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Ethical Times

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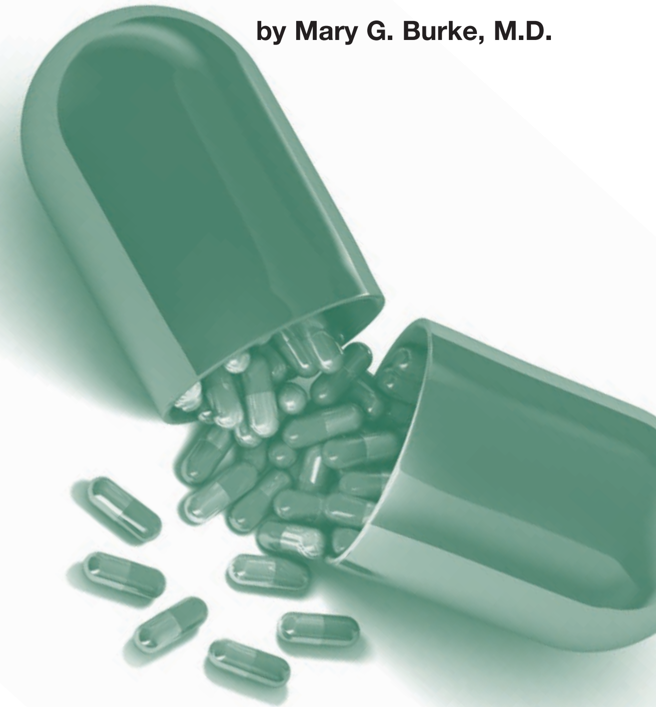
Beyond Medicine.

Pills for the Problem Child?

by Mary G. Burke, M.D.

12 year old Aiden is brought to a psychiatrist by his depressed mother. Aiden is throwing tantrums, has difficulty sleeping at night, is intensely moody, and his mother thinks he has bipolar disorder based on a popular book she has been reading. 15 year old Benita is living in a foster home. Despite her early trauma of loss of her family, she has been living successfully with her foster family for seven years, but now is having trouble sleeping at night. She feels like her mind is racing, and she is telling her school friends that she will be moving in with a boy friend who is a millionaire. Her friends know there is no such person. 10 year old Carlos is living with his elderly grandmother and his father, an alcoholic who is verbally abusive to him. He has angry, out of control outbursts where he runs around his house, threatening to kill his father, then locking himself in his bedroom for days at a time. He tells his teacher he doesn't need to do his stupid homework because when he grows up he is going to be the richest guy in the world. 13 year old Dimitra was exposed to drugs in the womb, and lived with her addicted mother until the age of three, where she was exposed to prostitution, neglect, drug use, and may have been sexually abused herself. She has lived in five different homes, and was physically abused in two of them. She currently lives in residential placement and has no family members who are in contact with her. She displays frequent suicidal ideation, cuts herself on her arms daily, explodes aggressively after minor setbacks, is sexually provocative and often has trouble sleeping at night.

PROBLEM CHILD, CONTINUED ON PAGE 4



Ethics and Quality Colloquium

The Program sponsored a two day colloquium on the relationship between ethics and quality improvement in health care. These two topics are certainly essential to good medical care but are rarely linked. While it is possible to count incidents of failure to provide appropriate care, it is very difficult to put numbers on ethical achievements or failures. On January 24-25, eight leading scholars from bioethics and from health policy gathered at CPMC to discuss this question and recommend how ethical care can be included in the ways in which the quality of health care is evaluated. The group is exploring further activities in this arena.

The Ethicist Is

…Organ Transplants for Jehovah's Witnesses?

by Katrina A. Bramstedt, PhD

Today's ethicist is Katrina A. Bramstedt, PhD

Organ transplantation is a very complex technology that becomes even more complex in the setting of patients who refuse to accept blood transfusions. The starting point for discussion of this topic is the concept of religious values as "special values". Various religious traditions espouse values or practices that seem unusual or even illogical. As a special value, patients' religious beliefs (in general) are to be respected by the health care team as long as these values don't result in providing harmful or non-beneficial treatments to them.

