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How Culture Influences the Perception of Serious Diseases

Elena TOADER[1]

Abstract

Currently, cancer does not benefit from an approach that explores cultural influences which are embedded in the modality by which patients define their sufferance, require and use medical services and therapeutic options. In this paper we aim to evaluate the manner in which the cultural background of the cancer patient may influence the perception of a serious disease. For illustration purposes we explored the cultural perception of the digestive cancer from the perspective of the communication and understanding capacity of the medicine student on what this disease represents for the patient. As research instrument we used the dialogue technique in the form of conversation. The analysis of the information yielded a series of common topics and similar significations which influence the health beliefs and the behavior of the cancer patient. The conclusion of our research is that the approach of cancer from the point of view of cultural beliefs and values supports the educational endeavor to emphasize in the training curriculum of future doctors the effective exploration of the potential to correctly acknowledge what cancer presently represents.

Keywords: serious disease; cancer; cultural beliefs; students; education curriculum.

Introduction

Starting from the definition of the *serious disease* entity, conceptualized through syntheses from symptom to patient's quality of life, both in theoretical analyses and practical approaches, cancer engages multiple controversies with respect to inequities in health behaviors. In current practice, the serious disease is differently described by the patient according to the personal experience but also to influences exerted from within the reference group (community, ethnicity, family, friends,

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and colleagues). From a global perspective cancer, as epidemiologic phenomenon, ranks as one of the most frequent causes for morbidity and mortality in the world. Data of the International Agency for Research on Cancer reveal that every year more than 18.1 million individuals are diagnosed with cancer and 9.6 million cancer deaths in 2018 (IARC – WHO, 2018). World Cancer Report underlines the need for concerted efforts in order to improve cancer control in the entire world, with focus on interventions aiming for the increase of life expectancy, establishment of early diagnosis and trends to change unhealthy behaviors (smoking, sedentary lifestyle, chronic alcohol consumption, etc.). Also in the evaluations of the Report it is estimated that in 2030 the number of new cancer cases will reach 20 million and the mortality will be over 12.9 million (Daher, 2012). It is interesting that in the assessments regarding the prevalence of cancer more opinions arise which, besides the size and statistical significance of the data also envisage the role and importance of cultural influences in the way the disease is perceived and controlled.

Cultural influences in cancer perception – a series of necessary lessons

Current approaches of serious diseases, namely cancer, tend to focus on risk factors, etiopathogenic mechanisms or molecular genetics, so that the association between cancer perception and cultural beliefs and values receives limited attention from specialists. Currently, cancer does not benefit from an approach which explores cultural influences embedded in the manner by which patients define their sufferance, interpret their symptoms or require and exploit medical services, as well as implications and therapeutic options (Dein, 2004). Within this context, we believe that there still are a series of lessons to learn regarding cancer. *Myths about cancer*: The fact that in the XXI-st century cancer stigmatizes comes in contradictions with numerous opportunities available for the exploitation of real and correct perceptions of cancer (Marlowm, Waller, & Wardle, 2015). Several examples that support the opportunity for positive changes are represented by availability of effective prevention measures, as well as for early disease discovery, to which we may add presence of effective therapies and good survival (Holman *et al.*, 2014). *Information about the disease:* In the Internet era, there still are individuals (too many) or, on the other hand, patients (too few) who report the insufficiency or unsatisfactory quality of *information* about cancer (Ofran *et al.*, 2012). Apparently, it is a *communication* issue, another necessary lesson. Although we have sources and resources for this aspect, the key resides in the correct modalities for information dissemination. It is important to clearly outline myths such as “the power of example”, or a personal cancer history in the case of notorious personalities, miraculous survivors, celebrity and information relayed through various mass-media channels, not always in a professional, correct and, implicitly, useful manner (Surbone, 2010). One solution could be *education* for

cancer a potential assessed as a high return investment which must be explored with the aim to increase the awareness degree, starting with high school students, on what cancer represents. However, in order to be able to do that we need lesson focused on the emotional capacitating of information, through which one can provide psychological support and manage the attitude towards the disease (Giuliani & Frenk, 2018; Frenk *et al.*, 2010) . It is noteworthy that this approach would be incomplete without lesson which refers to behavior, especially the unhealthy ones, as it is well known that such factors as tobacco, unhealthy nourishment, alcohol consumption, sedentary lifestyle are examples of major risks for cancer development (Odedina *et al.*, 2011).

