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Research and Applications

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Should parents see their teen's medical record? Asking about the effect on adolescent–doctor communication changes attitudes

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ABSTRACT

Objective: Parents routinely access young children's medical records, but medical societies strongly recommend confidential care during adolescence, and most medical centers restrict parental records access during the teen years. We sought to assess public opinion about adolescent medical privacy.

Materials and Methods: The Cornell National Social Survey (CNSS) is an annual nationwide public opinion survey. We added questions about a) whether parents should be able to see their 16-year-old child's medical record, and b) whether teens would avoid discussing sensitive issues (sex, alcohol) with doctors if parents could see the record. Hypothesizing that highlighting the rationale for adolescent privacy would change opinions, we conducted an experiment by randomizing question order.

Results: Most respondents (83.0%) believed that an adolescent would be less likely to discuss sensitive issues with doctors with parental medical record access; responses did not differ by question order ($P = .29$). Most also believed that parents should have access to teens' records, but support for parental access fell from 77% to 69% among those asked the teen withholding question first ($P = .01$).

Conclusions: Although medical societies recommend confidential care for adolescents, public opinion is largely in favor of parental access. A brief "nudge," asking whether parental access might harm adolescent–doctor communication, increased acceptance of adolescent confidentiality, and could be part of a strategy to prepare parents for electronic patient portal policies that medical centers impose at the beginning of adolescence.

Key words: ethics, adolescents, electronic patient portal, confidentiality, children

INTRODUCTION

With the advent of electronic medical records and associated patient portals, increasing numbers of patients are accessing their own medical records to better understand and manage their healthcare.[1,2] Parents, who have primary ethical and legal responsibility for their children's healthcare, generally have full access to young children's medical records. Medical records access could be helpful to help parents manage well-child care such as vaccinations[3] and is likely to be especially valuable for parents of children with chronic illnesses and those attempting to coordinate care across healthcare providers.[4–8]

However, during the adolescent years, medical confidentiality—including protection from parental notification—may encourage teens to seek care for sensitive medical issues that become newly salient at this time.[9] When confidentiality is not ensured or parental notification is mandated, adolescents may delay or avoid sexual

healthcare, or withhold information from healthcare providers.[10–13] One survey found that, if their parents were notified, almost 59% of adolescents seeking prescription contraceptives would stop seeking sexual health services but would not stop sexual activity.[11] Other topics adolescents might prefer to keep between themselves and their doctors could include sexual identity or questioning,[9,14] alcohol and drug use,[15,16] or other sensitive issues.[17,18] For these reasons, medical societies focusing on adolescent healthcare strongly recommend confidential care in this age group.[19–21]

Yet policies and actual practices about parental access to adolescent medical records and patient portal accounts are heterogeneous, varying by medical situation, care type, jurisdiction, healthcare organization policy, and even payer type.[22–24] Minor consent laws vary by state, granting adolescents different degrees of autonomy for different types of care, while some states mandate parental notification or authorization for specific medical decisions at different ages or leave these issues ambiguous.[25] To date, adolescent reproductive healthcare funded under Title X is confidential.[26,27] Physicians using electronic health records may find it challenging to keep information confidential and may have to use awkward methods such as putting some information in a separate confidential electronic encounter.[28–31] And even when doctors do offer confidential care, parents may find out about it later when they receive an explanation of benefits from the insurer.[32]

In our recent studies of electronic patient portals across the United States, almost all medical centers we studied restricted parental access to an adolescent child's medical record.[24,33] However, because the restrictions were developed locally in response to legal, cultural, and technical factors, they varied widely in terms of how much a parent could see of an adolescent's record (from nothing, to a partial record with sensitive information redacted, to the entire record), the extent of adolescents' access to their own records (from none to partial to complete), and age thresholds (with some centers providing confidentiality to patients as young as 10).[24,33] Policies also varied about whether teens could or should agree to parental access, and a few centers simply turned off portal accounts altogether (for both child and parent) during the adolescent years.[24] Regardless of the policy type, medical center leaders frequently encountered angry or bewildered parents when their child reached the age that triggered the restrictions.[24]

As a comparison to the medical leadership perspectives previously studied, the current study assessed public attitudes toward parental access to adolescent medical records. Given the complexity of the issues and the diversity of policies around the country, we conjectured that many people had not been exposed to a rationale for medical confidentiality for teens. Therefore, we also tested the hypothesis that support for parental access would decrease when respondents were presented with one of the primary reasons to offer confidentiality, which is to encourage adolescents to share information freely with their physicians.

