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Incarnating Heaven: Making the Hospice Philosophy Mean Business

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Hospice providers in the U.S. are on the horns of a dilemma. Survival of individual programs may require accreditation for third party reimbursement, but this stronger alignment with the business world of medicine may jeopardize their unique philosophy of care for dying persons. Hospice's current business/philosophy dilemma was expressed succinctly by a study participant as attempting to incarnate heaven. Data gathered through an ongoing participant observation study reveals the effects of current third party reimbursement on hospice practice. Further, these effects have implications for current U.S. health care reform efforts which are discussed in conclusion.

By the 1960s and 1970s, dying in Western Society was increasingly characterized as depersonalized, and death itself as denied or invisible, and costly (e.g., Aries, 1974, 1981; Blauner, 1966; DeSpelder and Strickland, 1992; Gorer, 1965; Glaser and Strauss, 1965; Kubler-Ross, 1969, Mor, 1987). These characteristics were considered to be problematic consequences of the dominant Western medical model, with its emphasis on the curing of disease; death had been displaced from people's homes to institutional settings like hospitals and nursing homes. It was in this climate of discontent that contemporary hospice evolved.

Hospice today is not so much a place as a philosophy which emphasizes palliative care, treatment of symptoms rather than disease, care rather than cure. Hospice concentrates on providing people with a terminal prognosis (generally six months or less) with the highest quality of life and personal control of the time which remains. Instead of dying in the depersonalized environment of institutions geared toward saving lives, hospice emphasizes dying amid familiar surroundings, friends and family (Corr and Corr, 1992; Mor, 1987). Moreover, hospice has often been discussed as a social movement, in part because it is attempting to change not only the way particular patients experience dying, but the nature of death and dying for society as a whole (Mesler, 1995a; Paradis, 1985; Stoddard, 1991).

With the advent of Medicare and Medicaid, hospice attempted to bring its philosophy into the business world of U.S. health care. While some practitioners perceive this as affording hospice several benefits, some also believe it has posed serious dilemmas for remaining faithful to the philosophy, and for the movement's future goals.

In this paper, we begin with a brief discussion of hospice's evolution into Medicare and Medicaid reimbursement. After a brief presentation of the research method and settings, we provide data exemplifying both the perceived *advantages* and *disadvantages* of third party reimbursement. We then conclude with a discussion of the implications of these findings not only for hospice, but for future health care reforms and, thus, the processes of dying in the U.S.

Background

Hospice evolved rather quickly in the U.S. from a mostly volunteer, grassroots, community effort in the 1960s into a full-fledged relationship with the insurance industry by the 1980s (Keller and Bell, 1984; Osterweis and Champagne, 1979). In the 1970s and early 1980s there was a definite push among most hospice providers to acquire payment for services (Paradis, 1984); for example, in the early 1980s the Director of education and training at the National Hospice Organization commented, "Hospices which are able, consciously or not, to make a transition to seeing the program as a business are the most likely to succeed" (quoted

in Mor, 1987, p.17). Nonetheless, some of those involved in the hospice movement did not want to pursue third party reimbursement. Some of the small, all volunteer hospices organized and lobbied against Medicare funding for hospice care, claiming that the hospice philosophy would be undermined if allowed to enter the traditional health care system. In fact, a survey of 48 mid-western hospice programs conducted during this period found that those " . . . that did not seek third-party reimbursement were truer, both in philosophy and practice, to the original hospice philosophy" (Mor, 1987; see also Cummings, 1985). Nonetheless, it seemed that the majority of providers were tired of asking for financial support through grants, donations, volunteers, and the United Way, and believed that hospice needed to enter the mainstream of health care in order to survive financially (Abel, 1986).

Payment for hospice services began after passage of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 and, as a result of this legislation, services provided to terminally ill Medicare beneficiaries were recognized as a legitimate part of the health care benefit package offered to elderly Americans (Miller and Mike, 1995). The method of reimbursement for hospice care under Medicare was quite revolutionary at the time. Instead of the traditional fee for service, Medicare would pay a daily set rate for each day in a hospice program, referred to as a prospective method of payment (Katterhagen, 1986). The daily rate was set at a particular amount, regardless of the services offered on any day. In the years following TEFRA, Medicare's model for hospice services also became available to the poor through each state's Medical Assistance (Medicaid) program; while the prospective method of payment was generally adopted by such programs, the daily rates were sometimes set at lower levels.

