

Families at the Bedside

An Ethnographic Study of Vigilance

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BACKGROUND. Vigilance, the close protective involvement of family members with hospitalized relatives, is a relatively recent phenomenon in the hospital setting. Before the 1960s, hospital visiting policies restricted the presence of family members at the bedside. Policies changed during the 1960s and 1970s when health care professionals recognized that parents' staying with their hospitalized children was beneficial for both the parents and the children. Vigilance later became a phenomenon that included family members staying with adult patients.

METHODS. Two ethnographic studies were conducted to examine the meanings, patterns, and day-to-day experience of vigilance. Sixteen family members, described by the nursing staff as staying with the patient, participated in informal semistructured interviews. Participant observation was also used in data collection.

RESULTS. Data analysis yielded 5 categories of meaning that describe the experience of vigilance: commitment to care, emotional upheaval, dynamic nexus, transition, and resilience.

CONCLUSIONS. Managed care, shortened hospital stays, and cost containment make early involvement of the family in the patient's care imperative. An understanding of the family's needs and experiences is prerequisite to that involvement. The categories of meaning discovered in this research can help health care providers understand family members' experience of vigilance. The implications for the family physician include sensitization and awareness of family members' experiences and the developing of specific actions and interactions fostering a commitment to family-centered care that extends to the hospital setting.

KEY WORDS. Family; hospitals; visitors to patients. (*J Fam Pract* 1999; 48:433-438)

Historically, hospitals maintained visiting policies that limited the amount of time family members could spend with hospitalized relatives. In the 1960s and 1970s, those policies were changed when it was recognized that parents' staying with their hospitalized children was beneficial for both the parents and the children. During the 1980s, this type of vigilance for hospitalized relatives moved beyond the pediatric population to encompass adults. Vigilance has become common recently. In this qualitative ethnographic study, we define vigilance as close protective involvement with a hospitalized relative.

There are few studies that explore what this experience is like for patients and their families. The hospital environment is alien to many family members who visit patients, and it is unclear how those who spend as much as 24 hours a day in the hospital experience their time. What is it like for them? What do health care professionals do that is helpful to them, and what could they do better?

Submitted, revised, April 1, 1999.

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PREVIOUS RESEARCH

Literature about the needs of family members with hospitalized relatives is dated, although findings indicate that being with the ill relative is important to the family.¹⁻⁵

All the previous studies were conducted in an intensive care setting and used either the Critical Care Family Needs Inventory (CCFNI) or modified versions to collect data. The exclusive use of the intensive care setting, where family members typically visit but cannot stay, limits transferability of findings to acute care settings. In addition, simple identification of the importance of the need to be with the patient in the intensive care unit (ICU) does not provide insight into the experience of staying with the patient during an extended period.

Several previous studies investigated the physiological effects of family presence on the patient. Again, these studies were conducted in ICUs. Their findings indicate beneficial effects of family visits on the health status of ICU patients.⁶⁻⁹

Although several studies mentioned vigilance as a strategy used by family members, none provided an in-depth description of the experience of vigilance, and most were conducted several years ago.¹⁰⁻¹⁴ Thus, the question remained: What is the experience of vigilance for family members staying with hospitalized relatives?

IMPORTANCE OF UNDERSTANDING FAMILIES' EXPERIENCES

The examination of this experience was important for a number of reasons. Managed care, shortened hospital stays, and cost containment make the family's early involvement in the patient's care imperative. An understanding of the family's needs and experiences is a prerequisite for that involvement. The family, rather than the individual, is the basic unit of care.¹⁵ Geyman and Schmidt^{16,17} suggest that family-oriented care is more likely to promote effective health outcomes than individual-oriented care. It is the family that defines and validates whether an individual is ill, determines use of health care services, and influences treatment and recovery.¹⁸

