

A Silent Anguish

Recognizing the Needs of Dying Patients and Their Families

A report prepared by Georgia Health Decisions

INTRODUCTION

This report captures the experiences and attitudes of family members of patients who died in a hospital setting from mid-1997 through 1998. Family members were solicited from the next-of-kin lists provided by eight hospitals across the state. The deaths of 100 individuals were represented by those who attended the eleven focus groups conducted by Georgia Health Decisions during the fall of 1999. Most of these patients experienced chronic, long-term illnesses, including pulmonary disease, renal disease, heart disease, diabetes, stroke, AIDS, and various forms of cancer. A few had died suddenly or following an illness of short duration.

Participants in the focus groups were asked to discuss a range of topics related to their loved one's illnesses and the health care their loved ones had received during the course of their illnesses. These issues included:

- Their knowledge and use of advance directives in planning for their loved ones' final health care
- Their hospital experiences, primarily what occurred during their loved ones' final hospitalizations
- Pain management
- Cost and insurance coverage

As can be expected, these conversations were often emotional, yet they also were informative and insightful. Participants were willing to discuss very difficult times in their lives and talk openly about topics they normally avoid. Their experiences were compelling and their reflections powerful. Their comments were thoughtful and carefully considered. Throughout these discussions, common themes and experiences became apparent.

A significant finding emanating from this research is the inconsistency in family members' perceptions of the quality of care their loved ones received. Participants whose loved ones had been in the same hospital during approximately the same time period would relate widely divergent experiences regarding their level of communication with doctors and

nurses, the personal attention given to their loved ones, compliance with patients' wishes, pain management, their own treatment at the time their loved one died, and many other topics discussed during the focus groups. Family members in every focus group from every hospital represented in the study had significantly different experiences. Yet, there are still remarkable consistencies of experiences when all eleven conversations are taken as a whole. This report attempts to present both the variety and the consistency of experiences.

"Luck of the draw" seems to be the only factor in why one family had such a differing experience from another within the same institution. It could have been related to the floor they were assigned, a doctor who was involved in their loved one's care, or most often, the compassion of one particular nurse or aide. As a general rule, the shorter the time a patient stayed in the hospital, the more positive the experience seemed to the family members participating.

It appears evident from this research that hospitals lack comprehensive policies and procedures related to the care of a patient who is actively dying and support of the family during and following the death experience. Rather, family members are left to fend for themselves or, with luck, find the support of a caring doctor, nurse or aide. Whatever the reason, the stories related by these family members are occasionally uplifting, but more often reflective of a system that responds inadequately to the needs of the terminally ill and their families.

COMMUNICATION WITH DOCTORS AND NURSES

The primary factor influencing how family members felt about the care of a terminally ill loved one was the degree to which they understood their loved one's condition and their ability to receive and comprehend information from doctors and nurses during hospitalization. While many participants believe their doctors provided all the information they needed to understand their loved one's condition, treatments and prognosis, far more said that trying to get information was their biggest frustration while their loved one was a hospital patient. The consequences of poor communication are far-reaching, often resulting in a patient's Living Will being ignored, futile care being provided, families being confused about a loved one's condition and bewildered by the system. A woman in Atlanta offered her perspective on this issue when she said, "I think we need a lot more communications with our caregivers. Otherwise, you're just standing there, and you don't know which way to go. Nobody is really there to help you." A North Georgia woman offered, "If you know what's going on with a family member, you know what to expect. You're prepared. But, if you're totally in the dark, you have no idea what to expect. The next thing you do is jump at something that may or may not exist."

A number of participants reported having had good communications with their doctors and nurses throughout their loved one's illness and hospitalizations. Not surprisingly, these family members also had the most positive experiences at the time of their loved one's death. A man in rural Georgia described his experience this way: "I think they did a good job of telling us different things. The nurse was real good. They would come and talk to us. When she died, the nurse came in and talked to us. The doctor cried with us." An Atlanta man added, "The heart doctor was excellent in keeping us informed. He had a nurse that preceded him in the morning. She would make rounds and then report to the doctor what the situation was. When he came in, he was in a good position to give us a good run down as to what was what." And a woman in South Georgia said, "I would say we had excellent communication. They were just continually telling us everything, giving us blood reports and x-ray reports." A woman in the Atlanta area was very appreciative of the concern and care provided by the doctor who treated her husband. She said, "The doctor couldn't have been better. He was very honest with us. And the minute my husband died, he was there with us. I don't know how he got there as fast as he did. He was there for us."

However, other family members across the state expressed frustration at not being given adequate information or being kept in the dark about their loved one's condition. They provide numerous reasons why communications break down when a patient is admitted to a hospital, and describe a system that, at best, is hit-and-miss when it comes to providing appropriate information to patients and families. An Atlanta woman commented, "It would be like I wasn't even there. He had more doctors than the hospital had. I didn't know what was really going on." A man in South Georgia noted, "My wife had a lot of different doctors looking at her. If you'd ask them a question, they'd just go, 'Well, we don't know. We're trying to find that out.' It was just that you couldn't get any information." A woman in another South Georgia group agreed by saying, "Getting a doctor to tell you anything or say, 'Yes, this is what is going on,' is absolutely impossible."

One of the reasons participants offer for the lack of communication is that doctors and nurses do not want to take time to explain a patient's condition or the treatments being given. A few family members believe that some nurses feel it is actually an inconvenience to speak with family members. A man and woman in an Atlanta focus group had the following exchange on this subject:

Man:

"The nurses think you're stupid, or don't want to admit that you might really be interested and want to hear the condition. They won't tell you. If you ask them, they give you a very generalized answer to get rid of you. They don't want to be bothered."

Female:

"The rolling of the eyes is what got me when you asked a question."

Participants say that family members have to be extremely diligent if they wish to talk to doctors about their loved one's condition. Family members try to make sure they are present when doctors make rounds so that they can ask questions. However, this tactic is not fool proof, as doctors change their routines or skip a patient's room altogether. "If you're not there at 7:00 or 7:30 in the morning, you won't catch the doctor," noted a woman in South Georgia, while a man added, "You do have some communications problems, but most of it is hemming the doctors up so you can talk to them face to face. If you can pin them down, you can talk to them." Participants would recount experiences of tracking doctors down in their offices or even in the operating room in order to get information about their loved one. An Atlanta man who recognized the demands on a doctor's time tried to be considerate by making an appointment so that his family could ask their questions. He angrily reported, "We were all sitting around down there, and he never showed up. Finally, I had him paged, and I got him there. It was like he was doing us a favor."

