

# Scared Witless About Death — Ovarian Cancer Narratives Compared

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Published online: 14 July 2013  
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**Abstract** Fifty years ago, doctors did not tell their patients they had cancer. Improved patient-physician communication, feminization of the medical profession and increased patient empowerment may have improved matters. However, death is still a subject many doctors find difficult to deal with. We explore this issue in the context of medical humanities. In order to examine the different strategies in coping with illness and death, we compared illness perceptions in a literary text, *W;t* by Margaret Edson, about a woman who dies of ovarian cancer, with a personal narrative of a patient with ovarian cancer. Although there are many differences between the two patients in historical and cultural background, similarities were found in the way they cope with illness and death anxiety. Insight into illness perceptions and coping strategies of patients with cancer is important for raising awareness in clinicians, leading to improved understanding and better treatment of patients.

**Keywords** Quality of life · Illness perceptions · Ovarian cancer · Literature and medicine · Medical humanities · Physician-patient communication

## Introduction

Ovarian cancer is a cancerous growth arising from different parts of the ovary. Vague abdominal discomfort and abnormal vaginal loss of blood are the first symptoms. Of the gynecologic tumors, ovarian cancer has the highest mortality rate, and it has a poor prognosis. This is due to the fact that

the tumor virtually has no symptoms in an early stage. Seventy percent of the patients begin their treatment in an advanced stage. Treatment of ovarian cancer exists by the removal of the uterus and ovaries and chemotherapy. The 5-year survival rate in stage I is 60 to 85 %, and it drops to 50 % in stage II. In stages III and IV, the 5-year survival rate is 5 to 10 % [1].

Until late in the twentieth century, cancer has always been an unspeakable disease [2]. Especially, ovarian cancer is not a well-explored subject in literary texts. In 1952, Thomas Mann wrote *The Black Swan*, one of the very few literary texts about the subject. The protagonist of this story is Mrs. Rosalie von Tümmeler, a post-menopausal widow of 50 years old who falls in love with a much younger man. She begins menstruating again. Perceived by her as signs of rejuvenation, these are too late diagnosed as symptoms of ovarian cancer. We, as readers, recognize the stigma still attached to cancer in those days, a curse which befalls on a patient with repressed passion, but the patient herself does not perceive her illness as punishment; she accepts her death as natural and dies in peace [3].

Where doctors would not tell their patients they had cancer 50 years ago, nowadays, they cannot be open enough to their patients, who demand all the information they can get. It has become more common to talk openly about cancer in our culture of confession, self-help books, and reality television. Society's attitude towards cancer has evolved; it is not a curse anymore, and not necessarily a death sentence [4]. According to Sontag, “the most truthful way of regarding illness, the healthiest way of being ill is one most purified, most resistant to metaphoric thinking.” (p. 3 of [2]). Can we say that we dare to tell the truth about cancer? Fishman et al. did a study on how cancer was reported in the media in the USA. It turned out that news reports about cancer may give patients an inappropriately optimistic view because they rarely discuss treatment failure, adverse events, end-of-life care, or death [5].

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In the Netherlands, around 1,100 women are diagnosed with ovarian cancer per year. On the website of the Dutch patients association for ovarian cancer ‘Foundation Olive’ [6], we cannot find anything about coping with the prospect of death, except for pain control. The personal narratives of the patients are about controlling the disease, not about confrontation with death, which in the case of ovarian cancer is a not uncommon reality.

In this paper, we will investigate how a patient nowadays copes with the diagnosis of ovarian cancer, how she makes sense of her disease, and – when the disease is terminal – how she copes with dying. In the context of Medical Humanities, we aim at comparing a narrative of a literary figure with the narrative of an actual patient with ovarian cancer.

## Methods

### Play

We studied the text of the play *W;t* by Margaret Edson, written in 1997 [7]. It has won the Pulitzer Prize for Drama in 1999 and was adapted into a film by Mike Nichols in 2001. It has been reviewed in medical journals [8, 9]. The plot concerns a woman dying of ovarian cancer in a university medical center. The patient, Vivian Bearing, 50 years old, is a professor of English Literature, and an expert on the Holy Sonnets of John Donne. In the play, she is followed from her diagnosis, through her treatment, and to her death [9]. Besides the main character, Vivian Bearing, there are two physicians, Dr. Kelekian and a young fellow Jason Posner, who is also Vivian's former student, and the nurse, Susie. Vivian's father and her old university professor Ashford play minor roles in flashbacks.

