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Review Article

Fighting cancer in the information age: The role of Internet

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Cancer is a major health problem worldwide which is likely to assume alarming proportions in the next two decades. Communication and information have increasingly been considered important in helping people to cope with cancer. The arrival of Internet offers the opportunity to fundamentally reinvent medicine and health care delivery. Medical professionals can now use the Internet for continuing medical education, access latest medical information, for fast confirmation of diagnosis, exchange opinion on treatment strategies and in palliative care. Internet can provide cost-effective and timely ways to deliver a complex mix of interesting and high-quality information and expertise to cancer patients. Patients can also independently search the Internet to know about their illness and treatment options. However, of concern is the quality of information that is available in the 'Net'. Some Internet sites may contain erroneous information on cancer and can pose serious problems. There are also many good sites, which provide quality information on cancer for medical professionals, researchers and patients. This article focuses on how the Internet will aid us in fight against cancer.

Cancer is a disease that knows no geographic boundaries. In virtually every country of the world, it is a major health problem. Despite decades of basic and clinical research and trials of promising new therapies, cancer remains a major cause of morbidity and mortality. The war against cancer is far from over. The post genomic era has now opened new avenues in cancer treatment, which is contemplated to be more effective and specific for tumour cells. The sequencing of the human genome is likely to speedup the identification of factors involved in cancer pathogenesis and lead to an age of individually tailored anticancer drug therapy. However, about half of the global cancer burden is carried by developing countries that ironically have access to only 5% of the resources available to fight the disease[1].

The arrival of Internet[2] offers the opportunity to fundamentally reinvent medicine and healthcare delivery[3]. Internet represents an enormous level of information exchange as over 500 million computers are now linked to the Internet[4]. The Internet has been described as the next frontier in the delivery of health care. Medical informatics and consumer health information systems are expected to emerge as integral components of future medical practice[5]. We are living in a time of exponential expansion in accessibility to medical information. Data that previously would have required hours of research in a medical library now can be found easily by anyone with access to the Internet[6]. Internet is becoming an increasingly important source of information on cancer[7]. Communication and information have increasingly been considered important in helping people to cope with cancer[8,9]. Internet based health information can be shared with many people despite distance and time constraints. Information media by computer is expected to become an important factor that affects health behavior[10]. The Internet and in particular the world wide web (www), has a tremendous potential to provide information for oncologists and their patients about cancer biology, diagnosis and treatment options[11]. This article focuses on the potential role the Internet will play in the fight against cancer.

Information for Clinicians and Oncologists

Communication between patients, family and health care professionals

Internet has permitted clinicians, and other health care professionals, patients, and other consumers to quickly access medical information in unprecedented volume. Such access has the potential to speedup the transformation of th e patient-physician relationship from that of clinician authority ministering advice and treatment to that of shared decision-making between patient and clinician[12]. One of the effects of the rapid development of information technology is that many tasks can potentially be accomplished without face-to-

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face interaction between patients and clinicians. Email for instance, can fulfill all the functions of 'snail mail' and the telephone. It also allows user to participate in group discussions and to obtain and provide medical opinions. Visioconferencing and high bandwidth services are creating new ways for patients and clinicians to interact and to benefit from specialist services not available locally. For example, cancer patients of Kerala can now get connected to the Regional Cancer Center (RCC) at Thiruvananthapuram through the nearest teleclinic and with the help of the doctor at the local teleclinic can access a specialist at RCC for consultation and follow-up[13].

Recent survey has shown that 40-45% of the patients access medical information via the Internet and this information affect their choice of treatment[14]. In a Canadian Cohort[15] consisting of 312 patients indicates that 29% had used the Internet to obtain information about their prostate cancer, with 17% doing so after diagnosis but before deciding on treatment. Twenty-eight patients stated that Internet information influenced their decision about treatment. The patients who used the Internet for health information were younger, and had higher education level. Many clinicians now report that a third or more of their patients are asking them about health information they've found in the Internet, asking them to recommend the best websites for their conditions, and asking for their e-mail addresses[16]. A growing number of patients are asking their clinics how soon they will be offering doctor-patient e-mail, consumer websites, online appointment scheduling and prescription refills, online self care guidelines, online support groups and other online patient services[17]. The growing demand for online patient services poses a dilemma for many clinicians. Some are still uncomfortable with computers or unfamiliar with the Internet. Some doctors are not pleased when patients bring in printouts from the Internet. If they refuse to read them, their patients take it as offence. But if they attempt to review and discuss them, they may precipitate long, inconclusive discussions. And since many Internet aware patients bring information which their doctors know nothing about, such discussion can sometimes be embarrassing. Consequently, some doctors are warning their patients, 'Whatever you do, don't go on the Internet'. A recent literature search[18] turned up 100 studies that attempted to rate the accuracy and completeness of health information on the www, rating ranged from about 15% to 85%.

The diagnosis of cancer is associated with substantial anxiety about prognosis, the availability and effectiveness of treatment and its side effects, and lack of long-term disease control in many cases[19]. Research has indicated that the vast majority of cancer patients want to be informed about their illness, diagnosis and treatment options[9,20]. Even prior to the advent of Internet as a source of medical information, patients have become more informed regarding their case[16] seeking increased amount of information regarding their diagnosis and primarily wanting more information regarding their treatment options. In the past, these patients would rely heavily on health professionals for this information through conversations or from pamphlets, videos, CD's or books available to physicians for office distribution. Some resourceful patients may have navigated through *Index Medicus*[6]. If patients do not get sufficient information there is a risk that they might rely on non medical sources to satisfy their needs[21]. And now patients can find a wide range of information on cancer in the Internet[22]. However, of concern is the quality of information on cancer received via the Internet. The free flow of information on the Internet permits anyone with good computer skills and modem to establish a web site with whatever information one wishes to share. In this respect the Internet becomes a great equalizer: experts, specialists, authorities, professionals, alternative therapy promoters, interested lay people and hucksters all may set up sites containing information regarding specific topic of interest. The study of Biermann and co-workers[6] has shown that some websites on cancer may contain information so out-dated as to be erroneous. "Misinformation" is now a top concern about cancer sites in the Internet[23]. Oncologists now should be better prepared and increasingly ask patients if they are using the Internet, and discuss the information on various therapies they get from the 'Net'. If the oncologists are not acquainted with the information then it behooves them to find out more. Oncologists having access to Medline should look for more evidences supporting these therapies. If the information relates to alternative or complementary therapies, there are websites that look for the best evidence supporting or refuting these treatments e.g. British Columbia (Canada) Cancer Agency website with information on alternative/complementary therapies and the CMAJ series (available online) on these treatments.

