

## **CONSUMER HEALTH INFORMATION: A BRIEF CRITIQUE ON INFORMATION NEEDS AND INFORMATION SEEKING BEHAVIOUR**

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### **ABSTRACT**

*A brief analysis of information seeking by consumers regarding health information. The field of consumer health information is emerging slowly but surely, as consumers strive to understand diagnoses, maintain states of wellness, or even practising precautions to avoid known triggers of illnesses.*

**Keywords:** Consumer health information; Health informatics; Information needs; Information seeking behaviour; User behaviour; User needs.

### **INTRODUCTION**

*“The development of the information society has been technologically driven ... Yet in human terms the provision of greater services does not necessarily mean the satisfaction of needs... We have embarked upon profound changes in methods of communication, yet have not bothered to find out about the nature of the communities that these technologies are intended to serve.”*

*Trevor Barr (1985).*

This paper intends to put into perspective the information needs as well as information seeking behaviour as regards health information. As globalisation extends into the far reaches of the world via information technology (the Internet in particular), there is a current shift towards giving patients more responsibility for their healthcare decisions. What was traditionally a paternalistic arena, the medical fraternity is slowly awakening to cultural changes in the delivery of care.

‘Patient education’ implies that a person with a sickness or disease needs to be educated about the condition afflicting him. Where physicians as well as hospital-based information services are designed to react to this need for information, most times there is a gap as regards the fostering of a proactive approach to improved lifestyle or what is now more popularly known as a state of ‘wellness’.

Among the reasons for the emerging paradigm (paternalistic doctors versus encouraging patient involvement) for both communicating and disseminating consumer health information is the fact that the health industry is fast becoming an expensive necessity within the societal structure. The proactive government

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and industry health care initiatives help the consumer in managing his health by empowering him with decisions in maintaining a state of health so as to avoid unnecessary visits to the doctors, thus limiting the increasingly high expenditure charged by the health industry.

Other reasons include comfort levels of life ‘after’ visits to the doctor. Physicians necessarily attend to the physical problem at hand, but are rarely concerned about pain management after the treatments, medication, etc. Also, there is currently a myriad of sources that may be utilised in the dissemination of health information. Libraries are seen as a non-threatening and inexpensive channel for the masses, as well as the ever-growing access to the Internet. With science and medicine reducing global mortality rates, an ageing society would also benefit from access to health information.

In other words, patients need information to :

- (a) understand what is wrong
- (b) gain a realistic idea of prognosis
- (c) make the most of consultations
- (d) understand the processes and likely outcomes of possible tests and treatments
- (e) assist in self-care
- (f) learn about available services and sources of help
- (g) provide reassurance and help to cope
- (h) help others understand
- (i) legitimise seeking help and their concerns
- (j) learn how to prevent further illness
- (k) identify further information and self-help groups
- (l) identify the “best” healthcare providers. (Coulter, 1999)

In 1995, a Consumer Health Information “White Paper” was drafted by the US National Information Infrastructure (NII) Task Force (Patrick and Koss, 1995), which gave credibility to the long simmering consumer need as regards information concerning health. The White Paper defines consumer health information as “any information that enables individuals to understand and make health-related decisions for themselves or their families.” The White Paper itemises consumer health information as that including :

- (a) information supporting individual and community-based health promotion and enhancement,
- (b) self-care,
- (c) shared (professional-patient) decision making,
- (d) patient education and rehabilitation,
- (e) using the health care system and selecting insurance or a provider, and
- (f) peer group support.

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From the perspective of the consumer, consumer health information can be actively sought or provided for through public or private education campaigns targeting specific health issues, which, in all fairness, encompasses a whole gamut of information content (essentially the who-what-how-where-why-when-how much?), as well as being available from varied sources and locations (library, doctor's waiting room, health store, supermarket etc). It is with this in mind that the yardstick for the effectiveness of consumer health information is measured not only by how rapidly and completely desired messages are communicated, but also by how completely changes in behaviour occur. The apex of consumer health information then, is the educational process that takes place only when the knowledge and understanding changes a person's behaviour (such as smoking cessation).

