

Parent and adolescent attitudes towards preventive care and confidentiality

Xiaoyu Song^{a,b} DrPH, Jonathan D. Klein^{c,d} MD MPH, Hanying Yan^e MS, Marina Catallozzi^{f,g} MD MSCE, Xianling Wang^e MS, Jenifer Heitelf MPH, Kristen Kaseeska^d MPH, Julie Gorzkowski^d MSW, John S. Santelli^{f,g} MD MPH

Affiliations:

^a Department of Population Health Science and Policy, Icahn School of Medicine at Mount Sinai; Icahn (East) Building Floor MC, Room 591425, Madison Ave, New York, NY 10029, United States.

^b The Tisch Cancer Institute, Icahn School of Medicine at Mount Sinai; One Gustave Levy Place, Box 1128, New York, NY 10029.

^c Department of Pediatrics, University of Illinois at Chicago College of Medicine; 840 South Wood St. Suite 1406, Chicago, IL, 60612, United States.

^d Academy of Pediatrics, Julius B. Richmond Center of Excellence; 345 Park Blvd., Itasca, IL 60143.

^e Department of Biostatistics, Columbia University Mailman School of Public Health; 722 West 168th St. NY, NY 10032, United States.

^f Heilbrunn Department of Population & Family Health, Columbia University Mailman School of Public Health; 60 Haven Avenue, New York NY 10032, United States.

^g Department of Pediatrics, Columbia University Medical Center; 622 West 168 Street, Vanderbilt Clinic 4th Floor, Room 402, New York, NY 10032, United States.

Address correspondence to: Jonathan D. Klein, Department of Pediatrics, University of Illinois at Chicago College of Medicine, 840 South Wood St. Suite 1406, Chicago, IL, 60612. jonklein@uic.edu

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Abbreviations: Clinical Preventive Services (CPS), Adolescents and Young Adults (AYA)

Implications and Contributions

Adolescents and parents often agree about confidentiality; however, some youth who think services should be confidential have parents who disagree. Many parents and adolescents think confidentiality should begin later than recommended by professional guidelines for adolescent care. Understanding adolescent and parent attitudes may help improve preventive care for adolescents.

Abstract

Objective

Little is known about whether parents and adolescents agree in their attitudes towards preventive care, private time and confidentiality for adolescent care.

Methods

We surveyed a nationally representative sample of 1,209 13-18 year-old U.S. adolescents and their parents. Parent and adolescents attitudes towards preventive services, private time and confidentiality were compared. Parent-youth dyad agreement was measured using Cohen's kappa and Spearman coefficients and modeled for association with demographic variables.

Results

Parents are more likely than adolescents to think preventive services are important (71% vs 48%; $p < 0.001$). Parent-youth attitudes were weakly to moderately correlated (Cohen's kappa coefficient = 0.22; $p < 0.001$). Parents and adolescents report similar ages for when teens should start having private time (median 16 years for both) and many think this age should be at 18, the legal age of adulthood). Fewer than half believe confidentiality should be provided for 10 services, ranging from routine care to abortion care (parents range: 12.8-52.3%; adolescents: 24.0%-58.8%). While most adolescents agreed with their parents, teens were more likely to report wanting confidential access than parents. Older age, Hispanic ethnicity, having divorced parents and higher family income were associated with both adolescent/parent and adolescent endorsement of confidentiality.

Conclusion

Adolescents and parents generally agree about the importance of preventive services, private time, confidentiality, and what should and should not be confidential. On average, parents value clinical preventive services more than youth, and youth value confidentiality more than parents. Both believe private time should start at ages older than those recommended in clinical guidelines.

