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A qualitative study of women's views on medical confidentiality

G Jenkins, J F Merz, P Sankar

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See end of article for authors' affiliations

Correspondence to:
Dr P Sankar, Department
of Medical Ethics,
University of Pennsylvania,
3401 Market Street, Suite
320, Philadelphia, PA
19104, USA; sankarp@
mail.med.upenn.edu

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Context: The need to reinvigorate medical confidentiality protections is recognised as an important objective in building patient trust necessary for successful health outcomes. Little is known about patient understanding and expectations from medical confidentiality.

Objective: To identify and describe patient views of medical confidentiality and to assess provisionally the range of these views.

Design: Qualitative study using indepth, open ended face-to-face interviews.

Setting: Southeastern Pennsylvania and southern New Jersey, USA.

Participants: A total of 85 women interviewed at two clinical sites and three community/research centres.
Main outcome measures: Subjects' understanding of medical confidentiality, beliefs about the handling of confidential information and concerns influencing disclosure of information to doctors.

Results: The subjects defined medical confidentiality as the expectation that something done or said would be kept "private" but differed on what information was confidential and the basis and methods for protecting information. Some considered all medical information as confidential and thought confidentiality protections functioned to limit its circulation to medical uses and reimbursement needs. Others defined only sensitive or potentially stigmatising information as confidential. Many of these also defined medical confidentiality as a strict limit prohibiting information release, although some noted that specific permission or urgent need could override this limit.

Conclusions: Patients share a basic understanding of confidentiality as protection of information, but some might have expectations that are likely not met by current practice nor anticipated by doctors. Doctors should recognise that patients might have their own medical confidentiality models. They should address divergences from current practice and provide support to those who face emotional or practical obstacles to self-revelation.

Research conducted in several countries, including England, Australia, Canada, and the USA demonstrates the importance of medical confidentiality to patients. Findings suggest, for example, that patients who believe that their privacy will be respected are more likely to seek treatment, discuss problems openly, and return for follow up care.^{1–13} In recognition of the importance of medical confidentiality to successful health outcomes, the US federal government recently adopted rules under the Health Insurance Portability and Accountability Act (HIPAA) to include the first comprehensive protection for the privacy of health information in the USA.¹⁴

The primary purpose of the HIPAA privacy rule has been to direct the creation of a system of rules, practices, and oversight to protect medical information. Patient understanding of confidentiality is addressed in the rule's requirement that healthcare providers explain to patients the conditions under which their information can be used and released to third parties.¹⁴ The rule also stipulates that this information be provided in "plain language".¹⁵ However there are reasons to suggest that additional effort might be required to communicate effectively with patients about medical confidentiality.

Firstly, research has shown that some lay definitions of terms such as "private" and "confidential" differ from professional and legal definitions that emphasise release of information.^{16–20} Secondly, the technique on which the HIPAA privacy rule relies for patient education differs little from past methods used to inform patients about confidentiality policies: the standardised form. Research has shown that these forms are ineffective as ways to explain to patients

the release of information policies that HIPAA has replaced.^{21–23} Recent anecdotal reports describe patients who do not read the new HIPAA forms or are confused by them, which suggests that these forms are no more successful than their predecessors.^{24–28} The shortcomings of standardised forms to explain confidentiality policies might undercut one of the putative goals of medical confidentiality protections: to strengthen patient trust. This could be the case either if patients do not understand the confidentiality rules in place or if the rules do not effectively address confidentiality as they understand it. Patient trust would seem to rely not only on how information is actually handled but also on what patients believe and understand about how it is handled.^{23 29 30}

The immediate consequence of the HIPAA privacy rule in the USA has been to direct much needed attention to patients' medical confidentiality concerns, set aside too long. To take advantage of this increased awareness, it is also necessary to take fuller account of how patients understand medical confidentiality and what they expect from it.