Answering patients' questions by e-mail can be surprisingly time efficient[24]. Many of the questions require only a minute or two. Questions can be an-

swered once, in considerable details, then adapted and customized for other patients. Providers who compile list of frequently asked questions or set up online patients group find that they don't have to start again with each new patient. Once they start communicating with their patients online, most clinicians are delighted to discover that it helps them save time, control their schedule, make them more accessible to their patients and help them to provide patients with better guidance and support than before. Clinicians can save additional time by directing patients who are facing a new diagnosis or considering surgery or other complex treatment to websites where they can find in-depth information on these procedures. Patients who visit the Johns Hopkins Medical Center's pancreas cancer site (http://pathology.jhu.edu/pancreas) require only 15 min of face-to-face time with their clinicians to absorb the same information which takes doctors half an hour to explain to their patients who don't use the Internet[17]. The Hopkins site has been visited nearly a million times in a span of one and half years. This is due to the growing popularity of health information online. Quality information aid in better decision-making as the patient understands what's going on. And clinicians need not to tell these patients where their pancreas is.

Continuing Medical Education (CME)

Online information sources over the Internet, now offer excellent educational material with the benefit of low cost and easy access at the desktop[25]. In oncology practice the medical professionals require constant upgradation of their knowledge and skills for providing best medical care to the patients. A number of CME programmes on various aspects of cancer are now being offered online. For more information one can visit the website (http://www.cmelist.com/oncology.htm). These CME programmes are accredited by accreditation councils. Oncologists from developing countries, for example India, can now have access to the state-of-art programmes and latest developments worldwide. Real time demonstration and visioconference via Internet is having the potential to greatly improve the medical care of cancer patients in developing countries[26]. A number of journals related to oncology are also available online. The web addresses of few of them are given in Table 1.

Facilitating diagnosis

Emerging genomic testing methods in the post-genomic era is likely to have a tremendous impact on pathology laboratory testing, especially in the area of molecular classification of neoplasms. Human tissue banking, tissue microarray and pathobioinformatics will greatly influence the pathology laboratories. Specific databases on tissue banking information systems will provide rich resources for pathologists in future[27]. Szymas *et al.*[28] studied the feasibility of the diagnostic accuracy of Internet-based dynamic-robotic telepathology using 83 neuropathology cases. The neuropathologist, operating a robotically controlled motorized microscope over the Internet from 3 different cities, individually reviewed the cases using computer workstations. The mean diagnostic accuracy for telepathology diagnosis was 95% with 2 of 3 observers achieving 100% diagnostic accuracy. Image quality was judged to be sufficient for correct evaluation, and the viewing time which ranged from 2-32 min to establish a final diagnosis by remote video microscopy was acceptable. Generally, user acceptance of robotic telepathology was high. A static image remote consultation network between 11 pathologists in nine European countries was set up. Consultations on 34 different cases were exchanged. The average case document contained seven images, and contained 1.97 Mbytes of data. For cases in which data were recorded, average case preparation and remote consultation time was 55 and 9.2 min, respectively. Transmission time averaged 3.9 min. In subjective impression, reservations were expressed in several cases regarding the confidence that could be given to the diagnosis from the images presented[29].

The morphologic diagnosis of tumor specimens with precise tumor typing, staging, and grading remains the basis of almost all cancer treatments. Thus, a histologic diagnosis of the highest quality should be the physician's priority. In approximately 10-20% of tumor cases, diagnostic uncertainty remains to some extent, requiring a second opinion in determining the biologic behavior, the histogenesis, the grade of dedifferentiation, or any other parameter. Facilitating the communication between pathologists and the exchange of cases, telepathology gains more and more importance. To get benefit from this technical development, the International Union Against Cancer (UICC) has decided to establish a Telepathology Consultation Center (UICC-TPCC) for interested pathologists around the world[30]. The idea is to provide rapid and inexpensive diagnostic aid to pathologists all over the world, offering the possibility of a second opinion in accordance with the UICC-TNM and World Health Organization (WHO) standards[26].

