The perception of language differences by ethnic minority patients with a metastatic cancer.

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The perception of language differences by ethnic minority patients with a metastatic cancer

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ABSTRACT

OBJECTIVE. Previous research has found strong resemblances in the expectations and perceived experiences between ethnic minority patients and native patients when confronted with cancer. However, ethnic minority patients experience some specific obstacles when dealing with the illness. For this subgroup of patients language difficulties and poor communication remains important problems. Little is known about how ethnic minority patients experience language differences when confronted with a metastatic cancer. In this study we aim to explore if ethnic minority patients with a metastatic cancer perceive language differences during their treatment and how it influences their trust in their health care provider and their need for a second opinion in their country of origin.

METHODS. This study is part of a larger study on the expectations of and experiences with health care in Belgium among ethnic minority cancer patients. For this study, semi-structured interviews with thirty patients were conducted. For the present article, all patients with a metastatic cancer (n=10) were selected. This selection was based on our assumption that patients in this phase of the illness have already had a longer history of treatment and thus have had more opportunities to be confronted with potential language differences. These interviews were coded using thematic analysis.

RESULTS. Ethnic minority patients perceive three language differences when confronted with a metastatic cancer: (1) a linguistic barrier, (2) non-verbal communication and (3) medical jargon .

CONCLUSION. Despite these language differences, ethnic minority patients have great trust in their health care provider and they are satisfied with the information given by the doctor. They do not feel the need to ask for a second opinion in their country of origin. To a great extent, ethnic minority cancer patients tend to rely on non-verbal communication.

PRACTICE IMPLICATIONS. Although the study is limited by methodological concerns, health care providers have to take care of identified language differences and pay attention to a efficient non verbal communication.

1. INTRODUCTION

In each country health care systems and the organization of health services are developed in accordance with the users and the practices of the native population of that country. Due to migration, society in Belgium is becoming more multicultural. This has implications, in particular, on the cancer care system, as more and more patients are from ethnic minority groups [1]. While there are strong resemblances between the experiences of native patients and those of ethnic minority patients, there are also important differences. Having a life-threatening disease such as cancer is a human experience, regardless of the origin of patients. Patients show universal reactions when confronted with cancer and exhibit strong resemblances in the expectations and perceived experiences: from the disbelief and anger at the time of diagnosis, over the suffering and despair during the disease to the great impact on family and relatives [2].

But there are also important differences between ethnic minority and native cancer patients. Cancer services prove to be less accessible to ethnic minority patients, resulting in lower screenings rates and poorer cancer outcomes [1,3]. They are also more likely to report higher levels of dissatisfaction with and distrust of treatment and care [4]. Effective communication with these patients is a challenging task for health care providers when they do not share a common language. A good doctor-patient relationship and efficient communication have a positive effect on the satisfaction of patients and health care professionals and on the quality of the delivered care [5-7].But language difficulties and cultural differences remain a significant barrier to good communication between ethnic minority patients and health professionals [8-11]. Findings in literature reveal that there are major differences in doctor-patient communication according to the patients' ethnic backgrounds. Doctors behave less affectively when interacting with ethnic minority patients than with white patients. Ethnic minority patients themselves are also less verbally expressive; they seem to be less assertive and affective during a medical consultation than white patients [12-17]. This results in these patients receiving significantly less information and having less trust in physicians than with white patients [18-19].

With regard to language, it appears that people who insufficiently master the national language are more subject to misunderstandings and discriminations. They also have more difficulties indicating symptoms and side effects such as pain and they experience problems in finding their way into the

health care system [2,4,20-23].This confirms previous research results on the communication between family physicians and non-Western patients with everyday problems which indicated that the language used by the physician and the patient is by far the most important inhibitory factor in the communication between the doctor and the patient, more than social, cultural and religious factors [2,24] .

This study focuses on the language used between the physician and the patient, specifically in the case of patients with a metastatic cancer. The study is structured around three central research questions:

1) Do ethnic minority cancer patients perceive language differences during treatment? If so, how do they perceive these language differences?

2) Does the absence of a common language between doctor and patient influence a patient's confidence in health care providers?

3) And, does the absence of a common language between doctor and patient have an effect on the patient's need to request a second opinion in their country of origin?

2. METHOD

2.1. Design

This study is a part of larger study, funded by the Flemish League Against Cancer, which aims to describe the perception of the Belgian health care among ethnic minority cancer patients. It is a qualitative analysis of semi-structured face-to-face interviews with a purposive sample of ethnic minority cancer patients. Ethical approval was given by Ghent University (B670201111587).

