Patients' health records in research: perceptions and preferences of patients in Bida, Nigeria

[1-4]Adeleke I. T., [2,5]Adekanye A. O., [1,2]Adebisi A. A., [2,5]James J. A., [1-3]Omokanye S. A., [2,6]Babalola A.

[1]Department of Health Records, Federal Medical Centre, Bida, Nigeria; [2]Centre for Health & Allied Researches, Bida, Nigeria; [3]Health Informatics Research Initiatives in Nigeria, Bida, Nigeria; [4]Editor-in-Chief, International Journal of Health Records & Information Management; [5]Department of Surgery, Federal Medical Centre, Bida, Nigeria; [6]Department of Family Medicine, Federal Medical Centre, Bida, Nigeria.

Corresponding author:

Adeleke IT. Department of Health Records, Federal Medical Centre, Bida, Nigeria. Email:

ibratadeleke_aliseyin@yahoo.com

Abstract

Background: The patient's health records is growing daily as a major source of information for health research; and evidences have shown that much healthcare research depend largely on these records. However, there have been reports of unguided and unguarded access to these records and increased awareness among the patients, who are the subjects of the records.

Objectives: To determine participants' level of awareness on the use of their health records in research and to define their preferences in granting consents for such uses.

Methods: This cross-sectional study deployed stratified random sampling in the recruitment of 383 participants.

Results: Nearly two-fifth (39.8%) of participants understood ownership of health records, most (85.3%) were confident that their health record is well protected in the hospital and many of them (77.7%) knew that their healthcare providers use their health records for research purposes. More than half (55%) would want to be asked for consent each time their health records are to be used in research and they would feel disappointed (51.6%) when such use took place without their consent.

Conclusion: Patients who access care at Federal Medical Centre, Bida were confident of security of their records in the hospital; they are equally aware of the use of their health records in research especially by their caregivers but would frown at any use in research without their consent. They would always want to be contacted each time their health record is to be used in research. Therefore, there is a need to obtain consent from patients at the time of services that their health records could be used for research purposes.

Key words: Patients; Health Records; Health Services Research; Informed Consent; Nigeria.

Introduction

The patient's health record is growing daily in importance as the source of information to meet a wide variety of needs especially, in clinical and health services research[1] and much of these researches are heavily dependent on access to accurately kept health records.[2] Historically, patients' health records were maintained and often understandable by individual physicians[3] but, nowadays, groups of physicians working together often share the same patients and their records.[3] Likewise, patients on their own may have multiple sources of care and

lately, third-party payers do request for access to patients' health records to document services provided. In the past, access to these records without informed consent was common.[3] Although new privacy laws allow access to personal information from health records without consent in certain circumstances,[3] these laws provide little guidance for research ethics boards and data holders as to the circumstances under which this may occur.[3] In United Kingdom for instance, researchers face a confusing situation in terms of accessibility to patients' health records for research.[4] However, the United States Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rules permit patient authorization to be waived in certain circumstances.[5] A covered entity, such as hospital, may give researchers access to health records without authorization by individual patients in two specific instances.[5] First, while preparing a research protocol and access to health records is needed for its preparation and secondly, when research concerns only dead people.[5] Similarly, the Victorian Health Records Act (2001) provides policies which acknowledge the desirability of centralized and integrated record keeping across hospitals in Australia.[6] In spite of these provisions, Lederman[6] reported that researchers in Australia were not able to access complete health records with absolute confidence and privacy.

The ownership rights of the patient to the content of health records are not widely understood[7,8] such that patients themselves believed that health records absolutely belong to them.[9] In patients' opinion, the fact that they pay the medical bills, which resulted in the production of medical charts that made up the health records, they must be notified of their rights with respect to their health information.[9] Such rights include rights to restrict the use and disclosure of such information, to inspect and copy their records, to amend their records, and the right to an audit of any disclosure of their records.[9] More so, ethical requirements[10] demand that when patients' health records are to be used in research, patients give explicit consent and should have received appropriate information about why and who will use them, be reassured of confidentiality and be given the opportunity to decline.[10] However, local research ethics committees have the discretion to approve such research and journals can publish findings when access to the health record is essential for the completion of the research and obtaining consent is not practicable[10] Willison *et al.*[11]

affirmed that size of population being researched, difficulty of contacting participants and resultant risk of introducing bias into the research were some of the reasons responsible for the difficulty to obtain individual patient's consent in a research into their health records.