For some, being able to get good information meant being on a specific floor or wing of a hospital. Since many of these patients had multiple hospitalizations, family members soon learned the floors where their loved ones received the best care and which nurses were the most accessible and open to answering questions. One participant explained, "I asked the doctor to have her transferred because she wasn't getting good care, and I wasn't getting good support. I was not getting good information. I had her moved to another part of the hospital where the nursing staff is much more supportive."

Communicating with physicians was particularly difficult for those who had loved ones in an intensive care setting and were only allowed to be with the patient during specific times during the day. These family members complained that accommodations are not made to keep families informed about their loved one's condition and treatments, and they would often go for days without talking to a doctor. "I sat there 22, 23, 24 hours at a time, and I had been there for 2-3 days. I never got to see a doctor," said a woman in South Georgia. A woman in rural Georgia had the same experience. She noted, "I was always in the waiting room across the hall all morning. Whenever the doctor was there, I was there. He used to leave and never say one word to me. I would go over and ring the bell and ask if he had been there and be told he'd just left."

Most participants indicated that once in the hospital setting, multiple doctors became involved in the treatment of their loved ones. This situation added to their frustrations in

getting complete and timely information. They are often confused by conflicting opinions coming from various specialists who, for the most part, are unknown to the family. "All the different doctors tell you different things. Communication is the biggest problem," observed a South Georgia woman. Receiving information from a number of different doctors can cause confusion on the part of patients and families. A woman in the Atlanta area commented, "I think we got information, but there were so many doctors, so many specialists. Each one is giving you bits and pieces, and they're in and out of there so fast. There is just so much to try to understand." Additionally, families note that these specialists do not appear to communicate with each other regarding the patient's condition, or worse, often disagree with each other about treatment options when they do talk. A South Georgia woman described this experience: "He had so many doctors that came in one right after another. One doctor from the same group would come in and tell us one thing. Thirty minutes later, another doctor from the same group would come in and tell us something different. He'd go out and change what the other doctor had done." "A lot of times, they'd have disagreements among themselves, and we knew it. Yet, when the final determination was made, we didn't know who was making it. They just need to communicate better with each other and then communicate back to the patient or the patient's family," suggested an Atlanta man.

In some instances, families said that the lack of communication between doctors prevented them from getting essential information about their loved one. They were confused about the procedures and treatments, frightened by their loved one's condition, and uncertain about what to expect. "I wasn't told how short his time was until Monday morning, and he died at lunch. I think it's because there were so many doctors on his case. Each one probably thought the other one had told me. I didn't know until almost the last three or four hours," lamented a South Georgia woman. A woman in North Georgia described the anxiety she experienced by not knowing that someone who had brain damage is likely to have seizures. She said, "He was having a grand mal seizure, and I was just in a panic. I thought he was dying; I thought I was about to lose my son. They had not told me anything like that." She went on to question who should have provided this information. "Was it the nurse's place to tell me this, or was it the doctor's?" she wondered. Another South Georgia woman was torn about making decisions regarding life-sustaining treatments for her mother. She reported, "They'd come back and say, 'Oh, yes, her eyes are moving.' But, they were really non-responsive moves. I couldn't tell from the coma she was in, and nobody would explain that to me about comas."

Family members desperate to get information about their loved ones would do almost anything in order to get information, even resorting to reviewing the medical records themselves. Here are some examples of their experiences:

Atlanta area man:

"I was looking at the numbers in her chart. I wanted to see if anything was going wrong. The pulmonary person came in and asked what I was doing. She said, 'We don't let family members look at the chart.' I said, 'Well, you do in this case. I'm interested.' I finished and left the room. When I came back, the chart was gone."

South Georgia woman:

"I went to her records because I wanted to see what the doctor had written in there. They came and snatched her records out of my hand and told me I was not allowed to look at her records. I said, 'Yes, I am. I have her Durable Power of Attorney. I can do the exact same thing she does, and she has the right to see her records.' The nurse proceeded to tell me that I didn't know what I was talking about, and that I had no business doing it."

Rural Georgia woman:

"I really found out everything that happened when I went to her records. I went down and pulled the records, the nurses' reports, the doctors' reports, everything. There were things going on that I was not aware of until I got those records."

Many participants were disappointed that the doctor had not adequately prepared them for their loved one's death. Too often, the reality of death was cloaked by medical terminology or evasiveness. An Atlanta woman spoke for many other participants when she explained, "That was one of the very frustrating things. All those big words and big tests and all of that. I pretty much got lost in a lot of it." From the perspectives of those who have been through this experience, these family members say that doctors and nurses should be more direct and up front with families regarding the inevitability of a patient's death. The reluctance of doctors to talk honestly about death leaves families surprised and upset when death does occur. The numerous references to this issue from across the state are illustrated below:

Atlanta area woman:

"They didn't tell me how bad he was. All they would say is 'This is a very serious illness. He will get worse before he gets better.' But nobody told me how much worse or what worse was."

North Georgia woman:

"The doctor was evasive to us. I think he took good care of my dad, but he never said, 'You need to talk about this.' I was so totally unprepared."

South Georgia woman:

"The whole time I'm wondering what's wrong with these doctors. Why don't they try to do something. Nobody ever said, 'We have done all that we can do.' When mother started crossing over, I thought she was having a reaction to the medicine they had put her on.

Atlanta area man:

"The only thing that was ever said to me was one doctor who was supposed to be a specialist for the angina condition said, 'Her capacity is very low.'"

Rural Georgia woman:

"They really didn't explain that he was dying. They didn't even tell me he was in the terminally ill section of the hospital."

South Georgia woman:

"They needed to tell us more than they did. I just feel like when death is certain, they know. They needed to say, 'She is dying, and we are sorry.' But, they didn't say anything."

