

# **ORIGINAL PAPER**

# Shame and Humiliation of Breast Cancer Patients – Communication Pitfalls with Oncology Cases

# Ioana Silistraru\*

#### **Abstract:**

Effective patient-doctor communication within Romanian healthcare system is one key element that could compensate the lack of resources, often blamed for the great distress patients and their families experience while being in contact with Romanian medical personnel. Oncology is above many other medical specialties in great need of implementation of good, effective patient-doctor communication, to alleviate sufferance and conduct to more effective healthcare. Inadequate communication may cause much distress for patients and their families, who often want considerably more information than is usually provided. Many patients leave consultations unsure about the diagnosis and prognosis, according to Fallowfield, L. and Jenkins, V. (1999). According to Maguire, P. (2002) doctors usually fail in listening to their patients' complaints and concerns, almost to half of the issues raised. The study reveals that medical personnel stops at obtaining information about patients' perceptions of their problems, either physical, emotional, or social impact of the above-mentioned problems. The article proposes a short review of a relevant life-history narrative of breast cancer patient, that emphasizes the importance of humane, clear and professional communication to better healthcare, alleviation of sufferance and clearer view on the patient's health challenges. Based on Eurostat data (updated in September 2017) more than one and a quarter million people died from cancer in the EU-28, just over one quarter (26.0 %) of the total number of deaths. Among the EU Member States, the share of deaths from cancer in the total number of deaths exceeded 30.0 % in Slovenia and the Netherlands. By contrast, 20.0 % of all deaths or less were from cancer in Bulgaria, Lithuania and Romania. Romanian patients witness that better communication in oncology wards would significantly strengthen their morale. The presentation shall provide access to patient's narratives, given through informal semi-structured interview, as life history analysis. The outcome shall point out the preponderance of concepts as of shame and humiliation in therapeutic approach in Romania, among other concepts established in the academic literature for oncology and patient in general narratives.

**Keywords:** oncology; patient-doctor communication; narrative medicine; breast cancer.

<sup>\*</sup>Phd Candidate, University of Bucharest, Faculty of Sociology and Social Work; Phone 0040 752 181 805; Email: ioana.silistraru@icloud.com.

## The patient exposed to shame and humiliation

The literature examining the communication in doctor-patients encounters suggests that shame and humiliation are important concepts frequently described in those encounters but insufficiently explored (Lazare, 1987). The wide palette of emotions experienced by patients, especially by cancer patients, ranges from fear to rage and blame, going through the phase of guilt and shame. A life-threatening disease as cancer sets patients in a state expecting and needing support, care, help and trust (Stiefel and Krenz, 2013) therefore appropriate communication with their healthcare practitioners and team contributes to the patient's welfare. Being able to care about their patient's emotions is part of their cure.

"It happened to me that a doctor, although a celebrity among oncologists, to ask me, mocking me, whether is Facebook where I find my information. Actually, it wasn't the social network the source of my information, but the medical reviews and journals. This is the point where I dismiss such a doctor, either because he's too sick and tired to practice his profession, he's either just so self-absorbed that he thinks there is nothing new he could ever learn. (M.C., life history, oncological patient)"

The chapter "Improving Communication Effectiveness in Oncology: The Role of Emotions" by Maria Antonietta Annunziata and Barbara Muzzatti (Stiefel and Krenz, 2013) explores the role of emotions in oncology patients, in relation to shame and humiliation experience and explained in life-threating illnesses. In oncology cases there are two main concepts which encapsulate the importance of emotions – emotional distress and cancer-related fatigue:

"These two aspects can interfere with medical communications (reducing the reception, comprehension, and recollection of information); they can also be an explicit object of communication, as they are the possible outcomes of treatments and could elicit the request for specific supporting interventions (Stiefel and Krenz, 2013)".

Thirty years ago, shame and humiliation were not widely researched in the medical setting, although the quality of medical care is extensively explored in patient-doctor communication literature. Only in recent years, communication professionals and healthcare providers became aware of the benefits of effective communication (Charon, 2011).

