

Review Article

Decisions in the Shadow of Finitude of Life: "Guided Decision-making" - A Classical Concept Adapted to Modern Times

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ABSTRACT

In this essay, important factors affecting decision-making in the care of cancer patients are identified and discussed in the face of actual socio-economic changes. The article is based upon a book chapter in German describing recent changes in Germany and other European countries and it expresses personal opinions that can be used as a basis for further discussions. The fundamentally altered practical framework of patient-care in oncology, its ethical dimension and practical significance are elucidated. These changes have profound influence on patient-doctor communication and have to be taken into account in the education of medical students

in this area of their future profession. This is especially true in the confrontation with eternal questions about the finitude of life and how to find a good ending with the most recent developments in medical oncology that force patients to make decisions on how they want to be treated. In this context, the ethical dimension of the patient-doctor dialogue is presented and a proposal is made to adapt the classical "shared decision-making concept" to a guided decision-making model.

Keywords: Socio-economic changes; Patient-care; Oncology; Therapeutics; Cancer therapy

SUMMARY

In this essay, important factors affecting decision-making in the care of cancer patients are identified and discussed in the face of actual socio-economic changes. The article is based upon a book chapter in German describing recent changes in Germany and other European countries and it expresses personal opinions that can be used as a basis for further discussions. The fundamentally altered practical framework of patient-care in oncology, its ethical dimension and practical significance are elucidated. These changes have profound influence on patient-doctor communication and have to be taken into account in the education of medical students in this area of their future profession. This is especially true in the confrontation with eternal questions about the finitude of life and how to find a good ending with the most recent developments in medical oncology that force patients to make decisions on how they want to be treated. In this context, the ethical dimension of the patient-doctor dialogue is presented and a proposal is made to adapt the classical "shared decision-making concept" to a "guided decision-making" model.

Introduction

The three most prevalent cancers in the USA and Europe are prostate, colon/rectum and melanoma among males, and breast, uterine corpus and colon/rectum among females. The death rates for these cancers have dropped by 23% since 1991 and the number of cancer survivors continues to increase. The reasons for this increase are medical achievements advances in early detection and treatment, as well as the aging and growth of the older population [1]. Not only life expectancy but also treatment-associated toxicities for these and other cancers has improved considerably since the 1990s. One of the reasons for this improvement is the definition of patient subgroups with defined biological cancer cell characteristics and the development of therapeutics that target these structures or signaling pathways. These result in more personalized therapies, increased therapeutic options and an associated increase in cancer therapy complexity.

In spite of these improvements in both cancer survival and

manifold treatment options, the diagnosis of cancer still has a major impact on a patient's life. Besides the burden of therapies, almost every second patient has to learn how to live with an incurable disease. Also, the indubitable achievements of cancer therapy are not always acknowledged and many patients still associate the diagnosis of cancer with agonizing death. The relative 5 year survival rates of cancer patients in 2009 and 2010 are estimated to be 61% for men and 67% for women. But despite all improvements and life prolongation by modern therapies, about 50% of the patients will ultimately die because of their malignant disease [2].

The increase in therapy options, including classical chemotherapy, small molecules, biological, hormones and anti-hormones, radiation and modern surgical approaches is associated with an increasing need for more complex explanatory medical briefings and consent discussions between patients and doctors than has been the case so far. This is not only true at the initiation of therapy but also during treatment

and especially in relapsed disease situations. The patient and his doctor have to come to a decision under considerable emotional strain. This communicative interaction plays a decisive role not only in making the medically correct decision but also in finding the adequate therapy that suits the patient's life situation. Despite the positive developments and availability of realistic and effective treatment options, diagnosis of cancer is still often experienced as a direct, existential threat - the patient is suddenly, often unexpectedly and unprepared, confronted with the finitude of his own life. At this stage, the successful patient-doctor communication is of crucial importance not only for the patient's satisfaction and well-being - unsuccessful conversations are associated not only with reduced treatment quality - but also with a worse life prognosis, e.g. due to more frequent treatment discontinuation [3]. In fact, the quality of the patient-doctor communication is one of the most important indicators of treatment quality for the patient [4].

