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Star Magazine interview | Hospice director helps patients on final journey

By CINDY HOEDEL
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Ann Allegre is director of medical programs at Kansas City Hospice & Palliative Care, www.kansascityhospice.org.

Last month the Hastings Center, a bioethics institute in Garrison, N.Y., honored Allegre with a national award for leadership in end-of-life care. For more than 20 years, Allegre has worked to develop training programs to educate medical professionals and caregivers on how to provide better care for seriously ill patients.

Allegre raises questions that eventually touch all families but that are not often addressed by the Western medical system: At what point should the focus shift from aggressive treatment to helping with a peaceful exit from life?

Is refusing treatment tantamount to giving up?

What are the patient's and the family's priorities for their remaining time together?

Allegre thinks it is important to address a dying patient's emotional and spiritual pain, because they affect physical pain.

She favors a provision in the health care reform legislation that would allow hospice consultation concurrently with traditional care for seriously ill patients. This conversation took place at Hospice House in south Kansas City.

You just returned from Colorado, where you were teaching a class for hospice workers and volunteers. What was the class about?

It was based on Buddhist teachings about taking care of yourself and being fully present with patients.

Fully present how?

We teach students meditation techniques for letting go of distractions and also listening exercises. It's about not letting your mind run in 60 directions and not thinking about what you are going to say next, but really listening.

How did you come to be involved with hospice care?

I'm an internist by training. In 1988 I started doing hospice work part time.

Why did you want to work with hospice?

I had a private practice in Kansas City, Kan., and I had something of an interest in working with people who were seriously ill. There was a small home health agency that was starting a hospice, and they asked me to be the director.

What made you want to work with seriously ill people?

In 1981, right after I finished my medical training, I was diagnosed with Stage 3 ovarian cancer. I was 31. I was fortunate — one of the more active chemo drugs had just come on the market. The treatments worked. That taught me a lot about being a patient.

Did you think you were going to die?

No one talked to me about death, not the doctors, not my family. But I had medical training. I knew it was a possibility, even though I was getting lots of reassurance.

Did that make it worse, that no one was willing to talk about the possibility of dying?

I don't know if I could have addressed it at first when I was dealing with the chemo and so on. But about a month into it I had to acknowledge to myself that I might not get the outcome I was being promised.

Did you keep that to yourself or did you talk about it to other people?

I kept it to myself. I was afraid my family members would not be able to discuss it because it would be too painful. Up to that point most people tried to push the thought of dying away. It was too scary. But I knew pushing it away wasn't going to work because the situation wasn't going away.

Looking back, it feels like I went past the fear to see what was on the other side, what death felt like without the fear, and it felt OK, like going to sleep. The point was to live every day.

You reached that acceptance by yourself, without support groups or books?

I was sick. There was no Internet. I didn't even go to the library to look up the odds. There was no support for me. I worked through it alone.

And then you didn't die. But did confronting death change you?

It caused me to realize how little we were doing to help patients and families deal with many aspects of serious illness, but especially the aspect of talking to them openly about what was going on.

In my practice I was more open with seriously ill patients. My colleagues would ask me to talk to their seriously ill patients. "You're good at this," they would say. I could put myself in their shoes.

Is there much science about death? Or just observations?

It depends on the aspect. There is more scientific evidence today about symptom management. There's not much science about what happens after life leaves the body.

Are there any studies on the effects of talking openly about death with seriously ill patients?

Yes. We used to think patients would get depressed if we discussed death. But studies have shown that not only do they feel better on an emotional level and a physical level, they might even live a little longer.

Do you have any idea why?

It could be they feel more in control knowing what they are dealing with. And probably a certain amount of very aggressive treatments in very sick patients could cause life to be shorter, not longer.

What's universal about the way patients deal with death and what is very individual?

No two cases are alike. One fairly universal aspect, I would say, is fear. Most people have to deal with a fear of death at some time in life. They may have dealt with it before they are in the advanced stages of illness, for example if they are elderly, but at some time they have to deal with it.

Another semi-universal thing is that loved ones keep us tied to this life. We try to live as long as possible for loved ones, sometimes even after we are tired and ready to let go.

Is there an American way of dealing with death?

