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ORIGINAL ARTICLE

Cancer patients' needs for virtues and physicians' characteristics in physician-patient communication: a survey among patient representatives

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Abstract

Background Data on patients' needs with respect to physicians' ethical behavior and virtues are important but not available in most cases.

Patients and methods In an iterative process together with patients' representatives, we developed a standardized questionnaire which was distributed to the representatives of the Women's Self-Help after Cancer in Germany. We started with the classical ethical virtues and clustered them to characteristics. The patients' representatives were asked to rate in different communications settings.

Results One hundred eighty-six patients' representatives took part in the survey. For four communication situations (first communication on symptoms, diagnosis of cancer, choice of therapy, doubts on therapy), competence was rated as very important by 80–89% and as important by 6–7%; honesty as very important by 78–89% and as important by 5–12%; respect as very important by 66–71% and as important by 19–21%; and patience as very important by 55–68% and as important by 6–24%. Compassion was rated as less important, with only 24–31% rating it as very important and another 26–32% as important. Additional desires expressed by the participants were physicians having more time (9.1%) and a better relationship between physician and patient (7.0%).

Conclusion Competence, honesty, respect, and patience are important characteristics which should be focused on in communication training of medical students and physicians. In spite of compassion being rated as less important, training on compassion/empathy might help doctors to improve coping with the continuous confrontation with complications, progress, suffering, and death of their patients.

Keywords Breast cancer · Ethical considerations · Patient needs · Virtues · Physician-patient communication

Introduction

Ethical issues are an important aspect of the work of physicians in cancer care. Yet, ethics are mostly discussed within the perspective of the whole health care system with most urgent topics being lack of resources with staff shortage or shortage of money.

In fact, ethical issues are important in the direct patient-physician relationship with communication being the main direct interaction of both partners. In many countries, efforts are made to offer communication skills training for medical students as well as physicians.

Patients want to be treated as individuals with unique properties and not as numbers among innumerable others. They expect to be met on an equal footing, to be involved in the

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decisions of their treatment, and to have good reasons to trust their doctor's judgment [1]. The physician should take time for detailed conversations, repeat important information more than once if needed, clarify doubts, and consider the patients' mood and state of mind [2]. Many patients anticipate that the optimal therapy does not mean to prolong their life at any costs. Therefore, a thorough weighing of pros and cons should be the fundament of any decision [3].

All those expectations are based on a basic trust that patients have in their doctors [4, 5]. The levels and reasons for this trust are diverse. The physician's profession is valued due to its high education and for the altruism being an essential part of the professional conduct. Among others, these attributes are the basis of a long tradition of an overall positive reputation doctors have in society [6]. Because of the complexity of modern cancer therapies, the patient has to entrust himself to the doctor in a situation of serious or even life-threatening disease. Moreover, he has to trust in the doctor treating him free of judgment with the only intention to achieve the best possible treatment. Accordingly, he has to trust that the doctor acts free from any conflicts of interest and focuses on the best possible solution for the individual [7].

Yet, with increasing lack of resources restrictions to physicians' autonomy in decisions are rising. There are several reasons why these restrictions might become even stronger in the near future. Rising expenditures for diagnostics and therapy lead to an increased demand for resources [8]. Moreover, the demographic change leads to an older population requiring more medical resources. Lack of time on the part of the physicians more and more affects the patient-doctor relationship in everyday life. Often, dedicated care for each individual is unrealizable due to the lack of personnel. The lack of time leads to stress and dissatisfaction among the medical staff who may not exert their job with the desired diligence [9]. From the side of the patient, this may lead to more efforts to get their "rights" (making them appear a nuisance to the physician); on the other hand, it may lead to disillusion and surrender to a "system" they feel delivered to.

In order to help physicians to understand the needs of their patients with respect to communication and the professional's behavior, we developed and conducted a survey on patient advocates focusing on virtues and ethical behavior within the patient-physician relationship. Answers to these questions might help improve the individual relationship but also might give some hints on how to improve cancer care in times of restricted resources.

Methods

This study is comprised of two parts: a pilot phase and the final study.