Introduction

Clinical preventive services (CPS) for adolescents and young adults provide opportunities to encourage healthy behaviors and discourage risk-taking behaviors through delivery of recommended screening, education, counseling and vaccinations.^{1,2} Professional society guidelines strongly recommend that screening and counseling for risky behaviors be done with preservation of adolescent's confidentiality, unless clinical circumstances or state law requires disclosure.³⁻⁵ However, the majority of adolescents in the United States (U.S.) do not receive recommended preventive services,⁶⁻¹⁶ and even fewer receive private, confidential screening and counseling,¹⁷ resulting in missed opportunities to promote optimal health.^{18,19}

Parents influence the behavior of their adolescents, and parental monitoring and expectations have been found to affect behaviors and outcomes—including sexually transmitted diseases, sexual behaviors, marijuana use, alcohol use, antisocial behavior, and violence.²⁰ There are few mandatory visits between age 12 and 19. Many states require only one evaluation for school health, except for pre-participation sports examinations. Thus parents' attitudes towards care use play a critical role in whether adolescents receive preventive services.

Adolescents are not always autonomous agents, and parents often direct and influence their adolescents' receipt of services through deciding health insurance, making appointment and transporting them to the doctor²¹. Nonetheless, concerns about confidentiality from parents can also prevent adolescents from seeking health care.²²⁻²⁴ Mandatory parental notification of prescription of contraceptives has been shown to impede use of sexual health services, potentially increasing teen pregnancies and STDs.²⁴ When confidentiality is not assured, young people may forego care altogether.²⁵ Conversely, when health professionals

offer explicit assurances of confidentiality, adolescents are more likely to disclose sensitive information and return for follow-up care.²⁶ Current professional guidelines vary in their recommendations, and in their relative reliance on evidence and expert consensus; however, all guidelines addressing the health care of adolescents are explicit about the importance of seeing young people for preventive care, and the need for confidentiality between young people and clinicians.³ However, one-on-one private conversation between providers and adolescents and confidentiality of these discussions from parents have been shown to be lacking for many youth in adolescent clinical visits.^{16,18}

Parents play a crucial role in whether and how adolescents receive preventive care and other clinical services. However, there are no published reports that examine the perspectives of both adolescents and parents together, and only limited prior data regarding parental views on confidentiality. One Australian study showed that parents hold conflicted views about confidentiality, recognizing the benefits associated with confidential care yet also believe they should be informed about a wide range of topics, even if their children did not want them to know.²⁷ These authors further recommended improving parent awareness of preventive care service guidelines and building trust with parents and adolescents to ensure that parents understand and support adolescent confidential care.²⁸

This study examines attitudes and agreement between parent and adolescent dyads about preventive care, private time, and confidentiality for adolescents using data from a survey of a nationally representative sample of the U.S. non-institutionalized population. We compare parent and adolescents' attitudes toward confidentiality for different types of clinical services, and explore demographic and other factors associated with patterns of agreement/disagreement between parents and their adolescents.

Methods

In June 2016, we conducted a nationally representative survey using an online panel sample of 1,209 dyads, comprised from 13-18 year-old U.S. adolescents and their parents, about their attitudes and experiences with clinical preventive services, private time and confidentiality in healthcare settings. We sampled from the GfK online panel, a nationally representative household sample of the adult US population.²⁹ Panel recruitment used addressed-based sampling methods from the United States Postal Service, with full coverage of all delivery points in the US and sampling included all households, regardless of their phone or internet status.²⁹ GfK provided free Internet service and a web-enabled device for recruited households without Internet access. Every household member over age 13 years was recruited. For teenage household members, consent was secured from a parent or legal guardian. In order to reach a representative sample of teens from US households, the study randomly selected households with active panel members who were parents of adolescents. One parent and one adolescent from the household were selected to answer the survey, generating parent/adolescent dyadic data.²⁹ Separate questionnaires and invitations were generated and self-administered, and confidential responses were encouraged, but there was no verification of whether or not parents or teen responses were made confidentially.