MATERIALS AND METHODS

Data source

The Cornell National Social Survey is a random-digit-dial telephone survey conducted annually by Cornell Survey Research Institute. Every year, the sample size of 1000 provides a margin of error of plus or minus 3.1 percentage points. The Cornell University Institutional Review Board approved the study, and respondents provided oral consent. Each year, sampling is conducted on a dual frame of landline and cell phone numbers in the continental United States for a simple random sample not stratified by region or other variables. The proportion of cell phone numbers is calculated from county-level data on prevalence of cell phone-only households. Listed and unlisted numbers are both included; known business and non-household numbers are excluded, as are disconnected numbers. When the telephone is answered, the interviewer asks to speak with the adult with the most recent birthday, a technique that ensures each adult in the household has equal chance of being selected.[34] Researchers submit potential questions, which are competitively reviewed by the Cornell Survey Research Institute. All questions are pilot tested with a small sample before being finalized.

Three questions about portals, medical records, and privacy were included by our research team, with the order of questions 2 and 3 randomized.

In order A:

1. Should a 16-year-old be able to have their own electronic patient portal account? (Options: Always, Only with parental permission, Never)
2. Should a parent or guardian be able to see their 16-year-old child's entire medical record? (Options: Always, Only with the 16-year-old's permission, Never)
3. Do you think teens would be less likely to talk to their doctors about sensitive issues (for example, sexual activity and alcohol or drug problems) if they knew their parents could see their medical record afterwards? (Options: Yes, No)

In order B:

1. Should a 16-year-old be able to have their own electronic patient portal account?
2. Do you think teens would be less likely to talk to their doctors about sensitive issues (for example, sexual activity and alcohol or drug problems) if they knew their parents could see their medical record afterwards?
3. Should a parent or guardian be able to see their 16-year-old child's entire medical record?

These questions were introduced with a brief definition: "An online patient portal is a website offered by your doctor's office. You can use a patient portal to see your lab test results, prescriptions, and medical record, or to privately message your doctor." "Don't know" was not offered as a response option but was recorded when given as an answer.

The entire survey, which required approximately 20 minutes to administer, contained multiple demographic questions as well as research questions submitted by other social science researchers.

Statistical analysis

Descriptive analysis was conducted with frequencies and percents. Bivariate associations were assessed with chi-square tests. Multivariable relationships between sociodemographics and the portal questions were assessed with logistic regression models; all variables significant at .05 were tested for interaction with question order in the multivariable models. In both bivariate analyses and logistic models for the question about whether parents be able to see the teen's medical record, we modeled "always" responses vs all other responses. All hypothesis tests were 2-sided with an alpha of .05. Analyses were conducted in SAS v.9.3 (Cary, NC).

RESULTS

Of 1703 eligible individuals reached by phone, 1000 completed the survey, for a cooperation rate of 58.7%.[35] The 1000 respondents were the result of calls to 8064 working numbers (including non-answered calls as well as calls to those who were ineligible, refused, or unable to participate), for an overall response rate of 12.4%.

The final sample of 1000 respondents was diverse and compared well with the US population in age, sex distribution, ethnicity, family composition, and geographic diversity, but had an overrepresentation of white and well-educated respondents (Table 1).

Most respondents thought that a 16-year-old should be able to obtain a patient portal account with parental permission, with another 20% endorsing adolescent accounts even without parental permission, and a similar proportion saying that adolescents should not have accounts at all (Table 2). About 83% of respondents thought that parental access to teen medical records would reduce the likelihood of teens consulting with their doctors, and question order made no difference ($P = .29$). However, the proportion who thought that parents should always have access to adolescent medical records varied by question order, falling from almost 77% to 69% among those asked the teen withholding question first ($P = .01$).

