Oncoinformatics For The Healthcare Professional: Oncology Databases And Blogs
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Citation

Abstract
Medical informatics is a basic biomedical science that has a wide variety of application areas which involve improvements in the management of any information relevant to patient care and community health. Oncoinformatics is an application science under this broad field. This area applies informatics, internet, and interactive technologies with the aim of improving the standards of care for the cancer patient. The rapid growth of the World Wide Web as a tool for global connectivity has impacted the way in which health-related information is distributed and accessed over the internet. Many people frequently use the internet for the searching of drug and other health-related information. Oncoinformatics has enabled the collation of a huge amount of information in the area of oncology. Several oncology-specific databases and blogs that are clinically relevant are described in this paper. The impact of informatics technologies and cybermedicine in oncology is also discussed.

INTRODUCTION
Medical informatics is a basic biomedical science that can be widely applied. It merges the study of computer, decision and cognitive sciences, and other basic fields with biomedical information and knowledge, thus providing the interface between these component sciences and biomedical science itself. Medical informatics is interdisciplinary since its principles can be applied to many areas to help identify and provide solutions to research questions in the fields of clinical medicine, nursing, dentistry, veterinary science, imaging science, public health, and even biology [,]. It studies and applies theories, methods, and techniques to solve pertinent fundamental problems in clinical research [,]. Its applications involve improvements in the management of any information relevant to patient care and community health such as patient and population data, and clinical knowledge [,]. Inherently, the application of medical informatics incorporates two main objectives: to search for new knowledge, and to utilize this knowledge to improve practice in the healthcare setting [,]. Since the ultimate goal is to improve the healthcare of patients, issues like genetics, social, economic and environmental factors, cognitive, emotional and behavioral domains can play a role [,]. In this aspect, no profession can address all these factors thoroughly, even though they all contribute to health improvement to some degree [,].

Medical informatics draws on both the informatics and health services arenas to develop studies and instruments to solve clinical issues in the practical setting [,]. There are many branches of medical informatics, including public and consumer health informatics, imaging informatics and bioinformatics, among others, which refer to their respective applied domains [,]. Oncoinformatics is an application science which is a branch under the broad field of medical informatics. This area applies informatics, internet and interactive technologies with the aim of improving care for cancer patients, and requires the expertise of the various health professions, including oncologists, nurses, and pharmacists. In this paper, we demonstrate how the informatics evolution has impacted healthcare and discuss how these technologies can play a role in oncology practice through several oncology-specific databases and blogs.

THE ROLE OF E-HEALTH IN HEALTHCARE
The role of information technology (IT) has increasingly gained acceptance among practicing healthcare professionals since the beginning of the 21st century, defining a concept known as “e-Health”. In essence, e-Health can be applied in any situation which involves the electronic exchange of health-related data for the purpose of increasing the effectiveness of health care delivery. E-Health aims to improve the quality of patient care, increase the healthcare practitioner’s commitment to evidence-based medicine, and
empower patients with knowledge of their medical conditions in order to improve their communication with their healthcare providers.\[1\]

E-Health has encouraged the use of IT in many aspects of healthcare at local, regional and national levels. Albeit concerns that if not utilized properly could potentially frustrate practitioners and threaten the confidentiality of patient records \[5\]. Many physicians are using electronic order entries for diagnostic tests, treatments, and prescriptions. The advantage of e-prescriptions is their potential to minimize the legibility problems associated with traditional prescription hand-writing. Computer systems can also remind the doctor about potential drug-drug interactions or a patient’s drug allergies through pop-up windows. In some hospitals, inpatient drug orders are bar-coded to ensure that they are given to the right patient. Last but not least, electronic medical records are one of the most well-known applications of e-Health which enables healthcare practitioners to easily access a patient’s medical record.

Although the advancement of technology has provided a great improvement in the safety, quality and efficacy aspects of healthcare, implementation of these systems in clinical practice has been slow. Healthcare professionals need tools which can combine various sources of clinical information so that they can access the information as and when needed. The internet or the World Wide Web (WWW) provides tools for this purpose. With a web browser and an internet connection, a healthcare professional can virtually access any information anywhere in the world, as long as he has the granted rights.

