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Book Review

Hospice House Calls: A Reflection

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Abstract

I describe the scope and practice of Florida's first pediatric hospice, with an emphasis on the crucial value of house calls. Three vignettes are included, all describing house calls to patients with terminal cancer, to illustrate three difference aspects of this work. In concluding reflections, I comment on the contrast between the usual curative approach of modern medicine and the entire focus of palliative medicine on care and comfort. I also emphasize the inestimable value of a "body-mind-spirit" approach, and on the primary role played by hospice nurses.

Introduction

When I was appointed as northern Florida's first pediatric hospice director in 2004, there were four-hundred-thousand children-from babies to teens-living in the US with incurable illnesses, of whom fifty-five-thousand died every year. But many of these deaths are not included in the four-hundred-thousand, because a lot are sudden-from sudden infant death syndrome, accidents, or suicides. In Florida alone, there are about three-thousand childhood deaths each year, over a hundred of them at my own university hospital. Of these children, less than one percent were receiving hospice care at the time of my appointment.

The first task facing myself and my hospice nurses was to identify the scope of our work. The accompanying table summarizes our tasks.

As I left this initial meeting of our pediatric hospice, I found the thought of house calls jumping into my mind, and felt a thrill of excitement. It took a minute to figure out why, until I realized my mind was back with the home visits I would make with my doctor-uncle as a teenager-perhaps the first time I became aware of just what my chosen profession could entail. I had rarely made one since, in almost forty years of doctoring in several university medical centers, but suddenly the opportunity had been handed to me on a plate.

Nobody was telling me how to spend my working time-and didn't seeing my patients and their families in their own homes come with the job? But it would not entail sitting with wives and children while we waited for the man of the house to breathe his last. We would have children to care for who were, yes, incurably ill, but by no means at the point of death. We would have time to enjoy each other's company, make some memories, and come to know what a child's and family's ultimate wishes were.

Patient Vignettes

Soon after this first meeting, my hospice nurse, Cendra, took me to meet sixteen-year-old Alicia at her home in Starke, a small town twenty-five miles northeast of Gainesville. Alicia had a slow-growing brain tumor, had gone through extensive surgery and radiation, and chemotherapy was not an option at this stage. Her life was in no immediate danger, but she was quite disabled and spent most of her time in her wheelchair in front of the TV. Dad was working fulltime as an electrician while Mom stayed home to care for Alicia, whilst raising two other school-aged children and taking in part-time work as a seamstress.

Alicia's biggest problem was that she craved food constantly, probably because of the tumor's location around a small section of her hypothalamus, which governs a person's appetite. It seemed to never switch off, and this wasn't helped by the corticosteroids she had to receive whenever she showed signs of pressure building up inside her brain-headache and throwing up early in the morning-because of the tumor swelling unpredictably. Mom knew these signs well, and would often dose her daughter with steroids before calling us.

When we arrived, Alicia's mom had tea waiting, and introduced me to her daughter. It proved hard to wrest Alicia's attention away from the TV, but she greeted me with a huge beam and grasped my hand vigorously with her one good hand. Cendra and I sat ourselves on each side sipping from our teacups, and Cendra quickly showed her skills at holding Alicia's attention.

"You've been on a cruise, haven't you, Alicia?"

Cendra had already filled me in that the Childrens' Wish Foundation had sponsored this trip for Alicia and her family, all expenses paid.

"Yes, yes, yes. It was fun. A big boat".

"Did your little sister come, too? And your brother?"

"Yes. And Daddy". More beaming.

"What was the best part, Alicia?" Cendra was grinning impishly, like they were sharing some private joke. Alicia simply beamed back.

"How was the food?" I prompted, pretty certain I was onto what the fun was about.

Now Alicia was giggling, almost as if she knew she had been caught doing something naughty. Cendra wrapped her arm around her waist and they both dissolved in mirth. Mom was laughing, too, though trying to hold it back.

"There were six restaurants, doctor," she told me. "After the first day, I gave up trying to keep Alicia away. It was like an all-day guided tour-she knew each one within a day, and what they had to offer. I couldn't hardly find clothes for her to wear any more. She must have got the whole idea of the cruise from the TV-that they were food city!"

"So a good time was had by all, eh?"

"I guess so, doctor-we gained a few pounds ourselves. But we did get Alicia walking around the deck some with the other children. And they had the best time-lots of stuff organized for them. It was hard getting them off the boat!"

I got down to business, checking off my list of relevant issues-Alicia's symptoms and signs, her meds and her compliance with them, financial worries, and how Mom and Dad and Alicia's sibs were coping. Mom was unflappable and at apparent peace with her situation. I mentioned the idea of respite for the family-that we could admit Alicia to hospice for a few days to give everyone a break. But Mom looked almost shocked that we would consider such a thing. As I was writing out the necessary refill prescriptions, Mom took us back to an unforgettable happening on the cruise.

