# Breaking Bad News: Different Approaches in Different Countries of Iran and Germany- an Expert Panel

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#### Report

In this expert panel report which was held in Isfahan, Iran, the participants were Carl Eduard Scheidt, Alexander Wunsch, Hamid Afshar, Farzad Goli, Azadeh Malekian, Mohammad Reza Sharbafchi, Masoud Ferdosi, Farzad Taslimi, and Mitra Molaeinezhad. Professor Scheidt was the facilitator and coordinator of the discussion. Therefore, he started it with a brief introduction. After all is said and done, he ended the discussion with a conclusion.

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#### Introduction

The topic is *the different approaches to breaking bad news to the patients in different cultures* (*Iran/Germany*) and what we have heard yesterday was that the legal framework and certain right which define what doctors has to do with the patients and what are not allowed

**Corresponding Author:** Farzad Taslimi Email: dr.ftaslimi@gmail.com to do have differences in different countries.

Also, we have different intercultural background because there are also ideas of religion and of course exceptions which influence on how we talk with our patients and what we are allowed or expected to involve. The idea of this discussion is trying to have exchange of ideas about the differences and the common ground of *breaking bad news* in oncological patients in

Iran and Germany.

We may have a classification on different aspects of breaking bad news, based on different views such as:

- Legal Aspect
- Ethical Aspect
- Cultural Aspect

We should separate these three topics and then, investigate on this in Iran and Germany. After that, we may think about the process of breaking bad news in two countries. For example, in cultural view we are in a transitional mode; because our doctors are gradually being introduced with psycho-oncology perspective. Then, we should study this cultural transitional mode. But, what we study and what we learn as doctors are deviated from legal issues. Legal issues and ethical courses are very close to each other; but they have some differences.

### **Legal Aspects**

**Ferdosi:** In Iran, we are very silent legally. We do not have any initial legal for telling or not to telling to the patients; but something is happening and we are developing some codes. Maybe, we can influence them.

**Scheidt:** Maybe it would be entertained to learn a little bit more about the legal frameworks and ethical thinkers in Germany. I wonder if you could explain a little bit how is it in Germany? Are the legal frameworks entrenching with practice in Germany?

Wünsch: I think the legal framework in Germany is quite clear and it is clearly advocating that the patient should be informed; however, there are also some limitations. For example, in our legal framework, the patient has the right not to be informed; and I think this is quite important in this discussion; but it takes the patient's role in Germany very seriously.

For example, about decision-making in Germany, lots of researches were done in all kind of medical fields like oncology and etc. and researches all said about 30% of all patients do not want to participate in decision making.

**Scheidt:** I think this legal framework also make a program in Germany because as Wünsch said, some people come to us and they do not interested in participating in decision making and also there is an obligation for doctors to inform the patients very extendedly before operation; but side effects and complications might coming up and this obligation can really makes difficulties.

Afshar: Of course, in Iran we have informed content too, for any procedure or surgery, but breaking bad news is another thing.

Malekian: But, may I ask if my understanding is true that even in your country, where doctors are legally obliged to tell the patients about their disease, there still remains the choice for the patient to decide if they like to receive the information at all, by themselves; and that how much and what kind of information they would exactly like to receive? Is this true?

**Scheidt:** Of course as Wünsch said, if the patient wants to know the diagnosis, it is respected. But, you have the problem with treatment, it is difficult to discuss about treatment with him/her. And this would be an open agreement with the law and family to participating to make decision?

Malekian: Of course we also have legal barriers against not to get the patient informed. So, maybe the legal codes would be a useful starting point. There are conflicts between different legal codes which should be addressed. For example in medicine, we have the privacy issue as a popular ethical principle as well as a known legal code. On the other hand, we do not have a code to advocate disclosure of bad medical news to patients and we have at least one legal code against it. Then, what you see in our practice cannot be in accordance with legal codes. I mean, here almost all doctors tell the cancer diagnosis first to the family; this is true about even those few doctors who intend to tell it then to the patient. This is in opposition to privacy code. Yet, patients generally do not claim legally against the doctor for their broken privacy. Some do not know about their rights, some see it natural from a considerate doctor; some others avoid legal claims not to make their family disturbed.