**HEALTHCARE AND THE INTERNET**

The WWW has been changing rapidly since its discovery and creation, and is one of the most significant developments in the history of the internet \[6\]. Healthcare has also rapidly evolved together with the informatics revolution. The rapid growth of the WWW as a tool for global connectivity has impacted how health-related information is distributed and accessed over the internet. Health-related information and data are currently all interconnected electronically in the world of cyberspace \[7\], and the growth and widespread use of the internet and the WWW has enabled both patients and healthcare professionals to use it as an important healthcare information resource. The challenge is for both the healthcare professional and the patient to critically evaluate the vast amounts of available information so as to provide the best care for the patient’s well-being.

In principle, a user can access any health-related information anywhere in the world with a web browser. Multiple online applications have been developed by various organizations and institutions to provide drug-related information to healthcare professionals, patients, and other academic and industrial scientists. A Google search will reveal a large amount of health information websites which are targeted at healthcare professionals. The focus for healthcare professionals is thus to be able to produce new knowledge in medicine and locate trusted clinical information efficiently to cater towards patients’ needs.

**INTERNET AND CANCER**

Cancer patients often seek information from the internet to know more about their disease, available treatment options, and ways to manage their condition. Providing freely accessible evidence-based information on the disease and drug therapies will not only increase their knowledge, but also provide them with better means to participate in the management of their condition. Furthermore, such online databases and software tools will also enable healthcare professionals to keep themselves updated in the latest developments in oncology, and also on proper management strategies for each individual patient. The intention of this paper is not to provide a comprehensive review of all available oncology databases, but rather to give an overview of the resources available for both patients and healthcare professionals, so that oncology practitioners can communicate more effectively with their patients, and also enable the patients to participate in their management more effectively. Table 1 provides short descriptions these databases.
Table 1: List of oncology databases and blogs.

<table>
<thead>
<tr>
<th>Name of site</th>
<th>Description of site</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Cancer Society (ACS)</td>
<td>The American Cancer Society (ACS) is a national organization dedicated to combating cancer. It provides resources and information for patients, healthcare providers, and researchers.</td>
<td><a href="http://www.cancer.org">Link</a></td>
</tr>
<tr>
<td>Cancer.net</td>
<td>Cancer.net is a comprehensive online resource for information about cancer, providing news, research, and support for patients and caregivers.</td>
<td><a href="http://www.cancer.net">Link</a></td>
</tr>
<tr>
<td>CancerCare.org</td>
<td>CancerCare.org is a nonprofit organization that provides free support services to anyone impacted by cancer, including patients, families, and caregivers.</td>
<td><a href="http://www.cancer.org">Link</a></td>
</tr>
<tr>
<td>CancerMD</td>
<td>CancerMD is an online community and resource for individuals with cancer, offering information, support, and networking opportunities.</td>
<td><a href="http://www.cancermd.com">Link</a></td>
</tr>
<tr>
<td>CancerToday</td>
<td>CancerToday is an online community and resource for individuals with cancer, offering information, support, and networking opportunities.</td>
<td><a href="http://www.cancertoday.com">Link</a></td>
</tr>
<tr>
<td>Cancer.org</td>
<td>Cancer.org is an online community and resource for individuals with cancer, offering information, support, and networking opportunities.</td>
<td><a href="http://www.cancer.org">Link</a></td>
</tr>
<tr>
<td>Cancer Connect</td>
<td>Cancer Connect is an online community and resource for individuals with cancer, offering information, support, and networking opportunities.</td>
<td><a href="http://www.cancercare.org">Link</a></td>
</tr>
<tr>
<td>CancerNet</td>
<td>CancerNet is an online community and resource for individuals with cancer, offering information, support, and networking opportunities.</td>
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ONCOLOGY DATABASES FOR PATIENTS

The advent of the internet and WWW has enabled patients to search for health-related information for many chronic diseases, and in this case, cancer. There are currently multiple internet databases that are available for cancer patients, their families, relatives and caregivers. Information on cancer on these sites is usually presented in a manner that can be easily understood by the layman. The goal of these sites is to allow the general public to learn about the condition, available diagnosis and treatment methods, and also how to manage or cope with the situation.

