

# The Construction of Hospice and the Hospice Patient Through Storytelling

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In February 1992, I had the privilege of interviewing seven persons who, in various capacities, have been involved with what I will call "Hospice Z." Affiliated with a county hospital and located in an Ohio city of approximately 40,000 residents, Hospice Z has for ten years provided in-home care to persons who meet three criteria established by Medicare: (1) they have been declared by their physician to be terminally ill, i.e., they are believed to have less than six months to live; (2) they have no recourse to curative treatment; and (3) they can arrange for a caregiver in the home (e.g., a spouse). The care Hospice Z supplies includes, at the least, medical services (especially pain management) rendered by nurses, and may also include, if a patient desires, assistance from volunteers, social workers and a chaplain. These hospice personnel, most of whom are women, have endured growing stress levels through the years as both the patient census and the average "patient-stay" have steadily increased.

The personal hospice experiences of the people I interviewed, which inevitably involve the experience of loss and all its attendant emotions, have—to use one of their favorite words—deeply "touched" them. So, I hesitate to leave my seat in their audience to assume an analytical stance toward their stories. It is indeed difficult to be analytical about death, about dying persons, about those who care for dying persons. But, given that storytelling in hospice, as elsewhere, is a complicated production of culture, and infused with ideology, the need for analysis presents itself. Analysis can expose as "constructed" what we may otherwise uncritically view as "natural" and therefore also as "good" or "better" or "right."

Over and against the impersonal and high-tech hospital, Hospice Z has historically represented itself as the mediator for the terminally ill of a more "natural" and therefore more "humane" death experience. The dying are allowed to die *at home*, and this, apparently, makes all the difference in the

world. Now, I have no reason to doubt and many reasons to respect the integrity and labors of hospice personnel. But one of their narrative genres—what I shall term the "making the impossible seem possible" (MISP) story—gives me reason to pause. What do narratives of this sort actually suggest about the hospice movement's professed challenge to the socio-medical status quo?

Before turning to two examples of this story type, I would like briefly to comment on two articles by Patrice O'Connor that have appeared in leading hospice journals. (Both articles were given to me to read by the former Volunteer Coordinator at Hospice Z.) O'Connor, who is the administrator of a hospital-based inner-city hospice, concludes an essay in *The American Journal of Hospice Care* with a summary statement of the hospice movement's mission:

The challenge of hospice is to sustain patients in a "personalized" environment, an environment that recognizes individual needs and attempts to reduce individual fears. And, without denying death, hospice philosophy accepts the limitations of a brief prognosis to promote maximum physical and psychological comfort. . . . *Hospice care generates hope in what often appears to be a hopeless situation.* (37, my italics)

Earlier, in an article published in *The Hospice Journal*, O'Connor includes a report on a hospice patient that can serve as an illustration of her claim that "Hospice care generates hope" for the hopeless:

One patient had abused drugs and alcohol to the point that her children had been taken away from her and placed in a variety of foster homes. In her 45th year her greatest desire was to be reunited with her four children under one roof. The [hospice] team found her an apartment, gathered the children from several states on the eastern seaboard, and instructed everyone in her elaborate medical care. This woman spent her last months with her family. We tried to meet her spiritual needs. We believe that she was finally, indeed, fruitful. (104-105)

O'Connor structures her narrative in the following pattern: (1) the patient's family, being absent, is unable to provide care; (2) the patient expresses a desire (to be reunited with her children); (3) the hospice, through its personnel, fulfills the patient's desire; and (4) the patient responds in a positive way (by becoming "fruitful").

Writing in popular hospice publications, O'Connor articulates the mission and constructs the myth of hospice very much as does "Grace," the Patient Care Coordinator at Hospice Z (see Appendix). Working fifty to

sixty hours a week, Grace supervises the nurses. She is deemed part of Hospice Z's "inner circle" because of her administrative position and because, back when Hospice Z was first established, she was the only nurse on its much smaller staff. Interestingly, many of her stories, including the two about to be discussed, harken back to those early days of Hospice Z, when she spent less time in the office and more time in the patients' homes.