"We had this one big scare, doctor. We set an alarm at night that connects through to our room from Alicia's, lets us know if she gets out of bed. We thought we had it all hooked up between the kids' cabin and our, but it didn't work this one time. I woke up in the middle of the night reckoning something was amiss. Mother's instinct, I guess. Sure enough, Alicia was gone from her bed, while the other kids are sleeping like a hurricane wouldn't wake 'em. I roused my husband, and we started searching around, finally came on this cleaner who said maybe she fell overboard someplace, which got even me rattled. We were checking every deck, most of them with scarcely a light on.

"But when we reached the top deck, it was lit up with a bunch of lights, and the restaurant was open for business. So who should be setting there by the buffet table alongside the waiter but our Alicia. Stuffing herself, she was, with the waiter chatting away to her! I guess he thought she had got the okay to be up here-her being almost a grown-up, and not talking back much. Heavenly Jesus, I couldn't stop crying, seeing my little girl not just safe, but having the time of her life!"

On the drive back to Gainesville, Cendra and I reflected on what we had witnessed.

"How long do you think she can live, Doctor John?"

"Well, she's sure happy, which must count for something. And her mother is utterly devoted, so she's getting the very best care. I don't see much point in repeating her CAT scans, but from what I can see, she could go on trucking for months. Who knows, years, I guess?"

The day after we got home, I was back on the road with Cendra, this time to meet eleven-year-old Warren and his family, who lived in a mobile home close to the airport. I had known Warren since he had first been diagnosed with bone cancer, and we had treated him with intensive chemotherapy and radiation. These treatments are successful in many adolescents, but Warren wasn't one of the lucky ones. About a year after diagnosis, the cancer had reappeared in both lungs. He had gone on to get second-line drug treatments, but they had had little effect on the growth of his cancer, so his mother made the decision to keep him at home for his remaining time. The hospice folks had been called in, so I was happy I would again be looking after him, even in these sad circumstances.

As we drove to his house, Cendra let me know that Warren's dad was working in Georgia, laying an extension to Interstate I-95. He could only get home at weekends, but Warren's three teenage sisters were always there after school to help Mom, while spending time with their much-loved brother. Mom had taught them to cook, and it was their task to prepare the evening meal, which I got to sample during our visit. Warren was receiving around-the-clock morphine, as well as nutritional supplements prepared by Grandma, long known as a powerful natural healer. Chief among these healing remedies was a prayer ritual conducted three times daily that the whole family joined in- this time with Cendra and me included.

My only medical task was to go over Warren's care with Mom and Cendra, and to renew his prescriptions. I figured out the average daily cost of his care, now he was in fulltime hospice, to be \$125, while during his earlier hospitalizations at the university hospital his bills had often run to over \$1,000 a day. Since there were few medical issues, and Warren was sleeping peacefully on the mattress that had been made up for him on the floor of the front room, I spent my time between the afternoon prayer ritual and supper getting acquainted with the family. I tried quizzing the girls about their homework, only to discover that most of it went straight over my head. Mom made a point of acquainting me with three generations of the family through the framed photos gracing every wall.

On my next visit, I got to meet about thirty of these family members, including many teens and twenty-something's, who hung out in the driveway drinking beer or coke. Sensing Warren did not have long to go, Mom had moved up a planned family reunion to make sure everyone got to visit and say their goodbyes. Warren had roused himself for the occasion, and recognized most of his cousins and uncles and aunts, even if he had trouble remembering their names.

My final visit came three days later. I was busy consulting on our university hospital's neonatology unit, where a baby had been born with a rare chromosomal abnormality, and was not expected to live more than a week or so. I got a call from Warren's mom, who told me

calmly that her son had just passed, and that Cendra and our social worker were on their way. When I got there, Warren was propped up on pillows on his parents' bed, with the whole family gathered at the bedside. After I had signed the death certificate, Mom hugged me as she sobbed quietly.

"Doc, I want a photo, just of you and Warren. You were so good to him. Could you maybe climb up on his bed?"

I treasure that picture of me and Warren, now dead some two hours, though I don't show it around to many of my colleagues.

The following weekend, I was on a trip with visiting friends to show them the old fishing village of Cedar Key, sixty miles south-west of Gainesville. We were about halfway there when my pager went off. It was Cendra once more.

"Sorry to bother you, Dr John, but I'm out at Marie's house. You know, the little girl with the hind brain tumor. She's getting very bad headaches, and I need a stat order to up her IV morphine dose. The pressure must be building up in her head".

This was a first for me-ordering IV narcotic doses over the phone to my new hospice nurse from fifty-odd miles away.

