Cancer patients' trust in their oncologist
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Trust of Turkish and Arabic ethnic minority patients in their Dutch oncologist

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ABSTRACT

Objective
To examine the nature of the trust that Turkish and Arabic (ethnic minority) patients suffering from cancer have in their oncologist and explore how this trust is established.

Design
Semi-structured qualitative interviews.

Method
Nine cancer patients of Turkish and Arabic origin were interviewed about the trust they have in their oncologist.

Results
The trust that these patients have in their oncologist appears to gradually evolve over time. According to the patients, three specific elements tend to promote trust. Firstly, patients attached importance to a strongly proactive physician approach, even in the palliative phase when treatment was no longer indicated; a wait-and-see attitude was perceived as a lack of willingness to help and was detrimental to their trust. Secondly, patients indicated that they needed their oncologist to reassure them and avoid discussing depressing topics, so that they would not give up hope. Finally, the oncologist’s non-verbal communication - particularly, facial expression - contributed to patients’ trust.

Conclusion
Among this group of Turkish and Arabic cancer patients, trust in the physician was not self-evident and, to some extent, might need to be ‘earned’ by oncologists. Because of the great need of these patients for a proactive attitude, oncologists need to clearly explain their motivation when choosing for a possibly less active approach. To preserve hope, oncologists need to unravel exactly what their patients’ information needs are. The results of this explorative small-scale study may help physicians to optimize the trust that Turkish and Arabic ethnic minority patients have in them.
“Trust in great things comes slowly.”
Ovid, Roman poet (43 B.C. to 17 A.D.)

INTRODUCTION

Improved oncologic treatments have led to an increased chance of surviving cancer, so that the number of people living with cancer is increasing [148]. However, because a life-threatening diagnosis and uncertain prognosis make cancer patients vulnerable, it is crucial that these patients can trust their oncologist [60]. Patients who have trust in their oncologist are less anxious, more likely to participate in decision making and to adhere to medical advice [138]. In general, cancer patients have a strong trust in their oncologist [138]. This results, in part, from how the oncologist communicates with the patient. Cancer patients have indicated that trust is strengthened in particular by the oncologist’s honest and open communication, caring and involved behavior, and acting in the patient’s best interest [149]. In addition, the oncologist’s medical expertise is important for trust, but is presupposed by most patients.

In the oncology setting, research on trust is scarce and mostly based on native Dutch patients; little information is available on the trust of patients from other cultural backgrounds. Although cancer is less prevalent among ethnic minority patients, the percentage of these patients is expected to rapidly increase in the coming years [150]. Within Dutch health care, ethnic minority patients form a particularly vulnerable group, resulting from language barriers, cultural differences, and (often) a lower socio-economic status. Moreover, physicians have indicated that they sometimes find communication with these patients difficult [151].

Recently, there has been increased interest in the experiences of, and communication with, ethnic minority cancer patients in the Netherlands. This is apparent from the reports ‘Allochtonen en kanker’ [Ethnic Minorities and Cancer] from the Dutch Cancer Society and ‘Palliatieve zorg aan mensen met een niet-westerse achtergrond’ [Palliative Care to Persons with non-Western backgrounds] from the NIVEL, Comprehensive Cancer Centre the Netherlands (Integraal Kankercentrum Nederland) and Pharos (Advisory Center) [152-154]. Despite the limited amount of empirical research among ethnic minority cancer patients, it is suggested that their trust is less solid than that of native patients [155]. Moreover, it is unknown whether ethnic minority patients attach the same importance to the behaviors of oncologists as do native patients. In the Netherlands, the non-Western ethnic minorities originate mostly from Islamic countries such as Turkey, Morocco and Egypt.
To gain insight into how Turkish and Arabic ethnic minority cancer patients experience trust in their oncologist, an explorative study was performed. Patients were individually interviewed about how they perceive the establishment of trust. Based on these findings, we provide some practical recommendations to help oncologists improve their communication with this vulnerable patient group.

**METHOD**

**Sample**

Semi-structured qualitative interviews were conducted with cancer patients of Arabic and Turkish origin. With the aim to achieve sufficient variation, we purposefully selected patients on age, gender, ethnic origin and education. Patients were approached through two hospitals - the Academic Medical Center in Amsterdam and the Zaans Medical Center in Zaandam - and via an Egyptian cultural organization in the Netherlands.