There are researches which show that the majority of Iranian patients like to receive medical news, including bad ones, by themselves. Other surveys show most people in general setting had told they wanted to receive bad medical news by themselves in the case they got cancer. There are also studies which show the discordance between what Iranian doctors believe as to be better for their patients (that is mainly not to tell) and what patients believe is better for themselves (that is to be told). So, when people preferences is so similar to that of the people of world's other parts. I think clarification of legal codes might be a better starting point to make the discordance decreased.

### **Ethical Aspects**

**Goli:** In such clinical situations, we always encounter with an ethical dilemma between the no-harm and the autonomy principles. Without any education in this issue and guideline, Iranian physicians manage these problems based on their individual traits, values, and experiences.

More duty-oriented and less empathic physicians usually do not stay ambivalent. Based on some autonomic beliefs, they straightly pass the buck to the patient and even sometimes inform her/him of some unnecessary statistics and all the possible complications. In my practice, I can remember at least two cancer survivors who even after having been treated successfully, still suffered from the trauma of such catastrophic informing of their illnesses.

The more empathic physicians are more sensitive to patient's hope and their psychological wellbeing. They think more about the way they can communicate bad news. In my experience, they prefer using implicit and indirect ways. They usually engage patient's family and relatives in the process of communicating with the patient. They emphasize more on no-harm principle and believe that if we, as physicians, can protect patients from such allosthatic load and lead them implicitly through their treatment procedure, they can save more of their vital force and be resilient in their life and fighting with cancer.

Wünsch: I would like to add some information about the history of communication. For example, in Germany patients would not informed about diagnosis maybe about 30 to 40 years ago; like about 50 years ago, there were no treatment options; but now it is changed. There are many treatment options and in Germany and many western countries, there is a right that every patient should be informed. However, we all have bad experience with that; and even we had bad experience with some patients had something like a trauma after they were being informed.

That was the reason the communication become more and more important to inform the patient in the way that is not traumatising. It is very important when you disclose a bad news that is depressing and distressing to the patient even with the best treatment options; but we hope to avoid this bad experience of our patient. So, not only the information but also "how" to tell them is important.

### **Cultural Aspects**

**Taslimi:** I think we can look at this topic biopsychosocially. For example, from biology aspect, is the patient at the end stage of illness? What is the psychological state of him/her? From social point of view, we should notice to the cultural delicacies and transpersonal relationship manners. For example in Iran, sometimes there is a benefit to have a cancer or an illness. For example, when a grandfather could not see his family for a long time, it could be an opportunity or a chance for him when his families come to visit him, when they hear about the grandfather's cancer.

So there is a hidden benefit in "having cancer". However, he is suffered from the illness; but this situation could lead to a good

benefit which is gathering the family together as a social value. As we are discussing intercultural, in Iran most of the patients especially old uneducated ones- do not decide by themselves. In fact, the family decides for them and decides what to tell or not to tell about the patient's illness. It means that the role of family is very important in our culture and should be applied in treatments protocols.

For example, they ask the doctor not to tell the name of "cancer" to the patient, because they believe he or she could not tolerate that; or they ask doctor not to prescribe chemotherapic medicines for the patient, because it would be very depressing to lose hair for him/her. I think from this point of view, through comparing social values, we can evaluate the differences of these two cultures.

And about the spiritual aspect of this topic, I think in Iran when the religious bases are stronger, like in some religious families, people attach the reason of the illness to some spiritual believes. For example, the reason of an illness in a patient is the reflect of what he/she did before; or sometimes it is known as a part of his/her destiny and sometimes it helps them to face more easily with their illness. But in nonreligious families, because of attenuation of spiritual believes, facing with the problems such as illnesses are a little different.

Sharbafchi: I think in our health system, the cultural background is very important to decide if the patient have the right to hear bad news or not. In many studies, when we ask the doctors they should say to the patient that he/she has cancer or not, about 60 to 80 percent answer that it should be said. And this is the same in eastern and western countries. The remained 20 to 40 percent, who do not agree with trough telling, mainly are who have less experience in palliate care settings; but finally in practice, they act according to the health system rules. In our health system, we have no legal or ethical codes for breaking bad news and the doctors influenced are mainly bv cultural background; so, most of them may not tell

the truth to the patient completely.