In summary, consumer health informatics is designed to empower customers by putting their own health information into their own hands. In this aspect however, it is best to remember that attaining information does not necessarily amount to information utilisation.

### **SOURCES OF CONSUMER HEALTH INFORMATION**

Literature gathered for purposes of this paper came from CD-ROM bibliographic and full-text databases, printed journal serials, as well as e-journals. To assess the relevancy of these papers, several common themes were identified. Foremost was the trait that the information seeking behaviour concerned was in the context of health information. Papers concentrating on specific interest groups were also of importance (cancer, multiple-sclerosis, etc) because these groups would enable the analysis of specific information seeking patterns. From the available literature, resources upon which the group turned to for the desired information could then be identified.

That these studies utilised a diverse array of data collecting protocols was also important. Where qualitative data from open interviews, or at the very least, semi-structured interviews, would elicit more in-depth information, several studies used solely questionnaires, which were rigid in form (Health on the Net, 1999; Pennbridge, Moya & Rodrigues, 1999). One study even managed to collect information through a diary where details of telephone calls made as well as the content of conversations were noted down (Williamson, 1997).

It is pertinent to note that the outcome of this paper is of a limited nature and would not have general application as the literature analysed was too large in scope.

## **CONSUMER HEALTH INFORMATION NEEDS**

Darby (1997) notes that information about treating ill-health is gained from a variety of sources, and on an on-going basis. From a consumer's position, information sought depends on factors such as knowledge gained from previous experiences, the particular context of the need, the availability of the sources, as well as the nature of the medium of information.

As itemised by Kai (1996), in most cases there arises an information need for:

- (a) advice on the management of the illness
- (b) explanation and details that are specific as well as practical, to help make decisions about the likely cause of an illness, how to assess the severity, and when to seek professional advice
- (c) implications of the illness
- (d) treatments that are available, and
- (e) potential for prevention in the future.

According to the literature, the first authoritative source of information that consumers go to for health worries, is still the health professional or physician. Although much has been said about self-caring behaviour and the availability of over-the-counter medication, consumers still go to doctors to evaluate their illnesses. Williamson's study (1997) for example, shows that 98% of her respondents offer the view that doctors as well as other health professionals were the most authoritative and used sources of health information (Table 1).

Table 1: Sources of Health Information

	<b>Percentage</b>	<b>Source</b>	<b>Reason</b>
1.	98%	Health professionals	Most authoritative and significant source of information.
2.	93.1%	Family / friends	Other people's experiences, reassuring to hear and discuss with others.
3.	88.6%	TV	Health programmes, informercials, commercials.
4.	87.1%	Newspapers	'incidental information'
5.	71.3%	Printed information	Pamphlets especially, but also books.
6.	69.8%	Radio	'incidental information'
7.	61.9%	Magazines	'incidental information'
8.		Other sources	Information centres (including mobile exhibits), government departments or local councils, hospitals, community health centres, health food shops, health insurance funds, organisations like National Heart Foundation, health videos, etc

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The second most important source of information seems not to be gleaned from further 'authoritative' sources (books, journals etc) but from family and friends. Almost all the literature covered showed that there exists interpersonal communication as regards finding out more about the illness or disease. Most consumers are apt to enquire more from personal networks – questions ranging from the basic facts to the how-to for wellness and comfort. As Wollin et al. (2000) points out, at the time of diagnosis, people tend to look for information about the disease or illness, as well as its social impact. It is only later on perhaps, that practical information becomes more important and personal networks come in handy at this juncture.

The mass media's role in disseminating information is also undisputed. Williamson (1997) shows that television plays the most important role as opposed to other forms of media. Publicity campaigns, specific health programmes as well as incidental bits of information found from TV dramas, all help in disseminating information to the consumer. Kai (1996) also notes that the most important factor about information sources is their accessibility to the consumer. He finds that although the mass media is particularly popular (magazines, TV dramas, publicity campaigns), most of his participants project that they would be most receptive to illustrated booklets with photographs, as well as to videos.

