Against a sea of troubles. Choosing between palliative chemotherapy and watchfull waiting

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Chapter

Deciding to cease active cancer treatment: issues in process and outcome

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Introduction

Decisions concerning use or cessation of active cancer treatment are usually made by more than one person. The involvement of several persons makes it unclear how decisions to withdraw treatment are made and who is responsible for the decision. Although it will be clear that a competent patient has the right to accept or refuse treatment, clinicians often make the decision. The first reason for this is that clinicians have the knowledge to judge the medical situation and to propose treatment. Secondly, research shows that most patients want to leave decision-making to their doctors. In this article we focus on cessation of palliative chemotherapy rather than other forms of stopping active treatment. Concentrating on palliative chemotherapy is based upon the absence of information and data in the literature on this topic. Although stopping palliative chemotherapy is part of stopping active treatment in general, it differs from, for example, stopping a ventilator, or nutrition and hydration. In most cases stopping palliative chemotherapy will not affect the length of a patient’s life.

The actual decision-making process concerning withdrawal of treatment is not clear. Both the medical staff as well as the patient and family might benefit from having insight into this process because of mutual expectations of information and participation. Notwithstanding the importance of nurses and family members in decision making, here we concentrate on doctor-patient communication.

Decisions regarding the last phase of life are bound to be difficult for all parties involved. They imply confrontation with impending death and giving up hope of survival. The decision to cease palliative chemotherapy may be especially difficult as it marks the moment of surrendering the hope that tumor growth may be influenced. Communication is crucial in this situation. Several studies have been undertaken in order to find out about patient participation.

Palliative treatment concerns treatment that is given after the cure of cancer appears to be impossible. Stopping palliative chemotherapy occurs often, but how, why and when seems not to be discussed in the literature. This is not because of the simplicity of this decision. On the contrary, lack of criteria forces physicians to decide by themselves alone. Decisions may be based on different kinds of considerations. In making a decision to cease chemotherapy, two aspects may be considered important: the characteristics of palliative chemotherapy itself and the communication between the physician and the patient, on issues such as diagnosis, alternatives in treatment and prognosis. This type of communication has always been, and still is, very difficult. However, in the mid-1970s communication between doctors and patients began to change. Physicians started to inform patients about their diagnosis. As a consequence communication has become more and more important. Especially when dealing with a terminal disease, communication is considered to be difficult though very important. In cancer, and in advanced cancers in particular, several decisions must be made: for example
whether or not to start or continue therapy, the kind of therapy, duration, and how to weigh the side effects. It is difficult for a physician to balance these aspects in order to benefit the patient. Patients themselves should participate in this balancing process, weighing quantity of life against quality of life. Being involved in the decision-making process will be necessary and communication between physicians and patients will play an important role.

This paper reviews elements that are important in decision-making concerning cessation of palliative chemotherapy. First the characteristics of chemotherapy should be looked at: why was it given in the first place, and why should it be stopped. The decision to cease therapy probably will not be made in the last consultation alone but will mostly take place during a period of time in which medical out-comes and emotions play a role. Therefore, secondly, aspects of communication are considered essential in this process and will be investigated as well.

Getting insight into this process is an important goal for future research and this article is meant to contribute to the understanding of aspects that could play a role in this decision-making process.

Palliative chemotherapy and cancer

Following a cancer diagnosis, three different phases in the disease process can be distinguished. In the first phase, cure is considered possible. When a patient is not cured, defined by the absence of tumor residuals and a survival time of 5-10 years, recurrence or lack of response results in the second, palliative, phase: advanced cancer. The third phase, though hard to distinguish from the second, refers to the last period of a person’s life: the terminal phase. Chemotherapy plays an important role in the treatment for cancer and can be used in the curative and palliative phases. Curative intent is only possible in a limited number of cancer types. Chemotherapy is commonly used as palliative treatment, directed at reducing tumor size or improving of quality of life.