Molaeinezhad: I agree with friends' discussions and I want to add a few points to see these topics in three forms of the cultural scenario of interpersonal and intrapersonal relationships. And during a qualitative exploratory study, we will find these cultural scenarios that govern the rules of human behavior in society. Because every individual, regardless of the therapist, is also affected by these cultural scenarios when it comes to bad news or faces a sensitive subject, such as cancer. For example, in some cases, severe suffering may be interpreted as a way to clean up or punish previous individual's sins. It is a cultural scenario that may affect the individual therapist and the patient and the surrounding people and refer to their interpretation of the situation. Therefore, even interpersonal relationships may also be affected by this cultural scenario and similar scenarios, and affect the patient's individual behaviors, follow-up treatment, and the detection of illness and help from others and therapists. All these can be discovered in a qualitative exploratory study that can possibly be done in a narrative way. Then, in the next step, the ethical code can be extracted by considering the qualitative stage outputs.

**Goli:** In our culture, covering the shortages and faults are received as a spiritual value because Allah is concealer of faults (*sattaraloyoub*). In my opinion, some misconceptions around this religious belief empowered more passive and implicit coping strategies and denial defenses.

There is a common latent agreement between patients, family, and doctors that they prefer skipping confrontation with death and the other existential experiences. I think in Iran, especially in the traditional subcultures, this trend is more dominant. I have had many cases that I am sure he/she knows his/her problem but deny it and even when everybody plays their helpful role, they are in a deep grief in their inner worlds.

Sometimes both the patient and his/her family, without showing it to the patient, are

aware of his/her critical situation; but they choose such a paradoxical way of coping to protect their family and to keep their lively atmosphere.

For me, as a therapist, such conditions are profoundly complicated and confusing. Should I explode this pink bubble in order to rescue them from their loneliness and paradoxical cathexis? Or is it better to respect their choice or to try to lead them to a more authentic and confrontative way of coping? We know that the patient and family lose many of their opportunities to integrate their narratives and to do their best for healing and personal development.

This strategy, in addition to suppressing active and confrontative coping of patient, forms alliances between relatives and also with their care-givers and induce some sort of isolation and alienation to the patient. Patient percepts some annoying whispering around him/herself. This makes him/her feel deeper loneliness.

**Scheidt:** I think this is an important point that religion helps patients to coping better with problem.

Wünsch: If we ever think about new recommendation, it is better to invite other religious persons; because they are important in the skills and we should ask them to come and answer about future. It is an extensional philosophical topic and they can add some their experience to the topic.

Malekian: We have some relevant religious rules. Indeed up to around ten years ago, we were banned from any prognosis communication due to Islamic rules. Men of religion at that time had a consensus over the matter that giving patients any estimation about their death time is "Haraam", (i.e.: absolutely forbidden religiously); so, there was no discussion and no training. Around ten years ago for the first time, some of the religious men started to comment otherwise (as a result of doctors' and patients' questions and discussions). Thereafter, some of them recommended to tell the patient about prognosis in limited situations on patient's

insisted and practically justified requests and when it is surely for patient's interest; there was also a recommendation about providing a broad estimation not a time-point as well as adopting a never-certain attitude and not a clear-cut answer.

**Taslimi:** I think one other point is religious belief of people. The people who have more spirituality in their life, it is easier to tell them bad news.

#### Process of breaking bad news

Afshar: I think the method of communication for telling bad news is very heterogenic in our setting and depends on personality of the doctor. Some oncologists have good ability to communicate with their patients and some of them never try to have communication with them. They already visit the patients and prescribe medications and sometimes they are very harsh at their practice. I think they use mechanism of isolation to separate themselves from painful situation. I see many oncologists who completely separate themselves from the atmosphere of this situation. They visit 60 to 70 patients in a day. So, little by little they should minimize their emotions to separate themselves and the communication will change little by little. They usually try to refer patients as soon as possible to the psychiatrist, psychologist, or psycho-oncologist. I do not know if there is any guideline that could be used in practice for oncologists or not?