I think there is a Western medical way. We have so much faith in medical science in this country that we're not willing to accept that death is a natural part of life. We think we can fix everything. It has been said that we are the only culture that thinks death is optional.

Have you seen changes in that attitude?

Certainly in the last two decades there has been more open discussion. Now there is an acknowledgment that, yes, it will happen some day, but still a feeling of, not today.

Are there any new developments in hospice care?

Not in terms of symptom management, but one trend I welcome is introducing a palliative care approach earlier in the course of illness. A Harvard study last August looked at metastatic lung cancer patients who either received usual treatment — chemo etc. — or usual treatment with palliative care consultation. The study found the group that got less aggressive care had better symptom control and were more likely to accept that they were dying and also lived longer.

Less aggressive care at the end of life probably means lower costs, too.

There is a cost to hospice, but overall, yes. The highest dollars go to patients who die in intensive care after lengthy treatments. Intensive care is meant to be a bridge to recovery. It doesn't make sense to use it to prolong the dying process.

What are the barriers to talking about hospice options in the hospital? Is there a feeling that it is tantamount to running up the white flag?

Absolutely.

Is it patients or doctors or family members who feel that way?

All of them. It doesn't help that the way insurance is set up you have to choose either aggressive life-promoting treatments or aggressive symptom management.

How is that problematic?

It sets up a Catch-22 situation where you can't find anyone to help you accept that you are dying until you get into hospice, but you can't get into hospice until you accept that you are dying.

We should be able to open the conversation of "hope for the best but prepare for the worst" earlier in the process.

How widespread is the resistance to hospice in hospitals?

The medical profession has come a long way in the last few years to being more open to hospice options, but there are still cases where physicians say, "Yes, I believe in hospice but not for my patient."

The whole movement toward advance directives arose in the '70s and '80s because doctors would not stop putting feeding tubes in people. They thought they were doing their job. I've seen a swing in the past few years. Now you see doctors saying, "This isn't working; why are we doing this?" but the family isn't willing to give up hope.

What should you say if a friend or loved one is diagnosed with a terminal illness?

It's very important to convey love and support, to show we care that this thing is happening to them and that we can be of very practical help: "Can I get the oil changed in your car? Can I sit with your kids?"

Most people are very uncomfortable talking about death. Can you offer some pointers?

Be willing to be part of the conversation if the sick person is willing to raise the issue. If they are not raising the issue, you can encourage them by saying, "Whatever is on your mind, you can feel free to talk about it with me."

What should you not say?

One thing that comes up is, when people know someone is dying, they do the how-much-you-mean-to-me, how-much-I-love-you thing, and the seriously ill person ends up comforting the people who are not dying.

It's fine to share emotions but not to the point where the sick person feels they need to take care of you.

Are there other things people do that unintentionally burden the seriously ill person?

When wider and wider layers of people stream through, and the dying person has to keep going through the story over and over again. Some families set up a website to provide daily updates on the person's condition and limit who can visit.

As the patient, if it's my best friend, sure I want to see her, but the other 16 ladies in the book club? No.

Is it a mistake to tell a seriously ill patient, "I know you're going to be OK"?

That reaction doesn't allow patients who are tired and suffering from treatments to be where they need to be emotionally. It doesn't let them express, "I'm OK with dying."

Loved ones need to be aware that saying, "You can beat this" can add to the patient's stress if the patient knows she can't live up to that expectation.

Does a patient's faith play a role in acceptance of death?

Some people are very supported and comforted by their faith and have a strong feeling everything will be OK. Some people have been active in their faith but feel they have not done well enough and fear they will be punished after death; they are not supported by their faith.

People who don't describe themselves as being supported by faith, and they are a minority in our culture, can be either comfortable that their molecules will return to the natural world, or they can be afraid.

When you thought you were dying did you address that personally — what would happen to your molecules?

I don't think I thought that through scientifically. I still don't know the answer.

Are you OK with not knowing the answer to that question?

Yes.

Often patients and loved ones struggle with deciding how much treatment to receive at the end of life. What is your advice for them?

You should always try to balance medical goals with the patient's priorities for their remaining time. It can take time to discover what those priorities are.

Have you seen cases where you think too much treatment was given at the end of life?