More recently hospice found a foothold in the private sector as well, for example through insurance coverage for those who work and receive health benefits. Many of these private insurance plans look very similar to the ones offered by Medicare and Medicaid. There is a daily rate which provides for a package of services, some of which the terminally ill person and family might not use, and sometimes a cap is set on the maximum amount allowed.

The benefit packages provided by these third party payors to hospice follows four guiding principles of care for the terminally

ill and their families: 1) the patient and family are the unit of care; 2) care is given by an interdisciplinary team; 3) pain and symptom control are paramount, and 4) bereavement follow-up is provided. These standards are operationalized in hospice through an interdisciplinary team which works on a plan of care to provide medical care, nursing, medical social work, counseling, home health aides, equipment, supplies, drugs, speech, physical and/or occupational therapy, volunteer services, and bereavement follow-up. Inpatient and family respite care can also be provided on a limited basis (Rhymes, 1990).

U.S. hospice services are provided mostly in the home environment, and the package of services and reimbursement mechanisms are fairly standardized, particularly under Medicare. Hospice care is provided and reimbursed at one of four levels of care; while rates vary around the country and over time, the following reflect approximate rates per category: home care (about \$90/day), inpatient care (about \$400/day), continuous care (during an acute crisis of 24–48 hours; about \$500/day), and respite care (a one-time option providing up to five continuous days break for the caregiver; about \$95/day). The hospice is paid a daily rate for each day the patient is enrolled in hospice under one of these four categories. Also, Medicare reimbursement is provided in four benefit periods of 90 days, 90 days, 30 days, and an unlimited period. Patients must choose (or “elect”) hospice over other Medicare benefits during each of these periods; should patients opt out of (or “diselect”) the Medicare hospice benefit during any of the four periods, the days left in that benefit period are relinquished. Therefore, patients are certified by their physician for each of the four time periods, and the interdisciplinary team reviews each case before a new certification takes place, to insure that the beneficiary does not lose days of their hospice benefit. Once the terminally ill individual opts out of traditional Medicare and elects the hospice benefit, the hospice is totally responsible (financially and professionally) for all health care needs. This means that the hospice must provide all of the above services within the daily reimbursement rate schedule. While most hospices solicit donations through various fund-raising activities, most also attempt to serve those terminally ill who have no insurance.

Methods and Settings

One of the authors collected the data reported here through an on-going participant observation study which began in 1991; I conducted the research in the home care components and a free-standing inpatient facility associated with several northeastern hospice organizations. In the interest of confidentiality I have referred to these settings collectively as Eastern Hope Hospice, and changed the names of all participants.

I entered the 12-hour volunteer training programs at each of two settings (home care in 1991, inpatient in 1992), and attended various meetings (e.g., clinical team, management team) at each of these settings. At two of the home care settings I spent some part of a full day apiece visiting patients with a nurse, social worker, chaplain, and admissions director, tape recording our conversations during car trips between residences. I also served as a part-time, fill-in volunteer at the inpatient facility. Thus far I have spent approximately 165 hours in the field, and have conducted formal, tape recorded, semi-structured interviews (ranging from about fifteen to seventy-five minutes in length) with more than thirty clinical and administrative staff. Lastly, I have had access to some organizational records and video taped interviews with patients and staff (collected for training purposes by one of the organizations). Throughout this process I have employed the constant comparative method of analysis to guide the research and organize the frequency and distribution of properties during analysis (Glaser, 1992; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Using this method, Eastern Hope's business/philosophy dilemma emerged as an early and enduring focus for the research: aligning themselves with the business world has advantages which must constantly be weighed against the costs.

Advantages of Reimbursement

Advantages to third party reimbursement were not among the first or most prominent aspects of the business/philosophy dilemma to emerge during observations; that is, advantages simply weren't articulated in an ongoing way by the Eastern Hope staff in the process of doing their work. When asked in interviews, however, most staff did identify some. Probably the most

significant of these are the increased *visibility* of hospice as a medical alternative, and increased *access* to its philosophy of care. In addition, and often linked with issues of visibility and access, many of the Eastern Hope staff felt that hospice had gained societal recognition and legitimation as a new medical service provider. For example, the executive director commented,

Well, I think finally hospice is being heard. I don't know if it's being heard as hospice, but the issue of patient empowerment, and the issue of shared decision-making, . . . the issue of prophylactic care such as bereavement, . . . and sort of the science of care now are being heard in major teaching hospitals and medical schools, and by the industry, so to speak, primarily because they're cost effective.