Cultural registry of cancer

Starting from the consideration that in a cultural context where people interact regularly, know the same rules and unwritten criteria for social life and share and relay from generation to generation the same set of ideas about the world, they will shape a cultural model for disease perception (Kim *et al.,* 2012). With respect to cancer, the fingerprint of cultural influences specific for communities or ethnicities determine different modalities for its perception and understanding. Towards this end, reading associates cancer with a multitude of cultural beliefs and values about the perception manner of the disease, interpretation of symptoms, usage of healthcare, implications regarding therapy, quality of life, etc. (Toader *et al.*, 2017; Kirsten, 2012; Coreil, Wilke, & Pintado, 2004). The cultural registry of cancer is supported by the results of the exploration of the perception of serious disease coming from researches centered on the relationship between cancer and the cultural context, focused on aspects that represent connection bridges between the pathological modifications generated by the disease and the psychological, social, economic, professional and religious dimension. In the XXIst century the cultural myth about cancer still stigmatizes and negatively influences the efforts to increase the awareness degree of what this disease truly is currently (Uyl-de Groot *et al.,*2014; Ling & Phelan, 2006; Ong *et al.,* 2002). Consequently, there is a negative impact on behavior, in the sense of adoption by the individuals of an attitude contrary to reducing cancer risks, or reticence in looking for support and exploitation of medical services necessary when they are diagnosed with this disease (Peretti-Watel *et al.,* 2016). Within this context, the perception of cancer, expressed in terms such as death, fear, pain, sufferance, loss of control and independence, helplessness and isolation reinforces the idea of influences and convictions about cultural beliefs on serious diseases in general and cancer in particular (Hebert, Moore, & Rooney, 2011).

Methodology

The aim

In this paper we aim to evaluate the manner in which the cultural background of the cancer patient may influence the perception of a serious disease. For illustration purposes we explored the cultural perception of digestive cancer from the perspective of the communication and understanding ability of medicine students on what this disease represents for the patient. The objectives of this paper envisaged the collection of real data referring to cancer in correlation with what patients feel, believe, know and think about this serious disease. Moreover, we attempted to emphasize the significations attached to the perception of cancer as serious disease which patients evoke through freely expressed words in dialogue with students. In order to maximize the relevance of the data contents we classified the information attached to evocations of cancer as an example of serious disease on descriptive categories referring to common topics such as attitude and behavior, time perception, religion, acculturation, therapy.

Method

We used the *technique of dialogue in the form of conversation* as research instrument for the exploration of the importance given to cultural factors in cancer perception. With the aim to gather the information needed for the evaluative endeavor we collected data from patients with digestive cancer (N=26 patients, 1 patient with esophageal cancer, 3 patients with stomach cancer, 10 patients with colon cancer, 8 patients with liver cancer, 4 patient with pancreas cancer) with the help of medicine students in IIIrd and Vth year, occasioned by training stages according to the educational curriculum (medical semiology for symptoms and diagnosis and gastroenterology modules for therapy, evolution and prognosis). A group of 3-5 students was assigned to each case; each of the students recording separately the information presented by the patient, and later collected and classified them by topics. The choice of students is justified by the fact that they possess a suitable training for a conversation dialogue, which credits them with the capacity to understand the information about cancer. For the empirical evaluation of cultural beliefs and estimation of values involved in cancer perception by patients the information obtained by students were classified in descriptive categories related to the experience of the clinical doctors. We must mention the role and contribution of the family in the providing or completion of certain pieces of information.

Results

Data obtained by students in dialogue with patients was analyzed with the aim to explore the significations referring to cultural perception of cancer. We selected from the information recorded by students only the items that evoke common topics and similar significations. The importance granted to evocation in the form of symbolic values took into account the manner in which the patient presents the disease and conditions the signification of the retained details. Cultural beliefs and values involved in cancer perception, sorted in descriptive categories with explanations, given in table 1, reveal convictions and behavioral aspects, therapy, perception and value of time, acculturation, religion and spirituality, and other aspects.