The aim of the pilot phase was to gain a first insight into patients' thoughts on virtues and physicians' behavior. We developed a first questionnaire and asked female patient representatives attending a meeting on physician-patient communication to answer them. It contained six questions. The first one was an open question about their thoughts with respect to "virtues in medicine" in general. In the second, they were presented a table containing a list of virtues which should be rated for their importance in daily life. The virtues were derived from the philosophical literature by compiling virtues from very different concepts Plato, Aristotle, the Romans, and Christianity (Catechism of the Catholic Church), and comprised as follows: smartness, justice, bravery, moderation, faith, hope, judgment, decision competence, fairness, courage, measure, compassion, trustworthiness, insight, integrity, love, conscientiousness, generosity, friendliness, and respect. In the third part, the patients were asked to write down a short statement for each of those virtues with respect to cancer care. Additionally, they were asked whether they could think of other virtues that might be important for them. The last two questions where open questions about the topic in general and whether the participants liked the test or not. As a result of this pilot questionnaire, we learnt that the participants were not able to rate the virtues in the abstract setting of cancer care (see below in the results section).

In order to get a more precise setting, we designed four different typical situations in the patient-physician communication:

1. You talk with a doctor about your symptoms/problems for the first time.
2. The doctor talks to you about your diagnosis and informs you about your disease.
3. You need to choose, together with your doctor, between several therapies.
4. You talk to your doctor about your doubts in the therapy and that you are thinking of aborting it.

Furthermore, we decided to cluster the virtues according to their meaning in the physician-patient communication. Two of the authors (MB and ES) independently clustered all virtues; differences were discussed. The final result of five clusters was send to two other authors (IR and JH) who proposed characteristics of the physician's behavior during a communication as terms summarize the virtues. The clustering and the terms were discussed with four representatives of the "Frauenselbsthilfe nach Krebs," the biggest women self-help group for cancer patients in Germany. Finally, five characteristics were used for the questionnaire:

1. Compassion
2. Competence
3. Honesty

4. Patience
5. Respect

The importance of these characteristics should be rated for every situation. The participants were asked to assign a mark from 1 to 5 with 1 meaning "not important" and 5 meaning "very important" for every characteristic in each situation. Additionally, there was one blank box in which participants could add another characteristic that they felt was missing. In a second part of the questionnaire, two open questions asked the participants to add general thoughts on the topic and to give feedback on the questionnaire.

This second version of the questionnaire was sent to the 6 members of Federal Executive Committee of the "Frauenselbsthilfe nach Krebs," the biggest women self-help group for cancer patients in Germany.

As the second version was well accepted and rated as adequate by the patient representatives, the questionnaire was handed out at the annual meeting of the group leaders of the "Frauenselbsthilfe" in September 2016. This annual meeting is attended by about 600 women, all being patients with breast or gynecological cancer.

Ethical vote

According to the rules of the ethics committee of the J.W. Goethe University at Frankfurt/Main, no ethical vote was necessary.

Statistics

We used SPSS version 24 to assess the answers. For correlations, the chi-square by Pearson was used, considering $p < 0.05$ as significant.

Results

Pilot study

All in all, 17 patients participated in the pilot study. Only six returned the questionnaire while eleven stated that they felt overstrained by the list of virtues. From the six patients who returned the questionnaire, we got a rating of the importance of some of the virtues in their daily life, none filled in the free-text field for question 1 (own thoughts on ethics in cancer care). For question 3, some patients commented on which virtues they esteemed as important, some added examples from patient-physician interaction. Yet, most patients did not fill in this field at all, a few commented on 1 to at the most 4 virtues.

Main study

A total of 186 patients' representatives returned the questionnaire.

Ranking of the characteristics

Situation 1—You talk with a doctor about your symptoms/problems for the first time This question was completely answered by 175 patients (94.1%). In this situation, the vast majority thought was important or very important (84.4% and 5.9% resp.) that the physician shows competence. Honesty was also considered as very important by most participants (78%) or important (12.4%). Respect was ranked as very important by 66.7% and important by another 19.3%. Also, patience was considered as very important by more than half of the group (55.4%) and important by an additional 28.5%. In contrast, compassion was considered as very important or important by a quarter of the participants (24.2% and 26.3% resp.).

