district hospital health services. Attitudes regarding privacy and confidentiality were measured using a five-point rating scale but middle point "neutral" was not used.

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Research question

What is the current status of privacy and confidentiality in District Hospital, Varanasi?

Objectives:

The objectives of the study are:

- To review norms and/or guidelines (if any) related to privacy and confidentiality in healthcare setting.
- To assess knowledge and practices of service providers, managers and users of facility-based public health services on privacy and confidentiality in public health facilities.

Material and methods

Study Design:

Descriptive study was conducted to review and assess the present status of confidentiality and privacy in district hospital.

Study Area:

Pt. Deen Dyal Upadhyay District Hospital Varanasi, UP was selected for the purpose of the study.

Duration of Study:

Study was conducted over a period of three months starting in February 2017.

Study Respondents:

The following respondents were covered:

- Doctors/ Medical officers -30
- Nursing staff - 90
- Users (Both men and women) of Public health facility services - 106

Data Collection Methods:

Both qualitative and quantitative methods of data collection will be used:

- Review of norms, guidelines, and records/ reports to understand what standards are available in terms of maintaining privacy and confidentiality at the health facilities.
- Interview with doctors, nursing staff, technicians, record room staff, and hospital superintendents and service users was conducted using written informed consent form. Interviews were conducted with doctors, nursing staff, health facility managers and using schedules. Interaction with the managers helped in assessing the knowledge and practices regarding privacy and confidentiality in health facility setting.

DATA COLLECTION TOOLS

Information was gathered by following methods:

- **Checklist** for review the including IPHS, guidelines or norms and all other relevant documents related to maintaining privacy and confidentiality at health facility level.
- **Interview schedule** – The interview schedule will include the general information, training received on privacy and confidentiality, their knowledge and practices in the context of maternal health, family planning and reproductive tract infections/ sexually transmitted diseases.
- **Interview schedule for patients**– Perception of the service users of privacy and confidentiality, whether they have any concern related to it, etc. will be covered.
- **Facility checklist-** To observe the compliance of the health facility inputs with privacy and confidentiality norms.

DATA ANALYSIS:

Data analysis was done by entering data into MS excel and graphs were plotted of the result drawn through analysis.

ETHICAL CONSIDERATIONS

Informed consent was taken from all the participants of the study. Care was taken to ensure privacy and confidentiality of participants and opinions expressed (data collected). Their voluntary participation was ensured. Data was used after compilation so that no one can identify the respondent. If anyone disagreed to become part of the data collection process, they were not forced by any means.

RESULTS

Socio demographic characteristics of providers

Socio demographic characteristics of the providers suggests that 58 percent of them had experience amounting to 1-5 year bracket, 18 percent had 6-10 year experience and rest had greater than 11 years of experience. Sixty seven percent belonged to nursing staff category, 28 percent were specialists with MBBS comprising only 6 percent of the respondents.

Table 1. Socio-demographic characteristics of the providers (N=90)

Characteristics		Number of respondents (Percentage of total (%)) Number (%)
AGE	18-33	64(68)
	34-49	16(17)
	50 and above	14(15)
SEX	Male	33(35)
	Female	61(68)
EXPERIENCE		
	1-5	53(56)
	6-10	16(17)
	11-15	15(23)
	16 and above	8(9)
OCCUPATIONAL CATEGORY		
	MBBS	5(5)
	Specialist	25(28)
	Nursing staff	60(67)
	Administrative staff	4(4)

Knowledge of providers regarding privacy and confidentiality:

Forty nine percent had heard about privacy and confidentiality. Majority of them hold experience the main reason behind their knowledge. Out of 49 percent provider knowing about privacy and confidentiality 100 percent doctors and only 23 percent of the nursing staff knew about privacy and confidentiality.

Table 1.1 Distribution of respondents by their knowledge of privacy and confidentiality (n=90)

Distribution of respondents by their knowledge of privacy and confidentiality		
YES	NO	DON'T KNOW
44	30	16

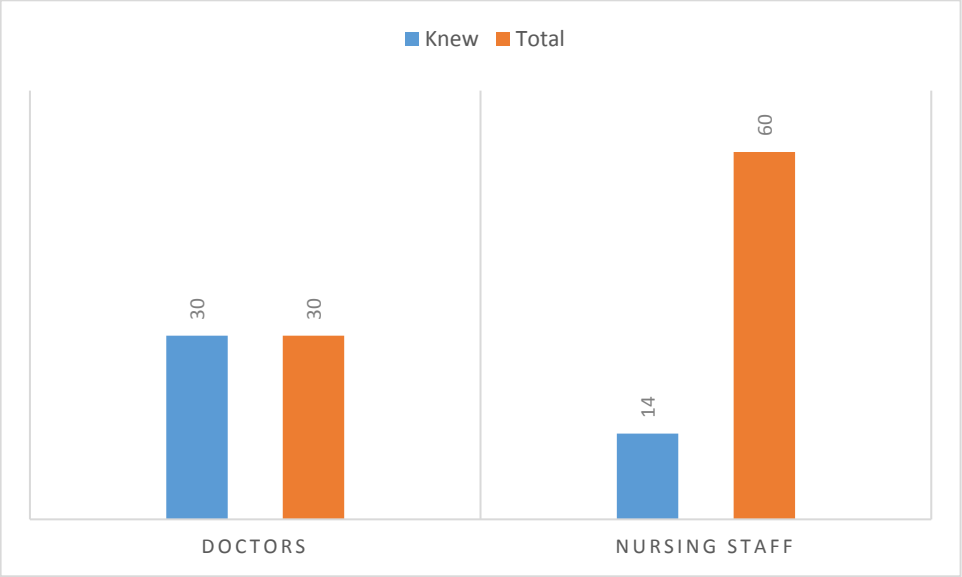

Figure 1: Distribution of respondents by their occupational category regarding their knowledge of privacy and confidentiality

Knowledge regarding the difference between privacy and confidentiality:

Only 22 percent could correctly point out the difference between privacy and confidentiality. Of which 67 percent doctors accurately defined the difference. No nursing staff was able to correctly pin point the difference.

Table 1.2 Distribution of respondents by their knowledge of privacy and confidentiality (n=90)

Distribution of respondents by their knowledge of difference between privacy and confidentiality (n=90)		
YES	NO	DON'T KNOW
20	45	25

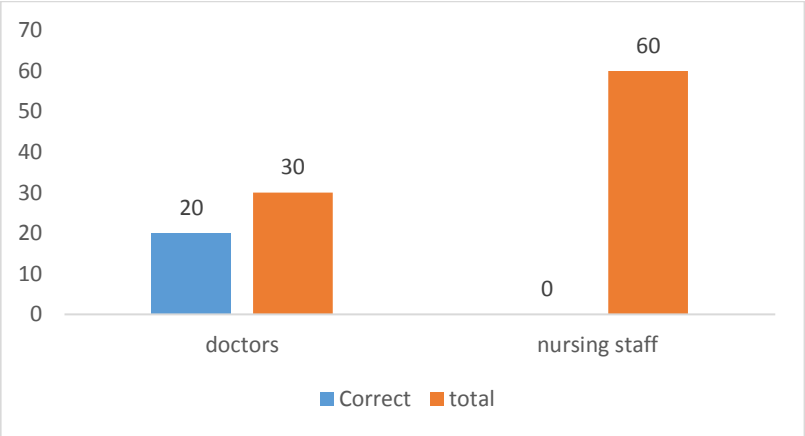

Figure 1.1: Distribution of respondents on the basis of their occupational category regarding their knowledge of difference between privacy and confidentiality

Knowledge regarding existing legislation for protection of privacy and confidentiality:

Only 17 percent knew about any legislation to protect patients' privacy and confidentiality. Of which 33 percent doctors and 8 percent nurses were able to name some legislative measures.

Table1.3 Distribution of respondents by their knowledge regarding existing legislation for protection of privacy and confidentiality (n=90)

Distribution of respondents by their knowledge regarding existing legislation for protection of privacy and confidentiality		
YES	NO	DON'T KNOW
15	45	30

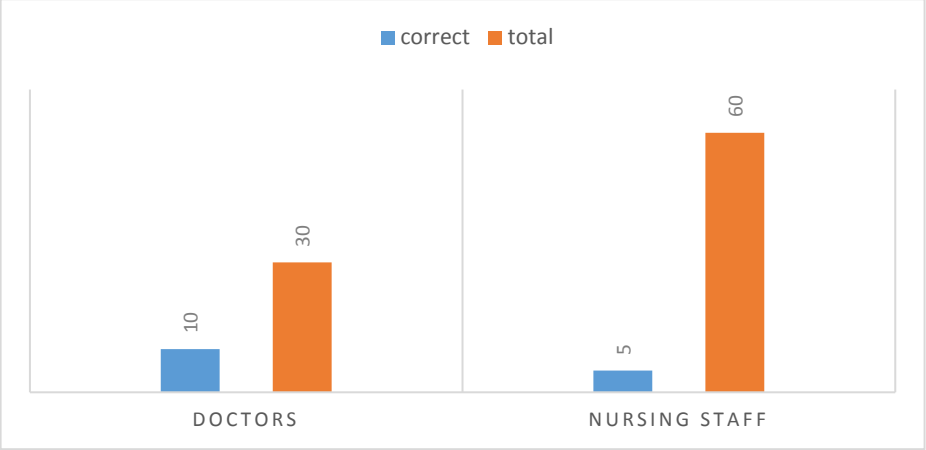

Figure 1.2: Distribution of respondents on the basis of their occupational category regarding their knowledge of existing legislation for protection of privacy and confidentiality

Knowledge regarding patients' entitlement to demand privacy protection:

Forty eight percent knew about existence of patients' rights to privacy protection, while 28 percent answered no and 19 percent were unaware of it.