The volunteer coordinator for home care (1) and the chief social worker for the inpatient facility (2) reflected these advantages to joining the third party reimbursement structure also.

1. I see a potential benefit in somehow, if possible, being brought up to a level of importance, as any other health care service that's available to the public.
2. Well, I think one of the pros of that obviously is that many more people are accessing hospice care, because there are resources to provide. . . . (Also) the resources of being able to pay people and train people, and have conferences. . . .

Third party reimbursement also provided opportunities for what was referred to in various ways by the staff as "creative management", in this case provision of hospice care to patients for whom it might not otherwise have been practically available. For example, Eastern Hope expanded its definition of home care to include nursing homes once that became financially feasible. As the coordinator of nursing home care noted,

It hasn't been that long—I think it was 1986 when Medicare came into the nursing home, and now the Medicare benefit can be used for hospice, [that is] if they're not using it to pay for their skilled nursing bed, a Medicare bed in a nursing home.

Barbara, one of the home care nurses, put it in the context of creative management:

Everybody's like fiscally tightening their belt, you know, and we have become much more creative than we were five years ago. We

have to look at hospice in the '90s, you know. This is a creative way, I suppose—of going into nursing homes.

While some of the staff were critical that the incentive to enter nursing homes may have been financial, it was acknowledged that this also brought about positive change, from the hospice perspective, in the way patients died in these facilities. Likewise the inpatient facility, whose existence was in great part made possible by third party reimbursement, brought hospice care to many people who would not otherwise have received it. The volunteer coordinator for the inpatient facility commented,

I mean, a lot of the people [here] would never be able to have home care hospice. I mean it wasn't a choice: 'Do I want home care or here?' It's that they didn't have primary caretakers. So, the fact that they're here is really a blessing. . . . It was either be in the streets, or in a shelter, or home alone, without any care, or patchy care and guilty families, you know.

The bottom line for some of the staff at Eastern Hope was that the traditional caring side of hospice simply must make room for its newer business counterpart. The volunteer coordinator for home care expressed it this way:

I think part of that is that hospices need to stop thinking about themselves as a Mom and Pop grassroots kind of thing. . . . Yes it's compassionate care, and all of those good things, but it's also a medical model, and it's a business.

As Barbara, the home care nurse, put it,

We are going into the '90s in hospice and we have to let go of that kind of hokeyness and altruistic feeling. . . . The reality of it is you have to look at the fiscal end of it, and that's the hard part for hospice to run. [But] that's as important as it is talking to your patients, teaching them about medications, doing anticipatory guidance. You have to be able to manage your case, and manage the fiscal end as well as the other part of it or else it will crumble down.

Even when expressing the advantages of reimbursement, however, positive sentiments were often tempered by many mixed emotions among the staff. Most saw the need for business, but reflected concern about its effects on the compassion they

were dedicated to provide. Betty, a home care nurse, reflected this well in our interview:

Most people that work in a hospice do so for reasons other than money: that it's a calling of a type, that people feel very strongly about what they do. And they're willing to understand the business part, as long as it's put forth fairly gently, and with a great deal of tact, because that's not the priority for most of the staff. But the business person has to pay the bills, or there won't be a hospice. It's a delicate balance is what it is. . . .

Disadvantages of Reimbursement

Although these advantages of third party monies were acknowledged, as the last quote suggests, the original fears of diminishing the hospice philosophy were still of great concern at Eastern Hope. In fact, these concerns were one of the first and most enduring categories of data in this research and, thus, have become the dominant theme of this paper. While we have attempted to organize the data into specific sub-categories here to facilitate discussion, the examples provided will reveal the dynamic interplay of these issues in the real world of hospice practice. We begin this section with one of the pivotal categories of perceived disadvantage, the hospice census, then move to some other related categories: primary caregivers, nursing home care, medications and palliative care, and becoming "hospicized".