Currently little is known about patient understanding of medical confidentiality. Recently, more studies reporting on patients' attitudes about confidential information disclosure have begun to appear,^{31 32} yet it is still the case that less than 2% of the nearly 6000 articles that MEDLINE indexes to medical confidentiality report on patient views.³³ Most of those that do address these examine vulnerable populations, including adolescents, mental health patients, and human immunodeficiency virus (HIV) positive patients. These studies show that a small but notable minority of patients misunderstand important features of medical confidentiality

and that some possibly misunderstand the phrase itself.^{16 17 19 20 34 35} Furthermore, based on their lay understandings of medical confidentiality, patients develop their own strategies to balance a need for medical care against threats posed by disclosure. Research has shown, for example, that patients will withhold information or delay care rather than reveal certain health information.^{1 35 36}

It is not clear what reassurances or explanations would be necessary to convince people to forgo these strategies. Complete privacy of information is rarely an option because continuity of medical care requires information sharing and, in the USA, because of requirements for insurance reimbursement. But failure to discuss confidentiality in terms that patients understand could exacerbate patient mistrust and strengthen the perceived need to conceal information or avoid treatment. To initiate collection of data about patient understanding of medical confidentiality, we designed an exploratory study to describe patient views and to assess how these views might differ.

METHODS

This study utilised indepth interviews with adult women. An interview guide was developed and piloted, addressing subjects' understanding and experiences regarding medical confidentiality.

Participants

We recruited women in southeastern Pennsylvania and central New Jersey through two primary care practices associated with large hospitals and through advertisements in three local newspapers. We chose the clinics and newspapers specifically to increase the chances of attracting volunteers from diverse socioeconomic backgrounds and age groups. Women over the age of 18 years were eligible to participate and each was paid US\$25.

Interview

We focused on women for this preliminary study because women on average have more overall numbers of interactions with healthcare providers due to the burden of reproductive health issues and because women are more likely to be responsible for seeking health care for members of their family.³⁷⁻³⁹ It is important, then, to understand women's beliefs about medical confidentiality as they negotiate health care for themselves and others. Furthermore, because there are relatively few articles that enquire directly into patient views limiting the research to women helped to focus the enquiry and lay the groundwork for future research.

The subjects were interviewed in a private room in a research or community centre close to their residence or in the clinic where they were recruited. The same interview guide was used for all subjects, although minor modifications were made over the course of the study; older women were asked an additional set of questions about menopause. The interviews were conducted primarily by GJ, at the time a postdoctoral fellow in bioethics, and secondarily by PS.

All interviews were audiotaped except two in which the interviewees declined taping. These interviews were documented with handwritten notes. The interviews lasted between 35 and 90 minutes. The institutional review boards of the University of Pennsylvania and the hospitals that housed the two clinics where we recruited subjects approved this research. All subjects participated in approved informed consent procedures.

The interview guide was piloted extensively in several healthcare settings and revised several times until we determined that its questions were comprehensible to the population we were sampling. Pilot interviews indicated that some women thought that confidentiality protections existed

to handle exceptional circumstances whereas others considered them standard practice. The final interview guide was a semistructured tool that included both closed and open ended questions. The questions were structured to explore the possible differences in patient beliefs about whether confidentiality practices were standard or routine and possible variation in interpretation of the term "confidentiality" reported in the literature.

The interview began with the interviewer asking the subject a general question, such as to explain how she chose a particular clinic for her health care. The interviewer then asked the subject to reflect on a recent routine healthcare visit, what information might have been collected during it, and what happened to the information after the visit. These questions were intended to elicit the woman's basic understanding of the collection, storage, and use of personal medical information. To determine whether subjects thought that all medical information was handled roughly the same or whether a range of procedures existed, these initial questions were followed by similar questions enquiring about medical information that was described specifically as *confidential*.

Questions about confidential medical information began by asking the subject to explain the meaning of confidentiality: "If your doctor or nurse tells you that they'll keep something confidential, what does that mean to you?". Additional questions elicited features that the interviewees might associate with the treatment of confidential information, such as specific rules governing its storage and circulation, and whether the subject experienced difficulty disclosing certain kinds of information.