Table1.4 Distribution of respondents regarding their knowledge of patients' entitlement to demand privacy protection (n=90)

Distribution of respondents regarding their knowledge of patients' entitlement to demand privacy protection		
YES	NO	DON'T KNOW
43	28	19

Knowledge regarding patients' entitlement to demand confidentiality protection:

Fifty two percent agreed to patients' right to confidentiality, which constituted all of the doctors and only 28 percent of nursing staff.

Table 1.5 Distribution of respondents regarding their knowledge of patients' entitlement to demand confidentiality protection (n=90)

Distribution of respondents regarding their knowledge of patients' entitlement to demand confidentiality protection		
YES	NO	DON'T KNOW
47	13	30

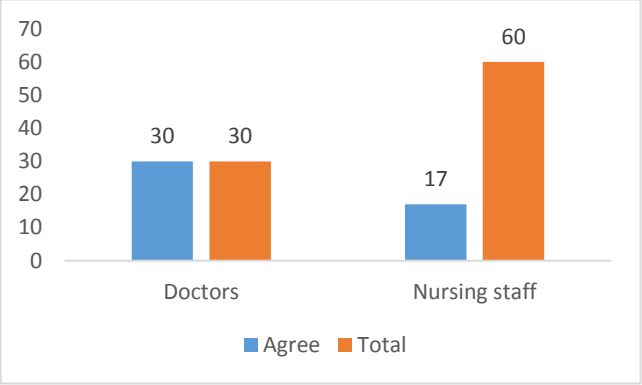

Figure 1.3: Distribution of respondents on the basis of their occupational category regarding their knowledge of patients' entitlement to demand confidentiality protection

Knowledge regarding patient seeking legal intervention for breach of privacy and confidentiality:

Thirty three percent of the providers knew that patients can move to court for breach of privacy and confidentiality, of which 67 percent doctors constituted the entire sum with no nursing staff having the relevant knowledge.

Table1.6 Distribution of respondents regarding their knowledge of patients' entitlement to seek legal intervention for breach of privacy and confidentiality (n=90)

Distribution of respondents regarding their knowledge of patients' entitlement to seek legal intervention for breach of privacy and confidentiality		
YES	NO	DON'T KNOW
30	23	37

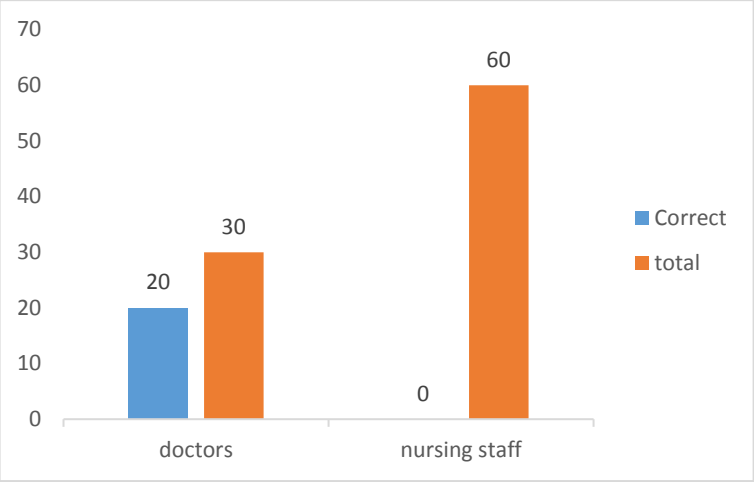

Figure 1.4: Distribution of respondents on the basis of occupational category regarding their knowledge of patients' entitlement to seek legal intervention for breach of privacy and confidentiality

ATTITUDE OF THE PROVIDERS OF HEALTHCARE TO ENSURE PRIVACY

Providers' behavior

Attitude of the providers in the context of visual privacy

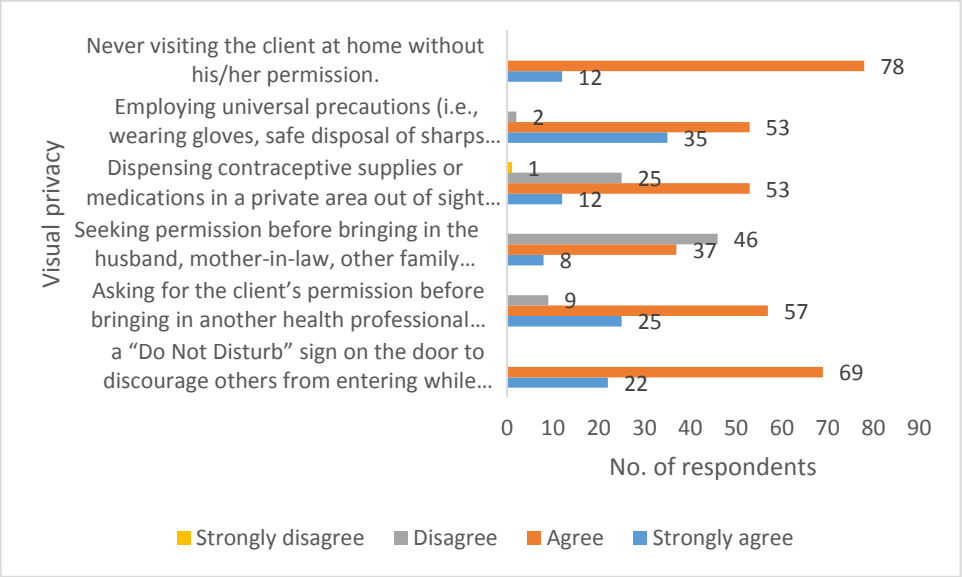

Figure 1.5: Distribution of respondents on the basis of their attitude regarding visual privacy

1. "Presence of a "Do Not Disturb" sign on the door to discourage others from entering while counseling or examining a client." (Program for Appropriate Technology in Health (PATH), 2003)

Sixty nine percent of the providers agree with only 22 percent showing strong agreement

2. "Asking for the client's permission before bringing in another health professional for consultation or observation of the client " (Program for Appropriate Technology in Health (PATH), 2003)

Fifty seven percent agree to seek clients' permission with only 25 percent strongly agreeing.

- "Seeking permission before bringing in the husband, mother-in-law, other family members, etc." (Program for Appropriate Technology in Health (PATH), 2003)
  Thirty seven percent agreed to not allowing family members/spouses without permission. On the contrary, 46 percent expressed disagreement for the same.

- "Dispensing contraceptive supplies or medications in a private area out of sight and earshot of others. " (Program for Appropriate Technology in Health (PATH), 2003)
  Fifty three percent showed agreement with 12 percent strongly agreeing and 25 percent were at variance regarding it.

- "Employing universal precautions (i.e., wearing gloves, safe disposal of sharps and sharps containers, etc.) with **all** clients to reduce calling attention to a particular client." (Program for Appropriate Technology in Health (PATH), 2003)
  Thirty five percent strongly agreed with 53 percent showing agreement. Only a meagre percent showed divergence.

- "Never visiting the client at home without his/her permission." (Program for Appropriate Technology in Health (PATH), 2003)
  A good percentage, 78 percent of respondents were not in favor of visiting clients home without permission.