Situation 2—The doctor talks to you about your diagnosis and informs you about your disease This question was completely answered by 179 patients (96.2%). Competence and honesty were the most important characteristics when speaking about the diagnosis (very important competence 89.3% and honesty 88.7%). Respect and patience were the virtues following in the ranking as very important or important (respect 66.7% and 20.9% resp.; patience 65.1% and 22% resp.). Again, compassion was considered much less important than the other characteristics (very important 25.8% and important 32.3%).

Situation 3—You need to choose, together with your doctor, between several therapies This question was completely answered by 177 patients (95.2%). Competence was rated as the most important characteristic (very important 87.1%, important 5.9%). Honesty was very important to 85.5% and important to 5.4%. Patience was the second most important characteristic for the participants. It was thought to be very important by two thirds (66.1%) and important by a fifth (21%) of the group. Respect was rated similarly (very important 65.6%, important 24.2%). Only 25.8% voted very important and 26.3% important for compassion.

Situation 4—You talk to your doctor about your doubts in the therapy and that you are thinking of aborting it This question was completely answered by 176 patients (94.6%). Competence and honesty showed almost identical importance to the participants. Competence was very important to 80.1% and important to 8.6% while honesty was very important to 81.2% and important to 9.1%. Respect was also quite important in this situation. Seventy-one percent thought to be very

important and 18.8% said it was important. Comparable ratings were given for the characteristic patience (very important 67.8% and important 15.1%). Compassion was again least significant for the patients. It was very important to 30.7% and important to 28%.

Free-text answers

1. A total of 114 respondents, which is 61.3% of all participants, used the possibility to express their own thoughts about the questionnaire and the importance of the topic. All of them stated that they thought the questionnaire to be important. Many of them addressed problems or wishes they have experienced as individual patients. Three desires were addressed by several participants in a more abstract description. Seventeen participants (9.1%) expressed their desire that physicians should have more time for them and their problems. They expected the doctors to take time and listen to the patients when they talk about their symptoms or doubts concerning the disease or treatment instead of losing interest and patience. Many of them felt this way and think it should be improved.
2. The desire for a better relationship between the physician and the patient was expressed by 13 participants (7.0%). During communications, they expect doctors to be met on an equal footing. A similar need was expressed by ten participants (5.4%), who asked for a demeanor of doctors which is more humane. Some of them felt they were only seen as a medical case instead of a human being. In this context, the participants asked for more empathy and appreciation.
3. A total of 12 participants (6.5%) expressed some troubles with the questionnaire as they felt all the characteristics which were suggested in the situations should be a natural part of communication for every doctor as it should be for every person. Many of them felt that doctors should be reminded of those characteristics, as they are crucial for their job. The lack of those characteristics was described as a serious problem in encounters with some physicians.

Discussion

The patient representatives ranked most characteristics as very important or important in all situations of physician-patient interaction. More than 80% of the participants agreed in these characteristics being very important or important. Compassion was the only characteristic that sometimes was rated as important by less than half of the participants.

To underline the importance of all the characteristics, one of the most frequently expressed thoughts in the free-text section was that all characteristics should be regarded as a regular frame in every physician-patient communication. Moreover, the participants pointed out that these characteristics also describe desirable "normal" behavior of human beings and not only of doctors.

Additionally, we were able to identify three requests of the participants. They are "more time," "act more humane," and "better relationship between doctor and patient." This need is reflected in the demand for more patience. Yet, these two notions address two different actors. While patience is addressing the behavior in the concrete physician-patient interaction, more time addresses structures and processes within the health care system. Although searching for solutions to improve cancer care should address both of it. In an economically driven health care system, incentives to improve communication might mean to increase reimbursement of time spent with the patient. Due to the lack of physicians and their higher incomes, nowadays, nurses are trained to interact with the patient and to take over communication tasks. Yet, our survey as well as others [4, 10, 11] and surveys we did in different settings [12–14] clearly showed that this substitution is no solution for the patients' needs.