Multilevel consensus coding

The tapes were transcribed verbatim and were entered into QSR NUD*IST V.4, a qualitative data analysis software program (Sage Publications Software, 1997; Thousand Oaks, CA). We developed a preliminary coding scheme based on results from pilot interviews and the literature. It was tested on early interviews and revised until it efficiently and adequately captured desired relevant information. The coding scheme had three levels that were applied sequentially and that required three separate readings of each interview. First level coding generated standard, comparable answers to close ended questions. Second level coding examined anecdotes and examples from the respondents' personal experiences with confidentiality procedures or expectations in medical settings. Its goal was to collect and characterise the central experiences, ideas, and issues that informed each interviewee's perceptions of confidentiality. Categories for these data were proposed based on insights garnered during first level coding. These categories were finalised through multiple trial codings of a subset of 20 randomly selected interviews.

Coders were trained intensively by coding several interviews that had been analysed during the development of the coding scheme. Two coders read and coded each level of each interview individually, then met together to compare their individual coding choices and to come to agreement on one set of codes for the interview. Disagreements were discussed. Those that could not be resolved were referred to a weekly consensus meeting, which all pairs of coders attended. Data that could not be coded in the consensus meeting were omitted from the analysis.

RESULTS

Between 1998 and 2000 we conducted 85 interviews with a diverse group of participants (average age 35 years; range 18-75) (table 1). This sample was younger than the general

population in the region sampled and reflected a higher level of education.^{40 41}

Collecting and using medical information

The subjects were prompted first to reflect on the interactions that occurred during a routine visit to their doctor and then asked about what part of the interactions would be documented and what would happen to this information following the consultation. Responses about these topics were similar across subjects. Some emphasised what the doctor would document such as, "Why I came in", whereas others highlighted the purpose of documentation, as in, "it may be data that they need to go back to if anything comes up down the line".

When asked what happens to their medical record or information after the visit, most answered that it would be processed by a secretary or nurse and stored in a file cabinet or in a computer database. Most added that the information could be sent or given to someone else, although they disagreed about exactly why or how this might happen. Two main distinctions in these examples were whether sharing information was routine and acceptable or whether it was exceptional and, at least at times, inappropriate. Some thought sharing was routine—but only within the clinical setting where the information was first collected—implying, and sometimes stating, that to use or send information beyond this setting was wrong.

I don't think it's sent anywhere. ... When they have to agree with one another, I think they show another doctor what's in here. Like in other words if I need a medication they'll show the other doctor or have another doctor come in and check me. I think they do that, like between their selves. But as far as it going any further, I don't think so. I really don't think so, you know. (A135)

Although some respondents recognised the need for medical information to circulate for medical or reimbursement needs, more than a quarter of subjects (n = 23) spontaneously declared that until the occasion of the interview, they had not fully understood the implications of this for their own medical information. An older woman who

worked as a secretary in a firm that handled pre-employment physicals and employee drug testing, stated:

Originally until I came here right now I wasn't thinking that way. I was like, I talk to my doctor and my file gets put away and that's it. But it really isn't so confidential if you think about it. (D254)

Medical confidentiality definitions

Enquiry into the handling of medical information designated *confidential* and into lay definitions of confidentiality began with the question, "If your doctor or nurse tells you that they'll keep something confidential, what does that mean to you?". Nearly all women described confidentiality as an expectation that something done or said would be kept "private", but their answers differed concerning the basis, limits, and significance of this protection.

The largest group (n = 50) of respondents emphasised the personal relationship in which information is exchanged, whether with a doctor, other professional, or a friend, and voiced the belief that confidential information was shared between only teller and listener.

It means that they won't tell anybody else the information. It's only information that they know. I mean, they know that that information belongs to you, but they won't tell anybody else. (B101)

These responses also sometimes emphasised the sensitive or secret nature of the information that women considered subject to confidentiality protections.