Scheller¹⁹ suggests that when a medical crisis occurs, patients and their families find that health care professionals do not have the time or interpersonal skills to adequately support them. Scheller posits that the hospitalization experience is often a dehumanizing ordeal rather than a healing experience. This research was designed to explore a version of the family's perspective of hospitalization that is in contrast to the historical perspective of health care professionals deciding what is stressful or helpful to good patient outcomes. When family members submit to hospital rules and procedures that do not feel right to them, they can sustain subtle but long-term negative effects on physical and emotional health. If families are listened to and allowed to participate more fully in the care of their loved ones, much of this can be avoided.¹⁹

Involving the family in hospital care, maximizing the family as a resource, and making the hospital experience a time of personal growth require a holistic understanding of the experiences of families who stay with hospitalized relatives. Family medicine emphasizes the importance of exploring health and illness within the context of the family and community.^{20,21} Family physicians are challenged to determine how to support the vigilant family during a relative's hospitalization, while meeting needs so that the family is empowered and acts as a positive link to the patient.

METHODS

DESIGN AND SAMPLE

Ethnographic studies were conducted to examine the meanings, patterns, and day-to-day experience of vigilance. Ethnographers observe, document, and analyze the patterns of a group in natural settings,²² such as villages, communities, and hospitals.²³ The ethnographic method is naturalistic and sensitive to context.²⁴ For this research, vigilance was examined within the cultural context of the hospital setting.

Eight family members participated through primary selection in each of the 2 studies for a total sample of 16. With primary selection, the researcher is aware of who has the knowledge required, who it would be useful to talk with, and who would probably be willing to participate in the study. Primary selection is efficient, and therefore the

sample size is as small as possible.²⁵ Participants were selected if they were described by the nursing staff as staying with the patient.

The 13 women and 3 men who participated defined themselves as family of the patients and ranged in age from 30 to 74 years. Eight of the participants spent 24 hours each day with their hospitalized relatives. The remaining 8 spent 6 to 12 hours each day with the patient. The researcher promised individual anonymity and obtained informed consent before collecting data.

SETTING

In the first study, 2 neurology units in a southeastern US hospital system were the sites for data collection.^{26,27} All study participants were staying with relatives in private rooms on the units, where they slept on fold-up cots. Two years later, a second study was done in 2 rehabilitation units at a northeastern US teaching hospital. Private rooms were not available at this site, but accommodations were made for family members to stay in the room if desired. Diagnoses for the patients in both studies included cerebrovascular accident, aneurysm, and closed head injury, which were representative of typical diagnoses on the units. Most patients had significant neurologic deficits resulting in cognitive impairment and limited or no ability to communicate.

DATA COLLECTION

Up to 3 interviews were conducted with each participant. When adequate data were collected in the first interview, another interview was not scheduled. Adequacy of data was achieved when participants were repetitive in their accounts of vigilance or if they stated they had no further information to provide. This was the case with 12 participants. Three participants were interviewed twice and 1 was interviewed 3 times. Interviews ranged from 30 minutes to 2 hours and were conducted in a private location near the units.

The interview began with what Spradley²⁸ calls a "grand tour" question: "How did all of this come about?" This gave the participants an opportunity to organize thoughts on a general level before responding to specific questions about the experience.

A semistructured interview guide focused on the everyday experience of staying with a hospitalized relative. Questions included: "Could you describe a typical day when you stay with your relative?"; "Tell me about your own physical and emotional needs while you stay here"; and "What are your relationships like with the nurses? The doctors?" All interviews were audiotaped and transcribed verbatim.

Through participant observation, the researcher observed the human and environmental aspects of the units and noted distinctive features and patterns. This kind of overt participation by an ethnographic researcher at the scene is common.²⁹ Observations were recorded in the form of field notes and were included in the data analysis.

DATA ANALYSIS

Transcripts from the first study were read, and transitions in topics were noted and coded. The initial codes echoed participants' own terms. For example, if a participant mentioned stress, that information was coded as "stress." This stage of the analysis resulted in a preliminary set of 44 categories that remained close to the data. Categories were then compared across all participants, clustered according to similarities, and given a name. For example, stress and anxiety were clustered under the term "anxiety." This stage of the analysis resulted in 6 emerging categories of meaning.

