

What Do People Affected by Cancer Talk about Online?

Text analysis of online cancer community usage in Bosnia and Herzegovina

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Abstract— Studies report that health information searching is among the top three activities on the Internet. Internet resources are a good alternative for initial information and health managing support, due to their accessibility and availability. However, *little is known about the type of support and information that people affected by cancer seek for and exchange via the Internet, in online communities, especially in non-English speaking environments.* To bring light to this important matter, we conducted a text analysis on an online cancer-related forum from Bosnia-Herzegovina. It revealed that the predominant topics of discussion are: *general cancer-related and time-wise discussions, various treatments, diet, doctors and how to interpret medical reports, information exchange on specific cancer-types, advice to caregivers, religious support, and community support to members suffering from cancer.* The most frequently exchanged word referred to the state of: being, being and doing something alone and by oneself. The majority of users of the online community were cancer patients' caregivers. This study represents a starting point for *identifying areas for improvement of online support and information for people affected by cancer, primarily in online communities, specifically for Bosnia-Herzegovina, but can be generalized to countries with similar social, cultural, economic and public-health situation.*

Keywords-online health communities; text analysis; cancer; online health information; Bosnia-Herzegovina.

I. INTRODUCTION

Cancer is still recognized as the leading cause of death worldwide [1]. To this day the “number [of deaths globally caused by cancer] is far greater than the total number of deaths caused by HIV/AIDS, tuberculosis and malaria combined” [2]. The latest worldwide statistics show that 14.1 million adults had cancer [1]. Cancer does not only affect the person suffering from it. It impacts the life of the cancer patient's closest family, extended family and friends [3]. This research refers to *all* the people affected by cancer, which includes those on whose life cancer had a *direct* and *indirect* influence, and even those who are interested in informing themselves about cancer for prevention purposes. The global population affected by cancer is, thus, evidently much larger. Moreover, given cancer prevalence, the duration for which caregivers are needed, in most cases, expands over the period of several years or more [3].

Despite the fact that the health sector is one of the most resistant-to-change industries, *technology adoption for healthcare service improvements* has been witnessed in some countries, but progress and needs are not uniform, even in the Western developed countries [4].

Bosnia and Herzegovina (B&H) was selected as the environment to conduct the study in, due to the particular situation in the country. Public health services in B&H are still in the process of recovery and reform after the 1992-95 war; they are characterized by institutional fragmentation, existence of powerful interest groups, informal payments, unequal access to health care and low service quality and efficiency [5]. Support groups and cancer associations do not cover all types of cancer, are not vocal enough, and are not always easy to access offline.

The accessibility and availability of Internet resources could present a good alternative to people affected by cancer to find initial information and support. Electronic health (eHealth) contributes to disease management by facilitating information exchange between and among interest groups – medical professionals, patients and caregivers, and empowers patients by providing improved online support [6] [7]. However, a preliminary investigation of online health resources in B&H revealed that those from B&H institutions and in Bosnian language are but a few [8]. These are mainly endeavors by non-governmental cancer organizations (NGO) or private initiatives that aim at promoting their activities. Importantly for this study, the information and facilities presented are not always relevant. Information provided is mainly related to general health, and reused from online health services from other countries. Little consideration is given to reliability and comprehensiveness of cancer-specific online support and information. Moreover, the actual needs and interests of the country-specific population who are suffering from cancer are not addressed.

Even worldwide, patient input and opinions are often disregarded in health-related product adoption decision [4]. Nevertheless, when it comes to introducing improvements in eHealth, what is essential is a deeper understanding of how these applications are utilized by the target users, and what they consider useful and easy to use technology [6].

This study addresses an issue in eHealth - *little is known about the type of support and information that people affected by cancer seek for and exchange via the Internet, expressed by their behavior and activities, in online*

communities, especially in non-English speaking environments, as is B&H. The goal was, therefore, to “listen” to the conversations led on the Internet by those members of the B&H population who are affected by cancer. In order to understand what it is they require, the usage of existing online cancer-related information and services was evaluated applying text analysis. This work extracted *topics most frequently discussed in a cancer-related online community*. The classification of topics of interest should serve in devising a set of content- and service-improvement recommendations for online communities for people affected by cancer, especially those from B&H.

This paper is structured around four remaining sections. Section II gives an overview of the research area and the related work. Analysis and results are presented in the third section, followed by a discussion of the findings. The last section concludes the paper and overviews future directions.

