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What the Chronic and Acute?

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About a year ago I received a request to come speak at the annual CRANE (Cancer Registrars Association of New England) meeting. I had spoken there before and was delighted to be asked to return. The topic? Hematopoietic. I had one hour. Now, if you know anything about the Hematopoietic rules, speaking on it for only one hour can present quite a challenge. Where do you start? What do you focus on? What is the biggest bang for your buck (or for an hour)?

Based on all the questions we were receiving in Ask a SEER Registrar, I had some ideas, but trying to get all of that into one hour still was a little overwhelming. I pondered this for a couple of weeks and then started developing the presentation. I chose to focus on same primaries and chronic/acute diseases. Mixed in with those two things, I also put in some ambiguous terminology and a couple of screen shots of the database. I hoped that was enough. I must admit I was a little apprehensive when I arrived, wondering if my presentation would be of any use.

The day of the meeting started off well. It was a great turn out (~140 people). I even recognized a couple of people. It was nice to be in the company of hospital registrars (I'm a former hospital registrar and loved the state meetings). The first speaker finished 30 minutes early. As I went to take my place, I was told I could use the extra time. Deep breath, okay here we go.

To me, talking at state meetings can be a little more daunting then speaking at something like NCRA. It's a much more intimate setting. Since I had extra time, I let everyone know that they could stop me at any time to ask questions. I didn't get very far before the first question. As I explained the same primaries concept through several examples, you could see some understanding on their faces. Then I moved into the section the on chronic/acute diseases.

Then the question came: "Why did you do this? What is the purpose of this?" So, I started off by asking the registrars if they remembered when the introduction of the myelodysplastic diseases occurred. Some did. Then I asked if they had taken a look at their acute myeloid leukemia (AML) data from 2001 forward? Have you looked at your AML data? It should have taken a pretty sharp dive shortly after 2001 and then started coming back up. If you look at it starting in 2010, it would have taken a sharp increase. The reason behind that is the chronic/acute concept. You see Myelodysplastic syndrome diseases (ICD-O-3 codes 9980/3-9992/3) and some others are chronic diseases. In and of themselves, they aren't necessarily life threatening. In some instances, they do "transform" to another more aggressive disease. In this case, the AML's. When we started collecting the MDS diseases in 2001, we stopped collecting the AML's that occurred after the MDS diagnosis. The result, a large decrease in the number of AML cases.

Now, if you know much of anything about MDS and AML, they are two very different diseases. The treatments and the survival rates are very different. Since we were only collecting the MDS (if it occurred first), we started losing information about AML treatment (usually chemotherapy) and survival. Our MDS cases looked like survival wasn't very good, but it was actually the AML they were dying from and not the MDS. Because we only collected the MDS, then we were losing all the information on the AML.

So, chronic/acute diseases were developed for the 2010 Hematopoietic rules. Over the past couple of months I have been reviewing SEER's 2010 and 2011 data. There are many instances of MDS diagnosed first, followed by a diagnosis of AML either months later or a couple of years. Now we have information on the diagnosis and treatment of MDS, the time interval between the MDS and AML, plus the treatment and survival for the AML. We have a clearer picture of the patient's cancer.

The other disease that is on the rise because of the change in rules is Diffuse Large B-cell Lymphoma (9680/3). This is an acute disease. Many of the lymphomas transform to DLBCL. The most common are the Follicular lymphomas (9690/3, 9691/3, 9695/3 and 9698/3).

The good thing about this change in how we collect Hematopoietic data is that we can finally monitor how many patients are progressing from a chronic disease (such as Myelodysplastic syndrome or Follicular lymphoma) to a much more aggressive acute disease (AML or DLBCL). However good this change is though, it also has caused a great deal of confusion for cancer registrars. So, here are some pointers for your registrars when looking at the Hematopoietic cases.

1. If you have more than one histology, go look at the "Transformations to" or "Transformations from" sections in the database for the histologies. For example, if you look at Follicular lymphoma, NOS (9690/3), you will see that it "transforms to" DLBCL (9680/3). If you look at DLBCL, you'll see that under "transformations from" that Follicular lymphoma, along with many other lymphomas, is listed. These are the chronic and acute diseases.
    a. Histologies listed under "transformation to" are ACUTE diseases.
    b. Histologies listed under "transformation from" are CHRONIC diseases.
    c. The Rules for the chronic/acute diseases are M8-M13.
2. If your second histology is not listed under one of the transformation fields, go look at the same primaries to see if it is listed there. Many times a second diagnosis will diagnose a more specific disease.
3. If no information is found in the database, then go to the Manual and start with Rule M1.

Of course coding Hematopoietic cases is a lot more complex than this simple little article. As I said, trying to cram all that information into something short is virtually impossible. So, what is the best way to learn or understand the Hematopoietic rules? One of my current tasks (I have many!) is to update the original Hematopoietic presentations that were developed by Carol Johnson, Peggy Adamo and Steve Peace in 2010. Many of them are outdated and no longer available on the website. We are estimating completing this project in 2016.

However, if you want some help NOW, I strongly encourage you to get on the SEER Educate website. (https://educate.fhcrc.org/Index.aspx). I have been going through the Hematopoietic cases to familiarize myself with what they are doing and how any changes I make may affect their cases or answers. The cases are fabulous (some even tricky). The rationale behind all the answers is priceless and worth every second of the time you spend on them. You will learn to apply the processes and rules in a logical and straightforward manner. Going through these cases will give you a much better understanding of how to apply the rules-plus, you get free CEU's!

And coming soon to the SEER website are the "comparison documents." These documents chronicle all the changes between the 2010 Hematopoietic Manual/Database, the 2012 Hematopoietic Manual/Database and the 2014 changes. These documents are based on the reviews that were done by SEER to see if the 2010 and 2012 Hematopoietic manual/database, plus the proposed 2014 changes, could be applied for 2010 forward. Also in the works is updating the Hematopoietic edits that are part of the NAACCR Edits metafile. You will be receiving information about that from the Edits Impact Workgroup later in the year.