"...the subject of shame and humiliation in medical encounters is rarely discussed, studied, or written about. Only one article in the medical literature during the past 20 years has the word "shame" or "humiliation" in the title. Highly regarded books on the doctor-patient relationship and interpersonal aspects of patient care do not even index the subject (Lazare, 1987)".

Especially in the oncology field, patient-doctor communication is to be considered a key element to better care and better health outcomes (Fallowfield and Jenkins, 1999). Taking into consideration the time span of an oncology clinician carrier and the number of patients he's seeing over the time, the investment into communication training of doctors is mostly recommended.

"During a clinical career spanning approximately 40 years, an oncologist is likely to conduct between 150 000 and 200 000 consultations with patients and their families. Thus, communication should be viewed as a core

clinical skill that merits a considerable investment of time and resources in training. (Fallowfield and Jenkins, 1999)".

# Life-history and narratives of breast cancer patient in Romania

The impact of doctor-patient communication is explored through single case story, recollection and narratives of female breast cancer patient, 50 years old at the moment of diagnosis, MC. The patient consented to a semi-structured interview on her life-history with breast cancer and the interaction with her multidisciplinary team of health practitioners. The moment narrated by the patients follows the moment of diagnosis and the subsequent medical consults, prior and after chemotherapy, surgery (double mastectomy) and radiotherapy. The patient's life history is condensed in a short, full of medical events year and the availability to recollect the medical encounters that shaped the path to recovery. By education and profession, as a lawyer, M.C. has requested an important amount of information regarding her illness, especially on innovative procedures and treatments. According to (Fallowfield and Jenkins, 1999) women receiving a breast cancer diagnosis would play a rather passive role, but simultaneously demand a large amount of information from their healthcare practitioners. Setting up the relationship based on trust and mutual respect is the key to a better care, according to the findings of "Doctors' communication of trust, care, and respect in breast cancer: qualitative study" (Wright, 2004).

"A doctor who explains to you your illness and he's not reluctant to depict it to you is a doctor who understands the illness and he's not afraid to state it to the patients, he's not afraid to talk to them. For me, this is the main challenge which sets up my relationship with a doctor. After some time in our relationship, I manage to observe the medical results as well - mainly if my illness confirms even if partially the facts I initially found out about from my doctor and if the prescribed treatment is working for me."

According to Wright, a patient with breast cancer would rather be concerned with the doctor's level of expertise, than his communication skills. The priority would be for the medical practitioners to show respect and give their patients the choice and autonomy in the medical decision and compliance to treatment. The autonomy of the patient, according to the study, is the main sign of respect.

"As a rule, from my conversations with my doctor, I am able to pick up whether he is updated with the latest information in his profession, if he is a dedicated medical professional, a passionate one, or he is one of those just waiting anxiously the end of the working day to get out from the hospital. (M.C., life-history of the oncological patient)".

Paying attention to their patient's narratives is crucial to effective and humane healthcare (Charon, 2011a). The aim, according to Charon is to build the bridges between doctors and their patients, "bridging the divides that separate physicians from their patients (...) for respectful, empathic, and nourishing medical care" (Charon, 2011b).

"As a patient with cancer, I interacted with many doctors (a lot of them, actually) who just cannot bear a patient opening his mouth, asking about treatment, especially the revolutionary or experimental ones. I am not sure whether this behaviour is the result of sheer incompetence or they are just fed up with their work and their patients. Whichever the case, I have my serious doubts about their abilities to heal their patients (M.C.)".