II. BACKGROUND AND RELATED WORK

One of the primary purposes of Internet usage is to seek information about health [9]. While the traditional means for obtaining health information have stagnated [10], there has been a worldwide growth in online health information usage [11], but a particularly noticeable increase of around 50% in European countries in the period 2001 to 2009 [10][12]. The Pew Internet Project [13] concluded that 59% of adults in the U.S. have used the Internet to look for health information, usually (55% of the cases) about a specific illness or medical problem, and 43% searching for available treatments; followed by topics related to diet, particular doctor and experimental treatments [9][14]. Moreover, Internet health seekers look in equal percentage (39%) for health and medical information for themselves or for someone else [15].

The research presented here focuses on *online health information usage by people affected by cancer*. In a US based study, approximately 40% of the sample used the Internet to search for cancer-related information [9]. While exploring how Internet usage influences men and women affected by one of five different types of cancer in the UK in the period 2001 to 2002, [16] found that cancer patients used the Internet for three main reasons: the extent of resources available; to secretly verify what was told to them by their physicians; the need to show others and prove to themselves that despite their illness they are socially fit.

Health information available on the Internet is particularly appealing to people affected by cancer, as the sheer amount and variety of this type of information “which could be used by cancer patients for treatment decisions, medical consultations and social support, as well as by non-cancer patients for prevention, screening and risk evaluation” becomes a means to ease their physical and psychological ordeal with this illness [17].

There are various major health portals worldwide, such as the US-based PubMed [18], the UK’s NHS [19], the German GoPubMed [20], as well as those that provide cancer-specific services and support, including the UK’s Cancer Research UK [21] and Macmillan Cancer Support [22], and the US American Cancer Society [23]. The step forward in healthcare is home care, in particular with the

aging of world population and increase in those requiring long term care [7]. Online health resources are the indispensable means for home care, and, thereby, patient empowerment. However, it is often the case that health consumers have to navigate through a sea of information, which is often difficult to understand [24], and sometimes irrelevant [25]. A user affected by cancer, whose needs are very specific, and who receives unsuitable, irritating information, might quickly terminate the visit to the health-website. To increase user engagement, online health services should address three main points: information quality, user interaction and tailoring information to user’s needs [26].

Information better matched to user’s health literacy and health situation, with a particular focus on patients with chronic medical conditions [25], is argued would lead to improved user engagement. Design of web tools for people with special health needs is another consideration. Including patients and caregivers in the decision making process [27] for eHealth design and information tailoring would result in more empowered patients, participating more actively in personal healthcare [14][25].

The lack of B&H online health services was mentioned in the previous section – the lack in number, but also in the provision of cancer-specific support. Some of the B&H health portals with an online presence are: *klix.ba* – a news portal offering health-related news and a forum feature used, among others, by cancer affected population; *port.org.ba* – a portal and community provided by an NGO for people with malignant diseases, mainly offering cancer-related articles from other sources; *source.ba* – a news portal; *srecaadjecu.ba* – a website, by a cancer association helping children suffering from cancer, used to present the NGOs projects and activities; *bhzdravlje.ba* – a health portal offering general health information, provided by a private organization in cooperation with one of the cantonal ministries of health. But often, online resources from the neighboring, similar-language-speaking, countries are used as an alternative, “the next best thing”, solution.

Moreover, in order to evidence patient empowerment, via their improved online engagement, health service providers would have to show interest in exploring and understanding cancer patients’ and caregivers’ needs, to be able to match these with adequate information and support. However, to the best of our knowledge, studies on online health information seeking among people affect by cancer in B&H are lacking. We have addressed this in a previous pilot study [8], which showed that the target population in B&H does use the Internet to seek cancer information - the main reason for going online to seek for cancer information or advice is having someone close diagnosed with a medical condition.

However, this was an isolated study applied to the B&H population, and one that focused on collecting participants’ perception on the matter. A gap still exists in *understanding the actual behavior and activities of cancer affected people in B&H*, and wider, when searching for cancer-related support and information on the Internet. To reduce the global burden of cancer, the specific needs of individual communities have to be addressed, primarily by the public health services, including those provided on the Internet.