Another source of information that seems to be picking up in popularity is the Internet. The March-April 1999 4<sup>th</sup> Health on the Net Foundation Survey (1999) showed that there was an increase in the utilisation of the Internet for health and medical purposes. The 4<sup>th</sup> survey attracted some 4,368 responses compared to 1,863 responses for the earlier 3<sup>rd</sup> survey (May-June 1998). With the growth of the World Wide Web, there seems to lately be a growth of an information source that is both invaluable as it is therapeutic. More and more consumers are turning to online support groups for the wealth of information that members can offer (Eaglesham, 1996).

Other sources of information from whence consumers seek information are varied. Public libraries play a role if books or other "serious" literature are needed. Hospital libraries or information centres also play a role in housing information in the form of pamphlets, handouts, and videos. These forms of literature can also be found at pharmacies, health food shops, community health centres, and supermarkets. Some consumers opine that they are also very receptive to information disseminated at doctors' waiting rooms (Kai, 1996). It is evident then, that consumer health information seeking is prevailing all around, limited only by how in-depth is the required information.

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In all this flurry of information seeking however, it is perhaps peculiar that there exists groups of patients who do not wish to find out more about their illness(es). The study by Leydon, et al. (2000) for example, has shown that cancer patients' attitudes to their illness as well as their strategies for coping can constrain their wish for information and their efforts to obtain it. A diagnosis of cancer (or any other fatal illness) may invoke uncertainty, fear and loss, which logically, may well be alleviated by information. The vast majority of patients want to be informed about their illness, but it is also recognised that patients vary in how much information they want. Then again, the amount of information needed also changes during the subsistence of the illness.

## **CONSUMER HEALTH INFORMATION SEEKING BEHAVIOUR**

In discussing information seeking behaviour of consumers regarding their health, it is important to keep in mind the variables that come as part and parcel of any study. In this respect, Nayga (2000) points out that there are a large number of factors that have been found to influence the extent of external information search. Of these, three basic groups can be identified:

1. *individual characteristics* that influence the information seeking behaviour (Ippolito and Matthios, 1990). This is further influenced by various other demographic factors like age, gender, ethnicity and education (Katona and Mueller, 1955).
2. *time pressures* which affect the types of information used in decision-making. Variables here include employment status as well as income.
3. *beliefs and perceptions* whereby the more a consumer feels that his / her health is likely to suffer in the future, the greater the perceived risk. Research (Feick, Hermann and Warland, 1986) on consumer risk suggests that perceptions of risk motivates people to accept reasons for increased information search.

Whilst it is undisputable that the first source of information in health information seeking is the physician (or any other health professional), many consumers are hesitant to enquire or delve deeper into the problem at hand when in their doctor's presence. According to Kai (1996), parents, (for example) often face dilemmas about whether to seek their doctor's advice. There is a strong desire to share responsibility for assessment of the illness with a professional, but often there is guilt or worry that these professionals are bothered unnecessarily. "Although parents sought more information from their doctors, they could feel uncomfortable or lack confidence in making their real concerns to the doctor. They were wary of questioning professionals' authority, and conscious of pressures on the doctor's time."

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Further, doctors tend to be patriarchal or paternal in their ministrations. Coulter (1999) interjects that “patients are often seen as ignorant children in need of instruction and reassurance, rather than as experts in their own needs and preferences. Benefits of interventions are emphasised, risks and side-effects glossed over, and scientific controversies hardly ever mentioned.”

Another factor that contributes to consumer’s hesitance when faced with doctors is “the apparent mystique of the professional’s assessment” (Kai, 1996). When a child sounds raspy, for example, the physician might pronounce her chest ‘clear’. Or the very general nature of the assessment itself (‘bug’ or ‘viral infection’) causes confusion, provoking anxiety rather than reassurance; sometimes even anger.

