

August 1986

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Recommended Citation

Carr, William F. (1986) "Clinical Sessions and Health Care Ethics," *The Linacre Quarterly*: Vol. 53 : No. 3 , Article 5.
Available at: <http://epublications.marquette.edu/lnq/vol53/iss3/5>

Clinical Sessions and Health Care Ethics

Rev. William F. Carr, S.J.

Father Carr, a member of the Fairfield University philosophy department, has a particular interest in the ethics of health care. He explains that his paper "describes my reflections on the clinical sessions I had at the Kennedy Institute of Ethics at Georgetown University and Georgetown University Hospital."

My first sabbatical at the Kennedy Institute of Ethics at Georgetown University was one filled with vivid impressions of the many clinical sessions I was able to attend at the medical center. After just a few sessions, I began a journal to help me remember this special introduction to the work of health care professionals, students, and patients. As I remember those first days, I began writing these entries at the suggestion of one of the Jesuits living at Georgetown to fulfill my need to put into words my reflections about the world of patients, doctors, and nurses which, up until that time, had been mine through books, conferences and workshops. In anticipation of a second sabbatical - this time at Georgetown and Children's Hospital, National Medical Center in Washington - I began reading the diary again.

Realizing what the clinical sessions had meant to me, I decided to rewrite the entries so that when I returned to Washington, I would be ready to use them to show how the regular attendance at rounds, staff meetings and patient conferences made a significant difference in the way I came to see and appreciate the ethical issues in the lives of patients, families and health care professionals who care for them.

"Clinical Sessions and the Teaching of Health Care Ethics" has come, therefore, from a reflection upon the entries I made each evening after I had left the medical center for the day. As I reviewed and rewrote these reflections, I also remembered how apprehensive I was about presenting myself to the health care professionals in their working and teaching situations — wondering how doctors and nurses would react to a visitor at their side during their meetings and rounds. The apprehension was groundless. What I found all during the year were men and women, social workers, doctors, nurses and administrators going out of their way to help me see what they did in the daily care of patients. I was grateful

then for their generous assistance during the year at the medical center. I am even more grateful for their subsequent permission to use their names in these reflections on the clinical sessions which I had with them.

In the first part of the paper some personal academic history will be given to show how the clinical sabbatical was conceived and how it evolved. The second section, in its simplest form, is about the conferences and rounds I had with social workers and nurses, medical students and their professors, and doctors and patients giving and receiving care. The last part is about the role of the professor in teaching courses about the ethics of health care.

I

Before the Clinical Sessions

I began studying health care ethics in detail when the first class of nurses at Fairfield University came into its senior year. This course was the last required one in philosophy, and I began teaching the nurses and some premedical students who made up the rest of the class. Even with my limited knowledge of the sciences of nursing and medicine, I thought that, with my direction and their contributions, I could bridge the gap between their practical sciences and my philosophical background. The differences, however, between our ways of thought grew more and more apparent. Both the nursing and premedical students were thoroughly trained in science. The measurable and the quantifiable were normative for them, while philosophy in general and ethics in particular were judged to be abstract and even arbitrary. The practical experiences of the students were also very different from mine: the nurses had completed three years of their academic and clinical requirements for their profession, while many of the premedical students had worked in hospitals to gain some insight into the profession they hoped would be theirs. My only work in hospitals, on the other hand, was long ago, when I spent a few months or more as a chaplain in Boston City Hospital. It was something, but not much.

After a while, I realized that my direction and their contributions were not enough to narrow the gap between my background and their experience. The reality of patient care was not a shared experience, and so I decided to ask for a sabbatical, to see for myself what my students had already experienced. The sabbatical I proposed was one which I hoped would be a time of private study and a time for joining medical students on their rounds and attending staff meetings of nurses. I wanted to have a clinical-ethical sabbatical in which I could test my own principles and find out whether they responded to the needs of real hospital situations. Another very important reason for my sabbatical proposal was an increasing awareness that my views on the morality of abortion and the related matters of sterilization and contraception, formed by my respect for the teachings of the Catholic Church and expressed in the "Ethical and Religious Directives for Catholic Health Facilities", were not always

shared by the students I taught, even though many of them were Catholics. Through a sabbatical in a major Catholic medical center, I hoped to see how medical students, nurses and doctors worked under the guidance of the directives which some of my students found difficult to accept.

One time in particular stands out clearly as an example of the way my views were at variance with many of the students I taught. The difference startled me then and I was uncertain about my own responsibility in this matter. It was in the first year of teaching the course. We had completed the unit on abortion, which covered the various legal, moral and ethical arguments concerning fetus and mother. We spoke of the ways in which nurses and medical students might be involved in abortion procedures if they worked in hospitals where abortions were done. We spoke about conscience clauses and the ways in which individuals could ask for exemptions from this kind of work or medical school requirement. When I thought of means of reviewing the unit and giving the students a chance to express their views, I decided to have a debate day or a panel discussion on the questions we raised. The choices I offered were two: one was to defend a liberal legal and moral position which protected and guaranteed a woman's right to have an abortion for any medical or personal reason; the second choice was to defend a position which would allow abortion only for serious medical reasons of a life-threatening nature, major fetal disorders, rape and incest. I hoped that we would have a good debate, but I also hoped that some of the volunteers would reflect the respect for human life which characterizes the teaching of the Catholic Church.

More Liberal Panelists

We had many volunteers for the panel, but the students on the side of the liberal view outnumbered the others ten to three, and to my surprise none of the three speaking for a more restricted view was a nurse — and this in a group of predominantly Catholic students. When I expressed my surprise about the silence of nurses concerning a moderate opinion about abortion rights and wrongs, one of the nurses spoke for herself expressly, but I believe she voiced the moral sentiments of many others in the class. She said that it was not a case of approving or endorsing the very liberal attitude toward abortion choices, and it was not that they were neutral or indifferent. Rather, they were strongly opposed to the trivializing of human life in the womb. They were, however, reluctant to stand, as she said, in moral judgment about what others thought was right. Talking with other nurses later, and not in the classroom situation, I found out that they were not only hesitant to judge others but they were uneasy about expressing personal views about abortion in class, even though some of these same nurses who were to graduate that year had given up trying to find non-Catholic hospitals where they could do obstetrics without being required to assist in the nursing care of abortion patients.

After teaching the course for four years, I asked Dr. Andre E. Hellegers, director of the Kennedy Institute of Ethics at Georgetown University, to spend the year as a visiting research scholar at the Institute and the Georgetown Medical Center. If some of the nurses and premedical students found it difficult to see the relevance of ethical theories and the place of religious values in their future work, the ethician was prepared to enter the world of nursing and medical care of patients as an observer of the hospital setting. The inspiration for this kind of a sabbatical, in addition to coming from my own needs, had been in the back of my mind for a long time after reading Paul Ramsey's *The Patient as Person*. In his preface, he expressed his indebtedness to the Joseph P. Kennedy Jr. Foundation for his appointment as visiting professor of genetic ethics at the Medical School of Georgetown University. The appointment, he said, enabled him "to be located in the middle of a medical school faculty—not in its periphery—and to begin some serious study of the moral issues in medical research and practice." "Not in its periphery" was further specified for me through the advice of a physician friend of mine, Dr. Mark D. Kelley, who urged me to spend as much time as I could with the students, residents and professors on their rounds. Since the teaching of nurses had introduced me to health care ethics I thought I should also try to listen in on staff meetings of nurses to see how they related to some of the situations I had only read about. If I wanted to see for myself, as well as a non-nurse or non-doctor can, what nurses and doctors do in the care of patients, this would be the way to do a sabbatical.

The clinical sessions eventually averaged 10 to 12 hours a week, and I attended them on a regular basis during the year. There, was, however, no formal program for this kind of sabbatical, although others at the Kennedy Institute had spent time with physicians on their rounds. For this reason, Dr. Hellegers introduced me to the director of social work at Georgetown University Hospital, Dr. Kathleen Shevlin. She generously invited me to do my first rounds with her social workers. Afterwards, she arranged for other meetings, rounds and classes which were thought best for my purposes. It was a most providential happening that I began the clinical work with this department, since the social workers helped me to adjust to the complicated setting of the hospital by gradually filling in the many gaps in my knowledge about patient care and needs in language more easy to understand than the technical terminology I would hear on subsequent rounds. Not only were they thoughtful and helpful, they were also the experts on the needs of patients in the non-medical concerns, needs sometimes more devastating than illness itself, such as the impact of illness on social functions, the costs of hospitalization and all that pertained to the care of patients after hospitalization. This special kind of professional work, different from medicine and nursing, brought me to meetings with nurses in oncology and in intensive care nurseries, conferences with physicians reviewing dialysis patients, rounds in

rehabilitative medicine and finally, to psychiatric evaluations of individual patients.

Rounds Led to Invitations

Besides acquainting me with these units in particular, the rounds throughout the hospital were sources of invitations to investigate other hospital services. What generally happened, frequently enough to mention, was that a doctor, a nurse or a social worker would introduce me to someone who would invite me to see another unit. When they learned that I was a priest, teacher, and fledgling health care ethicist, there was a warm welcome and an invitation to see what they were doing. After some experience with social work rounds, I branched out to preceptor rounds, which are offered to first-year medical students to give them some experience with patient care. The regular rounds, which were to come later, might have been too difficult for me at that time, but the preceptor rounds were designed to give the first-year medical student a chance to know something about medicine through a professor who was also caring for patients.

The first preceptor rounds were with Dr. David C. McCullough in neurosurgery. The second preceptor rounds late in the year, with Dr. John S. MacDonald, were in oncology and they, too, let me see the professor-clinician in his everyday work. Both rounds not only gave me a chance to be present when doctors talked with patients, parents or families but also, more important, they gave us exceptional opportunities to ask questions which would be expected to come from beginners in medicine and those still new to the clinical setting. After the first preceptor rounds, I began to sense that what the doctors and nurses said characterizes most of their work. There was the intermingling of the extraordinary and the critical with the ordinary and routine.

There were many other contact hours in the hospital setting which I got to know through the medical center. Some of them, the ones described in detail in the second part of the paper, were patient conferences in psychosomatic medicine conducted by Dr. John Collins Harvey and Dr. Henry D. Lederer; obstetrics and gynecology rounds with Dr. John J. Schrufer and his staff, and additional rounds in oncology with Dr. John S. MacDonald and oncology fellows at the Lombardi Cancer Center. These sessions were just what I had hoped for in the clinical experience I sought with health care professionals and their students. Through the year, my theoretical and academic background was tested and modified in many ways through the realities of the clinical context of the medical center, and from that time on, my knowledge of health care issues was not limited to reading or hearing about them in workshops. The experience I had was personal, and if not unique, it was different from the experience of many others who teach courses in the ethics of health care. After the sabbatical, my attitude about teaching was different.

It is this new direction which I hope to share with others in "Clinical Sessions and the Teaching of Health Care Ethics", through this account of the sabbatical and the impact it had on my work. What follows is chronological to some extent, since the Department of Social Work introduced me to the hospital with oncology rounds and I finished the sabbatical in this same area with Dr. MacDonald. It should be pointed out, though, that the order and pairing and the separation of health care professionals, nurses and social workers, and medical students and professors, doctors and patients, are for the sake of analysis only and not as an indication of the relative importance of the health care professional, since one of the great lessons of the sabbatical was the realization of the need of the many distinct and complementary professions working together for the single goal of helping patients.

The Clinical Sessions

Social Workers and Nurses

Dr. Kathleen Shevlin, the director of social work at Georgetown University Hospital, graciously received me when I suggested what she and her staff could do for me during my sabbatical. Dr. Andre Hellegers, the director of the Kennedy Institute at that time, had asked her to meet with me and give whatever help she could in directing me to the clinical experiences I sought. We spent a long time chatting about my plans and the ways in which the social worker's concerns and skills in helping patients would help me too. I made tentative plans to attend social work meetings with nurses in the Lombardi Center and I was told about rounds which would bring me through the hospital with social workers who accompanied physicians on their rounds.

