

A Conversation with Dr. Harold P. Freeman

An Interview with Amanda Patton, Associate Editor, ACCC

Harold P. Freeman, MD, is an internationally recognized authority on the interrelationships between race, poverty, and cancer. In 2007 the Harold P. Freeman Patient Navigation Institute was established to set and ensure standards for patient navigation programs through an emphasis on the navigation model developed by Dr. Freeman. In an interview, Dr. Freeman shares his perspective on why patient navigation remains a critical need in cancer care.

Q. Why do you think the use of patient navigators is becoming more prevalent?

A. Patient navigation is an important concept. The American healthcare system is fragmented. Many Americans, especially the poor and uninsured, meet barriers to receiving timely diagnosis and treatment of cancer. Patient navigation programs are becoming more prevalent because patient navigators serve to eliminate barriers to timely diagnosis and treatment.

Secondly, I think the larger issue is that there are an estimated 45 million uninsured in America and an additional 25 million American citizens who are underinsured and, therefore, may not be able to pay for treatment. Healthcare is the number one cause of bankruptcy in America.

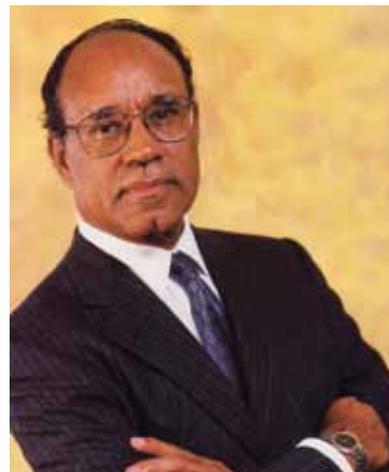
And thirdly, if you look at 32 million American people on Medicaid, a study published just a few months ago by the American Cancer Society showed that people on Medicaid have no better cancer outcome as measured by survival and mortality compared to people that are uninsured. So when you put together the 45 million uninsured, the 25 million underinsured, and add the 32 million on Medicaid—just those categories alone add up to 100 million people who are likely to have severe challenges when they attempt to enter the healthcare system. That's one-third of the American people.

The problem is very large and the issue is that in communities these people who have these barriers must

fight their way through the system. Often they become disillusioned and give up hope. So if there is a strategy which eliminates barriers for people who don't have the knowledge or the resources or insurance—if there's a way to create a program which causes these people to move rapidly through the system to earlier diagnosis and full treatment—then this is the reason that patient navigation seems to be working and catching on.

Q. In 1990 you developed the patient navigation model in an effort to remove the barriers you've just described. Do you see the primary mission of navigation still to be to address these problems?

A. I truly believe that navigation may benefit people of all socio-economic statuses, but it's most important for people who don't have the resources and the knowledge [about cancer detection and treatment] and that should be the target audience. However, as we learn more, we are finding that there are people who meet barriers who are insured or who do have knowledge [about cancer detection and treatment]. I think it's a broader issue that needs to be applied to the whole population of people who either develop cancer or are in the process of being diagnosed for cancer. I think that the critical part—and the most effective and the most necessary part—of navigation is to target it to populations that are underserved or less educated or uninsured.



But I do believe patient navigation has a universal benefit for all patients and is even being applied to diseases other than cancer.

Q. In January 2008 the Harold P. Freeman Patient Navigation Institute was launched. What was the impetus for the Institute?

A. By this time navigation had begun to spread rather rapidly to different sites throughout the country.... First of all starting with the United States government, the NCI has funded 9 patient navigation programs starting about 5 years ago, demonstration sites. The Centers for Medicare & Medicaid Services (CMS) has funded 6 patient navigation sites, which is very important because CMS oversees Medicaid and Medicare. And thirdly, most recently, HRSA [Health Resources and Services Administration] has 6 sites. In 2005 the Patient Navigation Act, based on the model in Harlem, was signed into law by President George Bush.