Chemotherapy is administered with cytotoxic drugs, which affect both tumor cells and normal cells in the patient’s body. When affecting tumor cells, chemotherapy may reduce tumor size (complete or partial remission), or stabilize tumor growth (stable disease). Palliative chemotherapy may improve survival and shrinkage of tumor size may reduce cancer symptoms, like pain, and thus improve the quality of life. Stabilization of the disease may finally delay the occurrence or deterioration of symptoms. However, side-effects of chemotherapy, such as nausea and vomiting, occur as a result of its effect on normal cells and the advantage of the effect of chemotherapy on the tumor can be outweighed by those side-effects. In other words, physician and patient cannot be certain about the effect of chemotherapy.

Several goals can be distinguished in palliative chemotherapy. The first goal is relief of
cancer symptoms and thus improvement of quality of life. The second goal is prevention of expected symptoms and the third is (progression-free) survival. Some authors consider the first to be the primary intention of chemotherapy\textsuperscript{5,6,9}. To be able to make decisions in this field a process of balancing the losses and gains is needed. The uncertainty about the (side-) effects of chemotherapy causes dilemmas in the decision-making process.

The first uncertainty concerns the effect of palliative chemotherapy on the relief of symptoms or on the prevention of occurrence or deterioration of symptoms. However, physicians can never be sure about the effect and the scope of the effect of chemotherapy.

A substantial reduction of the tumor size should have its effect on the relief of symptoms\textsuperscript{17}. MacDonald states that there is little clinical evidence that cytotoxic drugs can produce analgesia independent of tumor response. Although symptom relief is one of the important goals of chemotherapy, there is little data about the influence of chemotherapy on symptoms and quality of life.

Tannock et al.\textsuperscript{9} note that pain relief was also obtained shortly after the actual administration of chemotherapy and this could be a result from psychological effects (reduction of the anxiety level). It is therefore not entirely correct to assume that symptom relief is determined directly by a reduction of tumor mass\textsuperscript{6,9}.

The second uncertainty when considering the use of chemotherapy is raised by the uncertainty about the occurrence of side effects and to what extent quality of life will be influenced. Chemotherapy may cause severe side-effects, for example: hair loss, nausea, vomiting, fatigue and emotional problems\textsuperscript{10,11}. Several studies have investigated the effect of different dosages, different combinations or intermittent versus continuous chemotherapy, on quality of life\textsuperscript{9,10,12-15}. Glimelius et al.\textsuperscript{12} report that the results of their study were not as expected: it was found that a high dose with significantly higher toxicity did not result in a lower quality of life. Their conclusion was that greater palliation was achieved by a full dose of chemotherapy. Greater palliation was also achieved by a more aggressive regimen. In another study in which continuous treatment was compared to intermittent treatment it was expected that intermittent chemotherapy would provide greater palliation\textsuperscript{14}. It appeared that the scores for nausea and vomiting tended to favour intermittent therapy, but physical well-being, pain, mood, appetite and overall quality of life of patients improved more during continuous treatment.

After two or three cycles of chemotherapy in patients with lung cancer, continuation of chemotherapy was compared with supportive care. Self-assessment of the physical status revealed a slight improvement in the group which continued having chemotherapy\textsuperscript{13}. However, in another study of patients with small-cell lung cancer, it was found that continuation of chemotherapy only worsened side-effects while pain, sleep and activity were largely
unaffected\textsuperscript{15}. It can thus be concluded that chemotherapy results in the experience of side effects but that these do not necessarily go together with a worsened quality of life.

The third uncertainty is, in most cases, the unknown effect on survival-time. Only in a few cancer types, has palliative chemotherapy an effect on progression-free survival. Most patients, however, make the connection between chemotherapy and survival.

Although palliative chemotherapy is not primarily directed at the prolongation of a patient’s life, most studies focus on either survival or progression-free survival as a result of the chemotherapy. Several studies have been conducted in order to investigate the relationship between the dose intensity of chemotherapy and its effect in terms of response rate and survival\textsuperscript{16,17}. Although aggressive chemotherapy may lead to high rates of tumor response, improvement of survival was only observed in some of these trials\textsuperscript{12,18,19}. Partial remission may lead to enhancement of the growth of the residual tumor population\textsuperscript{20}. Thus, tumor reduction does not necessarily lead to improved survival.