At the time of our meeting I remember thinking that the work I was going to do was once removed from the people I most wanted to work with — patients, nurses and doctors. Later, I realized how fortunate it was to have social workers introduce me to the hospital. Not only did they guide me around the medical center, but they also knew the doctors and nurses who would be most receptive to me and my hopes for clinical experiences. And more than giving me just a good introduction to the hospital through her staff, Dr. Shevlin herself took an active and enthusiastic interest in my program. She made many of the initial contacts with nurses and doctors who were willing to have me along with them in their work and teaching.

Most important, though, it was through her department that I came to the realization that the human needs of patients in hospitals are not just medical ones, and that along with nurses and doctors giving their care, the continued welfare of the patient involves so many other concerns. Full health care had to attend to these needs of the persons affected by illness and to the consequent states of being dependent on others when they left the hospital. It was the social worker who sought out the private and public ways of helping patients and families cope with the many financial and social and psychological aspects of being ill.

At the time of the visit with Dr. Shevlin I had been reading Jo Ann Ashley's book, *Hospitals, Paternalism and the Role of the Nurse*, which helped me to see something of the long history of struggle nurses had behind them and to explain their desire to attain a professionalism and autonomy in keeping with the importance of their work. So when the social work in hospitals was presented to me as the beginning of my clinical contact hours, I had the good sense to realize that just as the nurse can be much more in tune with the human needs of the patient than the physician, the social worker, in turn, can be even more involved in a professional and human way with the aftermath of the medical crisis. Up until now I thought of the ethics of health care in terms of patients, nurses and doctors. After seeing the social work staff in action, I became much more aware of the complicated nature of the mechanics of helping persons back to health or to living with debilitating human handicaps.

My first clinical contact hour was spent on Second West, where cancer patients were cared for before the new Lombardi Center was built. I met with the nursing staff, a couple of nursing students from Georgetown's School of Nursing, and a social worker, Patti O'Donnell, in a small room near the patients' rooms. During these meetings, the nurses updated Patti on the condition of the patients, their psychological state and any special needs that were the particular concern of the Department of Social Work.

Before I was introduced to the group, the nurse coordinator told me about the unit, cancer patients with various degrees of disease, and health and prognosis. The treatments given ranged from the standard and orthodox to relatively new and experimental protocols. When the other nurses arrived and the meeting began, the patients were reviewed with respect, incisiveness and, at times with a bit of humor. Since I had never met the patients, the histories seemed like the cases I had read in textbooks. But these descriptions were about real people. I only had to walk along the corridor to see how real the subjects of this discussion were.

Unit Personalities

The nurses spoke about one woman in particular who would need a lot more help than she anticipated when she came to the Medical Center. She had been admitted under a false Medicaid name, and then cancer was discovered. The subsequent panic of the patient brought about the confession of her true name, and Patti had to find the proper means to provide care for her and her family. They also spoke about a patient's husband who seemed outraged at the serious nature of the cancer afflicting his wife. He complained that this was the end of any sexual life with her, and that it was the end of his own freedom. It almost seemed that she had no right to have cancer, since he was so inconvenienced. But the nurses and Patti noted that he was caring for their home and looking after their children. They seemed to take his anger in stride although they were attentive to the situation. The "Why me?" I would see later is not that unusual even for spouses of cancer patients. Another patient was going

home soon. They were concerned that he drank in the hospital and would drink at home, and they wondered whether he could take care of himself. One woman's story was particularly poignant. She had just recently sold her own furniture and was ready to move into the apartment of a life-long friend. There would be no need to look into her affairs at home. She would not be going home.

One patient they mentioned had accepted the reality of cancer, but his wife spoke only about her optimism that full recovery was still a possibility, even though the prognosis offered little or no hope. Her denial, unchallenged by the staff, seemed rather weak, since it was known that she was drinking heavily when she was home and away from her husband.

These reviews of the states of the patients and the way families coped with serious illness were precise and professional. The cases needing attention were discussed in full detail. Most of the details seemed to focus on the way the patient was reacting to cancer and the way in which his illness affected those who were nearest him. Payment for the hospitalization was a concern, and another was how dependents might find support and counseling if these were needed. These needs — the non-medical aspects of patient care — were different from the patient's fear of cancer, but they were still terribly threatening and disruptive in the lives of patients and families.

At one of the meetings, the ages of the patients ranged from 18 to 60. They were both men and women. The nurses said that a young man in his mid-20s would have to be told that, besides the tumor on his spinal column, cancer of the lungs was just discovered. One of the doctors would do this. Only aware of the first malignancy, the patient had spoken about going back to work in a few months. Another nurse said that he might not be as confident as they thought, since he had begun crying a bit at another time when he had spoken about returning to work. Another patient, a woman of 45, was almost detached about her illness. Her mother had died of cancer. Maybe this detachment was resignation to what she thought was normal for her, even fated. The nurses were also concerned about the oldest of the patients. They spoke of him as "well defended." Patti afterwards told me that the staff would wait for him to speak about the seriousness of his situation. They were ready to help him respond in the way he wanted. No one would force him to conform to a pre-established method of coping.

Difficult Health Care Work

Moments like these, understanding and strongly supporting the defending patient, made me aware of the different kinds of health care professionals working in this most difficult specialization. The staff as a whole was very helpful in assessing patient needs and alerting social workers about major problems, but one nurse in particular impressed me with something more than professional competence. To competence she added warmth and empathy for her patients. She knew them in a special

way. I remember how she talked about one patient in particular who, for the first time, spoke about his cancer as cancer. This patient had passed to a different level of acceptance and she knew that she had witnessed something important for everyone to know. She was special, not only because of her technical competence, but because of the ways in which her love and compassion noticed the personal in the patient.

When I was leaving the conference room, one of the nurses asked me about my interest in their meetings. I told her that although the routine was ordinary for her, it was new to me. It made me very much aware of the terribly human concerns of the cancer patient: fright, denial, anger, the financial burdens and the realization that their families are frightened, denying, angry, and wondering how long their insurance will cover medical expenses. These were the main concerns, and the meetings told me that the social worker and the nurse had to be prepared for the special needs of the cancer patient before, during and after cancer therapies.

Gloria Newcomb, another clinical social worker, brought me along with her on rehabilitation rounds conducted by Dr. Carol D. Sheridan. With them were physical therapists and medical students. We started on the run most days, but we spent a lot of time with individual patients. Between stops, I was asked about my interests and I told Dr. Sheridan about my work at Fairfield University. She said that I would be seeing rather routine work on the rounds, but that this was a large part of the life of a doctor in this specialization. Kind and encouraging with the patients, she stayed with them as long as they had any questions. When we left the room, she made sure that Gloria was alerted to any post-hospitalization care. The patients we saw had to have the assistance of the Department of Social Work for the ever-present financial and psychological effects of illnesses requiring ongoing rehabilitation. There was, I was told, nothing medically exotic or mysterious about the people we saw. They were simply people recovering from various illnesses — surgery, or accidents — and they needed continued therapy to help them back to a higher level of activity, if that was a realistic goal. This specialization — physical medicine — crossed many lines. Whether patients first saw an internist or a surgeon, they often enough needed the help of a therapy program worked out by experts in rehabilitation. The rounds that first day were typical. We saw a boy recovering from brain surgery and his rehabilitation was being planned. A 90-year old woman was waiting to get a place in a nursing home after a long stay in the hospital. Her placement was delayed because of her medicaid status. During the rounds, one had to think about the amount of money needed to care for the very young and the very old when they could not take care of themselves. The resources are limited, and people are living longer with infirmities which debilitate, but are not life threatening.

Neonatal Unit Next

My next series of clinical sessions was in the neonatal unit. The meetings, attended by the staff nurses and a social worker, were about

infants, parents and doctors involved in the early life crises now so well-known through newspapers and television. The important issues here were the ways fathers and mothers were reacting to the sudden and unexpected, and sometimes long hospitalization of their children. Some of the parents were strong, hopeful and accepting. Others were shattered and lost. Their anxiety was seen in their infrequent visits and their reluctance to get too close to their children.

Most of the infants were just days or weeks old, while some remained in the unit for a month or longer. The newborn patients were sometimes called by their full name and sometimes just by their last name with "Baby" almost like a first name. One infant, who had been in the nursery for at least four months before I began to attend these conferences, I remember by name. This long standing resident was the subject of most of the first meeting I attended, as well as the principal subject of the many meetings that followed. He was different. Baby Adams (not his real name) was one of those infants who was given no hope of development, even with aggressive specialized care. He had been a premie, and he still needed constant pulmonary assistance. Fed through a tube in his stomach and monitored, he was kept in the unit and treated only because his mother refused to accept any other options.

Baby Adams's long stay in the nursery exhausted the coping ability of many of the nurses. His mother refused to accept the judgment that nothing would help her son develop well enough to live and grow independent of tube feeding. Some of the nurses thought that the mother was wrong and they had asked to be excused from taking care of him. It was too much for them. Others, although disagreeing with the mother, accepted the responsibility of monitoring him. The coping ability of the nurses was not all that was exhausted. Insurance had run out long ago and the hospital was assuming the ever-increasing debt. At this time, the nurses and the social worker talked about some "what if situations." How would they react if he left their unit for another medical facility where care would be provided without the intensive care he was getting now? What if he remained in their unit and he was given a no-code? What if he left the hospital to go home in his mother's care? I could see that some of the nurses thought it was wrong to continue trying to save Baby Adams, but they were also concerned about his dying. They knew that his mother had lost her only other child in an automobile accident, and they thought she would blame herself for his death when it came. Their obvious ambivalence was not easy to resolve.

Baby Adams was an exceptional infant, not unique, but one of those infants who can be maintained for a long time in intensive care units without any reasonable hope of ever being free from mechanical means of sustaining life and, unfortunately, without any reasonable hope of growing and developing beyond the point of merely sustaining life. Other infants in the unit, no matter how tiny a hold on life they seemed to have, were given a chance to make it away from their support systems. The

Adams baby was different. He could go a long time, but he really did not have a chance to live. His story continued in the weeks following. At the next meeting, I heard that his mother had been told that the hospital wanted him to go home with her or go to another facility. She had chosen to take him home and care for him herself. The rest of the meeting was spent in discussing and evaluating the progress his mother was making in her training for his going home. Christmas was a target date for leaving the hospital after it was decided that he would leave. At this time, another person was introduced into the story — his grandmother. She, it was thought, had a great influence on her daughter's first decision to do everything possible to save her son. The nurses now thought that the grandmother might be the one who would be taking care of him when he went home, and that care would involve the continuation of tube-feeding. Both mother and grandmother had to know how to feed him and bathe him in this condition. Among other things, arrangements would have to be made for a supply of oxygen for the home. In the review, many questions were brought up by the nurses concerning the eventual emergencies mother and grandmother would inevitably face: How would they handle the infections that might come from where the tube entered his stomach? What if he arrested? His mother seemed so ill-prepared that the Christmas goal was not realistic. I could also see that the nurses were still uneasy with their views of what was right for this infant or rather, the practical consequences of what they thought was right. Stopping what they judged to be futile meant Baby Adams's death.

