

Patients' and healthcare professionals' awareness of and attitudes toward patients' rights

Zahra Saeed Yusuf¹, Noor Khaled Aljarba², Fahad Hasan Ali Barmandh³,
Mohammad Saeed Almathnny⁴, Zakia Jafar Ateeq Alnakhli⁵, Samah Zid
Alshuraymi⁶, Munirah Alhumaidi Alharbi⁷, Fawziah Ghazi Alharbi⁸, Hadeel
Khaled Abdulrahman Alharthi⁹, Raghad Sayer Aljuaid¹⁰

1. General practitioner
2. GP Internal Medicine , Hail
3. Emergency medical technician, Saudi Red Crescent Authority
4. Emergency medical technical, Saudi Red Crescent Authority_Asir region
5. Nurse Technician , Medical Rehabilitation Hospital
6. Nurse, Rehabilitation medical hospital
7. Midwife, qassim health cluster, Al-Jandal Health Center
8. Midwife, qassim health cluster, Al-Jandal Health Center
9. General Practitioner (ER resident) King Faisal Medical complex -Taif
10. Anesthesia , Eastern health cluster

Abstract

Background: The confidentiality and security of patient data are critical for fostering trust in healthcare and clinical research. While healthcare professionals (HCPs) are key stakeholders in safeguarding this information, their knowledge, awareness, and attitudes toward data privacy and security remain underexplored, particularly in the context of regulatory frameworks such as the Health Insurance Portability and Accountability Act (HIPAA) and the National Committee of Bioethics (NCBE) guidelines.

Methods: This study evaluate HCPs' understanding and perspectives on patient data privacy and security. A survey was conducted among physicians, nurses, and pharmacists (N=150) to assess demographic characteristics, , and perceptions of Institutional Review Board (IRB)/Research Ethics Committee (REC) regulations. Semistructured interviews, guided by the Theoretical Domains Framework, explored attitudes and barriers to compliance with privacy regulations. Quantitative data were analyzed using descriptive statistics, χ^2 tests, and regression models, while qualitative data underwent thematic analysis.

Results: Among respondents, women constituted 64.81%, and most participants were aged 44 years or younger. Nearly 65% reported prior research involvement, and active researchers demonstrated significantly higher knowledge scores. Over 80% of participants recognized the role of IRB/REC regulations in enhancing data security and participant trust. Qualitative findings highlighted barriers such as insufficient training and perceived complexity of compliance processes.

Conclusion: The study underscores the importance of fostering a culture of data security within clinical practice and research. Targeted educational initiatives and increased HCP involvement in research are critical for bridging knowledge gaps and promoting adherence to privacy and security regulations. Strengthening IRB/REC processes can further enhance the ethical conduct of clinical research.

Introduction

The effective delivery of medical care relies on the exchange of sensitive and confidential information between patients and healthcare providers (HCPs). This information is consistently documented and maintained in medical records and databases, where patients expect it to remain private and protected (1). Privacy refers to “a condition or state of restricted access to physical or informational resources, determining the scope and manner in which patient data can be disclosed to others” (2). On the other hand, security involves “the procedural and technical strategies employed to safeguard data from unauthorized access, alterations, or misuse, as well as to prevent deliberate disruptions of service,” thereby ensuring the protection

of health records from misuse (3, 4). In today's digital era, privacy is an essential aspect of security, safeguarding individual rights and affirming their dignity and value.

Upholding the confidentiality of healthcare information is a critical aspect of medical practice, especially in culturally sensitive environments. In certain cases, individuals may avoid seeking medical care for conditions such as substance misuse or reproductive and sexual health concerns due to fears that their private information could be disclosed or inadequately secured. Patients with mental health disorders may also hesitate to share crucial details about their condition, fearing discrimination or societal stigma, which could impact their treatment outcomes (5). Such concerns undermine trust in the patient-provider relationship and may deter patients from participating in research studies addressing sensitive topics.

There are established frameworks and guidelines that govern the use of health information for research purposes (6). For example, in the United States, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 sets robust standards for safeguarding patients' health information. These federal regulations specify who can access and use such data, as well as how it should be managed to ensure security and privacy (6, 7, 8).

In contrast, other regions have developed unique approaches to ensure ethical practices in research. For instance, a decree issued in 2001 mandated the establishment of a National Committee of Bioethics (NCBE), tasked with formulating and overseeing compliance with ethical guidelines for biomedical research. This approach integrates ethical standards with cultural values and principles to ensure alignment with prevailing traditions and norms (9).

