Confidentiality for Mental Health Concerns in Adolescent Primary Care

by Larry Wissow, Kate Fothergill, and Jane Forman

Guidelines from several national professional groups and a patchwork of state laws support the option to provide confidential mental healthcare for adolescents as a way to reduce barriers to treatment. These guidelines do not, however, help doctors decide when and to what extent confidentiality might be appropriate. We propose a set of practical considerations that clinicians can use to develop and justify confidentiality and family involvement in individual cases. Use of this framework may increase clinician comfort in discussing confidentiality and mental health topics with adolescents, and thus reduce barriers to the management of mental health problems in adolescent primary care.

About 15 percent of U.S. youth ages nine to seventeen are thought to have an emotional or behavioral disorder (Shaffer et al. 1996). Nearly two-thirds of depressed children and adolescents receive no formal mental healthcare, and only half receive counseling or some form of assistance at school (Wu et al. 1999). Providing care for this group of young people requires several strategies, including reducing stigma and financial barriers, educating young people and their families about the benefits of seeking care, and increasing the availability of effective services in accessible settings (National Advisory Mental Health Council 2001).

One way of broadening access and reducing financial and psychological barriers involves promoting the detection, treatment, and referral of mental health problems by primary care providers. Primary care providers already provide the bulk of mental health services to adults and children in the United States (Wang, Berglund, and Kessler 2000). At the same time, however, many young people with emotional problems do not tell their primary care provider, and providers' overall rate of detection of young people's emotional problems remains low (Chang, Warner, and Weissman 1988; Epner, Levenberg, and Schoeny 1998).

Concern about confidentiality poses one of the largest barriers to adolescents' discussion of mental health problems with primary care providers. By mid-adolescence, primary care guidelines suggest that teens should have an opportunity to speak confidentially to their doctors (Green and Palfrey 2000). Assurance of confidentiality increases teens' willingness to seek care for sensitive emotional medical problems, while concerns about parental notification have an opposite effect (Cheng, Warner, and Weissman 1993; Ford et al. 1997; Ginsburg, Menapace, and Slap 1997; Klein et al. 1999; Reddy, Fleming, and Swain, 2002; Thrall et al. 2000).

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In a recent statewide survey of Massachusetts high school students, 75 percent said there were some health concerns for which they would want to seek care without their parents' knowledge, but only 28 percent said their healthcare provider had ever talked to them about confidentiality (Thrall et al. 2000).

Some teens say that their doctors do not discuss confidentiality at all, while other doctors promise unconditional confidentiality that ultimately cannot be honored (Ford and Millstein 1997). Primary care physicians differ widely in their knowledge of laws relative to confidential care, and in their beliefs about the appropriateness of treating teens without the knowledge and participation of parents (Lovett and Wald 1985; Fleming, O'Connor, and Sanders 1994; Ford and Millstein 1997; Resnick, Litman, and Blum 1992).

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Provider Guidelines

Several professional organizations have developed guidelines that underscore the duty to serve teens and respect them as knowledgeable individuals with a right to a say in their own care (ACOG 1988; American Medical Association 1992; Center for Substance Abuse Prevention 1990; Council on Scientific Affairs 1993; Gans 1993; Sigman et al. 1997). These guidelines are rooted in the development of adolescent medicine as a distinct subspecialty, and grew largely from the need to reduce barriers to teens seeking medical care (Prescott 1998).

Guidelines generally recommend that, within legal and ethical bounds, providers ought to provide confidential care to teens if they request it. Family participation is encouraged as long as it does not limit the quality of care or set up a situation in which a parent's wishes can override strongly held and well-articulated teen beliefs. Guidelines suggest that providers explain this policy to teens and parents before care begins and explain situations (such as child abuse, suicidality, or homicidality) in which confidentiality cannot be maintained. The guidelines do not, however, provide clinicians with a systematic way of assessing the appropriateness of confidentiality in any given case, or a way of documenting their decisions and plans.

We believe that providing a framework for systematic decision making is an important step in reducing barriers to the prevention and treatment of teens' mental health problems in primary care. Our hope is that having a framework will increase provider comfort, increase the frequency with which confidentiality concerns are discussed and resolved, and thereby increase the likelihood that teen mental health needs will be addressed.

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Legal Framework

Within the United States, both federal and state laws determine when minors can give their own consent for care, and when they can receive confidential care. Because these laws vary considerably by state and over time, clinicians need to know the regulations that apply in their practice areas.