## Good communication, bad communication

The mandatory element of building a relationship with the patient is good, satisfying communication (Stiefel and Krenz, 2013). Once established through the exchange of information, the relationship changes how both actors see the illness, once more difficult in a narrowly defined environment as the hospital or in life-threatening conditions like cancer. The importance of quality doctor-patient communication is analysed based on the data from British National Health Service Ombudsman regarding patient complaints on the quality of their medical care (Fallowfield and Jenkins, 1999) showing that the complaints "usually concern communication failure rather than technologically negligent medical practice". What makes communication successful in medical encounters, especially in cancer patients regards the amount of adequate given information, which will be "understood, believed, remembered and acted upon" by the patient. (Fallowfield and Jenkins, 1999)

"There are a lot of doctors I see quite often for consults. My oncologist amazes me each and every time we meet because she knows with great accuracy, in every detail, what my medical record says about my illness, she remembers that I have a family and she inquires me about my family every time we meet. I trust this doctor because I feel she is involved and she cares about me. I am absolutely convinced that this doctor is trying to help me every way she can. She couldn't help herself but hug me when the good test results came in. I also must tell you that she doesn't accept any cash!" (M.C., oncological patient, life history).

Humanizing the medical act is perceived in connection with the humanization of the society itself (Accad, 2001), as stated that during medical procedures in breast cancer "The breast becomes an object, cancer a thing, the person a number. A dehumanized society cannot induce humane medical procedures." M.C., being interviewed for the purpose of the article recollected that patients were often reduced to their tests and procedures. As a single case history, it shows that in most of the encounters she had during her treatment, doctors seemed to ignore the patient's integrity and focus on the biomedical elements of the illness. "The Case Of The Vanishing Patient" (Blaxter, 2009) suggests that patients often "disappear" behind tests, procedures, lab results, and people end up reduced to their illnesses. Professional distancing, expressed by use of medical speech or technical information, appears in doctor-patient communication, which is, as the patient recollects, mostly one-way conversation, as defined by Mildred Baxter (Blaxter, 2009).

"... the doctor that operated on me has no idea what my name was and I found out for sure that he has no clue what's in my file. He's feeding me contradictory information every time I see him. He's operating non-stop, 3 to 4 patients in the morning, at the state hospital, and he does the same in the afternoons, at the private hospital. I accepted him as my surgeon because I knew he had an amazing expertise, he most probably knew exactly his thing during my surgery, this is something that we will find out eventually (M.C)".

# Respect as a pivotal concept in healthcare

According to Wright (Wright, 2004) women diagnosed with breast cancer would rather prefer being given a voice, rather than a therapeutic choice. The freely expressed opinion, thus respect shown to the patient, is correlated with another pivotal concept and trend in modern healthcare, which is patient empowerment and shared decision making.

"However, the option did not equate to choice as this is usually understood (Wright, 2004)".

The Romanian patient interviewed for the purpose of this study recollects clearly that although invited to have an opinion, the result was as if she was invisible.

"On the other hand, every time I have a consult, he has no idea who I am. He cannot stand me speaking to him, although initially, he's the one inviting me to speak, and then he's mad at me because I interrupt him (M.C., oncological patient, life history interview)".

Respect for the patient expressed in the medical ward is a matter of cooperation (Wright, 2004). Listening to the patient's story and observing details is defined in "The Chief Concern of Medicine" (Schleifer and Vannatta, 2013), as respect and honor for the patient's story and for the patient himself. Listening to narratives of illness coming from patients with life-threatening diseases is a form of connection, thus respect, a relationship based on trust and emotional affinity. The narratives of breast cancer women often recollect the pitfalls of patient-doctor communication, therefore connection, as the one of M.C.

"He always seems so unaware of the details. For instance, I just had started my radiotherapy, I already had my marks on my skin, you could clearly see the radiation traces and he kept asking me when in the world I am going to start my radiotherapy. He actually wasn't aware of my physical presence in his exam room, although I was just standing there in front of him. Note that a huge number of patients was waiting outside the room for a consult because he is one of the most reputed doctors! (M.C., oncological patient, life history interview)".

Compassion, alongside humility, is the core concept of the "white coat ceremony" at Columbia (Nussbaum, 2016). The ritual has been adopted in the majority of medical schools worldwide, to symbolize the induction of graduate students to the medical profession. Humanism, as defined by William Osler, whose assertion "it is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself" (Swanwick, Education and Ebrary, 2010, p. 195), sits at the core of medical training, though there are cases where doctors fail in behaving with empathy and humanism towards their patients. The ritual of seeing outpatients in oncology is depicted by the patient herself, describing the details of the failed medical act.