Although some HCPs may view privacy and security as interchangeable concepts, the two are fundamentally distinct. Privacy addresses the content of information—what is protected—while security focuses on the methods used to ensure that protection—how it is safeguarded (10, 11). Recent advancements in research and the growth of research facilities highlight the increasing importance of applying regulations like HIPAA to uphold the privacy and security of patient data.

Moreover, legal frameworks underscore the significance of public health and the safeguarding of personal information. General provisions emphasize the right to access healthcare and the inviolability of private communication (5). While these laws advocate for healthcare delivery and data confidentiality, specific guidelines addressing the security of patients' health information are often lacking.

Methods

a cross-sectional survey to assess HCPs' knowledge and awareness of HIPAA and NCBE rules, followed by in-depth, semistructured interviews guided by the Theoretical Domains Framework (TDF). The survey served as a descriptive tool, while the interviews, supplemented by focus group discussions, explored attitudes and perspectives in greater detail.

The questionnaire was developed based on an extensive review of literature addressing privacy, security, and their relevance in clinical research. It consisted of sections: the first gathered demographic information (age, gender, marital status, education level, and work experience), and the role of Institutional Review Boards (IRB)/Research Ethics Committees (REC) in safeguarding patient data in clinical research. The survey items were pilot-tested by ten HCPs for clarity and ease of understanding before distribution. The finalized questionnaire was made available both physically and through an online link and was distributed to physicians, nurses, and pharmacists between January and March 2022. Participants were required to have experience in both clinical practice and research to be eligible.

Interview Design

Follow-up phone calls were made to interested participants to provide additional details, explain the study objectives, and arrange interview times. Verbal consent was obtained before the start of each focus group (FG) interview. Three semistructured FG interviews were conducted with participants, and data collection continued until knowledge saturation was achieved. All interviews were digitally recorded with participant approval and transcribed verbatim for analysis.

Data Analysis

Quantitative data were analyzed using Stata 16 (Stata Corp, College Station, TX, USA). Descriptive statistics, including frequencies and percentages, were summarized and displayed in tables. The χ^2 or Fisher's exact test was utilized to compare group responses. Stepwise quantile regression was applied to identify factors influencing knowledge scores, with variables showing a p-value of less than 0.05 included in the final model.

Qualitative data were analyzed through thematic analysis using MAXQDA Analytics Pro 2020 (VERBI Software). Thematic analysis involves systematically identifying patterns, meanings, and themes within qualitative data (13). The process included familiarizing researchers with the data, generating codes, and refining themes. Multiple researchers were involved to enhance reliability, with two authors (N.A., M.A.) independently reviewing transcripts and a third author (A.A.) resolving discrepancies. Summaries of focus groups were validated by participants to ensure accuracy.

Researchers reviewed data after each interview to identify significant and novel findings. Memos were maintained throughout the process to capture observations, including participant expressions and hesitations, and were incorporated into the analysis. Data collection ceased once sufficient information had been gathered to address the study's objectives. Interview recordings and transcripts were securely stored to maintain confidentiality.

Results

The survey received responses from 150 participants, divided into two groups based on their professions: physicians (20.37%) and nonphysicians (79.63%). Women constituted the majority of respondents (64.81%). Most participants (nearly 90%) were aged 44 or younger. Among nonphysicians, over 80% held a bachelor's degree, whereas among physicians, most had either a bachelor's degree or a fellowship/board certification (40% and 31%, respectively). Additionally, a majority of participants (60%)—including 60% of nonphysicians and 68% of physicians—had more than five years of professional experience. Significant differences in gender, age distribution, and educational qualifications were observed between the two groups (Table 1).

Participants were asked about their involvement in research activities. A significant proportion (64.81%) reported previous research involvement. Out of the total respondents, 27 indicated current engagement in research activities, such as drafting proposals, collecting data, or analyzing data. Physicians demonstrated a higher level of current research activity and significantly more publications compared to nonphysicians (Table 2).

Respondents were asked about their perceptions of the Institutional Review Board (IRB)/Research Ethics Committee (REC) regulations related to protecting health information. Among physicians, half agreed that these regulations made conducting research more straightforward (50%), while the rest were either neutral (36.36%) or disagreed (13.64%). Most nonphysicians (80%) and physicians (72.73%) agreed that these rules enhanced participant trust in researchers. Additionally, both groups acknowledged the benefit of these rules in improving confidentiality (81.82% for physicians and 84.88% for nonphysicians). A majority from both groups also believed that these regulations improved the privacy and security of healthcare information (68.18% and 88.37% for physicians and nonphysicians, respectively). Opinions were divided, with no clear consensus, on whether these rules prolonged study timelines.

