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The General Practitioner and Information to Cancer Patients

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Information to cancer patients is a continuous process, and a considerable personal undertaking is usually needed. The general practitioner is in an unique position because of his contact with the cancer patient and his family during all stages of the diseaes. This gives him both opportunities and the responsibility for this information.

The basis for cancer patient information can briefly be given in the "three c's": Communication, Coordination and Cooperation—communication both to patient and family and coordination and cooperation between the multitude of professionals, who often take care of the cancer patient right through his illness. ***Key words: general practice, patient information, cancer.***

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It has been said that knowledge is the antidote to fear, and probably no other disease is so closely related to fear as cancer. Anxiety accompanies most cancer patients, even those with an excellent prognosis (1). Patients who feel they are not being told enough are often "suffering from a feeling of insecurity" (2).

Most of the studies of cancer patient information have been done in hospital since this setting is normally where the diagnosis is made and the prognosis discussed (3).

Studies show that most cancer patients want to be informed of their disease (3–7). However, it has been observed that this wish declines with progressing disease (8). Over the last 10–20 years there has been a change in the attitudes of the doctors in this field (9). More cancer patients are now told both diagnosis, prognosis and treatment alternatives, and most physicians no longer protect their patients by not giving them information.

There are perhaps many reasons for this change: improving therapy and better prognosis, a general increase in public awareness of cancer, less stigmatization of cancer, better consumer attitudes to the health professions and more consciousness about "patients' rights" (10).

The general practitioner plays an important role in this information. Usually the general practitioner represents the patient's entry to the health care system, and for most patients he also is the symbol of continuity. The general practitioner will have the best knowledge of the patient's total situation. In addition he is often the only available source of information when questions arise.

COMMUNICATION

Communication is the keyword to any information. The information for cancer patients should ideally be based upon a planned, continuous process and should be careful, phased and individual. Planned information means that doctors, nurses and other health-workers involved should discuss and decide together what to say and how and when to tell.

The cancer patient himself will often indicate when and what sort of information he wants, and a listening approach is recommended (2, 8). Every question the patient asks should be honestly answered, but information should not be forced on him. It has been shown that good patient-communication may be rarer than one would think and that many patients fail to understand what they are told (11). It ought to be obvious that an understandable language should be used, but unfortunately doctors often talk jargon, and this can lead to misunderstanding and dissatisfaction (12). Doctor means teacher in latin, and in patient-communication there is a very special teacher/learner situation (13).

The doctor's attitude to cancer patient communication seems to be related to years of experience in the way younger doctors find communication easier than their older colleagues. It also seems that the physicians who see numerous patients with metastatic disease are more positive in telling the patient the whole truth and find communication the easiest (14).

The diagnostic process

Every general practitioner is familiar with patients seeing him because of fear of cancer. Many patients fear that unspecific symptoms indicate cancer, and a study in my own practice has shown that almost 20% of the consultations were caused at least partly by thoughts of or fear of cancer (15). Fortunately most of these patients can be reassured that their fear is groundless. But in some cases there is a real suspicion and a diagnostic process has to be initiated. During this period of uncertainty the patient is in need of psychological support, and it is a great advantage if the doctor can discuss the diagnostic possibilities with his patient (16). An open communication at this stage forms the basis for further information if the suspicion of cancer is confirmed. There is a fine balance between adequate information of the diagnostic alternatives and the possibility of frightening the patient unnecessarily.

In Norway almost all new cancer patients, approximately 15000 per year, have their diagnosis finally confirmed in hospital, and most of these patients are told their diagnosis when admitted. The general practitioners who refer most of these patients have to prepare the ground for this information, and it is of importance that the hospital staff is informed exactly of what the patient and his family have been told regarding diagnosis as well as treatment before referral.

A Norwegian study of 133 patients with cancer showed that most patients were well informed of their diagnosis when admitted, though 1/4 wanted more information. The patients expected to be informed while staying in hospital, and they expected the staff to initiate this information (5).

Another study of 640 surgical patients admitted to hospital showed that 74% wanted to be told if their diagnosis should show up to be cancer. A prospective study of those who really had cancer verified the reality in this wish (7).

As shown in the Norwegian study (5) other authors also find that the patients in hospital want more information about their illness than they receive (3). This information has to be supplied by general practitioner after discharge.

It is important to discriminate between healthy and unhealthy emotional reactions to the information (9). If the emotion significantly impairs the ability to function for more than a week or two it can be considered as abnormal (9). The general practitioner will often be in charge at this stage and he will have to help the patient cope with the emotional crisis.

On the basis of a study of 56 cancer patients it has been concluded that advanced age, good social contact and an unneurotic personality are the factors which lead to a positive adjustment when the truth is learned. On the contrary negative reactions must be expected in younger, neurotic persons especially when suffering from lack of social contact (17).

