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Review article

Having cancer in a foreign country





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ABSTRACT

Objectives: Although immigration and cancer care are two frequently discussed topics in healthcare, the combination of both has seldom been done. Little is known about how immigrant patients experience having cancer in a foreign country. The aim of the study is to gain deeper insight into the meaning of having cancer, in a foreign country and to identify the expectations and experiences of immigrant patients confronted with this disease.

Methods: Thirty adult non-western immigrant cancer patients were interviewed by means of an in-depth interview technique. The technique of constant comparison, derived from the constructivist grounded theory, was used to analyze the data from the interviews.

Results: Having cancer is a human experience, regardless of one's country of origin. Patients show universal reactions and reaction patterns when confronted with cancer and dealing with cancer treatment. Immigrant patients experience specific obstacles when dealing with cancer, of which the language barrier is the most important. A general lack of accurate basic knowledge about health and disease was found, making certain patients more vulnerable.

Conclusions and practice implications: When dealing with cancer, immigrant patients are confronted with two major obstacles: a language barrier and a lack of knowledge about health and disease. The implications for a better practice occur on three levels: empowering patients, training healthcare professionals and adapting policy.

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Contents

1.	Introd	luction	1709
2.	Method		
	2.1.	Design	1709
	2.2.	Participants	1709
	2.3.	Data collection	1709
	2.4.	Data analysis	1711
3.	Result	ts	1712
	3.1.	Description of the participants	1712
	3.2.	Main results	1712
		3.2.1. Universal experience	1712
		3.2.2. Language barrier	1712
		3.2.3. Knowledge about health and illness	
4.	Discu	ssion and conclusion	1713
	4.1.	Discussion	1713
	4.2.	Conclusion	
	4.3.	Practice implications	1714
	Ackno	pwledgments	1714

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1. Introduction

Immigration and cancer care are two frequently discussed topics in literature. The combination of these two topics is a major issue in healthcare. Yet, little is known about the experience cancer patients of non-western origins have in their country of immigration.

The number of immigrants is rising at a good pace, resulting in a multicultural and diverse society [1]. In Belgium, for instance, more than one out of ten residents is from foreign origin. Compared to 2003 this is an increase of 3%, and it is known that in the future these numbers will keep rising [1]. The largest groups of non-Dutch speaking patients in Flanders, Belgium, are residents of Moroccan, Eastern-European and Turkish origin [1,2].

The continuous stream of immigrants has implications in many areas, including healthcare. The growing diversity of patient populations challenges both the healthcare system and the healthcare professional [3–4,9]. Although there is an immigration of people from both western and non-western countries, patients from non-western origin in particular seem to be confronted with barriers when using western healthcare systems. One reason is that the health services are developed in each country according to the customs and practices of the native population of that country [5].

Previous research found that non-western immigrants have less access to the usual sources of care, and even when they are confronted with a rather common disease, such as the flu or a common cold, they have difficulties in finding their way into the complexity of the western healthcare system [6–9]. More, when these patients are confronted with a life-threatening disease, such as cancer, their confusion and helplessness grows even further [10-13]. Research also reveals that consultations with these patients tend to differ from consultations between doctors and patients sharing the same cultural, linguistic and ethnic background [3,14]. Hornberger et al. stated that when a physician and patient do not share a common language or culture, communication difficulties may occur which can compromise the patient's care and even result in worse health outcomes, especially when dealing with complex or chronic medical problems [14]. One of these complex and often chronic medical problems, is cancer.

Cancer is one of the leading causes of death worldwide [15]. In 2008 7.6 million people died as a result of this disease. This represents 13% of all deaths. In addition, it is estimated that the number of deaths caused by cancer will continue to increase, thus in 2030 approximately 13.1 million people will die from cancer [15].

A number of bottlenecks and barriers are already internationally formulated [12,13,16–17]. The oncological setting is complex, making the bottlenecks and barriers to cancer care and treatment multifactorial. Besides language, social, cultural, religious and structural/organizational aspects play an important role in handicapping non-western cancer patient in their process of care. Intercultural medical consultations tend to have far more miscommunication and misunderstanding, lower satisfaction with the encounter and poorer compliance. These patients are often described as less verbally expressive and less affective during the consultation, and doctors also tend to express less affective and task-oriented behaviour when interacting with migrant patients [9].

Despite of existing literature of the bottlenecks and barriers mentioned above, little is known about this growing patient groups' perception on dealing with cancer and experiencing cancer care in a foreign country. The analysis of the perceptions of nonwestern immigrants on this life-threatening disease and personal experiences of cancer care in a western country has, to our knowledge, never been studied before.

To gain deeper insight into the meaning of having a life-threatening disease, such as cancer, in a foreign country and to identify the expectations and experiences of non-western patients – in this study defined as one or both parents born outside Western-Europe, North-America or Australia – confronted with cancer in a foreign country, following research questions were originated:

- What does it mean for non-western immigrants to have cancer in a foreign, western country?
- What does it mean for non-western immigrants to undergo treatment in a foreign, western country?

2. Method

2.1. Design

This study used a qualitative research method. Semi-structured face-to-face interviews with a purposive sample of ethnic minority cancer patients in Flanders, Belgium were analyzed. Ethical approval was given by Ghent University (B670201111587).

2.2. Participants

To recruit the participants, different hospitals with many immigrant contacts were approached. Inclusion criteria were (a) aged over 18 years and independent (i.e. not living with parents); (b) diagnosed with cancer; (c) and one or both parents born outside Western-Europe, North-America or Australia. The exclusion criterion that was used, was no inclusion of economic immigrants with high socio-economic characteristics immigrating for better job opportunities (e.g. diplomats, employees of multinationals, etc.). The interviews took place in the setting – hospital or home – which was most convenient for the participant.

The participant population consisted of patients who were recently diagnosed with cancer and just started the first treatment (either surgical, or any other form of cancer therapy such as chemotherapy, radiotherapy, etc.), and of patients who already have had more than one form of treatment. Having this mixture allowed a variation of patient views, ranging from the initial reactions related to the disease process and expectations (the first group) to looking back on several treatments (the second group).

2.3. Data collection

Data were gathered through semi-structured, open-ended face-to-face interviews. After the first five interviews, some minor changes were made to the interview guide. The interview guide is presented in Box 1 of the Appendix A.

Potential participants were informed about the study by a contact person in the participating hospitals. If the participant consented with the interview, an appointment was made. The language proficiency was determined by the principal researcher prior to the interview. The interviews in Dutch, French and English were done by the principal researcher. When the language proficiency of the participant in Dutch, French or English was insufficient or doubtful, the interview was done with the aid of an

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