ATTITUDE OF THE PROVIDERS IN THE CONTEXT OF AUDITORY PRIVACY

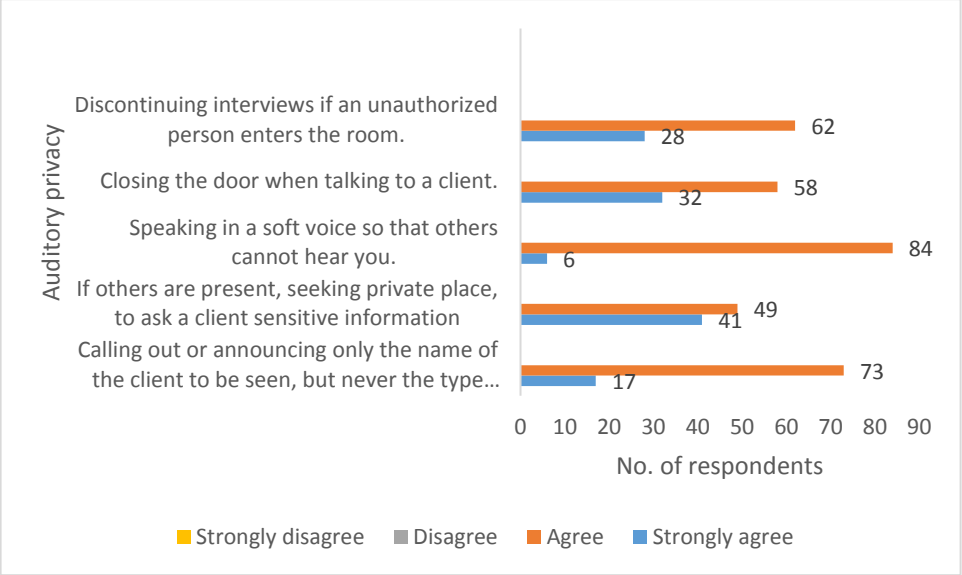

Figure 1.6: Distribution of respondents on the basis of their attitude regarding auditory privacy

- "Calling out or announcing only the name of the client to be seen, but never the type of service he/she is receiving" (Program for Appropriate Technology in Health (PATH), 2003)

  Seventy three percent agreed with only 17 percent strongly agreeing to never calling out aloud the type of service patient is receiving.

- "If others are present, seeking private place, to ask a client sensitive information." (Program for Appropriate Technology in Health (PATH), 2003)

  Forty nine percent expressed agreement with only 41 percent strongly agreeing.

- "Speaking in a soft voice so that others cannot hear you." (Program for Appropriate Technology in Health (PATH), 2003)

  Majority 84 percent agreed speaking in soft voice so that they are not overheard.

- "Closing the door when talking to a client." (Program for Appropriate Technology in Health (PATH), 2003)

  Fifty percent showed agreement for talking to the client with door closed with 32 percent strongly agreeing.

- "Discontinuing interviews if an unauthorized person enters the room." (Program for Appropriate Technology in Health (PATH), 2003)

  Twenty eight percent strongly agreed in discontinuing the session when an unauthorized person enters with 62 percent expressing agreement

ATTITUDE OF THE PROVIDERS IN THE CONTEXT OF HEALTH CENTRE DESIGN

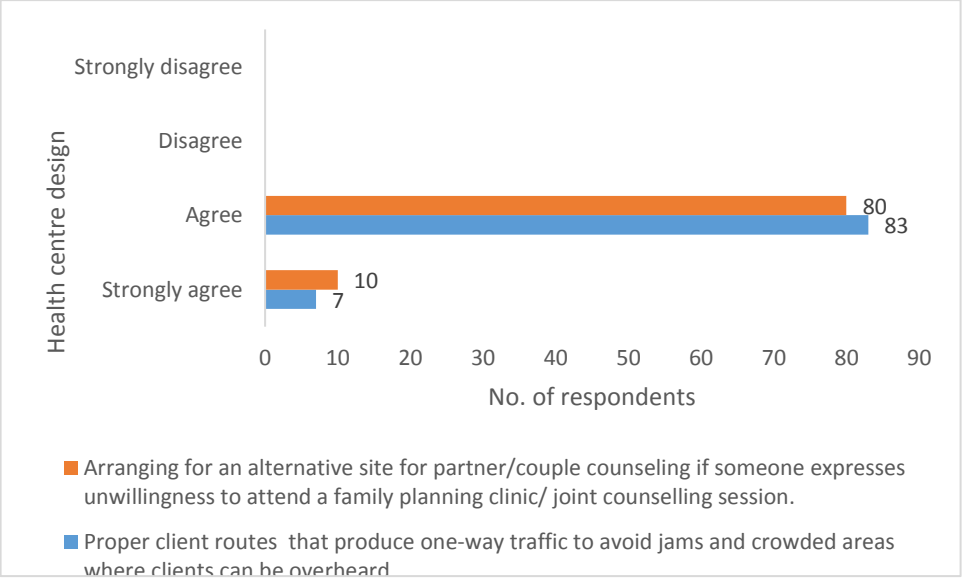

Figure 1.7: Distribution of respondents on the basis of their attitude regarding health centre design to ensure privacy

- "Proper client routes that produce one-way traffic to avoid jams and crowded areas where clients can be overheard" (Program for Appropriate Technology in Health (PATH), 2003)

  Eighty three percent agreed to have proper client routes with only 7 percent strongly agreed.

- "Arranging for an alternative site for partner/couple counseling if someone expresses unwillingness to attend a family planning clinic/ joint counselling session." (Program for Appropriate Technology in Health (PATH), 2003)

  Eighty percent expressed agreement to allow for alternative to joint counselling with 10 percent strongly agreeing.

ATTITUDE OF THE PROVIDERS IN RELATION TO COUNSELLING/EXAMINATION AREA

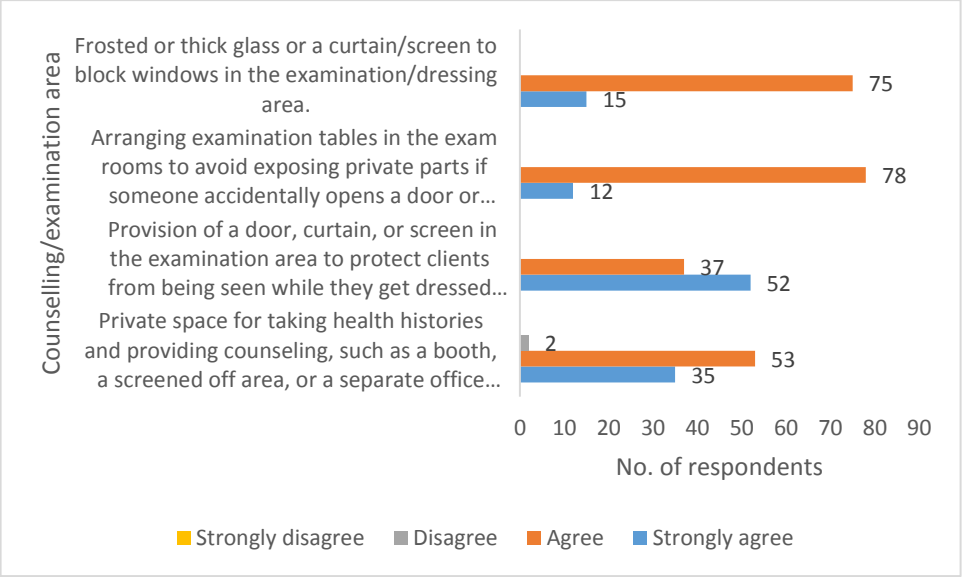

Figure 1.8: Distribution of respondents on the basis of their attitude regarding counselling/examination area to ensure privacy

- “Private space for taking health histories and providing counseling, such as a booth, a screened off area, or a separate office to improve visual privacy.” (Program for Appropriate Technology in Health (PATH), 2003)

  Fifty three percent agreed to a private area for histories/counselling, 35 percent strongly agreed.

- “Provision of a door, curtain, or screen in the examination area to protect clients from being seen while they get dressed and undressed should be there.” (Program for Appropriate Technology in Health (PATH), 2003)

  Fifty two percent of the respondents strongly agreed to it with 37 percent showing agreement.

- “Arranging examination tables in the exam rooms to avoid exposing private parts if someone accidentally opens a door or walks in while a person is being examined. “ (Program for Appropriate Technology in Health (PATH), 2003)For example, place the exam table facing away from the door or window.

  Majority respondents, 78 percent showed agreement for the alignment of the tables to ensure privacy while examination.

- “Frosted or thick glass or a curtain/screen to block windows in the examination/dressing area.” (Program for Appropriate Technology in Health (PATH), 2003)

  Seventy five percent were in favor of a screen/ frosted window with 15 percent strongly in favor.