The Hospice Census

The number of patients Eastern Hope served (a combination of admissions, dislections and/or readmissions, and deaths), was a constant in their struggle for financial stability. On the one hand, the number of patients helped to determine the monies they had to spend on quality care; on the other hand it supported, or not, the number of staff needed to deliver that care. Early observations and interviews reflected these as dominant concerns.

For example, during the first interdisciplinary clinical team (I-team) meeting attended the staff were discussing a patient who seemed to be getting significantly better (i.e. now continent and able to walk without a walker), and noted that he may have to diselect his hospice benefit before the next benefit period. This discussion continued around Medicare coverage as a more

generalizable issue: bemoaning the restricted problems/services patients are allowed under the existing regulations. The clinical director capped this particular discussion by saying, "Write to your Congressmen". Later that year I attended my first Management Team meeting, where the executive director was reporting on the Board of Director's concern over the declining patient census. Some field notes from that meeting indicate how this concern was conveyed to this group and its effect:

The executive director made it clear that while the Board may perceive hospice as a typical business, he does not. He said that dying is not like that, you can't coordinate it easily. . . . To this the admissions director for the inpatient facility responded, "I needed to hear that. . . . When I get focused on the numbers I get depressed and it distracts me from what I got into this work for".

As these notes suggest, there existed an inherent tension between the business and philosophy of Eastern Hope. Being a business with full-time employees meant balancing their patient census with the size of their staff; but the natural fluctuations in their terminal patient population exacerbated staff concerns about their own jobs and the quality of patient care. Catherine, the chief social worker for home care (1), noted the complexity of this problem, and Ken, the chief social worker for the inpatient facility (2), summed up the perceived problem in our interviews:

1. We all can remember too well the days when 19 people died in one weekend, and that was two nursing and a social work job. So I'm not asking for more people until we stay and are solid at 60. . . . In the meantime, you're under-servicing. . . . My friend Deena went to Episcopal Hospice and, you know, they seemed to be okay at 30. . . . And all of a sudden it just wasn't the case anymore. They budgeted for 30, and they haven't been at 30 for months. And you know it's hand over fist, and the episcopal diocese is kind of bailing them. You know; you also need a bailout, like we've got the hospital. If we can't make payroll, they lend us money.
2. My fear is that we're going to become more and more financially focused; so much so that we're not thinking about dying people, but we're thinking about the checkbook, which I think happens.

Primary Caregivers

Whereas patient census is a concern for all in the health care business, at Eastern Hope it tended to jeopardize not only patient care and staff jobs, but the heart and soul of its philosophy - care amid family and friends, with patients in control, at home whenever possible. This is not only what Eastern Hope promised to their patients and families, but what made hospice attractive to third party payors as a less expensive alternative to institutional care. However, putting this philosophy into practice effectively requires the availability of a 24-hour a day primary caregiver (PCG) and, for Eastern Hope, finding and keeping PCGs had become increasingly difficult. As Susan, the admissions director for home care put it,

It's very difficult to keep people at home if there is not a family member there. Most people have to work, and who will be with the patient 24 hours a day?

Clara, the clinical director and nurse with eleven years of hospice experience put it this way,

The primary caregiver is a dying breed now. How many people are staying home to take care of a loved one? How many can afford to do that? What we have to do is change some of the regulations we have.

Regulations being what they are, however, the Eastern Hope staff applied more of its creative management skill to this dilemma. Data from the first day out visiting patients with Barbara, a nurse, reflect how this concept applies here. Talking about one patient she said,

She does not have a primary caregiver. That's one of the criteria, you know, supposedly. People coming on hospice are supposed to have a primary caregiver, and that's one of the situations where we are a little bit more flexible. She does have a lot of friends living in that little elder community. . . . So we would get like 17,000 phones calls from the whole community if there was something wrong with Juanita. . . . We have augmented her care with elder services too. . . . So, in the past, we have taken people on—like I had a couple of gentlemen in Easttown who had AIDS and they were dying, and we kind of pieced together a plan with friends, and made friends

commit to so many hours. . . . So we are flexible. We're not going to turn people away because they absolutely don't have anybody.