TABLE I. FREQUENT WORDS IN THE KLIX.BA FORUM

Selected frequent words in Bosnian	Selected frequent words – translation in English	Weighted percentage (%)
sam	am / have / alone / by oneself	0.79
rak(a)	(of) cancer	0.47 ^a
danas	today	0.40
mama	mom / mother	0.21
bolesti	disease, illness(es)	0.18
godina	year(s)	0.18
nalaze	find, finding, medical report	0.17
doktor	doctor	0.13
terapije	therapy(s), treatment(s)	0.12
tumor	tumor	0.11
piti	drink, drinks, drinking	0.10
vrijeme	time	0.09
bogu	God (to God)	0.09
dojke	breast(s)	0.09
ulje	oil	0.09
b17	Vitamin B17	0.09
user VH	user VH	0.09
lijek	treatment / cure / medication / medicine	0.08
abd	abbreviation for ‘God willing’	0.07
caj	tea	0.07
herceptin	Herceptin ^b	0.07
hemoterapije	chemotherapy(s)	0.06

a. The sum of weighted percentages for rak (cancer) and raka (of cancer), i.e., 0.19 and 0.28, respectively.
 b. Treatment which can be used for breast and stomach cancer.

frequently sought topics found in previous research on target population’s perception. Categorization of forum discussions was self-developed by the authors, nevertheless, it was based on the findings of previous studies [9][13][14] that reported the most frequently searched online health information were the topics included in the 9 categories next presented.

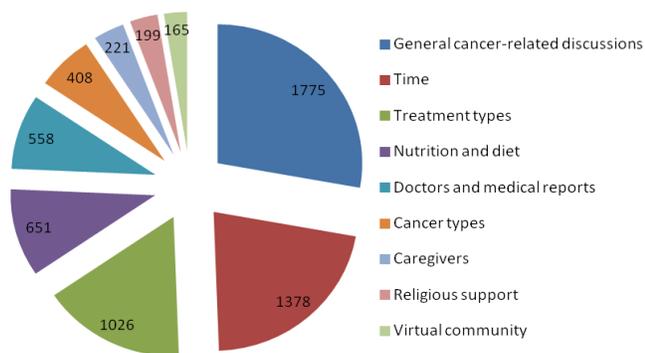


Figure 2. Categories of forum discussions and the sum of frequencies of the consisting words.

The 9 categories are listed below, sorted descending, based on the category level frequency (sum of counts of words making up the category). Each category is assigned the consisting total number of words, after excluding repeating occurrences of the same word (due to misspelling or missing symbols for affricates) and stemmed words.

- *General discussions* about cancer (76 words, e.g., *cancer, tumor, illness*)
- *Time* (45 words, e.g., *year, time*); which could be, but is not limited to, time since cancer has been diagnosed, duration of treatments and cancer prevalence, days stayed in hospital, or when a visit to the doctors is scheduled.
- Various *types of treatment* and medication (51 words, e.g., *therapies, b17 vitamin, cure, Herceptin, chemotherapy*); including alternative and experimental treatment, chemotherapies, and similar, and where to find it.
- *Nutrition and diet* (34 words, e.g., *oil, tea, drink*)
- *Doctors and medical reports* and findings (27 words, e.g., *doctor, find/finding/medical report*); who are the most renowned oncologists in the city, where they can be reached, experience others had with a specific doctor, doctor’s advice given, where specific medical analysis can be conducted, how to read medical findings and what they mean, are all questions asked within this topic category.
- *Type of cancer* (17 words, e.g., *breast, carcinoma, tumor*); narrowing down and specializing experience and information exchange to a specific type of cancer, and part of body where cancer occurred, rather than generic cancer information.
- *Caregivers* (9 words, e.g., *mother*); in this type of discussions, text analysis indicated that participants most often asked for support when a member of their closest family or a friend was affected by cancer, usually their mothers.
- *Religious support* (10 words, e.g., *God, God willing*); belief in God and help by a higher power.
- *Virtual community* (14 words, e.g., *user VH*); personal story sharing by forum participants who are suffering from cancer or are caregivers, and empathy and advice expression by their supporters.

IV. DISCUSSION

As cancer is not a local, but a global issue, all initiatives at supporting the needs of those affect by it resonate at a global level. The sample used for this study was geographically explicit, collected from an understudied population. Understanding what topics concern those who are affected by cancer in online communities around the world, not just in the Western developed countries, has various applications - from developing more geographically-tailored online support, to improved cancer prevention.

People affected by cancer in B&H are taking an action in improving their and their loved ones’ personal health, and/or doing this by themselves, as implied by the most frequent word - ‘sam,’ in the analyzed cancer forum. This study

indicates that women are predominant participants in B&H online health communities. It could be ascribed to the B&H culture, in which being a man still means hiding personal vulnerabilities. Nevertheless, worldwide studies also confirm that it is women who are more frequently online, seeking for health information and support [15]. What is remarkable in the B&H forum case is that the only two participants who were directly affected by cancer, and openly discussing their condition, were men. This occurrence also coincides with the B&H [30] and world statistics [31], which show that cancer is more frequent among the male population. On the other hand, the findings do suggest there is still a need to *encourage the male population affected by cancer to reach out for help and speak out about their health-related problems*. The majority of those using a cancer-related online community in B&H have joined these services in the desire to find *support for their loved one who was diagnosed with cancer*. The *members of the community mainly offer support – both emotional and information related* – to other members, who are cancer patients, or caregivers of cancer patients. Assistance is exchanged in *interpreting the diagnosis and approaching the specific type of cancer*.

