



Postprint Version	1.0
Journal website	http://www.pec-journal.com/article/S0738-3991(13)00017-7/abstract
Pubmed link	http://www.ncbi.nlm.nih.gov/pubmed/23395286
DOI	10.1016/j.pec.2013.01.005

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What patients want

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ABSTRACT

Objective: Although most health care professionals implicitly or explicitly will assume that they tend to use patient-centered communication strategies, there are reasons to believe that this might not always be a valid assumption. In everyday practice, professionals' own value system is often the dominant steering guide. This Special Issue aims to bring together ongoing research and reflections about the quality of health care communication from the patients' own perspective. In short: what do patients want?

Methods: This introduction presents a comprehensive overview of the papers in the special issue of *Patient Education and Counseling* within a framework that describes the collected papers according to the six functions of medical consultations, taking account of the studies' applied methodologies: quantitative versus qualitative.

Results: Two functions of the medical consultation are strongly represented in the collected papers on the quality of communication from the patients' perspective: 'fostering the relationship' and 'information giving'. There is a remarkable difference between the qualitative and quantitative studies, showing that if patients are not limited to prestructured questionnaires but completely free to express themselves, they tend to focus on 'fostering the relationship' with an emphasis on personal attention, warmth and empathy.

Conclusions: Patients' needs and preferences for personalized and humane medical care cannot be overestimated. For the rest, patient diversity is striking, showing the limited usefulness of general communication guidelines for the

other five functions of the medical consultation. Researchers should be aware that patients' views might be different dependent on the applied methodologies.

1. INTRODUCTION

In the shifting scene of patients' advocacy for centuries, doctors have considered themselves to be the patient's best advocate. Without reflecting too much or too critically on their own role in the medical process, they did their work based on a firm belief that everything they did was always in patient's best interest. This started to change when other disciplines entered the medical arena with their research and teaching activities. In the seventies, sociologists, such as Freidson [1] and Illich [2] unveiled the doctors' dominance and the power struggle that sometimes takes place in medical consultation rooms. They showed that the interests of doctor and patient may not always coincide. The thousands of citations to their work demonstrate that their then controversial view on the medical profession touched a raw nerve in many people.

Moreover, with the growth of medical knowledge and technology, it became clear that the patient's voice is not automatically heard when doctor use their conventional way of communication, which used to be characterized by structured history taking. As a reaction, medical psychologists became involved in medical education and showed doctors that listening to the patient might be more effective than asking questions in the diagnostic phase [3]. Communication training programmes were developed, initially inspired by Carl Rogers' concept of unconditional regard, with its emphasis on providing space for the patient, active listening and showing empathy [4]. Patient-centered medicine became the new buzz-word, and was defined by Henbest and Stewart [5] as 'care in which the doctor responds to the patient in such a way as to allow the patient to express all of his/her reasons for coming, including symptoms, thoughts, feelings and expectations' (page 28). Note that in these early years the emphasis of communication training was on the first part of the medical consultation, when the agenda still had to be made.

Fairly recently, the scope of most communication skills training has been broadened to incorporate the second part of the medical consultation, where treatment decisions are made and implemented [6]. Parallel to these conceptual developments, the training in communication skills itself became more comprehensive, covering all relevant functions of the medical consultation: (1) fostering the doctor-patient relationship (2) information gathering, (3) information giving, (4) (shared) decision-making, (5) strengthening patient self management and (6) attending to emotions, as presented by de Haes and Bensing [7]. In the meantime, a new generation of professionals stood up as patient advocates. This time the psychologists, nurses and doctors who were involved in teaching communication skills were the ones who claimed to know what patients want. The question remains whether these professionals indeed are better patient advocates than doctors are.

2. TIME TO LISTEN TO THE PATIENTS' VOICE

The idea for this special issue of *Patient Education and Counseling* was born during a scientific meeting in Verona, where professionals had a fierce debate on what patient-centered medicine really is. The guest-editors of this special issue were listening to this discussion and asked themselves the logical but unspoken question: where is the patient in this debate? What do patients themselves really want?