Table 1 — Informative web sites on cancer

Important sites on cancer	
Cancer Information Network	http://www.cancernetwork.com/
Cancer Information Center	http://www.cancergroup.com/
OncoLink: Global Resources for Cancer Information	http://www.oncolink.com
American Cancer Society - Cancer Information Resources	http://www2.cancer.org/wwwDir.cfm?ct=1
CancerLinks	http://www.cancerlinks.edu/
IMPATH - Info on Specific Cancers	http://www.impath.com/cancer/
Oncology Online	http://www.lynx2otn.com/
People living with cancer	http://www.plwc.org
Online Cancer Resources	http://www.acor.org
Cancer Organization	
International Union Against Cancer	http://www.uicc.org/
International Agency for Research on Cancer	http:www.iarc.fr
World Health Organization	http://www.who.int/home-page/
American Cancer Society	http://www.cancer.org/
American Association of Cancer Research	http://www.aacr.org
American Society of Clinical Oncology	http://www.asco.org
National Foundation for Cancer Research	http://www.nfcr.org/
Pan American Health Organization	http:// www.paho.org/
American Lung Association	http://www.lungusa.org/
Canadian Cancer Society	http://www.cancer.ca/
Canadian Cancer Society-Quebec Division	http://www.quebec.cancer.ca
Association of Community Cancer Centers	http://www.assoc-cancer-ctrs.org/
European Organization for Research and Training in Cancer	http://www.eortc.be
National Comprehensive Cancer Network	http://www.nccn.org
Federation of European Cancer Society	http://www.fecs.be
The Indian Cancer Society	http://www.indiacancersociety.org
Hospital and Research Institution in India	
TATA Memorial Centre, Mumbai	http:// www.tatamemorialcentre.com/main.htm
Cancer Research Institute (ACTREC)	http://dbtindia.nic.in/btis/sdics/cri.htm
Regional Cancer Centre, Thiruvananthapuram	http://www.rcctvm.org
Amala Cancer Hospital, Kerala	http://www.amala.com/
Chittaranjan National Cancer Institute, Kolkata	http://education.vsnl.com/cncinst
	http://www.bengalweb.com/calcutta/edu/list.htm
Civil Hospital, Ahmedabad.	http://www.cancerindia.org/
Dharamshila Cancer Hospital, East Delhi	http://www.cancerdch.org/
Dharamshila Cancer Hospital and Research Centre, Delhi	http://www.uicc.org/publ/directory/indchrc.html
GKNM Hospital, Coimbatore	http://www.coimbatore.net/health/cancercenter.html
Apollo Specialties Hospital , Chennai	http://www.apollo-ihc.com/
Cancer Hospital, Ludhiana	http://www.medphysics.wisc.edu
M. P. Shah Cancer Hospital, Gujrat	http://www.mdindia.com/jspexec/gujarat/index1.html
Sidda Cancer Hospital, Chennai	http://www.chennaionline.com/essential/hospitals.asp
Rotary Cancer Hospital (AIIMS)	http://www.india-today.com/iplus/1998_4/cancer3.html
Muni Ashram's Cancer Hospital, Baroda	http://www.baroda.com/diary.html
INCTR (Rajasthan Cancer Cure Hospital)	http://www.inctr.org/membership/listmember.shtml
Hospitals in Asia and the Middle East	http://www.123world.com/hospitals/
Rajiv Gandhi Cancer Institute & Research Centre, Delhi	http://www.rgci.com/
Cancer Welfare Home and Research Institute, Kolkata	http://www.cancercentrecalcutta.org
Kidwai Memorial, Banglore	http://www.kar.nic.in/kidwai/
King Edward Memorial Hospital, Mumbai	http://www.kem.edu/hospital.htm
Specialists'Cancer Centre, Cochin	http://www.specialisthospital.com/spe_canc.htm
Jeevanjyot Cancer Hospital, Thane	http://epages.wedindia.com/india/jeevanjyotcancer
Sanjay Gandhi PGI MS , Lucknow	http://www.sgpgi.ac.in

(*Contd*)

Table 1 — Informative web sites on cancer — (Contd)

Cancer Centers Abroad	
Anderson Cancer Center	http:// www.mdanderson.org/
American Health Foundation	http://www.ahf.org
Beckman Research Institute	http://bricoh.coh.org
Berinstein National Cancer Institute	http:// www.berinsteinresearch.com/stats_files/appi.htm
Dana-Farber Cancer Institute	http://www.dfci.harvard.edu http://www.dfci.harvard.edu/abo/medical/opportunities.asp
Frederick Cancer Research Center.	http://www.research.ibm.com/journal/rd/453/tsaiaut.html
Fred Hutchinson Cancer Research Center	http://www.fhcrc.org
Fox Chase Cancer Institute	http://www.fccc.edu
Geffen Cancer Institutes	http:// www.geffencenter.com/windows/intro.html
Jonsson Comprehensive Cancer	http://www.cancer.mednet.ucla
Kimmel Cancer Centre	http://www.kcc.tju.edu
Kaplan Comprehensive Cancer Center	http://kccc-www.med.nyu.edu/
Lineberger Comprehensive Cancer Center	http://cancer.med.unc.edu
Lombardi Cancer Center	http://lombardi.georgetown.edu
McArdle Laboratory for Cancer Research	http://mcardle.oncology.wisc.edu
Memorial Sloan-Kettering Cancer Center	http://www.mskcc.org
MIT Center for Cancer Research	http://web.mit.edu/ccrhq/www
University of Wisconsin Comprehensive	http://www.cancer.wise.edu
Vermont Cancer Center	http://www.vermontcancer.org
Cancer Research Institutes UK	http://science.cancerresearchuk.org/institutes/?version=1
ISREC - Institut Suisse de Recherche Expérimentale sur le Cancer	http://www-isrec.unil.ch/
The Institute of Cancer Research	http://www.icr.ac.uk/
Ludwig Institute for Cancer Research Brussels	http://www.licr.ucl.ac.be/
Tel Aviv University – CancerResearch	http://www.tau.ac.il/researching-eng.html
National Coalition for Cancer Research	http://www.cancercoalition.org/priorities.html
International Directory of Cancer Institutes and Organizations	http://www.uicc.org/publ/directory/idcio.html
Association of American Cancer Institutes	http://www.aaci-cancer.org/02_new_archive_2000_12_19.html
Research Institute for Radiation Biology and Medicine	http://www.hiroshima-u.ac.jp/english/Research/institutes.html
Hong Kong Cancer Institute	http://www.cuhk.edu.hk/en/research_m.htm
Databases	
Cancer Info Database: Carcinogens	http://www.bccancer.bc.ca/default.htm
National Cancer Data Base	http:// www.facs.org/dept/cancer/ncdb/
CDC Cancer Prevention and Control Database	http:// www.cdc.gov/cancer/natlcancerdata.htm
BC Cancer Agency: Drug Database	http:// www.bccancer.bc.ca/HPI/DrugDatabase/default.htm
IARC P53 Mutation Database	http:// www.iarc.fr/p53/
PDQ, NCI's Comprehensive Cancer Database	http:// www.usc.edu/hsc/nml/e-resources/info/pdq.html
CFRBCS Database	http://epi.grants.cancer.gov/CFR
Head and Neck Cancer Database.	http://www.baoms.org.uk/download/CANCER/WALTON/LIVERDB.HTM
WHO Databank	http://www-dep.iarc.fr/
Prostate Cancer Nuclear Matrix Proteins Database	http://www.lecb.ncifcrf.gov/prostateDB/
Phytochemical and Ethnobotanical Databases	http://www.ars-grin.gov/duke/
New Drug Database	http://www.virtualdrugstore.com/druglist.html
Cancer Care Resource Database	http://www.cancercare.org/database/database_search.html
Breast Cancer Database	http://www.cs.tamu.edu/people/jcj0650/ML/Project4/
Mutation Database	http://www.nfdht.nl/database/mdbchoice.htm
Journal	
CA - A Cancer Journal for Clinicians	http://www.ca-journal.org/
Lancet Oncology	http://oncology.thelancet.com
Acta Oncologia	http://www.tandf.com.uk/journals/titles/0284186x/html

(*Contd*)

Table 1 — Informative web sites on cancer — (Contd)