Atlanta area woman:

"I asked the nurse, 'If the end is near will you please tell me? My family wants to be here, and I don't want to be here by myself.' She said, 'No, I can't. I'm not allowed to tell you that.' I said, 'You need to help me out. I'm not going to hold it against you. I just want to have some idea.' And she said, 'No, I can't.'"

Rural Georgia man:

"They should have told us something. Everybody was looking for her to come home, buying gowns and doing things to the house. All of a sudden, pouf, she is gone. That is kind of a low blow. Doctors need to tell a family more than they do."

Atlanta area woman:

"All they would say is that, 'Your husband is very, very ill.' That was all they would say. They just didn't get real specific. So, I didn't have a comprehension of how serious he was."

Participants suggest that the best way to address the problem of communication is to hold regular conferences between all the doctors involved, the patient (when possible), and the patient's family. They call for a more enlightened approach to patient care, where doctors and other staff come together to communicate in unison with patient and family. One Atlanta woman observed: "It really has to be from top to bottom a philosophical change in the way that organizations are managed. If the organization is truly focused on the patient and the family, then a lot of the problems or concerns that we've heard about tonight wouldn't happen because systems would be in place to take care of them."

MAKING END-OF-LIFE DECISIONS

The difficulty of making treatment decisions for a person who is terminally ill was evident

throughout the conversations. For some, these decisions were made easier because of previous discussions they had had with their loved one or because their loved one had completed a Living Will. For others, even with a Living Will and knowing their loved one's wishes, the strain of making end-of-life decisions was evident. "I always thought a Living Will was to take some of the guilt away from the family, but hers didn't work that way. We were asked to make every decision," sighed a woman in South Georgia. Still others had no indication of their loved one's wishes and were faced with making difficult decisions on their own. One woman's comments about making decisions for her mother spoke for many others in similar situations. She said, "I didn't know how she would have reacted. I didn't want to go through it. I just did what I thought was right."

As would be expected, the most influential factor for families in making end-of-life decisions is the opinion of the doctor or doctors treating their loved ones. In some cases, doctors' opinions helped to relieve the family of the guilt of making decisions to withhold or withdraw care. Such was the case for one Atlanta woman, "She went into a coma, and they said the only way to keep her alive was to force feed her. But our doctor said he didn't recommend that. It was a hard decision, but we let my mother pass away." Another participant appreciated a doctor's suggestion that they "not do anything drastic" to continue his wife's life.

On the other side, some participants felt that the recommendation of doctors led them to pursue care that proved to be futile. One man in Atlanta was particularly upset that his dying wife had undergone five weeks of treatments in an Atlanta hospital. He said angrily, "I hadn't been through this before. I'd never seen anything like this in my life. It was five weeks of torture for everybody. And, I blame the doctors. They knew what they were doing. They could direct you. They could give you more information, and it would be a different thing." A woman participant felt similarly. She said, "We have all been taught to believe what the doctor says. He is always right, so it doesn't matter if they load you up with 24 prescriptions. You just take them. I'm just seeing more and more that we really need to take more control ourselves. I felt under extreme pressure from the doctors to just keep trying everything. It didn't matter what the quality of life was going to be, as long as the life continued."

A number of participants reported that either doctors, nurses or other hospital personnel questioned their decisions or put them in a position where families had to be diligent to ensure that their loved ones' wishes were followed. An Atlanta woman relayed her experience: "They did all these things he didn't want, that we didn't want. And we told them that, and he had a Living Will. He had a tube down his throat. We caused a scene and told them, 'If you don't stop this right now, we're going to stop it.' They did, and he died a few

minutes after they took him off everything." Another woman had the same experience, "They hooked him up to the breathing machine and everything. We had a Living Will, but that didn't stop them." Similar situations occurred across the state:

Woman in rural Georgia:

"Mother had a Living Will. As soon as she got into the hospital, they put her on a respirator before they asked us what her desire was. It wasn't the way she wanted it, but that is the way it happened."

Woman in South Georgia:

"They put a feeding tube in, and he always said he would never want that."

Participants who felt their loved one had been put on life support against the wishes of the patient and family were resentful of being placed in the position of disconnecting breathing machines or removing feeding tubes. "They put him on life support and the next morning asked us if we wanted to take him off. I said, 'I didn't want him on to begin with,'" reported a woman in rural Georgia. A woman in Atlanta was irate that her mother was placed on a ventilator in spite of having a Living Will and a Durable Power of Attorney. After 17 days, she insisted that the ventilator be removed. The doctor argued with her and told her that he thought her mother had a "potentially treatable condition." Another woman in rural Georgia questioned why her obviously dying mother continued to receive 12 hours of antibiotics every day for six days. She said, "It was not offered to me to refuse the antibiotics. That was never an option. But, then it fell to me to go to her doctor and say to him, 'We need to stop the antibiotics.'"

Communication issues and straightforwardness about the inevitability of death also played important roles in the decisions that families made about how aggressively to pursue care. Lacking the information they needed and wanted, families often agreed to treatments they later felt were unnecessary. Here are some of their stories:

"One day the doctor would say, 'The x-ray looked 100 percent better this morning.' The next morning, he'd say, 'Well, he's got pneumonia again.' It kept me and my whole family on a roller coaster. If they had just said, 'No matter what, I think we are going to lose him', I could have told them right then to take him off that respirator."

"Four doctors came in and said, 'He's not going to live through the night if he doesn't have the surgery.' So what do you do? You take your chance, but that was really confusing for us. We just had so many things happening like that."

"They didn't tell us anything. They were not honest with us. All these doctors visiting him and doing all sorts of things. Finally, we just said, 'No more procedures. We're putting an end to this.'"

"I believe that if the doctors know that the patient is terminally ill, they ought to explain fully the pros and cons of chemotherapy. Most people don't understand what they're getting into. It wasn't, 'Do you want chemotherapy?' It was more thrust upon us. These guys are the doctors. They're the professionals. They ought to know what is best. I think if we had been better informed, we would have put more stress on the quality of life."

"If I had known that she was dying when they were trying to make me make a decision about putting in a feeding tube, I would have made the decision not to."

"In hindsight, I wish that the doctor had just said to me, 'There is nothing else we can do.' She had two procedures within two weeks of her dying, and she suffered."

