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LETTER

An Illusive Cyst: Should My Mother Have Had Her Surgery?

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Dear Sir:

I am an oral and maxillofacial surgeon practicing and teaching in San Francisco, CA, USA. My mother is currently 83-year-old relatively healthy lady who was diagnosed 3 years ago with a mucinous cystic neoplasm (MCN) or intraductal papillary mucinous neoplasm in the neck of her pancreas.

This could have been the beginning of a very routine medical chronicle that any son or daughter (or any other relative) could have reported about their mother or father. What I am about to share here appears slightly different.

In 2010, my mother, who was 80 at the time, developed some minor discomfort on the left side of her abdomen radiating to her back and was referred by her primary doctor for the abdominal ultrasound.

An ultrasound showed about 2x1 cm cystic lesion in the body of pancreas. This followed by a referral for the abdominal CT scan that was done 1-month later and showed a "2 cm lobulated cystic lesion in the neck of pancreas with no pancreatic duct dilatation". Due to a suspicion of MCN, she was referred for a pancreatic endoscopic ultrasound (EUS) with biopsy. EUS (#1) was done soon after at the California Pacific Medical Center (CPMC) Hospital in San Francisco by a very experienced gastroenterologist. The result was a "25 mm cyst, with no mass, single compartment, no pancreatic duct dilation or communication." Biopsy showed "glandular epithelium without significant atypia", with pancreatic CEA of 816 ng/mL (reference range in non-smokers: 0-2.5 ng/mL). The gastroenterologist was almost certain of MCN (side-branch) and referred us to a surgeon of our choice. We had two consultations in San Francisco (at CPMC hospital and University of California San Francisco, UCSF). A well-respected transplant surgeon at CPMC after reading the EUS and CT reports suggested operating right away and proposed an open Whipple procedure with removal of the head and involved the neck of my mother's pancreas. "Yes, it will de-condition her for about 2-3 months, and yes, the complication rate is high, but everything should be all right", he "comforted" us.

At the same time, a well-known general surgeon at UCSF suggested a different route, an observation (unless we were eager to get rid of the lesion, which we were not) with a repeat of EUS in 4 months. So, we did.

EUS with aspirational biopsy (#2) was done in April 2011 by the same gastroenterologist and showed "20x11 mm cystic lesion in the neck of pancreas, no mass, a few thinly separated compartments"; biopsy demonstrated "rare clusters of cytologically bland mucous epithelium", and pancreatic CEA of 1,154 ng/mL. The gastroenterologist was concerned about rising CEA and recommended to "talk to a surgeon and possibly consider surgery". Our general surgeon at UCSF recommended continuing observing and having EUS procedures every 6 months and then once a year "because it is the best way to monitor the cyst size and have the cyst biopsy at the same time".

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Abbreviations CPMC: California Pacific Medical Center; UCSF: University of California San Francisco; USC: University of Southern California

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I discussed this with my mother at that time. She entrusted me to make the decision. It was hard for me to see my mother, torn between being afraid of a major debilitating surgery at her age on one side, and a possibility of cancer transformation and "dying in misery" on the other. We decided to follow the suggestion of the UCSF surgeon.

EUS #3 was done at the end of 2011, about 7 months later in the same place and by the same gastroenterologist, and showed "17x10 mm cyst, no mass, unchanged", as well as a "small amount of epithelium, mildly dysplastic", with CEA of 1,748 ng/mL. The gastroenterologist was really concerned now by the continuation of the rise in CEA as well as mild dysplasia, and discussed what he felt as a slow malignization of the cyst and suggested need for the surgery, referring us back to the surgeon. The UCSF surgeon gave us a choice: continuation of the monitoring or an open pancreatic (Whipple) procedure (if we wished). If we were to observe, he again preferred EUS as a way of monitoring of my mother's pancreatic condition.

Slightly confused at that point, I decided to obtain a second opinion from a senior general surgeon at Stanford Hospital. He ordered a CT scan (our second) prior to our first consultation with him. On the way to the appointment with the Stanford surgeon in mid 2012, an abdominal contrast CT scan was done at the Stanford imaging center that showed the "multiloculated cystic lesion in the pancreatic neck of about 2 cm, no mass and no change from the previous (first) CT (done a year prior at UCSF). Stanford surgeon discussed different treatment options for my now 82-year-old asymptomatic mother and suggested observation and periodic CT scans (every 6 months or so). He did not recommend EUS procedures due to lack of literature supporting this modality as a credible screening tool for the intraductal papillary mucinous neoplasm of the pancreas, as well as its invasiveness.

Because of the fact that both general surgeons, at UCSF (who favored EUS) and Stanford (who favored CT or MRI), suggested an observation as a credible alternative, we agreed and decided to wait.

EUS #4 was done in January 2013. It showed "no change, no mass, horseshoe configuration in the genu of pancreas, no duct involved, size of the cyst-about 15x12 mm", as well as "acellular smears and scant atypical mucinous epithelium", with CEA of 3,832 ng/mL. The gastroenterologist strongly recommended surgery due to a continuing rise in CEA. I had a phone conversation with UCSF surgeon who changed his opinion at that point: he now also favored surgery and agreed with recommendations of the gastroenterologist.

We met one more time with the Stanford surgeon in March 2013 who suggested MRI instead of CT that time. Our first MRI report read: "no change in the cyst size comparatively with two previous CT scans". The cyst size though was read as 31x12x18 mm with no mass and no pancreatic duct dilatation. Stanford surgeon looked at the MRI results that read 31 mm and also changed his opinion and suggested an open or, if possible, laparoscopic surgery (Whipple or central pancreatectomy). "Why are you changing your recommendations now?" I asked. "A radiologist said that it was about the same size." He pointed to the size of the cyst. It was now above 3 cm, one of the criteria for the operation.

