

NCI-SEER BREEZE SESSION
Multiple Primary and Histology Coding Rules
Lung Practicum
November 14, 2006

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Introduction

The practicum is up on the website. You can go to the NCI-SEER website, find the MP/H rules, and then find the cases and presentations.

Case 1

We have ten cases posted for lung. We will start with case 1 and see if you have any questions or any problems with that case. Case 1: Does anyone have any problems or questions? Case 1 was a relatively straightforward case. There was a single tumor and the final diagnosis was adenocarcinoma. So, there were not a lot of problems here. It was a good case to start with so everyone had a chance to go through the rules, go through the multiple primary rules, go through the histology rules and get a little comfortable with them doing the first case.

Case 2

Did anyone have any problems or questions with case 2? Okay. Hearing no problems we will go on to case 3.

Case 3

Question 1--case 3:

I did not really have a problem with case 3, but in doing these cases it would be helpful if the answer sheet had what M or H rule you used to derive your answer. In this particular case, I came to the same conclusion but I used rule H5 using adenocarcinoma as more specific than a non-small cell, but based on your answer in the answer sheet, you coded it to adenocarcinoma since it was more invasive using H11. I wonder if you could address that. Thank-you.

*Response to question 1--case 3: **Note: Post Lung Histology Coding Rules***

That is a very good question. Let me put the histology rules up. As you go through the histology rules, rule H1 talks about no pathology or cytology specimen. Let's start out with: you have already determined that you have a single tumor. Correct? "Yes." So we are in the Single Tumor Module. Rule H1 does not apply because you do have a pathology report; the same with H2. Now rule H3 says: "Code the histology when only one histologic type is identified." Is that the case for this particular path report? "No. This report has non-small cell and adenocarcinoma but they are in the same tree." Okay. One of the first things I want to comment on is for case 3 you actually have two tumors. According to the pathology report you have a tumor in the right upper lobe that is a poorly differentiated non-small cell and was taken out with a wedge resection. And then

right upper lobe of the lung you have a moderately differentiated non-small cell carcinoma (adenocarcinoma). So you actually have multiple tumors so you would never start with rule H1, you would want to go down to the Multiple Tumor Module. The first rule under multiple tumors is [H8] "Code the histology documented by the physician when there is no pathology/cytology specimen or the pathology/cytology report is not available." That does not apply because you do have a pathology report. Rule H9 is again used when there is no pathology/cytology specimen from the primary site. Rule H10 says, "Code the histology when only one histologic type is identified." That is not the case here. There is more than one histologic type. The next rule [H11] says: "Code the histology of the most invasive tumor." That is where you would look at the two tumors and say, "Is there a difference in invasiveness?" The answer is, "Yes."

You may have had a problem with this one in starting with the single tumor module. You mentioned H5 and that was why I started by saying, "Is this a single tumor?" The answer is, "No. There are multiple tumors coded as a single primary."

Question 2--case 3:

In using rule H11 it says it should only be used when the first three digits of the histology codes are identical and that is not the case. So I used rule H12 and I came out with the same answer.

Response to question 2--case 3:

You will come out to exactly the same answer. The rules are kind of foolproof so if you don't call it the same name you will come out with the same answer. The fact is we took most of the guessing out of these new rules. In most cases, you do have histologies that do have the same first three digits when you get to this rule but not all cases. The "not all cases" are exactly these types of cases where it is a very non-descriptive term for one tumor such as non-small cell or carcinoma, NOS, then a more specific histology such as adenocarcinoma or squamous cell; the first three digits won't be the same. If you are going to treat them as a single primary the multiple primary rules will lead you there. We took them out of all the rules [i.e. the first three digit rule] and we did miss this one; the fact is, the next rule will catch you and you will code the same thing.

Question 3--case 3:

I am glad you pointed that out. I had "single" in my mind and I started with Single Tumor [module]. If it is possible, it would be very helpful to put the rule on the answer sheet.

Response to question 3--case 3:

We found out during the Train the Trainers Workshop that it was not helpful [i.e. to put the rule on the answer sheet] because we had people arguing about who used the right rule. One person may say there is only one histologic type when it is squamous cell carcinoma, for example, and another person will say it's

a type and a subtype. No matter what you call it you will end up coding it the same way because there are two rules and you will get caught in one of them. Remember what I explained to you during the presentation that if a patient had multiple tumors none of which were biopsied, if one registrar said I don't know if they are all primary tumors so I am going to say there is an unknown number and another registrar diligently counted them all and said I have multiple tumors, one registrar would use rule M1 and say this was a single primary. The second registrar would use rule M12 but she/he would still say this is a single primary. Actually, there are two rules that would work for almost every one of these cases, but it is extremely difficult for people to understand that. In the past they have had only one rule. We have had some extremely vigorous arguments about whether one should call a case a single histology or a more specific histology. That really was not the point. The point was both of you coded it the same way. So it is very difficult to put the rule number down because I could actually give you two rules for each one of these.