Wünsch: Maybe I can add something about this discussion in Germany. Many surgeons in Germany do not like to talk about that and they say we are surgeon not psychosomatist or psycho-oncologist; and we do not like to discuss and go to them to do that. But in Germany, it is not legal. It is up to the physician breaking bad news and does it in a way that is not traumatizing. This is a talent. Many physicians do not have time for extensive interviews for being empathic. In my opinion, they should have some communication skills and they should be able to breaking bad news in 7 to 10 minutes with details. **Scheidt:** I want to add something could address one or two more other issues that came up in the discussion. One is what would you think about what patients hope for? Or into which direction should go? And the second question is what do doctors hope to which direction should go?

Malekian: I think the starting point cannot be like training etc. Iranian doctors do not tend to change the way they are dealing with bad news. Getting trained in communication skills will not readily make a big difference. There are problems like time issues, and not being paid for longer sessions. It remains an over-demanding task to the busy oncologists to communicate bad news and to consider patients emotions etc.

If convinced as to be beneficial in the long run, I think we need to start acting legally to get things changed. Maybe even if German doctors could be asked whether they would choose to communicate bad news if there were no legal considerations, many of them would say no and wish they could escape such a demanding process to break bad news.

**Taslimi:** In Iran, the oncologists have not enough time to explain about bad news and you said in Germany this duty is on the shoulder of general Physicians. Absolutely, it is not possible to have a special part in our health system to tell bad news to the patients; because it will be very horrendous for a patient when he/she is asked to go there. So, I think the best way is to train our general practitioners to learn how to tell bad news.

Afshar: According to my experience during 20 years, the most important part of this problem, not only in oncology and psycho-oncology but also in other parts, even breaking news about other's disease is very dangerous. Most of the doctors have not enough ability to communicate, even about a doctor who wants to tell about diabetes to the patient and give information and reassurance; or maybe they have not enough time or interest to communicate well and sometimes not enough education.

Scheidt: But, maybe this is a good point

that you opened which also include other specialties. Some discussion is about that is it necessary to use the word "cancer"? Or can we use other word? Because, it has horrified implication for the patients and the association with the word "cancer" is negative as here.

Wünsch: In Germany, it repeats clearly that should be addressed with cancer. It should not be tumor; it should not be neoplasia; it should not be carcinoma; it is cancer. Some patients do not know the other words. So, it should be clear. For example, the patient who had lung cancer which name was small cell carcinoma, and he thought it is a small problem. To prevent such problem, it should be clearly named cancer.

Our lecture is also very important to adjust the meaning for the patient; what does it mean to the patient? What are the consequences to the patient? And in my opinion, you should do explain the meaning of what you say it cancer or tumor or neoplasia or whatever.

Sharbafchi: Sometimes when we tell the patients that "you have a brain tumor", they accept it more easily and say "so I have tumor not cancer"!

Malekian: I think that something similar has been getting happened over the time. I mean we are gradually becoming more similar to each other. For example, in the case of breaking bad news, about 30 years ago it would seem so natural to any of us who are sitting here to see a mother is withholding his son from receiving bad news of his father's death telling: "your father has gone to a very long trip". While nowadays, I guess, most of us here would readily agree we would better do such a thing differently compared to what was acceptable to us in the past.

Also, there are more and more people who tend to see receiving the bad news related to their disease as their rights. More and more people who say: "it is my right to know and nobody has the right to withhold from me the information which belongs to me".

The main concerns of doctors, both who

agree and disagree with giving bad news to patients, think is the Ι а good communication. If you could convince oncologist that what you mean by giving bad news is not simply (and some harshly) doing that, but you are intending to do it for the patient's own interest and well-being, most of those who disagree would agree. When talking about letting patients know they have cancer, many oncologists disagree because they assume you mean doing it in the same way it is being done by some of their colleagues at present that is some harshly. But, if they knew in detail how you would assess the patients' information, preferences, and preparedness, and if they

could trust you know how best to do it, to prepare the patient and many things else, they would get relaxed and agree.

## Conclusion

There is a clear common ground in Iran and Germany and probably in most countries in the world that we want to act in the interest of the patient. Also, we are interested in helping and supporting the patients but the way how we do that may differ between two countries, culturally and legally. I think we should come to the end of discussion and I think maybe we could make a transcript of this discussion and we can see what we have done together. Thank you very much.