In this essay, important factors affecting decision-making in the care of cancer patients are identified and discussed in the face of actual socio-economic changes. The article is based upon a book chapter in German describing recent changes in Germany and other European countries and it expresses personal opinions that can be used as a basis for further discussions [5].

The number of older cancer patients is increasing in Western countries

One of the major demographic changes and challenges in Western countries as well as in China and Japan in the last four decades is the increasing number of older people. This is due, on the one hand, to a steady decline in birth rates, and on the other, to prolonged life expectancy. According to the actual mortality table of the Federal Statistical Office, life expectancy in Germany has risen again and is just under 81 years of age. 27% of persons living in Germany at the end of 2014 were 60 years or older, 21% 65 years or older, 11% 75+ years old, and 17,000 were centenarians [6]. This shift in the demographic structure, while most pronounced in Germany, can be observed in all EU countries, in the USA and even in China and Japan to a similar extent.

Concomitantly with extended life span and the associated aging of the population, an increase in age-related diseases, such cardiovascular diseases, arthritis, cataracts, osteoporosis, type 2 diabetes, hypertension, dementia and Alzheimer's disease and, particularly pronounced, the major cancer types can be observed. According to the Robert Koch Institute in Berlin, the number of newly diagnosed cancer patients in Germany rose by 21% in men and 14% in women between 2000 and 2010, which is in the same range as the increase of older people. In 2010 about 477,300 people were newly diagnosed with cancer and a further increase of 20% is predicted for the period from 2010 to 2030 [7]. Statistically, in the next ten years, one in four 75 year old men and one in six 75 year old women will get cancer. The effects of aging are mostly responsible for the overall increase in the most common types of cancer [8]. These epidemiologic changes result not only in an increase in the total number but also the proportion of older cancer patients who live for years with cancer as a chronic disease.

Special challenges in the care of older cancer patients are:

- More comorbidities and functional limitations as well as concomitant chronic diseases, such as impaired organ functions (heart, kidney, liver, bone marrow), hearing and vision restrictions, diabetes or dementia and Alzheimer's disease [9].
- The use of several different medications (poly-pharmacy) to treat these chronic diseases resulting in drug interactions - a serious risk for patients who are treated by several sub-specialists [10], and
- Social isolation, depression and anxiety disorders that impair rational decision-making [11].

While these considerations apply in principle to the treatment of all diseases, they have special implications in oncology. On the one hand, metabolic changes due to tumor disease and therapies can significantly exacerbate the concomitantly present diseases. On the other hand, the emotional and brain-organic situation can be aggravated by emotional stress. Also, further limitation of brain performance resulting from chemotherapies is well known and has been referred to as "chemo-fog" or "chemo-brain" [12]. These factors complicate the situation where the patient and his doctor are forced to make a rational treatment decision in the sudden awareness of life finitude due to a newly diagnosed or relapsed cancer.

Other major shifts in socio-demography

In addition to the graying of the population and the concomitant increase in the number of newly diagnosed cancer cases, there are other major transformations in Western societies. As a result of globalization and immigration, German society for example, is increasingly multicultural and multireligious. For instance, in 2010, Muslims accounted for 4.6-5.2% of the German population (about 3.8-4.3 million people); 0.3% were Buddhists, 0.24% Jews and 0.12% Hindus [13]. Future development in this area is difficult to predict, but it is likely that doctors and nurses will have to deal with the particular spiritual needs of their multicultural patients, especially in the situation of a potentially fatal disease. For instance, for many Muslims, it is important to be looked after by staff of the same sex, religious Muslims also reject alcoholic drug preparations or drugs derived from pigs. It is even under discussion if heparins, derived from gut preparation of pigs, are allowed to be used in the treatment of Muslims [14,15]. For Asians, the highest duty towards parents - the life-givers - involves prolonging life at all costs, even against the expressed wish of the terminally ill parents and even if it involves tremendous medical costs and causes infinite misery [16]. There is a potential for conflict and misunderstanding based on a different value system and cultural norms. Thus, lack of a common system of beliefs and attitudes to death will complicate patient-doctor communication. These factors are hardly taken into account in teaching medical students and issues reflecting real life situations will have to be included in medical school curricula.