**Data collection**

An investigator with a Dutch-Egyptian background (S.e.T.) interviewed patients in the Dutch and/or Arabic language. They were asked about the meaning, strength, importance, development, predictors and consequences of trust in their oncology specialist(s). During data acquisition, the interview protocol was adapted as and when deemed necessary. We aimed for data saturation, as indicated by the lack of new information/themes during three consecutive interviews.

**Analysis**

All interviews were audio-recorded, transcribed and, where necessary, translated into Dutch by the interviewer. These translations were checked for accuracy by a professional translator. According to guidelines for qualitative research, data analysis was performed in parallel with data acquisition [139]. Using the MAXQDA 2007 software for qualitative analysis [140], all interviews were independently coded by at least two of three researchers (S.e.T., M.H. and/or J.v.d.V.). Subsequently, the codings were compared and discussed until consensus was reached. The nature of the analysis was inductive; elements of trust previously identified among native patients were not compared or tested. The analysis proceeded from open coding (summarizing and categorizing data) to axial coding.
(confirming codes and identifying broader relations). Eventually, the data were clustered to reveal the main themes.

RESULTS

Sample characteristics
Data collection took place between April 1 and October 1 2011. During that period, of the 16 eligible patients, two refused participation, two were too sick to participate, and later on three could not be reached. Finally, nine patients (age range 20–73 years) participated who were being treated in four different hospitals by 7 different physicians. Of these, five were female, six had a low education level, and four were minimally or not proficient in Dutch (an interpreter was present during three interviews). The patients had the following background: Moroccan \((n = 1)\), Turkish \((n = 5)\), Egyptian \((n = 2)\) and Lebanese \((n = 1)\). All patients were Muslim, and seven of the nine were first-generation immigrants. Due to difficulty in recruiting sufficient patients, full data saturation was not reached.

Primary tumor locations were breast \((n = 2)\), colon \((n = 1)\), pancreas \((n = 1)\), uterus \((n = 1)\), lungs \((n = 1)\), thymus gland \((n = 1)\), bone \((n = 1)\), and sarcoma \((n = 1)\). Three patients were treated with curative intention, five received palliative care, and one patient no longer received active treatment.

When does trust develop?
All patients reported that they trusted their current oncologist, which appeared to result from the severity of their disease. For example, a 65-year-old woman of Turkish origin said:

Look, if you have a serious illness, for the most part you just have to trust your doctor, because he’s going to treat you. You’re dependent on him, he’s the doctor.

However, this strong sense of trust was not necessarily present at the start of the treatment relationship. Patients often indicated that, initially, they critically observed their
oncologist’s behaviors and actions. Only after the oncologist had repeatedly acted to their satisfaction, did the trust slowly develop. The following quotes illustrate this process:

The first trust grew over the course of the years. Because we’re satisfied with the doctor, we have grown to be more trusting. (51-year-old man, Turkey)

Yes, trust actually came after a year. He [the oncologist] has of course observed me for a year - and I have observed him. Back and forth, listening to what he says, and should I believe him? And checking what he tells you. (31-year-old woman, Turkey)

Only one patient reported that she had a strong trust in her oncologist from the start of the treatment relationship:

Yes, trust was present from the beginning - since the first time I entered his office. That man was good, his manners were right.’ (36-year-old woman, Egypt)

**Proactive behavior**

For patients, one of the most important factors for the development of trust was that the oncologist provided fast and maximal care. According to these patients, fast care meant that the physician rapidly reached a diagnosis and directly proceeded to treatment (or referred if necessary). They believed that this proactive behavior led to better cure, stabilization and/or improvement of their disease:

What matters to trust for me is that she [the oncologist] just goes for it. And, for example, I had planned an MRI, but my back started to ache again. And she just did her best to do the MRI sooner - but another oncologist wouldn’t have done that. So yes, she stays on the safe side rather than waiting. Another doctor would say: ‘Yes, we will wait until you are in pain and then we will do the scan.’ No, that’s not how it works. (20-year-old man, Morocco)