Consumers are also baffled when trying to make sense of the management of an illness, particularly when the attending physician’s prescribed medication or treatments vary from one doctor to another. These unsatisfactory assessments due to vagueness often lead the consumer to the question of whether the doctor actually knows what’s going on. There is generally a feeling of helplessness, which urges the consumer to want to actively participate in the treatment so as to diminish these feelings. And it is precisely this feeling of helplessness that provides the impetus to seek for further information.

Top most on the resource list is interpersonal communication. Generic information is readily available of course, and scholars have argued the effectiveness of the mass media in disseminating information, but from the literature, personal contact seems to be the preferred choice when responding to individual needs. ‘Personal networks’ can be defined (Valente and Saba, 1998) specifically along certain dimensions such as friendship, social support, professional advice and so on. Personal networks can influence an individual’s behaviour by providing information about, influence for (or against) and access to an innovation. Valente and Saba (1998) further reiterated that information may be priceless, but interpersonal communication is necessary for behaviour change to occur. And what good is information if it is not adopted into a consumer’s lifestyle?

Because the personal element of health professional / consumer relationship may have all the above-mentioned problems as well as the impracticalities of providing face-to-face education, patients and their families need to be aware of other sources of information. Support groups provide one avenue. The self-help movement is part of a post-modern philosophy, which embraces the notion that patients possess valuable information about themselves and need to become equal partners in the process of their therapy. “Self-help groups are based on the idea that people have what they need to help themselves and can be assisted in

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accessing this knowledge by people who have dealt with similar experiences. Trust is placed in ordinary people helping each other with their difficulties. While these self-help groups do not reject the involvement of professionals, they are not considered essential for recovery or change to occur.” (Eaglesham, 1996)

The World Wide Web now provides another aspect to this method. The popularity of online support groups begins perhaps with the perception of anonymity that the Internet offers. Computer groups have the benefit of not requiring physical presence, which may be good in the sense that patients may want to move beyond a label, diagnosis or difficult experience, or whom may have problems with face-to-face meetings. On the flip side of the coin however, online groups also offer an opportunity for unscrupulousness.

Participants of such groups noted feelings of belonging, camaraderie, and having a sense of community. However, it has to be ascertained beforehand, whether absence of physical proximity is well and good for the patient. In some cases, it has been found that these patients become more isolated and develop further difficulties (Eaglesham, 1996).

Use of the written text has also been shown as an important feature of online support groups as it helps accomplish relationships. A written record of their own as well as others’ responses are kept, and having the time to consider what others have written (as well as taking the time to consider their own posts) prove both beneficial as well as therapeutic.

The World Wide Web has also enabled a new emerging feature within the support group. There now exists ‘a new kind of patient’ who spends hours and hours on the Internet learning about their condition, communicating with other patients and clinicians who share their interests and tracking down every lead they can find on the best new treatments. “If it’s not the patient, then it’s the niece, or cousin, or the son or daughter...” (Ferguson, 2000)

Although these patients do not have the physician’s broad knowledge, their knowledge of their own condition can be impressive. Because they are patients themselves, certain topics which clinicians consider secondary but are important to the patient (quality of life, impact of their disease on their friends and family, the psychological aspects of the illness etc) can be emphasised. These patients appreciate both the patients’ as well as the clinicians’ points of view. In turn, the knowledge that they have amassed serves to help others in their endeavours in making sense of their conditions. This new genre of patients is now well recognised as ‘patient-helpers’ within the medical fraternity.



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It is also due to the World Wide Web that consumer health informatics is really taking off. Consumers are finding out more and more for themselves, without surrendering to the helplessness that comes with patriarchal doctors. The Internet has been touted as an invaluable source in information searching, and it would serve the consumer well to be wary of every quack that posts health information on his website. According to the HON survey (1999), a worrying 34% of the respondents actually profess to have no opinion about information quality.