ATTITUDE OF THE PROVIDERS IN CONTEXT OF POLICIES AND PROCEDURE GOVERNING PRIVACY

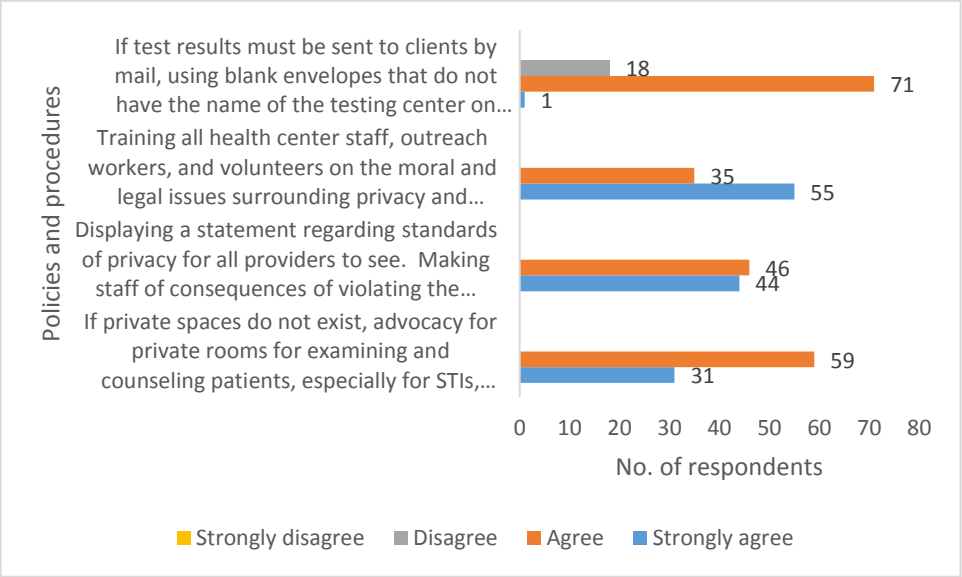

Figure 1.9: Distribution of respondents on the basis of their attitude regarding policies and procedures governing privacy

- "If private spaces do not exist, advocacy for private rooms for examining and counseling patients, especially for STIs, including HIV, and AIDS testing and counseling." (Program for Appropriate Technology in Health (PATH), 2003)

  Fifty nine percent respondents were in favor of advocacy for private rooms/spaces for counselling with 31 percent strongly in support of the same.

- "Displaying a statement regarding standards of privacy for all providers to see. Making staff of consequences of violating the client's rights." (Program for Appropriate Technology in Health (PATH), 2003)

  Forty four percent strongly agreed with 46 percent showing agreement.

- "Training all health center staff, outreach workers, and volunteers on the moral and legal issues surrounding privacy and confidentiality and ensuring privacy and confidentiality at all levels of service delivery." (Program for Appropriate Technology in Health (PATH), 2003)

Fifty five percent were strongly in favor of training regarding privacy and confidentiality with 35 percent in agreement.

- "If test results must be sent to clients by mail, using blank envelopes that do not have the name of the testing center on them, since other people (post office workers or family members) may see the envelope before the client does." (Program for Appropriate Technology in Health (PATH), 2003)

  Seventy one percent showed agreement in maintaining privacy even while mailing test results with 12 percent showed variance.

ATTITUDE OF THE PROVIDERS OF HEALTHCARE TO ENSURE CONFIDENTIALITY

Providers' behaviour

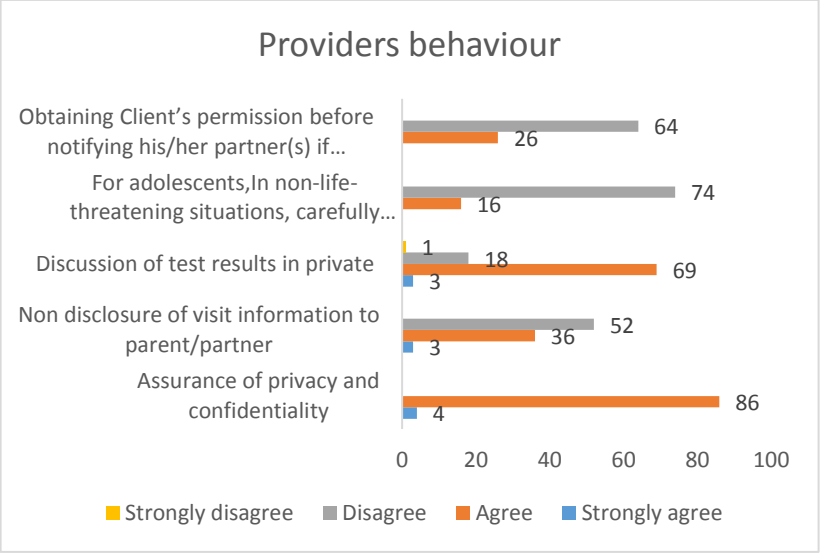

Figure 1.10: Distribution of respondents on the basis of their attitude regarding confidentiality

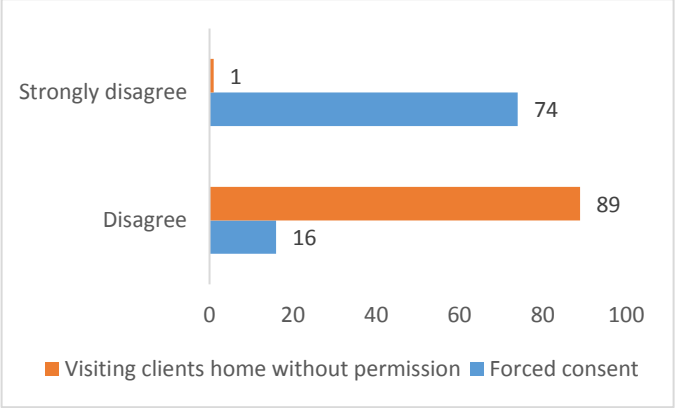

Figure 1.11: Distribution of respondents on the basis of their attitude regarding confidentiality

- "Assurance to the clients of privacy and that the confidentiality of all information including his/her visit will be protected, how the information will be used and that this information will not be disclosed to another person without the client's permission is explained **"** (Program for Appropriate Technology in Health (PATH), 2003)

  Eighty six percent agreed that client should be ensured of privacy and confidentiality.

- "In case client has been seen at a health center, taking care not to inadvertently disclose that information to a parent or partner during the client's subsequent visit." (Program for Appropriate Technology in Health (PATH), 2003)

  Thirty six percent agreed to not disclosing visit details to partner/family members with 52 percent in disagreement.

- "Calling the client into a private counseling room to discuss test results." (Program for Appropriate Technology in Health (PATH), 2003)

  Sixty nine percent agreed to it while 18 percent disagreed.

- "For adolescents: life-threatening, emergency conditions may require parental notification. In non-life-threatening situations, carefully weighing the potential harmful consequences for the adolescent before deciding to inform his/her parent(s)." (Program for Appropriate Technology in Health (PATH), 2003)
  Majority 74 percent showed disagreement in relation to adolescent privacy concerns with only 16 percent in favor of obtaining consent/ considering privacy of adolescent in otherwise non-life-threatening situations.

- "Obtaining Client's permission before notifying his/her partner(s) if STI/HIV/AIDS results are positive. Encouraging him to inform his/her partner(s) and offer assistance." (Program for Appropriate Technology in Health (PATH), 2003)
  Sixty four percent were not in favor of obtaining clients consent before notifying partners while 26 per cent expressed agreement.

- "Forcing the client to give consent to release information**"** (Program for Appropriate Technology in Health (PATH), 2003)
  A substantial percentage 74 percent totally disagreed for obtaining forced consent.

- "Visiting the client at home without his/her permission" (Program for Appropriate Technology in Health (PATH), 2003)
  Eighty nine percent of the respondents did not agree in visiting clients home without permission.

ATTITUDE OF THE PROVIDER IN CONTEXT OF HEALTH CENTRE DESIGN

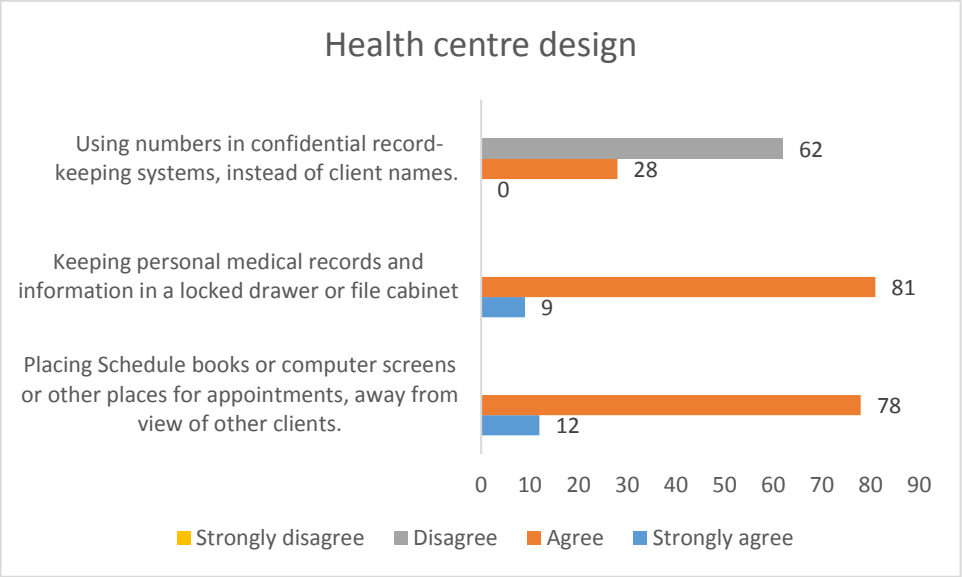

Figure 1.12: Distribution of respondents on the basis of their attitude regarding health centre design to ensure confidentiality

- "Placing Schedule books or computer screens or other places for appointments, away from view of other clients." (Program for Appropriate Technology in Health (PATH), 2003)

  Seventy eight percent were in favor of the same with 12 percent strongly favoring the proposition.