Segments of text were then decontextualized from the transcripts and placed on color-coded index cards corresponding to these categories of meaning. Categories were refined as the researcher compared participant with participant, participant with emerging category, and category with category. Eventually, 5 final categories of meaning were identified: commitment to care, emotional upheaval, dynamic nexus, transition, and resilience.^{26, 27}

Data from the second study were initially examined using a similar method. Transcripts were read and transitions in topics were noted. The 5 categories of meaning developed in the first study were then used to examine the data further. The categories of meaning developed in the first study continued to be adequately supported by data from the second study.

To establish interrater reliability, 20 students from the researcher's (J.M.C.) graduate level research course analyzed the 10 interview transcripts. Each student independently analyzed a transcript, first without, and then with the previously developed categories of meaning. Students and the researcher then compared findings and found that the categories of meaning describing vigilance in the first study were relevant and meaningful in organizing and explaining the data from the second study. Students and researcher independently coded in agreement in the majority of cases.

RESULTS

Commitment to care, emotional upheaval, dynamic nexus, transition, and resilience were the 5 categories of meaning used in our research to describe family members' experience of vigilance.

COMMITMENT TO CARE

During the interviews, the researcher asked participants to discuss their reasons for staying with hospitalized relatives. The reasons given included needing to protect the patient, wanting to be involved, and watching for changes in the patient. The conclusion that commitment to care was an appropriate category to explain these reasons for staying was supported by a review of the literature in which the same or similar concepts were described as components of the caring experience.³⁰⁻³²

Protection of the patient was expressed by all partici-

pants in both studies, and included feelings of love, advocacy, and vulnerability of the patient. The mother of a 16-year-old head-injured patient said: "I wanted to make sure that we had everything going for her. We had love, we had soothingness, we had touch, we had security, her music. The sound of our voices and just our being there."

Commitment to care was also evident in family members' descriptions of their involvement in the care of their hospitalized relatives. Provision of care was described by all study participants, and researcher observation supported participants' reports. Family members were observed feeding their relatives, providing range-of-motion exercises, transferring from bed to chair, suctioning, and providing general comfort.

Watching for changes in the patient was described by participants as observation and monitoring. One relative observed and recorded treatment information in a notebook while he stayed with his wife of 50 years. He said, "Well, sometimes I just observe what they're doing. Then I ask them questions if they have some type of medication, and when they take the pulse, I want to know what it is. I transcribe that in my book. . . . And her blood sugar, I get a report on that. . . because now they can give it to you right there in the room."

EMOTIONAL UPHEAVAL

Study participants described their emotions and the difficult decisions they encountered during their experience of vigilance. One family member, while participating in a second interview, stated that emotional upheaval described the feelings she had to manage. In the final analysis of data, it became clear that emotional upheaval aptly reflected the uncertainty, life and death decisions, and feelings of loss in participants' descriptions of vigilance. Uncertainty is reflected in this excerpt: "One thing in this particular terminal illness is the unpredictability about how long are we going to be holding here. Is it going to be 3 days? Is it going to be 6 months? Because there is the possibility that this could really drag out. And that's hard, the uncertainty of the whole thing."

Making life and death decisions was also characteristic of emotional upheaval. An elderly woman spoke of the difficulty in making a decision concerning the care of her husband: "For the simple reason, when a man begs you practically crying, don't put me in a nursing home. If you do, I'll die. I just will die there. And I had a hard time convincing him why we were doing it."

Finally, the category of emotional upheaval was characterized by living with loss. One family member said: "The hard part is that I can't share with her in the way I did in the past. And I think one of the things that is a given is the sense of loss. The grief of loss is ongoing all the time. . . regardless of whether the person didn't die, some things are gone. The normalcy of life is lost. The plans for the future are lost. And those are 2 big losses."