The different effects of chemotherapy (that is occurrence of side-effects, relief of symptoms and progression-free survival) imply dilemmas when deciding on whether to start palliative treatment, which combination of regimens to use and the length of therapy. Expected but uncertain side-effects must be weighed against expected but uncertain positive treatment results.

There appears to be no optimal duration of chemotherapy, although clinical trials have been designed in order to determine which dosage and duration yield the best results with regard to quality of life\textsuperscript{9}. It is therefore difficult to determine objectively at exactly what point initiation, continuation or cessation of treatment should take place and how considerations should be weighed from a medical point of view\textsuperscript{16,20}.

Conflicting arguments on the one hand and overlapping interest on the other make the decision-making process concerning palliative treatment complex.

Communicating about the decision to cease palliative chemotherapy

As described above, decision making is complex and because the experience of, and evaluation by, the patient concerning side-effects, pain and other symptoms are subjective, the patients’ opinion plays a role in doctor-patient communication. Due to the lack of literature on ceasing palliative chemotherapy, this topic should be explored by studying various aspects of communication and decision making in other areas. These aspects are investigated by several researchers.

Most communication between doctors and patients involves the exchange of information\textsuperscript{21}. This exchange of information consists of providing information and seeking information\textsuperscript{22}. In
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a review, Roter et al\textsuperscript{23} state that in physician-patient communication, imparting information was the most frequent interaction. According to Degner et al\textsuperscript{24}, lack of information-sharing with patients and families represents a major problem in the field of healthcare. The literature does not provide a clear picture of how much information patients need and what kind of information they prefer\textsuperscript{1}. Another aspect of the communication process is patient participation, both the desire to participate and the attitude of the physician towards participation of patients. The third element of communication presented in this article is the emotional involvement of both doctor and patient.

Information desired and provided

\textit{Patients' perspective}

Cancer patients and patients with other serious illnesses are in great need of information\textsuperscript{25-30}. Most patients want to know as much as possible about their illness and treatment options. However, although patients almost always want as much information as possible, they are reluctant to ask questions, and even when they do not understand the information already given\textsuperscript{31,32}.

Several factors were found to relate to the preference for information. Older patients often prefer less information than do younger patients\textsuperscript{33}. The length of the interaction during the patients' visit also appeared to have an impact on the number of information-seeking comments made by the patient, indicating that a longer interaction may be necessary to manifest the desire for information seeking behavior. Cancer patients with lower incomes and less education, and elderly patients were found to be intimidated by the healthcare system and therefore obtained less information than other patients. As a consequence they do not know what choices they have. This may lead to an inadequate or inappropriate use of the healthcare system\textsuperscript{34}. In other words, income, education and interaction time seem to be related to the preference for information.

The amount of information received by the patient was found to be related not only to patients' socio demographic characteristics but also to communication styles of patients, such as asking questions and expressing concerns\textsuperscript{35}.

One reason why patients need information is to enable them to participate in well-balanced decisions\textsuperscript{36}. Sutherland\textsuperscript{27} concluded that patients' preferences for information are related to other factors than desire for behavioral involvement in the decision making; for example, to satisfy an aspect of 'psychological autonomy' in order to reduce uncertainty or to enhance control.

\textit{Physician's perspective}

Giving information can be stressful for a physician, especially when terminal illness is involved\textsuperscript{37}. Taylor\textsuperscript{38} observed that although physicians disclose the diagnosis of breast cancer regularly,
this task is experienced as stressful and they often dissemble or evade informing the patient about the true nature of the illness.

