Ethical Concerns Associated with Childhood Depression

by Eve-Lynn Nelson

Children always merit special ethical concern in mental health research and treatment. But children with depression are a particularly vulnerable population because of developmental considerations and the severity of the illness. This article reviews ethical concerns regarding assessment of depression, clinical care, and research with children.

Until recently, children were not supposed to become depressed. The recognition that depression can begin in childhood opens the door to advances in clinical care for the one in forty children and one in twelve adolescents affected by mood disorders (Roberts, Attkisson, and Rosenblatt 1998). Children with depression face the same affective, cognitive, and behavioral symptoms as adults with depression (see Table 1, page 24). Suicide, a frequent complication of this disabling illness, is the third leading cause of death in young people between the ages of ten to twenty-four (National Institute of Mental Health 1999).

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Childhood depression has high developmental costs. It interferes with making friends, passing classes, and enjoying family. It also sets children up for a lifetime of affective illness; as many as 70 percent of depressed children have a recurring episode within five years.

In addition, risks associated with childhood depression include substance abuse, smoking, physical illness, early pregnancy, exposure to negative life events, and poor academic functioning/dropout (AACAP 1998; Lewinsohn, Rohde, and Seeley 1998). Long-term consequences include more severe physical and mental illness and impaired functioning in adult life (Fombonne et al. 2001a, 2001b).

Assessing Childhood Depression

Popular authors question the over-diagnosis of psychiatric disorders in youth. But well- controlled research suggests that childhood depression is significantly underdiagnosed and undertreated. For example, Wu et al. (2001) found that within a community sample, only one-third of the children with depression received professional assistance. Barriers to care include poor identification of depressive symptoms, insurance difficulties, stigma around mental illness, and provider shortages. In addition, few screening measures take into account the

Table 1.— Signs of Childhood Depression

AFFECTIVE

- reports sadness
- appears irritable
- reports guilt

COGNITIVE

- poor concentration
- poor memory
- talks about death

PHYSICAL

- change in sleep
- change in appetite
- weight gain or loss
- suicide attempts or talks about self harm

ACADEMIC

- little interest in school
- gives up easily
- drop in grades
- few friends or no best friend

influence of culture in the experience and expression of depressive symptoms, which raises ethical concerns about respecting human dignity.

Childhood depression is generally assessed in two ways. Children are screened by a general paper-and-pencil measure that compares their self-report of symptoms with that of same-age peers. If the child responds with more depressive answers than the average peer, he or she completes a more intensive evaluation. But who among children should be screened and in what settings (see Grimes and Schulz 2002)? For example, schools often wish to identify students in need of services, but schoolwide screening raises ethical concerns, including questions about protecting the student's privacy, providing access to care, and allowing for autonomous informed consent. In schoolwide screenings, sensitive screening questions, such as items about suicidal ideation, are often removed from questionnaires. This omission protects the family's right to privacy and decreases the school's liability risk, but it can also fail to identify children most in need of care.

Following screening, the issues are justice and a fair allocation of resources for thorough evaluation and treatment. Ideally, the identified child and caregiver will complete an extensive clinical interview and other assessment measures. This interview is important because many conditions mimic depression and should be ruled out, including physical conditions, reactions to medications, and adjustment/grief reactions.

The clinician may also identify comorbid psychiatric conditions in up to 90 percent of children with depression. But this follow-up evaluation is time intensive and expensive, and is sometimes not covered by insurance. In addition, we have a shortage of trained mental health professionals to complete the evaluation and an even greater shortage of professionals to provide timely treatment.

Genetic screening for depressive predisposition is also on the horizon (Merikangas 1993). Depression is a multifactorial illness with both biological and environmental contributors and thus genetic screening will have limited predictive power. Genetic screening raises many questions: who will have access to the information and how does early identification affect the child psychologically, socially, and financially (Nelson et al. 2000; Ross and Moon 2000)?

Treating Childhood Depression

There is no definitive course of treatment for children with depression. Each treatment option, therefore, has ethical implications for both providers and families. Providers must balance the principles of beneficence and nonmaleficence for the patient. Parents must be allowed autonomy

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in selecting the best treatment course for their child.

In making their treatment recommendations, clinicians seek to maximize positive effects in accord with the principle of beneficence while at the same time minimizing harm. One approach to this decision-making process is evidence-based medicine, or basing decisions on the best available research findings. Although evidence-based medicine also entails ethical concerns (see Kerridge, Lowe, and Henry 1998), it gives clinicians good information concerning treatment efficacy (or lack of efficacy) for a given population. There are two common treatment approaches for childhood depression—psychopharmacology and psychotherapy.