It means when you tell somebody something it's between just you and them. And you tell them in, you know, in other words, it's like a secret you can tell her, confide in them. You know, like if I tell my girlfriend, my friend, I can tell her anything and she'll hold it to herself. It don't go no further, you know. And whatever she tells me, it don't go no further. So, I mean, when you come to a doctor that's what it's supposed to be. It's supposed to be between patient and doctor. Whatever you tell your doctor is supposed to be just between you and the doctor. So I guess it's what they do. You know, I hope they do that, you know. (A135)

A subset of this group (n = 14) did stipulate that with express permission a doctor could reveal confidential information to another healthcare practitioner.

Another group of common responses (n = 27) characterised confidentiality as a set of bureaucratic procedures that allow information to be used for defined and discreet purposes, such as continuity of medical care, while protecting it from other uses. The information protected might be thought of as secret, but responses highlight the use of information rather than its concealment.

R: [Confidentiality means] that I would have an understanding with my healthcare professional that what I said to her was for medical purposes only and wouldn't have any entitlement to go elsewhere.

GJ: So, your information is just for medical purposes?

R: Sure, except for what insurance is entitled to know. (D173)

Another woman stated:

Table 1 Demographic characteristics of the interview population

	N	%
Age		
18-22	28	32.9
23-46	30	35.3
>46	27	31.8
Race		
White non-Hispanic	43	50.6
African American	28	32.9
Asian	8	9.4
Hispanic	6	7.1
Income		
<15 000	13	15.3
15 000-24 000	16	18.8
>24 000-40 000	20	23.5
>40 000-75 000	18	21.2
>75 000	16	18.8
Education		
Some high school or high school graduate	20	23.5
Some college	34	40.0
College graduate	30	35.3
Unknown	1	1.2

I would think that what's in my record, what's in my chart is in my chart and it doesn't leave that office unless I give permission for it to leave the office and be sent somewhere else. No one else has to view it except for those people who need to have access to that information for the reasons that I stated before. (C164)

A small number of subjects ($n = 7$) provided what we labelled "negative definitions" in the sense that they described only what could not be done with information, such as:

It means that it's private. It means that they may not share this information with an insurance company or with anyone if it's confidential. (A221)

Distinctiveness of confidential medical information

Enquiry into patients' definitions of confidentiality was extended through questions such as "So, what part of the information that you talk about with your doctor or nurse is *confidential*?". Through these exchanges two distinct concepts emerged of what constituted confidential information. The first highlighted the content of information, naming topics such as mental illness or sexual behaviour—for example:

Well, I think that, I don't have a problem with them knowing the fact that I have seen a cardiologist and all because it's family history and stuff. But when it comes down to private things that I've talked to them about, about maybe my relationship with my husband or my relationship with my children and stuff like that, I'm, depressed at the time. I feel like those are things that unless I give you permission to tell, I don't really want you sharing those. (D207)

Or, as one subject responded in answer to the question, "What kind of information really falls under that rubric of confidentiality?":

Like if she [the physician] asks you what age is your husband or how many people are you sleeping with. I think that should stay between her ... I think you shouldn't tell nobody about that. (A229)

Respondents giving these answers also often characterised relationships with doctors as a context where they could discuss

things that you can't tell somebody else, you try to tell like your doctor. (A135)

The second set of answers characterised *all* medical information as confidential:

I'd say all of it, all of it. I understand that when I go into the doctor's office and a nurse may bring me in initially and do a height and a weight and take my blood pressure, but I could care less. That's, you know, everybody has a height and a weight and a blood pressure. So that's, to me, non-important stuff. But anything, anything that happens from the point that that doctor enters the room that you're sitting in or waiting in to the point that the doctor leaves the room and you're done is supposed to be confidential. (D297)

Or,

Well actually all of it is confidential. I mean even weight (C258)

The women holding this view explained that all medical information was confidential because, by definition, whatever transpires between a doctor or clinic staff and patient is confidential. Some explained that this was the case because the meaning of information changes unpredictably in different contexts. One young woman whose family paid for her health insurance explained that even taking up running as exercise could be sensitive information and in need of confidentiality protection if her family disapproved of the activity because of the dangers she might encounter when running in her urban neighbourhood.