Because of the turmoil disturbing information may cause, it is understandable that physicians try to control the information flow. According to Miyaji\textsuperscript{39} there are three basic styles of truth telling: telling patients what they want to know; telling patients what they need to know; translating information into terms that patients can accept (intellectually and emotionally). The approach most doctors try to take can be characterized as: telling patients what they want and need to know in a way that they can comprehend. Most doctors provide a patient with a diagnosis and treatment options. However, an equal number of physicians may not fully discuss the prognosis unless the patient asks questions. Miyaji\textsuperscript{39} found 4 factors that influence the truth-telling behavior of physicians. The first is the impact of prognosis and treatment: most doctors only give vague information about the prognosis. Secondly, the uncertainty of prognosis is a frequent reason not to provide information. The third factor is action relevance, whether the information makes any difference in the patient’s choice, the physician’s action and the overall result. The fourth factor is the wish for counterbalancing: physicians want to couple bad news about treatment with hope about the prognosis.

The act of imparting bad news is perceived as stressful by physicians; they often feel powerless, frustrated and guilty about not being able to cure the patient. As a result they find complex, yet predictable, ways to make this task easier. Doctors prefer to develop techniques which reduce their stress rather than confront issues directly. The result of their actions makes disclosure a sensitive topic. Specialists who are used to treating patients with metastatic cancer may feel more positive about communication than other specialists because they may have closer acquaintance with cancer patients’ needs, are accustomed to communicating disturbing factors, or treating patients who have lived with cancer for some time and are emotionally adjusted to their illness\textsuperscript{40}.

In conclusion, it is suggested in the literature that most patients want as much information as possible but not all patients receive (sufficient) information. Different factors influence both the preference for information (age, income) and the possibility of obtaining information (education, length of interaction). Putting the patient explicitly in control of the flow of the information is most appropriate, since an obvious danger is that signals could be wrongly interpreted so that information that the patient might want to hear is withheld by the physician\textsuperscript{41}.

Participation in decision making
Different patterns of control over decision making have been described in the literature\textsuperscript{32}. The physician may be the sole decision maker, the patient may exert final control over the treatment decision or shared control may exist. When the physician is the sole decision maker,
patients may resent their lack of control, especially when treatment does not deliver what was promised. When the patient or family exerts final control over treatment, they may later regret their choices or feel that the health care system has failed them. Shared control provides a potential for avoiding both these problems. Northouse et al\(^1\) state that, especially in life-threatening illnesses such as cancer, sharing decision control with cancer patients is a complex and difficult process. If patients decide to stop chemotherapy, physicians tend to persuade patients more to continue treatment, especially patients with metastases\(^42\).

**Patient’s perspective**

According to the principle of patient-autonomy, good communication is required. The essence of autonomy is self-determination\(^31\). This refers to the freedom of the patient to decide about what will or will not be done to his/her body, without coercion, and after a period of deliberation. But not all patients will be able to make a choice about treatment options, nor do all patients prefer to participate in the decision making. Many will ultimately turn to their physician for guidance\(^43\). Siminoff et al\(^29\) found that the way in which physicians give information, the strength of their recommendations, the presentation of the side effects and specifying risks contribute to the explanation of acceptance or refusal of treatment. Patients’ choices were most strongly influenced by the physicians’ recommendations. Molleman et al.\(^28\) found that the more patients knew and the less sure physicians appeared, the more likely patients were to diverge from treatment recommendations.

Many seriously ill patients do not want to be involved in decision making, even when they are encouraged to do so. Siminoff et al\(^29\) found that 80% accepted their physician’s primary treatment recommendation and 63% of the patients wanted the physician to be primary person responsible for the decision. It appeared that 77% of the patients felt they had the opportunity to participate to the extent they desired. Most of the remaining 25% would have like to have had greater input.

Several predictors of the patients’ wish to participate in decision making have been found. Degner\(^44\) compared newly diagnosed cancer patients with members of the general public and found that newly diagnosed patients were less likely to want to participate. Also patients in the terminal phase were unlikely to seek an active role in selecting their medical treatment. Younger, female, and well educated patients were found to prefer more control over decisions\(^45\). According to Ende et al. (ibid), only a small proportion of the variance of patients’ decision-making preferences is explained by socio-demographic variables. Patients’ preferences for decision making were also related to health status, satisfaction and desire for information. Cassileth\(^46\) found that patients require assistance in becoming as informed as is necessary to participate effectively. Nothing was found in the literature about patients’ preferences and
decision making in (palliative) chemotherapy and it would be interesting to find out what position they take between the newly diagnosed patients and those who are in terminal phase.