The findings imply the primary type of conversation led in online health communities in B&H are those related to general discussions about cancer – admitting to be affected by cancer, the type of illness it is, finding out it metastasized, how it makes the person feel, what impact it has on the person's psyche and body, the pain it causes, help sought, the fight put into it, and similar. This type of online health information – about a specific medical problem, in addition to information on treatments, diet and doctors, has been reported the most frequently sought in Western countries [9][13][14]. However, this study is the first account, to the best of our knowledge, of Internet usage for health information seeking in B&H, based on actual user behavior on online health services, which, moreover, reports on cancer-specific information seeking. Furthermore, the findings show that people affected by cancer in B&H, when participating in online communities, are preoccupied with a type of discussion not commonly reported in previous studies on health information seeking on the Internet, this namely being the *time-related discussions*. They share information about when they had a medical appointment, the date of the next operation, how long they were receiving treatment, how long a loved one battled with cancer, up to a point of sharing how long their doctors said they are expected to live. Turning to online communities seems sensible for this type of personal story sharing; members want to exchange experiences, in an anonymous way, with others who have been in similar situations and, perhaps, to find consolation and a possibility for an alternative outcome. But, it is evident that this is a major concern of people in B&H who are affected by cancer, and thus, effort should be made by health professionals to inform this population about the time-related effects of cancer.

Similar conclusion can be drawn from turning to an online community to interpret medical reports. The *doctors and medical findings* category of discussions implies that health professionals are neglecting to explain the diagnosis to

their patients, and are not cooperating with each other to inform their patients of the best specialists for their type of cancer. The result is that those affected by cancer have to turn to each other for advice from personal experience and for interpreting the doctor's notes on medical reports.

Another issue that was revealed is the variety of types of treatments (especially alternative and experimental) and diets suggested by the forum participants. These include: cytostatic drugs, Herceptin, Laetrile (or Vitamin B17), Zofran, Alimta, Avastin, Melatonin, Ecomer, sodium bicarbonate, cannabis, marihuana, plant roots, oil, petroleum, teas, etc. Many of these are very expensive, have side effects, some are illegal in B&H, and some diets suggested are even of questionable effect on human health. Health professionals and agencies in B&H, should invest into informing about all available treatments, raise awareness about the specific types of treatments and foods, verify or dispute the information exchanged by laymen, and assist in making available to the target population the needed effective treatments.

The frequently occurring categories of forum discussions related to virtual community, caregivers, religious support and time imply that the greatest benefit of online communities for cancer-affected people is, moreover, having a place to express oneself in an anonymous way; exchange experience, talk about the burden of cancer, knowing someone is listening and responding even if all they can offer is empathy and a kind word. Providing additional, *cancer-specific online communities*, assisted by health professionals for information verification, and raising awareness about these online services in the cancer-affected population, *is the type of support that could have a resonating effect*.

To extend this and the previous work [8], and confirm the findings of other related research [16], further ongoing work looks at the cancer patients' motivators for internet-based usage. In future studies, the intention is to explore the relationship between user-created content and their emotions with the application of different text analysis tools, e.g., LIWC: Linguistic Inquiry and Word Count.

V. CONCLUSION AND FUTURE WORK

One of the approaches to reducing the global burden of cancer is diminishing the sense of helplessness and loneliness in those who are cancer sufferers, but also the sense of loss in those who are their caregivers. Electronic health can empower people affected by cancer, however, these online applications have to address the specific requirements of individual communities. This study evaluated the information exchange in an existing online community formed by people affected by cancer in B&H. Thereby, it identified the topics of discussions, type of support required, their concerns and information sought. It is primarily the obligation of public health institutions to take these findings into account to provide the target population the type of support they are evidently lacking. It is also up to online health service providers to offer people affected by cancer reliable information on the identified topics and the form of support this target population voiced a need for via their conversations. Thus, the future direction of this research is to enhance an existing major community platform with

personalized cancer-focused services, and evaluate the end-user acceptance and satisfaction via both actual behavior and

surveyed perception.

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