"I wish now that I had not agreed for her to have the last surgery that she went through because it didn't do any good. I just feel bad thinking about the discomfort I agreed for her to go through."

These comments, and the many more like them, illustrate that many terminally ill patients are receiving both unnecessary and unwanted care during the final days or weeks of their lives. It is obvious that improved communication between physicians, patients and families would go a long way in improving this situation. Families need and want to be told the truth about a loved one's condition, even if it is difficult to hear. However, they also need to be told in language that they can understand and that is not clouded in medical terminology and euphemisms. The families in this research who felt they had such communication reported far fewer instances of futile care, anguish in decision-making, or regrets about the care their loved ones received.

EXPERIENCES AT THE TIME OF DEATH

Family members frequently discussed having felt a sense of abandonment by doctors and nurses after it became clear that further treatment would not prevent their loved ones' deaths. "Once the doctor came in and told us that there was nothing more that could be done, they completely isolated us. It's like you've got leprosy, and they don't want to get near it. They just couldn't handle it," commented a woman in an Atlanta area group. Several participants shared this belief that the nurses and doctors who were treating their loved ones were not adequately prepared to deal with the deaths of their patients. A woman in a different Atlanta group felt that the nurses in the hospital "just didn't know how to deal with it emotionally."

Others thought that doctors and nurses would "write off" patients that were close to death. A South Georgia woman had this experience: "The kidney doctor came by the room and told me that Daddy's kidneys were failing, and that she had done all she could do. Then the doctor who was to insert the shunt came by and said that he couldn't do that because

Daddy would not be able to take it. I never saw a doctor again. No one came by or said a word." A man in Atlanta had this account: "They walked in and said 'We're taking her off dialysis. She can't handle it.' Then turned around and walked off. I never saw the urologist from that day on. Before that I had seen him 10 times a day. It was like they were running scared down the street." Several participants also felt that this type of abandonment was particularly true for elderly patients. A South Georgia woman said, "I think when it comes to the elderly, they go through the motions, but that's it. There's no compassion, no feeling, no nothing. I don't think they are cared for." An Atlanta man was distraught over the lack of care given to his elderly wife. He cried as he said, "These doctors never, as the Lord is my witness, never told me how critical she really was. They did nothing for her, absolutely nothing. They let that lady lay there. As far as I'm concerned, they deliberately let her die."

According to those who attended these focus groups, families are rarely told what to expect when a loved one dies in a hospital. Even those who indicated that their doctor had told them that their loved one was dying were seldom told what would most probably occur during the final days or hours of their loved one's life. A woman in Atlanta indicated that while the staff was very pleasant and helpful, "No one told me about the steps of dying." Others across the state shared these comments:

Woman in rural Georgia:

"Mom's fingers were already blue. Mom's breathing was rattling. I mean, these were signs that even I knew to recognize. When the nurse came in and looked at her feet and she was blue almost up to her knees, then she explained to me what to look for."

Woman in North Georgia:

"We knew she was going to die, but death is not a reality until it happens. I wish that I had known that when they gave her the pain medication that she would never wake up again. I was not prepared for that. But she never woke up again."

Woman in South Georgia:

"We thought she was going to die early one morning. Then she revived and smiled at everybody. I thought, 'Goodness, she is going to get better.' Later, I read in a hospice book that that's part of death. If I had had that book earlier, I would have known all the steps that she went through, which were just according to the book. When I read that book, I couldn't believe the anxiety it would have prevented had I had it before all that."

Woman in Atlanta area:

"I knew he was dying that day. I wasn't stupid, but I didn't know what to expect near death."

Most families were left alone as their loved ones were dying unless they were in an intensive care setting or on an oncology or similar type floor. Other than in these areas where patients often die, nurses, doctors, hospital chaplains, social workers, etc. were seldom present at the time of death even though it was often clear when the patient was actively dying. Here are examples of the experiences recounted in all focus groups:

"I was holding her hand, and my daughter was on the other side holding her hand. But no one ever came in. The caregiver we had hired said, "She's gone," and went out to get somebody. She died at 2:30 and nobody ever came in there. So at 3:30, I was hysterical, because they still had an IV in her, and Mother hated needles. I kept sitting there holding her hand. Finally about 3:30 a girl comes in there and starts talking to Mother like she didn't even know she was dead. My daughter said, "She can't hear you. She's dead."

"I didn't feel like the patient rep or the chaplain knew how to handle the situation after my husband died. When we asked questions about doing different things, it seemed like they were floundering around. I would think they would be the ones who would know exactly what needed to be done."

"When he was close to death, he was eliminating body fluids, throwing up and everything. The nurses brought in a syringe-type thing and showed me how to use it. I had no nursing experience. I expected that because I was in a hospital that they would take care of him. But they said, 'Here's the suction, and here's what to do.' And then they left."

"When she passed away, the nurses didn't come in and cover her up or anything. We went to leave the room and were kind of escorted out into the hall. We were all just very upset. It was like here we are in the hallway. Other people were there with their families. We had just lost someone. I thought it was terrible."

"When he was within five minutes of death, all of this stuff came out of his nose, his mouth, and everything else. I called for a nurse, and two of them walked in. They just stood at his bedside and looked at him and said, 'Well, he's just going to keep doing this.'"

"I'll tell you, none of the staff came into the room after he died. When we left, nobody said, 'Good bye.' Nobody said nothing. We just walked out. Nobody paid any attention to us. It was like they didn't know us. We'd been there for weeks, but they didn't know us. There was no connection that this was a person and a family."

"I could tell she was dying because she was breathing so strangely. When she breathed her last breath, it was a struggling breath. I called the nurse's station and said, 'Well, she's gone.' They sent the doctor in, and that was it."

"They put him in a room just to die. I was there by myself when he died. I felt like the nurses didn't want to be there or have any part of it. At one time I had to chase them down

and say, 'He's not breathing right.' So they came in, but they didn't do anything. Then when he actually died, I had to go and hunt them up to tell them he had died. I felt that they didn't want to be associated with it."

