Family meeting in the setting of progressive disease with advanced colon cancer

The family

Maria Nervo is a 65-year old, married Italian woman with two children, Flaviana 45 and Mario 43, each of whom has two children of their own, in turn. Maria's husband, Giuseppe, 70 years, has retired from his legal practice in Milan, is in good health and maintains a small vineyard as his hobby. While Flaviana followed her father into the law, Mario became a physician, working as a rheumatologist. Mario always speaks to the oncologist about his mother's treatment, follows test results and seeks to reassure his mother that she is getting the best cancer care.

The patient's disease

Maria has an advanced colon cancer, metastatic to liver and lung. She had a left sided hemicolectomy performed four years before and pathology showed stage II disease, with a high grade adenocarcinoma invading the muscularis propria (T2), but 0/12 lymph nodes involved (N0, M0), not necessitating adjuvant chemotherapy. She was followed by her surgeon and thought to be disease free until one year ago, when right sided discomfort led to a CT scan, which revealed multiple liver metastases. PET scan confirmed multiple, dispersed liver metastases, not suitable for liver resection, and small bilateral lung nodules. She was treated initially with first line chemotherapy of FOLFOX4 (oxaliplatin, leucovorin, and 5-FU) plus bevacizumab, with disease containment for 7 months and reasonable quality of life. When progression was evident on imaging and rising CEA levels, second line chemotherapy was selected, with irinotecan and cetuximab (monoclonal antibody against the EGFR). This time there was 4 months of disease containment, before nausea, fatigue and anorexia emerged as symptoms and imaging again showed disease progression. Liver lesions were now quite large, liver enzymes were rising, and her clinicians felt that her symptoms were related to emergent liver failure. It was felt time to review the goals of care.

The predicament

The oncologist spoke to Mario, who asked about continued treatment with capecitabine, and asked the oncologist to not tell his mother that they thought she was dying. He feared that this would take away all her hope. In his opinion, continued chemotherapy would always remain important. The oncologist had the idea that Maria was not going to accept further chemotherapy, as she had hinted that she felt she had gone through enough. Rather than debate this situation with Maria's son, he thought he would call a family meeting to explore what was best to do.

The oncologist asked a member of the psychosocial team (social worker, psychologist or psychiatrist – whoever is available) to join him for this family session as a way to introduce more support to the family.

Family meeting

The following people are about to attend this family meeting:

1. Maria Nervo, 65, patient with advanced colon cancer
2. Giuseppe Nervo, 70, husband, retired lawyer
3. Flaviana Nervo, 45, daughter and lawyer
4. Mario Nervo, 43, rheumatologist physician
5. Cancer doctor (can be oncologist, palliative care physician, primary care physician)
6. Psycho-oncologist (can be social worker, psychologist, psychiatrist, family therapist)

Instructions to the cancer physician

Who you are:

In this role play, you have been caring for Maria Nervo across the past year since her cancer recurred with metastases in her liver and lungs. Her spouse, Giuseppe, often comes along with her and seems supportive. She has a son who is a physician and has requested you call him with any test results. He wants to understand all of his mother's treatments. He always talks about not upsetting her with bad news, keeping her hope alive and using the chronic disease model to explain what is happening. You sense that he doesn't know so much about end-of-life care and that Maria's management might get harder when her terminal phase approaches. It seems that they lean towards the more traditional model of family decision making and avoidance of death talk. You think you'll call a family meeting when the time arrives and try and help Maria to guide her family through this. This approach usually sorts out whether this is a family that needs to protect their relative or not.

The patient's disease

Maria has an advanced colon cancer, metastatic to liver and lung. She had a left sided hemicolectomy performed four years before and pathology showed stage II disease, with a high grade adenocarcinoma invading the muscularis propria (T2), but 0/12 lymph nodes involved (N0, M0), not necessitating adjuvant chemotherapy. She was followed by her surgeon and thought to be disease free until one year ago, when right sided discomfort led to a CT scan, which revealed multiple liver metastases. PET scan confirmed multiple, dispersed liver metastases, not suitable for liver resection, and small bilateral lung nodules. You treated her initially with first line chemotherapy of FOLFOX4 (oxaliplatin, leucovorin, and 5-FU) plus bevacizumab, with disease containment for 7 months and reasonable quality of life. When progression was evident on imaging and rising CEA levels, you gave second line chemotherapy with irinotecan and cetuximab (monoclonal antibody against the EGFR). This time there was 4 months of disease containment, before nausea, fatigue and anorexia emerged as symptoms and imaging again showed disease progression. Liver lesions are now quite large, liver enzymes are rising, and you feel that her symptoms are related to emergent liver failure. It is felt time to review the goals of care.

