A Complex Matter: Parental Perspectives on Adolescent Health-Related Confidentiality

Since the inception of adolescent medicine in the 1950s, a basic tenet of the field has been to provide privacy and assure confidentiality to adolescent patients in healthcare settings. The rationale and expectation have been to encourage adolescents to initially seek care, maximize their openness when meeting with healthcare providers, promote independent communication and decision-making skills in preparation for emerging young adulthood, and thus enhance their health and wellbeing. Over the ensuing 70 years, research has generally supported the wisdom of this original assumption [1,2], which has become a cornerstone of adolescent healthcare [3,4]. However, we have also become more aware of the nuances, challenges, and barriers involved and the disparate practices of clinicians [5–7], perspectives of parents [8,9], and even the priorities and preferences of adolescents themselves with respect to this matter [10–12]. In this issue of Journal of Adolescent Health, Donck et al. [13] present a “snapshot” qualitative study of 20 Belgian parents of adolescents’ views on four clinical vignettes with respect to adolescent confidentiality. Parents were asked if they believed a physician should provide them with information, even if their adolescent specifically requested the physician not to. The opinions among these parents differed considerably but tended to fall into three main themes: trust, responsibility, and the nature/severity/frequency of the problem.

Although most of the parents acknowledged the potential benefit of their child trusting the physician to maintain their confidentiality, some parents questioned if they could trust a physician who withheld information from them. Some parents felt it was their responsibility as parents to know what their adolescent shared with a physician, whereas others were comfortable knowing that the physician was taking the responsibility of managing a sensitive matter. Some parents felt that for a sensitive or intimate problem (such as regarding mental health or a sexually transmitted disease) confidentiality should be assured, whereas other parents felt the opposite or were concerned that a matter may be serious and they should be informed.

These are all reasonable parental reactions, in any country. The parental anxiety and uncertainty that was expressed by these parents point to the need for healthcare providers to openly address the critical matter of adolescent health-related confidentiality in advance, preferably while meeting together with an adolescent patient and their parent. This discussion can take place at an initial visit with an adolescent of any age or at age 11, 12, or 13 years with an established patient of a pediatrician or family doctor at the time of an annual check-up. The importance of private face-to-face time between the physician and patient, and the assurance of maintaining confidentiality, its scope, and its limitations, will then hopefully be established, understood, and accepted by all.

Sadly, access to confidential care from clinicians with the time, inclination, and training to sensitively discuss such information with families and provide confidential care for adolescents is far from universal, consistent, or equitable in the United States. One recent study [6] reported that 90% of patients seeing a board certified adolescent medicine provider received a confidential consultation compared to 53% of those seen by a general pediatrician in the same urban healthcare system. In the United States, there are more than 60 times more pediatricians than adolescent medicine providers of primary care. The American Academy of Pediatrics’ Bright Futures Guidelines for Health Surveillance of Infants, Children, and Adolescents (fourth edition, 2022) includes many important priorities to cover during adolescent health visits and handouts for parents and adolescents (starting at an age of 11 years) which provide useful suggestions for promoting health and preventing risky adolescent behaviors. However, these priorities and handouts do not specifically mention privacy or confidential care.

All states in the United States and many countries have statutes allowing for certain types of confidential healthcare to minors for sensitive matters such as sexuality/reproductive healthcare, substance abuse treatment, and mental health concerns. The laws regarding confidentiality and consent differ from state to state [14] and country to country. Clinicians need to familiarize themselves with the statutes in their own state or

See Related Article on p.21

Conflicts of interest: The author has no conflicts of interest to declare.

1054-139X/© 2022 Society for Adolescent Health and Medicine. All rights reserved.
https://doi.org/10.1016/j.jadohealth.2022.10.004
country and aim to develop a level of comfort providing confidential care to adolescents.

In the earliest years of the field of adolescent medicine, the emphasis on adolescent patient confidentiality reigned supreme. In more recent years, the pendulum has swung somewhat to a recognition that assuring adolescent health-related confidentiality does not, and should not, preclude the important role that parents can play in promoting and modeling healthy behaviors, discussing routine and sensitive health matters with their adolescents, and encouraging and helping their adolescents to access preventive or specialized healthcare [4-7,15].

Likewise, there are numerous opportunities when physicians may seek to encourage an adolescent to involve a parent for emotional support or to recruit their help with a medical matter, even if that problem is not so serious as to require the physician to inform a parent. Building and maintaining a triangle of trust and responsibility between the adolescent, physician, and parent(s) will, for most families and in most situations, positively foster the health and wellbeing of the adolescent.

In 1980, our division of adolescent medicine was invited by a suburban town on Long Island, New York to establish an adolescent clinic within a community-based adolescent center. This was an unexpected invitation, since the town was predominantly middle to upper-middle class, with many physician practices. To help us better understand the situation, we were granted the opportunity to survey by anonymous questionnaire 9th—12th graders in the town’s public junior and senior high schools, to determine their unmet healthcare needs and willingness to use healthcare resources. We found that 90% of the students usually saw a private physician, 49% a pediatrician, and nearly all had a checkup within the past year. Nonetheless, four categories of unmet health needs emerged: sexuality-related, substance use, body image concerns (weight, skin), and depression. Few students said they would be willing to seek care for sexuality or substance use—related matters, and fewer than half for depression, with their parents’ knowledge [10].

This study was published in 1983 in The Journal of Pediatrics. The journal’s editor-in-chief, Dr. Joseph M. Garfunkel, added a comment preceding the article noting that this article had generated considerable discussion among the reviewers and editorial staff and that despite the problem of “data limited to a written questionnaire... the results seem of sufficient importance to warrant publication and discussion.” He noted, “Pediatricians are now being urged to assume the role of primary physician for adolescents who are older than most patients seen in the past. We may infer from this article that unless we improve our ability to communicate with these patients and to manage their medical problems, we may be ineffective in the very areas in which we have believed ourselves to be most skilled—the early recognition and prevention of threats to health.”

In 1985, we surveyed more than 100 pediatricians, mainly in private practice on Long Island (Nassau and Suffolk counties), to determine their involvement in adolescent healthcare. Very few (about 10%) saw adolescents for sexuality-related concerns, substance use, or an eating disorder and only 14% asked teens about depression. Obstacles most often cited for not participating more fully in adolescent care included a lack of time and knowledge, parents’ unwillingness to pay for longer visits, and parents’ objection to confidential care. Thirty percent expressed an interest in increasing their involvement with adolescents [5].

Now 40 years later, it is fair to wonder if perspectives and practices with respect to adolescent privacy and confidential care have progressed significantly. Although the sample size is small and skewed to include only parents who agreed to participate, and the demographic is Belgian, mainly highly educated parents, the respondents in this study accurately highlight that trust and responsibility, in all their combinations between adolescents, parents, and physicians, are essential for providing a comfort level for all involved. Since 10 parents were mothers and 10 fathers, it would be interesting to know if there were any salient differences between their responses.

Mutual trust and shared responsibility develop over time once a relationship is initiated with a healthcare provider. The challenge for healthcare providers and health delivery systems is to have the will, take the time, acquire the education and training, find the funding, and design electronic health records that will allow for those on-going relationships to begin and to flourish. Of critical importance, is to grow the adolescent health and medicine workforce to lead and to educate others. Today, more than ever, as we emerge from the most trying times of the COVID pandemic, and as the stressors accompanying social media are soaring, adolescents are begging us to pay attention.

Andrea Marks, M.D.
Department of Pediatrics
Icahn School of Medicine at Mount Sinai
New York, New York

References