In bivariate analyses (details not shown), support for teens to have their own portal accounts (Question 1) was significantly more common among respondents with younger age and liberal beliefs. Support for parental access to the teen's medical record was more common among men, older respondents, those with children in the household, and those with conservative beliefs. Belief that teens would be less open with their physician with parental medical record access was more common among women, younger respondents, and those with liberal beliefs.

Demographics significant in these bivariate analyses were used to construct the multivariable model (Table 3). This model demonstrates that individuals were significantly more likely to support full parental records access if they had question order A (did *not* answer the teen withholding question first), were men, were 65 or older, had conservative social beliefs, had children in the home, or thought teens should not have their own accounts.

In addition, there was a significant interaction between question order and gender, such that the effect of question order occurred largely among female respondents. In question order A (in which respondents did not answer the teen withholding question first), women and men were roughly equally likely to support parental access to adolescent medical records (AOR 0.92; 95% CI 0.58-1.47). However, in question order B (prompted to consider teen withholding first), women were only half as likely as men to support parental medical record access (AOR 0.46; 95% CI 0.29-0.74).

The participant's answer to the question about teen withholding (Question 2) itself was not statistically significant ($P = .24$), nor was the interaction between the question 2 answer and question order (data not shown).

Adding race, ethnicity, and household income as additional demographics to the model made no appreciable difference to the odds ratios or *P* values (data not shown). Census division was not a significant predictor at the univariate level and also could not be included in the multivariate models because of small sample sizes within cells.

Table 1. Characteristics of the sample

Characteristic	Sample n	Sample %	National %
Sex			
Male	498	49.8	48.6
Female	502	50.2	51.3
Age			
18-24	117	11.7	12.8
25-44	310	31.0	34.3
45-64	370	37.0	34.1
65+	203	20.3	18.9
Race			
White	815	81.5	75.1
Black	115	11.5	12.2
All other	70	7.0	12.7
Ethnicity			
Non-Hispanic	872	87.2	85.8
Hispanic	127	12.7	14.2
Declined	1	0.1	–
Census division			
1 (New England)	59	5.9	4.8
2 (Middle Atlantic)	129	12.9	13.2
3 (East North Central)	155	15.5	14.7
4 (West North Central)	75	7.5	6.5
5 (South Atlantic)	190	19.0	19.9
6 (East South Central)	58	5.8	5.9
7 (West South Central)	138	13.8	11.6
8 (Mountain)	62	6.2	7.1
9 (Pacific)	134	13.4	16.2
Education level			
HS or less	257	25.7	41.0
Some college or tech	284	28.4	31.3
College degree	266	26.6	17.6
Graduate degree	192	19.2	10.1
Declined	1	0.1	–
Social beliefs			
Liberal	310	31.0	26
Moderate	363	36.3	35
Conservative	327	32.7	35
Household income			
<$50K	359	35.9	45.5
$50K < $75K	290	29.0	17.8
$75K < $100K	91	9.1	12.2
$100K < $150K	115	11.5	13.5
$150K+	145	14.5	11.1
Has children in the home			
No	665	66.5	68.0
Yes	335	33.5	32.0

Dash (–) indicates not available.

National percentages represent estimates from the adult population (18 and older) from American Community Survey 2016 5-year estimates except for ethnicity distribution, which is from the 2010 Census, and the social beliefs estimates, which are from Gallup 2017.[36]

DISCUSSION

This survey suggests that majorities of the public endorse 2 somewhat conflicting views: that parents should have access to their teen children's medical records, and that this parental access would prompt teens to withhold important information from their physicians. Support for parental access was much lower among respondents who answered the withholding question first, as well as among women, younger respondents, those with liberal social beliefs, those without children in the home, and those who thought teens should not have their own portal accounts. Answering the withholding question was particularly influential among women. Very interestingly, the respondent's answer to the question about teen withholding was not a significant predictor of support for parental access.

