

Earning trust and losing it: Adolescents' views on trusting physicians

Specific physician behaviors—particularly those implying an assurance of confidentiality—encourage trust-building among adolescents

Practice recommendations

- Keep in mind that adolescents are generally more concerned than adults about confidentiality when deciding on a physician's trustworthiness.
- Approach adolescents who have chronic illnesses with the expectation that they will be more comfortable involving parents in their care than will healthy adolescents.

Abstract

Objective To explore how adolescents with and without chronic illness perceive patient-physician trust and to identify physician behaviors related to these perceptions that might be modified to promote adolescent health care.

Methods Fifty-four adolescents recruited from the community (healthy subjects) and from hospital-based clinics (subjects with chronic illnesses) participated in 12 focus groups divided by age (11–14 or 15–19 years old), gender, and health status. Major themes related to preferred physician characteristics and trusting one's doctor were derived through a multistep, team-based qualitative analytic process.

Results Adolescents hold varied percep-

tives of trust in their physicians. They describe elements of patient-physician trust similarly to the comprehensive model developed with adults, including fidelity, confidentiality, competency, honesty, and a global perspective intersecting several of the more specific domains. However, adolescents differ in the relative importance of these dimensions. Younger adolescents express more concern about confidentiality of their health information, and adolescents with chronic illnesses are more interested in involving parents in their care than are adolescents without chronic illnesses. Examples of specific behaviors to improve trust include asking for adolescent's opinion, keeping private information confidential, not withholding information, and engaging in small talk to show concern. **Conclusion** Understanding the importance of trust and listening to recommendations about behaviors to improve it, in the words of the adolescents, may help physicians build positive relationships with their adolescent patients.

In the primary care setting, a patient's trust of the physician is more strongly associated with self-reports of improved health than is any other characteristic of the

Brenda K. Klostermann, PhD, Gail B. Slap, MD, MS, Dawn M. Nebrig, MSW, Tanya L. Tivorsak, BA, and Maria T. Britto, MD, MPH

From the Illinois Education Research Council, Southern Illinois University, Edwardsville (BKK); Division of Adolescent Medicine, Cincinnati Children's Hospital Medical Center (GBS, TLT, MTB); University of Cincinnati College of Medicine (GBS, MTB); Department of Patient Services, Cincinnati Children's Hospital Medical Center (DMN). Ms. Tivorsak is now a student at the University of Rochester School of Medicine and Dentistry, Rochester, NY.

CORRESPONDING AUTHOR

Brenda K. Klostermann, PhD, Illinois Education Research Council, Southern Illinois University Edwardsville, Box 1064, Edwardsville, IL 62026-1064. E-mail: breklos@siue.edu

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Distrust in a physician to protect confidentiality can lead to avoidance of health care

patient-physician relationship.¹ Trust has been shown to affect a patient's satisfaction with health care services and willingness to disclose sensitive information, adhere to treatment, continue with a physician, and recommend that physician to others.^{1,2}

Increasing age of a patient has a modestly positive correlation with trust, possibly due to greater contact with physicians; other demographic characteristics have not been consistently found to relate to trust.^{3,4}

Studies examining health status and trust have shown a weak and inconsistent relationship.^{1,3} Persons with poor health, such as a chronic illness, may be more vulnerable and thus have a greater need to trust. Poor health may also cause negative feelings that may influence how patients trust their physicians.

■ Physician behavior and patient trust

The importance of patient trust to the process and outcome of health care has prompted the study of how specific physician behaviors may help to build trust. Among adults with and without chronic conditions, trust is associated with perceived physician caring, competence, and communication.^{1,5,6} Among adolescents, trust seems more strongly influenced by a physician's confidentiality, competence, honesty, and respect, than by any other set of characteristics pertaining to health care professionals, health care sites, or incentives to use primary care services.^{7,8} Distrust that physicians will protect confidentiality has been cited as a barrier to health care use and compliance among adolescents.⁹

However, unlike the adult literature on patient-physician trust, no study of adolescents has defined trust from the patient's perspective or identified physician behaviors that promote trust among adolescent patients. Directly asking adolescents about trust in their doctor may identify specific physician behaviors that encourage building trust. Understanding the importance of trust to adolescents and listening to their recommendations about

behaviors to improve it, in the words of the adolescents, may help physicians build positive relationships with their adolescent patients.

