

B O O K R E V I E W

Behind the tough decisions

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First, Do No Harm. By Lisa Belkin, Simon and Schuster, New York 1993. ISBN 0-671-68538-4

Lisa Belkin, a reporter for the *New York Times*, spent three years observing the ethics committee in a large private hospital in the US. The hospital cares for adults and children but her focus in this book is on the world of the ill children, the difficult choices their parents and the medical staff face in taking care of these children and how the ethics committee interacts with both to help them arrive at decisions.

'Difficult dilemmas'

As Ms Belkin writes, ethics committees are a recent phenomenon. It is only in the last two or three decades that medical progress has provided choices to both patients and doctors. Before that time, medical or surgical treatment could not prolong life sufficiently to require decisions to continue treatment or not. As technology now allows premature babies and children with chronic, debilitating illnesses to live on seemingly forever, we are confronted with difficult dilemmas. Will the baby have a meaningful quality of life? Who will provide ongoing care for a completely paralysed young man? Who will bear the cost of enormously expensive drugs, surgical procedures and hospital stay? What if patients or caretakers want everything done when the prognosis is hopeless — or what if they want to give up too soon?

With permission from the patients and the medical staff, the book describes a few cases in detail. What come through are the anguish, helplessness, uncertainty and eventually emotional and physical exhaustion of the parents. The author is equally good at describing the uncertainties inherent in medical science that doctors face daily as they make and help parents to make life and death decisions, and the toll that this takes on the doctors' and nurses' psyche. It has become fashionable to blame doctors or hospital administrators for denying care that some patients see as their fundamental right. This book shows how society has left these people to take the heat while the policymakers, legislators, and insurers move ever so slowly to keep up with the complexities of today's health care.

Ms Belkin describes how the initial ethics committee was formed at this hospital at the insistence of the hospital chaplain. Chaired by the chief of nursing, the membership has gradually expanded to bring in people from different disciplines with an attempt to provide scientific and emotional balance. The committee also includes persons outside the hospital staff, in this case, former patients or patient relatives/friends. The committee has policy meetings and also case consultations. The last was unusual at the time the book was written but is fairly standard now at all hospitals that have ethics committees.

Anyone can ask the committee to consult on a case where

they feel that the patient's care is being compromised. It could be a doctor, a nurse, a medical social worker, patient or patient's family or even a rank outsider though that is a very rare case. Once the committee convenes, the person requesting the consultation is asked to tell the group why she/he feel that the care is less than optimal, either too little or too much. Usually the family members who have requested the meeting attend as a group. The patient, too, is welcome but often too sick to participate. After the information is given, the family leaves the room while the group deliberates. Privacy allows members of the group to give their opinions without worry about hurting the family's feelings or fear of repercussions. Then the family returns to hear the group's decision which is never binding, it is merely an advice that they are free to reject. The opinion of the group is explained without medical jargon and the family is not under any pressure to make quick, irrevocable decisions.

Despite this support and extensive discussions, the decisions are still very hard. All parties involved are often in two minds about whether they have made the right decision. It is therefore not surprising that in the concluding section where Ms Belkin describes the consequences, several decisions appear in retrospect to have not produced the desired outcome. Yet she describes how different people cope with these. Life goes on

No saints, no villains

I found this book very touching and also very informative. It describes the complicated interactions that take place in a hospital between the patients, their caretakers, and the medical staff without trying to ascribe blame. There are no saints and no villains. Contrary to popular stereotypes, patients and their caretakers can be manipulative, excessively demanding and just plain "pain in the ass"; hospital administrators can be caring and striving to bend rules to benefit the patients; the medical staff can be so emotionally attached to their patients to almost become surrogates for them while others maintain a professional but distant attitude.

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