

## CLINICAL ETHICS

# Privacy and patient–clergy access: perspectives of patients admitted to hospital

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**Background:** For patients admitted to hospital both pastoral care and privacy or confidentiality are important. Rules related to each have come into conflict recently in the US. Federal laws and other rules protect confidentiality in ways that countermand hospitals' methods for facilitating access to pastoral care. This leads to conflicts and poses an unusual type of dilemma—one of conflicting values and rights. As interests are elements necessary for establishing rights, it is important to explore patients' interests in privacy compared with their desire for attention from a cleric.

**Aim:** To assess the willingness of patients to have their names and rooms included on a list by religion, having that information given to clergy without their consent, their sense of privacy violation if that were done and their views about patients' privacy rights.

**Methods and participants:** 179 patients, aged 18–92 years, admitted to hospital in an acute care setting, were interviewed and asked about their preferences for confidentiality and pastoral support.

**Results:** Most (57%) patients did not want to be listed by religion; 58% did not think hospitals should give lists to clergy without their consent and 84% welcomed a visit by their own clergy even if triggered from a hospital list.

**Conclusions:** Values related to confidentiality or privacy and pastoral care were found to be inconsistent and more complicated than expected. Balancing the right to privacy and the value of religious support continue to present a challenge for hospitals. Patients' preferences support the importance of providing balance in a way that protects rights while offering comprehensive services.

Two fundamental concerns now have potential to collide in hospital settings: the value of religious support or pastoral care from clergy and the rights and values of privacy and confidentiality. Each has great value and each is sometimes cast in terms of rights. The problem is that a prominent way of supplying pastoral care often depends on violating rules of privacy.

Two hypotheses seem to make religious support fundamental. Firstly, clergy may provide unique support for coping with the strife of illness.<sup>1</sup> Secondly, religious support may help in improving health and aid in somatic healing<sup>2–4</sup> (although there are important critiques of these ideas and studies that support them<sup>5</sup>).

Despite the evidence of the importance of spirituality and religious beliefs, doctors hesitate to become involved with their patients in spiritual matters.<sup>6,7</sup> Patients, however, consider spiritual and physical health to be of equal importance and recognise that spiritual needs may increase during illness.<sup>3</sup> To deal with patients' desires in these topics, many hospitals rely on local clergy who make regular rounds to visit members of their congregation or those identified to be of their faith.<sup>8</sup>

In the US, patients are admitted to hospital for acute care, with most patients staying in the hospital for 5–7 days.<sup>9</sup> Patients generally share rooms with one other patient. Every effort is made to protect the privacy of the patient. Hospitals have facilitated clergy approaching patients by making lists of patients available to clergy with their declared religious affiliation and names and room numbers. For example, on entering the hospital, patients or their proxy often indicate the patients' membership of a religious group or tradition. From that, hospitals create lists of patients' names and rooms organised by religious identity. The hospital has made those lists available to clergy to minister to patients of their faith. This practice seems inconsistent with rights of confidentiality

as well as with recent rules and regulations governing privacy in healthcare settings in the US. Safeguarding patients' confidentiality and respecting their privacy are ancient tenets of medical ethics and endure as rights of hospital patients. Those rights conflict with the hospital's practice of providing patient information without the patient's or proxy's permission. Skipping consent is clearly more efficient than seeking it and would include access to patients who lack a proxy and are unable to exercise their right to allow disclosure of their admission to the clergy.

On the other hand, confidentiality is too important to make it highly porous. Firstly, doctors need truthful reports from patients of their symptoms, actions, exposures and habits, to diagnose them effectively.<sup>10</sup> Secondly, respecting privacy and keeping confidences are fundamental to a person's achieving a sense of self and sustaining that sense. That is, without gaining a sense of having ultimate control over aspects of oneself and one's life, the self may never emerge, emerge very weakly or wither once it has emerged. "Total institutions" such as prisons, psychiatric hospitals and, perhaps, general hospitals can produce this withering. Rights in all these settings allow people to keep at least a small sense of individuality—self, self-identity and a sense of self-entitlement.<sup>11</sup>