- "Keeping personal medical records and information in a locked drawer or file cabinet, or a space where they are locked up." (Program for Appropriate Technology in Health (PATH), 2003)

  Eighty one percent were in agreement of keeping records and information locked up safely.

- "Using numbers in confidential record-keeping systems, instead of client names" (Program for Appropriate Technology in Health (PATH), 2003)

  Majority (62 percent) respondents did not agree to the usage of numbers in record keeping systems with only 28 percent showing agreement.

ATTITUDE OF THE PROVIDERS IN CONTEXT OF POLICIES AND PROCEDURES

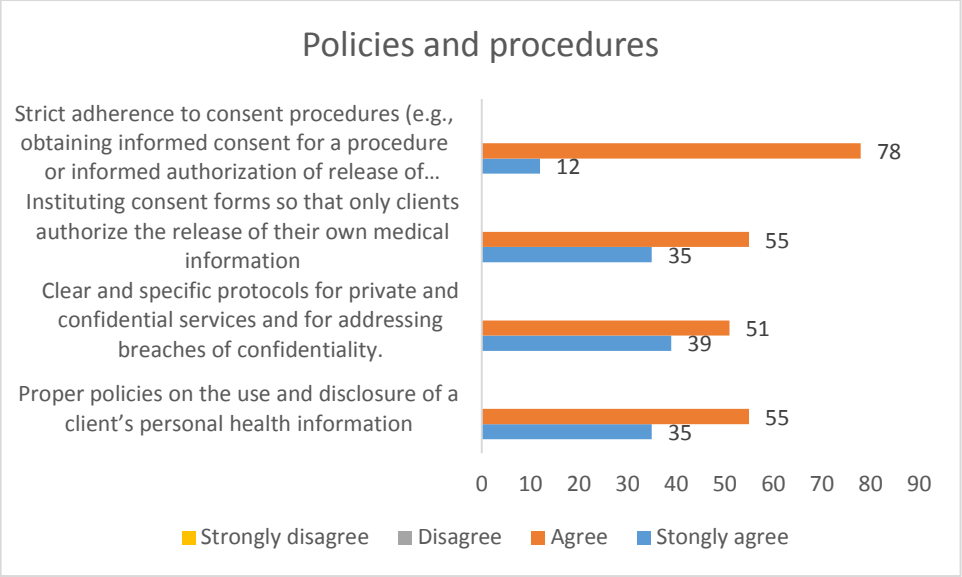

Figure 1.13: Distribution of respondents on the basis of their attitude regarding policies and procedure to ensure confidentiality

- "Proper policies on the use and disclosure of a client's personal health information." (Program for Appropriate Technology in Health (PATH), 2003)

  Fifty five percent agreed to have proper policies on the use and disclosure of a client's personal health information with 35 percent respondents in strong agreement of it.

- "Clear and specific protocols for private and confidential services and for addressing breaches of confidentiality." (Program for Appropriate Technology in Health (PATH), 2003)

Fifty one percent agreed to have protocols in place for addressing breaches in confidentiality while 39 percent strongly favored it.

- "Instituting consent forms so that only clients authorize the release of their own medical information." (Program for Appropriate Technology in Health (PATH), 2003)

  Majority of the respondents agreed and strongly agreed to institution of consent forms.

- "Strict adherence to consent procedures (e.g., obtaining informed consent for a procedure or informed authorization of release of information)" (Program for Appropriate Technology in Health (PATH), 2003)

  Seventy eight percent held the view that consent procedures should be strictly adhered to.

DEMOGRAPHIC CHARACTERISTICS OF THE PATIENTS

Socio demographic characteristics of the patients reveal that majority belonged to age group 20-50 years with 61 percent of them being males. Marital status revealed 44 percent of them being currently married and 35 percent fell into never married category. Majority of them were Hindus.

Forty one percent belonged to scheduled castes, 19 percent to schedules tribe and 33 percent were from general category. Large number were daily wage laborer and 31 percent had agriculture as main source of income. Seventy two percent hailed from rural areas.

Table 2: Socio-demographic characteristics of the patients, (N=106)

Characteristics		Number of respondents (Percentage of total (%) Number (%)
Age	20-35	(36)34
	36-50	(48)45
	51-75	(22)21
Sex	Male	65(61)
	Female	41(39)
Marital Status	Currently married	48(45)
	Divorced	5(5)
	Widow/widower	16(15)
	Never married	37(35)
Religion	Hindu	80(75)
	Muslim	11(10)
	Others	16(15)
Caste	Scheduled caste	43(41)
	Scheduled tribe	20(19)
	General	35(33)
	None of them	6(6)
Highest standard	Illiterate	41(39)
	Up to grade 5(primary)	28(26)
	Grade 6-9(middle)	29(27)
	Grade 10-12(secondary) and above	8(8)
Occupation	Agricultural laborer/ cultivator	33(31)
	Daily wage laborer	40(37)

	Domestic servant	16(15)
	Service (private/ Government)	18(17)
Place of living	Urban	28(26)
	Rural	76(72)

Knowledge of patients regarding privacy and confidentiality

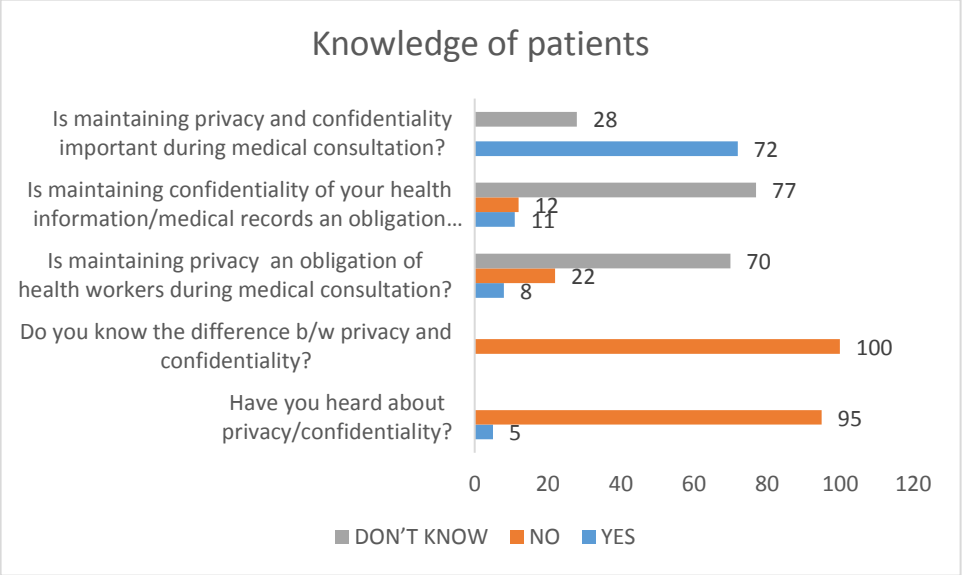

Figure 2: Distribution of respondents by their knowledge of privacy and confidentiality

Ninety five percent had never heard about privacy and confidentiality. Only 5 per cent of the total patient respondents knew something about privacy and confidentiality but couldn't correctly point out the difference between the two.

Knowledge regarding maintenance of privacy an obligation of health care providers during medical consultation

Seventy percent respondents didn't know that healthcare providers are obliged to maintain their privacy with only 8 percent being aware of the same.

Knowledge regarding maintenance of privacy an obligation of health care providers during medical consultation

Seventy seven percent respondents didn't know that healthcare providers are obliged to maintain their privacy with only 11 percent being aware of the same.

Knowledge regarding the importance of privacy and confidentiality during medical consultation

Seventy two percent believed privacy and confidentiality as an important component of medical consultation.

Perceptions of the patients regarding privacy

"Informational privacy

"The patients' perceptions of the degree of control over their personal information." (Program for Appropriate Technology in Health (PATH), 2003) "Individuals want to have the right to determine how, when and to what extent their data may be released to another person". (Program for Appropriate Technology in Health (PATH), 2003) "It reflects patients' control over the collection, storage, dissemination, and use of their personal information." (Program for Appropriate Technology in Health (PATH), 2003)

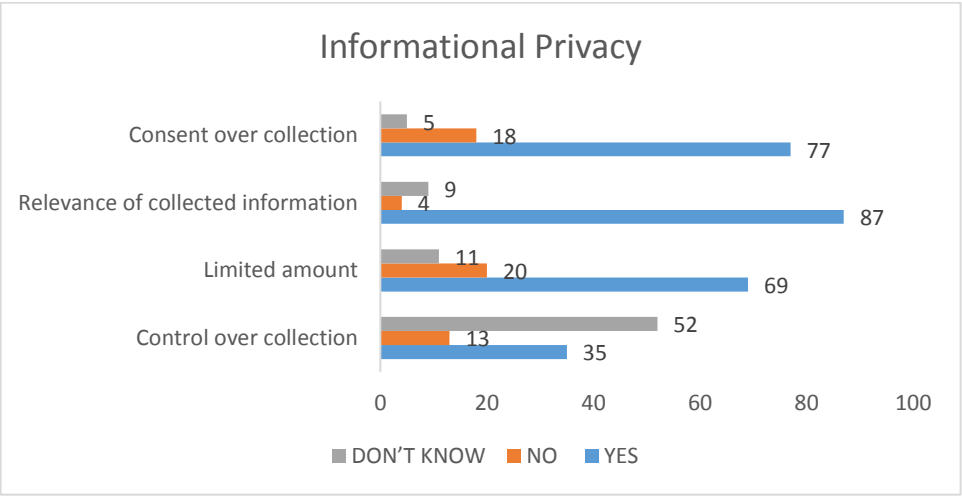

Figure 2.1: Distribution of respondents by their perceptions about informational privacy

- **Regarding control over collection of information**

  Only 35 percent of the patient respondents felt that they had control over the information being gathered from them, 13 percent denying and 52 percent not being sure of the same.