"I was the only one in the room when she died. I noticed that her breathing was getting labored. So I went over and held her hand until she went on out. I went down and got the nurse at the station. There was a little while before we got a doctor there. One thing that I wanted to do was to get that thing out of her nose that she had been living with for five years. I went over and took it out myself. They didn't want me to touch her, but I wanted to take that thing out."

"When it was obvious that she wasn't going to recover, they put her on morphine. You know how the machine will be when you run out or can't get it. Well, it started being thick. So, I went down to the nurse's station to tell them. There were several there, but no one ever came. A few minutes later she died. So, I went back there and said, 'Can you at least come and see that she's dead?' There was no response."

Families were also often disappointed that doctors who had treated their loved ones over a long period of time failed to send condolences or acknowledge that a patient had died. A man in the Atlanta area noted, "None of those four doctors, not one, has ever issued any condolence. Never called to say, "I'm sorry, we did everything we could. Nothing." A rural Georgian was hurt by the lack of concern from the doctor who had treated her mother. She said, "When she died, he did not even come to pronounce her. He called on the phone and told me, 'I hope you don't mind if I don't come.'" A woman in Atlanta was disappointed not to have heard from her husband's doctor because "we were real good friends with him." Families strongly feel that doctors should acknowledge, by card or telephone call, the death of a person who has been a patient for a long time.

PERSONAL CARE: A SHORTAGE OF NURSES AND AIDES

One of the strongest messages coming from the participants of this research is that there are too few nurses and aides to take proper care of the needs of patients in hospitals. Participants in every focus group echoed this comment made by a woman in rural Georgia: "I feel like our nurses are competent, but there are just too many patients for the amount of nursing staff." Over and over again, family members praised the talents and efforts of the nurses who worked in the hospital, but said the shortage of nurses and aides too often resulted in negligent care and lack of adequate attention to the needs of those who are terminally ill. They note that the nurses "who are working the floor are overextended" and "running like crazy because they have so many patients." It is important to emphasize that

participants rarely indicated that nurses or aides had bad attitudes, were rude, or disrespectful. Although a few participants did complain about a nurse's or aide's behavior, they were the exception to the overall attitude that nurses and aides were "nice," "polite," and "caring."

Participants did, however, think that the shortage of nurses and aides had a dramatic effect on the care their loved ones received. The large majority of participants felt that some aspect of a loved one's care had been jeopardized by this shortage. While a few told stories of negligence with medical treatments, the most significant impact is in the personal care given to hospital patients.

According to family members, the inability of nurses and aides to check routinely on patients has a tremendous impact on patient care. Participants often said it would be hours between the times that nurses and/or aides looked in on their loved ones. As a South Georgia woman described, "The nurses don't make rounds. They don't go in there and check in the rooms to see if the patient is doing all right or not." One woman in rural Georgia told of having positioned her father in bed so that he could see the television before she left for the night. When she came back the next morning, she said her father was "still turned the way I had left him the night before" and that the television was still on. Another woman in rural Georgia illustrated this point further when she told the following story:

"I went up there about 2:00 in the afternoon. Nobody noticed me going in the room. Nobody ever came in. At about 4:00, I heard the door open, but nobody came in. Then about 5:30 her doctor came by. He was the first person who had been in since 2:00. At 6:30, my sister-in-law came in, and I went home. Nobody but the doctor had been in that room since 2:00."

Several participants were emphatic that their loved ones had not received proper attention because the staff was too busy to check in on patients or respond to a patient's call for assistance. Here are a few examples:

"I was at the hospital in the morning, and I left to go home for a while. I got a phone call from her. She was crying. She had messed on herself, and she couldn't get anybody to help her."

"I came back from picking up my sunglasses, and I came in the room and found her on the floor. She had fallen between the frames of the bed. She broke her leg. That was a shock to me, finding her on the floor myself."

"I sat up there during the day, but would have to go home and fix supper. One day, I got home and got a call. It was the flower delivery boy saying that my mother wanted me to

come up there. She had to use the bathroom and her light was on and nobody was putting her on the bed pan."

The most prevalent comments participants made regarding staff shortages related to feeding patients, bathing patients, and changing linens. From the statements made by focus group participants, no one in the hospital setting appears to have responsibility for ensuring that patients who cannot take care of themselves are fed. This is of particular concern for terminally ill patients who are weak and in and out of consciousness. An Atlanta woman explained, "When the food is brought in on a tray and the patient isn't aware or able to sit up and feed himself, the tray will sit there. It won't get eaten. They'll come and take it away. They don't care if anybody eats." Family members were surprised by the lack of importance placed on proper nutrition. Several participants observed that the meals provided were inappropriate for these patients. A South Georgia woman remarked, "They gave her a regular meal. She had no teeth, no way to chew it up. She quit eating because she couldn't eat what they were giving her. They finally sat down a can of Ensure. I guess they expected her to open it and pour it in the cup and drink it."

"For \$1,000 a day, at least you could have a sponge bath," sarcastically commented a woman from South Georgia, illustrating the belief of participants that cleanliness of patients also suffers due to the shortage of personnel. Participants would routinely report a loved one having gone for three or four days without being given even a sponge bath by the hospital staff. In some cases, such inattention resulted in very unsanitary conditions, as explained by a participant who said, "I went to see her one day, and she had been lying in feces for so long that it had dried on her."

Having too many patients to care for can result in carelessness on the part of nurses and aides. Participants in several of the focus groups told of used syringes, gloves, and "bloody little items" being left in patients' beds or on the floor. The most extreme case was reported by a woman whose husband was "in the midst of a bowel movement, and there was a thermometer."

Some participants felt that too much emphasis is placed on hospital amenities at the expense of providing adequate staff. A woman in rural Georgia explained, "I think our hospital is looking too much to the cosmetic part of it. I know they have new carpeting, new everything; but what people want is nurses that will look after their loved ones."

The shortage of nurses and support staff leads to a universal belief that patients, particularly terminally ill patients, should never be left alone in a hospital. An Atlanta participant emphatically stated, "If somebody is not there to take care of your loved one, no one else is going to." A rural Georgia woman indicated that, "If someone had not been with

my mother-in-law all the time, she would not have gotten the care she needed.” And a South Georgia man offered this observation: “Family members have to be vigilant. You have to say something. You have to demand the care that you need.”