Recently, concerns about confidentiality have arisen with regard to new information technology such as susceptibility of computerised records to hacker penetration. But the warrant for concern need neither be recent nor based on technological vulnerability. In the 1980s, Mark Siegler<sup>12</sup> characterised confidentiality as a decrepit concept partly because of the high number of people handling and assessing

**Abbreviations:** HIPAA, Health Insurance Portability and Accountability Act; JCAHO, Joint Commission for the Accreditation of Health Care Organizations

**Table 1** Demographic characteristics of participants

Variables	Category	Frequency of patients (%)
Sex	Female	104 (58)
	Male	75 (42)
Education	Less than high school	45 (25)
	High school	64 (36)
	Vocational or some college	47 (26)
	College or graduate school	23 (13)
Number of times admitted to hospital previously	Never before	81 (45)
	Once	37 (21)
	Twice or more	61 (34)
Religious affiliation	Catholic	71 (40)
	Protestant	27 (15)
	Other Christian	25 (14)
	Other	4 (2)
	No religion	51 (29)
Frequency of prayer	Once a week or more	67 (37)
	Less than once a week	57 (32)
	Never	55 (31)
Level of religious beliefs	Very religious	43 (24)
	Somewhat religious	98 (55)
	Not very religious	21 (12)
	Not religious	15 (8)

the information in patients' files. Current concerns can arise from hospitals approaching wealthy patrons (even if only after discharge) without invitation or prior clearance from the patient to request donations for the hospital.<sup>13</sup>

Broad and highly visible new concerns have emerged about confidentiality. The Joint Commission for the Accreditation of Health Care Organizations (JCAHO) has promulgated rules about confidentiality. The implication of these rules is that it is a violation for hospitals to make the list of admitted patients, with or without their religious preference, known to local clergy without authorisation. For example, the *Comprehensive accreditation manual for hospitals: the official handbook* of the JCAHO requires hospitals to provide for "the patient's right to confidentiality of information".<sup>14</sup> In the same place, however, the manual says that hospitals have a duty to provide pastoral care services "for patients who request them". These two quotations from the same section imply that the practice of listing patients for clergy contact without the patients' consent is a violation of the rule. That is, JCAHO's position seems to recommend against hospitals making a patient's name, religious affiliation and room number available to clergy without that patient's consent. Given JCAHO's enormous power in determining reimbursement to hospitals, hospital corporations have a strong incentive to comply with its mandates.

Further, the Health Insurance Portability and Accountability Act (HIPAA), which became effective on 14 April 2003, is a federal law that was established, among other goals, to guarantee security and privacy of health information. This federal law specifies individually identifiable health information that can be used to identify a patient, and establishes regulations for the use of that information. Individually identifiable health information includes name, medical record number, birth date, address, telephone number and social security number. This information can be disclosed only with permission by the patient or by regulation. In addition, with few exceptions, the information can be used only for health purposes.<sup>15</sup> Under HIPAA, when patients enter a facility, they must sign a consent form that allows for treatment and payment as well as providing information about how the facility may use and disclose their health information. A patient may also be asked to sign an authorisation, which allows for the release of information to another entity. An authorisation is specific to a situation, is voluntary and can be revoked by the patient.

By implication, HIPAA's rules cover disclosure of admission and religious identity to clergy. The consent form at the time of admission states how information of patients will be handled. Patients must be given notice if their names will be made available through a directory and should be given the opportunity to have their names unlisted. Being unlisted would mean that no one receives information even about the patient's room number or condition, not even family members. Admission forms could also state that the directory will be provided to clergy and that the patient may opt out or restrict religious information. When information is shared with clergy, specific medical information is not shared.<sup>15</sup>

Although provisions can be made for clergy visits, hospitals may take a variety of approaches to such visits. Anecdotal information and a review of internet websites suggest that some hospitals may suspend providing patient lists for clergy visits, whereas others have given patients the option of refusing inclusion. Refusal of inclusion on a list, as opposed to only having the option for a clergy visit if it is specifically requested, may serve patients well, given their interests and preferences. Fitchett *et al*<sup>16</sup> queried 202 patients in hospital and found that only 35% of those requested spiritual care. Further, the authors found that "patients who potentially have greater needs for spiritual care are not likely to request it".<sup>16</sup>