I interviewed Grace at her kitchen table. She poured coffee for me and for "Mary," a trusted mutual friend and former Volunteer Coordinator at Hospice Z. Mary had recommended that I meet Grace, had scheduled our interview session, and now proved indispensable in putting Grace at ease.

Grace performed these MISP stories (and I could have included a third in the sequence) after I asked her to relate any memorable hospice experiences that came to mind. She first indicated that "memorable" could have different meanings, like "humorous" or "touching." "Touching" was the "emotional genre" of the narratives she elected to perform. Her later commentary upon these stories provided the thematic designation for the genre. In her words: "When you see people that are down so much, I think you have to keep reminding yourself to offer them something that seems impossible, because it may not be impossible."

Here is Grace's first MISP story:<sup>1</sup>

Grace: I guess the—the—what always comes to my mind is probably in our second year in hospice . . . Um . . . a young woman that lived in an upstairs apartment . . . um, with lung cancer (you might know who I'm talking about? *looking at Mary*)

Mary: Sure.

Grace: And, um . . . she and her husband lived there together. Their kids, I think they had—they had three older kids, who all had families, and were—one was in New York, and a couple in Columbus—oh, and one in Texas and one in Columbus, so nobody was right here. Really proud couple, really neat—she'd played golf, and she really enjoyed doing a lot of outdoors kinds of things, and as this lung cancer took its toll . . . uh, of course she became more and more confined to the apartment. And being in the second floor was a real problem, was posing a real problem, because leaving there was posing a real problem. So we were sitting there talking one day, and this was after we had another nurse or so on board, I guess. We were talking to them, and she said, "Boy, I would just love to go out and take a ride." This was after she had really been confined for a while. And I s-s-said, well, I didn't see why you couldn't, well, what was stopping you. And she says, well, "Getting down—up and down on the stairs. I can't do that

anymore." She wasn't that large a lady, that I said, "I—I know some men right now that could pick you up and carry you down those stairs if that's something you really wanted to do." And she said, why, she really did, so—this was an elaborate plan *{laughs loudly}*, this was an elaborate plan. . . . Um. . . . She needed then to be carried down—she had oxygen . . . she had to take morphine to help with her breathing along the way, just in case things didn't go so well. . . . Um . . . We had to line up two other—two volunteers—our male volunteers. Her husband was fairly large but had some breathing—respiratory—problems of his own, so he couldn't be one of the people to carry, but he could be one of the people to help with the oxygen and all those kinds of things. So we had two volunteers meet us at the apartment one day, and her husband and myself and maybe another nurse, I can't remember for sure, there was another nurse there maybe—to help with all of this. *{She begins speaking more rapidly.}* And she was to go on a ride—luckily the day was nice, that was one of the—there was a lot of contingencies—we had everybody on alert, so we hoped the day was nice. And it was a, I don't know, spring or summer, but it was a nice day. *{Her delivery becomes deliberate again, as in the beginning.}* So the two men came, and . . . bless their hearts, they picked her up and helped her down the stairs—to the car—and then we had this . . . *{emphasis created by pause}* plan that she was to be back at a certain time. I think we gave her, we figured, a half an hour; she figured too that would be plenty long. . . . So at the end of a half an hour—if she had to come back sooner than that, she was to call the office, and I would be sitting there waiting for the call, and the two volunteer—men volunteers—were at home being—waiting on a call. And if they didn't hear anything, they were still to come back at the end of the half-hour—to the apartment—and help her back up the stairs. Well, I'm sitting in the office, and I'm just hoping that this is going well *{laughing}* and that they're not going to be calling, and about twenty minutes into the half an hour, we got a call, and it was from her husband, and I thought, "Oh dear, things didn't go well." And he called up, and he wanted to know if they could have another half-hour—*{laughing very loudly}* that it was so much fun, they didn't want to come home. He says, "Mom-my *{as if imitating a pleading child}*, can I stay out for another half-hour?" *{very loud laughter by Grace; everyone at the table laughing.}* Said, "That sounds good to me." So that was really—that was really neat. And we called the volunteers and say, "Can you hang loose for another half-hour?" And, of course, they were delighted to.