The most common applications are websites from particular institutions, groups, and federal agencies. For example, the National Library of Medicine (NLM) and the National Cancer Institute (NCI) at the National Institutes of Health (NIH) use internet technologies to provide information on research, education and patient care. While the NCI deals mainly with issues related to cancer, the NLM’s database contains a broad range of resources that are related not only to cancer, but also on other areas such as HIV/AIDS, genomics and proteomics, and medical informatics. Besides information on the different cancer types, treatment and management options available; the NCI website also incorporates stories and experiences shared by cancer survivors. The dictionary of cancer-related terms is also useful for the layman to understand and learn about the disease.

Patients can also learn or cross-reference what they read about cancer with the American Cancer Society (ACS) and Cancer.Net websites. The content in these sites are developed, peer-reviewed and managed by oncology healthcare professionals and experts who are members of the American Cancer Society (ACS) and the American Society of Clinical Oncology (ASCO) respectively. While the ACS website also includes a message board which allows information-seekers to carry out open discussions with other cancer patients and oncology practitioners, Cancer.Net provides additional support for cancer patients through practical advice written by oncology experts on how to cope with the emotional and physical aspects of cancer.

OncoLink is a drug information website set up by the University of Pennsylvania which provides information about the various types of cancers and their available treatments. The website has become the web’s first cancer resource, providing news and other information related to the field of oncology. The “OncoLife” and “OncoPilot” sections also help cancer patients detail and record their disease and management plans, so that they can discuss these plans with their healthcare teams. This allows the patients to not only participate more in their own cancer management, but also promote a closer relationship between the patients and their healthcare teams.

The American Association for Cancer Research (AACR) website caters to readers who are interested in oncology-related research. The website not only provides opportunities for collaborations with other research organizations, but also the public and media industry. Their magazine “Collaborations Results” (CR) is targeted at cancer survivors and their families, other patient advocates and scientists in cancer-related fields.

ONCOLOGY DATABASES FOR HEALTHCARE PROFESSIONALS

Databases which are aimed at oncology healthcare professionals are usually more in-depth in nature, and provide more detailed information about the cancer disease, treatment and management plans. Many of the websites are also frequently updated with the latest news and information with regards to oncology practice and research, and some also allow the practitioners to keep abreast with the field through the accumulation of continuing education points. Although this section is not meant to be exhaustive, we outline here the different strategies used by several databases to provide cancer-related information to healthcare professionals.

Healthcare practitioners not only have to keep their knowledge clinically relevant, but also their oncology practice up-to-date. Thus, many websites provide their readers, mainly healthcare practitioners, with information on clinical practice guidelines, practice-related issues, and management and treatment updates. Often, the readers also have access to current practice- and research-related articles that are published in journals. An example is the ASCO website which is not only managed by oncology practitioners in various disciplines and subspecialties, but caters towards its members who are healthcare professionals as well. The Clinical Care Options (CCO) Oncology and Oncology Rounds sites provide current and extensive coverage on clinical and research developments in oncology, including diagnosis, treatment and management approaches. While the content in Oncology Rounds is determined by the Princess Margaret Hospital at the University of Toronto, CCO Oncology covers a broader...
scope of topics from journal articles, conference updates, expert opinions and case challenges. The use of interactive tools such as webcasts is included in the CCO Oncology website as well. This will allow oncology healthcare teams to learn about the latest updates for the management of various cancers.

On the other hand, Adjuvant Online [23] caters towards oncology health professionals through the incorporation of a software program which can estimate the risks of negative outcomes like death and relapse based on patient and tumor-related data. This program could potentially help oncolgists to make better informed decisions about management plans for their patients. However, the program currently caters only towards breast, colon and lung cancer patients.

The BC Cancer Agency (BCCA) cancer drug manual [24] focuses on providing anticancer drug monographs for healthcare professionals in general practice. There are currently over a hundred monographs written, reviewed and edited by the organization’s healthcare team. These monographs are arranged alphabetically based on brand and generic names, and include information on the pharmacological classification of the drugs, their mechanisms of action, pharmacokinetics, uses, side effects and interactions, among others. The National Comprehensive Cancer Network (NCCN) compiles drug information in the form of a drug and biologics compendium, and also provides users with chemotherapy order templates on their website. [25] The scientific rigor of the information contained in this site is based on independent evaluation of scientific evidence, integrated with the expert opinions of leading clinicians from its member institutions which comprise of 21 of the world’s leading cancer centers in the U.S. These websites would be good sources to get information of anticancer drugs and chemotherapy treatments of cancer patients.