Jehovah's Witnesses, as part of their religious tradition, do not accept blood transfusions and neither do they donate their own blood in advance for use in their own surgeries. Many surgeons have developed protocols that minimize blood loss such that many surgeries can be safely done with a low risk of extensive blood loss. Also, there are various types of medical equipment that can be used during surgery to facilitate return of the patient's own blood to him/her (in a manner not conflicting with church doctrine) during the operation. While this would seem to make organ transplant a clinical option for Jehovah's Witnesses, ethically, organ transplant in the setting of "bloodless surgery" is still inappropriate. Here's why…

Currently, there are nearly 100,000 people in the USA who need an organ transplant. In the first seven months of 2007, only 16,757 transplants were performed. These data reflect both organs obtained from deceased donors and live donors, thus showing there is an extreme shortage of donor organs available for transplantation. A scarce resource, donor organs are precious gifts that must be allocated in the fairest way possible, to patients with the capacity to benefit from them. To this end, organ transplantation is not a one time surgery but rather a lifelong event requiring a patient-medical team therapeutic alliance. A break in the chain such as medication non-compliance or alcohol relapse (in the case of liver transplantation, for example) could result in loss of the organ and need for re-transplantation or patient death.

Jehovah's Witnesses, as part of their religious tradition, do not accept blood transfusions . . .

Refusing a clinically needed blood transfusion at any point during the transplant process could result in preventable donor organ failure. When transplant is viewed as a surgery only, the prospect of doing "bloodless surgery" so that the patient can receive an organ transplant is seen as very doable. In fact, several hospitals around the world actively promote their bloodless surgery transplant programs.

Expanding the view of transplant surgery to a lifelong event changes things significantly, such that one now sees the possibility of future preventable organ loss. For example, patients who may not need a blood transfusion during surgery might need one (or more) after surgery. Such post-surgery transfusions might be needed as soon as a few hours after surgery (due to a complication) or months or years after surgery (for example, due to a traumatic injury such as a car accident). In this situations, when the transplant recipient refuses blood transfusion the survival of the donated organ is at risk of preventable loss. Further, a loss of this nature disrespects the gift given by the donor (and their family) and is a form of poor stewardship by the patient.

Having said this, it is ethically permissible to proclaim certain technologies as inappropriate for certain patients. Just as livers are not allocated to patients who are currently drinking alcohol, and lungs are not allocated to patients who currently smoke, no organ should be allocated to an individual who professes values or behaviors that jeopardize the survival of the donor organ. Clearly, refusal of blood transfusion, even though a "special value", jeopardizes the success of

ETHICIST, CONTINUED ON PAGE 3

ETHICIST, CONTINUED FROM PAGE 2

organ transplantation, and thus it is appropriate to view this value as an exclusion criterion for transplant.

Does this mean there are no options for Jehovah's Witness patients who need an organ transplant? No, there are two options that are ethically permissible and both are based on the same principle, namely, shared values. In the setting of two people who share the same value (refusal of blood transfusions) there is the same set of expectations between the parties. Both parties understand and accept that blood transfusion will not occur and both understand and accept the outcome (donor organ failure). (This is not the same situation as described above when there is the expectation that organ recipients will do everything in their power to take care of their body so that the donor organs will survive).

Another option is for Jehovah's Witnesses to sign transfusion contracts in which they commit to receiving blood transfusions when clinically needed (during and after surgery). These transfusion contracts are ethically and functionally similar to behavior contracts routinely used in transplantation, requiring patients to abstain from alcohol and drugs, or to maintain proper weight and eat a low sodium diet. The main problem with such contracts is that they are not legal documents and thus are very difficult to enforce. In the case of transfusion contracts, a patient can revoke their consent for transfusion at any time. Further, physicians should not force a patient to be transfused against their wishes as this is unethical and a form a battery (for which doctors can be held liable in the legal arena).

Transplantation is an amazing life saving technology but it is not clinically or ethically suitable for all patients. Organ recipients must be good stewards of the gift given to them by their donor and this can only be accomplished if recipients embrace the therapies and behaviors needed to ensure transplant success.

. . . and neither do they donate their own blood in advance for use in their own surgeries.

On the Calendar

Education:

Upcoming lectures include two Noon Conferences for residents of CPMC; February 21, 2007 & April 17, 2007. At our April conference, Dr. September Williams of Laguna Honda Hospital will be guest speaker, discussing the different values brought to medical care by patients from diverse cultures.