Baby Adams eventually developed ulcers, probably from his tube feeding. He would not be going home for Christmas. Maybe a hospital closer to home would be better for him, although it did not seem likely that another hospital would admit him in the face of massive hospital bills already accumulated and unpaid. Some of the other children and their mothers and fathers were mentioned. Some of the children were still in danger while others were given a very good prognosis. The parents, most frequently the subjects of the conferences, were the ones who seemed to be afraid to be with their infants. They thought, perhaps, that their children would not survive this stage. Someone would then call them and encourage them to come to the hospital more often. A few of the mothers and fathers were even hostile to staff members when it was suggested that they should stay longer with their children and even help to bathe them when they visited. These babies would most likely leave the hospital for a life at home, while Baby Adams would leave the hospital with no such hope. He was a newborn who was given no hope, while others were given a very good chance of healthy lives through the skills of modern medicine and nursing.

Cataloguing Babies in Need

At the beginning of one meeting in the nursery, I thought of how I had become used to the cataloguing of babies in need, and of parents

accepting or not accepting their troubled children. Then, as the report got under way, I realized that Baby Adams's name was not the first mentioned. I waited to hear an updating of his story only to find out later that when I was away at Christmas time he had died in the hospital. I found out about his death when I was speaking with a medical student who was spending some time on the unit. I knew that I would never forget him.

Another time I heard that there were three sets of twins in the nursery at this time, two of which were premies. The third set had been admitted to Georgetown after being home for awhile. Everything was being done for them. The mothers and fathers were frequent visitors, and there was a note of cautious hope that the babies were going to make it. The nurses preferred this kind of evaluation. They were ready to help or ask other services to assist parents like these mothers and fathers who never thought that they would have a child so precariously balanced between life and death, health and handicap as well as to accept the fact that babies like Baby Adams should not be given intensive care. And although the ethician's "sanctity of life" and "quality of life" phrases were not always used, these considerations were paramount in their professional and personal consciences. Every day the nurses tried to balance a respect of life itself with a realization that their technical skills must be humanely applied in this very difficult specialization.

The nurses spoke again of parents missing from the nursery, absent, they thought, without good reasons. One nurse smiled and said that she was convinced that the woman who answered her calls was the mother of the child. The message was always the same: "Mrs. is not at home right now but I will leave a note about the call." A social worker asked whether it would be good to try to visit the home since the baby would probably make it through its present crisis only to go home to a mother who had not been able to accept her child. The handling, holding and feeding of infants, suggested to mothers and fathers of dying children, was even more necessary for mothers and fathers of babies who would live.

The rest of the agenda another morning was routine. There were fewer babies in the nursery but the problems were the usual ones and the discussion revealed once again the professional and human concern of the nurses for their tiny patients. They mentioned a 16-year old mother who was going to take her baby home soon. They wanted to know whether she would also have some help from some social services in her home town. At this meeting, a new abbreviation came to my attention. I found out that a baby born this week had been kept in the unit for observation. With his eyes closed most of the time and with some palate irregularity, he was just a funny looking kid — FLK. One of the nurses told me that the letters were used once to indicate that a baby needed observation, although obstetrics said that he was not in any danger. They spoke of one mother, pregnant five times, who had elected abortion on two occasions. She was now terribly worried over the child of her fifth pregnancy. The baby was

critical. Another mother, one of whose twins had died, was counting on the survival of the second twin. The law of averages, she said, must be on her side. Someone had to teach a third mother how to handle a colostomy bag. Her baby was to go home and it would be a few months before additional surgery could be performed.

Discussion of Surviving Twin

The last meeting I attended in the neonatal unit ended with the nurses talking about the surviving twin. He had to be resuscitated twice, and they were not too hopeful that the law of averages was on his side, although they were prepared to do everything for him as long as there was hope. I thought again of the categories used to describe the babies I had heard about while attending the weekly meetings: newborns needing only time and technical skills to bridge the gap between the life they had in their mother's womb and their going home; newborns in varying critical conditions but given a good chance of healthy lives; and the newborns who would never make it. The categories are general and abstract; the babies are individual and real. The nurses know this, and they must balance what can be done with what ought to be done for their patients.

One morning I met with a nurse who had been in intensive care nurseries for many years and a psychiatrist who was ready to assist the nurses when the stress inherent in their work became more than ordinarily difficult. We went through the nursery together and then talked just a window away from the babies who were tubed, on ventilators and in isolettes. I told them that I was interested in seeing the ordinary work of nurses and doctors in their care of patients and that up until now I had been with social workers, medical students and doctors, but had not been with nurses caring for patients in their own right. The nurses I had met were those present at social work conferences or medical rounds, and since many of my students at Fairfield University were nurses, I wanted to see how nurses themselves responded to the questions raised in their day-to-day work.

The physician and the nurse both spoke about the competence of the nursing staff and said that serious conflicts were very infrequent. The intensive care nurse is specialized and appreciated in her work. She is also encouraged to express her opinions and to air any problems she experiences. Both said that the professional relationship between doctors and nurses is one of respectful cooperation. The nurses, though, have some conflict situations arise in their work with some residents. Sometimes the resident is merely defensive and sometimes an incompetent newcomer has to be corrected. The more incompetent, (the nurse said that she had a particular incident in mind), the more hostile the resident can become until the matter has to be reported to a nursing coordinator and to medical authorities. There is no easy way out of this kind of conflict when mistakes can be so costly. When I asked what happens when such a report is given, she said that a review is made, and in

the instance mentioned by her, the resident was relegated to an observer for a time. His decisions had to be corroborated by another doctor. When I asked what happens in the case of an incompetent nurse, she said that she would be asked to leave the unit.

Insights, Skills in Intensive Care

Most of the medical students, interns and residents appreciated the skills and the insights of intensive care nurses. Their specialization is essential to the care of newborns in critical situations. The nurse knows that her competence is not the same as that of the physician. She respects his ability and expects a return of this respect. We also spoke of a related characteristic of nurses now entering the profession, a characteristic taught in some schools of nursing and a source of consternation to a doctor more at home with a hierarchically constituted order of jurisdiction in hospitals. This is nursing assertiveness, very confusing to the doctor who has not been listening to what the new nurse says. This final point came up when we were talking about the way the nurses freely expressed their feelings and then their willingness or unwillingness to care for Baby Adams in his long stay. I was told that everyone in the unit was encouraged to say whether she would be comfortable or not, working in the care of this infant for whom a nurse might have to call a code if there was need. The ones who said "no" were excused from caring for him. There were others who were willing to care for him even though they thought it was futile. One nurse said that she would care for him only when a no-code became a reality.

On another occasion, I talked with a neonatologist about the ways nurses saw themselves as professionals and the ways doctors saw them as co-professionals. This physician spoke of the high quality of nursing at Georgetown and in the neonatal unit in particular; the nurses were talented, intelligent and respected. She then spoke of the importance she placed on answering any questions nurses asked her. Even with a great deal of uncertainty about diagnosis and prognosis, the nurse has a right to know what is relevant. Occasionally a new resident, at times even the seasoned specialist, will fail to do this. This is a mistake. Nurses report, suggest, make judgments and ask questions. All this is part of taking care of patients, and nurses and doctors should be the first to recognize the benefits of their distinct and complementary roles. This way of being health care professionals is not only the most sensible but is also the most beneficial for patients. Although different in what they do for patients, doctors and nurses should realize that they are caring for the same person.

Nursing for Cancer Patients

Other nurses working in a very difficult specialization were those caring for cancer patients. Some of them I got to know through my first rounds and I got to know them better later when I joined Dr. John S. MacDonald on his oncology rounds. This specialization, I found out,

demanding particular skills and occasioned many questions about life and death and the new and sometimes experimental medical means used to fight cancer. This is because the nurse frequently takes care of patients who have returned to the unit with the fear, and at times, the realization that they will not go home again. They also have to be prepared for other patients who say that they are coming in just for a few more tests or a follow up treatment, and who choose not to admit that dying is not far off.

Some nurses who accepted the inevitability of death as part of caring for patients who are seriously ill, found it difficult at first to get used to working on this unit where some experimental protocols were being conducted. When this kind of treatment began at the Lombardi Center, some of the nurses seriously questioned the therapies, and they wondered about their participation in this work. Dr. MacDonald said that there had been a lot of discussion involving the nurses and the medical staff, since some of them thought experimental therapies were frequently misleading, sometimes very painful for patients, very difficult for families, and more important, that the protocols prolonged hope in patients and families without solid justification. The nurses who stayed on eventually accepted the concepts and the values which justified the protocols which they were trying. They could still wonder about the decisions made by their patients when they agreed to be subjects in these trials, but they respected the way in which consent was obtained. They also knew that the patients could withdraw from the trial if they wished.

The concern and the compassion of the nurses were evident. Sometimes they had to detach themselves from too much involvement if they wanted to continue in this work. Nurses, it seems, had to do this even more than doctors since they were with the patients hours at a time and answered questions not always asked when their doctors were present. Answering their calls, changing dressings or just making small talk, the nurses found themselves doing for the patients what the patients were no longer able to do for themselves. This necessity of being "detached" necessarily conflicts with the other nursing requirement about being "involved", but the nurse knows she cannot die with every patient and grieve with every family. She has to work at being that special kind of person who has to learn again and again how to balance a concern for the patient and a concern for herself.

Toward the end of my sabbatical I attended a meeting which showed me one of the ways in which a nursing staff can present views on matters involving many different health care professionals and their patients. At the beginning of the sabbatical, I had asked about attending some staff meetings on a regular basis, but for various reasons it was a long time before I managed to sit in on a meeting initiated by nurses. This meeting was the first of this kind for me: staff nurses, a couple of residents, a psychiatrist and social worker were present. Much like the patient reviews I was attending in obstetrics and gynecology, they spoke about many

patients, but their special concern today was a baby boy, 18 months old, with a very poor prognosis. His "general cerebral syndrome" had eluded a more specific diagnosis, and there was now a great deterioration. One of the baby's brothers had died at the age of eight, and there was not much hope for him.

Giving Up Lifesaving Procedures

The questions proposed at this meeting were about giving up on further efforts to save his life, and before any option like this was given to his parents, staff members had the opportunity to speak about continuation or discontinuation of therapeutic efforts — heroic efforts could be continued or the boy would be given care and comfort without any more interventions. The child might be able to live for a while in the hospital with this care and comfort only, or in another hospital, or even at home. These alternatives were discussed by the staff with obvious concern for the baby, his parents and their own professional values. Most staff members wanted to have a no-code decision made as soon as possible and have the baby remain in the hospital. They saw no hope in their continued efforts. They also preferred to have him sent to another health care facility before asking his parents to care for him at home. They were afraid that his father and mother would not be able to take care of his going home and waiting for death. Once all the alternatives were discussed (going home, a transfer to another hospital, or staying with a no-code), the talk went on about how the parents were to be approached.

As a visitor, I hoped that somehow the concerned involvement of the entire staff could be communicated to the parents along with these tragic options. The choices offered no hope. They were just different ways of saying that the fight to save their son's life was coming to an end. The meeting was an impressive demonstration of how many different health care professionals presented their views without any one person or group dictating a solution. The social workers, nurses and doctors helped form the options, and although there seemed to be almost universal agreement in this case, their way of arriving at these options was valid for other dilemmas which would not yield the same kind of consensus. I suggested, toward the end of the meeting, that it might be good to ask the parents whether they would like to talk with someone from pastoral care, since other parents had been helped in times such as these. When I left the room, I realized that it would be the nursing staff — perhaps some of those present at the meeting — who might have to respect a no-code decision if that were the choice of the parents. This would not be easy on them, even though it seemed to be the right decision.

Patient's Distressing Death

On another occasion I was invited to attend a meeting of nurses who were more than ordinarily distressed by a young patient dying of cystic fibrosis. The disease and the patient's name became synonymous for me

because of this extraordinary grief session. A social worker got the group together — nurses and a resident who had been caring for him. The nurses in particular wanted to talk about his death, their own feelings and reactions about his last days. When I asked the social worker whether I, the only one of the group who had not known him, should be present, she made sure that my being there was acceptable to them.