Even when there is a PCG available initially, circumstances often called for some creative management of care for both. Barbara talked about two other patients where the wife had been listed as the PCG upon admission, but she eventually went to a nursing home.

They both came on the program at the same time and it was kind of a joke. Because the wife was supposed to be the primary caregiver to Johnny with his COPD, and here she was, somebody that had Alzheimer's and bladder cancer—more Alzheimer's than anything.

To make matters worse, while hospice may have incentive to admit cases without PCGs to increase their census, to do so increases their risks, because such patients sometimes require extra, often more expensive, care (e.g., hospitalization).

Nursing Home Care

We have already noted that another use of creative management to stabilize the census involved the expansion of Eastern Hope's home care program into nursing homes. This was beneficial in making hospice care available to more patients, perhaps helping to expand and stabilize the census in the process. It also helped to resolve the PCG dilemma to some extent, because nursing home staff fulfill that role. The coordinator of nursing home care explained:

Well, the nursing home is the primary care giver, because they are the ones that are there around the clock, not us. So, we treat them the same way home care treats the primary care giver. We teach them how to care for that patient and allow the patient to die. We teach them pain control, because most nursing homes don't give a lot of drugs to the patients. So they really need guidance. But we're there to guide . . . rather than tell.

For Eastern Hope, the hospice philosophy became potentially jeopardized in nursing homes, however, because it confronted the dominant medical model head on for each patient, every day, with all the shifts of nursing home staff. While the hospice staff provided formal in-service teaching as well as individual

socialization during patient visits, the learning accomplished was often less than complete. A big part of this problem for Eastern Hope staff was that hospice care was still provided for the most part indirectly. Consequently, coordinating PCG care for hospice patients in nursing homes was often cause for concern at team meetings, as the following excerpt from an early I-team meeting suggests.

The nurse reporting on the 11th patient said that he needs a lot of help. He is in a nursing home and the hospice is having problems with the home because the nurses there are afraid of the patch medication that the patient is receiving (durogesic). The clinical director said that apparently they need to do a pain control in-service at that nursing home. The reporting nurse added that there is another nursing home which also needs a similar kind of service. Several others around the table chimed in that perhaps this is something that all the nursing homes need, that they simply don't know what hospice care is about and, particularly, what kinds of medications they can expect hospice patients to be on.

Betty, one of the home care nurses, summarized this well in our interview:

I think from a hospice point of view it's somewhat difficult because we're a consulting service. Although we're charging and we're managing the patients to some degree, we are not taking over the patient. There is always some issue of territory, whose patient is it.

The above examples also suggest some disadvantages for hospice practice and patients that relate even more directly to current third party reimbursement structures regardless of setting, the use of medication for palliative care.

Medication Use and Palliative Care

At Eastern Hope, being responsible for patients' total care under a prospective payment plan caused them numerous dilemmas concerning the balance between quality of care and cost of medications. The executive director raised their dilemmas to focus early in this research when he expressed an interest in having an independent pharmacy consultant conduct a drug utilization review for the hospice. He said that their needs were multiple and complex ones which raised ethical dilemmas they were not

equipped to handle independent of some “expert” advice. For example, because the inpatient facility specializes in caring for AIDS patients, their medication bills already were exceeding the national average for hospices. Further, at that point a new drug had been approved, had clearly become the drug of choice in palliative care for particular manifestations of the disease, and all the AIDS patients were requesting it. The problem was that the new drug cost about four times more than the drug they were currently using. The chief social worker for the inpatient facility commented on this particular issue independently in our interview as well:

It was fine that people were on DHPG. Here in our program we decided having your eyesight is a quality of life that you certainly want to continue. . . . So we’ve done that. Then along came Foscarnat, which for people that the DHPG did not work, . . . Foscarnat was a wonderful thing. Well, you know how much more expensive Foscarnat was? . . . How do we end up paying for that with our little \$400 a day?

A similar dilemma regarding medications involved patients being admitted to Eastern Hope already receiving medications considered more appropriate for treatment of disease for cure than treatment of symptoms for care. While these determinations were often a process as much as an event, involving team discussion and considerable ambiguity, they were also important considerations in maintaining both the philosophy and budget. In some cases the medications were more clearly inappropriate for hospice care. For example, one woman in her 80s was admitted to home care with three terminal conditions (breast cancer, kidney and congestive heart failure) and 12 medications, one of them (epoetin alpha) costing an estimated \$400 per day. Clara, the clinical director, said that it was her desire to refuse patients admission until she could adequately discriminate and discontinue some or all treatment medications. She had not been granted the power to do this, however, because it would jeopardize an already tenuous census.