"What's she on at the moment?"

"2mg every four hours-I want to go straight to 3".

"I agree-and give her another milligram in ten minutes if it's not cutting it".

We were on our way back from Cedar Key when Cendra called again. "I've been trying to reach you. I think you must have been driving through a dead zone. Anyway, Marie is sleepy, but she's still very restless. I want to go up some more".

"I'm sorry, Cendra, I was all the way to Cedar Key. I'll try to join you as soon as I've dropped my friends back. So what weight is she?"

"Just over 30 pounds-say 15 kg".

I did some quick calculations. The usual pediatric dose of IV morphine is 0.1mg/kg, so we were already at over twice the normal dose. But what did we have to lose? Marie had been fading quickly, and on my last visit her parents seemed more than ready to let her go.

"Okay, let's go with 4mg stat, and another 2 every thirty minutes".

Forty minutes later, Cendra reported that Marie was still moaning and thrashing, even though she was barely rousable from her coma.

"And the local pharmacy has only one dose of IV morphine left, Dr John. There's a van on the way from the university hospital with further supplies, but I don't know how long she can last".

I detected a hint of desperation in this calm and usually unflappable nurse's voice.

"I'm on my way, Cendra, should be with you in twenty minutes or so. Give her 5mg every ten minutes till I'm there".

When I finally made it to the house, I knew at a glance that the little girl was at last at peace. Mom was cradling Marie in her arms on the sofa, while Dad and Cendra were holding Mom between them.

"She's been gone only about five minutes, John. It was peaceful at the end".

It was the first time Cendra had dropped the "Dr" in addressing me. I reflected that it was Cendra and myself who between us had brought what was left of this little girl's life to a quite intentional end. How the lawyers would have seen this whole scenario I wasn't too sure, but there weren't any lawyers around, and Mom's last words to me left me in no doubt that we had done the absolutely right and only thing in these tragic circumstances.

"Thank you, doctor, and Cendra, for helping us, for giving our dear little girl relief from her suffering".

I reflected that it was Cendra-in the tradition of so many of Florence Nightingale's descendants-who had done the heavy lifting, in giving such skillful and loving care to this family and their little girl (Table 1).

Concluding Reflections

The practice of palliative care is a one-eighty switch from modern medicine's abiding focus on pulling our patients back from the brink of death with our very latest therapies. The care and comfort of the patient and the whole family, for as long as they need us, has to be paramount. These vignettes illustrate that this can mean doing little beyond visiting, listening over a cup of tea, linking our own hearts to theirs. It is also essential to have champions among our physician and nurse colleagues, so that patients are referred in time for us hospice workers to be of real service. A consultation for 'terminal pain management' received a few hours before the patient's death offers no such opportunity.

Table 1: Scope of a Pediatric Hospice Service.

Our primary focus is every child's comfort and quality of life.
Suffering can be physical, psychological, social, or spiritual-or all four at once.
All our patients' needs are unique, not least because of difference in their ages-from new borns to college students.
We seek to offer these children the very best care setting-hopefully at home, but inpatient hospice or hospital when needed.
These illnesses affect not only children, but whole families and even whole communities.
Cure and care are far from mutually exclusive-it's not either/or but both/and.
We must offer round-the-clock care, especially to children who stay at home.
We must never forget respite and bereavement care for families, including establishing a camp for siblings.
It is vital to build in rituals, including memorial services and annual remembrances.
And we must not forget to care for ourselves, and each other, as allies and friends.

C.S. Lewis, in writing about his own grief over the loss of his wife, said, “One never meets just Cancer...one only meets each hour or moment that comes. All manner of ups and downs...bad spots in our best times, many good ones in our worst”. Perhaps the real essence of the work of serving the very ill and dying is to help families uncover the meaning behind Lewis’s words, so that they can take comfort in these best times, as long as they and their loved one are together on this earth.

One thing that has proved enormously helpful in my work as a hospice director is a commitment to bring my whole body, mind, and spirit to work with me each day. This is no easy task in a world where science reigns supreme, and our days are so often consumed by heady considerations of modern medicine’s latest approach to every disease. On these days, the patient in front of us can easily vanish from view. But moments of silent and total attention at the patient’s bedside,

especially that of a dying patient, can feel more like communion than conversation, and allow us to sustain true bonds with our patients and their families. I believe that children are often more in touch with their spiritual selves than are adults, perhaps especially when confronting life-threatening illness. It is a small step to intuit that they draw on their spiritual resources more readily at such times.

Last, but by no means least, I have come to acknowledge that it is our nurses-in the company of so many latter-day Florence Nightingales-who do most of the heavy lifting in giving loving and skillful care to these patients and their families.

References

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