Ordinarily, parental consent is required for medical treatment of minors (i.e., persons under eighteen) (Rozovsky 2002). Depending on the state and specific clinical setting, exceptions

allow minors to consent independently to care for some conditions, including sexually transmitted diseases and substance use. In about half the states, minors can give their own consent to outpatient mental health services, although the amount and type of care may be limited (English 1990; English in press).

Exceptions in some states allow certain categories of minors to give their own consent more generally. "Mature minors" are defined as adolescents who, although living at home as dependents, are thought to understand the risks, benefits, and alternatives associated with a potential medical decision (Morrissey, Hofmann, and Thrope et al. 1986). The "emancipated minor" is an individual who is legally recognized as independent of parental custody or control. Examples of minors who may be considered emancipated include those who are married, serving in the armed forces, or living apart from their parents and managing their own financial affairs. Some states have statutes establishing specific criteria for emancipation and setting out procedures for granting this status.

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Parents are also generally entitled to information about their children's care. Again, however, state and federal laws provide exceptions. Many exceptions are spelled out in state minor consent laws and in federal family planning and substance abuse treatment legislation. In Maryland, for example, minors sixteen and older can obtain mental healthcare without parental consent, but clinicians are permitted to decide whether to keep the care confidential from the minor's parents (Md. HEALTH-GENERAL Code Ann. § 20-104).

The Privacy Rule of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) gives parents new rights to control clinicians' disclosures of their children's health information to third parties, but defers to existing state laws regarding clinicians' disclosures to the parents themselves (HHS 2002).

Finally, state laws require clinicians to break confidentiality and alert authorities in certain situations, including suspected child abuse, and when an individual is thought to be at risk of harming himself or another. A study of fifty-three North Carolina high school students found that over 80 percent were aware that clinicians would break confidentiality if they perceived a risk of abuse, homicide, or suicide (Ford, Thomsen, and Compton 2001).

In sum, depending on where one is practicing, laws recognize a range of situations: in some, minors' requests for confidential mental healthcare must be honored; in others, confidentiality cannot be maintained; and in still others, clinicians may exercise their discretion. In addition to law, three major issues contribute to the assessment of these situations:

- the capacity of the adolescent to make treatment decisions (including the decision to exclude family involvement);
- the family context and potential for involvement in treatment (often based on limited information); and the
- possibility of making an accurate diagnosis and providing adequate treatment (while working with the adolescent alone without consulting his or her family).

In the following paragraphs, we will review these areas and suggest approaches to each in the context of a clinical interaction.

Adolescents' Decisional Capacity

To be seen as competent, individuals must show awareness of their current situation and choices, demonstrate their ability to think logically about their choices and communicate their decisions

(Applebaum, Lidz, and Meisel 1987). Studies suggest that when presented with hypothetical decisions about alternative medical and mental health treatments, adolescents about fifteen years-old and older appear competent; that is, they tend to make choices similar to those of young and middle-aged adults (Grisso and Vierling 1978; Weithorn and Campbell 1982).

Some legal scholars argue, however, that competency is too narrow a concept, and in particular that it does not take into account emotional and social influences on decision making that may distinguish adolescents from adults (McCabe et al. 1996; Scott and Grisso 1998; Steinberg and Cauffman 1996; Woolard, Reppucci, and Redding 1996). These potential influences include a greater reliance on the opinions of peers, a greater emphasis on short versus long-term consequences of a decision, wider swings in mood, and a decreased fund of knowledge about risk factors, illnesses, treatment options, and possible outcomes (Ponder et al. 1996; Secker, Armstrong, and Hill 1999).

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These differences do not appear, however, in all decision-making situations nor do they necessarily describe all adolescents. For example, in superficial "lifestyle" issues, teens' choices may reflect those of peers and their perception of popular culture. But teens appear to recognize when a medical or mental health issue is serious. In those cases they report a willingness to seek adult advice (Geller et al. in press; Villeneuve et al. 1996). Studies of adults and adolescents with or at risk for psychiatric conditions suggest that the majority are competent to make treatment decisions, with perhaps one tentative but notable exception. Adolescents with significant conduct problems had more trouble understanding a hypothetical person's need for treatment than did adolescents at risk for other mental health problems (Applebaum et al. 1999; Mulvey and Peeples, 1996).

Family Context and Involvement

We count on families to provide the social and emotional education necessary for healthy development (Nelson and Nelson 1995; Ross 1997; Steinfels 1982). Most families do this well, and their role evolves and continues throughout the lifespan, gaining new meaning and practical importance as family members age and new family members appear (Rolland 1994). Some family environments, however, through a variety of mechanisms, directly or indirectly contribute to young people's mental health problems (Group for the Advancement of Psychiatry 1996; Repetti, Taylor, and Seeman 2002).