PAIN MANAGEMENT

As with many other issues addressed in this study, successful pain management varied from patient to patient, even within the same hospital. Some family members said that their loved one did not experience any pain associated with their illness; therefore, managing pain was not an issue for them. Others indicated that their loved ones only had pain near the end of their lives, but they had mixed reports about pain management. Some of these participants felt everything was done to control pain, while others expressed frustration that doctors and nurses did not place enough emphasis on pain management. Still other participants reported that their loved ones had lived with pain for many years.

What becomes clear from these conversations is that very few patients had been provided any type of proactive pain management. Only one family member said that a pain specialist had been involved in their loved one’s care. Even in this instance, the family themselves took the initiative to consult with this specialist because “the other doctors just couldn’t control his pain.” When doctors could not manage their mother’s pain, another family sought alternative measures such as acupuncture and massage, although they didn’t feel that either treatment had any effect in alleviating pain. And, some family members had resigned themselves to the fact that nothing could be done to alleviate their loved one’s pain. “My husband had multiple sclerosis for about 15 years. He was in pain those 15 years. The doctors finally tried a narcotic, but he was out of his head immediately. So, he was in pain terribly all the time,” reported a woman in rural Georgia. A South Georgia woman was visibly upset that the pain medication prescribed by the doctor had not relieved her mother’s suffering. She related, “She had Darvocet. I could give them to her every four hours, but for the last month, she had gotten to where she begged for them about every two hours.”

For diverse reasons, a few family members appeared to be uncertain about the level of pain experienced by their loved one. A few, like a South Georgia woman, did not think a person who was unconscious could feel pain. When asked about whether or not her loved one had been in pain, she responded, “I don’t think my brother was in pain because he never came to.” When asked this same question, another participant responded, “They assured us that he was pain-free.”

What families considered to be successful pain management appears to be limited to the

administration of some form of pain medication. "I felt like pain management was the best. They really know how to put the pain killer on you," praised one Atlanta area man. "Our experience with that was excellent. We had the morphine before the doctor left the room," asserted a South Georgia woman. And, a rural Georgia participant attested, "He was given medication for the pain; he was never allowed to suffer."

Again, family members indicated that they often had to take the initiative to ensure that their loved one was given adequate pain medication. An Atlanta area participant described an experience with her father this way: "I felt like my dad was more uncomfortable than he should have been. I went out and asked what the orders were. They said, 'Just to keep him comfortable.' I said, 'You come take a look. I don't think this is comfortable.' So, she called the doctor, and they increased the medication. But you feel so guilty doing that." A woman in Atlanta took matters into her own hands in order to help ease her husband's pain in the hospital. She reported, "I had some of his medicine with me, so I gave him what I brought. He never would have gotten anything because it takes too long once they put the order in for it to get up there." An Atlanta man could not understand why doctors and nurses were not more proactive with pain management. He complained, "I thought pain management was a knee-jerk reaction to pain. For someone to stop screaming, they come in and give an aspirin or a shot. It seems to me that a hospital of well-trained professional health care people could diagnose the problem. They should have experience and know where to anticipate pain. It seems to me that there is no reason for a patient to have to go through this suffering."

Because some doctors and nurses feared the side effects of large doses of morphine or similar drugs, family members faced resistance from these professionals to providing the pain medications necessary for the relief of suffering, as illustrated below:

"My daughter was on duty that night. She called me and said they are denying my wife morphine. There was a written instruction in the file to give five milligrams of morphine every hour, if needed. The nurse had denied it, and my daughter was visibly upset. So, I called the head nurse and asked her why the medication was being denied. My wife was on a ventilator and had a trach. She had a lot of trouble breathing. She was in pain. The nurse's explanation was that morphine is a suppressant to the respiratory system. I knew that. It was a question of whether we would let her die in pain or not. So, I told her how I felt about that. The nurse said, 'Fine, she'll get it.'"

"My husband had morphine, and they were very free with it. But a nurse came on duty one night and decided he was getting too much morphine and cut it back. I don't know for the life of me why he did that."

Family members were often puzzled by this reluctance on the part of doctors and nurses to provide adequate pain medication. While participants were aware of many of the side effects of morphine and other drugs, they believe the relief of a loved one's suffering should be of primary concern. Almost all would agree with the rural Georgia woman who told her husband's doctor, "I understand that the morphine can have an effect. If he stops breathing, that's okay. I just don't want him to be in pain," and the Atlanta man who commented, "When they're in that much pain and that far gone, if the morphine is going to help, why not let them have it?"

HOSPICE

The intent of this study was to focus on the experiences of patients who had died in a hospital setting; therefore, few hospice patients were included. However, the very fact that so many patients with long-term and obviously life-threatening illnesses had never been referred to hospice is an indication of the under-utilization of these services. Those few family members who had had the benefit of hospice praised the services and expressed appreciation for the help that their family had received.

At least one of the hospitals participating in this study has a hospice unit within its facility. The family members whose loved one had been transferred to this unit prior to their death reported the highest level of satisfaction with their experiences which were in stark contrast to those who remained in the hospital setting. For instance, here is how two family members described their stay in the hospice unit:

"The treatment she received was great, it was wonderful. When the idea came up for hospice, I was a little leery of it at first, but after she got in there, we saw how she was being treated. In a sense, they pampered her a little bit before she died."

"The nurses were wonderful. The night that my grandmother started slipping into a coma they came in the room every 15 to 30 minutes to check on how she was progressing. They were very kind to her; they were very gentle. I can't thank them enough for that."

However, for most patients whose families were part of these focus groups, hospice was either never presented as an option or only offered during the final few days of their lives. The majority of family members were like the woman in South Georgia who bemoaned, "The doctor said for two years he didn't know how my husband was still alive, but not one time did he ever mention hospice." A participant in rural Georgia indicated that even though her husband had renal failure and septicemia, she was not aware that he could receive hospice services.

A number of family members expressed disappointment at not having had hospice available to them. A man whose wife had been ill for a number of years commented, "This is the first time I have ever heard of hospice care. That type of service would help the family to kind of ease the pain a little bit." An Atlanta woman who had cared for her Mother at home for several months was annoyed when she said, "They never offered that. I asked for all kinds of help, but no one ever mentioned hospice to me."