Psychopharmacology

Prescribing medications for children with depression is not a value-free enterprise. The providers' motivation is beneficence and relief of suffering, but the standard prescription practices are often not evidence-based. The problem is balance. Effective medications are needed to counteract the prevalence and severity of childhood depression. Following the success of antidepressants in treating adult depression, the use of antidepressant medications by children increased from 0.3/100 in 1987 to 1.0/100 in 1996 (Olfson et al. 2002). In addition, review articles and practice parameters often advocate the use of antidepressants in this age group (Hughes et al. 1999).

On the other hand, however, there is little well-controlled research supporting the use of antidepressants among children. The most commonly prescribed medications for childhood depression are selective serotonin reuptake inhibitors (SSRIs), but only two published randomized-controlled trials have addressed the efficacy of SSRIs in treating childhood depression (Michael and Crowley 2002). Despite their widespread prescription, the Food and Drug Administration (FDA) has not approved any psychopharmacological medication for the treatment of childhood depression.

Innovative drug treatments such as these are geared to help individual patients but they are not free of ethical concerns (Vitiello and Jensen 1997). Because the findings are not research based, the evaluation of the medication lacks Institutional Review Board (IRB) oversight and there is less consistent monitoring of untoward side effects.

In addition, the parent's and child's autonomy may be compromised because the risks and benefits are not known and cannot be fully expressed in the informed consent process (Fost 2001). The parent must rely on the individual clinician's experience and opinion, rather than collective research data.

Psychotherapy

A second common treatment course is psychotherapy, especiallly the use of cognitive behavior therapy (CBT). CBT is defined as "interventions that seek to promote emotional and behavioral change by teaching children to change thoughts and thought processes in an overt, active, and problem-oriented manner" (Reinecke, Ryan, and Du Bois 1998; p. 26). Treatments include generating more adaptive beliefs, practicing positive attributions, monitoring and increasing self-reward, practicing problem solving, learning social skills, and following relaxation procedures (Asarnow et al. 2001).

The goal of therapy is to encourage change in beliefs and actions that will decrease depressive symptoms. By encouraging change, therapy by its nature may limit the autonomy of the child. This risk must be balanced against the child's not being competent to make informed choices about healthy and unhealthy behavior. In addition, therapy often requires active participation by parents and other family members and thus, the autonomy and well-being of different family members may be in conflict.

Cognitive behavioral therapy for childhood depression fits the goals of evidence-based medicine. Four separate meta-analyses have found moderate to strong effect sizes for CBT (Michael and Crowley 2002), suggesting that the treatment is superior to a placebo in treating childhood depression. In addition, such interventions carry minimal side effects and assist in treating comorbid psychiatric conditions. Thus, clinicians may outline the risks and benefits of such treatment in the informed consent process.

From a bioethical perspective, the parent and the child should have autonomy in selecting the best treatment course to address the illness. But the amount of information sought by the family and provided to the family in reaching this decision varies. Parents must sift through the treatment options discussed here and alternative treatments. Even after parents choose a treatment, they may have to wait weeks or months to get an appointment or they may find that their insurance has limited child mental health benefits. Little information exists about how medication treatment directly compares with psychotherapy in treating childhood depression or how the two treatment modalities may be best used together.

Special risks

Suicide is a very real risk in childhood depression and any threat should be taken seriously. The threat of suicide may require caregivers and clinicians to decrease the child's autonomy to insure safety. As part of one's consent to treatment, the clinician will disclose the fact that threatening self-harm is a limit to confidentiality. If a child discloses suicidal thoughts, the clinician will assess the child's level of intent, his or her plan, the plan's lethality, and access to means. A safety plan will be agreed on with the family and hospitalization will be considered.

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Intervention is more complicated if the clinician assesses the child as being at high risk, but the parent or child refuses treatment or hospitalization. The clinician holds the protection of the child as paramount and must reach a solution with the family, even if it overrides the parent's or child's autonomy. The state's interest in the well-being of the child may at times outweigh the guardian's authority (see Melton and Ehrenreich 1992).

Researching Childhood Depression

Given the ethical dilemmas associated with research with children, one may ask why we do not simply extrapolate clinical data from adult populations. The reason is that children are not little adults; the course of depression and its symptoms profile vary in this age group (Rowell and Zlotkin 1997). Arnold et al. (1995) describe an "ethical imperative to conduct, or at least support, research" (p. 929), because not to complete research means a different set of risks: either we have no therapeutic options or untested treatments. But untreated childhood depression carries short-term and long-term disability. Interventions implemented without research support may fail to relieve symptoms and may have unforeseen side effects.

For example, some of the first medications for childhood depression were tricyclic antidepressants. These medications were prescribed for over a decade before well-designed, prospective studies and meta-analyses (Hazell et al. 1995; Birmaher 1998) established that they are not significantly better than placebo in treating childhood depression.

This class of antidepressants also carries the risk of cardiac side effects, high toxicity in overdose, and reports of sudden death. This experience

underscores the need for well-controlled research *before* widespread implementation of pharmacological and psychotherapy interventions with children.