Stan (not his real name) was 19 years old and a fighter. He had also died harder and sooner than expected, and, although they knew that C.F. is incurable, the nurses also knew that patients often passed severe crises and survived. Now, instead of leaving the hospital for home and school, this patient was dead. As the meeting went on, it seemed to me that the nurses were asking themselves, and especially the resident, why the death happened when it was really unexpected. There was also the question of whether the medical staff had given up too quickly. I thought that the doctor was asked to defend himself. It was good that he had a strong defense and it was even better for everyone to talk about him rather than having the questions unasked.

Stan had apparently reached a turning point at which the fight against C.F. should not be continued, at least not in him. Aspiration was not keeping up with the production of fluids. It was decided to place him on a respirator, which might make him more comfortable but which was also an admission of defeat against this young person's disease. The resident said that deciding not to continue aggressive therapy and try to make him comfortable for his last days was not easy. It was giving up. If they had worked a longer time trying to keep ahead of the fluids, all of them might have felt better, but Stan would not have made it. He also said that other physicians never place the dying patient on respirators. They did in Stan's case, to ease the pain of dying, but he passed away just a few days later.

When the resident finished explaining how Stan had been treated, one nurse thanked him. Then they all did. He said that he had admired Stan, and that he, too, wondered whether they could have done more. This is not an unusual reaction when the patient is one you know and like. The nurses then discussed when Stan had spoken to his priest, and wanted to call his mother before he was placed in the respirator. He said, "She would kill me if I do not let her know." Stan's parents, they said, were prepared for his death. Some of the nurses who attended his funeral Mass said that it was a sad, but somehow a joyful time.

Closeness to Patients

During the session I found out how close nurses and doctors can be to patients. I could also see how the telling of his death and the listening were therapeutic. Young and veteran nurses were present. One had come after being on the night shift with only a few hours sleep. The youngest was silent until the last few minutes when she began to speak of what Stan's dying had meant to her. Stan was the first patient she had come to know and love and had seen die. By the end of the session, it seemed that

they all had spoken. There was a kind of absolution given for their grief and the unexpressed feeling of responsibility for not having done enough for him. He had been a good patient. He had been a fighter.

After the session, I thought about the people involved in the meeting and how they tried to mend their feelings — talking, questioning, listening, and for the nurses, hearing the doctor speak about his own helplessness before the inevitable. He knew about the twists of C.F. and how it can attack a fighter like Stan or someone who might have given up. The nurses knew this, too, but they needed to speak about their own helplessness and to hear others say what they felt so deeply. It helped them, and it helped me to get to know how nurses and doctors admitted their own limitations in the face of death and disease. It was difficult, but it said something of the pathos of nurses and doctors when they lose patients they love. They lose something of themselves.

During the sessions in which nurses were directly involved, my understanding of some aspects of nursing and medicine became less abstract and atomistic. This showed me how many people are involved in the care of the patients. The physician, nurse, and social worker are just some of them. And one realizes that the doctor-patient relationship, or for that matter, the nurse-patient relationship, are not the only ones. There are too many people involved, and this theme — the professionals involved and the need of patients to be involved in their own care — kept going through my mind. This theme is also emphasized in the next section which describes one way in which medical students are asked to listen to their patients say something about themselves and their illnesses.

Professors and Students

Early in the sabbatical, I began attending psychosomatic rounds conducted by Dr. Henry D. Lederer, a psychiatrist, and Dr. John Collins Harvey, an internist. The conferences, which I audited on a regular basis during the sabbatical year, were part of the psychiatric rotation. They were intended to show medical students how individual patients reacted to their illness and to alert students to this aspect of patient individuality. For me, they were extraordinary lessons in the ways an ordinary patient's perception of his illness became an important factor in patient care. This seemed to be common sense but common sense perceptions are sometimes lost in the sea of data which has to be evaluated by doctors and medical students. Sometimes the patient himself is not noticed.

The word "psychosomatic" was interesting in itself since the rounds were not intended to show how the mind contributes to illness but only how mind and emotions make this illness the particular illness of this one patient. Later on I realized that the sessions were lived reminders of some of the forgotten aspects of the doctor-patient relationship which urged the students to listen to patients tell them they were persons and not just cases. Most conferences emphasized the second way of understanding the relationship of body and mind, that is, the way the patients looked upon

their illness with their fears, hopes, denials, or with courage and acceptance. The goal of the conferences was to show medical students how to see, with more sympathetic understanding, the emotional reactions of patients to their illnesses. The more common understanding of the body-mind relationship, the way fears and anxieties affect our health, were not the primary purpose of the meetings although these were not neglected if they appeared to be significant. Most of the time, though, some interaction of body and mind, spirit and matter, anxiety and illness was evident. Besides showing how illness was particularized in patients, the rounds also encouraged the student to acknowledge that some of the patients were likable while others were not only troublesome, but were very easy to dislike.

Present at these meetings were seven or eight fourth-year medical students, along with a few social workers and an occasional guest. One student was assigned to ask a patient to come to the conference, though a professor might also suggest that a particular patient be invited to the conference. At any rate, there were patients willing to come to the conference and talk about themselves. Then, when everyone was present, the student responsible for the presentation gave a history of the patient before bringing him to the conference room or if need be, we went to his room.

The patients we saw could not always be categorized as likable or unlikable, although a dignified old man said to be a problem for the nurses, and a woman liked by all nurses and doctors, won our admiration through their interviews. There were two others on the other end of the scale: a very difficult woman who seemed to get what she wanted from her doctors, and a man who despised women. Likable and unlikable, they were all patients and individuals. One of the other patients who came to the conferences, was a speechmaker. One woman was angry with all doctors, and finally, there was a woman who needed much more than the cardiac care she was receiving.

An Apparent Problem Patient

The dignified old man was in his late 60s, black, a double amputee, and confined to a wheelchair. He could not use artificial limbs. Admitted to the hospital with a great deal of disorientation, his diet was being regulated while other tests were conducted for diabetic-related problems. According to the report given by the student, he was a problem for the nurses. Manipulative, he wanted everything done for him. His incontinence did not seem to be totally deliberate, but his attitude toward it and about other matters disturbed the nursing staff so much that they made explicit mention on his chart of what he could and could not do without help. The patient did have other medical problems besides the diabetes and general disorientation — episodes of mild delirium. We were

told that neither the medical staff nor the nursing staff thought he could return to his own apartment where he had lived by himself.

After the patient had discussed his illness and his earlier days, he went back to his room. Dr. Lederer urged us to try to see a bit of what he had seen in this man judged to be manipulative and incapable of living on his own. He saw him as a strong and proud person who had good jobs during his working days. For many years, he had been head waiter at an exclusive club in Washington. During World War II, he served on a transport ship traveling without escort around the world. He was used to taking care of himself and now, at 69, he was understandably resisting life in a convalescent residence. He had his own home and he wanted to return to it. Dr. Lederer had encouraged him to continue resisting custodial care places if that is what he wanted to do. The social worker was later asked whether she could help him get the housekeeping assistance he would need if he returned to his apartment. Even though the patient lived in a difficult neighborhood, he wanted his freedom more than the protection of a nursing home.

Dr. Lederer noticed things. He pointed out to the medical student that the patient seemed to like him, and that he should look in on him soon. He mentioned that when he was being brought back to his room, the patient had reminded the student that he had forgotten his clipboard. The rest of us were told that we should be careful about the so-called troublesome patients, who were just asking doctors and nurses to let them take care of themselves as long as possible, which is not far from one of the first truths of caring for people.

Good Woman Patient

The presentation about the woman who was a good patient was detailed. Personal history, medical diagnosis and prognosis were given. The patient was said to be a good case since she presented the hospital and the medical students interesting teaching material — a rarely seen infection of the heart valve. She was also a good patient, liked by the nurses and the doctors, cooperative and not a complainer. She was just that way in the interview. When she had gone, Dr. Harvey and Dr. Lederer both felt that they had to point out that there were other medical problems present which might not be as interesting as a rare infection. She had some problem with her vision and there was a lesion on her breast, both of which needed their attention. The professors were concerned that the interest in the unusual and medically exciting might take attention away from other major medical difficulties.

Even with all the tests facing her, the patient was in good spirits. She was strong, educated, and thinking of retirement. She said her husband had wanted her to stop working and to begin "doing what she wanted to do when she wanted to." Both professors, in reviewing the interview, asked whether the students thought that her illness might have been the

occasion of retirement thoughts or whether retirement thoughts were the occasion of her illness. The second possibility was probed a bit with a discussion about the effects of stress during work and the stress which people face when they are thinking of ending the familiar and beginning the new. Research, it was pointed out, had shown some correlation of stress and infection.

The question of a cause-effect relationship between stress and illness was continued just briefly by mentioning the chemical changes brought about by stressful situations. The further question of how much she really liked her work situation was probed as one which could be followed. Perhaps the professors saw the need to press this question a bit, so that the students would not overlook something significant in this good, approachable, non-complaining patient. They wanted the students to see the whole patient, even if her cardiac disease was an interesting and rare infection. The students were probably more comfortable in talking about what medicine could do by way of cure or care than in speculating about the theoretical relationship between disease and stress. Most of the students did not have time for this kind of thought and investigation.

Philosophical Question

A last question proposed to the group was the philosophical one about why this woman at this time is the one who is ill. Responses given to this question by doctors and patients, as well as philosophers and theologians, ranged from fate or providence to determinism or random capricious chance. They were not the topic of the morning's session although I thought these common ways of looking at what happens to us, for better or worse. They are some of the explanations given by people when something goes wrong, and people become interesting cases and ask the doctor a non-medical question. Why me?

The session one morning showed another purpose of the conferences — to point out that students and doctors will have other patients, ones they really do not like. They have to understand this and find ways to deal with it. The patient who came to us this time was a very demanding woman, who did not know that this lesson would be learned from her visit. We had heard that she was a 65-year old woman with a long and detailed record of medical problems: an ovarian cyst, a tubal pregnancy and other problems not of life-threatening proportions. She was hospitalized often. This time she was admitted through the interventions of her "beloved" personal physician who convinced a staff member to take her in for observation and evaluation. After the interview, it seemed probable that the personal physician really wanted to have Georgetown take his patient off his hands. She had a whole litany of complaints to plead before us: "The admitting examination was impersonal; the nurses on her floor ignored her; the dieticians were not thoughtful." Everyone who did not give in to her demands and whining complaints was listed.

She would be tough to handle.

When she had gone, Dr. Harvey asked the students their opinion of the patient and the conversation. One student said he found the interview boring. He had begun to wander and found himself dozing. Others said it was difficult to pay attention to her. Then Dr. Harvey said: "Why not be honest and simply say that you did not like her, found her difficult to take, and that someone should tell her that she is a complainer?" He pointed out that many doctors are unwilling to admit they do not like some patients. Going back over what the patient had told us, he said that her personal physician must have given in to her demands all the time — that she could call him day or night and he would talk to her. Even at this time the patient's doctor could not say no to her and had arranged for her present hospitalization. Dr. Harvey told them to admit that they thought she had been spoiled and that someone should deal with it.

She was typical of some patients doctors would meet in their future practice, would be demanding and insistent upon extra special attention. The doctor should admit that he finds these patients difficult to take and even that he dislikes some of them. Stay away from them if it is possible or at least recognize the manipulating patient. It will be good for patient and physician. Admit the possibility of aversion, and do not pass patients like this on to others without letting the patient know that he or she has no pressing illness which demands such personalized and monopolized care. The good personal doctor took the easy way out, but he took a bed and time away from another patient.