For our study, as with others using the panel, probability-based sampling method were used to account for differential attrition and response rates of panel subgroups. Hard-to-reach and low response rate individuals, including young adults and minority subgroups, were oversampled, and weight-based analyses were applied to ensure each subject had an equal probability of completing the survey relative to detailed geographic and demographic benchmarks of the US adult population from the latest current population survey census supplement.³⁰ Design weights were produced using an iterative proportional fitting (ranking) procedure, and extreme weights were identified and, if necessary, trimmed or capped to

stabilize results. These procedures have been used in other national surveys, for example, for the CDC Behavioral Risk Factor Surveillance System (BRFSS) since 2007.³¹

Our survey completion rate was 65%, and, as described above, respondents were weighted to represent the non-institutionalized U.S. adolescent population by age, gender and race/ethnicity. Informed consent was obtained from parents and adolescents; parents also provided permission for participation by adolescents who were under 18 years of age. The study was approved by Institutional Review Boards at Columbia University, the University of Illinois at Chicago, and the American Academy of Pediatrics.

We considered three different types of measures for confidential care from parents and adolescents' perspectives:

- 1) *Attitudes towards clinical preventive services* were measured using a Likert scale ranging from “very important” to “very unimportant” for the question: “How important is it that adolescents and young adults have preventive visits?”.
- 2) *Age at which services should include private time* was measured by asking “At what age do you think that someone should start having private conversations with a provider?”. “Private” was clearly explained in the survey meaning “getting to speak with them one on one – without you or other people in the room”.
- 3) *Attitudes towards confidentiality* were measured by a series of items asking for the respondents' opinion about whether ten different specific health services should be able to be received confidentially by someone under the age of 18 without parental permission. The ten items included: going to their regular health care provider; going to an STI (sexually transmitted infection) clinic; getting treatment for an injury or assault; getting a vaccination (e.g. HPV, tetanus booster); getting tested for STIs; starting on regular medication (e.g. anti-depressant or birth control); getting emergency contraception; having an abortion; receiving counseling for drug or

alcohol use; and receiving treatment at an inpatient facility (e.g. rehab) for drug and alcohol use.

We examined the associations between each set of parent/ adolescent attitude variables and individual adolescent, parent and household-level demographic variables using weighted data, as our analyses focuses on the relationship between individual parent/adolescent dyads. Adolescent variables included adolescent age (≤ 14 years old, > 14 years old), gender (female, male) and race/ethnicity (White, Non-Hispanic, Black, Non-Hispanic, 2+ Race and other, Non-Hispanic, Hispanic). Parent-level demographic variables include age (≤ 40 years old, > 40 years old and ≤ 45 years old, > 45 years old and ≤ 50 years old, > 50 years old), gender (female, male), marital status (married, never married or living with partner, widowed, divorced or separated), educational level (less than high school, high school, some college, bachelor's degree or higher), current employment status (working - as a paid employee, working - self-employed, not working) and whether the respondent is a head of the household (yes, no). Household-level demographic variables include metropolitan statistical area (MSA) status (metro, non-metro), household size (≤ 4 , > 4), and household income (under \$25,000, \$25,000-\$49,999, \$50,000-\$74,999, \$75,000 and above). Our statistical analyses first estimated the marginal and conditional frequencies of parents' and adolescents' attitudes towards clinical preventive services, private time, and confidentiality. For categorical variables (attitudes towards CPS and confidentiality), we used Cohen's kappa coefficient and for non-normal distributed continuous variable of age for private time, we used Spearman's rank correlation coefficient (ρ) to robustly estimate the agreements/disagreements between parent and adolescent attitudes in the same household. The coefficient =1 indicates perfect positive correlation (parent and adolescent have the full agreement), and coefficient =0 indicates no correlation (parent and adolescent have the same agreement as they would by chance). All analyses were done using the whole sample and were also stratified by gender;

the full sample showed the same association patterns reported in the gender stratified results, thus we only presented the gender stratified results here.