DYNAMIC NEXUS

There was a recurrent theme in participant accounts of their relationships with others during their experience of vigilance. Although participants described support they received from an established network of family and friends, these relationships were changing and undergoing negotiation. At the same time, participants were also in the process of establishing and maintaining relationships with health care professionals. Most described communication difficulty in these relationships.

Although study participants reported support from family and friends during their experience of vigilance, some felt that support diminished as time went on. One said: "I think that in a lot of these situations, everybody is very helpful in the beginning. You know, what can I do for you, I'll do anything. And then it peters out, and when it peters out is when there you are all alone. I had told people who said I'll come, I'll do whatever. . . I said, no. It's later when he's out of here and when I'm all alone with whatever I'm left with."

Dynamic nexus was also characterized by communication with health care providers. The majority of participants provided accounts of situations with health care providers involving inadequate communication. Participants recounted the following: "The doctors. . . you'd see them and they'd see you, and they'd disappear. They'd float off, and they were gone. Boy, I'd really like [good communication skills] to be part of their education. They have a big gap, and they always have. Some of them are better, but for the most part, they don't do that well still."

TRANSITION

Participants in the studies described major transitions in their lives as a result of their relatives' illness and hospitalization. Transition in lifestyle, role, and daily rhythm included nursing home placement for 3 participants' husbands, anticipated loss of a partner for another (the partner subsequently died), extended leave of absence from work for 7 participants, and relocation for 2 who lived in distant cities. Transition is illustrated by the following excerpt: "In addition, there is about an hour of driving each way so that adds into the day. And so there have been a lot of days that have been incredibly long, where I haven't eaten until 10 at night, and I've been really exhausted by what's happened to him and what's happening to him but also by people who have called. . . when you have to spend half an hour to describe the whole thing over and over, it gets really exhausting. I found that I am able to deal with the things of daily life that go on. . . I've had to deal with them so they go on, and there have been a number of crises and emergencies in the house and with the cars and so forth that don't stop just because you have things that are more important to think about."

RESILIENCE

Despite maintaining constant vigils, participants realized

the need to care for themselves if they were to continue caring for their hospitalized relatives. The category of resilience not only included participants' describing concern for self, but also descriptions of remaining hopeful and optimistic in spite of an uncertain outcome. One family member expressed awareness of the need to care for herself: "I have felt like I was on sentry duty. Because I knew I was doing that, that's why I knew I had to eat, even when I wasn't hungry in the beginning, and I had to sleep, and I needed to make sure that I could do this. And I haven't been crazy either. . . I'm a solid kind of person, that's just my personality, and I'm not sure that I would recommend it. I know people that wouldn't have been able to do this, and I would have encouraged them not to, but I know me pretty well, so I knew I could do it."

All participants described feelings of hope despite the uncertainty. Hope is illustrated in the following excerpt: "I was thinking, we'll be home by the end of the weekend. I'm thinking she's superhuman. . . she's unconscious, and she's had a head injury, but we'll be home at the end of the weekend. . . I think you need to be a little realistic with families, but not take away their little pieces of hope that they have."

DISCUSSION

Stein²⁴ suggests that at its best, family medicine intuitively uses an ethnographic approach to understanding health and illness. Family medicine ideals of continuity and comprehensiveness of care share a theoretic, philosophic, and methodologic core with anthropology. The ethnographic approach allows the researcher and the clinician to discover and trace patterns, meanings, and feelings that other methods fail to notice, and it facilitates an understanding from within the experience of the family.²⁴

This qualitative research explored the meanings, patterns, and day-to-day experience of vigilance from the perspective of family members. The accumulation of data generated from the research supports the idea that every interaction involves 2 perspectives on a problem and begs the issue of bringing the views closer together, allowing each person involved to learn from the other.³³ The categories of meaning uncovered by the research can help health care providers understand family members' experience of vigilance. The implications for the family physician include sensitization and awareness of family members' experiences and developing specific approaches leading to a commitment to family-centered care that extends to the hospital setting.