Names for Difficult Patients

Difficult patients are given a variety of names. Turkey is one of them. Although the man who was described on another morning was not called a turkey, he was certainly a difficult patient. He was the living example of the patient no one likes. As it turned out, we could see he was not too happy with himself either. Described as successful in business, wealthy, married twice and divorced twice, the patient was now living with two women who took care of him. For their efforts, they were verbally abused and debased, as it was reported by the nursing staff. His illness, we heard, was a severe and crippling rheumatoid arthritis. Now a diabetic, with evidence of a mild stroke, his gnarled body commanded no great respect or occasioned any great fear, although his wealth had attracted some of the rich and famous to his summer places. It also brought women to his homes, some of whom took his abuse in exchange for a life style they could not have without him. The ones he now lived with were examples of this since they brought in food in violation of his dietary regulations, and in spite of this, he tried to embarrass them in every way possible. Nicely put, he was a management problem for the nurses and everyone dealing with him. He was, he said, waiting to be released from this prison

situation. Doctors were all right except for one woman resident who was humiliated by him. She was a witch, he said. I realized that he was divorcing her as he had divorced his two wives. He also waged constant war with the nurses.

The patient was all that his history said he was. His physical appearance would have inspired sympathy except for the way he ordered his private duty nurse to fix his bed and light a cigarette for him. Apparently the private duty nurse did what the staff nurses refused to do — accepted his demanding and imperious ways. Later, in the course of his conversation with Drs. Harvey and Lederer, he showed a different side of his personality, one not seen by the students and the nurses until now. His belligerent front broke down as he began to talk of his early family life and his mother, his phenomenal successes in business and his failures in marriage. He cried. He had nothing to live for. He was afraid of pain and suffering. He had had everything a few years ago and now he was nothing. The tears came when he told us that more and more in his isolation from all that he gained, he was dreaming of his mother and his youth. He was afraid of life although he said he was not afraid of dying. Born a Catholic and now a Mason, he was not going to go back to a religion given up so long ago.

Anti-Women Attitude

Whether he really loved his mother one cannot know. But he seemed to have used his life in great part as a weapon against women, even if they gave into his every demand. His attitude was simple: hire them, use them and fire them if they failed to submit themselves to him. This was a long, difficult session with a man no one liked. After the tears, he quickly returned to being a despot and bargainer. It was difficult for anyone to summon enough professional faith to see in him a person very much in need.

The other patients, not greatly liked or disliked, I remember just as different individuals in need. They gave their own signals about their illnesses and the way they should be treated. One patient was a speechmaker, his own patient advocate. When he came to the emergency room with complaints of chills, high fevers, and profuse sweating, his x-rays showed lesions on the lungs — tuberculosis. A policeman now, he had learned how to use city streets as his playground. When he was five, his mother, just 15 years old when he was born, gave him a quarter for the day and he would be practically on his own. He survived both the streets and fighting in Vietnam. Once married and now separated, he worked undercover, fighting heroin selling in the city. The patient, one could see, was in control. The medical student told us that he issued orders not to talk about him outside his room. He wanted to hear all, know all and validate all. When we met him, we found out that he liked to give advice and make speeches. Full of advice, cocky, self-affirming, he wanted his way in his care, even though he had no choice in his illness. He thought he

could survive the illness, however, just as he survived the streets in his childhood and the fighting in Vietnam.

The angry patient was a young woman with a colon disorder which was stressful, manageable, but by no mean life-threatening. Once informed that she would die in three years, she told the medical student that she had never been informed by the doctor about the exact nature of her illness. Understandably, she was distressed. We could see that she distrusted the doctor who first treated her and she seemed prepared to continue distrusting all doctors. As she told her story, it was clear that her anger was still strong. She thought she had been given an undeserved prognosis of an early death. She had lost a job, and had become very overweight. This was the account she gave to us.

Dr. Lederer was kind and gentle in his interview, listening attentively to her and talking about a possibly brighter future. She said again, however, that doctors were "jerks" and that any hope had to be tempered with their stupidity. Interestingly, she mentioned one exception to this indictment, the doctor who was treating her now, and according to Dr. Lederer, he was an authoritarian person. Dr. Harvey told her in very clear terms what her illness was and how it could be controlled. Later, when she had been taken back to her room, both physicians said they thought she really knew what her illness was but refused to accept it. She still hoped for a cure. The candor on the part of Dr. Harvey was not very well received, since she left the room without acknowledging the thank you given by the professors. She was sick and angry and needed help.

A Need More Than Cardiac Care

The woman who needed much more than cardiac care was described by a medical student as a white female, 49 years old. She had been admitted to the cardiac unit for observation. So far, there were no signs of a recent heart attack or, for that matter, of previous attacks, although she had told the residents she thought she might have had a mild attack once before. After the history we went to the cardiac care unit to talk with her. Calmly, quietly, and even plaintively she told us about her life. An alcoholic, now in A.A., divorced, with a son in prison on a drug conviction, she told us that her A.A. sponsor, on whom she was very dependent (it seemed to me that she was more dependent on him than on A.A.), had lapsed and was drinking again. She told us that he visited her only once during her stay in the hospital.

We left the room eventually. That is when Dr. Lederer asked whether a psychiatrist had been asked to see the patient. The medical student who had given her history said that she was to see someone in a day or two. Since she would ordinarily leave the hospital a few days after her stay in the cardiac unit, Dr. Lederer thought that someone should see her as soon as possible.

He pointed out all the signs of need she presented. She was very lonely, dependent and frightened. Even this one visit told us how isolated she felt when the one person on whom she depended — her sponsor — had abandoned her. She should not leave the hospital without some help or promise of help which the cardiac unit could not give. She was a patient who needed help to help herself, when the heart was not her problem.

The sessions with Drs. Lederer and Harvey and the medical students were invaluable to me. There were many “cases” and “persons” seen during the year. There were also many different kinds of medical students going through this rotation. The patients, some of whom were very likable or very unlikable, were more frequently ordinary men and women who volunteered to talk about themselves for the benefit of men and women who were learning through them and their professors that medicine is an applied science and they should remember that, as doctors, they would be treating persons and not just diseases. How important the sessions were to the medical students I do not know. Through the many conferences I attended, I could see that some medical students seemed to be far away, while others were very much involved in all the discussions. I hoped they could see how they were being taught respect for patients, liked or unliked, interesting or ordinary, a “turkey” or a good patient. I hoped that they could see how they were being taught to keep their promises, since the promise of respect and courtesy made to their volunteers was never compromised when they talked before the group. I hoped they learned that it was impossible to like all patients, and that they should not be surprised at these kinds of human reactions, and that no matter what their own reactions were, they had to see, through their likes and dislikes, the patient who needed them. Not all patients were likable, interesting and grateful.

Doctors and Patients

Neurosurgery

During the sabbatical year I spent a few hours every week with doctors and fellows and students on medical rounds. During the first few months at the center, I joined Dr. David C. McCullough, a neurosurgeon, on his rounds with three first-year medical students. Later I attended the early Friday morning patient reviews in obstetrics and gynecology with Dr. John J. Schrufer and his residents. Toward the end of the year, Dr. John S. McDonald took me with him on two sets of rounds in oncology. With Dr. McCullough, Dr. MacDonald, fellows and students, I went from room to room as they saw their patients. These sessions gave me an extraordinary opportunity to be present while doctors talked with or about their patients. At the same time, I could listen to patients talk about themselves and ask the questions. Besides experiencing this first hand, the students and I were able to ask our own questions once we left the patients. The rounds were clinical in nature, although many of the questions we asked were about consent, disclosure or the possibility of

discontinuing treatment in some cases.

My meeting Dr. McCullough typified what frequently happened during the year once I began attending rounds and patient conferences. One social worker called Dr. McCullough and asked whether I could speak with him about the work I was doing. When we met, he said I would be most welcome to join him on his preceptor rounds. The three first-year medical students were beginners and this kind of introduction might be best for me. Later, when I returned to the classroom, I realized that this call was an occasion of many extraordinary practical experiences so helpful in forming judgments about the cases I heard reported on television and read about in the press. At this time, I knew something about spina bifida and Down's syndrome, though I had never seen infants with these defects at the time of their birth. I was also unfamiliar with their treatment. With Dr. McCullough, I discussed some of the principles he used to make his own medical and moral determinations, and I listened to him talk with some of the parents of children born with severe or relatively minor defects.

The preceptor rounds were excellent ways to introduce first-year students, whose medical education for the most part consists of classes, lectures and textbooks, to the care of patients. When we met for the first time in Dr. McCullough's office, the students were wearing their white coats and I was given one to wear for the trip around the hospital where we were introduced to the patients as students and a visiting professor. Dr. McCullough asked us to observe and listen, but not to ask questions while we were in the patients' rooms. We were told to wait until later lest questions be asked which would alarm patients. He did not want to have this happen. Our questions after the visit were always answered in detail and some of them were best unasked in the presence of patients.

Four Month Old Spina Bifida Baby

First, we saw a baby of four months. Born with spina bifida, she had recently left Georgetown's Medical Center and the care of Dr. McCullough. Now she had returned with her young mother to the Spina Bifida Service where the two would come for the baby's medical care and where the parents could obtain the help they needed. Their medical, familial, and social needs would be many, and the service was ready to help them. The baby's mother was bright and capable, an employee of a neighboring hospital. She was understandably nervous, and I could see why Dr. McCullough did not want any questions during the visit. The mother had called the clinic often since her baby left the hospital and had spoken many times with Dr. McCullough and Cathy Quinn, nurse coordinator of the clinic. The baby, though, was one of the more fortunate of those afflicted with spina bifida. At this time, there did not seem to be any major problems. The baby was doing well. She would always have some bladder and sphincter problems, but she would be able

to walk with braces. Right now, she was alert and bright, and, it was hoped, capable of attaining considerable independence in the future if she had good care in her developing years.

We also saw a college senior, now an outpatient, making good progress after serious brain surgery. She was reading, talking, and seeing better, and was encouraged to hope for even greater progress. Injured a year previously, she was brought to Georgetown's Medical Center from another hospital whose medical staff was said to have given her very little hope. Her father had had her moved to Georgetown where there was this much more measurable success. I asked Dr. McCullough about the "other hospital" and he said that it was small and not at all prepared to do the surgery. Whether they were prepared to give up on her, as she seemed to think, he did not know.

On the way to the pediatric wing, we were told about a child of seven Dr. McCullough was about to see. The child had had seven operations in six months and was now terribly afraid of white coats. Dr. McCullough took off his own white coat and asked us to wait outside while he looked in on the the child and talked with his mother. The lad was not fooled, and he cried when he recognized the doctor even without his coat. While walking to the next room, I asked the doctor about parents and the way they had to make decisions about their children. One operation, a second, a third — and then I wondered whether they could be free and informed. He said that in this case, the parents seemed to know what they were doing but he also had noticed that the father and mother were handling the pressures with different degrees of success. The mother was very concerned and yet informed. The father was informed and very disturbed.

Time for Informed Consent

On these rounds in particular I thought about the importance of taking time to obtain an informed consent and the enormous difficulty parents have in understanding what they are accepting or refusing for their children. Parents are facing these decisions for the first time while physicians have seen babies like theirs often in their practice. The physician has to inform and try to present what he thinks best for the child and parents must do what they believe is best. I thought of those cases where the non-consent of parents seriously jeopardizes the health or life of the child and how the physician has to become the special advocate of the child, even if it means going to court. On rounds, I brought up another aspect of informed consent — when non-treatment is accepted by both parents and physician. When I asked what follows in these cases, I was told that sometimes the children are kept in the hospital where they are fed and kept free of pain. And they die.