Table 1. Cultural beliefs and values involved in cancer perception

Descriptive categories	Topic and signification	Source	Frequency of evocation
Convictions and behavioral aspects1	Fatality, symptoms, traditional medicine therapy, alternative medicine therapy	Patient, family	87%
[1]fatalist perception such as "cancer is always fatal", "if you have cancer, there is no escape, cancer is viewed as bad luck" and, consequently "nothing can be done to get rid of cancer".			
Perception and value of time2	Time orientation, Time processing	Patient	65%
[2] emphasis placed on the inner timer of the individual, often very critical about the time processing modality in past, present and future time. Evocations of the patients the regret of erroneous time processing „I should have come earlier" … "I postponed it many times"… "this is how one is, he thinks he will get passed it" … "but it wasn't meant to be" family involvement "I told him many times go to the doctor", "he wouldn't listen", time processing "he stayed at home until he couldn't bear it anymore" and regret for time lost "now it seems it is too late".			
Acculturation3	Originating collectivity, Personal esperience Information transference	Patient, family, friends	81%
[3]"many times it helped me to talk to other patients diagnosed with cancer" and it "was very useful to me" because "I, in turn, told several individuals about my struggle with the disease			
Religion and spirituality3,1	Support, Disease control Awareness of gravity of situation Maintaining hope	Patient, family, friends	91%
[3.1] For the cancer patient, religious assistance is as important as medication or other needs.			
Other aspects 3,2	Profession, legal aspects, personal aspects	Patient, family, friends	NSS No Statistical Significance
[3.2] As a possible explanation for the low frequency of this type of evocation in the dialogue with the students, we believe that the hospital environment represents an inhibiting factor in the unveiling of the convictions of this type.			

Discussion

From the information obtained we noted that a series of cultural conviction and values, such as fatalist perception, spirituality, time processing and acculturation influence health convictions and behavior of cancer patients.

Convictions and behavioral aspects

The accounts obtained by students from the patients are illustrative for convictions of fatalist perception such as "*cancer is always fatal*", "*if you have cancer, there is no escape, cancer is viewed as bad luck*" and, consequently "*nothing can be done to get rid of cancer*". With respect to *symptoms specific* for certain types of cancer (particularly rectal cancer) we noticed a higher reticence in the communication with the doctor and even a decrease of the readiness of the patient to undergo specific investigations. In many cases the family completes informationally the range of behavioral aspects and convictions, emphasizing by the "*tendency of isolation of the patient*", often manifested by silence, denial, avoiding contact or conversations with other people, the fatalist conviction of the patient that "*if I have cancer, it means I have no escape*" (patient with liver cancer) (Adams *et al.,* 2016). These assertions provide explanations as to why in some cases the modalities by which the cancer diagnosis is established become a major obstacle for disease detection and control (Cohen, 2014).

Therapeutic possibilities are also influenced by the fatalist perception (Estape, 2018). We noted evocations that reflect "*reticence…mainly towards surgical procedures*" for which there is the belief (conviction) that "*if they cut (operate), cancer will spread immediately in the entire body*", believing that "*cancer therapy is as bad as (or worse) than the disease itself*". A special chapter is represented by *alternative medicine*, o common situation for many of the patients afflicted by cancer. Many patients state their interest, trust and hope for alternative therapies (naturist, homeopathy, bioresonance, bioenergy etc.), especially when *conventional medicine* does not provide all the answers, guarantees, hopes or removal of convictions (Singh & Chaturvedi, 2015). In the case of opting for alternative medicine one must give attention to the "potential damage" of these therapies that the doctor should present to the patient. We noticed in the reaction manner of the patients faced with the disease the aspects involved in management of behavioral control, where the distinction for mobilization and exploitation of self-confidence, in the capacity of the individual to face the situation, adjust and give up unhealthy behaviors are estimated as real opportunities to build a positive attitude towards health (Klein *et al.,* 2014).