Cancer	http://www.tandf.com.uk/journals/titles/0008543x/html
Science Journals	http://www.sciencedirect.com/science/journal/03043835
Nature Journals	http://www.naturesj.com/redirect.html
Gastric Cancer Journal	http://www.ramex.com/sv/sv-ele44.html
Oncology: Journal Home	http://www.karger.ch/journals/ocl/ocl_jh.htm
British Journal of Cancer.	http://www.med.rug.nl/mdl/journal.htm
Countway Library of cancer.	http://www.countway.harvard.edu/
Prostate Cancer Journal	http://www.nlm.nih.gov/medlineplus/prostatecancer.html
Cancer Journals Online	http://www.acor.org/leukemia/sites2.html
Medicine Journals - Cancer.	http://www.emedicine.com/journals.html –
Bioline International – journals	http://www.bioline.bdt.org.br/journals
Radiation Oncology Journals	http:// www-radonc.stanford.edu/
Breast Cancer	http://www.tmc.tulane.edu/cancer/links.journals.html
The Cancer Letter	http://www.cancerletter.com/
Cancer Control Journal	http://www.moffitt.usf.edu/pubs/ccj
Cancer biology	http://www.landebioscience.com/journals/cancer.html
Electronic Journal of Oncology.	http://www.elecjoncol.org/Oncolynx/Journals.html
Electronic Journals - CMAJ	http://wwwlibrary.usask.ca/ejournals/08/2/0820-3946.html
Online medical journals	http://www.cancerbacup.org.uk
Free Medical Journals.com	http://www.freemedicaljournals.com
Lung Cancer Online	http://www.lungcanceronline.org
Medicine Online	http://www.meds.com
BBA – Reviews on cancer	http://www.sciencedirect.com/science/journal/0304419X
Breast Cancer On-Line	http://www.bco.org
Nature Reviews Cancer Articles	http://www.nature.com/nrc
European Journal of Cancer	http://www.sciencedirect.com/science/journal/09598049
Cancer Research	http://cancerres.aacrjournals.org
Research Medical Library Anderson Cancer Center	http://www.mdacc.tmc.edu/~library
Online professional journal in oncology	http://www.ipos.aspboa.org/multimedia/journals.asp
Cancer Control	http://www.moffitt.usf.edu/pubs/ccj
Online Cancer Journals & Abstracts	http://www.ipos-aspboa.org/multimedia/journals.asp
Clinical Cancer Research	http://clincancerres.aacrjournals.org
Cancer Links	http://www.meds.com/cancerlinks.html
On Line Medical Dictionaries and Journals	http://www.4woman.gov/nwhic/references/dictionary.htm
American Association for Cancer Research	http://www.aacrjournals.org
Carcinogenesis	http://carcin.oupjournals.org
American Association for Cancer Research	http://www.aacr.org/2100m.asp
Journal of the National Cancer Institute (e-journal)	http://jncicancerspectrum.oupjournals.org/
Indian Journal of Experimental Biology	http://www.niscair.res.in
Cancer Registry	
Cancer Statistics - National Cancer Institute	http://www.nci.nih.gov/public/factbk95/canstat.HTM
Cancer Registries on the web	http://www.ikr.nl/ikr/canregs.htm
North American Assoc. of Central Cancer Registries	http://www.naaccr.org
CDC - National Program of Cancer Registries	http://www.cdc.gov/cancer/npcr
North American Assoc. of Central Cancer Registries	http://www.naaccr.org
Finnish Cancer Registry	http://www.cancerregistry.fi
Thames Cancer Registry	http://www.thames-cancer-reg.org.uk
National Cancer Registry of Ireland	http://www.ncri.ie
Cancer Registry, Chennai	http://icmr.nic.in/chennai.pdf
ICMR Registry	http://rcctvm.org/resposurveillance.htm
CNCI- Regional Cancer Center, Kolkata	http://www.cancerhelp4u.com/cancegcnci.htm
Incidence of Breast Cancer in India	http://www.sunmed.org /cbe.html
Palliative Care	
The American Academy of Hospice and palliative care	http://www.aahpm.org
The Canadian Hospice Palliative care Association	http://www.chpca.net
End-of-Life Physician Education Resources Centre	http://www.eperc.mcw.edu

(*Contd*)

Table 1 — Informative web sites on cancer — (Contd)

European Association for Palliative Care	http://www.eapcnet.org
International Association for Hospice and Palliative Care	http://www.hospicecare.com
National Hospice and Palliative Care Organization	http://www.nhpco.ogr
National Council for Hospice and Specialist Palliative Care Service	http://www.hospice-spc-council.org.uk
Continuing Medical Education	
Online CME Web Sites: Oncology	http://www.cmelist.com/oncology.htm
CME Oncology - Teaching Resources	http:// www.cancerindex.org/clinks4f.htm
Pharmacia Oncology	http://www.pharmaciaoncology.com/DispPage.asp?DType=cme
ASCO - American Society of Clinical Oncology	http://www.asco.org/asco/ascoMainConstructor/1,1003_12-002094,00.asp
American School of Oncology: CME.	http://www.mdnetguide.com/oncology/v3n1/CMEonline.shtml
CME Journal of Gynecologic Oncology.	http://www.cme.hu/
Professional, OnTumor.com	http://www.cancerlinksusa.com/professional/
The Contemporary Oncology CME Program	http://www.lww.com/resources/cmeinfo/contemp-oncology.html
Academy of Medicine: Medical Oncology CPD	http://www.academyofmedicine.edu.sg/cpd/medicaloncology.html
Mayo School of CME Oncology	http://www.mayo.edu/cme/onc.htm
ONCOLOGY – Online Medical Textbooks	http:// www.emedicine.com/ped/ONCOLOGY.htm
Pathology CME Case Database	http://www.upci.upmc.edu/internet/benedum/ path.upmc.edu/cme/Privacy.htm
Physician Oncology Education Program	http://www.poep.org/
The Oncology Center - Cancer Research, CME	http://www.theoncologycenter.com/oc/research.asp
Miscellaneous	
Cancer Care Inc	http:// www.cancercaareinc.org
Cancer infonet	http://www.druginfonet.come/
Cancer Guide	http://www.cancerguide.org
CRC-Cancer Research Campaign	http://www.crc.org.uk
British Columbia – Cancer Agency	http://www.bcancer.bc/default.htm
Wellness Web Cancer Center	http://www.wellweb.com
Oncology drugs – Pharmaceutical Information Network	http://www.pharminfo.com/disease/cancer_db.html
Support-Group.com - Colon Cancer	http://www.supportpath.com
Oncology.com	http://www.oncology.com/
Reducing Your Cancer Risk	http://www.columbia.net/consumer/datafile/redurisk.html
Cancer Kids	http://www.cancerkids.org/
Outlook – Cancer	http://www.outlook-life.org/
Cancer Wellness Center	http://www.cancerwellness.org/
NCCS: National Coalition for Cancer Survivorship,	http://www.cansearch.org/
Cancer Research & Treatment Fund	http://www.crt.org/
ICRF- Imperial Cancer Research Fund	http://www.icnet.uk
Women's Cancer Center	http:// www.wccenter.com/cvakm.html
Cancer-therapy.net	http:// www.cancer-therapy.net/
Nargis Dutt Cancer Foundation	http://www.anglefire.com/ca/ndcf
AM Charitable trust	http://www.cancerhope.org/
CMAJ - Breast Cancer	http://www.cma.ca/cmaj/vol-158/Issue-3/breastqa/guide3.htm
Breast cancer research in Australia	http://www.nbcc.org.au/pages/info/research.htm
Breast cancer research	http://breast-cancer-research.com/weblinks/
Cancer personal stories	http://cc.ucsf.edu/afr/index.html
Steve Dunn's Cancer Guide	http://www.cancerguide.org/stories.html
Cancer Survivors Network	http://www.acscsn.org
Center for Alternative Medicine Research in Cancer	http://www.sph.uth.tmc.edu/utcam/reslnk.htm
Fellowships for Cancer Research - evidyarthi.com	http://www.evidyarthi.com/scholarships/cancerfel.htm