And they helped her back upstairs. . . . And—actually they'd stopped at Wilson's for a hamburger, and that's one thing they wanted to be sure and do before they came back. So when they came back, and she was really tired, but I thought it was just neat, because she asked all of us to sit d-o-w-n and have something to drink with her, and she talked about how important that was to her, and how nice that was, and it was the last time she really ever left the apartment. She got sicker after that. (Tape 8, Side B, 122-166)

Now Mary tries to elicit another story that she has heard Grace tell. Apparently it is a story of no little significance, because in later conversation both Grace and Mary refer to it as "the porch story," as if it has been invested with this title. Indeed, notice (\*\*\*) how Grace finally recognizes which story Mary is prompting her for:

Mary: The one—I'm trying to think of the patient's name and I can't. She was a younger gal . . . um . . . she ended up having one of her children go stay with her sister up in [\_\_\_\_\_] or someplace—her daughter—the daughter went up there . . . um . . . she went out on \*\* the porch—

Grace: O-oh. . . *{loudly; signal of instant recognition; tries to start reconstructing the story.}*

Mary: I can't think of her name—that's a neat story too, if you can—

Grace: For the last time, you mean?

Mary: Yeah.

Grace: M-m-m-m. . . . Uh . . . She was a young gal, this lady was, and had small children—well, her daughter was eleven, I think [*she and Mary try to sort out ages*], her son was a junior or senior in high school, yeah. And she had really been in bed . . . um, she was in bed in the living room of her home ever since she'd been home from the hospital, and that had been—well, not ever since, but I guess it had been maybe five weeks [*looks at Mary, who murmurs agreement*—five or six weeks probably that she had been really . . . um, in bed and unable to get out. And this one day I was there at the house—I'm probably going to get fuzzy on how this all came about—but anyway, she said something about—I said, I guess, "It's a bea-u-tiful day out there." (And I—I think that's so much of what we bring . . . to people, is the outside world—*{to Mary}* you see it all the time too. It—it's that you bring that outside

world to them, and let them know that if you want to participate, we can help you . . . do something about just laying there. And some people choose not to, but a lot of people choose to do that.) Uh, so I said, "It is a beautiful day," and she said, "Oh, I would love to get out." And I said, "Well, you could." And she says, "Oh, I don't think I could." And I said, "Sure you could. You got a wheelchair right here, and we could lift you out of that"—she had a lot, actually, of cancer in her, uh, bones, and so it was painful [] for her. Uhm-hm. (But again you have to give people the choice, I think, of is it too painful. What—what's—what's more important. If you want to get outside you'll probably do it.) [] We gave her some extra medicine . . . waited a few minutes . . . and said, you know, "Do you want to try it?" And she said, "Oh, I'd love to." So [] we got her in the wheelchair, and it was painful—[] but she still wanted to go for it, and we took her out on the front porch. (And I said, you talk about enjoying the—just the little things in life)—I mean, she just took that big breath and went *{she inhales deeply and audibly, leaning back in her chair}*, "A-a-h! That felt so good!" And about the time we got her out there the kids were coming home from school. So some little neighbor kids were coming across the yard with her daughter. And I—she looked—she looked really bad, the lady did, and I thought, "Oh, I hope those kids"—not her daughter but the others—"don't just walk right on by . . . 'cause that would make her feel so bad." And, bless their hearts, they came right up to her just like she was, you know *{chuckling a little, shrugging her shoulders}*, just fine, and she—that really took some doing on their part, I think, and they said, "Hi-i-i," and she was asking them how school was and all that—it was just really touching, and she said, "Oh, this just smells so good out here." And she sat for quite a while, a neighbor popped across the street, and she waved at her, and—it's like a new lease on life, just to be able *{laughing}* to provide a change of scenery, you know, it was really . . . [] really touching.

