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In 2006, ESMO members were invited to participate in an online ESMO research project to evaluate attitudes and practice of oncologists in how they communicate with patients with advanced and incurable cancers.

Despite repeated reminders from ESMO, the response rate was disappointing and only 298 completed surveys were returned. Obviously with a response rate of <10% it is not possible to draw strong conclusions for this dataset but, nonetheless, the analysis provided some important insights that suggest attitudes, practice trends and issues that are worthy of further exploration.

Telling diagnosis and prognosis to patients and family

Overall, the most common response was that diagnostic information is initially given to the patient alone and to the family only if the patient permits. A substantial minority of doctors reported that they often or always tell the diagnosis to the family first, and then to the patient, again, only if the family permits. Finally, there are doctors who tell the diagnosis to the patient and family together.

The survey identified that a common problem is families not wanting the patient to be told about diagnosis or poor prognosis. It is relatively uncommon however, for the patient to want information withheld from the family

When family members ask doctors not to disclose a diagnosis of advanced cancer to a competent patient, the most common response to the family is to try to explain that it is in the patient's best interest to be given any information he/she requests and that concealment usually harms more than it helps. However, in many situations physicians reported that they would sometimes explain that it is not for the families to decide, and ask the patient if he/she would like the physician to discuss the test result or try to respect their wishes partially by telling the patient they have a 'growth' or use some other neutral language - avoiding the word cancer, but essentially telling the truth. The overwhelming majority of oncologists

responded that they would not avoid this issue or lie to the patient.

Clinical scenarios

In a scenario where oncologists were asked how they handle the situation when it is clear that chemotherapy is not working and that the likelihood of benefit of further therapies is small, the four most commonly endorsed responses were (in order):

1. Explain the situation and offer a range of options including palliative care, alternative chemotherapy and experimental therapies (if available).
2. Explain the situation and ask how the patient and his family are coping and what their major concerns are.
3. Tell the patient that the chemotherapy is not working and suggest an approach of palliative care only, since the likelihood of harm is greater than the likelihood of benefit from further chemotherapy.
4. Explain that conventional treatments are no longer working and suggest consideration of an experimental treatment (if one is available).
5. Explain that you (the physician) are sorry that there is nothing more that you can do and suggest a hospice or palliative care referral.

Most oncologists responded that they would not avoid a confrontation that may undermine a patient's hope and suggest another course of chemotherapy.

In response to a scenario of presenting to a 45-year old man, with metastatic ca pancreas with multiple liver metastases, and his young wife, in discussing the treatment options, there was consensus to ensure that the patient and his wife understood the nature and extent of the disease, to explain that chemotherapy may make the patient feel better but, unfortunately, metastatic pancreas cancer cannot be cured. There was also a tendency, although not as strong, to explain that the major aim of the treatment is palliation and that this can be achieved with or without chemotherapy, yet explain that this condition is best treated with a trial of chemotherapy.



Respondents were divided about the following communication issues: whether to ensure that the patient not give up, tell the patient that the physician will help him get well, explain that the patient's life expectancy is unlikely to change with or without chemotherapy.

Second opinions

Physicians overwhelmingly reported that:

1. They are not offended when patients request a second opinion.
2. If patients ask to receive a treatment suggested by another doctor, physicians will agree if it seems reasonable.
3. In difficult cases, physicians recommend that patients get a second opinion before making a final decision.

Opinion was divided on if a patient asks to receive a treatment recommended by another doctor. Physicians said they would suggest that the patient receive care from the doctor who recommends the treatment.

Respondents' answers to when a patient with advanced cancer does not follow recommended treatment were most often: acceptance that the physician has given the patient focused care with respect for autonomy of decision-making. Many physicians also acknowledged feeling sadness that patients are doing the wrong thing or on the other hand, satisfaction that patients have made an independent decision. Negative reactions of indifference, anger, resentment, or offense were all uncommon.

Attitudes

31 items assessed various attitudes. Overall there was a very strong consensus regarding:

1. Respect for patient autonomy in information needs and decision-making.
2. Acknowledgement of importance of communication.
3. Readiness to communicate bad prognostic information.
4. Perceived need for benevolent paternalism and acceptance of role for benevolent paternalism.
5. Need for patience and tolerance with patient anger and questions.
6. Strong recognition of physician role in discussing palliative care.
7. Readiness to refer patients to mental health professionals.

On 11 issues there was lack of consensus:

1. As to how much a patient desires active involvement in decision-making.
2. As to how specific or general prognostic information should be.
3. As to whether information derived from internet is of help to patients.
4. As to whether it is important to convey hope for recovery, irrespective of the patient's situation.
5. As to whether the physician should be the person to decide how much information is conveyed to the patient.
6. Quality of training to meet the emotional needs of patients.
7. As to whether doctors have adequate time to address patients' emotional issues.
8. As to whether knowledgeable patients are more difficult to treat.
9. As to whether family members should be asked if the patient should be informed about a poor prognosis.

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10. As to whether the asking of family members if the patient should be told about a poor prognosis is the predominant expectation in their workplace.
11. As to whether patients who know that they have a bad prognosis cope better or worse.
6. If chemotherapy is not helping and the patient wants to talk to the doctor about his/her concerns about end of life care, they should ask the doctor about it. Oncologists are often reluctant to bring up these subjects unless asked expressly by a patient.

Geographic variability

The limited size of the dataset precludes major comparisons between regions. The data suggest that there are major differences in practice between Western European oncologists, who are more likely to discuss issues directly with patients and those from Mediterranean Europe, Eastern Europe and South America, where information was much more commonly filtered by family members.

Helping our patients with what we have learned: from a consumer basis there are some very salient lessons from this data for our patients:

1. Patients need to tell the oncologist how much they want to be involved in decision-making.
2. If patients want printed information or assistance in getting other information, they should ask. Oncologists are unlikely to give these things spontaneously.
3. Specifically ask if there is a chance that treatment may cure. Oncologists are often reluctant to discuss this when cure is not possible. This information may impact decision-making.
4. Don't be shy about asking for a second opinion. Most oncologists recognize that this is a patient's right and will not be offended by it.
5. If a patient chooses to follow a course of treatment suggested by another doctor, the oncologist is very unlikely to be angry. Most often the oncologist will accept that this is a patient's right and will be satisfied that the patient has made an independent decision. Be aware however, that in many cases the oncologist may ask that patient receives treatment from the recommending doctor.
7. Remember that oncologists are human too. Many (42%) feel that they were not well trained to discuss 'bad news'. Most oncologists feel uncomfortable asking patients about difficult subjects such as thoughts regarding death, unfulfilled life aspirations or regrets.
8. Regarding patient decision-making about treatment, some oncologists will want patients to become active partners in decision-making. Others will suggest that patients look after personal decisions but leave medical decisions to the doctor.
9. Some oncologists think that they need to protect patients from information when the prognosis may not be good. In this situation doctors may tell patients that there is hope for cure, even if there is not. If this works for patients, that's OK. If, however, a patient is concerned that he/she doesn't have the full picture and wants more accurate information, they should ask.

We need to tell patients to get to know their doctors! And we need to tell them: Don't be afraid to ask questions because questions are important cues to a doctor. Talk to the doctor about needs: for information, for honesty, directness, for involvement of family or others in decision-making and for time to discuss important medical or personal issues.

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