From this discussion, we see a strong clash of values and rules. The tension arises because there is an American cultural emphasis on privacy, autonomy and confidentiality—so called negative rights. These suggest a presumption for the position that JCAHO and HIPAA share. Unfortunately, that presumption conflicts with a widespread interest in receiving pastoral care. Resolving the conflict must take into account that desire and interests are important elements of rights. That is, rights protect choices that people

**Table 2** Responses of patients to specific privacy questions

Variables	Number of patients answering "Yes" (%)
In general, would you want your name and room number to be put on a hospital list that lists names by religion?	76 (43)
Would you want the hospital to give such a list to any clergy without your permission?	76 (42)
Would your sense of privacy be violated by the hospital disclosing your admission and religion to the clergy without permission?	82 (47)
If a hospital gives the clergy a list of patient names and religion without their permission, do you think that is a violation of the patients' right to privacy?	100 (58)
Would you welcome a visit by your own clergy even if he/she found out about you from hospital lists?	106 (84)

**Table 3** Cross-tabulation of responses to wanting to be listed by religion, sense of privacy violation and violation of privacy rights

Variables	Want to be listed by religion, n (%)		Total	
Patient's sense of privacy would be violated by disclosing	Yes	Yes (n=75) 13 (17)	69 (71)	82
	No	62 (83)	28 (29)	90
Disclosure violates patients' privacy rights	Yes	Yes (n=74) 26 (35)	74 (76)	100
	No	48 (65)	23 (24)	71

care about.<sup>17</sup> Thus, it is important to explore how much of an interest patients have in their rights of privacy and confidentiality compared with their desire for (and right to) attention from a cleric of their faith. We therefore undertook this study to assess willingness of patients to have their name included on a list by religion, their preferences about having the information given to a member of the clergy without their consent, their feeling (experiential) that their sense of privacy would be violated if their admission and religion were provided to the clergy without their permission and their sense (cognitive) that giving clergy such a list violates patients' right to privacy. In addition, data are shown regarding willingness of patients to have a visit from their own clergy. The response rates to the four primary questions were examined with regard to age, level of education and frequency of prayer to identify what factors may help explain a patient's attitudes about these issues.

**METHODS**

**Participants**

Participants were recruited from among inpatients admitted to general medical floors and to surgery units in a university-affiliated hospital. Patients were excluded if they were unable to answer the questions, identified as at least moderately demented or were under 18 years of age. From a total of 192 patients approached by the nursing staff, 179 gave consent and completed the interview. The University of Medicine and Dentistry of New Jersey School of Osteopathic Medicine Institutional Review Board approved the study.

**Procedure**

In the inpatient setting, nurses were told about the study and asked to identify any eligible patients. On a daily basis, the floor nurse approached patients who had been in hospital for a minimum of 24 h. Permission of patients was requested for the research assistant to approach them. If the patient

agreed, the research assistant described the project, obtained consent and interviewed the patient. The patient was given a copy of the questionnaire to read along with the interview. The interview took approximately 1 h to complete.

**Instrumentation**

A questionnaire was developed specifically for this study. Some questions (numbers 39–42) were derived from Neels's study.<sup>8</sup> The questionnaire consisted of 78 questions. Approximately 40 questions asked about preferences and attitudes about confidentiality and pastoral support. On most questions, patients were asked to rate responses on a scale of 1–5, ranging from "strongly disagree" to "strongly agree". The primary questions were as follows:

1. Would the patient want to be listed by religion?
2. Should hospitals give lists of patient names to the clergy without the patient having to consent?
3. Would the patients' sense of privacy be violated by the hospital disclosing their name and religion on such a list?
4. Does disclosure of name and religion violate patient's rights?
5. Would the patient welcome their own clergy if the visit was triggered by a list from the hospital?

The remaining questions asked for demographic characteristics including religion and religious practices. The instrument was piloted by administering it to 10 outpatients to assure readability and understanding of items.