Table 2. Perceptions about parental access to adolescent medical records

	Response options	N	%			
NONRANDOMIZED QUESTION						
1. Should a 16-year-old be able to have their own patient portal account?	Always	207	20.7%			
	Only with parent permission	602	60.2%			
	Never	189	18.9%			
	Do not know/refused	2	0.2%			
RANDOMIZED QUESTIONS		ORDER A		ORDER B		
		N	%	n	%	p
2. Should a parent or guardian be able to see their 16-year-old child's entire medical record?	Always	409	76.9%	324	69.2%	
	Only with 16-y-o permission	110	20.7%	128	27.4%	
	Never	9	1.7%	15	3.2%	.01
3. Do you think teens would be less likely to talk to their doctors about sensitive issues (for example, sexual activity and alcohol or drug problems) if they knew their parents could see their medical record afterwards?	Yes	436	82.0%	394	84.2%	
	No	93	17.5%	70	15.0%	.29
Total		532	53.2%	468	46.8%	

Table 3. Adjusted odds of supporting full parental access to teen records

Effect	AOR	95% CI		P***
Question order A vs B*	NA**	NA	NA	.004
Female vs male	NA	NA	NA	.01
Question order x gender interaction	NA	NA	NA	.04
Female vs male with question order A	0.92	0.58	1.47	
Female vs male with question order B	0.46	0.29	0.74	
Age				<.001
18-24 vs 65+	0.23	0.12	0.41	
25-44 vs 65+	0.46	0.27	0.76	
45-64 vs 65+	0.87	0.53	1.41	
Social beliefs				<.001
Conservative vs moderate	1.24	0.81	1.90	
Liberal vs moderate	0.44	0.30	0.64	
Children in home				.01
No children vs at least 1 child	0.63	0.44	0.91	
Would teen withhold from doctor? (Q2)				.24
Does not believe vs does believe teen would withhold	1.33	0.82	2.15	
Should teen have portal account? (Q1)				<.001
Always vs only with parent permission	0.23	0.15	0.33	
Never vs only with parent permission	1.63	1.00	2.67	

**Question order A: Parent access question before teen withholding question.*

Question order B: Teen withholding question before parent access question.

**Because of the interaction between question order and gender, odds ratios cannot be computed for the question order and gender variables; odds ratios are provided for the interactions only.

****Type 3 analysis of effects* P *value indicates significance of entire variable.*

In other words, the mere fact of prompting respondents to consider this withholding question was associated with reduced support for parental access, regardless of whether they answered the withholding question yes or no.

Strong arguments have been made both for and against full parental access to adolescent medical records. On the one hand, parents have both moral and financial responsibility for their children's healthcare, as well as their education about health and other topics. Healthcare providers seek to support communication and positive relationships between teenage patients and their parents, because such strong relationships are associated with better health-related behaviors among adolescents, including reduced rates of sexual risk factors.[37] In our recent key informant study, many medical center leaders explicitly hoped to develop portal access policies that would encourage teenage patients to discuss problems with their parents.[24] At a pragmatic level, some medical centers may decide trying to ensure adolescent confidentiality is futile because parents will ultimately receive an insurance company statement of benefits for the child's care.[24] Recent news coverage of college suicides suggests that many people consider it unacceptable to withhold a troubled student's mental health information from parents, even if colleges believe they are acting in compliance with federal education

privacy law. A front-page feature article in *The New York Times*, for example, included multiple stories in which keeping information from parents was followed by a tragedy, with no counterexamples in which disclosing information to parents had adverse consequences.[38]

However, lack of confidentiality is known to discourage young people from approaching their physicians with concerns about sexual health, mental health, drug and alcohol use, and other sensitive issues.[10–12] It is noteworthy that in a large longitudinal survey, teens who reported having poor communication with their parents were more likely to cite confidentiality concerns as the reason for skipping healthcare that they needed.[12] We have previously found that for these reasons, many medical centers do impose confidentiality restrictions on access to adolescent medical records through electronic patient portals.[24,33] The restrictions are idiosyncratic to each medical center, and include blocking parental access to the adolescent record entirely, or blocking parental access only to certain types of medical information considered sensitive, or requiring the teen's permission for continued parental access, or even turning off portal accounts altogether during the adolescent years.[24]

Previous studies on adolescent medical privacy have found varying attitudes in different populations. In a qualitative study, parents of adolescents in juvenile detention generally wanted the adolescents to have and to control online access to their medical information.[39] Another qualitative study among commercially insured adults found enthusiasm about potential teen use of a patient portal, accompanied by concerns that granting complete access to medical records, messaging, and scheduling would give adolescents too much autonomy and privacy.[40]