Professionals claim to be the patients' advocate, and maybe they are. But why don't we give patients a voice for themselves. This special issue shows that patients DO have a voice. Patients DO know what they need and want and are well able to verbalize their needs and preferences when invited to do so. In this special issue it also shown that there is not one patient voice, but there are many voices which sometimes sound in tune, but often have their own musical chords. The variety of their voices resonates in this special issue, and colors the debate on the quality of medical communication. We want to invite the readers to listen carefully to what these voices have to say.

The six functions of medical consultations [7] seems to be a useful instrument to show patients' needs, preferences and problems in medical consultations. The first impression which catches the eye after a global view on the papers in this special issue is that not all six functions are equally covered in studies on the quality of communication from a patient perspective: the functions 'fostering the relationship' and 'information giving' are ample present, while the other functions' seem to be underrepresented. This means that for the 'younger' functions in medical communication research, such as (shared) decision making' and 'strengthening patients' self management, patient-based studies are still in their infancy. A nice exception is Thorne's et al. study, which shows, in an oncological setting, that the now dominant ideal of shared decision making should be balanced carefully against patient preferences [8].

The second interesting finding is that although by far the biggest part of medical consultations is spent on information exchange [9] for patients, communication clearly involves much more than question-asking and information giving. The quality of the doctor-patient relationship and the emotional tone of the medical consultation seem to be very important from the patient perspective. Many papers in this special issue address this topic from different angles and in different patient groups. There is, however, an interesting difference in emphasis on the various functions of the medical consultation, dependent on the study's methodology. In particular a difference has been found between the quantitative, survey-based studies and the studies in which qualitative methods are used, such as focus groups or in-depth-interviews. In their review study Deledda et al. [10] show that in most quantitative, survey-based studies information exchange plays a prominent role, while the focus in qualitative studies is mainly on the function 'fostering the relationship'. Apparently, as soon as patients or lay people get the chance to talk in their own words about health care communication, there is an emphasis on the affective side of medical communication. What is perhaps even more interesting, is the fact that the content of

the papers in this special issue show the same general pattern. In the qualitative papers, the focus is mainly on the effective side, in the quantitative studies, information-giving is a prominent topic.

3. FOSTERING THE RELATIONSHIP

Many of the qualitative papers in this special issue have been performed in oncological settings. Unanimously these show the importance of a good doctor–patient relationship. Walczak's et al. [11] paper focuses on the patient perspective when discussing end of life issues. The authors show that talking about acceptance, readiness and adjustment to the inevitable situation may assist patients in helping to plan care, achieve more control and enjoy an optimal quality of life. The patients of this study stress doctors' communication skills and the necessity of a therapeutic doctor–patient relationship as crucial factors in facilitating these discussions [11]. The same point is demonstrated in Thorne's qualitative study among 60 cancer patients, who pointed to patients' main considerations in cancer communication: tone and setting of the consultation environment, the attitudinal climate of the consultation, the specific approach to handling numerical and statistical information, and the critical messaging around hope [8]. That hope can have many faces was shown in another qualitative study among breast cancer survivors and healthy women by van Vliet et al. [12], who – in focus groups – discussed two well-known dilemmas in oncological care: how to balance explicit with general, and realistic with hopeful information at the transition from curative to palliative care. It turned out that 'hope' does not seem to be restricted to the miracle of surviving against all odds, but can also be found in the (reassuring) perspective that you won't be abandoned by the medical staff, when the time is there. Together with honest medical information and the space to choose, these are the most important issues for breast cancer survivors and healthy topics alike.