Another societal change that has a huge impact on how doctors communicate with patients is the changing family

structure. One consequence of higher occupational mobility, with associated reduction in inter-generational coexistence, smaller families and smaller homes is that only 25% of Germans die at home nowadays; nearly half of them end their lives in a hospital (47%) or in-patient care facilities (30%). However, according to a representative survey conducted by the German Hospice and Palliative Association (DHPV), there is a discrepancy between this development and the wishes of the interviewees, as 66% of survey respondents said they rather wanted to die at home [17]. As a consequence of these changing family structures, death is rarely experienced in the family environment and our experiences with end of life patients are that death is frequently even not acknowledged as the natural ending, but more as a final complication of life. In addition, if the doctor enlarges the communication round and family members that do not live together with the patient are included, we frequently find significant differences in the processing of and dealing with life's finitude, which makes communication and shared decision-making even more difficult.

The "National Cancer Plan" in Germany

In the US, among the recommendations of the President's Advisory Commission's report on improving health care quality released on March 12, 1998 was "increasing patients' participation in their care". In Germany and other European countries, there has been similar development. The significant increase in the number of cancer patients in the coming years and the associated increase of costs to the health care system was recognized by politicians and led to the initiation of the "National Cancer Plan" by the Federal Ministry of Health in cooperation with the German Cancer Society, German Cancer Aid and the Working Group of German Cancer Centers in 2008. The plan describes a four-pronged approach to cancer in society, among them, strengthening of patient orientation [18]. The concept of "shared decision-making" (SDM) involves including both the patient's knowledge about his cancer-related issues and also his personal needs in the process of reaching a decision and is accepted as the gold standard of patient-doctor relationship - a high goal in the caretaking of cancer patients. According to patients' rights, the treating physician is obligated to explain to the patient in a comprehensible manner at the beginning and, if necessary, in the course of treatment, all the issues that are essentially involved in the therapy plan [19]. One of the reasons why it is difficult to fulfill these demands in the context of patients with malignant disease is that in most cases the response to treatment as well as the risk of relapse cannot be definitely foreseen. This and different interpretations of risks (e.g. is a 30% relapse-rate a high risk or is it a low risk?) makes comprehensive and clear information sharing with the patient and SDM difficult. More reasonable than the question if a decision is medically right is the question of its meaningfulness for the patient - a question that the patient has to decide by himself. More thoughts on communication concepts such as SDM will be discussed later.

Limited financial resources in the health care sector: increasing costs lead to prioritization debates

The growing proportion of old, sick and retired citizens

is responsible for increasing health care costs, but financial resources are limited. Instruments to manage with scarce financial resources are "rationalization" and "prioritization"; these are concepts in the health care sector that have ethical underpinning, are loaded with emotions and are hotly debated [20]. Rationalization in this context means to achieve an increase in efficiency, so that unnecessary costs are avoided, whereas prioritization involves ranking lists on the basis of which decisions are to be made as to which medical measures in which patients should be given preference and which are to be regarded as secondary [21]. The concepts are based on socio-economic optimizations, not upon strategies to find the best therapy for every individual patient, which make it difficult to include it in the SDM concept of patient-doctor relationships; the personal decision might not necessarily be in line with the prioritization-based guidelines.

The prioritization debate has been taking place worldwide since the 1990s. In particular, the focus is on the question the basic principles on which decisions should be made and which patients and treatments have priority. In the Netherlands, for example, the four principles of "necessity", "effectiveness", "cost-effectiveness" and "self-responsibility" serve as a basis for the use of the health insurance funds [22].