The participants' choice of patience might be the solution, as it is not only more time spent for the communication but also more quality in interaction. Physicians may show no patience in spite of spending enough time with the patient so they should be patient with their patient and take time to some extent. Patience could mean more listening than talking, realizing, and respecting patients' worries and fears (as well as expressing this respect) and accepting the desire to take time for decisions. All these aspects should be realized even within a dense time table.

Another important characteristic which mostly independent from time is honesty. Especially when dealing with cancer patients, honesty can be difficult for doctors because of the unpleasant experience of breaking bad news. Nevertheless, even in this demanding situation, honesty has shown to be of great importance for the patients in several studies [15, 16]. Dishonesty may not only be due to avoidance of unpleasant communication situations but also arise from physicians refraining from a full disclosure of all side effects in order not to risk adherence. Yet, adherence is worse in case of side effects arising without former discussion [17, 18] and seemingly considerate communication results in a worse adherence [19]. For some physicians, honesty might seem to be in conflict with acting humane. By withholding important information, physicians hinder patients and their families to prepare themselves for the future.

At a first glance, the low ranking of compassion seems astonishing. Compassion clearly is ranked less important as the other characteristics. While designing the questionnaire, we had some discussions with the representatives of the self-help organization about this vocabulary. In fact, our first idea was to name it empathy. The representatives opposed to this, as they were not sure if all participants would understand the

word. Compassion and empathy are two different attitudes, the one being more professional and one for understanding the patients' situation and their emotions [20]. In contrast, compassion describes an own emotion, feeling pity for the patient. The low ranking of compassion shows that patients do not want the physician to suffer with them. Compassion in cancer care could be demanding and might quickly be exhausting for the professional dealing with cancer patients every day. Moreover, compassion might hinder an expert judgment and make competence and honesty more difficult. Yet, from our questionnaire, we are not able to tell the patients' opinion with respect to the characteristic of empathy as we do not know how many of the participants knew about the two different concepts. All in all, with patients asking for more humane attitudes and patience, empathy might be a concept for skills training that would help doctors and patients to communicate on an equal footing.

Even though the vast majority reacted positive to the questionnaire, there were also people who felt contrary. Many of them expressed disillusion, disenchantment, and frustration with their doctors. Most important, this disillusion did not result in these patients expecting less respect than the other patients did. The ratings for respect in the group of disillusioned patients were almost identical with the whole group. This might indicate that those patients still have hope that things could change into positive. It might be important to stay in a professional position towards those patients' negativity and put much effort into treating them with the respect they deserve.

There are several limitations of our survey. First of all, we only may estimate the return rate as we do not know the exact number of participants (187 from about 600 being about a third). Moreover, we did not use a validated questionnaire because it does not exist one for this setting, as we know. Furthermore, we did not ask the participants for demographic data. From the statistics of the self-help group, we know that the participants represent all regions in Germany with diverse socio-economic backgrounds. We do not know whether this diversity is also true for the participants. Most women in this self-help group have breast cancer or gynecologic cancer. As a result, it is unknown whether our data may be also valid for male patients and patients with other types of cancers. Yet, it does not seem to be a strong argument to expect completely different results from patients with other types of cancer. Moreover, recall bias could be a reason for similar results in the four different situations as participants may not have been able to exactly recall their experiences in these different situations. Finally, the questionnaires were handed out at a meeting of patients' representatives; all participants were experienced patients who had a long history and training of interacting with doctors. Accordingly, we may not generalize to "normal" patients. On the other hand, those women are highly experienced and in close contact with members from their groups. Yet, with respect to socio-cultural diversity, our collective may be rather homogenous thus lacking transferability to patients from non-Western cultures or non-Christian religion. Patients with low (health) literacy may be under-represented in our study.

Conclusion

Respect, patience, compassion, honesty, and competence are desired characteristics from a physician attending cancer patients. These patients also wish for more time, a better doctor-patient relationship and doctors who act more humane. To sensitize young doctors to these issues could help to meet patients' expectations. Students as well as physicians should be trained on how to realize these issues in their daily work. Moreover, ethical issues with respect to individual patients' care have to be discussed urgently within the health care system.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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