The burden borne by parents and children who must live with permanent and recurring medical problems associated with spina bifida and other birth defects is awesome, and an awareness of this stayed with me a long time. I know that the birth and care of a defective newborn is sometimes said to be the worst and the best thing that has happened to a

mother and a father, since the care and courage needed to meet the challenges parents and children will encounter will be almost unlimited. I thought of the yet untouched Job lamenting his losses and afflictions and wishing he were never born. I knew that some mothers and fathers of children with birth defects feel this way about their children while others are able to give their wounded children their unconditioned love.

Many times rounds were routine. There were no emergencies. On these rounds, though, we were able to see how a doctor tries to explain what he believes is necessary for patients' care, then listens to their questions and waits for their response. This routine of informing and accepting a patient's choice was seen often, and once we saw two patients who were not receiving the treatment Dr. McCullough thought best. Information had been given but in one case a decision not to have surgery was made, while in the other, there was still indecision on the part of the patient. The decision not to have surgery was made by the parents of an eight-year old girl. Before we got to her room, Dr. McCullough told us she had begun a treatment of chemotherapy for a tumor discovered in the lower back of her skull. While chemotherapy was the choice of the parents, Dr. McCullough told us that the size of the tumor had indicated to him that both surgery and chemotherapy would have been the better choice. At this time, he spoke with the girl's mother and father outside of the child's room, and told them he thought a shunt might have to be placed in this area to relieve the pressure which was building up. He told them again that the surgery would be solely for this purpose since they had chosen to go with chemotherapy only.

Mother Asked Questions

The mother asked, what if the shunt were not inserted; how long would the operation last; would her head be shaven? The father cried and said he would agree if his wife agreed. Dr. McCullough stated that he would confer with the oncologist, and that both doctors would get back to them. There was no pressuring, though I know that Dr. McCullough did not doubt the necessity of the shunt. He said again that he had strongly recommended surgery with chemotherapy, but the other choice had been made.

Another classic case came up with the next patient. It was classic in the sense that one hears of patients and doctors in this kind of situation described in textbooks on medical ethics. An adult and a practicing Christian Scientist, the patient had been admitted to the hospital unconscious. Her children, not Christian Scientists, had given their consent to a life-saving surgical shunt procedure. When I saw her she was alert and waiting to speak with her Christian Science advisor about her decision on the recommendations made to her by the medical and surgical teams. In this case, Dr. McCullough later informed me, the standard treatment would be additional surgery and x-ray therapy or x-ray therapy alone. When we left the room, he talked about this kind of dilemma: the

conflict between what doctors say is a necessary medical intervention and a person's religious convictions. Later, I found out that the patient decided not to have the tumor treated. Discharged from the hospital in good condition, she did well for the two years Dr. McCullough was able to follow her, but then she decided not to come back for further medical evaluations. He thought that she had a great deal of guilt over her hospital treatments and the follow-up visits, so much so that she was reluctant even to have x-ray scanning.

One afternoon at Dr. McCullough's office we learned that he was in surgery repairing a shunt on a little girl. Told that we could join him in the operating room if we wished, we put on the required greens and went in to join him and one of his assistants. Looking up, he told us that if we felt uncomfortable watching him, we should not hesitate to leave the operating room. The girl's shunt was not draining properly and he was in the process of clearing it. He talked about the patient, saying that she was not doing as well as he thought she should, and that she had many hospitalizations. During the repair work, I realized that I was not really looking at a little girl but only her skull and a surgeon working on it. Later that year I met her wheeling around the hospital floor, talking with the nurses and the residents as she went by. She was in the hospital again.

From the operating room, we went to the ICU to see a patient just admitted after surgery in another hospital. He was showing signs of convulsing and Dr. McCullough wanted to check his shunt. We followed him to surgery but this time we waited outside the operating room while the shunt work was done. Maybe this was all that was needed. He seemed to be out of danger but he almost died.

Thoughts of Spina Bifida Baby

Leaving the hospital one night, I thought of the last patient we had seen in the nursery — a child born at a nearby hospital and brought to Georgetown University Hospital shortly after. She was a spina bifida baby, and, like the first child we had seen when we started the preceptor rounds with Dr. McCullough, there was no doubt about treating her. The opening in the spine was such that the baby's paralysis was not extreme and there did not seem to be other major defects. I thought not only of the baby, so new to life, but also of her parents, so new to having a child who would never be physically whole. She would look like other infants but she would be very different.

The whole day had been long, beginning with a patient conference in the morning and climaxing in seeing the newest neurosurgical patient. I was emotionally drained when we finished for the day. Later I got used to the routine of seeing patients who were seriously ill, although I never left the hospital without wondering about the parents and children whose lives were changed by nature's random selection of them as persons challenged in such a traumatic way. Many times, too, I said a non-philosophical prayer for these children and their parents.

Obstetrics and Gynecology

After several months at the medical center, I began attending rounds in obstetrics and gynecology. Held Friday mornings at 7 a.m., they were conducted by Dr. Schrufer who is now Georgetown's director of the division of maternal and fetal medicine. Consisting of a patient by patient review of the women in these units, the rounds were attended by residents, medical students, nurses and social workers. The meetings, lasting as long as there was something important to say about the patients, were of great interest to me not only because of the religious teaching of the Catholic Church on contraception, sterilization and abortion but also because men and women, despite the risks in childbirth and with all the difficulties in having a family, still choose to be fathers and mothers, and physicians still care about helping them bring new lives into their own lives.

On my first visit, Dr. Schrufer introduced me to the group as a priest, ethicist, fellow at the Kennedy Institute, and someone interested in learning about their work. Saying that I was going to be with them on a regular basis, he told them that I might be asked to comment on the moral aspects of some cases if the occasion arose. He not only made me welcome then but from the first meeting until the end of my time with him, he often gave me a simplified version of what was being discussed. Without this help, the technical language would have made it very difficult for me to follow the evaluations of the patients. Even with this help, I still had questions to ask after the reviews, but, I was able to follow them well enough to see that the residents and students were taught to be careful scientists, trusting in their experience and the experience of others and knowing also the limitations of their science. It was clear, too, that although they were scientists, the application of their science to the patient was more important than theory, for when they talked about the risks and benefits involved in therapies they were using, the lives and safety of mother and fetus were more important than theory or therapy. Applying therapies with caution, they were, it seemed to me, asked to remember everything that happened in the past and then be ready for anything to happen in the present. They lived with a watchfulness that came from the recognition of the certainty and uncertainty of their science. There was always a careful monitoring of all patients. Conventional and successful therapies were tried first, and only after this were other therapies considered.

What continued to impress me in all these sessions was the detective work going on and the tentativeness of the diagnosis given in some of the difficult cases presented for review. Each one was different in some respect, and procedures successful most of the time were questioned in other circumstances. The testing, I thought, must seem endless to patients, although in many cases one or two tests are sufficient for both the good and bad news. One discussion in particular focused on radical and

conservative approaches when surgery seemed to be the proper response to a damaged uterus. One method took both uterus and ovaries, while another removed only the uterus. The words I heard about both approaches, though, were "continued watchfulness." The pelvis hid a lot of tumors. The sessions were not, however, just medical detective work going on in the abstract; they were examples of specialists concerned with health, birth and the choices they would have to present to their women patients.

Some Cooperation, Some Lack

Some of the patients cooperated with the staff as these choices were presented to them. Occasionally, a woman made the staff wonder what she and they were doing. When the patients cooperated with their doctors, trying to do what is difficult but possible, such as bed rest, eating carefully and trying to follow instructions, there was a very strong patient-doctor unity in the care she was given. When a patient failed to take reasonable care of herself and the life in her womb, there was division and tension in this relationship. This lack of responsibility and failure to cooperate was rare, but it was a problem discussed one morning. The patient, in the fifth month of her third pregnancy, was a clinic patient who had been admitted for observation and, it was hoped, some education and motivation about her responsibilities to herself and to her unborn child, since she seemed to be on a disaster course. Overweight at 250 pounds, a diabetic, a diet-breaker, she went around the hospital when she was not being watched, searching out food which she then tried to hide from the nurses. She was living dangerously and the nurses and the doctors began to wonder why they should be so concerned when the patient herself did not seem to care and would soon be able to do anything she wanted once she left the hospital. The doctors saw many kinds of patients. One will do everything she is asked to do and more for the life in her womb while another is indifferent or even hostile to the life she is carrying.

One morning the session was going to be brief, the professor said, as he had a patient coming in an hour. The first matter, however, took a while and the meeting went beyond the appointment time. What led off was a complaint by the chief resident. A house case from the clinic had been admitted. Tests uncovered bleeding in the uterus and the presence of a large mass. Surgery had been called for. The unscheduled procedure was delayed until the end of a busy day and into the early evening. The residents on call were brought back from their homes only to hear at midnight that the anesthetist thought the operation was not an emergency. It could wait. The chief resident was angry. He had asked the anesthetist whether he would vouch for the woman making it through the night without hemorrhaging.

The resident then asked Dr. Schrufer whether the patient's status might have had something to do with the decision to wait. He wanted to know whether it was a matter of a double standard — one for the paying

patient and a different one for the house case. Dr. Schrufer listened and tried to diffuse the tension. He promised to make inquiries. He told the residents he understood their concern and their anger; he thought there was enough difficulty in their work and their hours without any added aggravation. I recalled that on another occasion, he had said there are two kinds of sweat: one kind when you operate and another kind when you worry. I thought he was explaining now that there are different kinds of anger — rational and irrational — and that he understood the kind of anger they experienced. The group relaxed a bit, but the reluctant anesthetist would be remembered. Besides learning that worry was one part of their residency program, they now saw that anger was another.

Discussion of Hospital Policy

After one morning meeting, I spoke with Dr. Schrufer about hospital policy concerning sterilizations. In particular, I asked about sterilizations when future pregnancies are considered grave risks for maternal and fetal health. I realized that the textbook cases of women who have dangerous pregnancies are realities in their lives and in the practices of obstetricians, especially in a university hospital. This question about the possible conflict between what some say is good medicine and what some Catholic moralists say is right conduct, was actually one of many queries which prompted me to ask for a sabbatical in a Catholic medical facility. What I had in mind were the very specific directives, concerning procedures involving reproductive organs and their functions, which are contained in the "Ethical and Religious Directives for Catholic Health Facilities."

The directives in question were those which exclude sterilizations, whether permanent or temporary, as means of contraception, and allow only those procedures which "are immediately directed to the cure, diminution, or prevention of a serious pathological condition, and are not directly contraceptive."

Dr. Schrufer told me that the policy of the hospital required that any proposed elective sterilization be reviewed and approved by a committee, while a sterilization done in an emergency would be reviewed by the same committee after the surgery. We talked about the principles used in coming to these decisions. I never heard the committee at work, but I did see how the staff had to balance great care for the integrity of their patients and respect for the directives they were asked to follow. This balance would be all the more difficult to keep if the committee adopted a strict interpretation of the directives since such an interpretation does not permit sterilizations aimed at preventing future pregnancies, even if it would be extremely dangerous.

The implications for obstetricians and gynecologists working in Catholic hospitals, to say nothing about women receiving care in these facilities, are obvious if this strict interpretation is said to be the only proper way to apply the directives. As I continued attending the weekly rounds, I became more and more convinced that the traditional distinction used in the directives, between a direct and an indirect

sterilization, (one contraceptive in intent as opposed to those directed to curing or preventing a serious pathological condition), was more than acceptable in theory and practice in the majority of cases. The terms describe procedures which save the lives of women and still respect and save, if possible, their life-giving power. The distinction did not, however, seem adequate for some cases when sterilization seemed necessary to prevent the possibility and the likelihood of future life-threatening pregnancies.