Question 3a--case 3:

When we did our training we provided the rule numbers and it generated a lot of discussion. The discussion was very helpful to the participants in the room and it validated the importance of understanding which module to go to. You could start from an earlier schema [module] and work through and still get the correct answer. But if you started, for example, in the Multiple Primary Module you would actually start further ahead in the rules and you would get there quicker so it would be more timely.

Response to question 3a--case 3:

I can appreciate what you are saying, but we did find in the early trainings that we spent a lot more time discussing what a certain presentation should be called as opposed to how to code it. It was extremely distracting. It was a decision of the training group that we would not put the rule numbers on the answer sheets when we did the training. There are pros and cons, absolutely.

Question 4--case 3:

In case 3 when you code the invasive tumor along with the histology, in this particular case would you code the grade as moderately differentiated because it is the most invasive or would you code it to poorly because that is the higher grade?

Response to question 4--case 3:

These rules do not affect the coding grade rules. That is something that we need to emphasize in our training. You don't apply these rules to coding grade or to coding stage of tumor of any other things. So, [coding the most invasive] that would not affect the way you code grade at all. That was a good question; I'm glad you asked that.

Question 4a--case 3:

Following the rules, if the non-small cell were the most invasive and not the adenocarcinoma, would the answer have been non-small cell?

Response to question 4a--case 3:

Yes, it would have been and that was quite a surprise to us when we first started working with the clinicians and pathologists. One of the things they explained to us was that the non-small cell tumor would be the one that would metastasize; it would be the one that caused the progression, so the symptoms and the disease process would be related to that most invasive tumor. By coding an adenocarcinoma because the other tumor was adenocarcinoma, we are assuming this one is as well and it may not be; the progression may not be that of an adenocarcinoma. They said you want to code the histology of the invasive even if it is less specific. That is a real change for us.

Question 4b--case 3:

Can you give us a list of criteria of what is most invasive and what is not?

Response to question 4b--case 3:

The list of the most invasive is actually found in the Equivalent Terms and Definitions and under “Lung” it is probably the least definitive of any of the sites. When you get to colon, for example, it will describe all of the layers of the colon. The problem with lung is that we can talk about the pleura and the parietal pleura and the visceral pleura but after that we are pretty lost because we don’t know if it’s going to extend into the media stinum; if it’s going to extend into the rib on the other side of the lung. So the definition that is in the Equivalent Terms and Definitions simply says, “the tumor with the greatest, continuous extension.” And, given that rather non-descriptive definition—all of the other sites will have the exact layers and so on—for lung that was a bit more difficult to do.

Question 5--case 3:

Will you reiterate why rule H11 was correct despite Note 1: “This rule should only be used when the first three numbers of the histology codes are identical (this is a single primary).”

Response to question 5--case 3:

My comment to you was that we had taken that note out of all of the rules but we found that we had missed that in lung. We left it because most of them are caught in the next rule; it ends up being okay. There is a point at which you cannot make any more corrections. We decided this was not a huge problem so we chose to let this one stand. In most cases that will be correct. It will be the rare case that you do have a difference in the first three digits.

Close the lung histology coding rules. Show Case #4—lung cases

Case 4

Let’s go on to case number four. Were there any questions or comments on this case? This is one of the ones that when it says bronchioloalveolar carcinoma,

mucinous, we had a lot of people code that to the rule that says code the single histology. We had an equal number that went down to the rule that says when you have an adenocarcinoma and a more specific adenocarcinoma, you code the more specific; either way you would end up coding the bronchioloalveolar.

Case 5

Were there any questions or comments on case #5?

Question 1—case 5:

In the body of the pathology report it says, “immunohistochemical studies support a separate lineage for these tumors. As per AJCC staging guidelines, separate staging would result in a pT2pN0 pMX for the larger tumor and pT1 pN0 pMX for the smaller.” Because of this information I said it was multiple primaries.

Response to Question 1--case 5:

This is actually one of the reasons we put this case in here. If you remember, when we went through these rules there is a place—let’s start with the multiple primary rules. You are supposed to code by the rules. Did you use the multiple primary rules or did you just code from the path report? [“I probably just coded from the path report.”] Okay. One of the things we are asking you is to please use the rules and not just code by rote. So if you did that you had multiple tumors, right? You would end up starting with rule M3 in the Multiple Tumor Module and that rule says if you have tumors in sites with ICD-O-3 topography codes that are different at the second and/or third character [they] are multiple primaries. That does not apply to this case. Rule M4 says at least one tumor is non-small cell carcinoma and another tumor is small cell carcinoma. Does that apply to this case? The answer is, “No.” You really don’t have a diagnosis of small cell and non-small cell. The next [M5] is adenocarcinoma with mixed subtypes and another that is bronchioloalveolar and that rule does not apply so you would go on to M6. That rule says a single tumor in each lung; that does not apply because both tumors are in the same lung in this case. M7 says multiple tumors in both lungs; the answer here is, “No.” You don’t have that in this case. [M8] Tumors diagnosed more than three (3) years apart are multiple primaries. Do you have an invasive following an in situ? [M9] The answer is, “No.” M10 says do you have a non-small cell, NOS and a more specific non-small cell? No. Do you have two histologies that are different at the first, second or third number? [M11] Again, the answer is, “No.” So you end up with rule M12 and that rule says cancers that do not meet any of the above criteria are a single primary. That is basically going to be one of the biggest educational issues that we have with the new rules.

Let me ask you a question just out of curiosity. Have you ever had two breast tumors both of them diagnosed as infiltrating duct and had a pathologist say these are individual primary tumors? How did you code them? [“We coded them as multiple primary tumors”]. So you coded them as multiple primaries? [“Yes”].

I think the difference we have is the fact that pathologists speak about individual multiple primaries meaning that one tumor did not spring from the other; they are *de novo*. They may be alike in histology but the same cells did not create tumor A and tumor B. So, they are individual primaries. The multiple primary rules that are used by IARC and SEER and pretty much the rest of the world agree that, indeed, they are individual primaries meaning that they did not spring from each other but the instructions are to code them as a single primary. So, I think that is probably where a lot of the interpretive part has been different from registry to registry or case to case and it is kind of important that everyone codes the same way. A lot of the country is using the IACR rules: a patient only has one tumor in one site—one primary in a given type—for a lifetime, end of story. So we have a lot of different ways of handling things; we do know that. We talked a lot about this with the AJCC physicians and with the physicians—the clinical specialists—who worked on the different rules. We said if we really coded every individual tumor as a separate primary, we have no idea what would happen to the incidence count. The incidence count has been counting multiple tumors as a single primary for many different cases and we couldn't just blindly start to count them all as individual. What we can do is put in a new data item that asks the number of tumors. We can pull every case of lung cancer that has more than a single tumor by using this data item. You can pull every case of breast cancer, every case of...but we don't have to ask our registries to create a separate abstract for each tumor. We can follow the surveillance rules in what is a single primary and what is a multiple primary and you can still find and pull all of these cases for analyses. They were very amenable to that; they thought that was an ideal way to handle it. We would not increase the incidence. The clinicians and researchers could access these cases quite easily. At the end of a few years we could actually count how many cases with this type of cancer in this site presented with multiple tumors. If we decided to change rules, we could account for the change, meaning that we could say we know x percent are multiple. So we can use that in our analyses so that we still can get the same incidence count, but we can't blindly just start to abstract every tumor. So that was how the conversation went, back and forth and everyone felt that we had reached a reasonable compromise among the clinicians, the epidemiologists and the surveillance people. Does that make sense to you? ["Yes it does. Thank you very much"].

I know this was a difficult part for everyone. I think the best thing I can tell you is that this is the first time that we can really keep count. Once we have done that we can make some decisions on how to collect this without affecting incidence. In the meantime we can still give clinicians and researchers the ability to find the cases.

Are there any other questions on case 5?

Case 6

Does anyone have any questions on case 6? No questions on case 6. Let's go on to case 7.

Case 7

Are there any questions or comments on case 7?

Question 1--case 7:

On case 7, I was just wondering why we have to use 8033 for the histology code rather than 8030, which is more specific?

Response to question 1--case 7.

Because we don't code "areas." "Areas" is not one of the terms that we code. The second reason is if you would look at the definition of sarcomatoid in the Equivalent Terms and Definitions. It is a group of tumors that are non-small cell in type and they contain spindle cells and/or giant cells. So, this description is actually the description of sarcomatoid. Sarcomatoid has a combination of spindle and giant cells or it has giant or spindle but there is not enough of the giant or spindle cells to call it a more specific carcinoma. That's why they are not saying, "giant cell type" or "spindle cell type." They are just mentioning that there are some areas of giant cell and spindle cell sarcoma.

Question 1a--case 7

Code 8030 is giant cell and spindle cell carcinoma.

Response to question 1a-- case 7

Again, we don't code "areas of." If you look at all the things you code, "areas of" is not one of them. "Areas of" is not a word that says "most of the tumor is made up of" giant cells and spindle cells. I think, again, you probably reverted to the old rules without thinking. If you go through the actual rules, what you will come down to is the rule that says: "Is there one type of carcinoma?" And, the answer is, "Yes." It is sarcomatoid. It is not "types of;" it is not "features of." The word used is "areas" and we don't code "areas of."