In addition to the dimension of palliative care suggested here, the issue of patient control over dying also became a concern in this regard. Providing palliative care often translated into comfort, particularly pain control, which was in great part achieved

through medications. The issues of patient control at Eastern Hope have been discussed elsewhere (Mesler 1995b) but will be explored briefly here in the following section.

Becoming Hospicized

Hospice exists primarily as an alternative within the larger medical model of cure. For Eastern Hope this meant not only struggling with issues of medication use, but getting a realistic six month prognosis for patients as well. It was not unusual that patients elected hospice care with little time left. As the executive director explained,

You have to move through a physician world that primarily is oriented towards treatment. . . . So we essentially have one paradigm knocking on the door of another paradigm. And usually the physician paradigm wins, and you get the patients towards the end of their lives, which I'm sure you've heard a thousand times during this research. We're always backing up to catch up to the symptoms that are sort of choked up by using the treatment paradigm.

While this was indeed the norm, Eastern Hope also took in patients who were not as close to dying as originally anticipated. This posed a rather interesting problem which was a direct result of the Medicare/Medicaid reimbursement structure: patients had to be certified as hospice-appropriate, in terminal decline, before entering each of the four benefit periods. By itself this was considered a reasonable prerequisite by the staff, a part of the business of managed care; it nonetheless caused several rather serious and complex ethical concerns surrounding the hospice philosophy. For example, once patients were certified for the fourth, unlimited period, diselecting the hospice benefit for any reason meant leaving reimbursable hospice care forever. During the day out with Barbara, this issue came up after visiting the COPD patient whose wife had Alzheimers. Since he didn't really seem to need much care, we wound up discussing why he was a hospice patient, and Barbara provided a rather candid response.

He is in his unlimited period, so if he were to sign off the program tomorrow, he would never have any hospice benefit left. Certainly the economic issue is, you know (pause) I could go and see Johnny five days a week and we're almost making money on him. You

know what I mean? He doesn't need a lot of care; we still get the \$89 a day for him. . . . Probably the reality is (pause) that the hospice programs probably have a few of those people, because you almost have to have a little bit of those people that aren't sick that you can make a few bucks on. . . . I personally have a harder time with that. I'm very much into really watching somebody, and making sure that they're hospice-appropriate, and I'm very much into saving someone's benefits. . . . But in this case the doctor didn't want to do that. He wanted him to stay on the program. He felt like things would just become disastrous if he came off the hospice program. . . . And I think that we have made him somewhat dependent on hospice, and it would be hard to pull away at this point.

The executive director confirmed the need to have some relatively healthy patients on the census to effectively manage the prospective payment method of reimbursement, so that ". . . the surplus would go to those 5% outliers that are very expensive."

Beyond the reality of this creative management juggling act, however, the more critical ethical dilemma suggested here is the issue of having patients become dependent on hospice care. While some patients, like Johnny, might have been of questionable terminal status when admitted, that was atypical. A more common dilemma in this regard involved patients who were realistically prognosed as in terminal decline but seemed to improve under hospice care. If these patients became significantly better they needed to disselect their hospice benefit, despite any dependence which might have been created. The Eastern Hope staff at the inpatient facility referred to this as becoming "hospicized". Since they specialized in providing care for persons with AIDS, an increasing proportion of their patients had come from the drug subculture of the streets, and Paul, a social worker there, explained becoming hospicized among these individuals.

Of course in the center people are waited on hand and foot. And so, in a strange way it can be rather dysfunctional. . . . There are people who come in here who have a pillow for the first time. They've been just sleeping over the heating grates down by the (transit) station or something. So if you come here, you're receiving medication to address your physical pain. There are people who genuinely love you, and don't expect anything from you. It might be the first time in a long time you've had that experience. You become what

we call hospicized. So, if you do become better, and many people do. . . . They really ought to be discharged, because we're an acute care facility, and Medicare's going to be breathing down our necks saying, "This patient is inappropriate for your setting," and they're right; and that does happen.

