Journal of Health Informatics in Developing Countries
http://www.jhidc.org/
Vol. 15 No. 1, 2021

Submitted: Jan 27th, 2021 Accepted: March 03rd, 2021

Barriers for patient-reported data collection, exploring the challenges, and solutions.

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Abstract

Background: The patient-reported data is the primary source for studying patient-related topics such as treatment satisfaction, quality of life, compliance to treatment, and many others. Collecting the data could be from surveys or interviews. To make use of patient-reported data, quality, reliability, and validity of the data must be considered before using the data. There are many difficulties associated with collecting data from patients. Recall bias is one of the expected issues with patient-reported data. Patients may have difficulties remembering clinical encounters or relevant information about symptoms or medication side effects. Problems include over-reporting or under-reporting of information. Factors affecting the recall bias include many factors such as cognitive problems, memory issues, and a long time (more than six months) between the encounter and recalling the details.

Aim: The aim of this study is to identify the barriers that prevent patients from providing valid data for clinical or research purposes focusing on the population of Saudi Arabia.

Methods: An online survey that discusses data collection barriers was distributed to clinicians and researchers who have experience in the field. We applied theme-based analysis to analyze the responses and identify the most relevant barriers and the solutions suggested by the respondents.

Results: Our sample included six participants with experience ranging from 10 to 33 years. The main issues for patient-reported data collection were fear of judgment and concerns for information privacy. The respondents suggested to assure the patients or collect the information using anonymous electronic surveys.

Conclusion: Patients/participants in the kingdom, similar to patients in other countries, are concerned about the exposure of personal information that may fear that it exposes them to societal judgment. Assurance of privacy and establishing trust with the patient allows for better collection of valid data.

Keywords: Data collection barriers, self-reported information, Privacy, Qualitative research, Theme-based analysis.

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1. Introduction

Scientific research is a base for development in all industries. Without research, there cannot be enough evidence to support new techniques, procedures, or tools. Experimental and observational research methods are pivotal in advancing evidence-based medical practice. In order to successfully perform a scientific study, researchers need valid, sufficient, and accessible data. Many barriers prevent data acquisition.

Furthermore, those barriers differ according to the purpose of the study and the study design. This paper is one of many papers that we plan to explore the challenges facing researchers when collecting different kinds of data. In this paper, we aim to explore the barriers that may face researchers' who are conducting research that requires patient-reported data. This paper revisits patient-reported data focusing on the patients' population in the kingdom of Saudi Arabia through the eyes of clinicians and researchers.

The patient-reported data is the primary source for studying patient-related topics such as treatment satisfaction, quality of life, compliance to treatment, and many others [1, 2]. Collecting the data could be from surveys or interviews [2-4]. In order to make use of patient-reported data, quality, reliability, and validity of the data must be considered before using the data [5].

There are many difficulties associated with collecting data from patients. Recall bias is one of the expected issues with patient-reported data [6]. Patients may have difficulties remembering clinical encounters or relevant information about symptoms or medication side effects. Problems include over-reporting or under-reporting of information. Factors affecting the recall bias include many factors such as cognitive problems, memory issues, and a long time (more than six months) between the encounter and recalling the details [2-4, 7].

Another issue is the willingness of patients to participate and how much information they are willing to share. Patients react differently to symptoms; they have different thresholds for pain, and that is why some of them report what they believe is relevant [4, 8]. Patients need to understand the purpose of the questionnaire-or the interview- to be able to productively participate with the right responses in the study [4]. Participants may not provide proper or honest answers because they do not trust the researchers or their goals behind the study. The mistrust may be due to personal issues or because the participants do not understand the reason for data collection [4]. Patients may be reluctant to report sensitive data because they are worried about the consequences or interventions from the care providers, especially for alcohol or illegal drug use [4, 9, 10]. Respondents may even provide unreal or false data to present a socially desirable image [11].

The use of confusing or unclear terms may confuse the patient when answering a survey. Designing the survey using unambiguous questions and avoiding vague terms while keeping the question relevant to the study is vital for getting a proper response from the patients [2]. The level of education and the understanding of patients regarding their medical conditions affect the accuracy of self-reported data. That is why the researchers must design the survey while keeping in mind the target population's level of education [12].

A study performed in Saudi Arabia demonstrated the cultural issues and language barriers affect the exchange of information between the patients and their assigned nurses [13].