Phyllis: Did you say something about "the last time—for the last time?"

Mary: [] That was the last time she was out.

Grace: *{In part, speaking simultaneously with Mary}* That was her last time, too. Yeah. That was like she just—it took every ounce of energy in her . . . to do that. But I think, when you see people that are down . . . so much, I think you have to keep reminding yourself to offer them something that seems

impossible, because it may not be impossible. You know what—[] you get that mindset that I'm sick and I'm dying . . . a-n-d I can't do it. That's kind of the whole mindset. And I think a lot of what we have to offer is, "Yes, you can; if you want to bad enough, we'll try to help you figure out a way to go about it." And that's . . . a lot of the satisfaction. (Tape 8, Side B, 180-253)

Compare Grace's contention that hospice's mission is to make the impossible seem possible to O'Connor's assertion that hospice "generates hope" for the hopeless. Furthermore, compare the structure of Grace's stories to that of O'Connor's anecdote:

	(a) O'Connor	(b) Car Ride	(c) Porch
(1) patient's family is unable to provide care (a) children in foster homes; no husband (b) children grown and scattered geographically; husband not healthy (c) children young; no husband	x	x	x
(2) patient is confined (a) (implied, because of illness) (b) illness; in second floor apartment (c) illness; in hospital bed	x	x	x
(3) patient expresses a desire (a) to reunite with children (b) to go outside and take a ride (c) to go outside [development:] (3-1) nurse suggests desire can be fulfilled (3-2) patient protests (3-3) nurse suggests way(s) to fulfill desire (3-4) patient chooses to try	x	x x x x	x x x x
(4) hospice fulfills the patient's desire	x	x	x
(5) the patient responds in a positive way (a) patient is fruitful (b) patient expresses appreciation (c) patient expresses appreciation (implied by the repetition of how much the patient enjoyed the fresh air)	x	x	x

Although Grace's performed stories are understandably more developed than O'Connor's journalistic illustration (i.e., [3-1] through [3-4]), they share an identical structure, revealing a conflation of institutional and personal narrative.

I would like now to look at Grace's stories in more detail. These MISP narratives, performed through the years for colleagues and close friends, have more in common than their story line. First, each patient is anonymous; several storytellers told me that this narrative rule is almost always heeded, even years after a patient's death, because the stories were originally told in a clinical setting where confidentiality had to be protected.<sup>2</sup> Next, Grace emphasizes the "terminally ill" role of each patient when, early in the narrative, she identifies the illness from which the patient is suffering ("lung cancer" in [b], "cancer in her bones" in [c]). The effect of this is, for the most part, to empty the nameless patient of all personal identity except the pathology which Grace, the agent of hospice, inscribes upon her.

In addition to the patient-character, Grace the nurse is also present in each narrative. Grace empties much of her own story-character of personal identity by frequently using first-person collective pronouns without a clear referent. Hers is the institutional use of "we": her character serves as the embodiment of Hospice Z. Thus, Grace inscribes upon her character the twin powers of the medical and the institutional powers that, in this story-realm, are deemed greater than the power of the personal. After all, in the figure of the patient, the personal is labeled as pathological.

With the characters thus constructed, an intriguing picture of agency unfolds. Structurally, each story seems to hinge on the patient's choice to try and fulfill her own desire, with hospice's help. The patient is portrayed as a unique individual, free and empowered toward self-realization. However, in actuality she has no freedom beyond choice, no power but to think. Since her body exists only as pathology writ large, her freedom is relegated to the realm of mind.

