DOI: https://doi.org/10.47391/JPMA.888

Patient's expectations of privacy and confidentiality in Pakistan: a mixed-methods study

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Abstract

Privacy and confidentiality are considered a cornerstone in the practice of medical ethics. However, these notions may play out differently in the cultural context of Pakistan. In order to understand the perceptions and expectations of privacy and confidentiality, a cross-sectional mixed method study was undertaken in a tertiary care hospital in Karachi, Pakistan. While the subjects demonstrated unfamiliarity with the Western terms, majority of them also exhibited a high expectation for privacy (both informational and physical) and confidentiality. Patients appeared most comfortable with sharing private medical information with the primary physician, indicating the level of trust placed in the physician. Participants also showed high expectations for confidentiality, thus, even in a collectivist society, patients may not want their private information shared across the medical team and also among family members. The onus is, therefore, on healthcare professionals to assess patients' preferences and choices.

Keywords: Privacy, Confidentiality, Patient perception, Pakistan.

Introduction

Practice of ethics in the largely collectivist society of Pakistan cannot be based on presumptions of "imported Westernised practices." It is important that local context is considered when developing pertinent healthcare practices.[1] Privacy and confidentiality are considered cornerstones of medical ethics. Cultural values, however, can pose challenges to the way practices of privacy and confidentiality unfold in traditional, collectivist societies like Pakistan.[2, 3]

In order to understand the local perceptions of privacy and confidentiality, a pilot study was undertaken at the two campuses of Dr Ziauddin Hospital, a tertiary care hospital in Karachi, from March 2016 to November 2017. This paper is a short communication of the study findings, and to the best of our knowledge, this is the first of its kind research originating from Pakistan.

Patients / Methods and Results

The study followed a mixed method approach with an exploratory qualitative arm using in-depth interviews with 15 participants, along with a survey-based quantitative arm with 138 participants recruited through convenience sampling. The participants were selected from both in-patient and out-patient clinics, all of whom were above 18 years of age and belonged to either gender. The qualitative arm allowed us to pick the nuances of the patients' choice.

The "Western" terms of 'privacy' and 'confidentiality' were unfamiliar to most participants. Once translated into Urdu (using words such as "*Posheida* [hidden] and *raazdaari* [confidentiality])" the participants defined privacy as "something that must be kept private" and "keeping one's secrets to oneself" and confidentiality as "things which cannot be told to just about anyone" and "[to] not tell things to everyone." One respondent touched upon the basic premise of confidentiality by stating, "trusting the doctor and his team to not broadcast [information] to just about anyone."

Ninety-five percent (n=131) were most willing to share private information with their primary physician. This decreased with the hierarchy of the medical team, particularly the students and nursing staff. One may postulate that the readiness to share information with the primary physician occurs due to the requirement for diagnosis and management. However, the position of physicians as "healer" or as many patients reverently state "after God there is only you (the doctor)" indicates the pedestal on which patients place physicians, and also conveys an inherent power dynamic in the doctor-patient relationship.[4, 5] This power dynamic potentially explains the seeming acceptance of practices within the healthcare system: fear of offending the doctor and limited available choices. Hesitation in sharing information with students and nurses may stem from inhibition of being judged or stigmatised, or also because patients believe that they do not need this information since the primary responsibility to treat rests with the main physician.

While exploring their choices of confidentiality one patient shared: "there are some things which should remain between the doctor and the patient. This is because other people can exaggerate it to a great deal." While patients may not voice this in clinical encounters, this communicates the trust and expectations that patients have towards clinicians. Furthermore, a participant also elaborated that information should not be shared with family members unless they are emotionally close to the patient, leaving the onus on the doctor to be able to assess the internal dynamics within the family unit.

The nature of the disease appeared to be important, as one participant stated, "I would not share information about Hepatitis C … because people have wrong beliefs that they cannot sit next to such patients." Patients believed that conditions specific to females, such as breast- or menstruation-related problems would limit marriage prospects in the traditional Pakistani society as a female participant explained, "menstruation issues may lead to infertility in the future thus influencing attitudes of people" and that they are also "personal issues".

Infertility in Pakistani society is a stigma and in such a context, such "private matters" can lead to problems for women, threatening the stability of their marriages; hence it seems natural that patients prefer such health issues to be hidden.[6]

Majority (94%, n=129) did not want information related to sexual health and sexually transmitted diseases shared beyond the primary physician. Possible explanation for this attitude could be that other medical conditions may be regarded as part of life, or due to fate, while STDs carry a huge stigma and may be perceived as occurring due to a lapse in morality, thus resounding a behavioural component.[7] However, the practical importance of sharing this information was highlighted: "It has to be told (to the doctor) because these diseases can spread in the society." A study from New Zealand also demonstrated that there was an increasing reluctance to share information once it acquired a sensitive nature.[8] This study also observed that more than 50% of the participants were willing to share information with people across the healthcare team for common diseases like diabetes and hypertension, and surgical procedures like hernias and gall bladder.

An important dimension that emerged on physical privacy was the influence of gender. Females showed greater preference to be examined by only the primary physician. According to one female participant, "it is better if it is the doctor who is examining" because "the doctor knows more." This expectation/choice again emphasises the importance given to the doctor-patient relationship, with the physician considered a confidante. Conversely, a male participated stated, "anyone can examine me, whether it's a doctor or student. This is because today's student is tomorrow's physician."

Conclusion

The findings of this study have direct impacts on clinical practice. Without being able to define terms, patients have a sense of these concepts and a preference that they verbalise when explored. The ideals of privacy and confidentiality in a society where physicians are powerful, authoritative and do not have enough time because of patient overload, requires focus and attention. This is further complicated in hospitals where treatment is provided at a subsidised cost, as in the case of one of the campuses of the teaching hospital where the study took place. Due to limited choice, patients may find it difficult to demand their rights. Research shows that participants may also not possess an understanding about their rights.[9, 10] This puts physicians at a higher moral ground to assess patients' preferences, and act accordingly.

The study has several limitations with regards to its generalisability with respect to the quantitative arm. However, the nuances are reflected in the information that comes from the qualitative interviews allowing for preliminary understanding of patients' preferences, and future directions for research.

Disclaimer: The first author was working at Ziauddin Hospital when the study was being conducted. Institutional approval and ethical clearance was obtained from the said institution.

Conflict of interest: No conflict of interest

Funding disclosure: No funding as required

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