While sorting the barriers and analyzing the possible solutions, we need to differentiate between interviews conducted for clinical purposes and others that are done as a part of scientific research because of the nature of questions that are directed at the patients. Different goals mean different questions and different barriers [14].

The problems associated with patients' self-reported data are many and the issues that we mentioned earlier represent the tip of the iceberg. We believe that is there is a great need to re-examine these issues through the opinions of professional researchers and practicing clinicians who have experienced many of those problems during their research efforts or daily patient care.

2. Subjects and Methods

2.1 Study design

This study is a qualitative study that adopts the grounded theory approach [15]. This approach is the most suitable to explore the professional opinions of researchers regarding the perceived barriers to data collection disadvantages of patient-reported data.

2.2 Research instrument

We distributed a survey that includes open-ended questions. The survey is designed in an interview-like format to discuss different topics about patient-reported data barriers through the participants' opinions. The survey comprised four open-ended questions and was distributed in an electronic format through the website surveymoney.com.

2.3 The survey

The survey included a few questions about the age, profession, years of experience of the participants. The participants then were requested to answer the following four questions providing as many details as possible:

1. What are the most common topics that patients avoid questions about?
2. Why -in your opinion- do you believe the patients avoid answering questions or discussing some issues regarding their medical condition or personal health, even with the presence of information security and confidentiality guidelines that protect all their information.
3. What are the topics or issues that patients usually are comfortable discussing?
4. What approaches or techniques do you recommend for using when interviewing patients for research purposes that would allow the patient to provide the most informative answers with minimal restrictions?

2.4 Target population

- Researchers who were involved in research that requires collecting information from patients directly (not using databases or historical data).
- Clinicians with at least five years of clinical experience. We selected this population because they are most likely familiar with various difficulties associated with patients' disclosure of information.

2.5 Sampling

We applied purposeful sampling by directly contacting researchers and clinicians whom we expected to have a sufficient understanding of the problem.

2.6 Ethical approval

We submitted this study for ethical review to King Abdullah medical research center, Riyadh, Saudi Arabia. An expedited review was performed, and it was approved. I.R.B number: RYD-21-419812-13899.

2.7 Data collection

An email with the information and the link to the survey was disturbed using email and social media. We contacted a group of clinicians/researchers directly and encouraged them to share it with any qualified professional who would like to participate.

2.8 Data analysis

We utilized repetition theme-discovery technique analysis to analyze the responses and extracted to most relevant themes that could provide insight into what governs patients' reluctance to disclose personal or health-related information [16].

3. Results

3.1 Descriptive statistics

We received six responses. The participants included: three researchers, two clinicians, and one researcher who is also a clinician.

The years of experience in the field ranged between 10 and 33 years, with an average of 19.8 years.

3.2 Qualitative analysis

Q1- What are the most common topics that patients avoid questions about?
Main theme: **Privacy**.

The responses focused on privacy issues such as such as "psychiatric conditions," "family issues," and "sexual activity." Patients avoid discussing their sexual activity or substance abuse, and more so if it involves illegal transgressions.

Q2- Why -in your opinion- do you believe the patients avoid answering questions or discussing some issues regarding their medical condition or personal health, even with the presence of information security and confidentiality guidelines that protect all their information?
Main theme: **Fear of judgement**.

The participants expressed their observation of the patients fear of exposure with regard to their personal information and scepticism about confidentiality of any information that they disclose to the provider or researcher. Such fear is based on the fear of being judged by society because of conflict with culture. We see terms such as "shyness," "mistrust," and "culture." "Unsuitable method of collecting information" was mentioned and unique to research interview rather than clinical history taking because the clinic is typically a private space where the patient is usually alone with his provider.

Q3- What are the topics or issues that patients usually are comfortable discussing?
Main theme: **Strictly medical.**

We saw terms such as "medical conditions" and "symptoms." Patients tend to keep the conversation about their medical complaints or medications while steering away from sexual or culturally sensitive issues.

Q4- What approaches or techniques do you recommend for using when interviewing patients for research purposes that would allow the patient to provide the most informative answers with minimal restrictions?
Main themes: **Anonymity, and assurance**.

Researchers suggested applying anonymous methods of data collection by mentioning." anonymous" and "electronic forms." The clinicians agree with researchers about ensuring that the setting is suitable for exchanging information which the patients consider sensitive while assuring them that the information is protected.