In the meantime, the number of agencies and nonprofits supporting patient navigation, such as the American Cancer Society, the Susan G. Komen Foundation, the Avon Foundation, have rapidly increased around the country.

So while hundreds of patient navigation sites were developed, there were no clear standards or definitions for what patient navigation is. In other

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words, the term patient navigation is being used in many ways. We saw the need to try to create some standards of patient navigation that people could at least compare to or with the hundreds of sites that were developing. And these sites were developing in very different ways throughout the country—sometimes concentrating on other elements such as diagnosis and/or treatment.

We saw the need for creating an institute that could define patient navigation and create standards and a certification process for people who were trained in the patient navigation program concept as it was developed in 1990 and which we now have 19 years experience with. And that was the impetus for the creation of the Patient Navigation Institute which has been funded by a leadership grant from the Amgen Foundation.

Q. What are the goals of the Institute?

A. There are two goals: One is to set and ensure standards for patient navigation programs through an emphasis on the Patient Navigation Model that I initiated in 1990. A second goal is to help others learn best patient navigation practices by creating a national database for the collection, analysis, and dissemination of information on best navigation practices.

Q. Can you briefly describe the Institute's navigation training program?

A. It's a three-day training course that we give usually once a month. We have developed training modules for the course. I generally start off the course with an Introduction Module about the origins and evolution of patient navigation. Then we have a module on how to create a patient navigation program; a module related to cultural sensitivity and cultural issues; and a module on the

[patient navigation] database—how it's been formed, and suggestions for how participants can create their own database.

Part of the training is done with our navigators at the Ralph Lauren Center. We have developed a program in which navigation is carried out by four navigators each of whom is responsible for a particular phase of navigation:

- 1) Outreach navigator
- 2) Diagnostic navigator
- 3) Treatment navigator
- 4) Financial navigator.

These navigators are in close communication with each other in the management of a given patient.

For the Institute's training program, all of these navigators come in and talk about their role in patient navigation. The idea is that there is a continuity that should take place for patients. It begins in the community where they live to get them into the center where the test is done—that's called outreach navigation. Then, at the point of an abnormal finding, the diagnostic navigator takes the patient through the point of diagnosis and the finding of cancer or no cancer. At this point, we have a treatment navigator to work with the patient through all the forms of treatment. And finally, as a sort of consultant to these navigators is a financial navigator whose work is to make sure that the patient has financial coverage.

Q. How many navigators have been trained to date?

A. Since we started the first Navigation Training Course in January 2008, we have trained 181 navigators from 85 institutions in 33 states, including Alaska and Hawaii. In addition, some trainees have come from the Caribbean and parts of Europe.

Q. And the Institute is still accepting applications?

A. Yes. We encourage people to apply and they can apply through our website (www.hpfreemanpni.org). The course gives the total picture of how patient navigation developed, and, with this much experience, we've developed navigation to a pretty sophisticated level at this point.

One thing to point out is that the concept of navigation has to do with addressing the entire continuity and movement of the patient through the system from the community to the healthcare site and ensuring that patients get the tests they need, such as a mammogram, to ensure that any abnormal findings will be rapidly resolved. Timeliness is a very critical part of navigation. And then to assure that anyone who has cancer will get rapidly treated by all modalities.

So navigation encompasses the concept of continuity from the community to the healthcare setting to getting the test, having the finding, and getting the patient all the way through treatment. Now the navigator in our concept is the only person in the healthcare system whose job it is to watch and guide and assist the patient through this entire continuum. In other words, the navigator's job is to see the entire movement of the patient across disciplines. One of the problems in medicine is that we have excellent areas—excellent surgeons, excellent radiation departments—but the patient doesn't easily pass through one part into another. So we are working across disciplines that have to be bridged through this navigation.

Q. So the training provided at the Institute can help bridge these challenges?

A. Yes. We've found that the four principal barriers patients face are:

1. Financial barriers—no insurance or not enough insurance, or lack of ability to pay for transportation, and other costs related to cancer care.
2. Communication barriers—people

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don't really understand the medical information that's been communicated to them.