This study addresses the call by Rosser and Kasperski for more research pertaining to the development of trust between doctors and patients.¹⁰ A model of trust between adult patients and their physicians, developed by Hall et al,³ was used as a framework to understand adolescents' perceptions of patient-physician trust. The 5 specific domains of this model include patient perceptions of physician fidelity, protection of confidential information, competence, honesty, and a global perspective that intersects several of the more specific domains and captures the holistic aspect of trust. This study's objective was to explore how adolescents with and without chronic illness perceive patient-physician trust and to identify physician behaviors related to these perceptions that might be modified to promote adolescent health care.

■ Methods

Participants

This study was part of a larger qualitative and quantitative research project examining health care preferences of adolescents with chronic health conditions.¹¹ The protocol for the research project on adolescent health care preferences and the analyses performed for the current study on trust were approved by the Institutional Review Board of the Cincinnati Children's Hospital Medical Center.

Adolescents aged 11 to 19 years with cystic fibrosis, sickle-cell disease, juvenile rheumatoid arthritis, or inflammatory bowel disease diagnosed at least 2 years previously were recruited from hospital-based clinics. We attempted to contact all patients aged 11 to 19 years in these subspecialty clinics for their participation. Introductory letters were sent, followed by phone calls, to these adolescents and their guardians to explain the study and to invite participation in a focus group. For

comparison, a convenience sample of adolescents aged 11 to 19 years without chronic conditions were recruited from local summer recreation programs, a church, and a school using flyers and personal contacts.

Written informed consent was obtained from participants who were age 18 years and older and from the legal guardians of participants who were younger than age 18 years. Participants were reimbursed 10 dollars for their time and travel expenses. The study sample consisted of 54 participants divided by age (11 to 14 years and 15 to 19 years), gender, and the presence or absence of chronic disease into 12 focus groups ranging in size from 2 to 10 individuals (mean=5) (TABLE).

Following focus group protocol recommendations for homogenous groups¹² and other similar studies,^{7,8} groups were divided by age due to differing developmental levels (early vs later adolescence) and gender, since same-sex groups are preferred for young adolescents. Participants were divided based on the presence or absence of chronic disease due to different health care experiences. For the groups of participants with a chronic disease, 17 were 11 to 14 years old (6 male; 11 female) and 12 were 15 to 19 years old (7 male; 5 female). For the groups of healthy participants, 13 were 11 to 14 years old (8 male; 5 female) and 12 were 15 to 19 years old (4 male; 8 female).

Data collection

Focus groups were conducted as part of the larger research project to explore adolescents' preferences on various aspects of their health care (eg, doctor-patient relationship, doctors' characteristics, physical environment, doctor-patient communication).¹¹ The current analysis examined one aspect of the doctor-patient relationship identified by participants: trust.

One professional facilitator led the 12 groups through 2-hour discussions about health concerns, preferred physician characteristics, and preferred visit characteristics. New topics raised by a given group were

TABLE

Demographics of sample (N=54)		
	N	%
Gender		
Female	30	56
Health status		
Healthy	25	46
Chronic illness	29	54
Cystic fibrosis	7	24
Inflammatory bowel disease	10	35
Juvenile rheumatoid arthritis	5	17
Sickle-cell disease	7	24
Age		
Range: 11–20		
Mean: 14		

highlighted by the facilitator for discussion by subsequent groups, and discussions were directed away from topics that had reached saturation in previous groups.¹³

In general, adolescents discussed the dimensions of trust in response to 2 questions: "What makes a good doctor?" and "How do you know you can trust your doctor?" Audiotapes of all discussions were transcribed verbatim, edited for accuracy, and supplemented by field notes taken by co-investigators who attended the group discussions as observers. The presence of the co-investigators enhanced understanding of the transcripts, without apparent discomfort or inhibition of the participants.

Data analysis

The analyses occurred in multiple stages. During the first phase of analyses, 4 co-investigators independently prepared summaries of each group transcript and initial lists of the themes discussed by the participants, using Crabtree and Miller's editing-organizing style.¹⁴ They then met as a team to discuss their observations and to begin preliminary interpretation of that focus group. Consensus on the themes was reached for each group.