It is challenging to consider what measures might be appropriate to address the conflict between professional society ethical statements (endorsing confidential care for adolescents) and current public opinion. This conflict (together with technical limitations, lack of standards, and other constraints[24]) places medical centers in the unenviable position of having to develop policies and procedures that are likely to be unwelcome to at least some of their stakeholders. Within medical organizations, a shared decision-making session at the onset of adolescence might be helpful to fully educate all parties (parents, the adolescent, and the medical team) about information available in the portal and through medical bills, and to help parents and providers understand each others' perspectives on confidentiality. Some healthcare organizations in our previous study had implemented such sessions.[24] However, such sessions place resource and time burdens on healthcare organizations.

More granular information control might help to strike an acceptable balance between the expectations of different stakeholders. Several medical organizations had implemented different levels of protection for different types of medical information, and one had tiered information access levels by age.[24] (Similarly, more granular control has been endorsed by members of another vulnerable group—patients receiving care for mental and behavioral health conditions.[41])

Professionals and professional societies endorsing confidential care for adolescents might also consider ways to address the unpopularity of this viewpoint. For example, collaborative policy development with patient advocates holding different opinions could potentially lead to novel policies or new ways to frame policy. Healthcare organizations already promote the benefits of accessing medical records through patient portals: in light of our study, perhaps educational or public communication interventions should also raise awareness about known adverse consequences of inappropriate information disclosure.

Because parents are among the most important stakeholders in the development of policies about adolescent confidentiality, it may seem irrelevant to assess the beliefs of non-parents. However, as we and others have demonstrated, many other stakeholders have input into policy. These could include advocacy groups (especially those advocating for minors), medical center staff and employees themselves, patients who might vote with their feet, donors, and voters considering legal issues. In addition, many people who are not currently parents of children in the home may be parents of adult children who previously lived at home, or may become parents in the future. This study therefore includes both parents and non-parents.

Limitations

The sample size of 1000 produced a margin of error of plus or minus 3.1 percentage points; subgroup analyses have lower power, and conclusions about subgroups should be drawn only with caution. The survey used up-to-date methods for sampling landline and cell phones and produced a diverse sample, but, nonetheless, the sample was somewhat likely to include more white and well-educated people than in the US population. The demographic questions allowed us to determine whether the respondent had children in the household, but not whether the children were adolescents; among respondents with no children in the household, we do not know how many were parents. Due to space limitations, we could add only 3 questions to the survey and therefore could not assess other potential confounders such as personal or family experience with electronic patient portals or with sensitive medical conditions. The description of the patient portal that was provided in the survey was general and did not list all types of potentially sensitive information that might be available. The policies studied here pertained to viewing the electronic medical record; notifications and other forms of communication might be covered by different policies.

Policy implications

Medical society guidelines suggest that ethical practice requires providing confidential care to adolescents, and many medical centers operationalize this guidance by placing various restrictions on parental medical record access. These restrictions are likely to lead to conflict, given our findings that public opinion is strongly in favor of full parental access.

It is likely that there will always be a diversity of parental viewpoints about the extent to which adolescents should have medical privacy, with opinions influenced by characteristics and beliefs as described in the current study. In addition, opinions are likely to vary in light of the situation and the adolescent in question; some situations are more challenging than others, and some young patients are more mature and capable of managing their own healthcare than others.

However, we also found strong endorsement for the statement that parental access impairs open communication between adolescents and their doctors about important topics. A very gentle "nudge" of prompting people to consider this potential negative effect reduced subsequent support for full parental access. It seems likely that broader educational interventions around the benefits of confidential medical care for adolescents would increase support for confidentiality, as well as help prepare parents for restrictions on medical records access triggered by the age of their child.

AUTHORSHIP AND CONTRIBUTORS

JSA conceptualized the study, formulated survey questions, conducted statistical analyses, and drafted the paper. MS, MH, and LW contributed to the study concept and survey question development, and provided critical feedback and final approval on the manuscript. The Cornell National Social Survey is administered by the Cornell University Survey Research Institute.

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