Question 1b--case 7:

So, what you are saying is, if it had said with those two types of differentiation, then we would have gone to 8030?

Response to question 1b-- case 7:

Yes, that is correct. The difference between the two terms, when they say "areas of," the pathologist is saying I do see some giant cells and spindle cells and when you look at the definition of sarcomatoid that would certainly be expected. But they don't see enough of them to define them as differentiation or to define them as a subtype or a type and so we don't code them.

Question 2--case 7

Where in our rules, is the “areas of” rule mentioned? Is there one in which that is mentioned?

Response to question 2--case 7:

Show the lung histology coding rules starting with Single Tumor Module

Yes, there is. Let me pull it up for you. It helps if you can look at it as we are talking. Let’s start out first with--this is a single tumor, right? So we are going to start out with the Single Tumor Module. We are not going to use rule H1 because it says when there is no pathology/cytology report available. Rule H2 is also how to code when there is no pathology/cytology specimen. So we start with rule H3 that says: Code the histology when only one histologic type is identified. Now, if you go past that what you are really going to get to is H4 that says code the invasive. Then H5 that says code the most specific term. In the notes it will say the specific histology may be identified as “type, subtype, predominantly, with features of, major, or with _____differentiation.” So when you see this, you are really going to know that you went too far because this [case] says “with areas of,” so there is no description that is telling you to code that more specific.

[“Thank-you”]. You are welcome. I think that is one of the hardest things, honestly. For so many years we have looked for the more specific term. So the different rules that are telling us to code something that is not the most specific term are going to be difficult. It’s going to take following the rules.

Close Lung Histology Coding Rules; Show Lung case #7

Question 3--case 7

What kind of confused me on this was that word “and.” I was looking at it as sarcomatoid carcinoma and spindle cell and then with the areas of. I knew not to code “with areas of” but I wanted to code it to sarcomatoid and spindle cell because of the “and” word.

Response to question 3--case 7

Okay. So you were making the “with areas of”—pleomorphic/giant cell--as a parentheses. You know what, that’s actually really a good observation. Maybe we should look at somehow rewriting that so nobody would look at it that way. That is not the object—to fool people-- with the way the phrase is written. We will make a note of that and take a look and see if we can put a comma in or do something that sets it off.

Comment on question 3--case 7

It probably is an example of an actual report. I just kind of read it as separate, not part of the “areas of.” I thought the spindle cell was a separate histologic type.

Response to comment on question 3, case 7:

It is an actual report.

Case 8

Are there any questions about case 8? Case 8 is the first one that gave you a chance to code the histology when there is no pathology report.

Case 9

Are there any comments or questions on case 9? That one went pretty well!

Case 10

Are there any comments or questions on case 10?

Question 1--case 10:

Is mucin secreting the same as mucinous?

Yes, for lung primaries, mucin secreting and mucinous are synonymous.

Are there any other questions or comments?

General Discussion

We would welcome any comments or recommendations that you have.

Comment 1:

If there are any changes that you know now that you are going to incorporate in the next version, would it be possible to receive those in advance? If you have a qualifier that explains a rule or something, I think that would be helpful now rather than waiting one or two years for the next revision.

Response to restatement of comment 1:

You are not going to wait one or two years. I assure you that won't happen. What we actually have planned, I understand your question much better, what we really plan to do is --we are going to have a reliability test in/around October of 2008 and based on that testing we are going to do improvements. It [the improvements] will be geared by things like your comments and by things we see that we didn't expect. So most of our changes are very registrar-driven. We add clarifications. We add things like that to the rules because you tell us you need them. We see we are not getting certain codes that we would expect so we put clarifications in. We talked to our registrars, the SEER folks, about whether we could do a reliability test in 2007. The managers actually seemed to think that if we did it around October that most of the people would have already used the rules. If we can do this in SEER, we would be able to make improvements by the end of the year. And we would like to try to make them in one document, one set of improvements, not because we are trying to hold back on you. But, what happens is some people get them and some don't and some write them in the book and some don't and we have a very uneven distribution and response when

we send them out in anything but a revised document. I can promise you, you would have them by the end of 2008 but our hope is by the end of 2007 we will be able to identify any areas that really do need clarification or help and get that out. So, we don't plan to leave you hanging for a long period of time. As long as the SEER schedule will let us work out a testing by October of 2007 we will be able to get a revision out at the end of 2007 that would be effective for cases diagnosed January 1 of 2008. We would like to do it that way; it's a lot easier. Our SEER people are marvelously good sports about being our testing people for new projects like this and it helps a lot. We have been able to get very good clarifications and very good comments. I understand why you would want them immediately but our fear would be that they would not be distributed and used in a very consistent manner and that's always a problem.

Okay. Thank-you.

End of Breeze Session