"In the Oncological Institute in Bucharest, it happens that appointments are not scheduled, and I consider it a great lack of respect for the patients. As it happens, you discharge yourself after surgery and you have to return to consult and change of bandages 2-3 times a week. All of one surgeon's patients (around 20 to 30 patients a day) are called in at 8.30, as the doctor comes in whenever he can, which might be after 11.00 as well. It happened to me that once the doctor just went out the consulting room during appointments and just came back after 2 hours, while his patients were still waiting outside the room.

Waiting for hours is a regular thing at the Institute. People are queuing by dozens of daily chemotherapy treatments as outpatients and I've seen people faint while waiting in line. (M.C., oncology patient)".

The neglect of the concepts of shame and humiliation is mentioned by A. Lazare, explaining that both have been massively ignored by the literature (Lazare, 1987). Lazare offers three possible explanations: first, doctors are not taught to inquire on their patient's well-being apart from the treatment they offer, secondly, it is quite difficult to evaluate the shame in patients while trying "to do no harm" and thirdly, neither patients, nor the doctors are largely willing to talk about shame and humiliation.

# Shame and humiliation in breast cancer – life history of Romanian patient

The narrative of the female oncology patient exposing her life history of battle with breast cancer shows that shame and humiliation in Romanian patients go beyond the concept depicted by A. Lazare, being more of a social phenomenon, affecting a large number of patients with cancer.

"Respect is something that you see from the very first encounter with the doctor. The doctor who diagnosed me with my breast cancer is considered a great professional. But during our first consult, I had this distinct feeling that she considers me at least imbecile, that patients generally bore her and are plain idiots because they didn't perform the usual investigations — mammograms, ultrasounds and biopsies at her private medical facility. (M.C., oncology patient)"

Wright's study with breast cancer patients emphasizes that while being interviewed, patients participating in the study focused very little on communication skills of their doctors. Therefore, the study has been organizing around attributes of doctors, as perceived by the patients: expertise, care and respect (Wright, 2004).

The patient interviewed for the purpose of this article recollects her doctor's attitude at the first encounter they had while discovering the mass which was, eventually, cancer. The recurrent word used by the patient, reproducing the dialogue with her physician is "contempt", which results in an unbalanced and shameful to the patient conversation.

"She started dictating to the nurse some medical terms like a nodular mass of some kind and I bluntly asked, 'do I have cancer'?

The doctor's answer is full of contempt 'it's not like I talk about small cysts, no?'

'How serious do you think it is?'

Again, profoundly bothered by my question 'how should I know how serious it is! You need more tests. I don't even know where to start. You might also have metastases, you know, that's how this illness work. You need MRI, biopsies and many more.'

Actually, I didn't have metastases, as proved later.

Apart from that, any other question I might have asked, she just answered like she was bothered by my presence. If she had a question for me, though, I was looked down as if I was stupid, no matter what I answered.

For instance, she asked me whether I had previous cases of cancer in my family with relatives of first and second-degree.

I asked for clarification 'you mean straight lines like parents and grandparent?'

She looked at me in contempt 'it's not like I ask about your husband, no?'

Well, I was asking because I had an aunt with breast cancer and I needed to know if she meant aunts as well. I am a lawyer and technically, the aunt is not first or second-degree relative.

I found out that this was a common attitude toward a patient, treating him like he's an idiot, asking idiotic questions. When a person finds out she has cancer, she doesn't necessarily react very smart, because of the shock. But a doctor has serious issues of communication if he or she cannot take that into account'

# The good doctor

Scientific literature often provides analysis of how patients portrait their ideal doctor, listing the virtues of the healthcare provider (Centor, 2007). Sir William Osler has provided a definition, recaptured in a teaching video addressed to medical students by Robert Centor, MD. "Sir William Osler said," The good physician treats the disease; the great physician treats the patient who has the disease." The great physician understands the patient and the context of that patient's illness. For you, physician readers, take Osler's challenge. Be a great physician. Understand the full story. Make correct diagnoses. Consult the patient in designing the treatment plans that best fit that patient''.