To examine agreement between parent and teen dyads, we used multinomial logistic regression models to estimate the effect of individual- and household-level demographics on the patterns of agreement/disagreement between parents and adolescents for receipt of routine care. Routine care was selected for modeling as there was least controversy about confidentiality as a component of routine preventive care. Other services in Table 2 were not modeled both to avoid multiple comparisons during model selection, and because we did not have sufficient power to examine the impact of variability in state laws or other access variables affecting these services for adolescents. Parent-adolescent dyads were omitted from the modeling if one respondent reported “don’t know”. Parents’ race/ethnicity were also excluded from the models, as it was highly correlated with adolescents’ race/ethnicity. Parent-adolescent dyads were grouped into four agreement/disagreement categories: *Parent No/Adolescent No*, *Parent Yes/Adolescent Yes*, *Parent No/Adolescent Yes* and *Parent Yes/Adolescent No*. A backward selection procedure was used and variables that were not significant (listed in the note to table 3) were dropped from the final model. The number of dyads, relative risk ratios (RRRs), P-values and 95% confidence intervals (CIs) with all predictors significant in one category from others are presented in the final model. All analyses were performed using Stata 14.³²

Results

We analyzed 1209 adolescent/parent dyads, 50.8% of the teens were male; 32.9% were age 14 or younger; 54.3% were White, Non-Hispanic, 13.8% were Black, Non-Hispanic, 9.1% were 2+ Race and other, Non-Hispanic, and 22.8% were Hispanic. Most

(85.1%) lived in metropolitan areas; 15.0% reported household income under \$25,000, and 20.1% reported household income between \$25,000-\$49,999. Of the 1209 parent respondents in the dyads, 58.1% were female; 27.5% were age 40 or less, 23.9% were 40 - 45 years old, 23.8% were 45 - 50 years old, and 24.8% were older than 50 years; 58.5% were White, Non-Hispanic, 15.1% were Black, Non-Hispanic, 6.7% were 2+ Race and other, Non-Hispanic, and 19.7% were Hispanic; 80.8% were married, 9.6% never married or living with a partner, and 9.6% were widowed or divorced or separated; 61.7% worked as a paid employee, 8.7% were self-employed, and 29.6% were not working.

Almost all parents and most adolescents believed that preventive services were important; parents were more likely to endorse this than are adolescents (Table 1). Overall, 95.9% parents and 90.2% of adolescents believed clinical preventive services were very or somewhat important. Only 4.1% of parents and 9.8% of adolescents believed that preventive services were somewhat or very unimportant. Parent and adolescent agreement about the importance of clinical preventive services (percent agreement) were 92.2% for very or somewhat important, and 57.4% for very or somewhat unimportant. Parent-adolescent responses overall were weakly correlated, with a Cohen's kappa correlation of 0.22 ($p < 0.001$).

Parents and adolescents often agreed about what age adolescents should be to have private, confidential time during their clinical visits (Figure 1). The median age for when they thought private time should be provided during clinical visits was 16 years old for both parents' and adolescents. Overall, 40.5% of parents and 31.1% of adolescents identified age 18 or older as when private time should be initiated. Parents and adolescents show moderately strong agreement on when teens should have private time, with a Spearman coefficient rho of 0.59 ($p < 0.001$), and many parents and teens identified age >18, the legal age of adulthood, as when private time should be initiated.

More than half of adolescents (58.8%) and almost as many parents (53.3%) reported that they believed care from an adolescents' regular health care provider should be provided confidentially. Somewhat fewer teens and parents endorsed confidentiality for each of several services that might be provided to an adolescent (Table 2). The lowest rates for confidentiality were reported for having an abortion: 12.8% of parents and 24.0% of adolescents believe that abortion services should be provided confidentially. Table 2 also examines parent and adolescent dyads attitudes towards confidentiality for each of the ten different clinical services. Overall, the type of service was not associated with total parent and adolescent agreement (52.6%-58.6%, summing Yes/Yes and No/No categories). However, whether agreement was positive (Yes/Yes) or negative (No/No) varied substantially with the type of service being asked. In contrast, overall disagreement between parents and their adolescents about whether a service should be confidential ranged from 18.3 to 28.9% (summing the Yes/No and No/Yes categories). The majority of these disagreements were due to adolescents reporting that a service should be confidential, and parents reporting that a service should not be confidential. The relative disagreement was largest for abortion services.