Time perception and value

Time perception highlights the manner of time orientation of the patient faced with this important change generated by the disease, in accordance with the cultural and social system as landmark in time management. From the selected affirmations we noted an emphasis placed on the inner timer of the individual, often very critical about the time processing modality in past, present and future time (van Laarhoven *et al.,* 2011). Thus, in the evocations of the patients, the students observed that in retrospective, the analysis for most patients is defined by the regret of erroneous time processing „*I should have come earlier*" … "*I postponed it many times*"… "*this is how one is, he thinks he will get passed it*" … "*but it wasn't meant to be*" (rectal cancer patient) (Hurwitz *et al.,* 2017). In many cases, we noted the evocations referring to family involvement which disclosed the encouragements to go to the doctor "*I told him many times go to the doctor*", the manner in which they were confronted with the convictions of the individual "*he wouldn't listen*", time processing "*he stayed at home until he couldn't bear it anymore*" and regret for time lost "*now it seems it is too late*".

Acculturation

From the personal context of the response to disease the students recorded information from patients that highlight the type of collectivity to which the individual belongs (rural, urban) and influences exerted on him within the reference group (family, friends, colleagues). We noted the cases where in the absence of a personal experience with disease, the patient adopts the values, behaviors and lifestyles of other individuals (famous persons, miraculous examples). In other cases, the patients transform the perceptions assumed in the representation of the serious disease (Dein, 2004). Concretely, modifications may occur in the self, the ego, such as it can be noted in the statements of these patients *"many times it helped me to talk to other patients diagnosed with cancer"* and it "*was very useful to me*" because "*I, in turn, told several individuals about my struggle with the disease*". Relevant towards this end is the increased value which can be detached from the relationship between culture and cancer, in the sense of mutual support between patients, enabled by the evocation of personal experiences and exchange of useful medical information about common symptoms, secondary effects and modalities of treatment, disease progression, as well as details about specific types of cancer (Matsuyama *et al.,* 2007).

Religion and spirituality

Although the emancipation of society, the development of medicine and medical technology lead to an increased medicalization of the situation of the cancer patient, religious belief still represents a strong resource in the adjustment of the individual to a serious life-threatening disease. For the cancer patient,

religious assistance is as important as medication or other needs (Balboni *et al.,* 2013). Awareness of the seriousness of the situation, with the particularities of the individual progress of the patient is reflected by the comfort which religious beliefs and spiritual values provide. In the data gathered by the students we can identify belief as the key source for maintaining hope. Religious beliefs are expressed in the opinions of patients regarding the disease and the manner in which they can find the necessary calm and support (Gullatte *et al.,* 2010). Even if not all patients frequented the church before becoming ill "*now I go to church every Sunday and I think I will be going more often*". We also noted the signification of the prayer "*I simply changed and I started to pray and to read prayer books*" because for many patients "*it helps to face the disease and the treatment*". The patients who did not assert their membership to a religious community out of personal convictions, considering that *"spirituality is between me and God",* still, faced with the disease "*I started to go to church every Sunday*".

Other aspects

Other aspects with cultural inferences in disease perception are evocation, with low frequency, referring to positive and negative aspects in healthcare provision, legal issues, work issues, personal matters, etc. (Browall *et al.,* 2013). As a possible explanation for the low frequency of this type of evocation in the dialogue with the students, we believe that the hospital environment represents an inhibiting factor in the unveiling of the convictions of this type.

Limits of the study

Although medicine students are, and, in turn, become a reliable information source, through which we can identify cultural influences and impressions in cancer perception, the conversation dialogue practiced during case stages is an empirical stage of research, subjected to limitations with respect to the truthfulness of the perceptions. The development of further studies is required for the establishment and validation of social inferences and effects generated by cancer as a serious disease, with a methodology adjusted to the evaluation measures for cultural beliefs and values.

Conclusion

The approach of cancer from the perspective of cultural beliefs and values expands the medical dimension of the disease towards ethical, moral, social and religious values associated with the behavior towards health and disease. For this stage of the study we believe that the importance of the research resides in the fact that the obtained data can be used in the evaluation of the influences of the cultural

context in the perception of the disease, their assessment becoming obvious and necessary as supplementary value in the management of the cancer patients. The involvement of students in the research endeavor, justified by the ability and skill to transform the scientific contents of the information, supports the educational effort to place an increased emphasis in the educational curriculum of future doctors on the effective exploitation of the potential to correctly acknowledge what cancer represents currently.

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