COORDINATION AND COOPERATION

It is not unusual that cancer patients are transferred from one hospital to another and from one specialist to another. A case from my own practice illustrates this:

Case. A 67-year-old man who had been a heavy smoker from early youth. He had had a long series of bronchitis and airway infections responding well to antibiotics. After one of these airway infections he did not recover. He had a persistant feeling of sickness and got an atrial fibrillation. He was referred to the medical department of the local hospital where a mass in his left lung was found. He was further referred to a lung-clinic where the cancer diagnosis was confirmed and here he was informed of that diagnosis. He was then referred to the surgical department of the central hospital 200 km away. There they planned to do a pneumectomia, but because of massive local infiltration only an explorative thoracotomi was done. After some time at home he was referred to the Norwegian oncological centre 600 km from home. Here he was treated with cytostatics and radiation.

In between his stays in hospital the general practitioner was responsible for the patient, and was consulted regarding cancer related symptoms, as well as other complaints and information both about the patient and his relatives. The local doctor had to contact the different specialists involved to gather the information needed to answer the many

questions concerning therapeutic side-effects, therapeutic alternatives and prognosis.

The disease progressed during the next three months, and during the last weeks of his life the patient stayed in the local cottage hospital for care and analgetics under the responsibility of the general practitioner.

In such cases, with four different hospitals and quite a lot of doctors involved, the general practitioner is not only a coordinator of diagnosis and treatment, but also of information. As every doctor feels that informing cancer patients is not easy, there is a higher risk that no information has been given when patients are transferred like this. Therefore it is necessary to know exactly what the patient is told in each place, and in the same way the general practitioner should inform the specialists or the hospital what the patient has been told when he is referred.

Most of the information from hospital to the general practitioner is given in the discharge letter. A review of 80 such letters about patients with cancer showed that only in three instances was there any reference to what the patient had been told (18).

Cooperation between the different levels within the health care system is a matter of necessity, but this has to be organized, and open lines of communication should be arranged (19).

During treatment

A study of 256 cancer patients showed that most of the patients wanted to know what was the likelihood of cure (4). But while only seven % refused information of how effective the treatment had been of other patients 22% refused information of cases where the treatment had not been effective. The same study showed that the patients who sought detailed information were younger and better educated than the others.

Although surgical treatment, radiation and chemoterapy are mainly given in hospital, the cancer patient will see his general practitioner because of cancer related symptoms, side-effects of the treatment or symptoms and complaints unrelated to the malignant disease. Many general practitioners will also be responsible for the control of cancer patients. Questions of different kinds will arise, and the general practitioner will be challenged in many ways. While the specialist has the advantage of first-hand knowledge of all the benefits and side-effects of the treatment, the practitioner probably knows the patient and his family better. At this stage of the disease "efficient and immediate interprofessional communication should not only be good, but seen by the patient to be good" (2).

It is important not to have a pessimistic attitude, and it is possible that general practitioners have a more optimistic view on cancer treatment than our specialist colleagues (20).

It is impossible to make an exact prognosis, and there will always be positive aspects that should be stressed (9, 21).

Cancer does not only invade the patient, but the whole family as well, producing anxiety and despair. It is important that the family is informed, and some doctors prefer talking to the patient and the relatives together (6, 22). This gives the patient and his family the opportunity to identify and discuss problems. It seems that some doctors are more likely to inform the relatives than the patient himself (3). The general practitioner is often the best to assess the impact of cancer on the entire family and to help maintain the functional wellbeing of the patient and his relatives (23).

Usually the general practitioner will also be responsible for informing the patient of his social insurance rights and he should make sure that the patient gets all the social support and technical remedies he is entitled to. The slogan of the general practitioner as "the patient's advocate" should be kept in mind.

The terminally ill

The terminally ill cancer patient represents a special challenge to the health care system. The general practitioner will at this stage usually be responsible for the patients who spend their remaining time at home.

There are minor differences only in the needs and the demands of patients dying at home and those dying in hospital (24). The general practitioner's task will be to relieve pain and other symptoms and to ensure that all support is given. Non-verbal communication has increasing value, and more than ever the doctor should take time, sit down and listen (1, 8, 25).

Even terminally ill patients prefer to be informed of their prognosis. A study of 43 terminally ill cancer patients who were aware they were dying showed that 31 (72%) were glad they were told openly (26). Another study of 60 terminally ill cancer patients showed that further information and

discussion of their condition was their greatest wish. Most criticism was of undue reticence by doctors (27). "How long will it last?" is a common question, especially from the family. This question should never be answered directly, because no-one can tell exactly (28). Both patient and relatives should be prepared to meet death. During the last phase the relatives may need as much attention as the patient himself. One main question for the family is what to do when death comes. It is important to discuss the practical procedure to avoid panic. Direct advice of how to close the patient's eyes and mouth and whom to call are useful. It is also important to prepare for the period of mourning.

Cancer is said to be a threat both to medicine in general and to the general practitioner's own status (29). This is of special relevance during the terminal stage, and perhaps this is one of the reasons it is so hard to deal with cancer patients.

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