

peace in the life after for the souls of T.'s deceased family members who had been wandering since their deaths. The ceremony brought a sense of joy and relief to T. as well as to members of her family and the support group.

### Conclusion

Our collaboration with the religious community is limited, but we hope our experiences at the Refugee Clinic will give clinicians who work cross-culturally the impetus and courage to look beyond the usual limits of clinical care. T.'s breakdown in the clinic over the recent alleged rape precipitated an emotional crisis that caused her to remember unresolved and unmourned loss and separation. We realized that suffering that results from severe trauma may not be managed successfully unless health care providers examine a patient's beliefs and values about dying and death and honor appropriate cultural and religious rituals. T.'s experience also demonstrated that support groups build a sense of trust and security that enable some patients to confront deeper levels of suffering. A support group format can foster partnership with the religious community to facilitate healing.

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## Necessary Ignorance

by William G. Bartholome

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I am frequently asked what is the most challenging aspect of playing the role of a "clinical ethicist." Although there is considerable controversy about this new role, I see the goal of my work as respecting and supporting the moral "agency" of health care providers, their patients (and patients' families) and the health care institution in which I work. How can a clinical ethicist support the moral development of individuals and institutions? By enhancing their ability to discharge ethical obligations and responsibilities. This work involves multiple tasks: (a) participating in a wide range of educational efforts for students and staff; (b) working with institutional forums such as ethics committees to develop guidelines and policies for addressing recurrent

ethical problems; (c) offering support to providers, patients and families in individual cases, often called "ethics consultation." In undertaking each of these tasks, I have encountered many challenges. However, the most intractable of these is what I call the problem of "acknowledging ignorance."

Although I have occasionally encountered this problem in patients or family members, it is endemic amongst health care professionals. Jay Katz has

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written extensively about a related aspect of health care which he terms the problem of "acknowledging, disclosing and coping with uncertainty." [See especially his book *The Silent World of Doctor and Patient*.] The problem is so basic that it is difficult to discuss without sounding simplistic. I will offer a number of formulations.

Health care professionals are unwilling (unable?) to admit that patients (and family members) possess knowledge relevant to decision making. They do not see themselves as needing to know much of anything about a particular patient in order to know which treatment is appropriate or "right" for that patient. When they encounter patients in clinical situations, they regard themselves as not only knowledgeable, but also as capable of knowing which particular intervention is "indicated" in the treatment of each patient. The bioethics movement has influenced physicians' practice to the extent that they see themselves as obligated to procure the patient's "informed consent" and to respect the patient's rights, especially the right of self-determination. However, these obligations are viewed as imposed on them from the outside. They are often regarded as "necessary evils." They are not seen as intrinsic to the practice of medicine or nursing. Many doctors see the emergence of clinical ethics as little more than an impediment to practice that resulted from the civil rights movement or the consumer movement or the influence of the legal profession. They regard this evolution as a sign that patients no longer trust them. Unfortunately, these attitudes leave the underlying parentalism of health care professionals largely intact. Professionals continue to see themselves as "knowing best." They continue to use the language of "compliance" in describing the patient's role in health care.

What is clearly missing is an acknowledgement by providers that extensive education and training do *not* prepare them to know all that they need to know to determine the "right" treatment for a particular patient; that medical or nursing or social work expertise does *not* include "ethical expertise"; that *no* health care intervention is ever "indicated" in the sense that objective scientific knowledge can be applied straightforwardly to an individual case. Encouraging highly educated and skilled professionals to see and acknowledge these limitations on their ability to know is the greatest challenge facing those of us who do ethics in a clinical setting. Patients and families bring knowledge that is both unavailable to providers and essential to good decision making. This knowledge is the highly personal insight one acquires by living with a disease, being the "subject" of an illness. It is also the knowledge of oneself as a person: one's history, social relations, work, values, goals, fears, hopes, dreams, plans and the like. For a health care intervention to be "right" it must fit into the lived life of a particular patient and be seen as "right" from that patient's perspective. The right treatment for an individual patient must always be a "discovery," the outcome of sustained dialogue between caregiver and patient. How are we to get providers to stop lamenting the alleged loss of patient trust in them long enough to see that the real problem is persuading them to trust their patients? How can we enable health care professionals to acknowledge this crucial limitation on their ability to know, to see themselves as depending on knowledge that only patients can bring to the decision making process? How can we support providers to see, acknowledge and cope with the extent of this necessary ignorance?

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## Imprisoned

by William G. Bartholome

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"He looks pale. Doesn't he look pale to you?" she asked.

"Would you stop with this pale-business! You've said David looked pale at least twice a week for the last month! If you think he's pale take him to the damn doctor, but I've had it with you and your constant fretting about that boy," he snarled back.

"That boy just happens to be the only thing in my life I give a damn about. And I *am* taking him to the damn doctor," she snapped.

It seemed like David was the only thing that either of them gave a damn about. It had been that way for as long as she could remember. He constantly accused her of "fretting" or "doting" or "spoiling." She constantly accused him of ignoring their son or picking on him. If they weren't arguing about David—his hair, his clothes, his room, his toys, his school work—they didn't have much of anything to say to each other. David was out of the house on his way to school as soon as he could get dressed in the morning and didn't come back until his mother had called for him to come home for