Public support for medical research is a function of public trust[5] and providing meaningful protection of the privacy of health records in research is an important goal in its own right which will increase public trust in the entire medical research enterprises.[5] One of the surest ways to protect patients' health information in research is to de-identify the information. When information is de-identified, all the personal characteristics have been stripped so it cannot be later combined to re-identify the individual.[12,13] Of importance also is the medico-legal responsibility of all healthcare providers who are the major contributors as well as users of patients' health records. Although existing laws[14,15] mandate them to maintain confidentiality of patients' health records at all circumstances, most of them do not fully understand their responsibility toward this tenet.[16-17] Melton[18] reported that patients' major fear when their records are used in research is that of inappropriate access to personal medical data as well as potential misuse by employers and insurers. Furthermore, patients were unaware that administrative staff had access to material in their primary care records[19] and those patients who were willing to allow their information for use in research would mostly want to be consulted first.[11] In the same vein, Aderibigbe and Sodipo observed[20] that patients in Nigeria would frown at the use of their health records in research without their knowledge and that they must be obliged when they need their health record on transfer to another facility.[20]

Federal Medical Center Bida is one of the many Nigerian tertiary health institutions with the mandate to provide qualitative healthcare services, as well as training through the conduct of pertinent researches. As research interests unfold from groups and individuals in the hospital, there are growing demands for patients' health records as a major source of information. Such massive impersonal use of these records may attract the attention of patients who are the subjects of the records. Therefore, the main objectives of this study were to determine participants' level of awareness on the use of their health records in research and define their preferences in granting consents for such uses.

Methodology

Study setting

The study took place at Federal Medical Centre, Bida, Nigeria, a 200-bed Federal Government owned non-for-profit hospital, between May and June 2015. The hospital was converted to a tertiary healthcare facility in 1997 having served as colonial and state governments owned general hospitals for several decades. The hospital has twenty-five medical and paramedical specialties and subspecialties and twenty three weekly consultative clinics. As a tertiary healthcare facility of more than two and a half decade, the hospital has treated more than 1.4 million outpatients and nearly 150,000 inpatients. The outpatient clinics are divided into two broad categories which include general outpatient and consultative outpatient clinics. The consultative outpatient clinics cover all specialty and subspecialty clinics. This current study took place at the general outpatient clinic, NHIS clinic, and antiretroviral therapy clinic. The two others are antenatal clinic and the conglomerate of subspecialty clinics called consultative outpatient clinics.

Study design

This is a cross-sectional study of outpatients on the use of their health records in research.

Study population

All patients (with the exclusion of paediatrics patients who are minors and may not be able to take decisions on the use of their own health records) who attended outpatient clinics at Federal Medical Center, Bida in the review period were the target population. The baseline hospital data used for the computation of sample size was the total outpatient attendance as contained in the hospital's statistical returns for the year 2013 as reported by the Department of Health Records of the hospital.

Sampling technique

Stratified random sampling was deployed to recruit participants into the study from five selected outpatient clinics of the hospital. These include General outpatient clinic, antiretroviral clinic, National Health Insurance Scheme clinic, consultative outpatient clinic and antenatal clinic.

Sample size

Based on the hospital's 2013 Statistics, a sample size of 383 was computed, using the Survey System online sample size calculator (www.surveysystem.com/sscalc.htm).

The formula used for calculating sample size with this software is:

$$ss = \frac{Z^2 * (p) * (1-p)}{c^2}$$

Where:

Z = Z value (e.g. 1.96 for 95% confidence level)
p = percentage picking a choice, expressed as decimal (.5 used for sample size needed)
c = confidence interval, expressed as decimal
(e.g., .04 = ±4)

This gave the following sample size per clinic respectively: General outpatient clinic, 196; National Health Insurance Scheme, 56; anti-retroviral clinic, 29; antenatal clinic, 39 and consultative outpatients' clinics, 104.