In many families, for example, disclosure of an adolescent's emotional distress may engender anger and disorganization rather than support. This outcome may occur particularly in families in which a parent has an untreated problem with alcohol abuse. Some parents have strong religious or cultural beliefs that limit treatment choices open to their children (Holder 1983), while others may block a child's help-seeking for fear of disclosing sensitive family information. Families in which parents have untreated or partially treated mental health problems actually may be less, rather than more, willing to seek treatment should their children show signs of distress (Flisher et al. 1997).

Resources and Information

We also count on families to provide most of the concrete resources their members require and to serve as the gateway through which children access healthcare and other important services. Teens' treatment options may be limited when families are not involved. Teens may have no independent means of paying for medical visits, laboratory tests, medications, or transportation.

In optimal treatment of both adults and children, families often provide support, monitor progress, or play an active role in medication adherence or cognitive therapies (Birmaher, Brent, and the Workgroup on Quality Issues 1998). In other chronic illnesses, such as diabetes, collaboration between teens and parents produces better outcomes than simply asking teens to take on management responsibilities alone (Anderson et al. 1999).

Family members also contribute to the formation of an accurate diagnosis. Parents and children frequently provide different ratings when asked to report on children's behavior, emotional health, and experiences (Costello 1989; Fisher 1992; MacLeod et al. 1999; Yeh and Weisz 2001). As a rule, parents are more likely than children to report behavior problems, and to consider them more severe. On the other hand, parents tend to underestimate the frequency and severity of low mood and anxiety and the extent to which children have been exposed to traumatic events (Richters and Martinez 1993). Discrepancies tend to be greater among families referred for mental health problems than among community samples (MacLeod et al. 1999).

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Ethical Considerations

Existing clinical guidelines are based largely on the consequentialist concern that lack of confidentiality poses a barrier to care and on respect for adolescents as persons. These positions view families as potential sources of risk to the adolescent who has his or her own opinions, decision-making capacity, and developmental needs. While, in some cases, families may indeed pose a threat to adolescents' well-being, this view, when applied across the board, does not adequately focus either the special factors that should be considered when assessing adolescent decision-making capacity or the special moral significance that families have for their members and society.

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Family members are bound together by relationships that have a heavier moral weight than relationships with outsiders. Interests of a person in a family include the good (well-being) of other family members and the functioning of the family as an intimate group. An approach to confidentiality that focuses solely on adolescents as rights-bearers, morally unmoored from their family, misses this realm of ethical considerations.

Our framework rests on the notion of family integrity as a good, but it also recognizes that situations exist in which breaches of confidentiality can pose a danger to the adolescent or a barrier to care. Respecting an adolescent as a person includes seeking to build a partnership with him or her about when and what to disclose to family members. Family relationships matter emotionally, developmentally, practically, and morally. We propose an approach based on moral discernment, in which the clinician attends to the morally relevant factors in each particular context, and makes judgments that respond to the needs of the adolescent patient and his or her family. We start by recognizing that an adolescent's perceived need

for confidential care is accurate and legitimate. Our duty to the adolescent, however, goes beyond a developmentally appropriate recognition of his or her need for autonomy. Our duty extends to the recognition and examination of the patient's role as a member of a family.

An Assessment Framework

Although the ethical, legal, and developmental issues surrounding adolescents' confidential care are many and complex, we propose that primary care clinicians assess and act on them by addressing four main topics: legal and procedural questions; the family context; informational and practical issues related to treatment; and capacity. All such topics may not be addressed at a single visit, but elaborating answers to them over time should establish the justification for working with the young person alone or with one or more family members. Each major topic is accompanied by an example of questions a clinician might ask and ways to document the information.

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We presume that in most jurisdictions there is a legal basis for clinicians to provide some forms of confidential outpatient mental healthcare for minors, based on the minor's unilateral request; and a range of situations in which a clinician would be allowed (or required) to disclose information to parents. We also presume that parents and minors, after joint or separate discussions with their clinicians, may agree to a range of parental involvement in, or knowledge of, the minor's treatment. To maintain individual privacy and family integrity, and to provide effective care, clinicians may need to make separate confidentiality-related decisions before disclosing (a) that treatment is occurring, (b) the nature of the treatment, or (c) information disclosed by the teen in the course of treatment.