2.2. Data collection

To recruit the participants for the overall study, several organizations with many contacts with ethnic minority patients were approached. Inclusion criteria were (a) age over 18 years and independent living conditions; (b) diagnosed with cancer; (c) and/or both parents born outside Western-Europe, North-America or Australia. Patients were selected regardless of their language proficiency. For this article, all the participants with a metastatic cancer (n=10) were selected from the total population (n=30), because - in general - patients in this phase of the illness have already had a longer history of

treatment and thus have had more opportunities to be confronted with potential language differences. The information about metastases was obtained from the patients' medical record.

Data were collected using semi-structured interviews with open-ended questions. The interview protocol was based on the research questions which were developed through a broad search of the literature. The protocol was adapted after the first five interviews. First, potential participants were informed about the study by a contact person in the participating hospitals. If the patient consented to the interview, an appointment was made. All the interviews were conducted by a researcher trained in qualitative interviewing methods. Interviews in Dutch, French and English were conducted by the principal investigator. The other interviews were done with the aid of an ad hoc interpreter unknown to the patient (e.g. students of the university). There are two different forms of interpreting: ad hoc interpreting and professional interpreting. An ad hoc interpreter is an untrained person who is called upon to interpret, such as a family member, a bilingual staff member, etc. A professional interpreter is any trained individual paid and provided by the hospital or health system to interpret [25].

The interviews took place in the setting - hospital or home - which was most convenient for the patient.

2.3. Data analysis

All interviews were audio-taped with the consent of the participants and transcribed verbatim by external volunteers. The interviews with interpreters were transcribed and translated by another, independent translator. All volunteers were bound to keep the information confidential. Afterwards, all transcripts were anonymized. After selecting the interviews of the patients with a metastatic cancer, they were coded by two researchers using thematic analysis in accordance with the research questions. This all happened under the supervision of experienced qualitative researchers.

3. RESULTS

3.1. Sample characteristics

Eight of the ten patients with metastatic cancer were female and half of the patients (n=5) were diagnosed with a breast cancer. More than half of the patients were 50 years or younger at the time of the interview. With regard to the origin of the patients, the group was varied. Four patients were of

Turkish origin, four of African and two of Eastern-European origin. Four of the ten patients had entered the health care system through their family physician. Also, half of the patients had a middle or higher educational background. In 4 interviews an interpreter was used.

3.2. Perception of language differences

3.2.1.Linguistic difference and use of medical jargon

Four patients explicitly mentioned not having fully understood all the information that was given during a consultation with the oncologist due to linguistic differences. Two of these patients only spoke Turkish, one patient only Moroccan and a third Russian patient spoke Dutch. Except for the Russian patient, they all used an interpreter during the interview. All four patients also used an interpreter during their visits with the doctor. The other six patients did not explicitly mention language differences. Four of these patients spoke Dutch, one English and a sixth patient spoke Turkish. Only the Turkish patient used an interpreter during the interview and during her visits with the doctor.

> *'It's not always easy. Sometimes I don't understand everything. I have a language problem. If they speak in Turkish, I understand it better.' (43-year-old Turkish woman with a breast cancer)*

Besides the absence of a common language, two patients also mentioned the difficulty of not sharing the same jargon. They referred to the difficulties they experienced in trying to understand the medical jargon by their oncologist. One of these patients always went to his general practitioner after seeing the oncologist to translate the consultation in layman's terms.

> *'Doctors are in love with their own language. They sometimes speak Latin. For me Latin or Chinese, it's the same.' (54-year-old Bulgarian man with an oropharynx cancer)*

> *'My general practitioner speaks my language, my specialist speaks a doctor language I do not understand. Tumor markers, the first time I heard that word…With a doctor you should be able to speak your own language.'(46-year-old Turkish woman with a breast cancer)*

3.2.2. Use of interpreters

In four interviews an ad hoc interpreter was used. These patients also used an interpreter during the consultation with their oncologist. Two of them expressed the wish to use a professional interpreter, because they felt that family members tend to filter or even hold back some information provided by the doctor. Despite this explicit demand, professional interpreters were not always present during consultations. Only one patient, a 50-year-old Turkish woman with a metastatic cervix cancer always used a professional interpreter.