After the groups' results were analyzed separately, the research team compared and contrasted the group themes and generated

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"Doctors show they care by trying to understand how you're feeling ... [and not just] trying to fix things."

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Confidentiality: younger males even expressed concern about information they shared as children

a comprehensive coding scheme for all of the focus groups combined. Emphasis was placed on a comprehensive coding scheme (ie, topics discussed less often were included along with topics discussed more often). Trust was identified as a major theme discussed in all 12 focus groups.

In the next stage of analysis, the edited transcripts and the coding scheme were imported into the qualitative text analysis software package N5 NUD*IST.¹⁵ Two authors (TT and MB) independently coded the first 2 transcripts using the comprehensive coding scheme. Discrepancies in coding were resolved by negotiation. The remaining transcripts were then coded by one of the authors (TT). Unclear or confusing statements were discussed with other team members for coding clarification.

Trust emerged as an important concept and was selected for more detailed, theoretical analysis. For this analysis, a team member (BK) reviewed the transcripts and used the N5 NUD*IST search feature to identify comments in the transcripts related to trust. Then, the research literature was surveyed for frameworks to help us further understand and analyze the data pertaining to physician-patient trust in adolescents. Hall et al's model of trust between adult patients and their physicians was selected as a framework for categorizing the comments into 5 specific domains.³ One team member (BK) assigned each comment to a category using the data matrix method of Miles and Huberman¹⁶ and noted in which gender-age-health groups it had been discussed. Although the analytic plan called for no categorization of comments that did not fit the schema of Hall et al, all comments discussed by all groups were readily assigned to categories.

To ensure trustworthiness of the data, another team member (MB) reread the transcripts to identify and categorize statements related to trust that might have been missed by the software search and to confirm the assignments made by the first reviewer. The reviewers looked for patterns of similarities and differences in responses

from the participants. Specifically, groups were compared by gender, age, and health condition for the dimensions of trust and the specific topics within each dimension that were discussed. Once the 2 reviewers agreed on the categorization of the comments, their interpretations were reviewed, discussed, and finalized by 2 other team members for further verification and to look for disconfirming data.

■ Results

All groups discussed topics related to at least 2 of the 5 dimensions of trust. Nine of the 12 groups discussed topics in at least 4 of the 5 dimensions.

Fidelity

Fidelity—the physician's pursuit of the patient's best interest, not taking advantage of the patient's vulnerability—was discussed by 9 of the 12 groups. The words used by the adolescent participants to describe fidelity included caring, respect, and advocacy, as demonstrated below.

13-year-old male without chronic illness:

"Doctors show they care by trying to understand how you're feeling rather than just coming in to try to fix things."

15-year-old male with Crohn's disease:

"If he asks for my opinion or if he takes my advice seriously...or how he talks to me. I know if he either respects me or not...if he doesn't talk down to me, like, still doesn't think I'm a little kid."

13-year-old female with cystic fibrosis:

"[A good doctor is] someone that you can trust to take care of you and do what's right for you."

When asked about behaviors that would diminish trust, several participants gave examples of how a physician might take advantage of an adolescent's vulnerability. For example, a 15-year-old female without chronic illness mentioned she would lose trust if her doctor "touched her in the wrong way." A 13-year-old male without chronic illness

stated: "This never happened, but I just feel like it would happen like, as soon as my mom walks out of the door, the doctor would pull out that clipboard [and say] 'Oh, I'm trying to ask these questions [about sensitive topics].'"

Confidentiality

Confidentiality (ie, keeping sensitive or private patient information from others) was discussed by nearly all of the groups. Although there was consensus about the overall importance of the dimension, adolescents varied in their beliefs about specific definitions, such as the types of information that should be kept confidential or from whom information should be withheld.

The general concept of confidentiality, however, was incorporated by many adolescents into descriptions of a good doctor and a trusted doctor. For example:

13-year-old male without chronic illness:

"[A good doctor is] somebody who protects what you say and keeps things in a closed record to where nobody else can get to 'em."