This brings us to the topic of trust which was mentioned in several studies. Trust is an important topic in Piers' study about Advance Care Planning (ACP) in elderly people with a limited life perspective [13]. Most, but not all, of the 38 patients in this qualitative study wanted to talk about dying and about those issues of end-of-life care which were directly related to personal experiences and fears. Trust in family and/or physician were important factors in proceeding to ACP, as was a personal need for control. Patient trust has proven to be an important quality indicator for the doctor–patient relationship in many studies. However, a caveat is needed as one of the papers in this special issue has demonstrated that patient trust seems to be explained more by patient characteristics than by doctors competence or performance, compromising its potential use as a quality indicator by Smets et al. [14]. Trust can easily be damaged when patients have the feeling that they are not listened to. In a reflective practice paper, Plum et al. [15] in their Reflective Practice paper, found that this is a common experience which is reflected in many of the formal complaint procedures in hospitals. An open conversation between professionals and patients at eye-level can help to create a mutual understanding [15]. The importance of an open empathic climate when talking about medical errors is also demonstrated in the

qualitative study by Mazor et al. [16] among patients who believed that something had gone wrong during their cancer care. Patient's values, apologies, expression of remorse, empathy and caring, explanation, acknowledgment of responsibility, and efforts to prevent recurrence, but these key elements were often missing. For many patients actions and evidence of clinician learning were most important. What clinicians say should be congruent with their actions [16].

The importance of empathic communication and a trusting doctor–patient relationship is not restricted to cancer care. Mazzi et al. [17] found, in a fairly large-scale, international, mixed methods study that participants in all four participating countries consistently favored space-giving physician responses to patients' signs of distress (in particular: showing empathy) over space-reducing responses, and – to a lesser degree – explicit responses over non-explicit responses. The authors conclude that listening skills and showing empathy should be taught as a core competency in medical education. In their paper about patients with medically unexplained symptoms. Hartman et al. [18] also showed the importance of listening to the patients' story. However, they added that just listening is not enough to bring the process further. When family physicians do not structure the conversation, for instance by summarizing, patients' evolving narrative on reasons for visiting the doctor, their beliefs and concerns, the medical consultations tend to remain a bit unfocused. But in this study, this proved not to be what most family physicians tend to do. Instead, they give extensive explanations of the origin of the symptoms and often do not take patients' own viewpoints into account. This study is another nice example of information giving not reaching its goal, because the patients, own perspective is not taken sufficiently into account [18].

4. INFORMATION GIVING

The quantitative studies in this special issue generally cover a number of topics, but – compared to the qualitative studies which tend to focus on 'the soft side of medicine' – the attention to the function 'information giving is striking. Mismatch is a popular topic. Although a large part of the medical consultation is spent on medical information giving, this information does not always fit with patients' needs. In the paper by Kelly et al. [19], it is reported that 40% of a sample of 141 breast cancer patients perceived that doctors had not talked about their breast cancer recurrence risk, while only one person of the study group (one!) actually did not want to talk about the recurrence risk. No wonder that perceived risk of breast cancer recurrence was inaccurate. In a study about preoperative information by Puro et al. [20], patients assessed the information in general as sufficient. However, only two thirds of the patients were satisfied. In particular information about risks and effects on quality of life was lacking. One third of the anesthesiologists only gave information about risks when asked by the patient. Information is not always correctly interpreted. In a study by Jenkins et al. [21] on patients' interpretation of DNA, test results for familial hypercholesterolemia (FH) was reassuring when positive, but inconclusive results

were often misunderstood. A study by Collins et al. [22] on information giving on screening results, evoked as many positive as negative comments, both in particular about the use (or not) of jargon and a personalized approach. Doctors should always show certain calmness. The message itself evoked the most reactions (72%), but traits (47%) and aspects of the setting (30%) were also often mentioned, showing again that patients views on medical consultations encompass much more than the mere exchange of information.

In a thought-provoking paper, Vegni et al. [23] elaborated on the fact that not the content of the message itself has an impact on the patient, but the meaning that patients attach to the message. The authors argue that patients' recall and (mis)understandings are more effected by this meaning than by the message itself, which means that the same message can have a different impact on different patients.