> *'My husband is always with me to translate. There are certainly things that he doesn't say. He skips the bad parts. Even to our children he will not tell the whole truth. A professional interpreter is better for me, because I can easily ask all my questions. And if I ask something, a professional interpreter is forced to answer me, but my husband not. '(42-year- old Turkish woman with a breast cancer)*

The other two patients always used family members as interpreters, but indicated that if a family member would not be available they would like to have a professional interpreter during the consultation. They mostly use family members as ad hoc interpreters for two main reasons: firstly, because of the immediate availability of their family members and secondly, because of the support - emotional and practical - the family member can give during the consult. They could comfort the patient; in one case the patient's sister-in-law, who was a nurse, always came to the consultations.

One patient who spoke Dutch also used a family member as an ad-hoc interpreter as she couldn't speak Dutch very well. This 38-year-old Russian woman with a metastatic breast cancer was very satisfied about this.

> *'I was there with my husband, he gave me support. It was a difficult moment. When I did not understand all the doctor said, my husband could tell me afterwards and we could discuss together.' (38-year-old Russian woman with a breast cancer)*

> *'My son is available at each time. That will not be the case with a professional interpreter. But if shortly my son will start working, I will need a professional interpreter.'(69-year-old Turkish man with a papillar cancer)*

3.2.3. Use of non-verbal communication

The results show that all interviewed patients attach great importance to the non-verbal communication of the doctor. It affects their experience with our health care system and its providers. A smile, a handshake, non-verbal signs of empathy: it all increases their satisfaction and trust.

> *'Laughing…so true. Until now I have in my head only an image of a laughing doctor. And that's such a nice experience, no?'(52-year-old Somalian woman with a cervix cancer)*
>
> *'Their kindness and their smile, at the first place.'(42-year- old Turkish woman with a breast cancer)*

Non-verbal communication also helps the ethnic minority patients to obtain a better understanding of what the doctor tells them, even if they don't have a common spoken language.

> *'I understand most of the words, but from facial expressions I can understand a lot.'(43-year-old Turkish woman with a breast cancer)*

Also, ethnic minority cancer patients and health care providers who do not have a common spoken language tend to rely more on non-verbal behavior for information about the illness or treatment.

> *'My friend who came with me asked the doctor if she could tell me. I saw the doctor signing, but I could also already see it from her face. I understand most of the words, but from facial expressions I understand also a lot.' (42-year- old Turkish woman with a breast cancer)*
>
> *'Some things you can also distract from facial expressions. I understand most of the words, but from facial expressions I can also understand a lot. (43-year-old Turkish woman with a breast cancer)*

3.3. Information and need for a second opinion

All the interviewed patients knew that they had cancer. It is not clear if they also knew in which stadium their cancer were. Notwithstanding this, the majority of patients was satisfied by the way they received information about their disease. Eight of the ten patients were of the opinion that the information they received was sufficient and that it was provided in a correct and literal manner. One

patient thought she did not receive enough information and another one only received information if she asked for it.

> *'Everything you ask, you get an answer' (52-year-old Somalian woman with a cervix cancer)*

> *'From the beginning I told my doctor I wanted the truth. Cancer? Cancer. Three months to live, seven months to live, I want the truth. And he told me: yes, cancer.' (54-year-old Bulgarian man with an oropharynx cancer)*

> *'They told me everything: the diagnosis, what will happen, which examinations I have to undergo. A lot of information for a first time' (38- year-old Russian woman with a breast cancer)*

> *'I really wanted to get the right information. And actually, they don't give so much information.' (54-year-old Moroccan woman with a breast cancer)*

> *'Nowadays the disease is told directly to the patients, it's no longer hidden for the patient.' (70-year-old Turkish man with a kidney cancer)*

As they were satisfied with health care providers, none of the patients had a need to ask for a second opinion in their country of origin. Not only were they satisfied, they also had great confidence in their physician.

> *'The doctors tell you what to do. I'm in the hands of the doctor, so he decides' (52-year-old Somalian woman with a cervix cancer)*

'If you get dependent on the doctors, it's difficult to do something yourself. You use the medication the doctor give you, even if you don't know if it is good or bad' (70-year-old Turkish man with a kidney cancer)

4. DISCUSSION AND CONCLUSION

4.1. Discussion

The aim of this study was to explore if and how ethnic minority patients with a metastatic cancer perceived language differences during their treatment, and how it influenced their trust in health care providers and in the search for a second opinion in their country of origin. The results of this study show that they perceive three levels of language differences during their treatment: Firstly there are linguistic differences between health care providers and patients. Secondly there is the medical jargon used by the doctor. And finally there is the use of a non-verbal language by the health care provider. The linguistic difference is caused by a different mother tongue between patient and health care provider. Even with a spoken lingua franca[1] or with the use of an interpreter, there are still parts of the conversation that ethnic minority patients don't understand. This is also seen in literature [3,12,26-27]. The patient's understanding is further hampered by the medical jargon doctors are using, nevertheless this was merely mentioned by two patients. To this day, the perception of medical jargon by ethnic minority patients is a topic that has not yet been explored in academic literature.