When treatments are planned and given, it is always with the expectation that it will benefit the patient. Let me be clear that I am in favor of aggressive treatment when it has the potential to extend life significantly. I am here today because of aggressive treatments.

The question is, how much will it help? Is it aggressive treatments for cancer patients that might only extend life a few days or weeks and most of that time will be spent receiving treatments, or is it a heart valve replacement that can significantly add to length of life and quality of life?

Do you see people who want to hang on at all costs and against all odds?

We see that. One man couldn't accept that he was dying and wanted more and more treatments. His wife asked, "Is it more important that he take more chemo or go on a cruise with his family?"

What did you advise?

He chose the chemo. His wife would have chosen the cruise.

As a doctor, do you feel comfortable talking to him about the possibility the cruise might be better?

I believe we should always address what the options are and how they support goals.

What age group has the hardest time facing death?

People in their 20s, 30s and 40s have the hardest time. Children do it easier, and old folks do it easier.

Why is it easier for children?

We don't know for sure. Some people have postulated that they haven't fully developed themselves as individuals, so they don't fully see what the possibilities are for the future. They also don't feel so in control of their lives as we adults think we are.

Do most people want to die suddenly or do they want advance notice?

Most of my patients say they want to have a normal day and then go home and die in bed. Less than 10 percent of deaths are sudden, and in that 10 percent you've got murders and suicides and accidents, so it's very unusual to die in your sleep.

Most people don't want to have to go through a final decline, but most of us will.

How would you prefer to die?

I would want to know. I would want time to get my life in order. It would be best if we lived life totally caught up, with the finances tied up and easy to turn over to someone else and to have no unfinished business with loved ones. Most of us don't live in that caught-up way, so it can be good to have time to tie up loose ends.

You often hear stories of family members being distressed by seeing dying loved ones in pain. Why can't hospitals control pain better?

Many good hospital caregivers haven't had good training in how to use pain medications. In the hospice world we are more comfortable with higher doses that hospital staff are not comfortable with.

Do you confront ethical issues in hospice care, when it comes to alleviating pain at the end of life?

We have good medications to relieve pain, and we don't have an ethical dilemma about using them because they are safe when used properly.

There have been discussions about the double effect principle, which says basically that if the intention is to treat pain, it is OK to hasten death. But pain meds don't hasten death. In Oregon, where assisted death is legal, they use barbiturates, not pain meds, for that purpose. And we don't apply the principle of double effect to chemo or other aggressive treatments.

Do you have an opinion about euthanasia?

I'm glad I work in states — Kansas and Missouri — that don't have that option. If I were practicing in a state where that was legal, I would not provide that service for patients, mainly because I don't want any patients thinking falsely that I am giving them morphine to hasten the process.

Even in states where assisted death is legal it is very seldom used, if you look at the statistics.

Is some pain untreatable?

In 90 percent or more of cases, we can control pain.

Why is hospice able to control pain better than hospitals?

We are better trained; it is our specialty. We want to know about pain every time we see you. In hospitals they are more concerned with other things, vital signs and such. The pain number is being used in some hospitals as the fifth vital sign.

The other part is, pain is multi-factoral. It can be an expression of emotional pain or spiritual pain. If you don't address those issues, it's hard to get the physical pain under control. Addressing the fear of dying is key to addressing pain.

What do you say to a dying person who is afraid?

Let them know they are in a safe environment: "You are safe. We will take care of you. You won't be abandoned."

Should you say, "Don't be afraid"?

It doesn't make much sense to say that. It's better to try to think what they might be frightened of and how to address those specific fears. Are they afraid of being in pain? Is it how the kids are going to do after they are gone? Is it who will look after a disabled family member? Ask yourself how you can give reassurance that things will be OK after they are gone.

Death or serious illness can bring out the worst in people and create turmoil in families. Do you have any advice for family members about how not to behave?

It is very helpful to keep arguments out of the dying person's room and try to give them some peace. Try to focus not on whether Jimmy or Mary gets to make the decision but about what's best for Mom.

What triggers bad family scenes?

Often all family members are trying to act out of what they think is the best approach, so disagreements become emotional. Tensions that have been building for years play a role. And estrangements.

Is it common that people want to air grievances at the deathbed?