We used the agreement/disagreement between parent and adolescent dyads for going to their regular provider as the dependent variables in multinomial logistic models with adolescent, parent and household level variables as independent variables (Table 3). Using the Parent "No" & Adolescents "No" as our reference group, we found significant variables predicting Parent "Yes" and Adolescent "Yes" agreement included older adolescent age (> 14 years old: Risk Ratio (RR)=2.08, $p<0.001$), race (Hispanic: RR=2.10, $p=0.004$), parent age (45-50 years; RR=0.54, $p=0.016$), parent's marital status (widowed, divorced or separated: RR=2.10, $p=0.036$), and higher household income (\$50,000-\$74,999: RR=2.10,

$p=0.025$; $>\$75,000$: $RR=3.15$, $p<0.001$). No first order interaction terms were found to be significant in these models.

We found similar demographic variables predicted Parent “No” and Adolescent “Yes” disagreement. As with Yes/Yes agreement, this group was associated with older adolescent age (>14 years old: $RR=2.19$, $p<0.001$), race (Hispanic: $RRR=1.93$, $p=0.025$), and household income ($\$50,000$ - $\$74,999$: $RRR=2.43$, $p=0.017$; $>\$75,000$: $RRR=2.12$, $p=0.027$). In contrast, models for Parent “Yes” and Adolescent “No” only found MSA status (metro: $RRR=0.47$, $p=0.031$) and parent’s marital status (widowed, divorced or separated: $RRR=2.67$, $p=0.04$) as significant predictors.

Discussion

We found that adolescents and parents generally agreed about the importance of preventive services, private time, and confidentiality. Adolescents and parents also generally agreed on what should and should not be kept confidential. Adolescents’ attitudes and parents’ attitudes were often correlated. While the overall correlation for this agreement is weakened by those teens who think services are unimportant and by the variation between very and somewhat important between parents and teens, almost all parents and most adolescents believe that preventive services are important. Parents tend to value preventive services more than youth, while youth value confidentiality more than parents.

Adolescents and their parents also tend to agree with each other on what age young people should have private, confidential time during adolescent health care visits, although overall parents endorse a slightly higher age for starting confidentiality than do adolescents. Many parents and teens endorse private confidential time between ages 13-16; however, almost as many parents and teens identify age 18 as when private time should be initiated. Interestingly, a substantial majority of both adolescents and parents believe this should start

well beyond age 13, as recommended in professional guidelines for adolescent health care.^{1,3,4}

Many adolescent parent dyads agree about whether a service should be provided confidentially; however, their beliefs of whether a service should be provided confidentially differed by the type of service. However, more than 1 in every 6 adolescents think that some kinds of care should be available confidentially, even though their parents do not agree. These differences are largest for services that are usually protected by state minor consent laws, such as substance abuse counseling and reproductive care. While we do not know from this study whether adolescents who have needed or had specific experiences with these services may be more likely to recognize and endorse the importance of confidential care, it is possible that this may be the case.

Fewer than half of either parents or adolescents believe that confidentiality should be provided for all of 10 services an adolescent might need, ranging from routine care to abortion care. Adolescents generally agree with their parents about access to confidential care, but are also more likely to think that confidential care should be available than their parent. Disagreement was largest for abortion services, with adolescents almost twice as likely as parents to think it should be confidential. Older adolescent age, Hispanic ethnicity, having divorced parents and higher family income were each independently associated with both adolescent/parent and adolescent only endorsement of service confidentiality. In contrast, single parents and those in rural areas were more likely to endorse confidential care even when their teens did not. These findings may reflect older youth (and thus older parents) higher likelihood of engaging in behaviors needing confidential interventions, distance or transportation access barriers, as well as some parents' recognition of the potential benefit of additional responsible adult interactions for their adolescents. Interestingly, although the effects of gender on parents' assumptions about adolescent behaviors³³ and clinicians'

differential screening and counseling about sexuality and other risky behaviors¹⁹ have been documented, neither adolescent gender nor gender/age interactions were significant predictors of whether parents and teens agreed on whether services should be available confidentially.