The predicament

You spoke to her son, Mario, who asked about continued treatment with Xeloda tablets (capecitabine), and asked you to not tell his mother that you thought she was dying. He feared that this would take away all her hope. In his opinion, continued chemotherapy would always remain important. You had gained the impression that Maria was not going to accept further chemotherapy, as she had hinted that she felt she had gone through enough. Rather than debate this situation with Maria's son, you thought you would call a family meeting to explore what was best to do.

Sensing that some family strain existed here, you asked a member of the psychosocial team (social worker, psychologist or psychiatrist – whoever is available) to join you for this family session as a way to introduce more support to the family. You asked them to make sure that the husband, daughter and son all accompanied Maria.

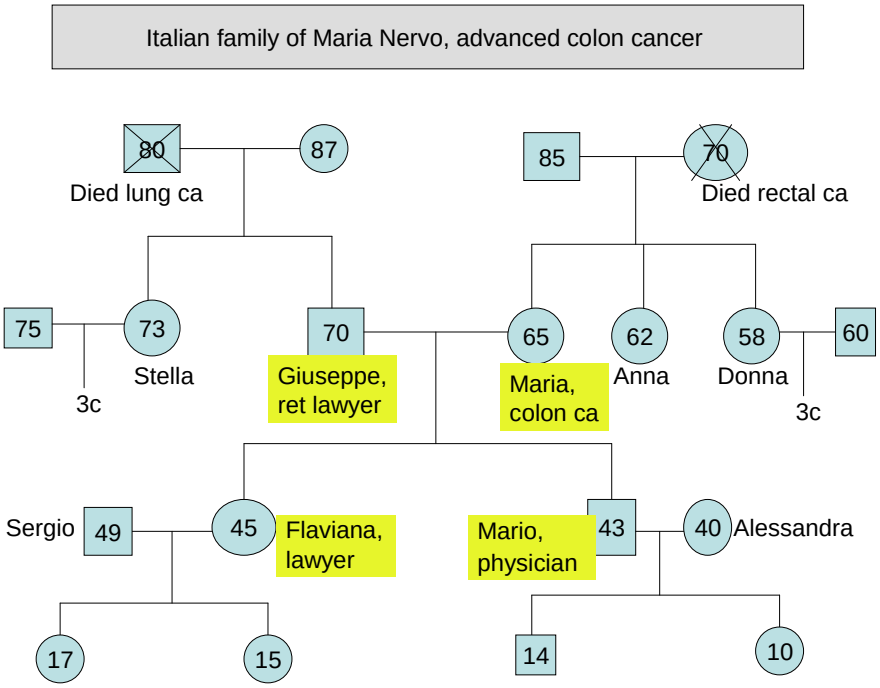
Your goals in this role play:

1. You plan to review the status of Maria's illness and recent test results. It's important that the family understands the clinical reality. You plan to ask Maria to explain to them all that you have told her.
2. You will introduce the notion that the goals of care shift depending upon what symptoms are present. You fear that more chemotherapy may make Maria feel worse, and that different medicines for nausea and appetite may be more helpful here.

3. You will introduce your psycho-oncologist as a colleague who will help the family process their concerns about all that is happening.
4. You wonder if this will be a good time to bring up notions of health care proxy and having Maria write an advanced directive to guide her future treatment wishes.
5. Symptom management is always important, and so you will need to check in about Maria's nausea and anorexia to make sure that these are not too distressing for her.

Who to expect at this family meeting:

The family member's highlighted are expected to attend.



Instructions to the Psycho-Oncologist

Who you are:

In this role play, you will be either the social worker, psychologist or psychiatrist working with the oncology team that has been caring for Maria Nervo. Her oncologist is wanting a family meeting established.

Mrs Nervo has disease progression despite first and second line chemotherapy, and there is some sense that she is approaching palliative care now. You understand that she has a son who is a physician and he appears to present some management concerns in asking that his mother not be told the truth. The idea of this family meeting is to explore the patient's and her family's wishes and help them to adjust as best they can to the clinical reality. There is further chemotherapy that can be given, but the oncology multidisciplinary team meeting wondered whether this might become a family that asks for futile care in the future if they cannot be helped through this phase.