Research guidelines

Intervention research for childhood depression generally falls under Category 2 of federal guidelines for Institutional Review Boards:

> Research involving greater than minimal risk, but presenting the prospect of direct benefit to an individual subject. Research in this category is approvable provided: (a) the risk is justified by the anticipated benefit to the subject; and (b) the relationship of risk to benefit is at least as favorable as any available alternative approach [45 CFR 46.405].

Studies of childhood depression must meet other minimal requirements, including increasing our understanding and having a scientifically sound design. Throughout the consent/assent process, research participants must be fully informed of the essential aspects of the study including design, risk analysis, and possible alternatives.

Consent/assent

The purpose of consent (the parent's) and assent (the child's) is to respect the child's and parent's autonomy in choosing to participate in research. The risks and benefits must be clearly outlined for parents and children. The intent of the consent/assent process is to build on the natural protections provided by parents. But parents are often confused by the amount and complexity of information presented in the consent. Studies suggest that parents often do not understand their rights such as the ability to withdraw from a study at any point (Broome 1999).

The concept of developmentally appropriate assent applies to children with depression. The question becomes not "whether one has autonomy, but rather how much autonomy" at different ages (Arnold et al 1995). Ethical assent with children must be requested in age-appropriate language (written and verbal). It must be conveyed by a neutral clinician to help minimize undue influence, and the child should be encouraged to ask questions.

Based on the child's cognitive development, the investigator describes information about the illness, its treatment, and the basic study procedures such as randomization. The child's social development also affects the consent process, with younger children struggling with the concept of voluntariness. Depression may influence consent to participate. For example, information may need to be repeated several times since depressed persons often have poor concentration.

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There is no consensus among IRBs about when a child is capable of giving assent. Children over twelve years of age typically possess the decision-making capabilities required for an informed and voluntary decision. Children under twelve tend to have difficulty synthesizing the risks/benefits described in the assent and are more trusting of investigators. However, school-age children appear able to express a preference about research participation.

It should be noted that strict age guidelines are not as helpful as a consideration of the child's developmental stage. In general, "situations involving induced anxiety, stress, fear of failure, lowered self-esteem, intrusions of privacy, guilt, embarrassment, or compromised trust present greater risks to children than to adults" (Conrad and Horner 1997; p. 166). Childhood depression

researchers work to limit these risks, particularly because of the depressed child's heightened vulnerability.

Risks/benefits

The risks and benefits presented in the informed consent do not come neatly packaged. Determining what constitutes "risk" and "benefit" depends on a forthright investigator and careful consideration by the IRB. It is crucial to have a diverse board including scientists, community members, child specialists, and parents. This balance provides the strongest protection for children.

The direct benefit of participation in treatment studies is the potential remediation of depressive symptoms. Other benefits include subsidized care, better monitoring of treatment, the possibility of open-label trials following the trial, expert diagnostic assessment, a multidisciplinary treatment team, and the satisfaction of contributing to science (Fost 2001).

Financial inducements for research participation may be a benefit. Many people disagree, however, about how to determine appropriate compensation without unduly compromising voluntariness, particularly when both the child and parent must consent (Grady 2001). Arguments in favor of inducements include fairness across socioeconomic status and recognition of the contributions made by the family.

The concern is that poorer families may take greater risks based on the inducement and thus, choice is compromised. Children are more easily influenced by monetary and nonmonetary rewards than adults, and researchers must be creative in compensating participation without compromising autonomy.

Barriers to Research

Despite the ethical imperative to complete research, there are many challenges to investigations with children. One challenge is the expense of conducting trials with enough participants at each developmental stage to answer the research question definitively. Researchers must take extra precautions to safeguard children, such as frequent monitoring of symptoms, but such safeguards require additional resources and involve other ethical concerns, such as the neutrality of research that is funded by private industry.

A second barrier is recruitment. Past abuses in research, some involving children, have made parents cautious about enrolling children. In addition, rural and other underserved communities do not have access to research protocols. Researchers often look to multicenter trials to increase the diversity and generalizability of results, but these trials are costly and logistically difficult. Technological advances may help increase the number of participants across multiple sites.

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Ideally the roles are separated but if this is not possible, the roles of each investigator should be outlined for the IRB and the family.

Conclusion

Three decades ago childhood depression was not recognized as an illness. The last thirty years have resulted in many advances in childhood depression's assessment and treatment. These advances have also increased our responsibility to protect the patient's autonomy and dignity and to find treatments that maximize benefit and minimize harm.

Evidence-based medicine can significantly inform the clinician's and family's decision-making process about treatment. Participation in research also raises ethical concerns and needs safeguards for the family. Future treatment research will likely include multidisciplinary collaboration to address the high morbidity associated with childhood depression.

Researchers and clinicians must also address how families may have access to treatment advances in an equitable manner. Meeting these challenges will advance the goal of making untreated depression a rarity in childhood.

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