Schleifer and Vannatta (2013) mention that the list of virtues of the ideal physician is provided starting with Aristotle, whose list comprises all the traits of the moral agent.

"Aristotle offers a long— but not exhaustive— list of the virtues of a moral agent. Those that are most fully useful in examining the ethics— and the ethical narratives— of everyday medical practices include competency, conscientiousness, discernment, compassion, trustworthiness, and common decency (as well as *phronesis* conceived as a virtue possessed by a *phronimos*)."

Empathy is mentioned in close relation to the medical profession(Charon, 2012). Empathy, as other skills in the medical profession, can be practiced and actually taught, therefore the literature offers the scheme of practicing empathy. (Schleifer and Vannatta, 2013: 402).

'Schema for Expressing Empathy (from chapter 5)

- 1. Attend to the primary emotion of the patient.
- 2. When an emotion is expressed, explicitly acknowledge its importance.
- 3. When the patient agrees with the physician's identification of the primary emotion, then the physician should legitimize this feeling and empathize with it.
  - 4. Identify the patient's "chief concern" as demonstrated by steps 1-3.
  - 5. Paraphrase the expressed concern to the patient.'

<sup>1</sup> Centor, R. M. (2007). To Be a Great Physician, You Must Understand the Whole Story. *Medscape General Medicine*, 9(1), 59.

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Attending to patient's emotion is quite the last thing described by the patient M.C. in relation to some of the medical personnel from the oncology ward in a Romanian hospital. Here she recollects how her consent was never asked before showing her off as a teaching material for residents. As defined by M.C, the fact that she never consented to a consult, ordered to get undressed with a group of terrified residents, was equal humiliation both to the patient, and the young doctors. A cancer patient is, by the definition from "The Wounded Breast: Intimate Journeys Through Cancer", a person in a weak position, feeling powerless in a medical environment (Accad, 2001).

'I was called in by the professor, who specifically asked the resident to come in with me. When I entered the room, there were some other residents, and he asked them to feel my breasts, not even asking me whether I was ok with that — he just ordered me to get undressed. Once the residents performed the manoeuvres, he started yelling at them for not knowing things, humiliating them and myself, as well. I witnessed how the young doctors were so afraid that they couldn't spell their names if they were asked to do so. And that was not the last time I was treated like teaching material without my consent.'

The literature concerning shame and humiliation of breast cancer patients in particular state very clearly how important the hospital environment is to the patients and how the doctor's behaviour impact a person with a fragile state of mind (Lazare, 1987). Doctors, according to Lazare, have the ability to influence their patients during medical procedures. On the other hand, all patients feel 'frightened, depersonalized and dehumanized' while being examined. Therefore, the healthcare provider's behaviour is crucial to producing an environment where the patient feels cared for and respected (Lazare, 1987).

"It all depends on how he let me down – professionally or personally. If he was a professional disappointment, it is pretty much obvious that I will have nothing to do with that doctor in the future. If he had disappointed me as a human being, I might accept some behaviour, within limits, but I am capable of accepting and moving on. I try to balance the good and bad. It is very hard to find an oncologist who always smiles and behave calmly. We must understand that one working in the oncology ward for years cannot be in his right mind all the time, regardless of all the routine he goes through. I came across with unbalanced behaviour even of doctors whom I care about and with whom I hold a very good relationship. I've seen those reacting badly to patients, especially to those who do not follow their recommendations. But people are very sensitive in oncology, they get depressed from the illness, from the chemo. I've seen people bursting into tears when de doctor raises the voice at them. I myself cried once when my doctor shouted at me just because I dared to ask questions. The cleaning lady came to me afterwards saying that what I did was a mistake, that I should have kept my mouth shut and bow my head. This is what the majority of those patients did. Everybody was shaken with fear and they didn't even dare to blink when the doctor was performing his rounds."