Procedures Cited

The procedures cited as the kind of sterilization permitted that involving removal of an organ, ovaries or uterus, which are themselves diseased. These and other procedures, some justified by the principle of totality and others by the principle of double effect, are the only ones permitted, according to the traditional moral teaching contained in the directives. They, as indirect sterilizations, are contraceptive in effect, but not in intention. Direct sterilizations, on the other hand, even though they are frequently therapeutic, in the medical sense, are seen as contraceptive in effect and in intent, and for this reason are said to be unjustified and so forbidden. Contraception and not therapy, such as the removal of a diseased organ, is the purpose of such sterilizations, and a future pregnancy, even with the likelihood of grave consequences, is not the same as an existing pathological state of the reproductive organs as a justification for this kind of surgery.

Strict Interpretation Questioned

Like so many other matters, though, a strict interpretation of the directives is questioned by Catholic moralists, and as I listened in on more and more patient reviews, I had greater difficulty with the kind of distinctions which generate hard and fast precepts governing physicians in Catholic health care facilities. I disagree with those who say that every sterilization done to prevent future and dangerous pregnancies is wrong "in itself," no matter what the consequences. I saw too much grey between the extremes of direct and indirect sterilizations. I thought that the concepts and the categories they build were too narrow to satisfy the clinical necessity of many medical interventions which do not fall nicely into "the either or" of the types of sterilization described by the directives and said to be allowed or not allowed in a Catholic health facility. It seemed that those sterilizations done to prevent both very dangerous pregnancies and especially life-threatening pregnancies should be judged in their totality, and that values other than a woman's reproductive integrity, far from being unimportant, are a major consideration. In the language of common sense, this kind of sterilization is not just contraceptive, even though infertility is the result or even the intention of the procedure. Rather, this kind of sterilization is therapeutic in both the medical and human sense of the word and, for that reason, justified.

Respecting, as I do, the philosophical and religious values which helped to form the "Ethical and Religious Directives for Catholic Health Facilities," care for women and a concern for their power to give life to another, I would also like to point out how important these values are for those who find fault with the rigidity of the categories expressed in the directives. These moralists emphatically note that not all contraceptive sterilizations are selfish and merely self-serving. Many times they are sought by women who not only have their own lives to live but are also mothers of children who are still young and very dependent on them. And these are just some of the grave concerns that matter to mothers and fathers and moralists who believe that some sterilizations fall between a purely contraceptive sterilization and those sanctioned by the directives.

Looking around the conference room when some very difficult pregnancies were the concerns of the Friday rounds, I saw residents who had come to Georgetown University Hospital because the Medical Center and the hospitals affiliated in the residency program presented an excellent opportunity to experience a wide variety of obstetrical and gynecological training. Many had sought the program because Georgetown is a Catholic hospital, and they knew that they would not be forced to do abortion work or be made very uncomfortable if they asked to be excused from this kind of work. I did not, however, get the impression that many of the residents, students and other health care professionals, except for Dr. Schrufer, myself and a few well-instructed and sincere Catholic residents and medical students, were concerned with the terms and the implications of the directives allowing one kind of sterilization and forbidding another. If the residents and the medical students choose to abide by the spirit of these directives in the future, they may or may not be at ease with the policies they find in the different Catholic hospitals where they will work. If they do not choose to work in Catholic hospitals, they know that they and their patients will have greater freedom. Whatever their choices will be, they were united in their concern for the total health of their patients and not just their reproductive ability. Having children is important and not having children is also important in some cases, and these choices have to be made and evaluated by patients and physicians in the light of good medicine. Moral theologians and ethicists are aware of these strongly competing values, and such an awareness should make them more careful about issuing statements and forming precepts for all cases and at all times. The categories of right and wrong which their disciplines have formed can be right in the majority of cases. They can, however, fail in those cases when some sterilizations fall between the "either or" of indirect (and morally justified) and direct (and morally wrong).

Oncology Rounds

When I began my last clinical session, I realized that I was finishing the year. This time the rounds were with Dr. John S. MacDonald, a medical

oncologist, who invited me to go along with him on two kinds of rounds — one with residents and research fellows, and the other with first-year medical students on preceptor rounds. I would be with specialists and beginners, and instead of just hearing about cancer patients as I had done on social work rounds in oncology, I would be with Dr. MacDonald as he talked with and examined patients in the hospital and the clinic. This was another very difficult specialization I had wanted to see, and the invitation gave me many opportunities to listen and learn about patients and doctors.

The rounds were brief the first time, and they left me with impressions deep and difficult to define. They were very different from the feelings I had when I had seen other patients since most of the oncology patients did not appear to be critically ill or dying, or even in great pain or discomfort. There was not a lot of time spent talking about symptoms, although the patients were always asked how they were feeling before and after their chemotherapy. Their progress, I knew, was measured by this norm, and the laboratory reports were more important than the presence or absence of other symptoms. We visited just five patients the first afternoon. We started with one who had undergone surgery and had begun chemotherapy, which he found very difficult. He asked many questions about his progress and what he should expect from the treatments. He was concerned about his wife, who was not coping very well, was very depressed and did not believe the reasonably good reports she was hearing.

The next patient was a young man with a rare pulmonary cancer. The third was a gentle and genial elderly woman who wanted to know who all of us were. The residents and fellows were introduced by Dr. MacDonald as doctors, and I quickly volunteered the information that I was not a doctor, but that I taught premedical students and nurses. Other times, the rounds were longer and the conversations personal. So much time is spent waiting for laboratory reports that I thought it would be wrong not to take time to listen and talk to the patients, especially since their waiting is a waiting for signs of success and failure. Patients then and later always seemed to hope, although they knew that failure is also a function of treatments so imperfect in many cases.

When I met Dr. MacDonald one afternoon, he was waiting for a patient who was coming in for a procedure which would last about four hours. He was to be hooked up to a machine which would exchange cancerous elements in his blood with healthy replacements. This treatment is a last resort, not for arresting the cancer, but as a means of prolonging life after all other therapies failed. The patient looked pale and weak when he came. He apologized for being late. His wife (he said his "life") had left him off at the wrong entrance, and he had to make his way through unfamiliar parts of the medical center. When I saw him again, he was lying down with tubes attached. The four hour procedure was life saving for him. His wife wanted him to have this treatment,

although they both knew that it would not do any more than delay the inevitable.

Additional Procedures

The first hospital patient we saw one afternoon was a 65-year old woman with an infection of the spinal column, thought to be a side effect of her chemo. Though this was being treated, the patient looked very ill and understandably depressed. There would be a neurological consult for this long-suffering cancer patient who could not forget her many hospitalizations. Another woman, with cancer of the pancreas, had surgery to free the liver which had been impeded by the enlarged pancreas. The patient was jaundiced, and she asked about other difficulties. She was alert, strong and self-possessed.

On the way back to the office, we spoke about procedures, protocols, experimental and standard problems associated with obtaining consent from patients who hoped for too much or did not hope enough. Patients must know that some are experimental and not just a matter of a reasonable medical risk. Acquainted with the uncertainties, some still hope that the research is also going to be therapeutic in their case. How difficult it is to inform this kind of cancer patient about the hopes and possible failures involved in this kind of intervention! And the patient has many different reasons for saying "yes" or "no" to what is presented.

The first preceptor rounds in oncology were with three first-year medical students just as new to this as I was. After this first time around the hospital with them, I felt a little better, since one of them said that this kind of experience with cancer patients was a "bummer." So much has to be done and there is so much waiting and uncertainty. There is also a beginner's impatience and feeling of helplessness.

The first patient we were to see was not in her room when we came back to her later. Dr. MacDonald told us that she would not be helped by further therapy but that she had asked for anything that had some possibility of success. A regimen that might delay the course of her cancer for a short time was started. No promises were made when treatment began again. She refused to accept failure and she remembered only the initial, partial and temporary success of her first treatments. "You did it before." She was a "never say die patient." Another woman, in her 70s, had had a mastectomy prior to this hospitalization. Now treated for angina, she says she is not afraid. She is even happy to be in the hospital. Tests have ruled out any serious cardiac condition and there have been no indications of additional attacks. Dr. MacDonald talked with her, examined her and encouraged her after she had begun to speak of her depression, which she said was "not about her mastectomy." One doctor, previously her own, had suggested psychiatric help, and then she went to another.

One session was an abbreviated one. We went right to the clinic which was crowded into a small area for offices and examining rooms. The Lombardi Center is now a happy contrast, with its offices and patient care

units. One patient was in her late 50s. A massive breast tumor had been removed some time before and subsequent chemotherapy had been successful. She had passed the waiting time for any reappearance of the cancer, and she was a happy woman, grateful for the care she had been given. Her examination had already begun when we came into the examining room, and the oncologist was not prepared for us. Covering the woman's chest, she asked whether all of us had to be present. The patient herself then said: "It's all right with me, if it helps you teach about cancer." Once more the doctor noted that there were a lot of people in the room, and I admired her for giving the patient a chance to say "yes" or "no" to the rounds group. We would not have intruded and it was good to see that the staff members were sensitive to the feelings of patients. I knew that it did not always happen in teaching hospitals.

Final Week of Rounds

New patients were to be admitted my last week on rounds, and we saw only three who were in different stages of treatment and care. One would receive only care from now on, since all the treatments tried had been unsuccessful. She was comfortable, but it was just a matter of time until the cancer, resisting surgery and radiation, would take her life. Another patient, a young man in his early 20s, had just been admitted. He had gone immediately to his doctor upon discovering a lump in one of his testicles. The hope was that early detection and subsequent surgery would be successful in this case. The chances were very good that he would be one of the fortunate ones. This cautious good news he heard though he still looked frightened.

The last patient had been treated for Hodgkins disease, which some say is the best kind of cancer to have since the percentages are on the side of the patient. I understand what is meant by this "good news", but I wonder whether the person who first called this disease "the best kind" to have, ever had cancer. The patient was a professional woman, bright and successful. The questions she asked were specific and intelligent.

Going back to the office with Dr. MacDonald, I thought of the ways doctors and nurses managed to protect themselves in oncology work, since even the good news is so qualified. With good news, there is great relief and some caution on the part of patient and doctor, and there is continued waiting, watching and testing. At this time, in particular, there had been a number of deaths. Cancer had won, and the staff, especially the nurses, felt the loss, since some of the patients had been with them a long time. Some they knew through one long hospitalization; others they knew through a series of admissions. But in both cases, knowing them so well made it very difficult, and I saw how this close nurse-patient relationship in cancer care can be so strong that the very sensitive nurse is also very vulnerable, unless she is a person who has made her peace with the limits of medicine. What made me think of this before I heard of the recent deaths was that I overheard one of the nurses — one who

impressed me much earlier in the year — talking happily with two patients who were ambulatory. Relaxed and friendly, she was the one I remembered being so quick to point out any significant changes in her patients. One of the research fellows had also noticed how great she was with the patients and how at ease with the medical staff. She was “tops”, he said, and the patients knew it. I thought it could very well be the best way for a doctor or nurse to care for cancer patients. With all their waiting, watching and testing, there is still life after cancer for the fortunate and it is necessary to remember these successes as a source of hope.

III

After the Sabbatical

The many sessions in the medical center were helpful to me in two different but related ways. I was gradually able to fill some of the gap between my limited knowledge of health care work and the clinical experience of my students, especially the nurses who had almost finished their degree requirements. I was also much more at ease with the fact that my students and I differed in the way we viewed some of the moral stands of the Catholic Church.