**ONCOLOGY BLOGS**

A new kid on the block, known as “blogs” or “web-logs” have been gaining popularity in recent years. This is due to the rapid advancement of the WWW which has enabled the sharing and discussion of information among multiple users. [26] Blogs are analogous to online diaries in which the user frequently updates with whatever they like. These entries or posts are filed in reverse chronological order with the most recent entry at the top of the page. [27] Most blogs are read for their entertainment value, and bloggers commonly relate their daily-life experiences, thoughts and updates as part of their entries. Blogs which are networked among several users usually focus on thoughts of common themes. [28] One feature of blogs is their ability for users to provide immediate feedback and comments on a post. This allows communication in a lighter and less formal way.

Blogs are useful to disseminate and share medical information with the public. While some medical bloggers relate their experiences online, others use their blogs to provide updates from medical conferences which they attend. [29] This can be both an advantage and a limitation for its readers. If the blog contains entries which objectively describe the conference proceedings, this information can be a clinically useful update for the reader. However, blogs are largely subjective since bloggers usually pen their thoughts in their entries. A conference update could potentially be biased towards the view of the blogger if its entry is not sufficiently substantiated with facts. Thus, there must be a balance between the subjectivity and objectivity of the blog entries, and readers should always interpret such entries with caution, bearing in mind the possibility of bias. Nevertheless, blogs can serve as a platform for information about cancer treatments, strategies, experiences, advances, and advice to patients and healthcare professionals. A blogger’s point of view can also provide useful insights to practical issues pertaining to oncology practice.

Several factors should be taken into consideration for a blog to gain credibility, as anyone can put up a blog and this could lead to misleading information being disseminated. A way to overcome this problem would be to provide careful moderation of entries by a well-informed and sensitive moderator. Ideally, this moderator should be a healthcare professional who can critically evaluate posts and provide helpful analysis on the blog entries based on his clinical knowledge and experiences. [30] The cancer blogs at MedicineWorld.org is one such example. [31] An American board certified physician in oncology, hematology and internal medicine maintains the entries posted by bloggers at the site, which can range from personal stories to research news and treatment advances. On the other hand, updated news and information about oncology is also regularly posted by a group of enthusiasts from the Health Sciences Consortium at OncologyBlog.org. [32]

Disclaimers provide a way to inform readers that the blog should not be their only source of oncology information. The Cancer Blog [33] powered by Weblogs Inc. was a popular website set up to share information and generate discussions.
about the many sides of cancer to its readers. However, its bloggers were made up of cancer survivors and enthusiasts. Even though the posts were about reports and updates on the news, it is clear to the reader from the disclaimer at the top of the page that the information should not be substituted as medical advice or professional care.

Blogs hosted by reputable organizations or whom bloggers’ biographies are available could also be a way to gain its credibility from readers. The Archimedes and Précis blogs [24233] published by the British Medical Journal (BMJ) group was set up for the journal Archives of Disease in Childhood (ADC) and maintained by editors Bob Philips and Ian Wacogne. These blogs were intended to communicate to their readers about the latest articles that have been published in the ADC journal, as well as respond to them. The well-known Lancet medical journal has also embraced blogging to provide its readers with updates in the various healthcare fields, with oncology as one of its categories.[3]

The WebMD blog provides biographies of its bloggers who are also health professionals to its readers. For example, its entries on cancer treatments and care are contributed by an academic professor who is also an oncologist.[3] Entries on the General Electric (GE) Healthcare blog target a niche group of readers, the GE Healthcare leaders, to inform them about the activities, projects and events happening within the organization. Lastly, a unique blog site known as Clinical Cases and Images has recently been accredited as an “acclaimed internet resource for physicians and students”.[56378] This blog is different from the others previously mentioned as it showcases a collection of case studies to help medical students, and even professionals, apply their clinical knowledge and practice. Cases are presented on a wide range of topics, and each case provides details on case and medication histories, imaging and clinical examination results, as well as links to other relevant websites.