3. Complexity of the healthcare system—when people have to move from a surgeon who says you need a biopsy to medical clearance and then back again, or from surgery to chemotherapy—they get lost in the system.
4. Barriers related to fear and distrust and emotional issues.

Our navigators work with all of these barriers. While we use lay navigators as the principle navigators in our system, we realize that there's a role for navigators who are professionals, especially social workers and nurses, to navigate people at more complex points. For example, if the lay navigator finds that the person is experiencing social problems...then that navigator will refer the patient to the social worker. Or when patients with cancer have challenges with respect to understanding the disease and the options for treatment, the navigator will call in a nurse or an oncology nurse to navigate those issues.

But we find that the trained lay navigator can eliminate many barriers faced, particularly in poor communities. These barriers include: lack of medical insurance, under insurance, and how to obtain various medical and support services.

We believe there should be an interconnection between the lay navigator and the professionally trained navigator, such as a nurse or social worker, and that they should be working together to move the patient through the treatment of cancer. This approach is also cost-effective in that highly trained healthcare professionals are not spending time on work that can be handled by non-clinical staff members, such as a lay navigator.

I know there's been debate about the use of lay navigators versus the use of clinical navigators, but I think we need to work together on who should navigate. I don't like the idea of any

single group of people arguing that they "own" navigation because that's simply not correct. There is room for all kinds of people to be navigators. And certainly, if navigation is going to be cost-effective, part of it can be done by lay navigators who are not clinical professionals. We should concentrate on what has to be done for the patient as opposed to what we want to do in our specialty. And if we do that, we soon come to the realization that everybody has a role in navigation. From the lay person, the nurse, the social worker—all the way through to administration, it's a team effort with everyone having their eyes on what has to be done for the patient as opposed to turf issues.

We should embrace the philosophy that navigation is a continuum of actions that need to be carried out for our patients, and that at certain levels these actions are relatively simple and can be done by a lay navigator, but as cancer treatment becomes more complex in terms of social services or clinical services, a clinically trained navigator should step in. It's important that the navigation system is set up so that the entire healthcare institution will embrace this as an idea so that the team can really work together rather than have conflicts over turf.

Q. From your patient navigation database do you have any emerging best practice information you can share?

A. It's too early at this point. What we are finding is that in sites around the country people are concentrating on segments of the navigation problem, working with the screening part of navigation for example. The concept we're teaching is that you have to initiate the navigation at some point, whatever your definition is for when that starts, and then you have got to finish the navigation. Close the case. The case isn't over until it's over. In other words if you have an abnormal finding, you have to resolve this through diagnosis. And

if it's cancer, it has to resolve with the treatment of cancer.

We're getting the sense from talking to people around the country that people are working on segments of the navigation problem without the full continuum of care in mind. If you have cancer, it's not over for you until the cancer has been treated. We're seeing navigators that do parts of navigation very effectively, but we are teaching at the Institute that while it's okay to do whatever your part is, we also have an obligation to connect the whole system for the patient. So that's a very important navigation concept: to open the case and to define when your navigation begins and to close the case and define when your navigation ends. We believe, in cancer care, navigation should end at the end of treatment.

And we have to develop survivorship navigation support systems for survivors who have recurrent disease of special areas that need to be addressed through special training. What I see is that navigators in various sites around the country are taking on parts of the navigation process and not necessarily connecting to the next action that needs to be done for the patient. And to use an analogy from surgery, it's not over until you close the case.

Q. Some programs begin navigation services with a single disease site, such as breast cancer. Is it your sense that this is a good way for programs to begin to work with navigation services?

A. I think that is generally the way it has been happening. My wish is that navigation programs will cover all cancers. We would like to encourage institutions to navigate all cancer patients. It would be better for society if patient navigation programs were made available to eliminate barriers to diagnosis and treatment of all cancers, as well as to other chronic diseases such as diabetes, heart disease, and psychiatric and neurological conditions. ✓