- **Regarding amount of information collected**

  Sixty nine percent of the respondents were comfortable with the amount of information sought from them with 20 percent denied the same.

- **Regarding relevance of collected information**

  Eighty seven percent felt that information only related to their health concerns was being asked for.

- **Regarding consent over information collection**

  Seventy seven percent of the patients agreed that information was only collected after informed consent while 18 percent did not share the same viewpoint.

Physical privacy

"The patients' perceptions of the degree of physical inaccessibility to others." (Program for Appropriate Technology in Health (PATH), 2003) "It includes avoiding unwanted actions from others, such as invading personal space by the physical presence, touching body parts, observing or monitoring acts, video surveillance, overhearing sounds or noise, and smelling odor." (Program for Appropriate Technology in Health (PATH), 2003)

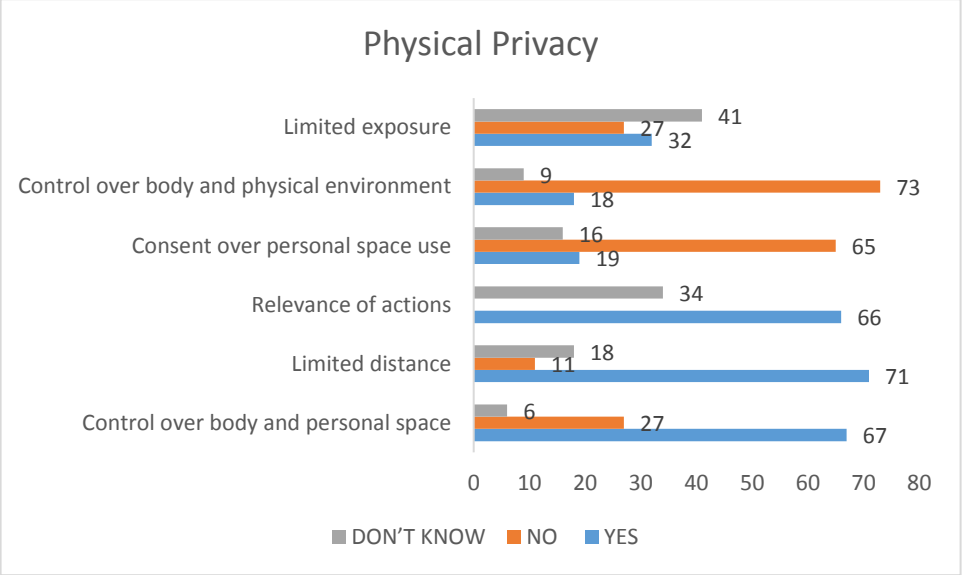

Figure 2.2: Distribution of respondents by their perceptions about physical privacy

- **Regarding control over body and personal space**

  Sixty seven percent felt that they had a sense of control over their body and personal space while interacting with doctor, 27 percent felt otherwise.

- **Regarding limited distance**

  Seventy one percent answered that their doctor chose appropriate physical distance during appointments while 11 percent replied otherwise.

- **Regarding relevance of actions**

  Sixty six percent answered that their doctor *only* examines or treats parts of their body that are related to health concerns, while 34 percent would not know.

- **Regarding consent over personal space**

  Only 19 percent replied of being verbally informed every time by the doctor when he/she touched, 62 percent replied otherwise.

- **Regarding control over physical environment**

  Only 18 percent agreed that the space and furniture arrangement in doctor's office created a sense of privacy, 73 percent answered otherwise.

- **Regarding limited exposure**

  Only 32 percent agreed that in doctor's office, their actions and conversations were not observed or overheard by people outside, while 27 percent answered otherwise.

Psychological privacy

"The patients' perceptions of the extent to which the physician respects patients' cultural beliefs, inner thoughts, values, feelings, and religious practices and allows them to make personal decisions." (Program for Appropriate Technology in Health (PATH), 2003)

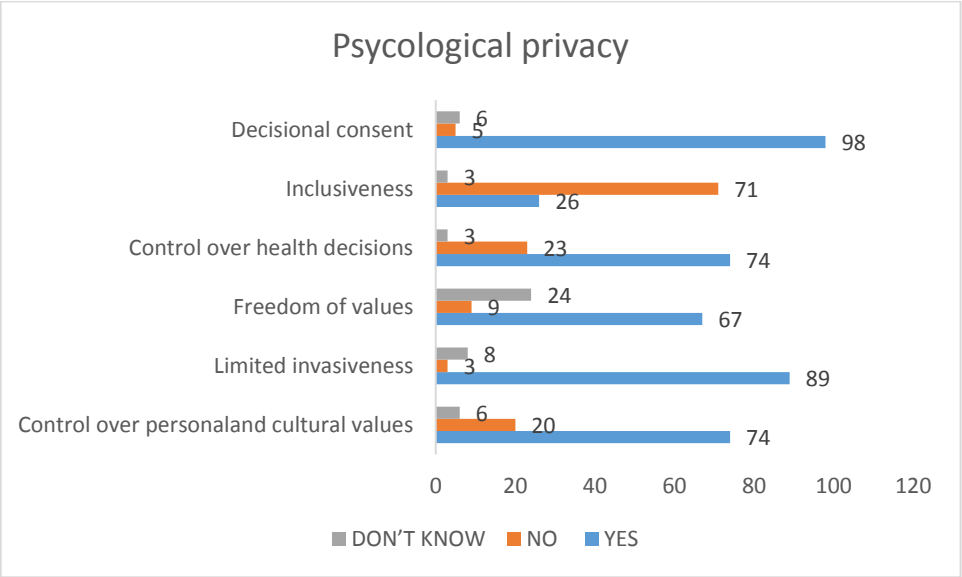

Figure 2.3: Distribution of respondents by their perceptions about psychological privacy

- **Regarding control over personal and cultural values**

  Seventy four percent agreed that they don't have to hide their personal and cultural values when they interact with their doctor.

- **Regarding limited invasiveness**

  Eighty nine percent answered that their doctor did not question their personal and cultural values.

- **Regarding freedom of values**

  Sixty seven percent patient replied that their doctor did not impose his/her cultural and personal values them.

- **Regarding control over health decisions**

  Seventy four percent of the patient respondents felt that they were in charge of their health decisions, 23 percent answered otherwise.

- **Regarding inclusiveness**

  Seventy one percent replied that their doctor considered their opinion about their health.

- **Regarding decisional consent**

  Ninety eight percent answered that their doctor makes decisions about their health with their consent.

Compliance regarding inputs available at facility to ensure privacy and confidentiality

Table 3: Table shows the compliance of the health facility inputs to ensure privacy and confidentiality

INPUT	Compliance	Partial Compliance	Non Compliance
One Patient is seen at a time in clinics			
Curtains have been provided at windows			
Screens provided at Emergency			
Provision of a counselling corner/designated area			
Availability of Breast feeding corner			
Separate queue for female at registration			
Demarcated male and female observation areas			
Separate toilets for male and females			
Availability of female staff if a male doctor examine a female patients			
Patients are dressed/covered while been shifted from one department to other			
Medical records room where records of the patients are kept locked in			
No two patients are treated on one bed			

DISCUSSION

The purpose of this study was two-fold. The first was to review the present literature and existing laws and regulations governing privacy and confidentiality in healthcare setting. "Review of the present legislature and regulations suggests that the Right to Privacy has been embodied in a multitude of domestic legislations pertaining to the healthcare sector but a strong foundational framework where the rights are addressed and find mention in a single document is still awaited." (cis-india, 2014)

The second part of the study assessed the knowledge, attitude of the providers of healthcare and also the knowledge and perceptions of patients about privacy and healthcare. The embodied laws and regulation need to seep down to the level of service delivery at the healthcare facility level and should be reflected in the knowledge and practice of healthcare providers which is presently not satisfactory. On the knowledge front, approximately half of the providers did not know about privacy and confidentiality.