Despite problems with the credibility of blogs, they can be an invaluable source of information to both patients and professionals if managed properly. As correctly commented by a reader of The Cancer Blog (http://www.thecancerblog.com/2007/09/17/the-cancer-blog-retires/#comments), he notes that major healthcare issues are discussed more extensively on blogs than on academic articles. The interactive format of blogs in the form of readers’ comments is important as it provides rapid and valuable feedback on moral, ethical and legal concerns not available through traditional media sources. The knowledge gained by the reader about disease and treatment options, as well as the sharing of experiences will not only improve the patient’s quality of life, but may also indirectly impact the pharmaceutical care of patients since they can better participate in the management of their conditions.

THE IMPACT OF INTERNET AND INFORMATICS TECHNOLOGIES IN ONCOLOGY

The roles of internet and informatics technologies brought about by the cyber era have been critical in transforming the public’s attitudes towards healthcare and medicine. Albeit the uncertainty as to whether cybermedicine will ever be comparable to non-cyber medicine,[9] the WWW has nevertheless impacted the way healthcare is being practiced today. However, several issues have also arisen from the use of cyberspace technologies which we will attempt to address in this section.

A major concern of the use of cybermedicine is that the information obtained from the internet by patients may conflict with recommendations made by their physicians.[6] This poses a problem in oncology practice, since the miscomprehension of information by the patient can lead to a sense of uncertainty and confusion and may result in him delaying his treatment, or turning to other inappropriate forms of therapy.[7] Some patients may also challenge the authority of their physicians with the knowledge they obtain from the internet.[8] Furthermore, online consultations with health professionals are gaining popularity over the internet,[9] and misunderstandings may result from patients relying on the advice of these “virtual consultants” who might not have a full appreciation of the patient’s health status.

Bioethical issues have also become an increasing concern in recent years, especially with the discovery of pharmacogenetics and pharmacogenomics for complex diseases such as cancer. The privacy and ethical issues with regards to an individual’s genetic makeup, disease susceptibility, prognosis and treatment options have yet to be resolved.[10] The use of telemetry-capable medical tools and biosensors which can electronically link patients and healthcare workers also contribute to eroding the privacy and confidentiality boundaries of the patients.[11] It has been postulated that the uniqueness of an individual will be difficult to distinguish as people become more connected to databases.[12] Furthermore, the ability of a healthcare professional to obtain informed consent from the patient may be compromised when the circumstances under which the
person orally agrees cannot be seen by the healthcare professional.

The WWW has opened up many channels for internet-based promotions of various drugs which claim to improve our health and lifestyles. This phenomenon is not only common with “lifestyle drugs” such as Viagra, [105] but has also caught up with chronic diseases such as cancer. Patients who learn about newer therapies for cancer treatment, such as bevacizumab (Avastin) and erlotinib (Tarceva) for the treatments of advanced bowel and non-small-cell lung cancers respectively, tend to self-prescribe by shopping online so as to get the best treatments for cheaper prices.[59] This poses widespread safety fears for both oncology health professionals and government agencies since cancer drugs can interfere and compromise with the patients’ ongoing treatment therapies. [59] Concerns regarding such online sales of prescription medicines include the fact that some online suppliers may not have the appropriate professional qualifications or healthcare expertise, and some medicines may not be subject to quality and efficacy controls, thus leading to substandard or fake medicines.[59] One of the measures undertaken by the Royal Pharmaceutical Society of Great Britain (RPSGB) in the attempt to educate the public about the dangers of illegal online drug sales is through the use of an approved internet pharmacy logo which helps consumers and pharmacists identify legitimate online registered pharmacies in the United Kingdom.[59]

However, the role of e-Health is not without its advantages. It has been argued that internet and informatics technologies have led to internet users and patients being significant producers and providers of health knowledge, information, and advice.[5258] The proliferation of online health information has encouraged patients to be more well-informed and a greater balance in their relationships with their physicians.[5258] Patients become more empowered and actively involved in their health management and this leads to improvements in practitioner-patient communications, as well as patient satisfaction.[56578]