Using the Assessment Tool

Topic 1: Prior discussions and understanding regarding confidentiality

Although teens may be aware that some things cannot be treated confidentially, they (and their families) may not know what topics can be discussed confidentially under local law, or even that the clinician is willing to work within this framework (Ford, Thomsen, and Compton 2001). In cases in which the clinician has had a long-term relationship with the family (particularly if the relationship began prior to the patient's adolescence), it may be necessary to revisit past understandings and state explicitly that different rules now apply to the clinician's discussions with parents. Such discussion will preserve the clinician's relationship with the parents and allow a relationship with the teen to evolve. Consider, for example, the following questions:

- Have you discussed confidentiality or adolescent decision-making with the adolescent and/or family? In particular, have you discussed the limits of confidentiality (abuse, homicidal or suicidal thoughts)? What do the adolescent and his or her family understand about their confidentiality options? Is the family familiar with adolescent medical procedures or the medical system in general?
- Did you have a prior relationship with the adolescent's parent or parents, or is your only contact that between you and the teen?

Chart note/Clinical reasoning. X is a sixteen-year-old boy whom I have followed for the past five years for general medical care. Since the beginning of our relationship, I have conducted at least part of each visit with him alone. Until today, I had not had an explicit conversation with him or his family about confidentiality. At today's visit, his mother

said that he had been keeping more to himself. A teacher had called her to say that X had been acting differently. Mother asked that I talk to X to see if he might reveal any problems he might be having. I talked with mother and X about confidentiality issues: I told them that except for abuse, suicidality, and homicidality, I would respect X's wishes to keep things between us.

Topic 2: Family context

Here we start from the position that confidentiality for teens can be appropriate and even necessary, but that family relationships are also important on many levels. The questions in this section are designed to help clinicians discern the initial balance of these two considerations, and to assess the potential for adjusting the balance as treatment progresses.

- Based on the adolescent's report or prior knowledge, can you develop a picture of the family regarding key areas of family functioning that are important to supporting adolescent development (Group for the Advancement of Psychiatry 1996)? For example: warmth and empathy versus negativity and nonsupport? Ability to handle crises and loss? Cohesive, flexible, and resilient versus chaotic and conflicted in situations of stress? Ability to balance closeness with respect for privacy, separateness?

- Do you have reasons that would justify excluding the family? Has the adolescent suggested that involving the family would put him or her at some form of risk? Have the family and adolescent already expressed strong disagreement over a set of clinically reasonable treatment options favored by the adolescent? Is this a situation in which care must be offered urgently and attempts to contact family members have not been successful or are not feasible?

Chart note/clinical reasoning for topic 2. When I saw X alone, he told me that he was worried because his father had recently resumed drinking heavily and had been aggressive toward his mother. He was concerned that approaching his mother might lead to her refusal to let him speak further to me, since both the drinking and the domestic violence were kept secret (indeed, they had not come up in prior visits). He denied having been threatened or feeling physically at risk himself; he said he was angry with his father but had no intention to physically retaliate. He said there were times he felt hopeless and even guilty about the situation, but that he had not felt suicidal.

Based on what X told me about past incidents and his father's drinking, I thought it reasonable to be careful about involving the family. I think there is reason to be concerned for both violence and difficulty with X getting care. X agreed, though, that his mother likely suspected that he was divulging information about the family, and that leaving this suspicion in the air might make matters worse.

Although teens may be aware that some things cannot be treated confidentially, they and their families may not know what topics can be discussed confidentially.

We agreed that if mother called and asked me directly if X had discussed the drinking or domestic violence that it would be hard for me not to tell her the truth. At the end of the visit, I spoke to mother and told her that X had revealed some concerns that he wanted to keep between us, and that X and I agreed that this was a reasonable position. I told her that I would keep her informed in general terms, and that I hoped she would feel free to call me with any new concerns or questions.

Topic 3: Resources and information

Except for some school-based health services, most adolescents in the United States face substantial financial and logistical barriers to obtaining medical care without their family's collaboration. Clini-

cians and teens need to weigh together whether adequate care can be provided confidentially, and, if not, what other avenues might be open. Similarly, clinicians need to ask themselves whether they feel that information from the minor alone (or from the minor plus nonfamily sources) is sufficient to develop an accurate diagnosis and corresponding treatment plan. For example:

- Has the adolescent stated directly that involving the family would preclude his or her accepting any treatment?
- Can the diagnosis be formulated given the available information? In what ways might the diagnosis or initial treatment plan differ if other information were available?
- Can effective treatment be offered within the financial or other logistical limitations imposed by confidentiality or adolescent autonomy?
- Is there reason to be concerned that *not* involving the family may have negative consequences for the adolescent (for example, no opportunity for continuity of care, or an adolescent with a condition that could rapidly deteriorate)? Will the adolescent consider the condition that the clinician can unilaterally break confidentiality in certain circumstances beyond the usual exceptions (e.g., should the adolescent drop out of care at a time when he or she appears to be significantly distressed)?
- If the family is already involved to some extent (e.g., by having brought the adolescent for care but not being privy to particular disclosures or treatment decisions), can the adolescent and clinician agree about what the family can honestly be told, and how the family can be kept abreast of progress in a way that maintains their support for the treatment but protects the adolescent's request for confidentiality/autonomy? If the family is not now involved, can the adolescent and clinician agree on how the clinician should respond to questions that the family might ask?

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Chart note/clinical reasoning for topic 3. Though X had initially asked that we not involve his mother, I thought it important to propose a discussion with her. First, I was concerned that it was difficult to understand the severity of the situation without hearing directly from her. Second, our treatment options were overly limited without family collaboration; only limited help was available at school, and there didn't seem to be a way X could access mental healthcare or community support groups on a regular basis without his mother's help or knowledge.

I went over these things with X and he seemed to understand them. He said that he felt better having talked with me and asked if we could continue this way briefly while he thought about the options. I agreed that this was reasonable for the short term as long as he was not feeling in danger and his school work was stable. I got permission from him and his mother to contact his advisor at school to get a report on his functioning there. We agreed that I would say only that I was X's family doctor and that he had come to me for some concerns about mood.

Topic 4: Decisional capacity

Clinicians have a responsibility to create a setting in which an adolescent has an opportunity to make thoughtful decisions. Although the law gives clinicians more leeway with minors than with adults, clinicians always have a responsibility to understand that their patients have the ability to engage alone in decision making. In the case of potentially confidential mental healthcare, a particular issue is whether the teen is able to thoughtfully discuss the

pros and cons of not involving the family. The level of "capacity" required is proportional to the risks involved; some risks relate to the teen's condition, others to concerns about the family's response.

- Has a good decision-making environment been established in the clinical setting (provision of information in an age-appropriate manner, sufficient time to make a decision, lack of interruptions, opportunities to ask questions, availability of supportive individuals)?
- Is there any a priori reason for feeling that this teen may have diminished capacity to discuss clinical decisions (e.g, is he or she intoxicated, in a state of crisis, or seem focused entirely on the present as opposed to longer term consequences; or does he or she have serious cognitive or language issues, involvement in criminal or antisocial behavior)? Is this a situation (suicidality, homicidality) in which the involvement of others is mandatory?
- Does the teen seem to be meeting basic competency criteria (e.g., does he or she seem to understand the nature of the situation, and can he or she process information and/or articulate an opinion)? For example, can he or she express in a clear and balanced way his or her reasoning about the involvement of other family members? Or can the teen be engaged in a discussion of the practical pros and cons of seeking care within versus outside the context of the family?
- Does the teen appear to be reasoning based on his or her own beliefs, as opposed to being overly influenced by negative or harmful opinions held by others?

Confidentiality is an unavoidable issue for primary care providers who want to increase the extent to which they help adolescents with mental health problems.

Chart note/clinical reasoning for topic 4. I saw X today in a follow-up visit. His mother had agreed to allow him to return "to talk more about what had been on his mind before." We talked more about X's feelings of anger and guilt toward his parents, and about approaches to adult alcoholism and domestic violence. We went over options for ongoing support and treatment for his mood, and possibilities for approaching his mother and father with his concerns. He felt his mother might ultimately be receptive, but feared approaching his father would lead to violence toward himself or his mother.

X asked reasonable questions and seemed to understand the options for himself and his family, and the difficulties we faced finding him ongoing support without his mother's knowledge. I think he was also able to understand that this was a difficult situation for me, because I had known his family for several years and felt an obligation to communicate and help.

Conclusion

Adolescents clearly value confidentiality and consider it strongly in their decisions to seek care for sensitive issues, including those related to mental health. Confidentiality is thus an unavoidable issue for primary care providers who want to increase the extent to which they help adolescents with mental health problems. Although there are many complicated legal, ethical, and clinical issues surrounding confidentiality, we believe that providers can use a structured approach to think about these issues and document their thinking. The process we propose will lead to greater provider comfort with mental health issues, and subsequently more disclosure and discussion of mental health problems on the part of teens.

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