At that appointment at Stanford, we discussed what I already knew (i.e., three parameters for the operation on MCN of the pancreas more or less accepted by the medical/surgical community): 1) tumor (mass) developing in the cyst; 2) main pancreatic duct dilation; 3) size more than 3 cm.

My mother was miserable seeing that we had no other way except for scheduling her surgery and, in fact, we did schedule her surgery at the Stanford hospital for May 2013.

Before the surgical procedure, I just wanted clarification regarding the MRI radiology report that to me was still confusing. I called the Stanford radiologist who read it. The radiologist happened to specialize in pancreatic lesions and was truly surprised by the Stanford surgeon's decision. When I mentioned to him the size of the now 31 mm (a parameter for the surgery) and a contradictory statement that there were no changes in cyst size since two previous CT scans (which both showed a 2 cm size lesion), he replied that MRI and CT imaging can be slightly different, as well as 31 mm included "the whole cyst with small branches but the main body of the cyst had not changed and was the same and about 2 cm, like it was on the two previous CT scans". I argued "But doctor, your colleague, a Stanford surgeon, who read your report as 31 mm cystic lesion, made his decision to operate because of the change in size of the cyst. Has the cyst changed its size since the previous CT scans, or not?" If it was not true 31 mm but less, could you re-write the report, so no one would be confused by such discrepancy in the number and the description?". The Stanford radiologist held his ground and did not agree to change the report but his reply gave me a new prospective that the cyst probably had not changed in size and then surgery might not be really necessary.

My asymptomatic 83-year-old mother, quite depressed at that point due to prospects of a major operation that she might not recover from, was looking at me to make the decision; her surgery was scheduled in 3 weeks.

I was truly torn between opinions and controversies of medical community regarding this condition and decided to do the following. After many days of online search, references form surgeons-friends, MEDLINE search of latest articles on pancreatic MCNs, I chose six prominent pancreatic surgeons in USA for a third (and last) opinion(s). These general surgeons were either heading their institutional departments in a teaching centers or actively operating (and publishing) on pancreatic neoplastic lesions. I wanted to talk to them and solicit an opinion as a doctor and surgeon, as a colleague.

There were phone calls and conversations with secretaries who were trying to find a suitable time in a busy surgeon's operating and teaching schedule for my short consultation. When I finally talked to surgeons, I gave them all the CT/MRI/EUS data in details and mentioned the same thing to each of them that my mother (who remained asymptomatic) would do the surgery, if needed, but she would not "volunteer" for it. I was very thankful to those professionals who took time from their busy schedules to discuss my mother's condition with me on the phone.

Dear Sir, I would like you to see the results of my inquiries and diverse opinions I received from the USA leading pancreatic surgeons. Their associated pancreatic centers and responses are below.

1. Columbia University, The Pancreas Center, New York, NY: observe, keep taking MRI every 6 months or so;

2. John Hopkins University, Pancreatic Cancer Research Center, Baltimore, MD: observe, keep taking MRI every 6 months;

3. Massachusetts General Hospital, Boston, MA: no need for surgery, no need for monitoring (what would you do with the results?), and "tell your mother that she should leave her life trying not to worry" (my mom's favorite!);

4. University of Illinois, Chicago, IL: recommended surgery (central laparoscopic pancreatectomy, robotic or not).

5. Mayo Clinic, Rochester, MN: observe, MRI once a year;

6. University of Southern California (USC), Center for Pancreatic and Biliary Diseases, Los Angeles, CA: operate (meets the size criteria); central pancreatectomy, likely laparoscopic.

In addition to two responses by Stanford and UCSF surgeons who both eventually recommended surgery, the statistics for my mother to have pancreatic surgery or not were the following. From eight USA leading pancreatic surgeons who received identical information about my 83-year-old asymptomatic mother's pancreatic side-branch MCN cyst, 4 suggested to operate and 4 suggested to observe (with MRI). This was 50-50 split of opinions. From those who suggested surgery, their decision was based mainly on the size of the lesion (that was disputed by a Stanford radiologist).

At the time of this writing, July of 2013, we have not done the surgery (yet). My mother and I made a mutual decision to wait ("I won't develop cancer, will I?" she often asks). We plan to repeat MRI in a few months to have a better sense of the cyst size and compare two MRI reports with two previous CT scans. No plans to repeat EUS at this point.

This is the story (so far) about my mother's precancerous pancreatic lesion in progress. Did we make the right decision? Can anything be learned from this?

Being a surgeon (in an entirely different field) and a researcher, I would think that the international pancreatic community, including specialists from all related medical and surgical branches, like radiology, interventional gastroenterology, and surgery should try to standardize the available data and come up with uniform recommendations regarding pancreatic mucinous cystic neoplasms. Are they truly as dangerous as they sound? Can they be safely observed in the senior patient population? Patients (and their relatives) should probably be encouraged to learn more about their condition and seek additional opinions, especially in the controversial areas of medicine, like the one described in this letter.

The question regarding my mother's situation remains: Have I been correct with my decision so far in delaying the surgery? Should my mother have had her surgery?

Commentary A comment to this letter is published in the present issue of JOP. Casadei R, *et al.* JOP. J Pancreas (Online) 2013 Sep 10; 14(5):525-527.

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