Data from the categories of commitment to care and resilience suggest physician approaches that enhance these elements of family vigilance. Physicians must recognize that family is the constant in the patient's life and, although the hospital personnel fluctuate, the family should be encouraged to maintain its commitment to care for the patient. Family physicians are in the ideal position to do this because of their long-term knowledge of the indi-

vidual within the context of the family. Physicians can preserve resilience by encouraging and supporting family members' self care and preserving their feelings of hope. Integral to this support is an assessment of their support systems. Awareness of the need for family members to sustain their feelings of hope directs physicians to be cognizant of both their nonverbal and verbal communication with family members.

Participants in this study described emotional upheaval in terms of uncertainty, making life and death decisions, and coping with feelings of loss. Physicians can assist family members in managing their feelings through communication on the basis of mutual trust and sincere interest in the family. Support groups may also help families cope.

A dynamic nexus, evident through participants' descriptions of their new and changing relationships, is particularly relevant to the family physician. Physicians must recognize the difficulty family members have managing and negotiating relationships with friends, family, and health care professionals. Participants described problems with lack of information and communication about their relatives' hospitalization and care. The family physician is in the ideal position to enhance communication among all those caring for the patient by continually sharing complete information with the family.

The findings of this research can broaden health care providers' awareness of the changes vigilant family members experience physically, emotionally, economically, and socially. Physicians can holistically assist family members to adapt in ways that are congruent with the family's usual pattern of functioning, while recognizing the inherent changes in lifestyle and roles.

A philosophy of family-centered care means that physicians should work to change the hospital environment to make it hospitable to vigilance. A number of family-centered approaches have been successfully integrated into hospital care. New York University's 120-bed Cooperative Care Unit is an example of a setting where families actively participate in patient care.³⁴ Another example is the Planetree Alliance, a group of innovative hospitals and health care institutions that implement a philosophy of patient-focused health care. This personalized care in a nurturing environment includes a focus on family involvement through care partnering.

Although family-centered care can be inconvenient and unwieldy for clinicians, it broadens the focus of care and responsibility to include those who are invested in the patient.³⁵ According to Ransom,³⁵ family-centered care "forces a provider's practice to be more visible. It requires communication with the patient's intimates, in series and simultaneously in conjoint meetings, and this can lead to complicated and troublesome situations. It puts pressure on the doctor to deal face to face with what is important to both patient and family members. Yet it may increase patient satisfaction and lead to better cooperation and better health in the long run."

LIMITATIONS

Transferability of findings is limited by the use of neurologic and rehabilitation settings for participant selection. The experience of vigilance for family members with relatives in these types of units may differ from the experience of family members staying with patients in other types of units. We are not able to generalize the results of the study, because a small and nonrandomized sample was used. However, the study provides information about the experience of vigilance that allows those interested in the topic to reach a conclusion about whether transfer to other samples and settings is possible.³⁶ Study findings also serve as a foundation for future studies in the area of families and the hospitalization experience.

CONCLUSIONS

A philosophy of family-centered care is congruent with the findings of this research and with the beliefs underlying family practice. Family practice is a medical specialty that provides continuing and comprehensive health care for individuals of all ages within the context of the family.³⁷ In most cases, the family physician is the patient's means of entry into the health care system, and he or she is the referral agent to other sources when indicated. Ideally, the family physician, as coordinator of care, can minimize fragmentation and maintain continuity of care. At the center of the family practice specialty is the physician-patient relationship, and what distinguishes family practice from other specialties is what the American Academy of Family Physicians³⁷ refers to as the "extent to which this relationship is valued, developed, nurtured, and maintained." The family physician, who serves as the patient's and family's advocate in health care matters, has unique attitudes and skills essential for comprehensive health care. The categories of meaning described in this research illuminate the meaning of vigilance for family members with hospitalized relatives and are useful for the family practice physician providing comprehensive care in a contemporary health care system.

ACKNOWLEDGMENTS

The second study reported in this article was supported by a grant from the University of Vermont's Committee on Research and Scholarship.

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