## Conclusions

Practicing the ethics of doctor-patient communication had been a concern, once stated that communication can be taught (Mauksch *et al.*, 2008) (Aspegren, 1999) (Roter, Hall and Katz, 1988) (Schiavo, 2007). In everyday practice of medicine the authors of "The Chief Concern of Medicine" (Schleifer and Vannatta, 2013) offer a simple, yet effective solution to rehearsing empathy.

'We can apply the virtue ethics (...), specifically the schema of virtue ethics embedded in the heuristic phrase: Doctor Dogood Comforts the Crying Child (Decency, Discernment, Conscientiousness, Trustworthiness, Compassion, Competence).'

American and European medical associations joined in the effort of publishing in 2002 the physician's chart 'Medical Professionalism in the New Millennium', the one document that identifies the three principles of practising medicine.

'The charter identifies three principles—patient welfare, patient autonomy, and social justice—and expands them into ten commitments. The commitments are all reasonable—engaging in lifelong learning, being honest with patients, maintaining patient confidentiality, respecting appropriate boundaries, improving the quality of care, increasing access to care, pursuing cost-effective care, appropriately using science and technology, avoiding conflicts of interest, and self-policing the profession—but toothless.'(Meakins, 2003a)

According to the document issued by ABIM Foundation, ACP-ASIM Foundation and European Federation of Internal Medicine, medical practitioners today are subjected to different challenges due to fundamental changes within society, technology and science, and markets (Meakins, 2003b). Frustration is present within medical profession according to Jonathan Meakins, as those changes threaten the core values of the medical profession. Therefore, stating the three principles, although abstract, will guide doctors on their professional path of caring for their patients. There, the fundamental principles are: 1) the principle of primacy of patient welfare, which in Meakins' opinion it serves primarily the interest of the patient, and the doctor-patient relationship is built on positive emotions as trust and altruism; 2) the principle of patient autonomy which resides in the respect that the suffering patient receives from his healthcare practitioner, while honest, informed decision-making process is deeply ethical and empowering; and 3) the principle of social justice, which primarily means the righteous distribution of healthcare resources to patients, which are by no means discriminated based on race, gender, age, socio-economic status, religion or ethnicity<sup>2</sup>. Patient's real expectation of a doctor is guidance to the safe harbor of health, according to Abraham M. Nussbaum (Nussbaum, 2016). Very few physicians are aware of fact that professional associations have joined on their behalf the charter, defined as an attempt to enhance curricula, ideas and initiatives of doctors, eventually regulating their behaviour related to patients. One doctor can choose to engage or to ignore those principles, but he will respond to systems that govern his profession in the present (Nussbaum, 2016). In recent years, once developing as a scientific discipline, Rita Charon was able to distil and emphasize the importance of patient-doctor

<sup>&</sup>lt;sup>2</sup> "Medical Professionalism in the New Millennium: A Physician Charter", 2005.

communication through narratives of illness. Through the stories of illness, sick people would connect to their doctors, who will better understand the impact of the disease and how his patient's quality of life has changed. 'The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others.' In Charon's opinion, if to reclaim a new model of medical practice, the proposed model is the medical act performed with narrative competence, therefore narrative medicine is the suggested path to better patient-doctor communication. Although it doesn't imply that narrative medicine is the one substitution for traditional evidence based medicine (EBM), with an enhanced narrative competence the physician joins his patient in his illness-marked personal journey (Charon, 2011).

While acknowledging that only scientifically competent medicine cannot alone help one patient who is experiencing a change in his health, narrative medicine could help him make sense of his journey, accompanied by his physician with narrative skills. (Charon, 2001, p. 1897)

'Illness is not algebra, but a journey into dark waters. When you are ill, you need a captain.' (Nussbaum, 2016).

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#### Shame and Humiliation of Breast Cancer Patients - Communication Pitfalls...

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