Summer Workshop – 2008:

Our two day educational seminar for hospital ethics committees will be June 13 & 14. The primary topic will be the clinician's competence in determining whether some patients have impaired ability to make decisions in their own behalf. Please contact us for more information.

These four fictional children present the range of symptoms commonly, and often incorrectly, ascribed to Pediatric Bipolar Disorder (PBD). Adult Bipolar Affective Disorder (or Manic Depression) is a well understood psychiatric illness, which exists in about 1% of the adult population, world-wide. Medication treatment, including Lithium, anti-convulsants, and antipsychotics, are all part of standard care. But controversy has dogged the concept of PBD since it appeared in the literature, where diagnosis is usually made by use of a checklist of symptoms. Critics have consistently pointed out that the symptom checklist is too broad, covering normal childhood distress and symptoms typical of other illnesses. Further, proponents' claims that bipolar disorder exists in up to 13% of the childhood population seem absurd, given that it exists in only about 1-2% of the adult population.

Further adding to the controversy is that the rise in diagnosis has been followed by increased use of medications whose effectiveness, other than sedation, is not always clear. The use of psychiatric drugs for children, including antipsychotics and anticonvulsants, has more than tripled in the last decade. All carry significant side effects: from weight gain and diabetes, to blood and liver abnormalities, to life-threatening rashes, among many others. The long term effects on mental development for almost all of these medications are also unknown. It must also be noted that many of the major researchers on PBAD have extensive financial ties to pharmaceutical companies.

In contrast, another group of senior researchers has demonstrated that children with "atypical" bipolar illness do not, in fact, have an illness continuous with the adult illness of manic depression. Children who have suffered early neglect and abuse, or even milder disturbance of key attachments will predictably lack a coherent sense of self, empathy and self-soothing. These children are horribly anxious, leading to impulsiveness, explosiveness and in cases of abuse, dissociation which looks psychotic. In addition, children with attention deficit disorder (ADHD) and severe oppositional behavior, may present with grandiosity, impulsivity and excessive energy which resemble "PBD".

Perhaps the toughest dilemma for child psychiatrists is whether it is ethically appropriate to reduce a child's symptoms of distress, in order to compensate for the deficiencies of the environment. I believe the best response to this subtle dilemma is through an ethical approach that begins with "Mutualism." Mutualism, described by Thomas Murray in *The Worth of a Child*, states that parents flourish by fully understanding and accepting their children, and acting in the child's best interest. It is this mutual relationship that should be the first area of focus when a child is brought for psychiatric help. Mutualism or its clinical corollary, healthy attachment, is also the foundation for successful development, regardless of underlying disease.

The second, important difficulty is accurate diagnosis. In the above cases, only Benita presents symptoms that are persuasively manic. The others present with non-specific symptoms that, in conditions of significant adversity and stress, require much closer evaluation. Unfortunately, the drastic financial changes in health care over the last twenty years do not allow psychiatrists the kind of long-term contact with children and families that allow them to intervene effectively in these situations.

In fact, the increase in medications in children has been accompanied by a reduction in many children's services, including drastic cuts in hospital and residential beds for children in crisis. It could easily be argued that all of these children would benefit from a medication to reduce the danger of their behavior. But all would benefit from other interventions as well, without the danger of adverse effects. Aiden and his mother need family therapy to help them establish understanding and open communication, and he might benefit from Cognitive Behavioral Therapy. Carlos needs to be in a home where he is safe from verbal abuse, and where he has companions who keep him busy and safe after school. Dimitra will need long-term, intensive psychotherapy and diligent efforts to find her a significant adult she can relate to. Medications cannot fill this gap.

(Dr. Burke is the Associate Medical Director at Edgewood Center for Children & Families)

Happenings

Andereck Traveling:

Dr. Andereck enjoys taking the discussion of ethics on the road. After a summer that included taking the Program's work to a week-long conference in Cambridge, England,, the fall season allowed him to work with our colleagues closer to home. He led a Grand Rounds for the Medicine Department at our facility titled, *"An Analysis of Clinical Ethics Consultation Service at CPMC: A 22 year perspective."* This provided a complete analysis of the near 350 consultations that our Program has handled. One month later, a lecture that discussed the difficulties of a physician being overmatched by the patients' disease was given at Seton Medical Center.