A dismal portion of those who knew could not tell the difference accurately. Only 15 percent knew of any existent legislation providing for privacy and confidentiality safeguards. Regarding patients' entitlement to privacy, confidentiality and seeking courts intervention doctors were better aware than nursing staff, none of whom could correctly respond which is again indicative of the dearth of knowledge due to missing training and adequate relevant teaching in professional courses.

The attitudes of the providers to ensure visual and auditory privacy was satisfactorily positive, whereas in relation to health centre design and policies and procedures they seemed very positive in maintenance of patient privacy. Regarding the attitudes towards maintaining confidentiality, they seemed rather unsure in agreeing to certain points (like confidentiality in case of adolescents, obtaining clients permission before notifying partner etc.) which is only indicative of their lack of training, exposure and knowledge.

Knowledge of the patients regarding privacy and confidentiality was rather nonexistent with 95 percent of them not knowing anything about their right to privacy and confidentiality, which is the reason for their not being empowered enough to seek private and confidential

health care. Their perception regarding informational, physical and psychological privacy were recorded, which showed gaps in consent over personal space, physical setting of the hospital to ensure privacy, inclusiveness etc., which is reflective of the way services are delivered in the facility. Also if we see the compliance to privacy and confidentiality regarding inputs at facility, it has fallen short fulfilling only 4 criteria out of 12 observed.

CONCLUSION

"Considering that the concept of privacy is gaining increasing significance world-wide, there is an inevitable need to develop approaches to this issue in the health care system in accordance with the rich cultural characteristics of Indian society. However, to ensure that patients' rights are observed it is not sufficient merely to issue guidelines and instructions." (cis-india, 2014) "It is essential also to provide education for care providers and medical students, as well as patients and their families, so that a joint approach may be adopted by all concerned" (cis-india, 2014)." "A comprehensive strategy is needed to engage with members of the public and the media through educational programs and information campaigns regarding all aspects of patients' rights." (cis-india, 2014) "Furthermore, cases involving breaches of patients' rights should be addressed appropriately and a suitable legal framework for patients' rights needs to be developed and implemented." (cis-india, 2014)

"It is imperative that frequent discussions, deliberations, conferences and roundtables take place involving multiple stakeholders form the healthcare sector, insurance companies, patient's rights advocacy groups and the government." (cis-india, 2014) "This would help in evolving a policy that would support in the protection of privacy and confidentiality in healthcare sector in an efficient and synergetic manner." (cis-india, 2014)

Limitations of the study

Total of 196 respondents participated in the study against the proposed number 222. Lab technicians, few patients and a part administrative staff did not participate in the study

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ANNEX 1

Consent Form for Interview

Namaste! I am ……... representing the Indian Institute of Health Management Research (IIHMR), Jaipur. I would like to talk to you about privacy and confidentiality in the district hospital

Purpose of the research: This study aims to understand Knowledge, attitude and practices of healthcare providers and patient towards privacy and confidentiality in district hospital..

Why selected: You are invited to participate because you are one of the key functionary of the district hospital who deals patients and their information and can make a significant difference in the way services get delivered.

Procedure: You are being invited to take part in this discussion because we are interested in learning about the situation of privacy and confidentiality in the facility. If you accept to participate, you will be asked to share your personal experience and observations regarding knowledge and practices on issues related to privacy and confidentiality. You will also be asked to share some basic demographic data with us. Participation is voluntary. The choice that you make will have no bearing on any of your relationships with patients, colleagues and other stakeholders to provide health services. You may change your mind later and stop participating even if you agreed earlier. If you agree to speak to us, it will take about 10 minutes.

Risk and Benefits: It is possible that you may feel uncomfortable talking about some of the questions, issues and topics. However, I do not wish for this to happen. You do not have to respond to a question if you feel it is too personal, if talking about the issue makes you feel uncomfortable, or if you are unsure about the nature of the information you are going to share. We would greatly appreciate your honest responses, because they will be useful in developing research, programs and policies to improve privacy and confidentiality in the facilities. Your participation is also likely to inform the design of future program and policies, although you may not experience this personally.

Right to Refuse or Withdraw: You do not have to take part in this research if you do not wish to do so, and choosing not to participate will not affect your situation in any way. Your decision to participate is not binding – you can withdraw from the interview at any time and you can also inform us later if you decide that your responses should not be included in this survey.

Privacy, confidentiality and anonymity: We will not be sharing information about you or your responses with anyone. The information that we collect from this survey will be kept private and securely protected. Your information will not serve any other purposes than informing policies and programs for adolescent girls. Your identity will not be disclosed in the final report because all the data will be presented after compilation. It will be ensured that nothing recorded will allow the tracing of your identity. All information obtained from you will be confidential and only members of the survey team will access it. Information will be compiled and results will be shared for the group as a whole. Therefore, nobody will ever come to know your identity.

Whom to Contact: If you have any questions, you can ask now or later. If you wish to ask questions later, you may contact

Dr. Priyanka Sharma, IIHMR, Jaipur
Mobile No- 9878040988
E-mail – piia3088@gmail.com

May I speak to you? Yes ☐ No ☐

Name of Interviewer _____

Date of Interview	*D*	*D*	*M*	*M*	*Y*	*Y*	*Y*	*Y*
Starting time of Interview	*HH*				*MM*			
Ending time of Interview	*HH*				*MM*			

Signature of Interviewer _____

ANNEX 2

Questionnaire for Data Collection on Knowledge and attitude of providers towards privacy and confidentiality at Pt. Deen Dyal Hospital Varanasi

SECTION 1: DEMOGRAPHIC INFORMATION

S.NO	CHARACTERISTIC	CATEGORY		CODE
1.	Age	Specify……		
2.	Sex	Male	1	
		Female	2	
		Transgender	3	
3.	Experience	0-1	1	
		1-5	2	
		6-10	3	
		11-15	4	
		16 and above	5	
4.	Occupational category	MBBS	1	
		Specialist	2	
		Nurse	3	

SECTION 2. ASSESSMENT OF PROVIDERS KNOWLEDGE TOWARDS PRIVACY AND CONFIDENTIALITY

S.no	CHARACTERISTIC	CATEGORY		CODE
1.	Have you heard about privacy/confidentiality?	Yes	1	
		No	2	
		Don't know	9	
2.	If yes, from where did you hear?	Experience	1	
		Medical education	2	
		Training	9	
		Others ……..		
3.	Do you know the difference b/w privacy and confidentiality?	Yes	1	
		No	2	
		Don't know	9	
		If yes, Please mention_____		
3(a).	If yes Please specify	a. Name of the training _____ b. Name of the organizer _____ c. Duration of training _____ d. Month/year _____ e. Content/topic _____ f. Material provided _____ g. Usefulness _____		
4.	Do you know about any legislation in place to	Yes	1	

	ensure privacy and confidentiality of patients?	No	2	
		Don't know	9	
		If yes, Please mention _____		
5.	Are patients entitled to demand protection of privacy?	Yes	1	
		No	2	
		Don't know	9	
6.	Are patients entitled to demand confidentiality of information?	Yes	1	
		No	2	
		Don't know	9	
7.	Can the patients move to court for breach of privacy and confidentiality?	Yes	1	
		No	2	
		Don't know	9	

Ensuring Confidentiality of Client Information

Interview schedule for Providers

(This interview schedule is designed to review the attitudes of providers of healthcare to ensure confidentiality)

Serial No. _____

		Strongly agree	Agree	Disagree	Strongly disagree
		1	2	3	4
Provider Behavior	1. Assurance to the clients of privacy and that the confidentiality of all information including his/her visit will be protected, how the information will be used and that this information will not be disclosed to another person without the client's permission is explained.				
	2. Forcing the client to give consent to release information.				
	3. In case client has been seen at a health center, taking care not to inadvertently disclose that information to a parent or partner during the client's subsequent visit.				
	4. Calling the client into a private counseling room to discuss test results. Not mentioning test results or the availability of test results out loud				
	5. Keeping the purpose of the client's visit and any personal information about a client or				

	his/her test results confidential and not revealing to others within or outside of the clinic.				
	6. For adolescents: life-threatening, emergency conditions may require parental notification. In non-life-threatening situations, carefully weighing the potential harmful consequences for the adolescent before deciding to inform his/her parent(s).				
	7. Visiting the client at home without his/her permission.				

	8. Obtaining Client's permission before notifying his/her partner(s) if STI/HIV/AIDS results are positive. Encouraging him to inform his/her partner(s) and offer assistance.				
	9. Offering clients the opportunity to have couple's counseling and test results to be given to each partner separately. Leaving it to him/her to decide whether to share the results with his/her partner.				
Health Center Design	10. Placing Schedule books or computer screens or other places for appointments, away from view of other clients.				
	11. Keeping personal medical records and information in a locked drawer or file cabinet, or a space where they are locked up.				
	12. Using numbers in confidential record-keeping systems, instead of client names.				