The patient's disease

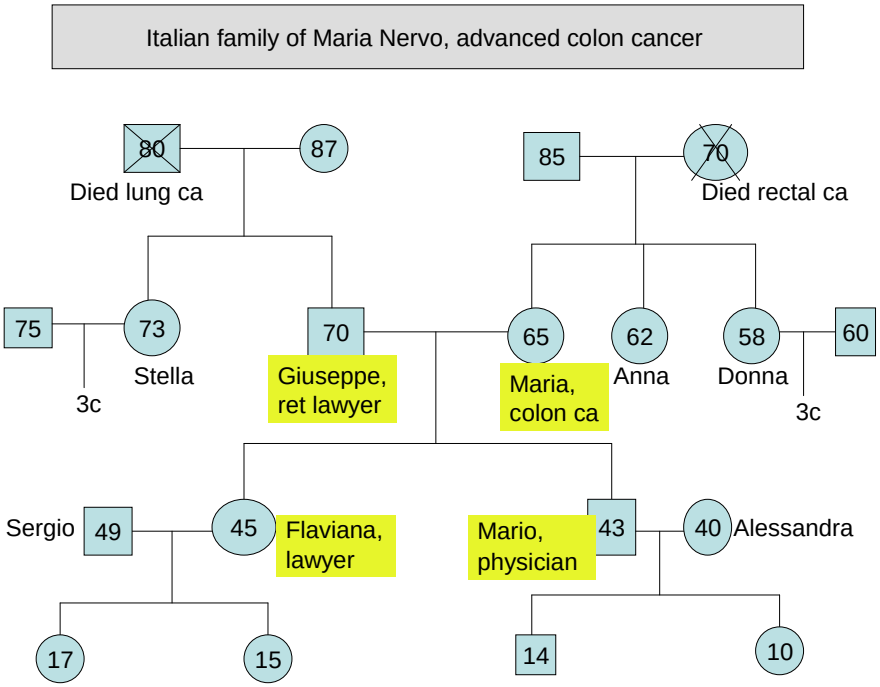
Maria has an advanced colon cancer, metastatic to liver and lung. She had a left sided hemicolectomy performed four years before and pathology showed stage II disease, with a high grade adenocarcinoma invading the muscularis propria (T2), but 0/12 lymph nodes involved (N0, M0), not necessitating adjuvant chemotherapy. She was followed by her surgeon and thought to be disease free until one year ago, when right sided discomfort led to a CT scan, which revealed multiple liver metastases. PET scan confirmed multiple, dispersed liver metastases, not suitable for liver resection, and small bilateral lung nodules. She was treated initially with first line chemotherapy of FOLFOX4 (oxaliplatin, leucovorin, and 5-FU) plus bevacizumab, with disease containment for 7 months and reasonable quality of life. When progression was evident on imaging and rising CEA levels, second line chemotherapy was selected, with irinotecan and cetuximab (monoclonal antibody against the EGFR). This time there was 4 months of disease containment, before nausea, fatigue and anorexia emerged as symptoms and imaging again showed disease progression. Liver lesions are now quite large, liver enzymes are rising, and her clinicians feel that her symptoms are related to emergent liver failure. It is felt time to review the goals of care.

The oncologist spoke to the physician-son, who asked about continued treatment with Xeloda (capecitabine), and asked the oncologist to not tell his mother that he thought she was dying. The son feared that this would take away all her hope. In his opinion, continued chemotherapy would always remain important. The oncologist has the idea that Maria is not going to accept further chemotherapy, as she hinted that she felt she had gone through enough. Rather than debate this situation with Maria's son over the phone, the oncologist thought he would call a family meeting to explore what was best to do.

The oncologist asked that a member of the psychosocial team (social worker, psychologist or psychiatrist – whoever is available) join him for this family session as a way to introduce more support to the family.

Who to expect at this family meeting:

You have called Maria and Giuseppe and they indicated that they would bring their daughter and son to the meeting. The following genogram could be extracted from the clinical genetics file in the medical record.



Your concerns in this role play:

1. You want to connect with each family member, as this proves helpful in the months ahead to support them when such help is needed.
2. You want to ensure that all family members make sense of the clinical information that the oncologist will go over. You will watch for their level of comprehension and question any family members that appear uncertain.
3 You notice that family deaths have occurred previously and plan to ask what the experience of these was like.
4. You want to find out if the family carries any concern for the coping of its members.
5. You want to understand who supports whom in this family, who talks to whom, who worries the most and who helps in the care provision of Maria?
6. You want to help the family to become a stronger team in working with the oncologist as Maria's illness is treated in the future.
7. You will ensure that they understand your continued availability to speak with them as needed in the time ahead.