Jonsen Lecturing:

Even though semi-retired, Dr. Jonsen takes great pleasure in lecturing to the various groups that request his instruction. He lectured to an Eastern European delegation of doctors and administrators who were visiting our medical center. He was then invited to lecture to the American Academy of Dental History on *The Sins of Specialists: A History of Codes of Professional Ethics*. Last but most certainly not least, he lectured at a Grand Rounds for our Pediatrics department. He reviewed the famous "Baby Doe" case of 1982, showing how that case is still relevant when parents make decisions about babies born with birth defects.

Bramstedt Bustling:

Our Clinical Ethicist, Dr. Bramstedt, has her calendar continually filling up with engagements to lecture on the various aspects of medical ethics. In recent months she has lectured at two CPMC nursing symposiums; first on end stage liver & kidney disease, the other with Dr. Jonsen on general ethical principles. In displaying how our work touches all areas of the medical center, her lecture at Transplant Grand Rounds discussed the ethical dilemma of religious values excluding an individual from transplant candidacy in the case of a Jehovah's Witness patient, whereas at Cardiology Grand Rounds, she was joined by Drs. Andereck & Jonsen to lead a discussion titled, "Acute Aortic Dissection in the Elderly; An ethical moment?" Her final external duty of the calendar year came from our neighboring institution, University of Pacific School of Dentistry, as she was asked to sit in on and provide feedback on their ethics curriculum.

Alon Conferencing:

Our scholarly intern, Alon Neidich, presented at the Biocultures Graduate Student Conference at University of Illinois, Chicago. His talk was entitled: "The Effects of Physician Trust on Preferences for and Beliefs about Genetic Testing."

In the News

Bramstedt on Kidneys:

Dr. Bramstedt co-authored a paper that appeared in the journal Progress in Transplantation. The paper focused on high-risk kidney recipients; patients who had a high risk of not surviving a transplant surgery due to significant medical issues. This creates an ethical debate about whether to proceed with living-donor surgery.If you would like a copy of this paper, please contact our office.

Lancet Visit:

In November, the British journal Lancet, one of the worlds leading medical journals, sought our Program's feedback as they redesign their website for 2008. Two of our staff were asked to review multiple on-line content designs for the journal and provided suggestions that pleased Lancet's representative.

Bramstedt & the A.P.:

Dr. Bramstedt was asked by the Associate Press to comment on research at Johns Hopkins into the impact obesity has on the waiting time for a kidney transplant. She was asked if there might be an ethics based reason why overweight kidney patients wait longer for a transplant than those not overweight. She speculated that possible overweight people were put on the transplant list that perhaps shouldn't have been as they were not a suitable candidate for transplant. Her comments, though not her name, were included in an article titled, "Very Obese Wait Longer for Transplant."

Healthcare Article:

Dr. Bramstedt was pleased to find that the Monash Bioethics Review accepted her research paper, "Exploring the Gap in Healthcare for Injured and Uninsured Research Participants in the U.S." This article discusses the issue of healthy research study volunteers becoming ill due to their participation in research and proposes guidance for the informed consent process.

Heilig and Healthcare:

Steve Heilig had opinion pieces on the innovative and controversial San Francisco universal health access plan published in the San Francisco Chronicle (co-authored with former UCSF Chancellor Philip Lee, MD) and was quoted in the AMA newspaper and other publications on this topic.

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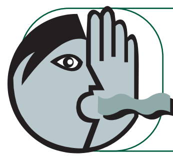

Stop Talking Medicalese

Tracheotomy: A surgical procedure that opens a hole in the trachea, the windpipe that runs down the neck, in order to insert a plastic tube to assist breathing

Percutaneous Endoscopic Gastrostomy: A surgical procedure that opens a hole through the abdomen into the stomach for a feeding tube.

Trach & PEG: Abbreviated expression for Tracheotomy and Percutaneous Endoscopic Gastrostomy as defined above. They are often used colloquially to describe using these procedures as a final effort to sustain life when there is no hope of improvement in the patients' condition, and to prepare them for transfer to a long term care facility.

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