Learning more about patients and their care came through the repetition of rounds and conferences. Beginning with the assistance of Dr. Hellegers and the direction of Dr. Shevlin, it continued through the year as social workers, professors, nurses and doctors encouraged me to know more about the very human science and art of caring for patients. More than assisting me in my work, they enthusiastically endorsed my efforts to be with them in their day to day professional work. Their willingness to let someone outside their profession observe their work in such a personal way was a special reward of the sabbatical. Through the sessions, the many relationships of responsibility came to life. Besides the ways in which doctors and nurses related to patients and to each other, I began to see how social workers and other professionals were involved in the hospital setting of obligations to patients and professions. Social work rounds were the first to exemplify this many-faceted effort of caring for patients and respecting fellow professionals. Subsequent rounds continued to show the complementary nature of their work, and this increased awareness of the complexity of the medical decision-making process helped me to understand in more concrete terms the different conceptual models used to explain professional relationships. It also made me more comfortable with questions about patient rights, professional cooperation and potential role conflicts. Most of all, the year gave me the opportunity to see that health care decisions are not just the estate of any one professional group. Patients are not the doctor's or the nurse's or the hospital's. They are their own persons. They belong to no one.

With this multi-professional caring for patients, there were many benefits both for patients and their families. There was also a possibility that nurses and doctors might forget how dependent patients become when they enter a hospital. By being admitted to the hospital, their capacity or their willingness to decide for themselves could be diminished, and doctors and nurses, as well as all health care professionals, have a special obligation to foster those conditions which preserve this right and even encourage patients to make informed choices about their care. No one I met wanted to return to what used to be so prevalent in health care — the paternalism, maternalism and the childism of the past — with doctors and nurses expected to care for patients as if patients had lost their right and obligation to decide for themselves simply because they were ill. This kind of hope in the active agency of the patient is admittedly difficult to realize and yet it should remain an ideal. It also should be presented to patients in ways which help them assume responsibility in their treatment and be confident that the health care professional is willing to wait for their word when difficult decisions have to be made. If this ideal cannot be realized in its entirety, patients should be encouraged to be self-determining to the extent that this is possible. Rather than basing health care on the hierarchical superiority of health care professionals, the primacy of the patient should be asserted.

Visits to Intensive Care Nursery

Perhaps the most valuable experiences of the sabbatical were the regular visits to the intensive care nursery. These visits and the neurosurgery rounds with Dr. McCullough would have been enough to make the sabbatical worthwhile. They introduced me to the doctors, nurses and social workers caring for infants who were in great need, and the visits have been recalled very often as examples of all that technical skills and human caring can do for the patients who cannot speak for themselves. Especially through the many social work conferences filled with concern for Baby Adams, I came to a better understanding of the reasons why other babies, now famous as Does and Roes, might be allowed to die because of handicaps, or be treated in spite of handicaps.

Seeing for myself the dedication of the doctors and nurses was important to me. Most impressive, however, was understanding how all of these highly trained specialists worked together. In their care for these patients so new to life, I saw the best example of what can come from the cooperative relationship of nursing and medicine. In this unit in particular, the nurses were highly skilled, respected and trusted. Physicians accepted their competence and relied on their judgment. There was no need to play the "doctor-nurse game" in which the nurse would have to give physicians any necessary information about the infants in their care by indirection rather than by openly stating the nurse's observations about the state of the patient. There was no need to suppress the nurse's competence for the benefit of preserving any

hierarchical superiority of physicians. Nurses volunteered information which was theirs through monitoring the critical infants in their care, and they asked doctors questions in very direct ways. Doctors, in turn, volunteered information to the nurses, sought information from them, and never treated them as purely auxiliary professionals. Most of all the visits to the ICU gave me a chance to experience for myself what I had read in articles and textbooks. One obvious insight was that the clinicians had to make their decisions, at least in many cases, without the time to weigh a lot of alternatives. Unlike the ethicists and theoreticians who have the luxury of time to decide on what should be done or not done, time factors and the necessity of doing something or nothing were of paramount importance for the doctor and the nurse. Of course their decisions were made on the basis of the principles of medicine and caring for others which they formulated through their experience with the crises and emergencies of the past. But they had to apply these principles and make these decisions when lives were in their hands. The urgency and the finality of these kinds of decision making were not easy to live with. They were also new to me.

Differences in Value Judgments

Appreciating the differences in value judgments among the students in my classes, (the other principal benefit of the sabbatical), had its beginning in the realization that many of the health care professionals I met in the medical center were very much at home with the "Ethical and Religious Directives for Catholic Health Care Facilities" while others disagreed with the absoluteness of some of these directives. Accepting the differences continued as I talked with those who spoke of their views concerning contraception, sterilization and abortion. I also became more familiar with some of the medical reasons for these views and had a better understanding of the ethical theories which I thought preserved the religious values in the directives and still responded to the medical needs of patients.

The beginnings for some of these changes came through one meeting in particular early in the year. This was with Rev. Robert C. Baumiller, S.J., a professor in the department of obstetrics and gynecology. I had asked to talk with him in connection with a course in medical ethics which he directed, one which Dr. Hellegers thought I would like to audit. Father Baumiller said I would be welcome to come to all lectures in the series or come when a particular topic interested me. As it turned out, the time of the lectures was in conflict with the rounds I was to begin with Dr. McCullough, and I decided to do the rounds rather than attend the lectures. During our conversation, though, Father Baumiller and I talked about the content and purposes of ethics courses in general and medical ethics courses in particular, the kind of courses offered in medical school, and the courses offered in undergraduate colleges. After a while we spoke about obstetrics and genetics, his fields of specialization. It was in this

context that I mentioned how many of the pre-professional students I taught accepted abortion as a moral option, and I expressed my own personal ambivalence toward abortions in general — an ambivalence which understands abortion in some life-threatening situations while rejecting it as the solution to any and every unwanted pregnancy.

After the meeting with Father Baumiller, I often thought of ways to discuss some of the issues associated with the use of amniocentesis and genetic counseling since they are generally accepted as medical practices and diagnostic tools by health care professionals and because many people believe that the use of amniocentesis brings with it a hypothetical approval of abortion. One first step in teaching about such matters was to realize that I had developed some rather firm views through a longstanding and thorough Catholic philosophical and theological orientation. A second step was to admit I did not want to say that my faith and reason responses were the only good faith answers to these questions. A third step was to try to show persons of different faiths and consciences how the Church's principles concerning respect for life lead to conclusions which I have accepted. Students would be invited to do the same in any class discussion. This, I thought, any course in ethics should do and especially a course in medical ethics, given in a Catholic school. I also thought these steps were wise ones to take, not only in the discussion of delicate issues such as abortion, but in questions about the termination of pregnancy or the termination of a treatment for an irreversibly dying patient. Understand your own values, appreciate the values of others. Be ready to show how your opinion is justified and invite others to do the same.

Course in Speculative Analysis

An alternative to taking such stands on moral questions, one that should be resisted even though its neutrality might be easier in some respects, would be to offer a course which limits itself to a formal and abstract exercise in speculative analysis, far removed from the life and realities of moral decision making. This kind of ethics — speculative thought about the science of ethics and its norms — is important, but it can be taken as an end in itself, and in the case of medical ethics, it might be used to shelter professor and student from the necessity of making difficult decisions about life and people. Then and now I thought that any course in applied ethics should have a practical orientation and that this practical orientation should bring those taking the course to moments when they have to make moral evaluations about concrete, particular, existential situations. A course in ethics should, therefore, be one that not only tells how arguments and conclusions come about, but it should also help a person make particular judgments about the rightness and wrongness of different actions. I know that the conviction that ethics can lead a person to moral truths about particulars is not philosophically popular, but for me, it seems a very important reason for doing ethics. I also am aware that a person with such convictions might appear dogmatic

or prejudiced. This danger, if it is a danger, can be avoided if the ethicist reminds himself of the many different opinions others have about mortality in general and health care ethics in particular.

One very successful way of making myself aware of the opinions of the students taking a course was to introduce a case day at the end of every unit studied. The cases were taken from standard textbooks such as *The Nurse's Dilemma*, an International Council of Nurses publication, printed by the American Journal of Nursing Company; *Critical Incidents in Nursing*, a compilation of cases and opinions written by health care professionals; and *Case Studies in Medical Ethics*, the well-known case book written by Robert M. Veatch. The syllabus listed cases we would do for each unit, and students were required to volunteer for one of the cases in particular and be responsible for all of them in general. I also decided to have the cases discussed in an informal way. On the case day, I would ask for a volunteer to review the essentials of the case he had read, and then to make any observations. Others were invited to add their comments. There was a lot of agreement on many issues and yet, there was always someone who saw something different and expressed another moral point of view. With the good intention of just leading these discussions, I tried to wait until all the volunteers had something to say before I gave my own opinion. After a while, the case day became the best way for me to listen to others and still be able to take my own stand on particular issues. Listening to others helped everyone take a stand and express personal opinions in an atmosphere of mutual respect.

Silence on Morality of Abortion

Besides giving everyone a chance to see how ethical principles were applied to common situations which nurses, doctors, and families would meet, case days helped me to understand some of the silence of the students when abortion was the moral issue in the cases for discussion. Through these informal exchanges I could see that the reluctance of some students to take a stand against abortion and to express such a view was due to an uncertainty about what they would do if they or someone they loved were pregnant, frightened and forced to decide about continuing a pregnancy. Besides their unwillingness to judge others, a number of students simply approved of abortion when pregnancies were of a life-threatening nature, a grave danger to a woman's mental health, and when fetal disorders of any great magnitude were discovered. Most students who accepted abortion as a moral option in these cases were sympathetic to the other more common reason for abortion — any unexpected, unplanned, and unwanted pregnancy. And even though both groups viewed abortion as a disorder or regrettable, the many exceptions to a responsibility for fetal life proposed to them through the moral climate of their young lives and in the civil forum helped to make their reluctance to judge others even stronger.

At times like this I spoke of my own unwillingness to judge others, but I

also said that I did not want to give the impression of neutrality on this issue by not expressing an opinion about taking fetal life. Reasons could be given for saying that abortion for non-life threatening reasons was a moral disorder, even though all of us understand how some women see this as their only choice. It was a chance to say that such an opinion is not a condemnation of the ones who think and act differently, a chance to say that the act and the actor are different and that they should be seen as such. One should judge the first. One should not judge the other.

This separation of what abortion is and why it is accepted by so many women is very difficult since we all know many men and women who maintain that only the woman herself has the right to say yes or no to abortion. Abortion for her is seen to be morally acceptable. Abortion, in the words of Magda Denes, is done "in necessity and sorrow," and in the minds of some, it is seen as the only choice of women unwilling to have a child. They not only do not believe they are doing anything wrong but believe it would be worse to bring a child into the world in their circumstances. In spite of this situational and personalistic kind of reasoning, I still hoped that some of the students would be able to separate the "objective" and the "subjective" elements in any decision to have an abortion, that is, what an abortion is in itself, and why abortion was chosen. By making this kind of distinction, I hoped that those who had accepted a pro-choice position would then look upon the frequency of abortion with more concern, even though I did not think that they would modify their position. On the other hand I thought making this kind of distinction would be a help to those students opposed to a pro-choice position to speak out on the side of life without being judgmental.

Both transformations — learning more about the hospital setting as well as appreciating the differences in value judgments — came in time. The first development was often exciting and dramatic. The second, quiet in coming, left me with the realization that teaching others and respecting their consciences, is not unlike the responsibility of doctors and nurses towards their patients. Both professor and health care professional have values of their own and both must respect the values of ones they touch professionally. And just as the doctor or the nurse may say no to abortion work in particular, while understanding how their patients have come to a choice which they themselves would not make, the professor, especially the ethicist, may have his own strong convictions while understanding how his students have equally strong and personal views to the contrary. In this way, the doctor and nurse are not indifferent to practices they believe are wrong and the ethicist is not indifferent to what he believes is an inadequate theory about the value of fetal life. And just as the patient is not the doctor's or the nurse's or the hospital's patient, the student is not the school's or the professor's student. The student is his own person with his own rights and responsibilities to form and follow his conscience.