Sweden, on the other hand, has remarkably set "human dignity" as the most important criterion, followed by "needs and solidarity" and "cost-effectiveness". In addition to these principles, Sweden has drawn up specific ranking lists. These are intended to assist physicians in decision-making and, on the other hand, to assist patients in understanding treatment measures [23]. In Germany, a discussion on the topic of prioritization was called for by the medical profession at the 2009 National Doctors' Day. At that time, the Federal Minister of Health, Ulla Schmidt, criticized prioritization in the field of health care, as being contemptuous of human beings [24]. Since 2012, there has been a working group of the Federal Chamber of Physicians "Prioritization in Health Care", which has the task of sharpening the concept of prioritization in Germany and delimiting it from rationing.

Even though the prioritization debate in Germany has only just begun, the cost pressure in the health care sector is already perceptible. Especially for the employees in this sector and through emotionally colored media contributions, this issue is kept in the forefront of citizens' perceptions. As a consequence, the physician no longer has to take into account only the wellbeing of the individual patient, but also increasingly the economic aspects of treatment. The German Hospital Association, the Federal Medical Association and the German Paramedic have also pointed out that the cost pressure in the clinics is increasingly leading to a shortage of staff and time, so that, in particular, the necessary care at the patient's bedside is made more difficult [25]. This situation, which is precarious for the doctor, is being intensified by the public discussion about scarcity of resources and funds in hospitals - it can seriously affect the doctor-patient relationship and lead to a loss of trust. There is a serious risk that communication will be neglected even further because of the conflicts in this field, as well as the

lack of staff and time. This is in sharp contrast to the necessity of significantly more discussions and more complex explanatory medical briefings for patients with the diverse modern treatment options and choices.

Specific guidelines in oncology must be frequently complemented and modified

In current medicine, including oncology, therapy decisions are based on guidelines. Evidence-based medicine (EBM) has the task of compiling the current state of the art clinical research in order to provide decision-making support for the individual patient [26]. However, older patients are strongly underrepresented in clinical studies, because of the described comorbidities that occur very frequently [27]. These differ from individual to individual, so that findings on this patient group would be very inhomogeneous - a fact that would be an exclusion criterion for comparing clinical trials. The decision for or against a specific therapy can therefore often only be worked out in interaction and discussion with the patient under jointly defined therapy goals. This is particularly the case in the oncological palliative situation in which the course of the disease is influenced by the therapy, but the disease itself cannot be cured.

Some important goals of the treatment in a palliative oncological situation are:

- Prevention of complications due to tumors.
- Prevention of unwanted effects and side effects of treatment.
- Maintenance or regaining of the best possible quality of life.
- Alleviation of suffering.

The individual aspirations of patients and their relatives regarding quality of life must therefore be identified and taken into account - they can vary greatly from person to person; they can even vary for the same patient over time, which means that they have to be redefined repeatedly over time. These requirements place high demands on the attending physician and require special training in the art of patient-physician communication. The ethical dimension of communication in oncology becomes clear at this point. In the dialogue, the physician guides the patient through decisions on various therapy options. With the medical possibilities and necessities in the background, responsible action includes empathy and awareness of the patient's wishes with respect for the patient's autonomy and self-responsibility.

Change in attitudes towards finitude of life

The finite nature of life is being frequently addressed in the public sphere. For example, in 2012, the German stately television ARD devoted itself to the topic of "life with death" with various contributions to TV, radio and the Internet. In addition, there are ongoing public discussions on the ethics of physician-assisted suicide, especially in cancer patients. As a result of these developments, the attitude in the society towards

the finiteness of human life in the modern world has changed. These aspects must be addressed now in the sense of a holistic treatment concept in oncology. Some universities are already dealing with the consequences of the changed spiritual and psychosocial needs of cancer patients; the University of Munich for example implemented a research area for "spiritual care" to deal with the common concern of medicine, care, psychotherapy and other health care for the spirituality of patients. Social opinion also plays an important role in the context of an increasingly secularized society where the current opinion of the Christian churches is increasingly being questioned and disregarded. The World Health Organization (WHO) also underlines, in its definition of "palliative care", that one of the most burdensome complaints of oncological patients, besides physical ones, are psychosocial and spiritual problems [28]. These aspects should be taken into greater account in medical teaching than in the past, because otherwise the doctor and the patient will not be able to define and pursue common goals such as quality of life and the design of the last phase of life in the awareness of life's finitude.