Handling confidential medical information

To further assess what labelling something *confidential* meant to subjects, we also asked specific questions such as: "Does this confidential information go into your medical record?" and "Would your doctor ever reveal this confidential information?" These questions were analogous to the preceding part of the interview when we posed similar questions but without specifying or labelling the information as confidential. Some women provided different answers to these two sets of questions, stating that confidential information was handled differently from other medical information. For example, whereas almost all women had indicated that medical information (*not* specified confidential) could and would be shared with others (even if some respondents restricted this sharing to the clinic where it was collected), nearly half of subjects responded that they thought that *confidential* information was subject to special controls that would strictly limit its circulation. In support of this view some also stated that confidential medical information would not go into the record and that the doctor would never reveal it.

Disclosure deliberations

In response to open ended questions, women sometimes related instances when they had deliberated whether to tell a doctor about a health behaviour or health condition. We coded these passages as revealing a concern with either "psychological privacy" or "informational privacy". Sometimes respondents described deliberations over whether to disclose information to doctors that incorporated elements of both kinds of concern.

Psychological privacy is defined as the emotional experience of self-revelation and the right to determine "with whom one will share thoughts and feelings or reveal intimate information".⁴² The concern expressed in these passages was with feelings caused by the demand to reveal information typically unknown to others. The feelings included embarrassment, shame, and being judged. The commonest topics in such passages included conditions associated with sexual behaviour, followed by mental health and smoking. One woman explained why she did not tell a new doctor that she had had a gonorrhoeal infection that had been successfully treated.

It paints a picture. They don't ask how long ago. They just say, did you have it? It puts something there in their mind that would be negative about you and doesn't necessarily need to be, especially when it's so old. (B258)

Informational privacy is defined the right to determine "what data about the self will be released to another

person".⁴² The concern expressed in these passages was with the potential release of information to third parties, including insurance companies, employers, and family members. Mental illness was the topic most often of concern, except with younger women for whom it was onset of sexual activity. One woman described her thinking about disclosing in a college application her history of depression, repeated suicide attempts, and hospitalisations:

And obviously you know how they always ask you on applications like college applications, they say like give us your history. And I never checked the depression thing obviously because I don't want anybody to find out about that ... (B169)

ANALYSIS

We examined patient views of medical confidentiality to describe those views and assess whether they varied. The interviews also were structured to examine the finding from pilot interviews that some respondents thought of confidential information as categorically different from other medical information, and the suggestion from previous research that some patients used the term *confidentiality* differently from standard legal or medical definitions. We interviewed women to focus the study and because women experience a particular confidentiality burden—reproductive health issues and frequent responsibility for health care for other family members.

We have been able to describe patient views of medical confidentiality and to demonstrate that both definitions of medical confidentiality and expectations of confidentiality protections vary among patients. We found that views about the proper handling of medical information not specified confidential were similar across the subjects. For example, subjects generally agreed that this information could and did circulate. Views on whether information designated *confidential* was treated differently, if so and how, however, did vary among subjects. Table 2 summarises the major findings about the definition and treatment of medical information designated *confidential*.

In support of findings from our pilot interviews, some subjects did report considering confidentiality protections as exceptional rather than routine and described them as existing primarily to protect information deemed particularly sensitive, such as mental illness. Our interviews also

demonstrated that some women defined confidentiality substantially different from the standard legal or medical definition. This was most evident among women who offered definitions of medical confidentiality as private or secret information held between two people, or "just between you and the doctor". Furthermore, in at least some subjects, these findings were linked together in that the definition of confidentiality as private or secret information complemented the assumption that confidential medical information is distinct from other medical information and is subject to special treatment, such as not being entered in the patient's record.

DISCUSSION

Medical confidentiality provides an essential element of the trust needed to build a successful doctor–patient relationship. Research has shown that patients who feel that their confidentiality is respected are more likely to seek treatment and comply with recommendations.^{1–13} Our study, one of the few to enquire directly of patients about their views of medical confidentiality, suggests that while there is considerable overlap between professional and legal definitions and patient views, there are also important differences.