In his article, Eysenbach (2000) notes that the quality control of health information on the Internet rests on four pillars :

- 1 educating the consumer
- 2 encouraging the self-regulation of providers of health information
- 3 having 3<sup>rd</sup> parties evaluate the information
- 4 enforcing sanctions in cases of dissemination of fraudulent or harmful material.\*\*

Consumer health informatics is paving the way for healthcare in the information age. Where previously medical informaticians looked at medical practise mainly through the eyes of health professionals rather than through the eyes of patients, this focus is changing due to the emergence of evidence-based medicine, and the growing awareness of the need to equalise relationships between health professionals and lay people.

“Information technology and consumerism are synergistic forces that promote an ‘information age healthcare system’ in which consumers can, ideally, use information technology to gain access to information and control their own healthcare, thereby utilising healthcare resources more efficiently.” (Eysenbach, 2000).

Obviously, while these systems do not and cannot replace visits with physicians, they can, however, make such encounters more productive for both doctors and patients. Consumer health informatics will no doubt attempt to systemise and codify consumers’ needs, values and preferences, as well as enable research into how the information is digested and is best presented.

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<sup>1</sup>\*\* ongoing projects include :

- MedPICS Certification and Rating of Trustworthy Health Information on the Net (MedCERTAIN). Available at <http://www.medpics.org/medcertain/>
  - <http://www.quick.org.uk>
  - <http://www.discern.org.uk>
  - <http://hitiwed.mitrotek.org/>
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## **INFORMATION BLOCKERS**

At the other end of the spectrum there exist pockets of consumers who have no wish for further information on their conditions. For example, in 1980, Ingelfinger, at that time an oncologist and editor of the *New England Journal of Medicine*, reported that when he discovered he had cancer, he did not want all available information, nor to have to face the uncertainties of the different treatment choices offered to him. This goes to show that information may be ignored or avoided by patients, regardless of their prior knowledge or occupation.

In their study concerning cancer patients, Leydon, et al (2000) synthesised that this “information blocking” (as opposed to “information seeking”) results from three factors; faith, hope, and charity. Firstly, information is not actively searched for because of these patients’ faith in their doctors (perception of “doctor-knows-best”). Some patients believe that (and undeniably, as some have found) additional information can confuse their situation even further. Although it is recognisable that medical information can be difficult to understand at times and as such, too much information may sometimes confuse the patient as to available treatments. Some patients feel that ignorance is bliss, and yet there are others who think that information seeking might be perceived as transgressing their role as being a good patient, who would “do as you’re told” and “be a good customer”.

Hope also plays a large role in information blocking. A sense of hope, although closely linked to fear, is indispensable for survival. For some, this translates into avid searching for information (particularly for alternative treatments) and yet for others, hope meant limited searching or even total avoidance of new information. This is because at different times, information seeking was halted due to fearful or contradictory information, which often confuses treatment decisions already made. Some patients resolve this conflict by calling on other patients and lay contacts to help judge between conflicting accounts. Some avoid information seeking simply as a means to avoid the risk of uncovering information that could threaten their hope.

The third factor, charity, acts as a supporter of faith and hope. Although these patients acknowledge that frequent visits to their doctors are beneficial in helping to interpret additional information, patients express concern about taking too much of their doctor’s time when other patients were waiting to be seen. By comparing their situations with others, patients perceive that their situation was better, and thus try to rationalise their attitude towards a rationed health service.

Hope and fear are indeed intertwined, and in this respect, perhaps knowledge of what the clinical facts mean is not always priceless. Sometimes it is too threatening. These patients, it would seem, do not wish to know the hows and whys of their illnesses. Ignorance is indeed bliss because then 'what you don't know won't hurt you'.