Most often when hospice was suggested to family members, it was by someone other than their loved one's doctor. Either a hospice nurse would visit the family in the hospital or another staff person would suggest hospice. But too often, the suggestion of hospice came far too late in the patient's illness, as these comments indicate:

"One of the girls that takes patients in and out said to me, 'When your mother goes home this time, you need to talk to them about hospice.' But Mother died the next day."

"They offered hospice to us for that 72 hours. I couldn't figure out why in the world I needed hospice for 72 hours."

"Over the weekend the hospice lady came in, and we talked at length about what they would do and how things would be handled. We were going to do that on Friday, but she died on Monday morning."

In many instances, patients and families obviously could have benefited from hospice but never were given the option of these services. Doctors appear to put off referral to hospice until the last days of life, and families, not familiar with the hospice concept, do not know how to access these services on their own.

THE IMPACT OF INSURANCE AND MEDICARE COVERAGE

An interesting finding of this research is that no family member reported a single case of a recommended treatment being denied for coverage by a private insurer, Medicare or Medicaid. This is of particular note since the patients represented by families in these focus groups were, for the most part, individuals who had been extremely ill over a long period of time. Denial of coverage was simply a non-issue and generated no discussion within the focus groups.

Coverage issues did surface in other ways, however. A number of participants were angry that a loved one's care had been jeopardized by policies regarding set numbers of covered hospital days for various illnesses. Participants from across the state reported that a loved one had been sent home too soon or moved out of an ICU because their "Medicare days had

run out." A woman in rural Georgia was upset that this policy had affected the quality of her mother's life. She explained, "They discharged her with a kidney infection because her Medicare days had run out. Mom died with that same kidney infection." One man was disturbed that an Atlanta hospital wanted to get his dying wife out of the hospital when she had been given only five or six days to live, and participants in a South Georgia focus group shared this exchange:

First Woman:

"At the time she died my husband was down at the nursing home making arrangements for her to go there. I have often wondered how they could even think of dismissing her if she was that near death."

Second Woman:

"Sometimes the hospital won't keep them because there are only so many days that Medicare pays."

Man:

"When the money goes, you go."

Home health care is one area where limits on coverage place enormous strains on families. Taking care of a loved one who is seriously ill over a long period of time can have both emotional and financial consequences. In several cases, family members felt they had been forced to provide medical care that they were ill-prepared to handle. "Mother was scared. I was scared. I didn't know how to hook up an IV drip, and the central line was going right into her chest. I was a nervous wreck. I said, 'Oh, my God. This is my mother. I'm not playing with a doll here, and she was so, so sick,'" related a South Georgia woman.

One of the most poignant stories from this research is that of an elderly man who was forced into bankruptcy because of the cost of home care and medications needed for his seriously ill wife:

"My wife took probably 140 pills a day. I crushed at least that many pills a day for the last eight or nine years. I was working two jobs for the past seven years, and it was hard to keep your mind on all that. It finally got to the point that she only had one sister that was able to come down and stay with her while I worked. Then I would come home for an hour, change my clothes, eat a sandwich, and go to work at the next job. I had a neighbor stay with her then, but she wasn't even able to take care of herself let alone my wife. The neighbor would call me up and say, 'I'm sorry, but your wife fell down. I can't get her up. What do you want me to do?' I finally had to quit my second job."

This man's trials were exacerbated by a number of shortcomings in the health system beyond inadequate coverage for home care and prescription drugs. Doctors would prescribe new medications for his wife, which he would purchase at a cost of as much as \$200 per prescription. It was not unusual for his wife to have an allergic reaction to medications, requiring yet another prescription. Since his wife only had Medicare coverage, he had to pay for medications out of pocket. Yet, no one made the effort to offer this man samples or write a prescription for a small number of pills in order to test his wife's acceptance of the medications. Additionally, his wife was not referred for hospice care until she was days away from death. The anguish this dedicated husband had suffered was still evident eighteen months after her death when he told his story at the focus group.

The primary issue brought up by participants regarding payment is the complexity and hassles involved in the processing of their bills. The first challenge participants said they faced was in understanding the bills: what the bill was for and what portion of the bill they were expected to pay. "You can't tell when a bill is miscoded or if they charge you too much or charge you too little or you get a bill from some people you can't even remember seeing," complained an Atlanta man. Trying to resolve billing issues with insurance and/or Medicare coverage sends family members into a revolving cycle of telephone calls and paperwork that can continue for months on end. One man relayed an experience typical of many others when he said, "It has been almost a year, and I'm still reconciling bills. You have to explain to them how it was miscoded or how somebody should pay it. You call the insurer and while they are reviewing one bill, you get another bill. I just kept making notes all the time, keeping track of it, reading back to them what we had talked about before." Of enormous frustration to those trying to deal with these problems is their inability to get through to the person who can rectify the problem. "It's almost a full-time job to communicate with the hospital, the doctor and the insurance company. You have to start whenever their office is open, and you just keep calling them and going through the computer telephone messages. When I kept getting bills, I just kept calling," lamented a woman in the Atlanta area. It is not at all uncommon for hospitals to turn bills over to collection agencies during this process. More than one participant in every focus group reported that they had been contacted by a collection agent while trying to resolve the hospital bill incurred by their loved one's death. A bemused man who had tried to be responsible may have found the solution to this dilemma. He explained, "When I got a bill from them, I would just mail them a check. Well, all of a sudden, I started getting checks back. Now when I get bills, I just throw them in a pile. When I get one that says they're going to sue me, then I'll pay it."

MAKING A DIFFERENCE

As family members related their stories of the death of a loved one, it became apparent that for many families one caring doctor, nurse or other hospital staff person made a difference in their experiences. The encouraging aspect of this research is the understanding that one person can provide the support and compassion necessary for families to view their loved one's death as a positive rather than a devastating time. Unfortunately far too many families did not find that one person to help them through an experience that is always emotional and often very difficult. But those who did are grateful, and say they will always remember the person who was kind and helpful at their time of need. Their stories speak for themselves:

"We had a nurse that got to be part of the family. When she was on duty, she would stay in the room with him most of the night."