16-year-old female with cystic fibrosis:

"He needs to keep that [conversation during doctor visit] zipped, especially when they talk to your parents afterwards. You may tell him something that you don't want your parents to know about, and he should respect that if you tell him something."

The following comment conveys how quickly an adolescent might lose trust in a doctor if confidentiality is broken:

19-year-old male with sickle-cell disease:

"If I told my doctor something really personal that nobody else needed to know, and then he went and told everybody, I don't care if it's people on the hospital staff, sometimes I'll be like 'Uhhh, could you just keep this between us' and if they go and tell everybody, that would make you lose trust in the doctor."

Several younger males in one focus group expressed concern about information that might have been shared years earlier, when they were children:

SUBJECT #1 (13-year-old male without chronic illness):

"Because, some doctor, a doctor a long time ago when I was about 6, he sent my records all the way down to Children's and it was not like what a normal doctor would do."

MODERATOR: "And that made you feel uncomfortable?"

SUBJECT #1: "Yeah."

SUBJECT #2 (13-year-old male without chronic illness):

"Like they were telling them everything."

SUBJECT #3 (11-year-old male without chronic illness):

"And then next time you come: 'Oh there's the sick boy.'"

SUBJECT #4 (13-year-old male without chronic illness):

"Yeah."

Competency

Six of the 12 groups, particularly the older female groups, discussed competency in terms of trusting their doctors and identifying what makes a good doctor. As with other dimensions, the discussions explored both the presence and absence of competency:

17-year-old female without chronic illness:

"Like a doctor that gave you the wrong like...gave you a bad diagnosis or something and was, you know, had made a mistake, and they knew that they had made a mistake. You would naturally not go back to them."

17-year-old female without chronic illness:

"I think that you can get people to trust you and respect you and stuff by being efficient, professional, doing a job well and making it as painless as possible. Not necessarily, you know, talking to them about this that and the other thing."

Honesty

Eight of the 12 groups identified honesty as an attribute of a good doctor and a trusted doctor. Adolescents defined an

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Honesty: "I don't want them to say 'you're feeling better'... and then [find out I have something bad]."

honest doctor as one who is realistic, accurate, and does not withhold information. For example,

15-year-old female with sickle-cell:

"But I would like to know if I have bad news so I can, like, pump myself up to feel better. I don't want them to come in to say 'you're feeling better, you'll probably be out soon', and then [find out I have something bad]."

12-year-old female with cystic fibrosis:

"Yeah, if they lie to you, you kind of feel like you cannot trust them anymore."

15-year-old female without chronic illness: "If there's something's wrong with you, you trust 'em to tell you."

When asked if there were times when a doctor should not share bad news, all participants responded that the doctor should either share the news directly with the adolescent or with a parent, who would then discuss it with the adolescent. Access to all information was particularly important to participants with chronic illnesses, as demonstrated by this comment:

16-year-old female with cystic fibrosis:

"I think it's very important and if he didn't, if my doctor didn't [tell me the bad news], it could result in weeks of hospitalization. But my doctor does tell me the truth. I mean there's hardly any time where he keeps something from me. I think the only way he'd keep something from me is if I wasn't ready to hear it or if it really didn't concern what I did just as long as my parents know about it."

Global

Hall et al describe the global dimension of trust as serving 2 functions. The first is for comments that intersect 2 or more of the other areas but do not fit exclusively in one. The second is to capture the holistic quality of trust.

Group discussions about this global dimension involved a "friend-like" relationship with the doctor, comfort with the doctor, and an overall sense that the

doctor could be trusted. The comments noted below are organized into these content areas:

Friend-like.

14-year-old male with Crohn's disease:

"[The doctors] know their patient as a friend and not as a patient...they know them like a friendship and everything."

16-year-old female without chronic illness: "[A good doctor] would be a friend with the patient, not just be an authority [figure]."

When asked how a doctor should relate to an adolescent patient as a friend, several adolescents suggested the doctor telling about his personal life (eg, family, children) and asking about the adolescent's personal life (eg, sports, school). A 14-year-old male with Crohn's disease suggested, "Have a conversation with them, not like question-answer, question-answer, having a conversation so it all flows."

Comfort. Participants described physician use of introductory small talk as a means of building comfort, and the premature introduction of sensitive topics (eg, drug use, sexual behavior, family issues) as a barrier to comfort.