Table 1. Baseline data of study participants

Variables	Total (n = 150)	p value
Female	(64.81)	<0.001
Age groups, years		0.01
25–34	(54.63)	
35–44	(26.85)	
45–54	(12.04)	
55–64	(3.70)	
65+	(2.78)	
Educational level		<0.001
Bachelor's degree	(77.14)	
Master's degree	(4.76)	
Medical degree	(5.71)	
Fellowship/board	(11.43)	
Doctorate's degree	(0.95)	
Work experience		0.07
6 months–5 years	(39.05)	
6–10 years	(23.81)	
11–15 years	(13.33)	
+16 years	(23.81)	

Table 2. Research history of survey respondents

Variables	Total (n = 150)	p value
Have you ever been a part of or conducted a research study? (Yes)	(64.81)	0.22
Are you currently working on a research study? (Yes)	(25.47)	<0.001
In which phase are you currently working on?		0.57
Proposal writing	(17.65)	
Data collection or data analysis	(47.06)	
Publication	(29.41)	
How many publications do you have?	(0–3)	<0.001

Discussion

The protection of patient data in clinical research is of paramount importance (17). Studies have shown that healthcare professionals (HCPs) may lack adequate knowledge regarding the safeguarding of patient privacy (18). This study aimed to evaluate the understanding, awareness, and attitudes of HCPs regarding these guidelines. To achieve this, both quantitative and qualitative methodologies were employed, allowing for a more comprehensive exploration of the topic. This mixed-methods approach enabled a deeper examination of the factors influencing HCPs' knowledge and attitudes toward data security in research, thereby enhancing the robustness of the conclusions.

The study sought to bridge the gap in understanding how well HCPs comprehend these guidelines. Additionally, attitudes toward the importance of patient data protection in research settings were assessed. These findings highlighted key areas for improvement in HCP compliance and ethical behavior, aligning with the study's primary goals.

The research utilized a survey and interview format. The survey involved 108 participants, comprising physicians and nonphysicians with differing levels of experience and professional

backgrounds. The findings emphasized the necessity for enhanced training in data privacy and security protocols. Factors contributing to better knowledge included prior research experience, engagement in research projects, years of professional experience, and age.

The interview component added depth to the survey results by identifying specific concerns about patient data security in research. Participants expressed apprehension about the handling of sensitive data and the risks posed by human error and inexperienced staff. Recommendations included restricting access to sensitive information to authorized personnel, conducting regular educational initiatives, and implementing frequent reminders about privacy regulations to reinforce compliance.

Comparatively, other studies have highlighted related concerns. For instance, a survey involving over 1,500 epidemiologists assessed the effects of HIPAA privacy rules on health research, with only a minority agreeing that the rules improved confidentiality (19). Another cross-sectional study among HCPs in a training hospital revealed limited awareness of patient rights, with varying levels of knowledge among nurses and physicians (20). Similarly, research on medical ethics among resident physicians reported widespread ethical challenges, underscoring a lack of preparedness in addressing these issues (21). A qualitative assessment of information systems in healthcare institutions recommended the establishment of national health information security policies modeled on HIPAA to standardize practices (22). Additionally, studies assessing nurses' awareness of patient rights identified work experience as a significant factor influencing knowledge (23).

In contrast to prior studies, this research revealed distinct demographic influences, such as age, gender, and education, on HCPs' understanding of privacy regulations. Despite similarities in perceptions regarding the importance of research ethics and the role of institutional review boards (IRBs) in safeguarding data, differences in methodology and participant composition set this study apart.

This study highlighted gaps in HCP knowledge and attitudes regarding patient data protection in clinical research. Greater participation in research activities and targeted educational programs can improve HCP understanding of privacy guidelines. Strengthening awareness of data security practices is essential to build public trust in research. Factors influencing privacy culture and the role of emerging technologies warrant further investigation (24, 25). Future research should explore innovative strategies to strengthen privacy protocols and create robust systems for data security.

Conclusions

The protection of patient data remains integral to ethical clinical research. Enhancing HCP knowledge, addressing gaps in compliance, and fostering a culture of data security are vital steps. IRBs and research ethics committees play a critical role in this process. Encouraging HCP participation in research and providing ongoing education can strengthen adherence to regulatory guidelines, ultimately supporting the integrity of clinical research practices.

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