Note – The site were visited on 01.12.2002

Treatment and palliative care

Internet offers new possibilities for multidisciplinary care of cancer patients, allowing direct communications between different complementary and geographically distant specialists. Thus, it is possible to form oncology committees in small hospitals where all specialties are not represented. Studies conducted by Sezeur *et al.*[31] on the medical and economic impact of visioconferences in the therapeutic management of cancer patients without access to oncology centers revealed that visioconference improved management of cancer patients for a weak working cost. Some operated on cancer patients require specialized complementary chemotherapy, often; this takes place in another institution, where the patient consults the medical oncologist before hospitalization. Sezeur and co-workers[32] analyzed the potential benefits of a visioconference consultation in 16 operated on hospitalized cancer patients with chemotherapist from different places. Fourteen of the 16 patients considered that teleconsultation had its advantage. Teleconsultation neither altered the doctor-patient relationship nor the quality of the message transmitted. Furthermore, it encourages closer links between complementary teams working at a distance and multidisciplinarity in cancerology. Some websites e.g. (www.albertapalliative. net, the EPERC project in the USA and the International Association of Hospice and Palliative Care) has excellent information online related to palliative care and supportive care. More information of palliative care is given in Table 1.

Increasingly palliative patients and their families are going online[33]. The study of Klemm and Hardie[34] indicates more depressed patients with cancer use Internet support groups instead of face-to-face support. Traditional cancer support groups can help people cope with their cancer, but the efficacy of Internet Support Groups (ICSG) in providing psychoeducation and psychotherapeutic intervention remain to be proven before it can be implemented effectively. Many health care professionals now argue that relying more on the Internet will further erode the already weak communication link between physicians and patients[35]. However, the number of online support group is increasing. These groups consist of individuals seeking assistance with problems such as depression substance abuse, cancer, AIDS, eating disorders etc. Although online support groups are apparently popular, little is known about their therapeutic efficacy[36]. Content analysis of 300 messages[37] posted on an ICSG were analyzed and eight categories of responses were identified: 1) information giving/seeking; 2) personal opinions; 3) encouragement/support; 4) personal experience; 5) thanks; 6) humor; 7) prayer; and 8) miscellaneous. The ICSG is a means of offering support to cancer patients, their families, and caretakers in a nontraditional format. Medical caregivers should be versed in the use of Internet resources and the advantages (e.g. 24 hours availability, accessibility to the homebound) and disadvantage (e.g. cost of Internet access, lack of a face-to-face communication) for Internet support groups.

Genetic counselling

A recent study[38] on an international population of women about their perceptions of breast health education and risk assessment indicates that Internet is an appropriate medium for health-related research. Family history is an important risk for inherited cancers. Obtaining a family history is therefore a key component of cancer genetic risk counselling. Many clinicians do not have training in cancer genetic counselling. However, it is possible to obtain a basic family history. The family history can help in identifying patterns of cancer transmission in families. Clinicians can then refer families with a strong history of cancer to genetic counsellors, or other qualified to make a further assessment risk. If those resources are unavailable locally, the Internet can be of assistance[39].

Information for Researchers

Scientific information on cancer

Research Institute—Numerous public and private universities, specialized cancer research centers, and private research institutes provide online access to scientific information regarding their ongoing cancer research projects. A starting place for identifying such sites is the National Institute of Health (NIH) website (http://www.nih.gov) which contains links to news and press releases. Some European research organizations, including the UK Medical Research Council (http://www.mrc.ac.uk) and the European Molecular Biology Laboratory (http://www.embl.org) also maintain highly informative website that contains data relevant to cancer research[40]. A list of useful cancer institutions is given in Table 1.

Search Tool—The National Center for Biotechnology Information (NCBI) was established in 1988 as a division of National Library of Medicine (NLM). NCBI's primary search tool is the PubMed biomedical literature search engine (http://www.ncbi.nlm.nih.gov/Entrez), which links several databases containing information on nucleotide and protein structure, as well as genomics, taxonomic structure and other information. The NCBI

Internet site (http://www.ncbi.nlm.nih.gov) contain a number of search engines that serves as useful tools for scientists conducting both fundamental and applied research on cancer.

