



Caring for the Caregiver

Hosted by: Howard Hochster, MD

Guests: Ruth McCorkle, PhD, Florence Schorske Wald Professor of Nursing; Professor of Epidemiology, Yale School of Nursing and Dena Schulman-Green, PhD, Research Scientist, Yale School of Nursing

August 27, 2017

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Welcome to Yale Cancer Answers with doctors Howard Hochster, Anees Chagpar, and Steven Gore. I am Bruce Barber. Yale Cancer Answers is our way of providing you with the most up-to-date information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week Dr. Hochster is joined by Ruth McCorkle and Dena Schulman-Green for a conversation about oncology nursing. Dr. McCorkle is the Florence Schorske Wald Professor of Nursing and Professor of Epidemiology and Dr. Schulman-Green is a Research Scientist at the Yale School of Nursing.

Hochster Can you start by telling us a little bit about what you do and when you got involved in this field?

McCorkle I have been an oncology nurse since the early 1970s and of course, initially, a diagnosis of cancer was really associated with a death sentence and it's greatly changed today. We could not talk about cancer openly and today, we talk with patients about goals of care, and of course not all ethnicities and diverse populations are always open about talking about it, but we have made a lot of progress since the early years and it has been, during my lifetime, really exciting to see.

Schulman-Greene I come to oncology nursing via the route of psychology and gerontology. Gerontology is the science of aging, but I realized as I was studying what I was most interested in was serious illness and helping people to cope with serious illness over the course of the care trajectory and so I came to Yale to study with Ruth to learn about what palliative care is and how patients and family caregivers could use palliative care to help them manage the challenges of cancer.

Hochster That is a very big topic and obviously our perspectives on that have really changed over the years, As a practicing medical oncologist who gives chemotherapy, my point of view is that the best palliation is when we can shrink the tumors so people feel better, but then they have to deal with the side effects and sometimes we do not get to shrink the tumors. How do you take all that into account and how have you helped us deal with the way we interact with our patients?

Schulman-Greene Palliative care is described as an extra layer of support that is provided by a multidisciplinary team of healthcare providers that includes physicians, nurses, social workers, and chaplains to provide patient-centered care. One of the hallmarks of palliative care is that it is provided to the patient and the family caregiver as a unit to help them to manage pain and symptoms and to provide psychosocial, spiritual, and emotional support for families as they deal with cancer. Part of it is about controlling the cancer or shrinking the cancer if that is possible, but part of it is learning to live with cancer and the affect of its treatment over time and to help people to be able to match what is important to them in their life, their personal values and goals and cultural preferences to the plan of care.

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- McCorkle So the team working together, the palliative care team and the medical team working together can really maximize the effects, and often the palliative care team will help patients stay in cancer treatment and that is really our goal, to get the cancer treated as long and as effective as possible. So, by combining forces, we will often see these positive effects where the patient does much better by this team approach.
- Hochster Yes, there was actually a study performed in Boston where patients were randomized to treatment alone or treatment plus palliative care and the group with the palliative care actually did much better.
- McCorkle Interesting. We did a similar study in the early 1980s randomizing patients with lung cancer to 3 groups and we actually got similar results. At that time, palliative care was not even known. We were still doing hospice care and trying to get reimbursement. Palliative care really evolved in the 1990s.
- Hochster The world was not ready for your message.
- McCorkle I don't think so, but the really important part of that in our search is you are wanting to get common results across studies to reinforce the effects to show the differences. Dr. Timmel's study was also done with lung cancer. Deena and I have done a somewhat similar study with ovarian cancer and Dr. Peter Schwartz and got very positive results. This palliative aspect when you call it quality of life and include healthcare utilization by how much people go to the emergency room or how long they are in the hospital, whether they get referred to long-term care, the point is to reduce that burden on the family and it also has this other effect of reducing the cost burden, so these outcomes of working at the effects of cancer and cancer treatment are tremendously important.
- Hochster Tell us what your research has shown about the palliative care team? What does the team usually consist of and how does that provide the support to the patients and families?
- McCorkle I have been doing research since the 1970s, being funded by NIH consistently and the main part of our intervention is directed by the advanced practice nurse. An advanced practice nurse is a master's prepared clinician who has a bachelor's and then a specialty of 2 years training in oncology and she is a member of the specialty team and we have many of those at Smilow, I think we have 12 specialty teams and then have these practice providers in them. We did a clustered design in our trial where we randomized the units instead of the patients, the clinics, and we were really able to show that the advanced practice nurse helped coordinate, navigate patients through, get them seen by palliative care quickly or cardiac, the oncology team, or the dermatology team, any place that person was having side effects and this coordination with the oncology team and then other specialties, because so many people have comorbidities, they will have not only cardiac problems, but you want to involve the primary care physician too, and the

reason that you want the primary care physician is because they often see the other family members associated with the patient, so they also can help to support them in a positive way. It is critical that the advanced practice nurse coordinates among the team members recognizes early what the patient's problems are so that they can be minimized and maybe even stopped. The reason that this works is the relationship that the nurse forms with that patient, and you will find that the patient often will call the nurse or text the nurse or communicate with them, often afterhours, and is able to get a response very quickly. These are very special relationships.