Now, if the patient is confined to the life of the mind, how is she to overcome her physical confinement? How is her particular desire to be fulfilled, if material agency is impossible? Ah,—these stories argue—material agency is not impossible. It must simply be relocated, from the personal realm to the institutional. These narratives effect that relocation, in two ways. First, they explicitly construct Hospice Z as the patient's "surrogate family," a metaphor Grace herself employed during the interview. Second, they implicitly construct Hospice Z as the patient's "surrogate body."

Grace can easily depict Hospice Z as surrogate family since she can characterize the patient's relatives as having either no presence or no power, for various reasons. Consequently, Hospice Z can move in and fill the vacuum. The authority of the medical thus extends itself beyond its traditional domain, the hospital (of which Hospice Z is an affiliate), into the home, henceforth to govern the means of fulfilling desire.<sup>3</sup> This marriage of the medical and the familial becomes quite evident in story (b). Grace's



"elaborate" planning is rewarded when the patient's dutiful husband calls in and asks "Mommy" whether he and his girl might stay out past curfew.

Here hospice as "surrogate family" is, more specifically, hospice as "surrogate mother." That the care of the terminally ill should be associated with the maternal (and rendered largely by female staff members and volunteers) is not surprising. Caregiving is "woman" at her best, according to the patriarchy. Furthermore, if medicine, as Robbie Davis-Floyd and others have argued, has been an estate of the patriarchy, the patriarchy can through hospice reassert its authority over the maternal/female, as well as its authority over the home. As institutional "father," the medical establishment *provides* for the maintenance of the terminally ill patient while giving immediate responsibility for that patient's *nurture* to the nurses. Through all of this, the nurses and their ward as a unit remain segregated in the home as the socio-medical "other."

Now, just as Hospice Z attempts, as "surrogate family," to fill a vacuum left by the patient's absent or impotent family unit, it moves into the role of "surrogate body." The institution (in the person of the staff and volunteers) becomes the "healthy" substitute for the patient's body. For example, Hospice Z makes it possible for patient (b) to get up and down the two flights of stairs; by carrying her in its arms, Hospice Z in essence becomes her legs. Through its surrogacy, Hospice Z redeems the patient's body from its disease, as it were, and by implication the patient is depicted as becoming (at least for the moment) "whole" again.

The redemption pattern in these MISP stories shares the "ontotheological quality" that Susan Ritchie has identified as characteristic of medical case histories. This should not be surprising, since these MISP stories were originally told in a clinical setting. Ritchie describes medical case histories (1) as narratives which physicians tell "overtly about patients, but in which they are nonetheless covertly inscribed as heroes" (217); (2) as narratives which textually construct a patient's oppression and redemption (218); and (3) as narratives which shape the patient as a subjectivity "freed" by medical intervention (218). This is not to say that either physicians or hospice storytellers so structure a narrative as to elevate themselves at the expense of their dying and deceased patients—quite the contrary. Ritchie notes, for example, that "the creative act [of writing a fictional or non-fictional account of a doctor's first years in the profession] becomes the place to declare that the young medico is successfully resisting dehumanization" (212). Likewise, I suspect that hospice workers like Grace may tell MISP stories less to prove themselves noble than to prove themselves not ignoble. After all, they daily fight a battle they can never hope to win. Grace underscores the "ontotheological" nature of her MISP narratives (as well as the success of Hospice Z's mission) by announcing in each story that this was "the last time" the patient ever did *x*. In this way, Grace lets

her audience know that each patient made her choice and allowed Hospice Z to help her "in time," before it was too late.

One might think that death would be at the front and center of a hospice drama. However, Grace never directly alludes to the deaths of these patients; death occurs off-stage, behind the dramatic curtain. Perhaps the reason is that, in this story-realm, death is doubly scandalous. First, it finally exposes the illusory nature of the autonomy that hospice grants a patient through its surrogacy. Furthermore, it exposes the ultimate impotence of high-tech medicine—medicine so valorized in mainstream American culture as to become the subject and object of faith.