Epidemiology—The cancer epidemiology link in the Internet, Epidemiology (*Public Health Bioscience Medicine*) (http.//www.epibiostst.ucsf.edu/epidem/epidem.html) maintained by the Department of Epidemiology and Biostatistics at the University of California San Francisco (UCSF) is a useful tool for navigating the Internet for information on human studies. This site contains links to many leading epidemiology programs, including the NCI Division of Cancer Epidemiology and Genetics, the Canadian Cancer Etiology Research Network (CCERN), and the International Agency for Research on Cancer (IARC). The NCI's Surveillance, Epidemiology, and End Result (SEER) program is the most authoritative source of information on cancer incidence and survival in the USA. The Health Canada Cancer Bureau (http://www.hc-sc.gc.ca) conducts cancer surveillance programs and addresses issue ranging from underlying causes to access to palliative care. The WHO Cancer Mortality Databank contains regularly update cancer mortality data. The entire WHO web site can be searched for statistical and epidemiological information via. the WHO Statistical Information System (http://www.who.int/whosis)[40].

Clinical Trials—Clinical trials are the best way to access the latest treatment. Moreover, the only way to move closer to a better care for patients is to participate in well-designed trials such as those described in CancerNet® which provides information on understanding trials, deciding whether to participate in trials and finding specific trials. Information on clinical trials can also be obtained from the NIH NLM Clinical Trials database (http://ClinicalTrials.gov). The NCI sponsored clinical studies can be accessed at http://cancerTrials.nic.nih.gov.

Miscellaneous Information on Cancer—Center for Disease Control conducts several programs for cancer control and prevention of interest to clinicians and researchers through the Division of Cancer Prevention and Control (http://www.cdc.gov.cancer/index.htm). BC Cancer Research Center's Cancer Imaging (http://www.bccrc.bc.ca/ci/index.html) is devoted to information on cancer screening and imaging. Cancer Imaging describes information on current research in early cancer detection for breast, lung, cervical, and skin cancers and serves as a launch for identification and investigation of other sites. Another site of interest is the FDA Certified Mammography Facilities (http://www.fda.gov/cdrh/mammography/certified.html). The Guide to Internet Resources for Cancer (http://www.cancerindex.org/clinks1.htm) and the Cancer Genetics web (http://www.cancergenetics.org or http://www.cancerindex.org/geneweb/) provides information to geneticists and other cancer researchers.

Pointer Sites

There are many collections of excellent information in oncology to be found on government academic, organizational and commercial Internet. Several websites provide large collections of hyperlinks to additional sites about cancer-related topics. These pointer systems also have the common characteristic that they are useful to both researchers and the public. Few pointer sites are discussed below:

i.) CancerNet™ (http://cancernet.nci.nih.gov) produced jointly by the International Cancer Information Center (ICIC), National Cancer Institute (NCI), and the office of Cancer Communications USA is the best place to begin the search for almost any question concerning cancer treatment, staging, diagnosis or care[41]. The NCI websites have recently been revamped and are very user friendly. It provides recent and accurate cancer information for a broad audience. The CancerNet™ website provides www access to peer-reviewed information about virtually every aspect of every common cancer type. From the CancerNet™ homepage, users can branch down different paths for information tailored to health care professionals, patients or researchers. Physician data query (PDQ) (http://cancernet.nci.inh.gov/pdq.htm) is the NCI's comprehensive, computerized cancer information database. It is a knowledge base detailing "original research papers, peer-reviewed summaries on state-of-the-art treatment, supportive care, screening, and investigational drugs" that is updated monthly. PDQ contains the most up-to-date information available about cancer prevention, early detection, and treatment that can be found currently on the Net.

ii.) CANCERLIT© database is especially recognized as a valuable source of information for most cancer researchers CANCERLIT© contains more that 1.5 million citations and abstracts from over 4000 different sources including biomedical journals, proceedings, books, reports, and doctoral thesis. Produced for more than 20 years by the NCI's International Cancer Information Center, CANCERLIT© references a vast realm of cancer literature published from the 1960s to the present.

iii.) CancerIndex (http://www.CancerIndex.org) is a family of resources on cancer. The British web site is noteworthy for its scale and effort to index the information provided. The website is updated regularly and links are periodically verified using a link checker. The main page provides entry into five separate data indices and a 'Quick Browse' function that links to information on the 20 most common types of cancer.

iv.) Oncolink (http://www.oncolink.com) located at the University of Pennsylvania, is often cited as one of the best resources anywhere on the web. It indeed has much to offer for both the patients and the practicing physicians. Although much of the physician's specific information is copied directly from the NCI sit. However, it is presented in a way that is sometimes faster and easier to navigate.

v.) An Indian cancer site (www.indiacancer.org) designed by the oncologists of Mumbai can be of great help to Indian cancer patients. The site is available in three different Indian languages and further translation is in progress[42]. A list of few informative web sites that may be of help to oncologists is given in Table 1.

Information for the patient

Cancer Prevention

The first line of defense against cancer is prevention, especially among those at higher risk. Prevention can involve lifestyle or dietary choice of agents that prevents the initial sages or slow down the development of cancer. At NCI, the Division of Cancer Prevention (DCP) is the primary unit devoted to cancer prevention research (http://www.cancer.gov/prevention). DCP's Nutritional Science Research Group web site gives prevention strategies and general prevention information (http://www.cancer.gov/prevention/nsrg/). Another website for information on the prevention of cancer through diet and nutrition is maintained by the American Institute for Cancer Research (AICR) (http://www.aicr.org). The Harvard Center for Cancer Prevention (http://www.hsph.harvard.edu/cancer) web site is also noteworthy.

Internet resources for patients

Most of those who "surf" the web site seeking medical information have little way of knowing for sure whether what they find is science or snake oil. Not only is this confusing, it can also be dangerous. Trying to get information from the Internet is like drinking from a fire hose, you don't even know what the source of the water is[43]. There are many professional-looking sites that offer little more than anecdote, opinion or inaccurate information[41]. Good quality information for patients with cancer does exist on the Internet[44], but may be difficult to find if users do not use suitable 'gateways'[45]. It is also important to understand that the Internet is very fluid[40]. New sites appear and old sites disappear daily. Government agencies, publishers, manufacturers, professionals trade associations, and academic institutions are constantly upgrading the information available on their Internet websites. Thus, there can be no review that can substitute for the user actually accessing a website and exploring its contents. Although many sites offer high quality information anyone can publish on the Internet. The user should access each information site by asking the following questions. What are the authors' experiences and qualifications? How reliable is the evidence that findings are based on? For medical information, does the site have an editorial board that includes independent medical experts? Can you determine when the information was last updated? How is the site funded, and does this pose any potential conflict of interest?