Guided decision-making (GADM) in modern oncology

The paternalistic style was the predominant way of doctors to deal with patients for a long time. However, as early as 1977, the stimulus to develop a conversation style that emphasizes SDM was already provided by Charles et al. [29]. While the concept of SDM is firmly entrenched in medicine and can be called the gold standard nowadays [30], its implementation in oncological clinical routine is far from easy. Also, since the seventies, the objectives of these dialogues and the framework conditions as elucidated above have become more diverse and complex and need to be redefined. Apart from the changing external conditions, there are, in my opinion, inherent conceptual arguments for an adaptation of the concept.

Firstly, the considerable imbalance between the interlocutors:

If there is to be sharing between people in a just manner, the partners have to be more or less equal. Otherwise, it cannot be called a shared decision but rather a decision on a professional or business basis. Despite all efforts to clarify the advantages and disadvantages of therapeutic options and the multiple provision of information, the inequality of doctors and patients will never be overcome. The lack of information sources is not a problem in the modern Internet-based world, but ability to make a distinction between correct and incorrect information and make a qualified interpretation of available data is. The patient needs and uses the doctor as a specialist who can help him distinguish between useful and irrelevant information - he needs the doctor's support and guidance to make a decision.

Secondly, the distinction between the person concerned and the person responsible: The counseling of patients in difficult situations and at the end of their lives belongs to the daily routine of oncologists. For the affected patient, on the other hand, the situation is unique and often final, and the decisions that have to be made in the shadow of life's finitude are associated with deep emotional and ethical distress and agitation. A doctor in his daily routine does not want to share them but with empathy, he guides the patients through them.

The adapted concept of "guided decision-making" (GDM) in the light of the considerably altered situation in modern oncology seems to be more feasible and practicable. The concept needs to be further refined and translated into a teaching concept.

Conclusion

In the 1950s and earlier, the dominant style of patient-physician communication in the context of decision-making in medicine as a whole was clearly paternalistic.

However, the concepts of informed patient consent, patient autonomy and patient-centered care that developed in the late fifties and thereafter in biomedical ethics were quite directly opposed to that of the paternalistic style of health care. In parallel with the introduction of these specific ethical concepts in the field of medicine that underline both the instrumental and absolute value of patient involvement in medical decisions affecting them, increased and easy patient access to newest information in medical developments has led to increased self-confidence of patients. Patients demand a share in healthcare decisions – they no longer want decisions about them to be made without their active involvement in the decisions. The concept of "shared decision making" (SDM) developed in 1977 is a further refinement and concretization of the earlier concepts and is considered today as the gold standard in patient-doctor conversation in oncology. Since then, however, fundamental changes in the health care system including economic considerations in budget allocation to national health care systems, the vast and ever-increasing amount of information available to patients, enormous societal and demographic changes and, most importantly, the variety of treatment possibilities in oncology have made a re-analysis of the concept of shared decision-making both challenging and necessary. Today, the patient has several choices in almost every oncological situation including palliative oncology.

We believe that the patient/ doctor relationship and the conversation style between the two have to be redefined and adapted to the current situation. Certainly, the patient has to make the choice by himself. The doctor does not share the decision – the concept of sharing suggests that the doctor somehow makes the decision for the patient - but he is needed as a specialist and guide to help the patient weigh the available information so that the patient autonomously makes his own decision. The concept of GDM should be understood as an adaptation and further development of the classical SDM concept. Further research to define more precisely the details of the GDM concept against the background of massive societal transformations is being carried out.

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