5. GENERAL GUIDELINES VERSUS PATIENT DIFFERENTIATION

Most communication training programs tend to train general communication skills, based on general guidelines about what constitutes 'good' communication. However, several papers in this special issue show that patients are different and need or prefer different communication styles in similar situations. We already referred to Smets' study on the influence of patient characteristics on their report on trust in the physician: the more anxious patients were the less they fully trusted their radiation oncologists [14]. How important patients' own characteristics are in their assessment of the quality of communication is also shown by Moskowitz et al. [24], who showed – in a quantitative study that patients' perceived quality of interpersonal care may be influenced by his/her perceived social position, even after controlling for age, sex, ethnicity, depressive symptoms, physical functioning, income and education. Apart from objective SES-factors, patients' subjective feelings about social position are relevant as well, asking for sensitive doctor communication.). Another study by Cousin and Schmid Mast [25], using analog patients, shows that agreeable persons benefit the most from the affective qualities of doctors. De Boer et al. [26] found in a quantitative study among different patient groups that patient-centered care is valued above-average by all patient groups with small but significant differences between different types of patients.

6. OUT OF THE BOX: PATIENT CENTERED COMMUNICATION FROM A DIFFERENT ANGLE

Marketing research is a sector which is specialized in differentiating between various target groups. Closely linked to the private sector, which needs advanced knowledge how to reach different target groups, communication researchers, with their tendency to general guidelines might learn from unusual alliances between academics and marketing specialists. Kravitz et al. [27] paper about a collaborative project involving academics and marketing people demonstrates that such initiatives, although with some caveats, may inspire the field of communication in health care with new insights in how patients with different backgrounds can be reached by targeted messages, in which possibilities for identification, supported by visual material do play an important role, apart from the content of the messages. This project also showed that the translation from academic knowledge to everyday practice is not

always a linear process, which can be difficult for academics to understand and accept. The fact that for marketers patient diversification is a well-developed and self-evident route in communicating messages to the general public could be useful in health care as well, as it is becoming clearer and clearer that general guidelines in doctor–patient communication are not sufficient to reach the relevant target groups and tailored communication is the next big challenge for health care providers as well as communication researchers. This seems an interesting venue for further research, and Kravitz et al. [27] paper gives a nice acquaintance with this new type of collaboration, including an honest introductory view into the do's and don'ts of this type of effort.

7. CONCLUSIONS

The papers in this special issue lead to a number of conclusions. Some of these are not new, but are important to mention, because they confirm the existing literature, and thus the validity of views of a number of professionals who claim to be the patients' advocate. The strong preference and the need for an empathic doctor who is willing to take the time for listening to the patients' story, and is prepared to seek for tailored solutions is a nice example of a quality indicator which is shared by patients themselves, trainers in doctor–patient communication skills, and doctors who adhere to a biopsychosocial approach in health care. In this respect there is no discrepancy between the patients' self-chosen advocacies and the patients themselves. Patients want a trusting doctor–patient relationship and a doctor who takes time and does his/her utmost to show a personal interest in his/her patients. From the patient perspective, this seems to be conditional for the quality of care. A related conclusion is that even issues which seem rather technical at first glance, such as risk communication, are often loaded with emotional meanings and ask for clinicians sensitivity in the affective domain. So, communication training will never be a purely technical affair without losing the patient perspective, which usually is holistic in nature. That being said, this special issue also demonstrates that in many aspects personalized communication will be needed as well personalized health care.

Tailoring communication to various patients' needs and preferences is the main challenge for clinicians as well as teachers and trainers. A final remark is, who is to be seen as an advocate for the patient perspective. Although cynical people will consider the use of the ideological concept of 'patient-centered medicine' as an alibi to proceed with their own views and traditions, this special issue demonstrates that people in every position, clinicians, trainers and researchers may sometimes rightfully claim to act in the patients' best interests, but that all of them runs the risks on certain pitfalls. The fact that, in general, qualitative studies reveal different issues that bother the patients compared to those in quantitative research, where questionnaires are completed by patients or lay people, but developed by researchers, should make researchers modest about the idea that they are the new patient advocates. Listen to the patients. They will tell you what they want and need is a message for researchers as much as it was and is for doctors and trainers.

ACKNOWLEDGEMENT

We would like to thank the authors for their patience. We are very grateful to Catherine Newman (Elsevier) for her continuing great support

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