Data collection tools

A 25 – point structured self-administered questionnaire designed by the researchers was administered to participants. The questionnaire was designed by the authors and validated through a pilot survey conducted. Items C1 to C4 in the questionnaire were adapted from the work of Campbell *et al*.[19]

Data analysis and management

The IBM SPSS Statistics version 16.0 (2007) manufactured by IBM Company was used to analyze the data. Data analysis done includes simple frequency, cross tabulation, means, standard deviations and test of association.

Inclusion and exclusion criteria

All outpatients at Federal Medical Centre, Bida with the exception of paediatrics were eligible to participate in the study. The clinics include; general outpatient clinic, consultative outpatient clinics, NHIS clinic, antenatal clinic and antiretroviral therapy clinic.

Ethics

The approval to conduct this research was obtained from the Health Research Ethics Committee (IRB) of the hospital. After the ethical clearance, the tool was pretested among a small group of people. This group consisted of twelve Nupe speaking trainees of health information management who were as at the time of the study, undergoing a hospital-based practical training in the hospital. This group served as interpreters to the Nupe speaking majority of the target population. The objectives, techniques involved, the researchers and users of the research were fully explained to the

interpreters during the brief training and same was explained to the participants during questionnaire administration. Furthermore, written informed consent was obtained from each participant before administration of the questionnaire.

Results

Three hundred and eighty (99.2%) participants completed the questionnaire. Though a few of participants (1.6%) did not report their age, the majority (69.3%) were between 21 and 40 years, most (51.1%) of whom attended general outpatient clinics (Table 1). The majority (69.2%) of participants had accessed care from the hospital for five or less years (Table 1). Many (76.1%) participants possess secondary or higher education and most (61.8%) were either gainfully employed or into trading (Table 1). Almost two-fifth (39.8%) of participants recognized the physical and content ownership of health records as that of the hospital and patients respectively, and the vast majority (85.3%) believed that their health records is well protected in the hospital (Table 2).

A greater portion of participants (91.1%) acknowledged the relevance of scientific research to healthcare and they were fully aware (77.7%) that their healthcare providers in the hospital partake and use their health records for research purposes (Table 2). Based on their knowledge on the use of their health records in research, more than half of the participants (55.0%) would want to be asked for consent each time their health records is to be used in research (Table 4). This is especially so when such requests require access into their diagnosis (91.7%) and age (90.6%) (Table3). When requested to enlist hospital staff they would wish to grant access to their health records for research purposes, participants arranged the staff in the following order: medical doctors (49.4%); health records professionals (15.0%); nurses (12.1%); medical laboratory practitioners (11.6%); pharmacy staff (6.3%); some were unsure (2.4%) while the rest (3.2%) did not respond (Table 2). Nevertheless, most participants would feel disappointed (81.8%) if such use took place without their consent or notification (Table 4).

As shown on Table 5, some demographic characteristics of participants were associated with participants' consent preferences and perceptions of the use of their health records in research. For instance, participants' preference to be asked for consent when their medical history is to be accessed was associated (.013; .004 and .038)

with ethic group, level of education and types of clinic attended respectively. So also, participants' belief (perception) that their health record is protected in the hospital was associated (.000; .029 and .024) with ethic group, level of education and participant's occupation respectively.

Discussion

The quest to complement the existing body of medical knowledge and improve healthcare services delivery has propelled the conduct of health services researches, which largely depend on patients' health records[1,2] However, conducting such researches has met with serious challenges. These challenges range from the diverse view of medical ethicists; institution review boards (IRBs), healthcare providers and the patients themselves. Such views were mostly centered on unguided and unguarded access. For instance, IRBs on one hand have the mandate to waive the requirements for informed consent in minimal risk protocols[18] and they have a preference for individual patient's consents[3] at all times their health record is used in research.