**Physician's perspective**

Without knowledge and information, neither healthcare professionals nor patients and their families are able to participate effectively in treatment decisions. However, professionals usually have more access to medical information than patients do and they can effectively exclude patients. Several background factors have been found to influence decision-making styles of physicians. Specialty, years of experience, gender and features of practice (such as solo) are related to the attitude physicians take towards communication and decision making.17,48

**Emotional aspects**

Decisions are often made on an intuitive base which is quite appropriate and results in reasonable choices. However, sometimes intuitions lead patients to make choices that are not in their best interests. Emotional aspects influence the decision making. Especially in medical situations, emotions and risks are essential elements in the decision making. Communication in which emotions have a place, might influence decision making in a positive way.

**Patient’s perspective**

Several studies have been undertaken in order to find out about patients participation. Patient anxiety and dissatisfaction are directly related to uncertainty and lack of information. Receiving information reduces the uncertainty about illness and therapy which will have a positive influence on coping with cancer. Thus, helping patients become well-informed does not necessarily create negative emotions but may actually assist many patients in dealing with their disease.

Patients who preferred active involvement in their own care were more hopeful than those who did not want to participate. Also, patients who wanted as much information as possible, good and bad, were more hopeful than those who preferred minimal or only positive information. However, hopefulness can also be maintained by patients through denial. Patients may use selective denial as a protection against hopelessness despite knowing the details of their condition and thus continue their optimistic outlook.

Concerning the cessation of chemotherapy, almost no emotional dilemmas, such as uncertainty, powerlessness and anxiety, could be found in the literature. Owen et al. found that the desire to cease treatment and a desire for death became associated with loss of hope. On the other hand, similar to physicians, many patients want to maintain hope. They have a strong interest in
the idea that there is still some treatment left, that they do not need to prepare for death immediately. As a result they will stimulate the physician to say that there is some treatment to offer them. Gilbar found that patients who refused chemotherapy scored higher on psychological adjustment to physical stress. They also found significant differences in confidence in physicians, information about illness and expectations from treatment.

Physician’s perspective

Different emotions are involved from the physician’s perspective. Two sources of uncertainty among physicians relevant to communication regarding the cessation of chemotherapy are distinguished by Beresford. The first is the technical uncertainty which refers to whether the physician knows everything about the disease or not. The second source is personal uncertainty, as a result of being responsible for making a sensible decision.

During the procedure of treatment initiation, the physician is expected to inform the patient about all the possible treatment (side) effects and options; bad news is imparted, but hope is offered at the same time. In cessation of treatment, there are usually no treatment options available which might prolong survival. When therapy has to be terminated and there is no hope left, the physician is the bearer of bad news. This is experienced as difficult and stressful. Doctors may feel that to inform the cancer patient fully may confront them with their own negative emotions. Physicians tend to give hope by saying that some treatment is possible. Stopping treatment makes them feel powerless. Avoiding their own fear of death and the fears of the patients, physicians continue treatment.

Taylor suggests that physicians may also be un convinced that it is always in the patient’s best interests to be given full details of their case. They are often afraid that providing patients with detailed information about their disease may create despair.

All in all, it may be expected that uncertainty, hope, fears, and anxiety are relevant emotions in decision making with respect to the cessation of chemotherapy and although it might be a stressful experience for physicians, information must be provided and does not necessarily work out in a negative way for patients.

Considerations relevant to decision making

As mentioned earlier, several considerations play a role in the process of deciding upon cessation of palliative chemotherapy that are inherent to the treatment itself. The first is the chance that chemotherapy effects the tumour. The second is the extent to which symptoms can be relieved and the third concerns the side-effects of the therapy. Apart from these considerations, financial costs, ethical considerations and emotions may play a role in the decision-making
process as well. Questions such as who should receive chemotherapy or not, why, when, and for how long should it be continued, may arise.