**Data analysis**

Data were summarised for the total group, focusing on critical items, such as the patient's attitudes about being listed by religion, clergy notification of being admitted to hospital through hospital-generated lists, and whether disclosure of name and religion violated privacy rights. Age, level of

**Table 4** Logistic regression of prayer frequency, age and education as related to willingness of patients to have their name and room number on a list of names by religion

Outcome	Variables	Odds ratio	95% CI	p Value
In general, would you want your name and room number to be put on a hospital list that lists names by religion?	Praying frequency			0.000
	≥ Once a week	5.090	2.279 to 11.366	0.000
	< Once a week	1.561	0.677 to 3.600	0.296
	Never			
	Age (years)			
	≤ 60	0.721	0.367 to 1.417	0.343
> 60				
Education				
> High-school diploma	0.698	0.303 to 1.605	0.397	
< High-school diploma	0.559	0.241 to 1.301	0.177	

**Table 5** Logistic regression of prayer frequency, age and education as related to patients wanting the list given to clergy without their consent

Outcome	Variables	Odds ratio	95% CI	p Value
Would you want the hospital to give such a list to any clergy without your consent?	Praying frequency			0.000
	≥ Once a week	5.413	2.410 to 12.161	0.000
	< Once a week	2.030	0.880 to 4.684	0.097
	Never			
	Age (years)			0.633
	≤ 60	0.848	0.432 to 1.665	0.633
	> 60			
Education				0.295
	> High-school diploma	0.831	0.363 to 1.902	0.662
	High-school diploma	0.534	0.230 to 1.239	0.144
	< High-school diploma			

education and frequency of prayer were examined as they related to responses, using the  $\chi^2$  test and logistic regression.

**RESULTS**

Table 1 summarises the demographic characteristics of the study participants. The patients’ mean age was 60.4 (SD 19.8, range 18–92) years. Most respondents were women; most had a high-school education or less and almost half had not been admitted to hospital previously. Most were part of an organised religion and described themselves as somewhat or very religious.

Table 2 lists responses to the five critical questions. Most of the patients would not want to be listed by religion and did not think hospitals should give lists to the clergy without their consent. In all, 84% would welcome a visit by their own clergy even if it were triggered by the list. Only 47% thought their sense of privacy would be violated by the hospital disclosing their name, whereas most thought disclosure violated patients’ privacy rights. Interestingly, patients’ preferences for themselves were not completely consistent with their sense of privacy or their sense of patients’ right to privacy.

Of those who wanted their name listed by religion, 17% thought their sense of privacy would be violated by the hospital disclosing their admission and religion to clergy without their permission and 35% thought the hospital giving clergy the list of names without permission was a violation of patients’ rights to privacy (table 3). Conversely, 29% of the 97 patients who did not want their names on a religion list did not think their privacy would be violated by the hospital disclosing their admission and religion to clergy without their permission and 24% did not think the hospital giving clergy a list of names was a violation of patients’ right to privacy.

Responses to these items were analysed by age, sex, number of previous admissions to hospital, educational level

and frequency of praying, by using the  $\chi^2$  test. Frequency of praying was used as a measure of religiosity instead of religion as we found no differences in responses to those items between Catholics, Protestants and other Christians. Only age, educational level and frequency of praying were considerably related to response to the items of interest.

Logistic regressions were used to identify whether age, education and frequency of praying were related to willingness to have patient’s name and room number on a list of names by religion, to wanting the list to be given to the clergy without their consent, to their feeling that their sense of privacy would be violated by the hospital disclosing their name and religion on such a list and to whether disclosure of name and religion violates patients’ rights.

Tables 4–7 show results from these analyses. Those who prayed more frequently were five times as likely to be willing to have their name on a list by religion and wanting the list given to the clergy without their consent. Praying more often was also related to being less likely to feel that their sense of privacy would be violated. Being a high-school graduate, as compared with having less education, increased the odds that the patient believed that disclosure of name and religion violated a patient’s rights. Also, education (specifically having a high-school education) tended towards increasing the odds that patients believed their sense of privacy was violated. The logistic regressions explained about 10–17% of the variance of the questions.