The doctors said: ‘Well, mister X., we are incredibly busy, we don’t have time, we have to wait for three months.’ So then I lost my trust. Because when I’ve seen the tumor sitting there on the monitor, I’ve lost my trust because I’m very ill
and people should take action as quickly as possible. Then I became a bit angry and I didn’t trust them anymore. So that’s important. (64-year-old man, Turkey)

Some patients related a lack of oncologists’ proactiveness to the Dutch healthcare system. Compared to experiences in their own country of origin, they perceived their Dutch doctors to be somewhat reticent:

They wait until a situation happens, and only then they start to think about what could be done. They don’t try to prevent the damage before it occurs. No, they wait until the damage occurs and then they search for a solution for it. While with us in Egypt, if something like this happens the doctor tries to help you in every way possible.’ (37-year-old woman, Egypt)

Palliative phase

Even patients in the palliative phase (for whom active treatment was no longer indicated) had the idea that something could always be done. If not for cure, then to improve their health or stabilize their disease. Similarly for these patients, the oncologist’s proactive behavior determined their trust.

When the oncologist says: ‘We cannot do anything for you here, but you could go to another hospital for a second opinion - there they may be able to see what they can do for you, even if there is nothing more to do.’ If a doctor says that, that’s a reason for me to trust him. That creates trust, like: hey, yes, they really want to help me. (70-year-old man, Turkey)

If the doctor says: ‘There is nothing more I can do for you.’ Then I would never trust him again, never again.’ (31-year-old woman, Turkey)

The examples of the behavior of proactive oncologists reported by patients in the palliative phase appear to border on the phenomenon of oncologist’s preserving hope.

Preserving hope

Patients indicated that preserving hope for curation, improvement of their health, and/or disease stabilization, kept them going ‘mentally’. For trust in their oncologist it was important that the oncologist delivered positive messages. Ways in which the oncologist
could preserve hope were by continuing treatment, reassuring, and by not too openly discussing somber topics.

The radiotherapist delivers the message a little... not pleasantly, but at least better than the surgeon does. He delivers bad news, but, for example, he adds something positive. (…) Therefore, I trust him more than that surgeon, who will only say 'just go home.' He immediately gives up. (20-year-old man, Morocco)

Trust is that if I visit him, I'm not scared...and I feel spiritually reassured. Reassured in what way? (…) The conversation, the words that reassure me. For example, that he tells me there are many people with this disease who’ve been cured, giving me hope. Hope means that he reassures me. (36-year-old woman, Egypt)

Then they stand next to the MRI-scan and say: ‘Yes, three months, four months, that's how much time you still have. And here, and here…’ [patient points to an imaginary MRI-scan]. You see, I would deliver this news like: Look, this is what we’ll do and then maybe you will improve. Using that sort of phrasing. But I wouldn’t say: ‘Oh, in a few months it will be over.’ He should say it more positively. Because, you see, you’re already at rock bottom - you’re already a cancer patient. You know it’s very likely that you will die...you know - that feeling is with you all the time. On the other hand, there’s hope... and you should never let go of that. (31-year-old woman, Turkey)

Only one patient emphasized that, in addition to optimism, realistic and open information giving by the oncologist contributed to his trust.

He needs to be honest, even if it’s painful, but...it is important. (20-year-old man, Morocco)

Non-verbal communication

Striking was that patients explicitly mentioned that the oncologist’s facial expression contributed to their trust.
He was very sweet and he laughed, and that face created trust in me. Facial gesticulation is important. (64-year-old man, Turkey)

His contact with me is important for my trust. Like, for example, if someone has one child, his only child - he treats it with tenderness and attention…exactly like that. Tenderness, that is…the smile, his smile. (36-year-old woman, Egypt)

**DISCUSSION**

The results of this explorative study suggest that, among Turkish and Arabic ethnic minority cancer patients, trust evolves over time. According to these patients, the most outstanding elements contributing to trust were the oncologist’s proactive behavior, supporting the preservation of hope, and their facial expression. However, because of the small patient sample, these results should be considered as being preliminary.

Based on this explorative qualitative study we are unable to draw any definite conclusions about the strength of trust among Turkish and Arabic patients; for this, additional quantitative investigations are needed to collect more evidence. However, we can cautiously posit that for this group of patients, trust grows only after repeated interaction with the oncologist. Patients may often adopt a critical stance because they are unfamiliar with the Dutch healthcare system, resulting in initially low expectations with regard to their oncologist. Only when patients have found that their oncologist acts in their interest, does trust increase. Oncologists may realize that trust is not self-evident among these patients and that they may have to work harder to win their trust.