The formation of virtual communities and online social support groups has also been a critical component of e-Health, particularly in relation to terminal illnesses such as cancer.[55] Besides websites and blogs, other resources such as email groups, discussion forums, chat rooms and newsgroups have also sprung up in response to the cyberage. It was reported that cancer patients shared a large amount of information and found forms of peer support on the internet which might not be available to them through conventional health care.[60] These forms of online social support enabled the patients to share information about their experiences of their illness in a more intimate, emotional and personal manner.[60] OncoChat was an online chat room that was specifically developed to offer such online peer support for cancer survivors, families and friends.[60] The use of online networks for cancer patients also enabled a sense of connectedness and empathy over their survival, which was particularly important for patients suffering from certain cancers which carried specific cultural connotations, such as losing a breast.[60] These patients not only shared their physical pain, but also their experiences and cultural meanings attached to their “womanhood”. Many women suffering from breast cancer also wrote autobiography accounts of their diagnoses and treatments.[60] Besides alleviating the embarrassment or “stigma” associated with certain conditions,[60] breast cancer in this case, these biographies also functioned as “catalysts for recovery” which could also offer therapeutic benefits for the patients.[60]

Thus, the roles between patients and healthcare practitioners have evolved with the information age. Unlike traditional practice of medicine whereby the doctor tells the patient what is wrong and how to get better, this information is as likely to be accessed and produced by the patients themselves in this current information age. In fact, a patient can also highlight various possible therapies, treatments and risks to the practitioner.[60] Informatics technologies and the WWW have provided opportunities for the layman to be more aware of their health and understand the science behind various illnesses. Is traditional therapy being translated to the internet, or has e-Health become a new form of alternative therapy – “e-therapy”? In either case, e-Health is here to stay and will be the driving force for oncology health professionals who continually strive to better their patient care.

THE FUTURE OF ONCOINFORMATICS IN HEALTHCARE

With the advent of e-Health, many informatics and internet applications have emerged for healthcare professionals. Oncoinformatics has enabled the collation of a huge amount of information in the area of oncology. Several websites relevant to oncology have been described, and blogs which provide disease and treatment information and experiences about cancer have also been discussed. However, several other internet applications that have become popular in
recent years could also have a possible impact for cancer patients and healthcare professionals.

Medical wikis are currently gaining popularity after the example of Wikipedia, but they are still in its infancy stages. Two popular medical wikis are Ganfyd, an online medical reference edited by medical professionals and invited non-medical experts, and Flu Wiki, an online resource on influenza-related information such as flu prevention, avian flu and possibly how to prepare and cope with a possible influenza pandemic. To our knowledge, there are currently no “onco wikis” which provide detailed information about anticancer drugs and chemotherapy treatments. It has been argued that the fact that wikis allow anyone to create new information, and alter or edit existing ones can be considered a limitation since this might make its contents inaccurate and unreliable. This translates to a potential healthcare risk to patients should they follow the medical advice proposed. However, this same limitation can be an advantage through a concept known as “Darwikinism” modeled after Charles Darwin’s theory of evolution in which an evolutionary change occurs between individual organisms thorough survival of the fittest. Following this “Darwinian process”, wiki pages undergo an evolutionary selection process alike to that of natural selection in living organisms. “Unfit” sentences or sections are edited and replaced, while “fit” ones are further developed, thus resulting in content which are more relevant and of higher quality. Nevertheless, “onco wikis” which integrate information about cancer treatment strategies and anticancer drug-related information from various large and validated databases are definitely attractive. This will transform the web into a powerful giant database which can be centrally accessed by patients, clinicians and other health professionals in their practice.

Bliki hybrids (combination of blogs with wiki support) and third party applications like a hypothetical “Drugbook for Oncology” in social networking sites such as Facebook or MySpace might possibly be the future for improving patient care as well, since they can be accessed and shared among various network groups of healthcare professionals such as oncologists, pharmacists and nurses for continuing professional development, and where they can all benefit from various expertise and clinical elements, as well as to keep up to date with the latest advances in drug and chemotherapy treatment strategies.

Through interdisciplinary training under the broad field of medical informatics, a new breed of healthcare professionals who have a combination of knowledge and abilities to develop tools that are usable in clinical oncology practice will emerge in time to come.

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