Once a diagnosis of cancer is received, there is an urgent need to gather as much information as possible on the various treatment options. Patients can obtain selected treatment references free-of-charge from the NCI CIS web page at http://cissecure.nic.nih.gov/ncipubs/. Hundreds of online support groups (for example, self-helpgroup.com) now offer newly diagnosed patients a chance to communicate with experienced self-helpers coping with the same condition[17]. An excellent publication, available online from the American Institute of Cancer Research is the Cancer Resource Manual: A Resource Guide For Those Living With Cancer (http://www.aicr.org/crm-contents.htm) [29].

Support for Patients

Maintained by the National Coalition for Cancer Survivorship (NCCS), CanSearch® (http://www.cansearch.org/canserch/canseach.htm) provides a step-by-step approach to assist persons who have been diagnosed with cancer in finding resources in the Internet. Some of the other sites highlighted by CanSearch® include: the Warren Magnuson Clinical Center (http://clinicalstudies.info.nih.gov) for information on the latest research. M. D. Anderson Oncolog® (http://www.mdacc.tmc.edu:80/~oncolog) which provides general practitioner information on new treatment development; Healthfinder™ (http://www.healthfinder.org) a gateway consumer service information website from the US government; Medicine

On Line-Cancer Information Center (http://www.ons.org), and the American Association for Cancer Research (http://www.aacr.org). The sites also contain extensive information on clinical trial and support from the cancer survivor's perspective. CancerFax® provides cancer information via a fax-back document delivery system. Through CancerFax®, patients and their family and caregivers can obtain PDQ® full-text summaries on cancer treatment, screening, prevention, genetics and supportive care, fact sheets on various cancer topics, and topic searches from the CANCERLIT© database[40].

Information on alternative cancer medicine

Complementary and alternative therapies are quite popular among cancer patients through out the world. These therapies are actually a vast collection of disparate, unrelated regimens and products, ranging from adjunctive modalities that effectively enhance quality of life and promising anti-tumor herbal remedies now under investigation, to bogus therapies that claim to cure cancer and that harm not only directly, but also indirectly by encouraging patients to avoid or postpone effective cancer treatment. Complementary therapies such as acupuncture, herbal tea, music and massage relieve nausea, yoga, tai chi and meditation have shown to be effective in relieving stress and enhancing the wellbeing of cancer patients[46]. Many diet-based remedies may contain harmful ingredients and can result in severe consequences if taken without any proper medical supervision. In a recent incidence[47] a 55 years old man with squamous-cell carcinoma of the maxillary sinus who accessed an Internet web site that proclaimed benefits from hydrazine sulfate for people with cancer. He purchased the chemical from a source identified by the website and forsaking medical supervision, took it for 4 months before presenting with evidence of combined renal and liver toxicity. The patient ultimately died of these complications. Hydrazine sulfate, although of uncertain benefit in management of certain type of cancer like non-small-cell lung cancer. These seem to be little evidence to support its ability to shrink tumors or cure cancer, by the virtue of its inhibition of gluconeogenesis. The Internet has brought a new opportunity to promoters of alternative medicine, allowing free advertisement with few restrictions[6]. Both good information and misinformation that appear in Internet appeal to better educated consumers, who are, in fact, most likely to try complementary and alternative methods[46]. It is essential for patients to inform and discuss with their oncologists before going ahead with any alternative cancer therapy.

Conclusion

The convergence of information and information technologies has aided two vital developments: the emerging field of consumer health informatics (CHI) and interactive health communication (IHC) applications. Because of rapid increase in the availability and adoption of technology in the healthcare community, well-planned and well-developed CHI infrastructure and IHC application are greatly improving the quality of cancer care and research[48]. The cancer treatment scenario for the next two-decades is predicted not to change substantially[49]. Half of the global cancer burden is carried by the developing countries that have limited resources to fight the disease. The use of Internet in developing countries is growing[50] and it will play an important role in the fight against cancer in these countries. Internet offers almost endless possibilities for the delivery of information and education to both care givers and patients. The technologies will go some way to redressing the all too unequal balance between physicians and patients, and if used properly can help patients to be more closely involved in managing their own care. Internet has the immense capability of complementing care, but may not replace skillful face-to-face communication where the health care professionals can respond to verbal and non-verbal cues of patients. It also remains the responsibility of the medical community to ensure adequate quality of online medical content, to educate the public regarding quality measure and to direct patients to sites offering appropriate information.

References

1 Pal S K, Use of alternative cancer medicines in India, *Lancet Oncol*, 3 (2002) 394.
2 Pal S K, Nazir A, Mukhopadhya I, Saxena D K & Kar Chowdhuri D, Internet: A major resource for toxicologist, *Indian J Expt Biol*, 39 (2001) 1207.
3 Coiler R C Jr, The digital transformation of health care, *Physician Exec*, 26 (2000) 8.
4 Gentile J A Jr, Database, websites and the Internet, *Oncology*, 12, 1998, 356.
5 Licciardone J C, Herron K M, Clark A J & Squires D, Clinic-based health information website for international travelers, *JAMA*, 280 (1998) 1310.
6 Biermann J S, Golladay G J, Greenfield M L V H & Baker L H, Evaluation of cancer information on the Internet, *Cancer*, 86 (1999) 381.
7 Sharp J W, The Internet. Changing the way cancer survivors obtain information, *Cancer Pract*, 7 (1999) 266.
8 Coulter A, Evidence based patient information, *BMJ*, 317 (1998) 225.

9 Leydon G M, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M & McPherson K, Cancer patients' information needs and information seeking behaviour, in depth interview study, *BMJ*, 320 (2000) 909.

10 Kim H S, Kim E & Kim J W, Development of a breast self-examination program for the Internet: Health information for Korean women, *Cancer Nurs*, 24 (2001) 156.

11 Glode L M, Challenges and opportunities of the Internet for medical oncology, *J Clin Oncol*, 14 (1996) 2181.

12 Winker M A, Flanagin A, Chi-Lum B, White J, Andrews K, Kennett R L, DeAngelis C D & Musacchio R A, Guidelines for medical and health information sites on the Internet, *JAMA*, 283 (2000) 1600.