The strong emphasis of these patients on fast and maximal treatment, and their concerns about disease progression resulting from a less active approach, may be culturally driven. In these patients’ countries of origin, e.g., Turkey, Morocco and Egypt, treatment often starts early and is continued at considerable length, so that the palliative phase is often not distinguished as such [156]. As a result, patients may expect Dutch physicians to have a similar attitude [157]. Apparently, these patients derive their opinion about their physicians’ medical skill from their degree of proactiveness. However, oncologists will not always be willing or able to change their medical policy - simply because the Dutch healthcare system deviates from policy elsewhere. Instead, oncologists could attempt to explain even more clearly to this patient group why (in some situations) treatment is not advisable or may even be harmful. In this way they might avoid loss of
trust and the search for a second opinion – which is often made in the patient’s country of origin.

Patients preserved a strong need for hope, even when there was no prospect of cure or prolonging life. The extent to which the oncologist supported this hope had a strong effect on patients’ trust. This need for hope qualifies the desire for honesty that was earlier detected as an element of trust among native Dutch cancer patients. For ethnic minority patients, although being realistically and honestly informed was considered important, they did not wish that only the negative aspects be emphasized. Patients clearly indicated that they were aware of the severity of their situation, but also indicated that receiving a positive message helped them to keep going. This corresponds with previous findings among ethnic minority patients [158,159], but appears to apply (to some extent) to native patients as well [149,160]. For oncologists, this does not mean that they have to outline the situation more positively than it actually is, but they can meet a need for hope by emphasizing their continued availability for their patient. This allows the patient to at least preserve the hope that they are not being abandoned.

Patients emphasized the importance of their oncologist’s non-verbal communication. Especially facial expression seemed to determine how caring they perceived their oncologist to be. However, because the present study was not a comparative one, we cannot assess whether ethnic minority patients set more value on non-verbal communication than native Dutch patients in constructing trust. It is possible that Turkish and Arabic ethnic minority patients placed particular emphasis on these aspects in their narratives. However, we do know that among native Dutch patients, non-verbal communication is not spontaneously mentioned in relation to trust. Increased attention paid to non-verbal communication may be explained in several ways. Patients in the present study originated from cultures with a stronger emphasis on non-verbal communication (‘high context cultures’) than others, such as the Netherlands (‘low context cultures’) [161]. Another explanation may be that these patients pay more attention to non-verbal signals because of their limited proficiency in the Dutch language. For oncologists, it is important to realize that the non-verbal aspects of their message may be more important for this group of patients than they are accustomed to.

Our results may not reflect all possible variations in attitudes and experiences. Because of the difficulty in recruiting sufficient patients for this study, we interviewed fewer patients than planned and did not reach data saturation. Therefore, the results of this study need to be interpreted with caution. Moreover, we cannot conclude whether trust is established in different ways between sub-groups, e.g., depending on age, gender or education level. Additional qualitative and quantitative studies are required to
corroborate these preliminary findings. Also, it is important to note that all interviewed patients had an Islamic background, so that their experiences and opinions do not reflect those of ‘the’ ethnic minority patient. Similar to native Dutch patients, there is considerable variation in the evaluation of oncologists’ behavior between ethnic minority patients.

PRACTICE IMPLICATIONS

It is important that the physician assesses the patient’s preferences and level of understanding. If the patient expresses a strong need for hope, the physician may provide less detailed information and place more emphasis on positive aspects. If the patient does not appear to understand or accept the medical policy, it may help if the physician explains his/her motives in much more detail, preferably corresponding with the patient’s worries. By consciously and explicitly applying their communication skills, physicians can discover and hopefully fulfill the individual preferences of ethnic minority patients, in order to gain and preserve optimal trust among this patient group.

CONCLUSION

The results of this explorative small-scale study indicate that Turkish and Moroccan ethnic minority cancer patients do not automatically trust their oncologist, but that winning trust is a process that takes time. Physicians can enhance these patients’ trust by clearly explaining their medical policy, by emphasizing more positive aspects when necessary, and by being aware of the importance of their non-verbal communication.