**DISCUSSION**

Few data are available in the literature about patient preferences regarding privacy, confidentiality and clergy visits. The findings from this study suggest a complex set of values and interests as well as a sense of rights and desires. On the one hand, these findings fit with common observations about

**Table 6** Logistic regression of prayer frequency, age, and education as related to patients feeling that their sense of privacy would be violated if the hospital disclosed their name and religion on a list

Outcome	Variables	Odds ratio	95% CI	p Value
Would your sense of privacy be violated by the hospital disclosing your admission and religion to clergy without your permission?	Praying frequency			0.004
	≥ Once a week	0.286	0.131 to 0.626	0.002
	< Once a week	0.770	0.351 to 1.692	0.516
	Never			
	Age (years)			0.716
	≤ 60	1.131	0.582 to 2.199	0.716
	> 60			
Education				0.070
	> High-school diploma	1.570	0.677 to 3.640	0.293
	High-school diploma	2.653	1.137 to 6.188	0.024
	< High-school diploma			

**Table 7** Logistic regression of prayer frequency, age and education as related to whether patients believe the disclosure of their name and religion violates their rights

Outcome	Variables	Odds ratio	95% CI	p Value
If a hospital gives clergy a list of patient names and religion without patients permission, do you think that is a violation of the patients' right to privacy?	Praying frequency			0.058
	≥ Once a week	0.492	0.225 to 1.076	0.076
	< Once a week	1.207	0.524 to 2.783	0.659
	Never			
	Age (years)			0.317
	≤ 60	1.416	0.717 to 2.798	
	> 60			
Education			0.006	
> High-school diploma	1.642	0.723 to 3.731	0.236	
High-school diploma	3.950	1.667 to 9.357	0.002	
< High-school diploma				

general interest in religion. For example, it is commonly noted that the American populace is very religious. Many Americans believe that prayer is efficacious and attendance at places of worship on a regular basis is frequent. On the other hand, these findings display a strong sense of rights and a resonance with privacy as a major element of the culture. Given both these elements, it is not surprising that our findings suggest a complex set of values and dispositions about the patients' feelings about privacy rights and their interests in unsolicited contact from clergy. Ultimately some findings seem contradictory. Hence, whereas most patients welcomed a visit by their own clergy resulting from their name being listed by the hospital, almost half believed that giving clergy their name without permission violated their privacy, and a slight majority thought this disclosure violated the rules.

Consistent with expectations, those who prayed more often were more likely to want a visit from their clergy, have their name on a list and were less likely to believe that it violated their sense of privacy. Frequency of prayer was not, but level of education was, related to believing that putting the patients' names and religion on a list violated the patients' privacy rights. Personal preferences and patients' rights were not perceived as the same issue; about 17% of the people who were willing to put their name and religion on a list believed their personal sense of privacy would be violated if their names were put on a list without permission. The current HIPAA approach, which requires that patients be informed about their right to not be included on such a list, fits with this intuition of the patients, but may prevent access that patients would welcome.

Thus, there is no happy solution to this conflict of rules, values and rights. The simplest solution favouring confidentiality is to have hospitals ask permission on admission or as soon as someone can speak for the patient. The simplest solution favouring patients' desires is to have hospitals continue making the lists and notifying clergy without patients' consent; then some sort of opt-out mechanism should be available.

More investigation is needed in exploring the boundary created by policy intended to protect privacy and institutional procedures aimed at assuring holistic care, which includes the spiritual dimension. Hospitals should make a concerted effort to provide or facilitate the receipt of pastoral-type care by patients in the context of respect for their privacy sensibilities and rights. Balancing the right to privacy and the value of religious support continue to present a challenge for hospital administrations. Preferences of patients support the importance of providing that balance in a way that protects rights while offering comprehensive services.

Limitations to this study include the possibility of sample bias. The sample may not be representative of the patients

admitted to the hospital, as those who consented to be interviewed may be biased towards those who are more religious and, therefore, more interested in this issue. The second limitation is that key questions regarding privacy rights were asked at the end of a long interview. It is not clear whether fatigue influenced those responses.

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