### Patient

To compare the illness narrative and patients' perceptions in *W;t* with the personal narrative of a patient, we interviewed a woman of the same age as Vivian Bearing. E. is a hairdresser, 49 years old, and has been diagnosed with ovarian cancer 2 years ago. She had varying problems with her ovaries throughout her life. When she was 23, she was diagnosed with endometriosis. At the age of 30, ovarian cysts were found. When she was 46, the doctor found the tumor during a routine check-up, it was still in an early stage. E. underwent surgery 2 weeks after the diagnosis and received chemotherapy for several months. Now, she is declared tumor free. We contacted the patient via the Leiden University Medical Centre and interviewed her at home. In addition, the authors and the patient watched the movie *W;t* together, and the authors explored whether the patient recognized certain

themes or, on the contrary, found certain themes in the movie to be very different from her story.

Brody and DeShazer served as sources for the analysis of the two narratives [10, 11]. The analysis focuses on three themes: the doctor-patient interaction, coping strategies, and confrontation with (possible) death.

The study followed principles in the Declaration of Helsinki.

## Results

### Interactions Between The Doctor and The Patient

In *W;t*, Dr. Kelekian tells Vivian she has stage IV ovarian cancer. She agrees to undergo an aggressive treatment of chemotherapy on an experimental basis. According to Dr. Kelekian, this treatment will make a significant contribution to scientific knowledge. He does not talk about the inevitability of her death, or about the pain that will come. Vivian is fully aware that she will die. During the play, she continuously hints with irony and often with gallows humor on her coming death. Her monologues about her life, her work, and Donne's poetry are alternated with doctor visits and medical treatments. A clear example of the doctor-patient interaction is shown in the ward round, a parade of doctors and students, a degrading routine with the paternalistic Kelekian, who is only interested in Vivian as a research object. He addresses her with an impersonal and strictly formal politeness and plasters her with medical terms which Vivian counters with her own jargon. Doctors and technicians are by turns inappropriately cheery, overly familiar, presumptuous, and rude [9].

A normal human interaction only grows with the nurse Susie in the course of Vivian's hospital stay. Susie truly cares for her patient; she supplies what no one else provides: handholding, pain control, and truth. She is the one who brings up with Vivian the issue of her code status, saying aloud what the doctors will not, that she is dying [9].

The interviewed patient, E., has a very different experience with doctors. Of course, her narrative is set some 20 years after Vivian's. She has been seeing the same doctor for years, and is on a friendly basis with her. She feels she can tell her doctor everything, and that she will be listened to. Because of her long history of gynecological problems, she was not surprised when cancer was diagnosed. Where Vivian finds out that she has a practically incurable stage of cancer, E. hears she has a small tumor and that the chances are high that she will be completely cured. During watching the movie, E. remarks that she sees an enormous discrepancy in the doctors' behaviors; she perceived her physician and the medical staff caring for her as supportive and warm, without any signs of paternalism.

## Coping Strategies

Vivian and E. cope with their diseases differently: E.'s story is about controlling her disease while Vivian's about confrontation with death, yet there are similarities to be found in the way they cope; they both do not want to be victims and are soldierly and stoic patients. When E. had chemotherapy, she went to the gym twice a week. She says she has always been a physically strong woman, and she thinks that her strength helped her through it. She feels she can control her illness by keeping her body strong.

Last summer, she climbed the Alpe d' Huez – a mountain in the French Alps – with her family and other cancer survivors to prove her body was strong again. Every year, this tour is organized by the foundation Alpe d' HuZes, created with the aim to empower cancer survivors and to raise funds to fight cancer [12]. One could say E. uses fitness as a shield against death.

Vivian copes with her illness in a different way. Her body already gave up; she has not really something to fight for except her dignity and identity as a poetry expert. Willingly being a research object is a heroic act; her body, rather than her own work, becomes her last contribution to academic research. She has to be tough to make it through eight cycles of full-dose chemotherapy. She has no control over her illness, but she tries to control her part in the hospital and on stage as much as possible by presenting herself throughout the entire play as a professor. She gains her scholarly detachment and courage from wit and uses it as a shield.