"The head nurse on that floor was just very, very nice to me. He came in one day and said, 'I want to talk to you.' He carried me out in the hall and he was very, very nice to me all through it."

"The hospital chaplain came, and she was absolutely wonderful. She was the calm in the whole room. She talked to my husband like it was a two-way conversation. She said a prayer, and it was gorgeous. It just gave me so much comfort. When he died, she stayed with us until we left. I got a nice little note from her later on. I have undying gratitude for her."

"The nurse was very helpful. She came in when he was about to die, and she said, 'I think this is it. I've seen a lot of them, and I think this is probably it.' So, my experience was quite positive."

"The nurse came down to give him some pain medication. I knew he was to the point where that would put him to sleep. She told me that I needed to be able to turn loose. She let me know she would do whatever I wanted. I couldn't have asked for anything better. We were blessed."

"When I would leave at night, I would have a sitter that would come. The night he died, I told the nurse that I was going to keep the sitter, but that I was going to stay outside in the waiting room. She said, 'No, you're not.' And she fixed me a bed next door. Later that night, she came in and got me, and said, 'I think you need to come and be with him.' He died within 30 minutes. I will never forget how emotional that was, but it helped so much to have someone treat you like you felt you wanted to be treated at that time."

"A very sweet thing happened. The nurse who was with my husband when he died came to the funeral."

"His two main doctors would each one come in and just hold me and cry with me, telling me all the time that they were praying for him and me too."

"The nurse in charge of the floor said that he still might hear me. So, I was there trying to talk to him. She sat right there by me the whole time. I was the one who finally realized that he was gone. But, she was sitting there with me just as long as I wanted to sit there. It meant a lot to me."

"She became my best friend toward the last. When she was not there, I felt absolutely lost. But you know, on her day off, she would call up there to see how we were. I just appreciate that more and more."

"One of the nurses came back and told my daughter, 'Tell your mother that your dad talked about her all the way down to get his test.' It made me feel good that she would do that. I think that's very, very important to people at a time like that."

MOVING FORWARD

When viewed as a collective experience, the findings of this research may be seen to present a somewhat bleak picture of the nature of end-of-life care in the hospital setting across Georgia. Families of patients who have died brought up repeated areas where a negative encounter left an equally negative impression about the overall hospital experience during the death of a loved family member. Yet these are the very areas that hold opportunity for hospitals and health systems who wish to bring improvements to the dying experience for all involved. Of particular note is the finding that an expression of compassion and support from a single physician or staff member can have an overall positive impact on the entire death experience and hospital stay. Taking concrete positive-action steps in these areas will have profound impact on the experiences and perceptions of patients and families during the delivery of care at the end of life.

Communication with doctors and nurses: Hospitals that wish to bring improvement and consistency to these experiences should give close scrutiny to issues of communication throughout the patient and family support experience. One participant made a particularly enlightened call for a multi-disciplinary team approach to patient care, where doctors, nurses, social workers, dieticians, pastoral care and other staff professionals come together frequently to communicate with each other – and with patient and family members – and set forth a unified, holistic approach to patient care and family support. Such an approach is one being adopted successfully by hospitals across the country and is particularly effective in developing care plans for the terminally ill.

Making end-of-life decisions: These findings indicate that many terminally ill patients are receiving both unnecessary and unwanted care during the final days or weeks of their lives. The emotional impact to patients and their families, as well as the financial implications to

hospitals are clear. Physicians and health care professionals can begin taking positive action by conveying straightforward information about patient status in understandable terms, including the inevitability and nearness of death when this is the case. Such mutual understanding can avert placing families at odds with physician opinion. Most important, families who receive this communication report far fewer instances of futile care, anguish in decision-making or regrets about the care their loved ones received. Additionally, hospitals must focus more attention on patients' wishes as expressed verbally or in a written advance directive. Policies regarding the accessibility and compliance with advance directives should be reviewed and strengthened.

Experiences at the time of death: As a patient nears death, the focus of care shifts from one of pursuit of medical treatment to educational and emotional preparedness for death. Much positive benefit can result by raising staff awareness of this "shift," and preparing them to meet the valid informational and emotional needs of patients and families that begin to take precedence. Family members become better prepared if given details about what to expect as their loved one dies. A sense of presence at the time of death by physicians and hospital staff can make a particularly profound impression that family members will long remember as positive. Finally, giving a verbal or written expression of condolence offers an immediate step toward a lasting, positive impression.

Personal care of patients: Family members in this research hold a strong belief that their loved ones will not be adequately cared for unless they are present and see to it themselves, and they attribute this oversight to a lack of adequate numbers of nursing and aide staff. While this may present formidable challenges in terms of staffing issues, hospitals may see the ultimate benefit of a change in focus toward personal care issues. Clearly, this is ground upon which patients and their families measure the overall quality of their care, and a lack of attention in these areas taints the entire hospital experience. Much benefit can be gained by structuring frequent, routine checks by nursing staff and by providing more support and diligence in areas of personal care and proper handling of medical items.

Pain management: An attempt to streamline the physician order process for pain medication would create greater patient comfort, reduce response time, and create a number of efficiencies for staff. A more proactive approach to managing pain among the dying would reduce stress among patients and their family members and lead to a more compassionate overall approach to the dying process.

Hospice: Clearly, terminally ill patients and their families could benefit from hospice services much earlier in the process. The need for a targeted effort toward increasing physician

referral to hospice services is evident. Likewise, increased awareness about access to these services may motivate patients and family members to take a more proactive approach with their physicians about referral to hospice care.

Impact of insurance and Medicare coverage: Like patients, hospitals certainly can be at a disadvantage in dealing with the tremendous variety and complexity of insurance coverage plans and utilization management issues. Clarifying hospital bills and focused attempts at earlier reconciliation would provide benefit and relief for all involved. In areas related to coverage: increasing physician awareness of the financial strain created by multiple prescribed medications could ease this burden for those without prescription drug coverage. For those who are terminally ill and require sophisticated medical care at home, particular attention should be given to helping family members become better prepared to administer these treatments at home.

Improving the dying experience for Georgians and their families will require commitment from all those involved in the process. The groundwork for assisting hospitals to move forward has been established through this look at the experiences of family members of dying patients.