Some of these beliefs—for example, that confidential information will not appear in the chart nor be released to third parties—are most likely not what doctors intend to communicate with the statement that something will be kept confidential, nor the meaning of confidentiality embodied in the HIPAA privacy rule. Furthermore, anecdotal reports suggest that the recommended methods under HIPAA for explaining confidentiality policies to patients are unlikely to address or even detect such assumptions.

Forging a trusting relationship with such patients presents a conundrum. Explaining the current limits of confidentiality (as for example required by HIPAA) could trigger a retreat into silence or dissimulation about certain conditions. At the same time, ignoring the misunderstanding could result in an even greater rift in the event that the patient learns elsewhere what confidentiality actually means in most healthcare settings. The truth is that medical confidentiality simply fails the needs or expectations of some patients. To pretend otherwise and allow these patients to continue believing their information is secret when it is not is shortsighted and paternalistic. A more open approach to this issue might engender the continued public debate needed to advance beyond the current impasse.

A more productive starting point is perhaps to recognise that patients have their own models of medical confidentiality, to ask what they are, and if necessary to explain how and for what reasons actual practice differs. For some patients, this gesture alone may help. A 1999 study found that people at risk for HIV were more likely to agree to testing that could result in contact tracing if the public health advantages of contact tracing were explained to them.⁷ Many situations, however, will call for more than an explanation, and additional research into what fosters the need for secrecy among some patients can help.

To respond to patients who desire that their information remain secret when it likely cannot, we need to know more about these concerns. What feeds the emotional dread of self-revelation in medical settings? Is it a fear of social stigma resulting from beliefs about the cause or consequences of a condition, or assumptions about what can, or what should, be said to doctors? What is the role of worries about loss of life insurance or diminished employability? Research needs to assess how well current medical confidentiality policy addresses all of the identified concerns.

Reinvigorating medical confidentiality and creating an atmosphere of trust between doctor and patient in which all

Table 2 Features of patients' views of medical confidentiality

Definitions of medical confidentiality
Information stays between two people
Information restricted to medical care or insurance
Negative definition
What information is confidential
Specific topics such as mental illness or sexually transmitted diseases
Everything in the medical record
Handling confidential information
Remembered by doctor, not recorded
Recorded but not where others might easily read it
Entered in medical record
Release to third party of confidential information to third party
Would not be released
Could be released under exceptional circumstances
Routinely released for medical care or reimbursement
Concern when deliberating confidential information disclosure
Disclosed selectively. Concerned with emotional consequence of self-revelation
Disclose all needed for treatment. Some concern with institutional consequences, such as insurance eligibility

patients feel secure enough to easily communicate their concerns is an ongoing and challenging project. Continued research and policy reform efforts are required. This research suggests that one practical step is to recognise that patients have their own beliefs about the function and procedures of medical confidentiality and to begin to enquire about them.

Limits

Our analysis revealed that views of medical confidentiality differed among subjects; some reported views were demonstrably different from the conventional definition of medical confidentiality. Additional research is needed to determine the extent to which views expressed by women in our sample are also present in the general population. Because we relied on volunteers, our sample might have consisted of women with heightened concerns about confidentiality that could have biased the responses.

Furthermore, the research examined only views held by women. We made this choice to narrow the range of potential findings and because of the distinctive considerations of confidentiality that accompany women's health, such as reproductive issues and their frequent responsibility for seeking health care for members of their family. As many of the subjects' comments were related to reproductive health, primarily pregnancy, interviews with men will likely produce different results, although the basic definitions and beliefs might remain the same. Also, the interviews in the present study were conducted in one region of the USA among a predominantly urban population that might limit the populations to which these findings can be generalised.

Authors' affiliations

G Jenkins, Johns Hopkins University, Phoebe R Berman Bioethics Institute, Baltimore, MD, USA and University of Kansas, Department of Anthropology and Women's Studies Program, Lawrence, KS, USA
J F Merz, University of Pennsylvania, Department of Medical Ethics, Philadelphia, PA, USA
P Sankar, University of Pennsylvania, Department of Medical Ethics, Philadelphia, PA, USA

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