Yes. Dying is the last chance to get even.

Would you prefer people refrain from that sort of thing?

I think people have to do what they have to do. I want the experience to be as peaceful and healthy as possible, but it's difficult when there is a big issue that has never been expressed, and this is the last chance to air it.

What kind of regrets do dying people have? Is it common for people to say they wish they had gone to Hawaii?

Some people have written that as we look forward, we regret errors of commission: things we have done wrong. As we look back we regret errors of omission: things we didn't do.

People say, "I wish I hadn't given up all that time to that person. I wish I hadn't passed up that trip to see the world after graduation before going straight into the work world."

In your experience what brings comfort at the end? What can loved ones do beyond sitting and holding the dying person's hand?

It depends on the individual. Some patients respond to prayers from their faith tradition. Others respond to special music that has meaning for them. Reading to patients is often a comfort. And people enjoy hearing favorite family stories and reminiscing about vacations and trips.

What about physical comforts?

Soft fabrics are good. Putting lotion on their hands or feet if they are not too sensitive to touch. Fixing their hair, always paying attention to whether it is painful.

One issue that always comes up is food. Part of the dying process is a loss of appetite. The body can't use food anymore and doesn't want it. Family members will fix a favorite food and are distressed if the patient won't eat it. So don't spend three hours making that elaborate dish; that time could be better spent.

How different does death look from patient to patient?

There is a final pathway that occurs in a majority of cases. Most people don't realize that the dying person will be too weak and too out of it to respond for several days before death. In movies and on TV, people say their last words and then are gone. It's not like that. It is like the patient is asleep with congested breathing for two days. Pain is not as intense at the very end, there is just a profound weakness.

Why does it take so long to die?

I've often asked myself that. In addition to it just taking time for the body to shut down, I think part of it may be that it gives loved ones time to come to terms with the final separation.

A few hours before my cousin died of breast cancer, she sat bolt upright in her hospital bed and said, "I have to go." Do you see things like that?

Yes. People often speak in metaphors: "I have to get packed." "I'm waiting in line." "The train is leaving" or "The bus is leaving without me." "I'm getting ready to take a trip." Or they say, "I want to go home," and you wonder which home they are referring to. I think some are talking about being ready to go to heaven.

Have you seen other unusual things at the end of life?

We see what I call glimpses of mystery, things we can't explain. Many of our patients see beings in the room no one else can see. Many describe the beings as deceased loved ones. I don't know what that means. Does it mean my grandma who died in 1976 can come back to comfort me at the end of my life, or that the divine is coming to me in a form that is comforting to me?

It is as if people who are dying are in two worlds simultaneously.

Is that common?

Very common. It also happens that bereaved persons frequently can see the presence of the recently deceased person. Children and animals often can be seen responding to a presence the rest of us can't see.

How is it not depressing being around dying people every day?

We come to medicine to help people. There is so much we can do to help people at the end of life. If I felt every death was a failure I couldn't do it.

We get so much back. We get spiritual comfort when we see people who think death is a positive experience in their life.

A positive experience?

Yes. One young woman dying of cancer had 8- and 11-year old children. Her attitude was, "This has been so precious because I have gotten to know my children so well. We have shared so much we wouldn't have shared if we were just busy going about our lives."

It is not all gloom and doom. There is still time to have fun. There is something very precious about working with people at this stage of life. They are not on a superficial level. They have no time for small talk. They don't care what is going on in Egypt. They want to talk about things in life that are important and things they are proud of. They also want to tell funny stories. We have fun doing hospice.

Can some people keep a sense of humor up to the very end?

Yes. One patient sat outside in the sun every day during a string of beautiful weather. He said, "This is my church, sitting out in the sunshine watching the bees buzz." I said, "You're the only patient I'm ever going to send to the undertaker with a sunburn." We shared a good laugh.

Another man had been at Hospice House about four weeks, and one day he said, "That's it. I'm through." He stopped taking his pills; he would only take his pain meds. He called his family together. His wife was taking a walk, but he said, "She needs to come in right now." The family members all sat down, and he started telling jokes. He told jokes for two hours and then stopped talking and died a few days later.

It's a great comfort to know it can be like that at the end.

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