13 Sharma D C, India takes to telemedicine for cancer treatment, *Lancet Oncol*, 2 (2001) 128.

14 Meric F, Bernstam E V, Mirza N Q, Hunt K K, Ames F C, Ross M I, Kuerer H M, Pollock R E, Musen M A & Singletary S E, Breast cancer on the world wide web: Cross sectional survey of quality of information and popularity of websites, *BMJ*, 324 (2002) 577.

15 Pautler S E, Tan J K, Dugas G R, Pus N, Ferri M, Hardie W R & Chin J L, Use of Internet for self-educated by patients with prostate cancer, *Urology*, 57 (2001) 230.

16 Ferguson T, Health online and the empowered medical consumer, *Jt Comm J Qual Improve*, 23, 1997, 251.

17 Ferguson T, Online patient-helpers and physicians working together: a new partnership for high quality health care, *BMJ*, 321 (2000) 1129.

18 Ferguson T, From patients to end users, *BMJ*, 324 (2002) 555.

19 Chen X & Sin L L, Impact of the media and the Internet on Oncology: survey of cancer patients and oncologists in Canada, *J Clin Oncol*, 19 (2001) 4291.

20 McPherson C J, Higginson I J & Hearn J, Effective methods of giving information in cancer: a systematic literature review of randomized controlled trial, *J Public Health Med*, 23 (2001) 227.

21 Carlsson M, Cancer patient seeking information from sources outside the health care system, *Support Care cancer*, 8 (2000) 453.

22 Markman M, Cancer and the Internet: The good, the bad, and the very ugly, *Curr Oncol Rep*, 3 (2001) 77.

23 "Misinformation" topics concerns about cancer sites at Internet healthcare coalition's e-health ethics summit, *J Oncol Manag*, 9 (2000) 13.

24 Kane B, Sand D Z for the AMIA Internet Working Group, Task Force on Guidelines for the use of electronic mail with patients, *J Am Med Infor Assoc*, 5 (1998) 104.

25 Norris A C, Essential of telemedicine and telecare (John Wiley & Sons, Chichester, UK) 2002.

26 Pal S K, Pandey G S , Kesari A, Choudhuri G & Mittal B. Telemedicine: E-health and hospital of the future, *J Sci Ind Res*, 61(2002) 414.

27 Becich M J, The role of the pathologist as tissue refiner and data miner: The impact of functional genomics on the modern pathology laboratory and the critical roles of pathology informatics and bioinformatics, *Mol Diagn*, 5 (2000) 287.

28 Szymas J, Wolf G, Papierz W, Jarosz B, Weinstein R S, Online Internet-based robotic telepathology in the diagnosis of neuro-oncology cases: A teleneuropathology feasibility study, *Hum Pathol*, 32 (2001) 1304.

29 Tucker J H, Busch C, Spatz A, Wells C & Brugal G, An experimental inter-expert telepathology network using static imaging, *J Clin Pathol*, 54 (2001) 752.

30 Dietel M, Nguyen-Dobinsky T N & Hufnagl P, The UICC Telepathology consultation centre. International Union Against Cancer. A global approach to improve consultation for pathologist in cancer diagnosis, *Cancer*, 89 (2000) 187.

31 Sezeure A, de Gramont A, Touboul E , Beaugerie L, Gallot D, Cattan S, Betton P O, Carbonnel F, Martel P, Tarlat E, Louvet C, Cosnes J, Housset M & Malafosse M, Contribution of telemedicine applied to digestive cancer, *Gastroenterol Clin Biol*, 23 (1999) 342.

32 Sezeure A, Degramont A, Touboul E & Mosuier H, Teleconsultation before chemotherapy for recently operated on patient, *Am J Surg*, 182 (2001) 49.

33 Pereira J, Bruera E, Macmillan K & Kavanagh S, Palliative cancer patients and their families on the Internet: motivation and impact, *J Palliat Care*, 16 (2000) 13.

34 Klemm P & Hardie T, Depression in Internet and face-to-face cancer support group: A pilot study, *Oncol Nurs Forum*, 29 (2002) E45.

35 Bottomley A, Cancer support groups – Are they effective? *Eur J Cancer Care*, 6 (1997) 11.

36 Fintgeld D L, Therapeutic groups online: The good, the bad and the unknown, *Issues Ment Health Nurs*, 21 (2000) 241.

37 Klemm P, Reppert K & Visich L, A nontraditional cancer support group, The Internet, *Comput Nurs*, 16 (1998) 31.

38 Thomas B, Stamler L L, Lafreniere K & Dumala R, The Internet: An effective tool for nursing research with women, *Compt Nurs*, 18 (2000) 13.

39 Loescher L J, The family history component of cancer genetic risk counseling, *Cancer Nurs*, 22 (1999) 96.

40 Junghans T B, Sevin I F, Ionin B & Seifried H, Cancer information resources: Digital and online information resources, *Toxicology*, 173 (2002) 13.

41 Sikorski R & Peters R, Oncology ASAP, Where to find reliable cancer information on the Internet, *JAMA*, 277 (1997) 1431.

42 Jagannath P, Indian website aims to improve cancer awareness, *Lancet Oncol*, 3 (2002) 206.

43 Wilson P, How to find the good and avoid the bad or ugly: A short guide to tools for rating quality of health information on the Internet, *BMJ*, 324 (2002) 598.

44 Gatherer L, News paper reading is a good predictor of information needs, *BMJ*, 321(2000) 47.

45 Gillies M, Access to the information should be made easier, *BMJ*, 321 (2000) 47.

46 Cassileth B R, Evaluating complementary and alternative therapies for cancer patients, *CA Cancer J Clin*, 49 (1999) 362.

47 Black M & Hussain H, Hydrazine, cancer, the Internet, isoniazid and the liver, *Annals Internal Med*, 133 (2000) 911.

48 Mayer D K & Hubbard S M, Consumer Health Informatics. Silva J S, Ball M J, Chute C G, Douglas J V, Langlotz C P, Niland J C and Scherlis W L (Eds.) Cancer Informatics: Essential technologies for clinical trials (Springer, New York) 2002, 329-354.

49 Cavalli F. The future of oncology: More of the same, *Lancet*, 354 (1999) siv42.

50 Pal S K, Singh M K, Pandey G S & Mittal B. Internet resources for human geneticist. *Indian J Exp Biol*, 39 (2001) 503.