While this provides the advantage of increased autonomy for such patients, it also creates a disadvantage in that they usually return to a life on the streets, deterioration of their health and quality of life. Betty, a home care nurse, talked about some of her nursing home patients becoming hospicized in their own way:

You get an occasional patient who really is attached to the hospice team, and that probably made all the difference. And the family's and the staff's concern, the nursing home staff's concern is, when we stop, that patient will plummet. And is that fair, to set that patient into that type of scenario?

Betty had one female patient with Alzheimer's who provides a good example of this phenomenon. Not only was the course of this patient's disease difficult to predict, but her deteriorating mental status made communication and understanding difficult if not impossible. Nonetheless, her condition after electing hospice and entering Eastern Hope's program improved to the point that she had to be considered for diselecting hospice as one of her benefit periods approached. Betty's, the family's, and the Eastern Hope staff's concern was that diselecting hospice care (loss of visits and attention from the aide, nurse, social worker, chaplain, etc.) could not be adequately explained to the patient, and might also be associated with a relapse. Evoking the baseline medical ethic of 'do no harm', Betty explained their concern this way:

Even if we say, "well if that happens and your mother or your patient stops eating again and withdraws, and really declines, we will be back," we have done some harm, at least psychologically, and that's a tough issue. What I would like to see, as Alzheimer's disease becomes more understood . . . perhaps the guidelines that are used for other specific clinical conditions, such as cancer, or cardiac, or COPD, real specific medical conditions . . . maybe the guidelines, timewise, can be changed.

Discussion and Conclusion

Before discussing the data reported here, the representativeness of Eastern Hope and generalizability of these findings deserve some comment. As in most ethnographic research, both representativeness and generalizability must be qualified by the ways in which the research settings are dissimilar from others of their kind. In this case Eastern Hope's urban/suburban location surrounded by teaching hospitals in a northeastern state, its federal and state accreditation, its free-standing inpatient facility, and the relatively large paid staff must be taken into account. Representativeness and generalizability are also enhanced in this case, however, by gathering data from several organizations that provide a wide array of services to a broad-based patient population. They are also enhanced by reflections of others on the impact of reimbursement for the movement as a whole (noted earlier, Cummings, 1985; Mor, 1987); where hospice is practiced within similar contexts, people's experiences are likely to be similar as well. It is our belief that, on balance, much of what is presented here will ring true for many of the people in contemporary hospice work.

To the degree that this is a generalizable problem for hospice, it seems to be a problem of institutionalizing compassionate care for the dying. This problem was expressed metaphorically by the executive director of Eastern Hope as incarnating heaven. That is, for hospice practitioners the benefits of incarnation (joining the world of business) include greater visibility, patient access, recognition and support for doing work they love. However, it appears that bringing a little bit of heaven (compassionate care for the dying) into the world makes it vulnerable to worldly concerns. From the perspective of hospice practitioners, the business world of medicine simply does not accommodate the concerns of the dying and their families as much as it could. Clara, the clinical director, stated the strongest of the sentiments in this regard; "When Medicare and Medicaid came in, hospice went out the window." John, a nurse at the inpatient facility summed up the situation of hospice's good efforts to change the nature of dying with his own metaphor for such an institutionalized approach to care:

[Patients] are having to sign forms with it all written out in a very obsessive-compulsive fashion, because that's the way it has to be for liability and legality and reimbursement, which is not really what it's all about. . . . You have to sort of realize on both sides of it that a lot of what we perceive as outgoing and education, and teaching and wonderful and great alternatives, can still be perceived as institutional and alienating and scary, and frankly . . . inapplicable, not applicable to the situation. The situation is such an intensely human, primeval situation: someone is dying. And where does a Xerox form fit into that?

The implications of this dilemma for the larger society seem to relate rather directly to the current deliberations surrounding health care reform generally. Where will dying patients and hospice care fit into these efforts? It would seem that the hospice movement and the society's current movement toward managed care are both responses to several of the same evolutionary circumstances, in particular the increasing proportion of elderly, chronic illnesses, and the high cost of care under the current medical model. How and/or whether these two movements converse in their efforts will help determine, in great part, the type of care and quality of life available to people in this country during their last days, weeks, and months of life.

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