16-year-old female without chronic illness:

"It's sort of like an introductory question, like they'll get you in there, try to make you feel comfortable, and they're like, 'how's school going'...I think they try to strike up a conversation to make you feel more comfortable."

11-year-old female without chronic illness:

"But if the doctor is a guy, then you probably won't feel comfortable talking about that [peer pressure and menstrual cycles]."

Comfort was a prerequisite for trust for some adolescents. Participants described feeling comfortable telling their doctor and then trusting them with the information. The following comment illustrates the relationship:

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Adolescents said physician use of introductory small talk increased their comfort level

15-year-old female without chronic illness: "If you're comfortable, you have more trust in the person."

Overall sense of trust. The older, healthy female group was the only group that described trust from a holistic perspective:

MODERATOR: "I mean, what is it that makes them trustworthy? (Pause.) Just 'cuz they're doctors? Ok."

17-year-old female without chronic illness: "I mean, you kinda want to trust your doctor and you don't want to believe that they're trying to get you...there's nothing behind their back. You do want to be able to trust them."

■ Discussion

Adolescents in our study defined a good doctor as one they can trust and, similar to other studies of adolescent populations, said trustworthiness is a core attribute they seek in a physician.⁷⁻⁹ The comprehensive model of patient-physician trust developed by Hall et al in adults depicts trust as perceived by the adolescent participants in our study.³ The dimensions of caring, confidentiality, competency, honesty, and holistic trust captured the beliefs expressed by the adolescents, suggesting that adolescent and adult models of physician trust may be similar.

Confidentiality is the one dimension in which the specifics may differ for adolescents and adults. Similar to other research with adolescents,^{7,9} adolescents in our study indicated that confidentiality (ie, keeping health and personal information private) is an important characteristic of a good doctor and a trusted doctor. Adults, on the other hand, are less concerned about confidentiality as it relates to trusting their physicians.^{2,3,6,17}

Adolescents may be uncertain about a physician's obligation to inform or not inform parents about private information, which, in turn, may increase their sensitivity to confidentiality. Because adolescents, unlike adults, are accountable to an adult who controls access to activities and

friends, they may be more likely to conceal sensitive activities for fear of losing privileges. Chronically ill teens may conceal certain symptoms or lack of compliance with treatment for similar reasons.

Developmental differences may help explain the reason younger adolescents in our study expressed more concern and uncertainty about how health information is protected than did older adolescents. The capacity for formal operational thinking that develops during adolescence enables abstraction and leads to an increasing interest in how the outside world views personal attitudes and behaviors.¹⁸ Until adolescents test the responses of the outside world, they may feel center-stage, as though "everyone" is judging them. Keeping personal information private thus becomes extremely important to maturing adolescents.

Adults who have tested the views of others' responses are better able than adolescents to keep in perspective the interests of the outside world and, therefore, may have fewer concerns about how their personal information is managed. In addition, adults are more likely to have a better understanding of confidentiality policies within a healthcare system and thus realize their private information is safeguarded.

Given that this analysis was part of a larger study and issues surrounding confidentiality were not studied in-depth, future research involving both adolescents and adults focusing on confidentiality and the uncertainty about parental involvement that often accompanies adolescent health care could shed light on this topic.

Although adolescents with and without chronic illnesses discussed the same dimensions of trust, honesty and advocacy were noted more often by the former. This resembles findings reported in studies of adults with serious illnesses.⁶ Adolescents with chronic illnesses tend to consider parents acceptable recipients of bad news. In addition, adolescents with chronic illnesses expect physicians to reveal bad news to either the adolescent or their parent, given the potential dire health consequences of withholding important medical information.

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Younger adolescents are more concerned and uncertain about confidentiality

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Honesty and advocacy were noted more often by chronically ill adolescents than by healthy peers

The issue of honesty may have been mentioned less frequently by healthy adolescents since they have not had to contend with major health issues and receiving bad news. Adolescents with chronic illnesses expect good doctors to “go the extra mile,” a task that is increasingly difficult in a health care environment that seeks to limit reimbursement and expenditure.¹⁹

Keeping in mind the qualitative nature of our study and size of our sample, the findings from our focus groups suggest that physicians working with adolescents with a chronic illness be cognizant of their increased need for complete and accurate information, as well as the higher expectation that the doctor will act on their behalf. Additional studies are needed to investigate whether adolescents with a chronic illness have a higher need for honesty and advocacy than healthy adolescents.