Table 1: Socio-demographic characteristics of participants

	Frequency	Percentage
Gender (n=380)		
Male	181	47.6
Female	199	52.4
Age (n=374)		
<=20	34	9.1
21-30	142	38.0
31-40	117	31.3
41-50	47	12.6
51-60	23	6.1
>60	11	2.9
Education level (n=364)		
Primary	15	4.1
Qur'anic	98	26.9
Secondary	54	14.8
Tertiary	179	49.2
None	18	4.9
Occupation (n=374)		
Employed	133	35.6
Trading	98	26.2
Schooling	70	18.7
Unemployed	54	14.4
Farming	19	5.1
Clinic(n=380)		
GOPD clinics	194	51.1
COP clinics	63	16.6
NHIS unit	56	14.7
ANC	38	10
ART clinic	29	7.6
Duration of patronage (n=240)		
<1 year	69	28.8
1-5 years	97	40.4
6-10 years	43	17.9
11-15 years	15	6.3
>15 years	16	6.7

*Differences in total frequencies (n) per item from total number of participants (N) were as a result of number of no response to each item. NOTE: GOPD-general outpatient department; COP-consultative outpatient; NHIS-National health insurance scheme; ANC-antenatal clinic; ART-anitreroviral therapy

Table 2: Participants' perceptions on their health records in research

Variables/Values	Frequency	Percentage
Ownership of health records (n=372)		
The hospital	164	44.1
The patient and the hospital	148	39.8
The patient	31	8.3
Don't know	29	7.8
Do you believe that your health record is well protected in the hospital? (n=373)		
Yes	318	85.3
No	15	4.0
Unsure	40	10.7
Research is very relevant to health service delivery (n=370)		
Yes	337	91.1
No	7	1.9
Don't know	26	7.0
Are you aware that healthcare providers at FMCB use your health records in research (n=372)		
Yes	289	77.7
No	83	22.3
Would you grant access to the following hospital's staff when asked (n=561)*		
Medical Doctor	289	51.5
Health Records Officer	88	15.7
Nurse	70	12.5
Medical Lab Scientist	68	12.1
Pharmacist	46	8.2

*The frequency here is more than the sample due to the multiplicity of responses required.

Table 3: Participants' consent preferences for the use of their health records in research

	*Preferred to be asked (%)	No preference (%)	**Preferred not to be asked (%)
When your age is to be accessed (n=362)	328(90.6)	16(4.4)	18(5.0)
When your ethnicity is involved (n=359)	325(90.5)	21(5.8)	13(3.6)
When your medical history is to be reviewed during the research (n=361)	320(88.6)	13(3.6)	28(7.8)
When the diagnosis or your reasons for seeking healthcare services is involved (n=360)	330(91.7)	8(2.2)	22(6.1)
When researchers from outside the hospital wish to use your health records in research (n=353)	293(83.0)	17(4.8)	43(12.2)
When health maintenance organizations (HMOs of NHIS) are involved in a research into your health records (n=354)	297(83.9)	18(5.1)	39(11.0)
When research into your health records is sponsored by non-governmental organizations (n=350)	286(81.7)	22(6.3)	42(12.0)

*This includes those who definitely want to be asked and those who preferred to be asked for consent
**This includes those who definitely not want to be asked and those who preferred not to be asked for consent

Table 4: Participants' specific preferences on consents

Values	Frequency	Percentage
Why do you prefer to be asked for consent before your health records is used in research? (n=331)		
Personal reasons	120	36.3
Don't want my personal health information in research	79	23.9
Fear of the unknown	61	18.4
I don't need to know	28	8.5
I don't know	28	8.5
Don't believe in research	7	2.1
Others	8	2.4
How would you want to be asked? (n=356)		
Verbally	219	61.5
In writing	67	18.8
On phone	52	14.6
Via email	9	2.5
I don't know	9	2.5
How frequent do you want such requests? (n=347)		
Each time my records is to be used in research	191	55.0
Once for all times	92	26.5
Every quarter	39	11.3
I don't know	25	7.2
How would you feel if your record was used in research without your consent? (n=347)		
Highly disappointed	179	51.6
Disappointed	105	30.3
Unconcerned	49	14.1
I don't know	14	4.0

Table 5: Factors associated with participants' preferences and perceptions of their health records in research (*significant)