Hochster You are talking about the APRNs, specifically working in the palliative care?

McCorkle All of them, they are wonderful.

Hochster There is no question about that, we would not be able to function without our APRNs on every team, but while they are certainly very valuable members of the treatment team and can help bridge some of the stuff, there is a separate palliative care team often and who do you usually find on such palliative care teams?

McCorkle Within our own system, we have Dr. Jen Kapo and Morrison and Leslie Black and the PA and social worker and what has been really wonderful is the addition of palliative care from the inpatient unit to the outpatient unit in which it is becoming more integrated into routine care with the increase of referrals and with so much demand that we have to expand.

Hochster Yes, obviously the outpatients are a lot of them and many of them can use the additional help.

Schulman-Green One of the challenges for patients and family members is to know what palliative care is because very often people mistake palliative care as being hospice care and palliative care to be most effective really should be started upon diagnosis of a serious illness, so that there is time to have these very personal and important conversations about what the situation is, what kind of treatment best fits the patient's values and personal goals and what it is going to look like from here on out, what are the expectations and those are conversations that need to happen beginning early and then to be ongoing throughout the patient's care trajectory. Time is really important, so that is why they need to start at diagnosis and that is why people need to know that palliative care is not for people who are at the end of their life but upon diagnosis of a serious illness.

Hochster I think that is a very important concept. We are talking about palliative care here as people who are going to help us manage the symptoms of the disease and symptoms of the treatment. It is not necessarily just end of life care, that is a different thing altogether. Thank you very much for that interesting discussion. We are going to take a short break for a medical minute. Please stay

tuned to learn more about oncology nursing with Dr. Ruth McCorkle and Dr. Dena Schulman-Green.

Medical Minute

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There are many obstacles to face when quitting smoking as smoking involves the potent drug, nicotine, but it is a very important lifestyle change, especially for patients undergoing cancer treatment. Quitting smoking has been shown to positively impact response to treatments, decrease the likelihood that the patients will develop second malignancies and increase rates of survival. Tobacco treatment programs are currently being offered at federally designated comprehensive cancer centers such as Yale Cancer Center and at Smilow Cancer Hospital. Smilow Cancer Hospital's tobacco treatment program operates on the principles of the US Public Health Service Clinical Practice Guidelines. All treatment components are evidence based and therefore, all patients are treated with FDA-approved first line medications for smoking cessation as well as smoking cessation counseling that stresses appropriate coping skills. More information is available at YaleCancerCenter.org. You are listening to WNPR, Connecticut's public media source for news and ideas.

Hochster Welcome back to Yale Cancer Answers. This is Dr. Howard Hochster and I am joined tonight by my guests, Dr. McCorkle and Schulman-Green, who are oncology nurses and we are discussing caring for caregivers and palliative care. For this portion let's really focus more on the caregivers. It seems as though the unsung heroes of medical care today, especially as we tend to shorten the length of hospital stays and push people out of the hospital sooner, are the family members and the caregivers who really take on a lot of duties including nursing and things that they really didn't necessarily sign up for or thought they had signed up for. Tell us a little bit about what's happening with the caregivers today?

Schulman-Green There are about 2.8 million family caregivers in the United States and they are most often adult daughters of the care recipient, there is some variation by cancer diagnosis. For example, among women with breast or ovarian cancer, most often the family caregiver is the male spouse or a partner. So what kinds of caregiving tasks do they engage in? There are very practical tasks of managing medications, of transportation to appointments, of meal preparation, but then you get to these other, perhaps more challenging tasks of helping to manage pain and other symptoms, of providing emotional support, of providing spiritual support, of helping patients to activate the resources they need to be able to have a high quality of life. We can talk about this list of tasks, but really what it is when you are engaged in caregiving is thinking about how you are going to have a good day, what needs to happen for the family to have a good day, what

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does a good day look like? You hope that the patient does not have any pain or other burdensome symptoms, you hope maybe they are going to be able to eat something, you hope they are going to have some meaning in their day, some joy in their day, be able to get some things done on their to-do list. You hope as a caregiver you are going to be able to get some of the things done on your to-do list and that is what a good day is and it is a day that for people who are not dealing with cancer care, it is something they take for granted, but for someone who is managing cancer that is what a good day looks like. So the idea is, how do we enable family caregivers to be able to make that happen? How do they support the patient, and how do they support themselves to be able to have a period of good days? Some challenges are that most caregivers do not have training in how to be a caregiver, they do not even recognize much of the time that this is a new role for them because they see this as a role that they have always had, that they have always taken care of this person, but suddenly taking care of that person within the context of a cancer diagnosis is a different way of being and yet the same way of being with them, but they do not have training in how to provide basic nursing care. This is a real challenge for some people who have not been in this position before or do not have medical or nursing training or maybe do not have the personality to be a caregiver, it is a difficult role to be in.