Participation in deliberations on the type of treatment, the comprehensiveness and the extent of detailed explanation about the illness as well as the chemotherapy, whether the patients were told that the treatment would improve their physical condition, and 'good' communication were found to be related to patients accepting or refusing chemotherapy\textsuperscript{43}. Preference for different treatment options was also determined by patients' values and beliefs\textsuperscript{33}.

Redelmeier et al.\textsuperscript{49} found that the reference point from which options are balanced are very important and doctors have a considerable power to define the reference point. Secondly predicting future feelings by trying to imagine how certain choices will work out, influences decision making. Thirdly past experiences may play a role in the decision making. Patients may be too worried to be able to make decisions. Doctors may be able to react on these aspects of patients decision making thresholds.

Kiebert et al.\textsuperscript{56} studied what explicit considerations play a role when patients must choose between quality and quantity of life. The most important factor was the chance of cure or survival. If there is a good chance that the disease will be cured, patients are willing to accept a treatment that affects their quality of life in a negative way. However, when chances of cure are small, quality of life becomes more important. Next in importance was the baseline level of quality of life. Also age and the presence of a partner and children were considered to be important. The nature of the side-effects and the ability to continue work were not seen as important factors.

It seems clear that socio-demographic factors, communicative behaviors of physicians, quality of life as well as treatment and disease-related factors influence patients' decision making. Physicians' choices are not only based on medical and emotional considerations, they consider other aspects such as professional acceptability, patient demand and personal experiences\textsuperscript{57}. Also, according to Lo\textsuperscript{58}, the financial cost of care may be taken into account. A physician does not have a moral or legal obligation to provide therapy that will neither cure the disease nor relieve the symptoms. However, deciding the therapy is futile is difficult. Effectiveness is often a matter of probabilities, interpretations and clinical judgment: there is no absolute certainty. As already described, physicians may continue futile treatment for compassionate reasons\textsuperscript{53}. Physicians state that giving treatment as such, independent of its medical result, might be a consideration in treating patients\textsuperscript{59}. 
Discussion

Deciding to treat cancer patients with chemotherapy is difficult and complex because of the character of the treatment itself. Doctors cannot be sure of the consequences when they suggest a certain type or combination of chemotherapy. There is uncertainty about the effects on the tumor, whether it will reduce the tumor or improve the progression free interval and there is uncertainty about the possible side-effects. On the other hand, overlapping interests complicate decision making as well. When it is clear that cure is not possible it can be difficult to decide whether to bother the patient with the cytotoxic drugs and their consequences or to enable the patient to have a 'good' last period in life. Communication therefore is of great importance.

However, it should be noted that recognizing these dilemmas and consequently balancing quality of life against the uncertainties of cancer treatment, is mostly done in Western European countries and North America. In places such as East European and Mediterranean countries, the doctor-patient, relationship is much more traditional, and sharing information and prognosis is not a habit. Much literature on the topic of patient decision making stems from research in Canada. Hardly any research was found from other than Western countries. It seems interesting to investigate the cultural differences between physicians and patients concerning communication and cancer in different parts of Europe.

Because it is almost impossible for a physician to balance possible benefits and risks on their own, patients should be involved in the decision making concerning their lives and their quality of life. In order to achieve this participation of patients, physicians have to inform the patient as well as possible about the diagnosis, treatment options, and consequences and prognosis. On the other hand, to achieve joint-decision making, patients should be willing to become involved in this process. A review of the literature showed that many patients did not want to participate. However, not all of these studies involved cancer patients and none was found on cancer patients in the palliative phase. It would be interesting to study this particular group of patients because of their (long) medical history and their experience with burdensome treatments. This experience could influence patients' behavior. More knowledge about the content of side-effects and the possible effects of treatment might stimulate or encourage patients to participate in decision making concerning their illness and lives.

It seems worthwhile to investigate the particular considerations of physicians and patients when deciding to stop palliative chemotherapy. To what extent are these considerations manifest or latent? What kind of information did contribute to be able to make a decision about continuation or cessation of chemotherapy?
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