## **FUTURE DIRECTIONS**

### **Information Centres and Libraries**

Consumer health informatics is a branch within our healthcare system that is fast developing. Although always concerned with the patient, the focus of healthcare has now shifted from the eyes of the healthcare provider to the eyes of the patient. Consumerism, it seems, has arrived; and the customer is always right. Due to the varying degrees of information required by consumers, information providers must know the balance between too little and too much information to deliver. Too little, and the consumer is left confused as to his situation. Too much, and the consumer is still left confused with his situation. Information providers, be they health professionals or the lay librarian, must endeavour to be efficient in their role as gatekeepers to information and knowledge. As gatekeepers, the information needed may be kept locked up, or be freely accessible to those who require it, and as gatekeepers, it is their role to ensure that they are able to point the consumer in the right direction.

According to Dahlen (1993), even in the economically depressed early 1990s, large public libraries added to their health collections. However, in analysing health related requests, a majority of patrons seeking health information in public libraries are high school or college students working on assignments and adult users seeking personal health information. It therefore stands to reason that it is in the information providers' best interest to ensure that existing resources and information centres are not under utilised.

As the Internet grows in popularity as an information source, libraries have got to pick up their feet and follow suit. Information is a commodity, and libraries are still an unobtrusive and inexpensive channel through which health information can be obtained. There is a need to coordinate efforts in indexing and updating consumer health information. Hospital libraries as well as public libraries would no doubt benefit if there were integrated and central (or regional) repositories maintaining consumer health information. Libraries can then assist patients and consumers alike in scripting specific questions to be asked, refining aspects of those questions, or providing options for expanding queries. Further, according to Dahlen (1993), libraries are acceptable vehicles for disseminating information.

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Dahlen (1993) also recommended that there should be improved mechanisms for translating research summaries, abstracts and results into popular formats. As Kai (1996) had mentioned previously, the key to information seeking is the medium's accessibility. With the Internet, a lot of these problems are alleviated, but it also has to be borne in mind that despite the wide availability of communication technology and devices to improve safety and quality of life, the average older person lives without using any of them.

When it comes to consumer health information, the role of libraries has yet to be thrust into the limelight. Libraries need to take a proactive approach in collecting and disseminating health information. Access to information is not just about providing bibliographic citations, but to satisfy the consumer's demand to locate such information through databases comprising important aspects of health literature.

### **Electronic Channels for Communications**

Many doctors today have exchanged e-mail addresses with their patients. Fast becoming a feature within the healthcare system, doctor-patient e-mail is fast evolving as a method for the patient to seek more information, or simply to clarify certain situations. Not yet recognised as a useful tool in consumer health education, e-mails have the very benefit that most patients crave for – that of interpersonal communication. What better way to communicate than with your own doctor and without the hesitance that fly in the face of most patients when they come face-to-face with their physicians. With e-mails, consumers can draft out their queries as and when the need arises, and the physician is able to ensure that the patient is well and cared for.

In Malaysia, 'telemedicine' is a popular buzzword that has claimed legal recognition via the Telemedicine Act 1997, but has to date, remained a concept that has yet to take off. Defined as the practise of medicine using audio, visual and data communications, telemedicine is perhaps the best launch pad Malaysia has in utilising as well as disseminating consumer health information.

Telemedicine is not only about the technology but also concerns the process that focuses on the individual to provide greater access and increased knowledge on healthcare. Telemedicine promises to empower the individual in managing his own health, and integrates information so as to allow the smooth flow of services and products throughout the whole system. In effect, telemedicine will play an ever increasing role in the future of healthcare in Malaysia, and offers a mechanism for reversing the healthcare pyramid, that is, healthcare through the eyes of the consumer.

Apart from that, the recent adoption of 'smart cards' to replace Malaysian identity cards (NRIC) also act as enablers of consumer health information. The

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idea that the individual's health records can be ingrained into the card for ease of reference would technically mean that health information can be tailored to the individual's needs. Should he require information about his condition, any health information provider would instantly be able to pinpoint and allocate materials of interest to him. Also, smart cards enable the sharing of health information between the masses. Any individual with a rare blood type, for example, need no longer worry about the availability of blood reserves should he be involved in an accident, because these smart cards would enable the keeping of a database of such information. Support groups as well as networks can also be identified regionally in accordance with the address programmed into the smart card.