	Ethnic group	***Education level***	***Clinic***	***Occupation***	***Gender***
Reasons for wanting to be asked	.001*	.002*	.001*	.038*	.009*
How frequent should consent for access be sought	.096	.000*	.018*	.044*	.000*
Whether patients would grant consent to researchers from outside	.006*	.004*	.038*	.177	.006*
How much healthcare research do you know?	.005*	.000*	.001*	.000*	.142
When your ethnicity is to be accessed	.000*	.025*	.034*	.616	.046*
When your medical history is to be accessed	.013*	.000*	.041*	.016*	.106
When reason for treatment is to be accessed	.009*	.000*	.141	.000*	.475
Mode of seeking consent preferred	.002*	.001*	.000*	.630	.73
Believed that patient's health record is protected in the hospital	.000*	.029*	.322	.024*	.098

On the other hand, healthcare providers believed that if they could freely access patients' health records for the purpose of diagnosis and treatment without consent, there should be no difference when the record is used in research.[9] They seem to know less as regards their limits to access patient's health records as many of them discuss patients' matters freely with their relations.[21] Other studies[16,17] have even revealed that they lack adequate understanding of their respective responsibilities toward the tenets of medical confidentiality. In addition, they have lost confidence of patients based on patients' experience of unauthorized information release.[22] As regards patients who are the central focus of this subject, our study reveals that participants believed that their health record is adequately protected in the hospital. This is incongruent to a study[23] where most patients felt that their health record is not sufficiently protected in the hospital. In any healthcare enterprise, trust and confidence are two important aspects that enhance provider-patient relationship. Trust, encourages the patient to divulge all information that is required to help the care provider serve him or her best. Anything contrary to this may portend poor healthcare delivery.[17] Confidence on the other hand, reassures the patient that the information contained in his health records is protected.

More so, the majority of participants appreciated the relevance of scientific research to healthcare and they were aware that their healthcare providers partake in healthcare services research, in which their records are used. Based on this awareness and their conviction of record's protection, participants would want to grant consents to their healthcare providers in the hospital especially, physicians, health records professionals and nurses, when their records are to be used in research. This ranking though seems realistic, may be as a result of physicians' closeness to the patients. This finding is not in agreement with a report that patients were unwilling to be partners when they believe research takes advantage of their personal data without their knowledge for a benefit that may be elusive[24] Hence, they do not wish to entirely relinquish control.[24] Almost all participants from our study would want to be asked for their consent especially, when such research requires access to their diagnosis (92%) and age (91%) and would be disappointed, should their health records be used in such or any other researches without their consent. This preference from our study is similar to those from a study as reported by Willison *et al*. that participants would grant consents when they are explicitly consulted first before such use.[25] When asked for their reasons for wanting to be asked, more than a third advanced personal reasons while a smaller

portion (18%) indicated fear of the unknown. Our study reveals that participants admitted the fact that though they were the reason the health record is initiated, the physical records are the property of the hospital. This reiterates earlier reports[7-9] that the fact that patients were the reasons the records were created does not make it their absolute reserve to deprive the hospital her own rights of ownership. In line with this, several studies[5,12] have advocated the use of patient's health records in research; they equally advanced the importance of de-identification of such records especially when used in research with a view to protecting the interests of the patients. Nevertheless, our study also advances the right of the patient to be adequately notified[9-10] of the proposed use of their health records in research and the right to give explicit consent for their records to be used in research.

Study limitations

The time it took the researchers to recruit research assistants who served as interpreters since the first language of the majority of participants was Nupe and the time taken by the interpreters to explain items in the questionnaire to the participants, was to an extent, a major limitation. Secondly, as at the conception and implementation of this study, there was dearth of relevant literature from Nigeria specifically on this study. This constrained the researchers to largely depend on literature from countries outside Nigeria. Another noticeable limitation in this study was that the study did not find out the participants' in-depth knowledge of the use of their health records in research.

Conclusion and Recommendations

Patients who access care at this Nigerian tertiary hospital were confident of security of their records in the hospital; they are equally aware of the use of their health records in research especially by their caregivers but would frown at any use in research without their consent. They would always want to be contacted each time their health record is to be used in research. Therefore, there is a need to obtain consent from patients at the time of services that their health records could be used for research purposes.

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