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Translated by an ACC Survivor

The ten most common misunderstandings about cancer

An interview with Oncologist Dr. Miklos Pless by journalist Martina Frei
(With notes by the translator where ACC differs from other cancers and cancer misunderstandings)

The doctor says *tumor*, the patients understands *death* – and the patient believes that stress is the cause of their cancer. An oncologist responds to the ten most common misunderstandings.

1. Concentration and listening

When a patient is told that he/she has a tumor, how long can he/she still concentrate on what the doctor says? Oncologist Dr. Miklos Pless' answers: "Two minutes".

(Note from the translator: Try to take your partner or a friend along to important doctor meetings. Two brains understand and absorb more, and you can assure that you heard right and are then able to discuss what the doctor said.)

2. Misunderstanding and remaining silent

When the doctor says *tumor* and the patient hears *death* – to avoid such misunderstandings Dr. Pless recommends that the patient checks back with the doctor and expresses what she/he hears and understands. Both the patient and doctor should be honest with each other. For example – patients often remain silent about pains, being afraid to attract bad news or trigger more check-ups. But also doctors have an obligation to support patients, for example if the patients want to obtain a second opinion.

(Note from the translator: If you did not understand something, do not be afraid to ask. Do sum up of what you heard and understood at the end of the visit. If the doctor used words you did not fully understand but he/she could not offer a layman's term, ask that the doctor write the term down for you to research on the internet at home.)

3. Cancer personality

Many people think that psychological factors trigger cancer. That has been proven wrong. It is a preconception and finger pointing, criticizes Dr. Pless. However, psychological factors can influence the course of the disease: hopelessness has a negative effect, while a good social network is a positive. The often quoted fighting spirit however, thinks Pless, does not play a big role. Psychotherapy can increase both the patients and their loved ones quality of life, but not the rate of survival.

(Note from the translator: This is a subject of many discussions, particularly among patients. Dr. Pless expresses what most scientists will advocate.)

4. Environmental pollution and stress

Many concerned suspect pollution, stress and psychological problems to be the cause for their disease. But much more important are other factors. "According to scientific research one third of all cancers are attributed to tobacco consumption", says Dr. Pless. "If we did not smoke, cancer would be much more rare." Wrong nutrition accounts for more than one third of all cancers.

(Note from the translator: Studies on ACC suggest that genetic mutation is the cause, since no study so far can link either lifestyle issues like tobacco or nutrition, nor stress or pollution to this rare type of cancer. It is suspected that ACC is caused by a combination of nature and

nurture issues which combine r a cellular mutation propensity and immune system suppression.)

5. Infiltration, destruction, metastases

Malignant tumors are characterized by three facts: They infiltrate or invade surrounding tissue, grow larger while causing destruction to normal tissue, and spread via metastases. Cancers are graded according to a TNM system, whereby T describes the size of the tumor, N reports if and how many lymph nodes are affected, and M1 or M0 define that mets are present or not.

(Note from translator: Many oncologists who are familiar with ACC know that it has a tendency to be a slow growing type of cancer, but still recommend grading ACC as a high grade malignancy due to it's propensity for microscopic spread through nerve tissue and a high rate of metastasis to other areas in the body.)

6. Metastases

Mets in a bone with an original diagnosis of breast cancer is not a bone cancer! Cancer is usually named by its primary site, not according to where mets develop. The primary or original site will define the therapy.

(Note from the translator: ACC can have its original site in many organs, which is one of the reasons for its frequent misdiagnosis.)

7. Curative or palliative therapy

If there is hope for a cure, a curative and, thus, aggressive therapy is recommended. But if a cure is not possible, the goal changes to palliation, meaning the alleviation of symptoms. This means putting life quality issues to the forefront. A doctor has an obligation to inform a patient fairly. It is the patient who makes the final decision about his/her therapy. According to Pless, "The patient is the captain, the doctor the helmsman".

(Note from the translator: ACC is considered a non-curative cancer as it has a high incidence of recurring, coming back at the original site, and spreading. However, standard treatment is used as an aggressive treatment to delay recurrences and metastases, and thus extend life. As ACC generally is a slow growing cancer, time between recurrences and metastasis development can be long. Doctors often apply treatment methods the same way they would approach the more common, fast growing types of cancers.)

8. Check-ups

How often should one undergo early recognition and post therapy check-ups? According to Pless, "Frequent checks are only of any value if good therapies are available. If a tumor is recognized early but cannot be cured, early diagnosis can extend life expectancy."

(Note from the translator: ACC's slow growth and misunderstood high recurrence and metastasis rates often mislead doctors to limit scans. However, as surgery and early radiation can eliminate ACC tumors or prevent them from invading sensitive organs, frequent tests do have a positive effect on life expectancy and quality.)

9. Trials and studies

Whether one chemo substance is superior to another or not can only be proven in human studies. According to Dr. Pless, "Trials and studies over the past years have generally tested substances to be equal or the same over previously used substances, thus most often bringing some progress. Hence, participating in a study is of advantage to a patient."

(Note from the translator: ACC studies and trials are rare and it is suggested that we patients participate when a study is available.)

10. Death rate

Is death through cancer increasing? “No“, says Dr. Pless. Statistics rather show a decrease in death rates since the beginning of the 1990s.

(Note from the translator: Cancer occurrence has increased primarily due to the increasing population of the world, but the death rate percentage per capita has decreased. ACC prevalence figures are very hard to find, but improved therapies would suggest the above to be true.)