Our study is limited by the several issues inherent in surveys, including survey item design, sample coverage and response biases. Some of the survey items described several similar services; attitudes about each of the separate component services were not obtained, and respondents might have considered some of these services as more sensitive than others (e.g, HPV vaccine compared to other routine vaccines.) Confidential responses were encouraged but unable to be guaranteed in online survey; thus the youth behaviors reported might be lower than actual rates, especially for risky behaviors or for confidential care use. While we made efforts to oversample subpopulations with low completion rates, and the resulting data matches the demographic composition of the Current Population Survey by age, race/ethnicity, and income of families for families with one or more adolescents aged 13-18 years³⁰, sampling biases exist when considering more and higher order of demographic variables and these may have affected our findings. Our sample also limits our ability to examine separately the agreement between parents and adolescents across different subclutres and among underrepresented groups, to detect subpopulations whose agreement or disagreement may be different in a systematic way³⁴, or to examine agreement in multivariate models for all of the services we asked about. We were not able to fully account for the influences that specific prior care experience, insurance coverage or other determinants of access may have had on both adolescent and parents reporting of attitudes towards care and did not have the ability to examine whether these attitudes affect adolescents' future care experiences. Further studies to understand the impact of prior care and communication about confidentiality and private time as well as how these attitudes on

selection of clinicians and care sources are needed to better understand the role of clinicians and health care systems in helping adolescents obtain appropriate health care. The “don’t know” responses also warrant further study. This category was a small but significant proportion of responses, but these combine 5 possible parent/teen answer combinations. The factors associated with each of the 5 categories could be discordant in either direction, and likely mean different things depending on the direction of disagreement; however, we did not have sufficient power to in our sample to separately model these categories.

Conclusions

Parents and their adolescent children both believe that clinical preventive services are important. However, a substantial proportion of both parents and adolescents think that confidential, private time during clinical service delivery should start during mid or late adolescence, rather than in during the earlier adolescent years. This is in contrast to professional clinical guidelines, in which recommend preventive care for adolescents include opportunities for confidential screening and counseling about a variety of potentially sensitive issues. While some of the evidence for guidelines is based on expert opinion, other recommendations, especially those for reproductive health and STDs, are solidly grounded in evidence for their effectiveness. Additionally, most state laws also provide confidential access for certain services to those under 18.⁴ Interestingly, while most parents and adolescents agree about the ‘right’ age for confidential care, adolescents think these services should be provided at a slightly younger age than do parents, and a substantial proportion of adolescents think they should have confidential care, even when their parents disagree. Our findings have implications for clinical organizations, as it seems many parents and adolescents are unaware of or disagree with professional and legal guidelines for adolescents’ access to care. Providing the best possible care for adolescents and young adults will require

increasing the number of adolescent who receive preventive services, including the recommended confidential screening and counseling interventions in preventive care guidelines. This suggests a need for education, both for parents and adolescents, and for clinicians, about the importance of confidentiality in providing preventive services and including the rationale for professional guidelines for confidentiality in delivery of care. The American Academy of Pediatrics (AAP) and HRSA/MCHB Bright Futures guideline suggests that patient education should begin by age 10.² Furthermore, although most parents and adolescents agree about their expectations for confidentiality, a significant minority of young people who endorse confidential care have parents who do not. Thus, clinicians need to make sure parents are aware of the importance of adolescent preventive care, and that adolescents know about their rights and how they can access care, even if their parents disagree about whether care should be available confidentially. For most teens, a shared understanding and better communication with parents and adolescents may be as relevant as laws, policies, and clinician guidelines as it pertains to delivery of confidential care and specific preventive services for adolescents.

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