Patient E. tells the authors about how she had (female) friends with her, during the chemotherapy sessions. She and they fostered optimism about the outcome of the medical treatment of her tumor.

## Confrontation with Death

With the semicolon in the title of the play, Edson wants to show us Vivian's personal statement about death, and she stages dying as full of pain *with* an exclamation point. At the same time, Edson makes *W;t* a witty lecture on the different interpretations of Donne's wit with one of the possible conclusions that wit can help you try to make sense of death, but when the body is failing, language falls short. The main difference between the narratives of Vivian and E. is that Vivian's is chiefly a quest narrative [10]. Vivian knows that she is dying, she reflects on the choices she made in her life and has to confront death. E.'s narrative is a restitution narrative [10]. She never thought she was going to die. When the tumor was detected, she had great confidence in her doctors and felt they treated her with respect. Now, she feels almost completely recovered and is convinced that the cancer will not return.

Another difference between the two narratives is that Vivian is without support from family and friends. Maybe it would have been easier for her having that support. E. has many family and friends to support her and share her story with. She feels she can talk openly about her illness to anyone. On the other hand, she had to deal with the fact that her boyfriend, 9 years younger, blamed her for being ill and needing all her energy and time for herself. According to DeShazer, in many popular novels about a woman dying of cancer, the importance of family support is overstated and romanticized. Cancer survivors often have to cheer up their family and eject despair from their texts (p. 224 of [11]).

E.'s narrative is retrospective and her memory can be selective. It is plausible that she also had to deal with moments of despair. Maybe E. never experienced death anxiety and a spiritual struggle like Vivian, but she knows as well the struggle to keep death at bay. While Vivian uses wit as a shield, E. uses fitness to keep her body as far as possible from death. Climbing the Alpe d'Huez has been her ultimate experience of beating the cancer. It is a symbol for being a survivor, a metaphor for transcending death. You do not have to believe in a life after death to have a transcendental experience, to go beyond death. At this point, there is a clear similarity between E. and Vivian who both are not religious — they cope with their illnesses with all their personal powers. Every patient has to make his own (spiritual) quest, and in the end, everybody dies alone [13].

## Discussion

In our study, the major results pertain to the degree of similarity between the two patients' stories. Although their illness narratives are different, they both cope in their own way with death and anxiety. In addition, we found that the doctor-patient communication in both stories differs greatly and that this has influence on coping with anxiety.

Compared to the empirical literature on biopsychosocial effects of ovarian cancer, we found similarities as well, namely that patients who are informed about treatment cope better with their disease but that coping with death anxiety is always an individual struggle [14].

This paper has its limitations. Only one literary text was studied and only one patient with ovarian cancer was interviewed. This interview could be no more than a first exploration. To interview a patient in a scientifically sound way, there has to be a basis for trust. For us, as outsiders, it was not possible to interview a patient with terminal ovarian cancer. Therefore, this paper focuses on the analysis of the literary text which is available to everybody, to emphasize the importance of literary texts for understanding the complex experiences of a patient confronting death.

According to Weston, in the process of becoming a doctor, more attention should be given to the dying patients. It is strange that an intern must attend a set number of births, but not a set number of dying patients [15]. Doctors should learn how to deal with death and how to communicate with a dying patient. A doctor does not have to be a specialist in literature or in the Holy Sonnets of John Donne, but s/he has to have insight in the complexity of illness experiences and confrontation with death, the differences in coping strategies and styles between patients, and above all, in her/his own fear of death.

The limitations in our study lead to suggestions for new studies in this area. They might benefit from extending the number of patients with ovarian cancer, and exploring whether the patients take points from seeing the movie, or reading the book, which will help them on their cancer journey. This would also allow taking the stories of several patients with ovarian cancer and analyze what their thoughts and emotions to the play are.

Cancer was always unspeakable. Nowadays, we seem to speak the truth about cancer as an illness, as was Sontag's aim by elucidating cancer metaphors. A patient seems to control her illness by having all information about treatments and eventually pain control, but “in every calm and reasonable person, there is a hidden second person scared witless about death” [16], and when control fails, the shield of fitness and wit is useless. Vivian has to disarm before she can face death. “For those who live neither with religious consolations about death nor with a sense of death as natural,

death is the obscene mystery, the thing that cannot be controlled. It can only be denied.” (p. 55 of [2])

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