Although identified as a *predictor*, rather than a *dimension*, of trust,³ duration of the patient-physician relationship was discussed by adolescents with and without chronic illnesses in our study. Comments similar to “he’s been taking care of me for a long time” or “because I’ve known her all my life” were repeated often. Studies in both adolescent^{7,20} and adult populations,^{2,4,17} have reported similar findings. Adolescents in our study varied in their estimations of sufficient duration, from 4 to 5 visits to knowing the doctor “forever.”

Unlike the many comments pertaining to duration of acquaintance, there was no discussion of the frequency or intensity of visits. Comfort appears to be a prerequisite for trust for adolescents in our study and may perhaps be a moderating factor when examining how the duration of the patient-physician relationship influences trust. The length of time necessary to feel comfortable may vary among individuals and may be influenced by other factors (eg, experience with doctors or the health care system, friendliness of the physician). Thus, it may not be possible to determine a standard time period (eg, 6 months) in which adolescents feel comfortable to trust their doctor. Future studies examining what influences

adolescents’ comfort level (eg, length of relationship, intensity of health care experience) with their physician may provide additional insight for improving adolescents’ trust in their physicians.

When asked how doctors could gain the trust of adolescent patients, participants in our study responded “be truthful,” “be friendly,” and “be there.” More specific behaviors included asking for the adolescent’s opinion, keeping private information confidential, not withholding clinical information from the patient, and engaging in small talk to show concern.

Participants were quick to point out that physician violation of gained trust is viewed as serious behavior that leads to rapid deterioration in the doctor-patient relationship.^{3,19} They identified examples of violated trust as medical mistakes, breaks in confidentiality, and taking advantage of patients when vulnerable (eg, during the physical examination). These descriptions highlight the importance of proactive discussions early in the doctor-patient relationship, clarifying the legal and ethical limitations of issues such as confidentiality.

There are several limitations to this study. First, these analyses were part of a larger study examining health care preferences of adolescents with a chronic illness. Because the issue of physician-patient trust was not the focal point of the original study, there may be issues relating to trust that our study did not address. Further research with additional samples is needed to confirm if all aspects of trust were explored.

Second, while our findings support those of earlier studies in both adolescents and adults, our sample was drawn from the patient population of only one mid-western city in the US.^{7-9,20}

Third, adolescents who declined participation in the study may differ in their attitudes or beliefs about health care providers than adolescents who agreed to participate, thus introducing a potential selection bias.

Fourth, we were unable to perform member checking or reactor panels to examine “external validity” due to the

participants' cognitive level (ie, difficulty discussing abstract concepts). However, corroborating evidence from earlier studies supported our findings.

Fifth, our study was designed to collect qualitative data and to use analytic methods that are appropriate for such data. The data and statistical methods were not intended to be quantitative, and the interpretations of the reported findings therefore were appropriate for those of a qualitative, not quantitative study design.

In conclusion, our study provides the first steps in suggesting that adolescents and adults agree on the major dimensions of trust but differ in the relative importance of these dimensions to the overall definition of trust. Adolescents in our study expressed the broadest range of beliefs within the dimension of confidentiality. Younger adolescents expressed more concern and uncertainty about how health information is protected than did older adolescents.

Adolescents with chronic illnesses seemed more comfortable involving parents in their care than did adolescents without chronic illnesses. Since adolescents with chronic illness have more experience involving their parents in their care, future studies could examine whether having a chronic illness makes a difference in whether an adolescent would involve their parent more when faced with the same health concerns typical of healthy adolescents (eg, sexual health, psychological issues).

Additional studies focusing specifically on physician-patient trust are needed to further explore similarities and differences between adults and adolescents' perceptions. Understanding the importance of trust to adolescents and listening to their recommendations about behaviors that promote it may help physicians build positive relationships with patients that will continue into and beyond young adulthood. ■

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CONFLICT OF INTEREST

The authors have no conflicts of interest to report.

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