- Hochster What are some of the resources that can help out these caregivers, who obviously are taking on a big burden?
- McCorkle One of the first things we have to do is identify who the caregiver is and you can't always assume it is the person necessarily that lives with them. In one of our studies we found that in fact over 50% of the people who got cancer were taking care of someone who is already ill in their family. So, the health of the person you live with makes a huge difference to their ability to take care of the person with cancer. You need to know who could be the caregiver and once we identify that person, do they want to be a caregiver, are they local, do they live with the person, or do they come in from a distance. Then we have to know whether they have any special skills to care and most importantly, we have to know whether the patient is willing to accept the care from that person. These are negotiable situations and often patients get discharged with a piece of paper that says to do this and the person who picks them up is handed it, you're it.
- Hochster I think we don't really formally identify this caregiver person necessarily, and if they are not there, they may have missed the whole educational experience.
- McCorkle And if it's a long-term situation, it is important that we check in with them regularly. Cancer treatment now has evolved where much of chemotherapy and the importance of medications, medication reconciliation, making sure they do not interact with each other is absolutely essential and this is an important role for the caregiver.

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Hochster I have the feeling, as you said many times it is the spouse or partner, but for older individuals whose spouses may be not around anymore or they are too ill themselves, it tends to be the daughter who lives closest, is that what your research shows as well and how do they balance their families and taking care of their sick parents?

Schulman-Green That is one of the key challenges that family caregivers face is how to integrate these new tasks of cancer caregiving into what is often an already busy life where people have these competing roles at work, of caring for children, perhaps caring for aging parents, and now there is perhaps yet another person who they need to provide care for. People often feel very conflicted in those roles and do not feel like they are doing the kind of job that they would like to in all of those roles which is why activating resources and getting support for themselves is so very important. I think one of the biggest challenges for family caregivers is being able to accept help. Often family caregivers feel like they need to perform the role entirely on their own and they want to be sort of superman or superwoman in that role, I mean they think that they are doing a good job if they can do it independently. One of the things that I would urge is for people to use the resources around them, very often there are other family members or friends and community services that are available to help alleviate some of that burden from caregivers.

Hochster Can you give us some specific examples of what kind of resources might be available?

Schulman-Green One of the things that comes to mind immediately is support groups for caregivers so that they can speak with others who are in a similar position as they are. That can be very supportive for some people, but it is also another appointment on their calendar and people need to decide if that is a form of support that they can integrate into their day well. Community services, like seeing a counselor, like going for a massage, like meal preparation or transportation services, can provide different kinds of support that can take even a little piece of the caregiving job off of their plate.

Hochster And visiting nurse services are helpful?

McCorkle Certainly and I think some people very much like to have visiting nurse services and I think it varies by people's insurance. If they are able to have those sorts of services and can they have those services for enough hours of the day that they would really find useful. So those are the things that need to be coordinated.

Hochster And how can caregivers tap into these resources, what is the best way for them to access these?

McCorkle There are two major national organizations, CancerCare out of New York and then the Wellness Community Cancer Support, which their headquarters are in Philadelphia, and both of those groups have support groups. Cancer Support Community also has a weekly radio show that you

can call in and ask your questions about the kinds of problems you are experiencing and unfortunately, we do not have one here in Connecticut, but the neighboring states do and the national one is very responsive. There are local groups that help, the American Cancer Society still helps with rides at the regional office, but they can be arranged for people, there are also dietary groups that help patients so that their nutrition is kept adequate during cancer treatment.

Hochster I mean here at Smilow, we have social service people and nutritionists and all the teams and also palliative care. So those things certainly can be accessed through their regular appointments.

Schulman-Green Which is another way that the palliative care service can be of help because they can assess what the needs are of both the patient and the family caregiver and direct them to the resources that will help to address those needs.

Hochster What have you, in your research, discovered about caregivers taking care of themselves? Does it seem like they tend to put that at the bottom of their priorities?

McCorkle It is certainly a neglected area and one in which additional research is needed and again, this is the importance of the oncology team working together. The physician in charge of the case may be having very important treatment decision, discussions about the patient with the social worker, the nurse may be really supporting the family, telling them what a good job they are doing and getting them plugged into a mental health provider for some breaks.

Dr. Ruth McCorkle is the Florence Schorske Wald Professor of Nursing and Professor of Epidemiology and Dr. Schulman-Green is a Research Scientist at the Yale School of Nursing. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer. You are on WNPR, Connecticut's public media source for news and ideas.