One factor need to be noted. The application of these technologies in this manner necessarily means the encroachment of privacy. And until and unless the legalities are ironed out, these technologies will remain possibilities, and remain dormant resources.

### **CONCLUSION**

According to the HON survey (1999) the use of the Internet for medical and health purposes have indeed increased in recent years. Five major trends could be detected:

- (a) Baby-boomers, now entering middle-age, are by far the largest user group
- (b) Use of the Internet for medical and health-related information is growing strongly in Europe, especially in the medical profession
- (c) Medical and health information on the World Wide Web is increasingly perceived as 'useful' by consumers
- (d) A big majority believe that the quality of information needs to improve, and the longer users have been on the Net, the more they appear to emphasise this need.
- (e) A worrying 34% from non-medical professions profess to have no opinion on information quality.

However, although this is so, another survey (Pennbridge, Moya and Rodrigues, 1999) has also shown that physicians and healthcare providers have traditionally been responsible for both providing health information and maintaining the confidentiality of medical information, and they remain the most trusted sources of health information. This consumer trust remains despite projections that the Internet will be used by millions of Americans for their health information, and the recognition that the Internet can provide emotional support groups for those with specific conditions. It is also possible that most individuals are unlikely to make medical records available via the internet even if protected through encryption etc.

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It must be borne in mind that with all this talk about obtaining and disseminating information, the point that is most important is the impact that the information will bear on the consumer. No amount of information will be useful if it does not bring about behavioural change. The information will in fact be useless if it remains that, and fails to become practicable knowledge.

When relating consumer health information seeking behaviour to theory, Dervin's (1992) sense-making approach seems to apply perfectly. Dervin points out that information seeking occurs when the individual needs to make sense within their confused states and that they need to form some new sense of the situation before being able to move on. This occurs when a diagnosis is made, and the patient is all agog about his illness. To 'move on' the patient needs to understand his condition, and make sense of the complications that might arise. The information need, as Dervin further points out, is situation bound, and thus makes each situation unique in itself.

The significance of Dervin's approach is the fact that it focuses on the individual. As the information need varies, the level of need also varies from patient to patient, from the need to avidly search for more information, to those who only wish minimal exposure. Dervin's situation-gap-use model also aptly describes the changing level of information needs as the illness progresses. The sense-making that patients are faced with is constantly being altered and refined as the patients' strives to accept and understand his illness.

The world is slowly changing, and healthcare is of no exception. The emergence of the World Wide Web has indeed taken a stronghold, and we are still in the process of putting up the framework upon which to live by. Until the infrastructure is in place, consumer health information will continue to evolve. One thing is for sure is that, in the move towards becoming a knowledge society, information is the commodity, and information seeking will hopefully become second nature.

## **BIBLIOGRAPHY**

Barr, Trevor. 1985. *The electronic estate : new communications media and Australia*. Ringwood, Victoria : Penguin Books.

*British Medical Journal* [e-journal]. Available at <http://www.bmj.com>

CAPHIS (Consumer and Patient Health Information Section, of the Medical Library Association). 1990. *Levels of response to information seeking behaviours in a specialised consumer and patient health information service*. Handout from a Medical Library Association poster session, May