4. Discussion

4.1 Barriers to sharing information.

Patients have concerns about their information being exposed or viewed by others. The fear is still present even with the presence of electronic and physical security measures that restrict access to protected information. This makes us wonder about these fears, are these fears exaggerated?

Bearing in mind the differences in cultures around the world, we look at the responses gathered from professionals who are currently practicing in Saudi Arabia.

We noticed that the first barrier was a concern for the privacy of information. Private information was mainly about sexual activity, alcohol, or illegal behavior. Patients being protective of such information is shared by patients who were surveyed in the literature but to a lesser extent where recall problems were the more prominent [4, 6, 12].

While not sharing the information is an issue that prevents or delays the intervention, sharing false information to improve their image is much worse and was reported in the literature. Hiding the information or providing false information stems from the fear of judgment by the provider in case of not following the treatment plan or judgment of their society about culturally condemned behavior or illegal acts.

Patients were comfortable discussing information about their medications, symptoms, and treatment plans. However, any conversation about sexual acts, particularly, is avoided by the patients. Thus we believe the interviewer can use their communication skills to start the conversation with information the patients are comfortable and open to discuss to establish rapport, trust, and better information acquisition [14].

4.2 Enabling factors

Enabling factors are different regarding the purpose of the interview. The researchers' information needs, and methods of collection are different from those of clinicians.

4.3 Data collection for research

Our participants focused on using anonymity for collecting the information. Anonymity could be best achieved through the use of electronic surveys to collect the data. Anonymity will allow -in our participants' opinion- to share their sensitive information without the fear of exposure or judgment.

Anonymity, however, cannot be feasible in the case of face-to-face interviews, which are essential in some studies to gather detailed data that are relevant and important for accomplishing the research objectives.

The other suggestion was preparing a proper setting for the interview in a quiet, private setting. Such a setting may encourage the participant to share the information away from prying eyes and curious ears.

Patients -like any participants in any surveys- want a justification for joining or participating in a study, even if it is for a very short time. Patients may refuse because of a "lack of time" according to one researcher. To solve that, it was suggested to provide a sort of acceptable incentive to encourage the participants/patients to share their time and information.

Protecting the patient's privacy is not a luxury or an added value; it is the patient's right. Assurance of the patient that we are protecting this information and that there are policies and laws, physical and electronic security measures that protect information confidentiality are essential every time we gather information from patients. While this is a routine step in any research project via written consent forms, it would most definitely serve to negate the participant’s/patient's fears to discuss and assure the patient's privacy concerns.

4.4 Data collection for clinical purposes

Establish rapport and gain the patient's trust. Gaining the patient's trust can be achieved through assuring confidentiality of the shared information showing empathy to the patient's condition. The application of communication skills and being tactful of the patient's circumstances, family issues, and the cultural aspects of the topic in question allows for the best delivery of the question and deriving the most beneficial responses subsequently.

The clinical setting is typically designed to be a quiet setting that ensures the patients' privacy. Patients could be reminded of that while starting the interview with topics that they are open to discussing. After discussing with the patient different topics with the patient, it may be easier to start asking about culturally sensitive issues.

As one of the clinicians stated to "Assure them about their role in improving quality and safety of care that will be receiving in the future." Telling the patient that the provided information is essential for improving their treatment plan and outcome and that withholding that information may affect the quality of care shall encourage the patients to be frank about their complaints or issues in question.

4.5 Limitations

The interviews were conducted via electronic surveys due to the ongoing pandemic. We believe that face-to-face or panel discussion may provide more details about the topic of this paper. Also, having a bigger sample would have provided a better insight into more barriers perceived by professionals in the field.

5. Conclusion

Some barriers that prevent patients from sharing information are universal, while others unique to particular areas in the world. Cultural and societal values play crucial roles that prevent patients from sharing information due to privacy concerns or fear of being judged. According to the professionals that we interviewed, the magic words were: anonymity and assurance. To get the most out of the interview, be it a clinical or a research interview, researchers and clinicians always need to assure the patient that their information is enforced by law. The right setting, time, and method and the right time also can help the patient open up and share more about their condition.

6. Declarations

6.1 Conflict of Interest Statement

The author has no conflict of interests to declare.

6.2 Funding Disclosure

None.

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