I would argue that "making the impossible seem possible" stories indicate that a hospice may help to reify existing power relations between the medical establishment and the patient, *despite* the hospice movement's professed determination to challenge those relations—and, yes, despite the endless and compassionate toil of Grace and other hospice workers. This is unfortunate, on two counts. First, it seems that, as an institution, a hospice may not, and perhaps cannot, live up to the philosophy its members espouse. On the other, it seems that MISP storytellers may unwittingly subvert, albeit in a small way, the very cause which their daily labors embrace.

By this analysis I have not meant to denigrate the work and experiences of those persons associated with Hospice Z. Rather, I have sought in these stories to discover signs of how significant the hospice movement's challenge to the socio-medical hegemony may be. The stories discussed here, admittedly few, have proven disappointing on this score. However, I fully recognize that MISP narratives are but one type of story that Grace and other hospice workers tell. And I am convinced that, whatever else they disclose, MISP narratives have positive value for storytellers like Grace. If nothing else, they provide catharsis—as Grace says, they are "therapeutic." What is more, they validate the struggle of hospice personnel to retain dignity and to resist dehumanization; dehumanization of their patients, and of themselves. Grace and other hospice workers are, like their patients, confined—not physically, perhaps, but certainly politically. They are constrained by the competing demands of both their employers and their patients. To use Foucault's term, they are bound by their historical "subject-position."<sup>4</sup> To this boundedness, their narratives also testify. I am left to respect these strong women (and these "tired" women, as Grace laughingly confessed) who can occupy such a position, caught as they are between the faces of dying persons and the faceless powers that daily dispatch the hospice workers to death's door.

### Notes

- 1 Transcription key: . . . pause  
 [] garbled or deleted words  
 () an aside  
 {italic} editorial remarks  
under emphasis (by loudness or change in pitch)  
 w-o-r-d elongated word

2 In a later conversation Mary mentioned that while Hospice Z insists on its commitment to protecting patient confidentiality, some of its personnel nevertheless display hospice bumperstickers. Their cars are clearly identifiable when parked outside patient homes and do not go unnoticed in the area's small towns and along its rural roads.

3 In constructing Hospice Z as "surrogate family," Grace also creates "the family" and "the home," but that would be another essay.

4 See Foucault 1972.

### Appendix: Interviewee Information: "Grace"

- Interviewed: 4:30-6:00 p.m., Sunday, 2/9/92, while sitting at her kitchen table and drinking coffee
- Others Present: "Mary," who is Grace's friend and formerly the Volunteer Coordinator at Hospice Z; Phyllis Cole, collector
- Birth: 2/28/38, Cleveland, OH
- Family: Married in 1968 to a widower who had four children; all the children are now in their twenties
- Ethnicity: Ancestry is German, Scotch, Irish and Welsh; proud that she is a descendant of Sir Walter Raleigh
- Education: High school graduate; three years of nurse's training (diploma program); graduate study in neurological nursing
- Experience: Occupational Nursing instructor, clinical manager, staff nurse, nursing home care; for the last eight years, full-time Patient Care Coordinator at Hospice Z
- Religion: United Methodist for thirty years; became Roman Catholic when she married her Catholic husband; was very involved in

church work when raising their children; now less involved, in part because of her demanding hospice schedule, but very concerned with issues of spirituality

Travel: Extensive travel in the United States; also travel in Canada and the Bahamas

Skills/Hobbies: Church-related activities, cross-stitching, crocheting, enjoying music (e.g., singing in ecumenical church choir), and, most recently, playing computer games

### Acknowledgements

I wish to express my deep appreciation to Dr. Susan Ritchie as well as to Dr. Amy Shuman and my graduate school colleagues at the Center for Folklore Studies at The Ohio State University for their kind help in the preparation of this essay.

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