

Chapter 04

Meaningfulness as Ethical Principle for Decision-Making in Oncology

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In this essay, the aspect of meaningfulness in treatment decisions of older cancer patients is elucidated. The significance of meaningfulness as a central concept of solving problems, especially under life-threatening conditions such as being ill with cancer, became obvious to us in our daily oncological practice and through interviews with older cancer patients. Meaning-making can be seen as an on-going process of composing and recomposing one's life story through sharable values. One of the major differences between young and elderly cancer patients is that older people are able to look back on their life stories. Meaningfulness as a guiding structure for making decisions about treatment is closely rooted in the highly personal life history of the individuals involved. The doctor must aid and invite patients to tell their life stories in the context of the "disturbing element", namely the cancer diagnosis and fears about treatment side effects, and assist them to integrate their treatment decision into that story. Empathic witnessing of the existential experience of suffering is a basic part of the concept of "guided decision-making" (GDM), developed by our group, where the doctor guides the patient to the right decision on the grounds of evidence-based medical guidelines and individual factors (see chapter 3 in this book).

Currently, the median age of patients with a diagnosis of lung cancer, which is the most common cancer type in the world, is 72 years; in contrast, from 1975 to 1999, the median age for a diagnosis of lung cancer was only 66 years [1]. Similar trends can be observed for the other major types of cancer, e.g. colorectal cancer. In parallel, the chances to survive a cancer are steadily increasing; the 5-year survival rate, e.g. for lung cancer, rose from 11.5 % in 1975 to 19.8% in 2009 [2]. The reasons for this positive trend, despite the increasing age of the patients, are early detection and better, age-adapted, therapies. Advances in the treatment have taken place not only in surgery and radiation therapy but also in medical treatment, which is especially important for patients with advanced cancer stages. From January 1, 2009 to December 31, 2013, the US FDA approved 51 new drugs in oncology for 63 different indications. Many of them are not

chemotherapeutic drugs as in the decades before, but antibodies, kinase or multikinase inhibitors or immunomodulatory drugs [3].

Whereas these developments have increased the number of treatment options, they have also increased the necessity for doctors and patients to decide which treatment should be taken into account. Often, the clinical studies that ultimately resulted in approval of the new drugs for the specific indication were performed with younger patients due to the necessity to define inclusion and exclusion criteria for a given study group [4]. However, the majority of cancer patients today are older. This situation makes it even more imperative for patient/doctor communication to be intensive and personal, taking into consideration the comorbidities of the older patients, their personal wishes and needs, as well as the therapeutic options. These talks cannot be delayed, as the doctor and the patient have to decide on the therapeutic route right after diagnosis.

Philosophically, meaning or value refers to two aspects: the concept of “good”, which served as a precursor of the concept of “value” until the nineteenth century, and “emotions” that can be viewed as “seismographs of meaning” [5]. In ancient philosophy, especially in Plato’s Moral Philosophy, these two concepts coincided. Plato understood the “good” as that, which man needs existentially: the removal of suffering was regarded as “undeniably the ultimate”. The good possessed the character of salvation [6]. This existential connotation is still relevant to the question of meaning until today, for example, when it is linked to the existential dimension of human existence [7]. Due to the pluralizing tendency in the course of the 20th century, the concept has become increasingly relativized and individualized; nevertheless, the question of meaning has retained its basic existential connotation. Albert Camus, for example, declared meaning to be the fundamental question of philosophy: whether life is worthwhile or not [8]. More recent works view “happiness” as a natural characteristic, whereas meaning has strong cultural anchoring, we believe that “meaningfulness” as a guiding principle in decision-making is closely rooted in the unique personal life

history of individuals [9]. The significance of meaningfulness as a central concept of solving problems, especially under life-threatening conditions such as having to deal with cancer, became obvious to us in our daily oncological practice and through interviews with older cancer patients. One of the major differences between young and elderly cancer patients is that older people are able to look back on their life stories. Making meaning can be seen as an on-going process of composing and recomposing one's life story through sharable values [10]. "Meanings come into being through an interplay of the happenings in a person's life and the on-going social process of organizing these happenings into a story that provides coherence and preserves the fundamental permanence and uniqueness of the self", as Katie Collie and Bonita Long put it in their essay on meaning in the context of breast cancer [11]. Cancer diagnosis is a "destructive element" that needs to be integrated into the life story. Agreement between doctor and patient regarding treatment can only be expected if the patient not only understands the treatment concept and its consequences, but is also able to integrate it into his/her personal life story.

In this concept, meaning and identity, or self, are closely linked. The definition and perception of self is a highly debated philosophical topic [12]. In the context of decision-making in lifethreatening situations, such as the diagnosis of cancer, we have learnt that especially for older patients the distinction between a "personal self" and a "social self" is important - personal self, meaning a highly individual self-perception based on experiences and traumata and social self, defined as the inter-personal being and the result of the influence of interaction on self-perception [13].

"And then I made this decision - after all that suffering my body had gone through. And so, I told my doctors: Shortly, I will be 85 years old, then I can say I have had a good life. I mean, it sounds very curt when I say this, but why should I torture myself with these pills that I cannot tolerate? Also, it is no fun for me to have breast radiation for 52 weeks". This is an original citation from interviews with a cancer

patient (Valerie Schaefer, *The Oncologist*, 2018). This old lady refused continuation of the onerous evidence-based therapy that was offered to her by her gynecologist. This patient was able to integrate both the cancer diagnosis and therapy rejection into her life-story (“...I can say I have had a good life”) by looking back into her life’s storybook. This shows that “meaning” might have different definitions depending on the book’s chapter that is currently opened. Another older patient said that she would have made another decision if she had cancer when she was younger and had to take care of her children.

As with all stories, life stories need to be told and shared to be of value. If the doctor understands this idea, he/she will give patients a chance to tell their stories - to find the decision, which is right in their situation, patients need to become aware of them. Kleinman used the term “empathic witness” to refer to the necessary function of a person with a commitment to be with the sick person and to facilitate his or her building up an illness narrative that will make sense and give value to the experience [14]. In that sense, empathic witnessing of the existential experience of suffering is a basic part of the concept of “guided decision-making” (GDM), where the doctor guides the patient to the right decision on the grounds of evidence-based medical guidelines [15 and chapter 3 of this book]. He/she must aid and invite patients to tell their life stories in the context of the disruptive element—the cancer diagnosis and fears about treatment side effects - and assist them to integrate their decisions into their life stories. From our point of view, this has to be integrated as an essential element in the structured patient/doctor communication in the context of guided-decision making as well as in modern teaching concepts.

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