But despite these language differences, ethnic minority patients with a metastatic cancer have a great trust in their health care provider. They are satisfied with the way information is given and how they are treated by their health care provider. They have no need to ask for a second opinion in their country of origin.

This is contrary with literature which suggests that levels of trust are substantially lower for black patients compared with white patients [28]. This also influences second opinion seeking. Patient-initiated second opinion consultations occur in all fields of medicine. In oncological practice, second opinion seeking is frequently occurring due to the life threatening character of cancer [29]. Patients

[1]Lingua franca: a language systematically used to make communication possible between persons not sharing a mother tongue.

with greater trust in their physician are less likely to change physicians[28]. It is not know in literature if and to which degree ethnic minority cancer patients seek second opinion in their country of origin.

The use of a non-verbal language by health care providers tends to have an important influence on the patient's level of trust in their doctors. This is consistent with the existing literature, which suggests that ethnic minority patients rely heavily on the oncologist's non-verbal behavior, in particular his or her facial expression[17]. It helps them to trust their health care provider. In a similar study with 9 ethnic minority cancer patients, conducted by Hillen [21], results suggest that three specific elements tend to promote trust. Firstly, patients attach great importance to a proactive physician approach, even in the palliative phase. Secondly, it is important for them that their oncologist tried to reassure them. Finally, the doctor's non-verbal communication contributes to patient's trust.

The fact that language differences are not necessarily perceived as a barrier may also be explained by the strong adherence to religion by ethnic minority patients. All interviewed patients attach great importance to their religion. They believe that their god can give them answers and help them deal with their problems. For eight of the ten patients, God takes a very important place in their lives. He decides about life and death and inspires patients to continue the treatment as far as possible.

> *'With the help of Allah, I will survive' (46-year-old Turkish woman with a cervix cancer)*

> *'God told me to continue the treatment as long as possible' (48-year-old Somalian woman with a cervix cancer)*

> *'The doctor told me it is over, but Allah still gives me life.' (43-year-old Turkish woman with a breast cancer)*

This is also seen in literature, which suggest that religion and spirituality play a central role in the way patients cope with cancer. Providing comfort, hope and meaning, religiosity is reported to aid patients in their struggle to cope with cancer. Religious and spiritual beliefs may alter patients' perceptions of their illness and symptoms and thereby influence treatment decisions. Studies also suggest that

religious individuals more frequently request aggressive measures to extend their life. Patients with cancer who used spiritual coping to a greater extent were more likely to desire life-sustaining treatments [14-15] .

Furthermore, in translating the interviews, it appeared that the ad hoc interpreters used during the interviews did not always translate in a correct manner. A difference between an ad hoc interpreter and a professional one is also seen in literature. Studies suggest an improved clinical care when professional interpreters are used for patients with limited English proficiency, more than when ad hoc interpreters are used. Professional interpreters appear to raise the quality of care for limited English proficiency patients to equal that for patients without language barriers [20,22].

This study has important strengths and limitations. The findings of this study should be interpreted from within the context of several limitations. The data from this study are collected from a few cases, so findings cannot be generalized to a large population. For the interviews an ad hoc interpreter was used. This can impoverish the results if the interpreters don't translate in a literal manner. We used existing interviews, those were not principally focused on our research question, which can impoverish the results.

Data in this study were collected from the subjective opinions of patients. Patients are satisfied about their health care provider and the way information is given. But it is not known from the interviews if they actual received the correct information. To find out which information the doctor actually said and the patient actually understood, a consultation has to be followed.

4.2. Conclusion

Ethnic minority patients with a metastatic cancer perceive language differences on three levels during their treatment. Despite these, they all have great trust in their health care provider and have no need to search for a second opinion in their country of origin. The use of a non-verbal communication by the health care provider plays an important role in these patients' perception of health care.

4.3. Practice implications

Although the study is limited by methodological concerns, it has provided insights into the perception of language differences by ethnic minority patients with a metastatic cancer. Health care providers

have to reckon with these differences in their communication with ethnic minority cancer patients and pay attention to a efficient non verbal communication.

It is worth to do further study on the perception of these language differences by ethnic minority cancer patients.

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