Policies and Procedures	13. Proper policies on the use and disclosure of a client's personal health information.				
	14. Clear and specific protocols for private and confidential services and for addressing breaches of confidentiality.				
	15. Instituting consent forms so that only clients authorize the release of their own medical information.				
	16. Strict adherence to consent procedures (e.g., obtaining informed consent for a procedure or informed authorization of release of information)				

Ensuring Visual and Auditory Privacy

Interview Schedule (Providers)

This interview schedule is designed to review the attitudes of the providers of healthcare to ensure privacy)

Serial No. _____

			Strongly Agree	Agree	Disagree	Strongly Disagree
			1	2	3	4
Provider Behavior	**Visual privacy**	**1.** Presence of a "Do Not Disturb" sign on the door to discourage others from entering while counseling or examining a client.				
		2. Asking for the client's permission before bringing in another health professional for consultation or observation of the client.				
		3. Seeking permission before bringing in the husband, mother-in-law, other family members, etc.				
		4. Dispensing contraceptive supplies or medications in a private area out				

		of sight and earshot of others.				
		5. Employing universal precautions (i.e., wearing gloves, safe disposal of sharps and sharps containers, etc.) with **all** clients to reduce calling attention to a particular client.				
		6. Never visiting the client at home without his/her permission.				
	Auditory Privacy	7. Calling out or announcing only the name of the client to be seen, but never the type of service he/she is receiving.				
		8. If others are present, seeking private place, to ask a client sensitive information.				
		9. Speaking in a soft voice so that others cannot hear you.				
		10. Closing the door when talking to a client.				
		11. Discontinuing interviews if an unauthorized person enters the room.				
		12. Discussing client's exam or test results out				

		loud where others can hear.				
		13. Never calling out or otherwise reveal a client's HIV status to co-workers. If HIV status must be revealed to a doctor or other health professional for medical reasons, maintaining complete auditory privacy				
Health Center Design		14. Proper client routes that produce one-way traffic to avoid jams and crowded areas where clients can be overheard				
		15. Arranging for an alternative site for partner/couple counseling if someone expresses unwillingness to attend a family planning clinic/ joint counselling session.				
Counseling and/or examination area		16. Private space for taking health histories and providing counseling, such as a booth, a screened off area, or a separate office to improve visual privacy.				

	17. If a client is referred for another service, taking an informed consent form that authorizes the health center to disclose his/her health information to the referral center.				
	18. Provision of a door, curtain, or screen in the examination area to protect clients from being seen while they get dressed and undressed should be there.				
	19. Arranging examination tables in the exam rooms to avoid exposing private parts if someone accidentally opens a door or walks in while a person is being examined. For example, place the exam table facing away from the door or window.				
	20. Frosted or thick glass or a curtain/screen to block windows in the examination/dressing area.				

Policies and Procedures	21. If private spaces do not exist, advocacy for private rooms for examining and counseling patients, especially for STIs, including HIV, and AIDS testing and counseling.				
	22. Displaying a statement regarding standards of privacy for all providers to see. Making staff of consequences of violating the client's rights				
	23. Training all health center staff, outreach workers, and volunteers on the moral and legal issues surrounding privacy and confidentiality and ensuring privacy and confidentiality at all levels of service delivery.				
	24. If test results must be sent to clients by mail, using blank envelopes that do not have the name of the testing center on them, since other people (post office workers or				

	family members) may see the envelope before the client does.				

ANNEX 3

Questionnaire for Data Collection on Knowledge and perception of patients towards privacy at Pt. Deen Dyal Hospital Varanasi

Serial No. _____

SECTION 1: DEMOGRAPHIC INFORMATION

S.NO	CHARACTERISTIC	CATEGORY		CODE
1.	Age	Specify …….		
2.	Sex	Male	1	
		Female	2	
		Transgender	3	
3.	Marital status	Currently married	1	
		Divorced	2	
		Widow/widower	3	
		Separated	4	
		Never married	5	
		Others (specify)…….		
4.	Religion	Hindu	1	
		Muslim	2	
		Sikh	3	
		Christian	4	
		Jain	5	
		Others (specify) …….		
5.	From which caste/tribe do you belong?	Scheduled caste	1	
		Scheduled tribe	2	
		Other backward caste	3	

		None of them	4	
		Don't know	5	
6.	What is the highest standard you completed?	No education	1	
		Up to grade 5(primary)	2	
		Grade 6-9(middle)	3	
		Grade 10-12(secondary) and above	4	
7.	What is your main occupation?	Agricultural laborer/ cultivator	1	
		Daily wage laborer	2	
		Domestic servant	3	
		Skilled/semi-skilled worker	4	
		Petty business/ small shop	5	
		Large business/ self employed	6	
		Service (private/ government)	7	
		Transport worker	8	
		Others (specify)		
8.	Place of living	Urban	1	
		Rural	2	

SECTION 2. ASSESSMENT OF PATIENTS' KNOWLEDGE TOWARDS PRIVACY

S.no	CHARACTERISTIC	CATEGORY		CODE
9.	Have you heard about privacy/confidentiality?	Yes	1	
		No	2	
10	If yes, from where did you hear?	Relatives	1	
		Friends	2	
		TV/Radio	3	
		Newspaper	4	
		Other (specify) ……		
11.14	Do you know the difference b/w privacy and confidentiality? If yes, elaborate	Yes	1	
		No	2	
		Don't know	9	
12.	Is maintaining privacy an obligation of health workers during medical consultation?	Yes	1	
		No	2	
		Don't know	9	
13.	Is maintaining confidentiality of your health information/medical records an obligation of health workers during medical consultation?	Yes	1	
		No	2	
		Don't know	9	
14.	Is maintaining privacy and confidentiality important	Yes	1	
		No	2	

	during medical consultation?	Don’t know	9	

Interview schedule (Patient)

(This interview schedule is designed to gather information from patient about their view of the way services are carried out in the hospital)

Informational privacy

The patients' perceptions of the degree of control over their personal information. Individuals want to have the right to determine how, when and to what extent their data may be released to another person. It reflects patients' control over the collection, storage, dissemination, and use of their personal information.

INFORMATIONAL PRIVACY	Control over collection	1. When my doctor collects my personal information, I am not worried about my privacy.	□ YES □ NO □ Do not know
	Limited amount	2. I am comfortable with the amount of personal information my doctor collects about me.	□ YES □ NO □ Do not know
	Relevance of collected information	3. My doctor *only* collects my personal information that is related to my health concerns.	□ YES □ NO □ Do not know
	Consent over collection	4. My doctor collects my personal information *only* with my consent	□ YES □ NO □ Do not know

Physical privacy

The patients' perceptions of the degree of physical inaccessibility to others. It includes avoiding unwanted actions from others, such as invading personal space by the physical presence, touching body parts, observing or monitoring acts, video surveillance, overhearing sounds or noise, and smelling odor.

PHYSICAL PRIVACY	Control over body and personal space	5. When I interact with my doctor, I feel a sense of control over my body and personal space.	□ YES □ NO □ Do not know
	Limited distance	6. My doctor chooses appropriate physical distance during my appointments.	□ YES □ NO □ Do not know
	Relevance of actions	7. My doctor *only* examines or treats parts of my body that are related to my health concerns	□ YES □ NO □ Do not know
	Consent over personal space use	8. My doctor verbally informs me every time he/she touches me.	□ YES □ NO □ Do not know
	Control over physical environment	9. The space and furniture arrangement in my doctor's office creates a sense of privacy.	□ YES □ NO □ Do not know
	Limited exposure	10. When I am in my doctor's office, my actions and conversations may not be observed or overheard by people outside	□ YES □ NO □ Do not know

Psychological privacy

The patients' perceptions of the extent to which the physician respects patients' cultural beliefs, inner thoughts, values, feelings, and religious practices and allows them to make personal decisions.

PSYCHOLOGICAL PRIVACY	Control over personal and cultural values	11. When I interact with my doctor, I don't have to hide my personal and cultural values.	□ YES □ NO □ Do not know
	Limited invasiveness	12. My doctor does not question my personal and cultural values.	□ YES □ NO □ Do not know
	Freedom of values	13. My doctor does not impose his/her personal and cultural values on me.	□ YES □ NO □ Do not know
	Control over health decisions	14. I am in control of my health decisions.	□ YES □ NO □ Do not know
	Inclusiveness	15. My doctor considers my opinion in his/her decisions about my health.	□ YES □ NO □ Do not know
	Decisional consent	16. My doctor makes decisions about my health with my consent	□ YES □ NO □ Do not know

ANNEXURE 4

Facility checklist to review the compliance of inputs to ensure privacy and confidentiality

S.no	Input	Compliance	Partial compliance	Non compliance
1.	One Patient is seen at a time in clinics			
2.	Curtains have been provided at windows			
3	Screens provided at Emergency			
4	Provision of a counselling corner/designated area			
5	Availability of Breast feeding corner			
6	Separate queue for female at registration			
7	Demarcated male and female observation areas			
8	Separate toilets for male and females			
9	Availability of female staff if a male doctor examine a female patients			
10	Patients are dressed/covered while been shifted from one department to other			
11	Medical records room where records of the patients are kept locked in			
12	No two patients are treated on one bed			