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- 21 1990. Available at [http://caphis.mlanet.org/resources/MLA\\_HIC\\_poster\\_.html](http://caphis.mlanet.org/resources/MLA_HIC_poster_.html).
- Chalmers, Iain. 1995. What do I want from health research and researchers when I am a patient? *British Medical Journal* [e-journal]: 310:1315-1318 (20 May). Available at <http://www.bmj.com/cgi/ijlink?linkType=FULL&journalCode=bmj&resid=310/6990/1315>.
- Coulter, Angela. 1998. Evidence based patient information. *British Medical Journal* [e-journal] ;317:225-226 (25 July). Available at <http://www.bmj.com/cgi/ijlink?linkType=FULL&journalCode=bmj&resid=317/7153/225>.
- Coulter, Angela, Vikki Entwistle and David Gilbert. 1999. Sharing decisions with patients: is the information good enough? *British Medical Journal* [e-journal]:318:318-322 (30 January). Available at <http://www.bmj.com/cgi/ijlink?linkType=FULL&journalCode=bmj&resid=318/7179/318>.
- Dahlen, Karen Hackleman. 1993. The Status of health information delivery in the United States : the role of libraries in the complex health care environment. *Library Trends*, Vol.42, no1: 152-179.
- Darby, David N. 1997. *Seeking information for self-caring behaviour*. Available at <http://marketing.byu.edu/htmlpages/achr/proc97/darby.htm>.
- Dervin, Brenda. 1992. From the mind's eye of the user: the sense-making qualitative-quantitative methodology. *Qualitative Research in Information Management* : 61-84.
- Dicker, Andrew. 1995. Patients' views of priority setting in health care: an interview survey in one practice. *British Medical Journal* [e-journal]: 311:1137-1139. Available at <http://www.bmj.com/cgi/ijlink?linkType=ABST&journalCode=bmj&resid=311/7013/1137>.
- Eaglesham, Susan L. 1996. *Online support groups : extended communities of concern*. Ph.D thesis.Virginia: Virginia Polytechnic Institute and State University. Available at <http://www.scholarlib.vt.edu/theses/available/etd-28>
- Eysenbach, Gunther. 2000. Consumer health informatics. *British Medical Journal* [e-journal], 320:1713-1716. Available at <http://www.bmj.com/cgi/ijlink?linkType=FULL&journalCode=bmj&resid=320/7251/1713>.
- Feick, Lawrence F., Robert O. Hermann, and Rex H. Warland. 1986. Search for nutrition information: a probit analysis of the use of different information sources. *The Journal of Consumer Affair*, Vol.20, no.2:173-192.

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- Ferguson, Tom. 2000. Online patient helpers and physicians working together : a new partnership for high quality health care. *British Medical Journal*, Vol.321:1129-1132 (4 November). Available full text in UM Expanded Academic ASAP Int'l Ed. (online database).
- Hanley, Bec, et al. 2001. Involving consumers in designing, conducting, and interpreting randomised controlled trials: questionnaire survey. *British Medical Journal* [e-journal], Vol.322:519-523 ( 3 March ). Available at : <http://www.bmj.com/cgi/ijlink?linkType=ABST&journalCode=bmj&resid=322/7285/519>.
- Health on the Net. 1999. *HON's fourth survey on the use of the internet for medical and health purposes*.1999. Available at <http://www.hon.ch/Survey/ResumeApr99.html>.
- Impicciatore, Piero., et al. 1997. Reliability of health information for the public on the world wide web: systematic survey of advice on managing fever in children at home. *British Medical Journal* [e-journal], Vol.97, no.314:1875 (28 June). Available at <http://www.bmj.com/cgi/ijlink?linkType=ABST&journalCode=bmj&resid=314/7098/1875>.
- Ippolito, Pauline M. and Alan D. Mathios. 1990. Information, advertising and health choices: a study of the cereal market. *The Rand Journal of Economics*, Vol.21:459-480.
- Kai, Joe. 1996a. Parents' difficulties and information needs in coping with acute illness in preschool children: a qualitative study. *British Medical Journal* [e-journal], Vol.313: 987-990 (19 October). Available at <http://www.bmj.com/cgi/ijlink?linkType=ABST&journalCode=bmj&resid=313/7063/987>
- Kai, Joe.1996b. What worries parents when their pre-school children are acutely ill, and why: a qualitative study. *British Medical Journal* [e-journal], Vol.313:983-986 (19 October). Available at <http://www.bmj.com/cgi/ijlinks?linkType=ABST&journalCode=bmj&resid=313/7063/983>
- Katona, George C. and E. Muller. 1955. *A study of purchase decisions. In consumer behaviour. The dynamics of consumer reactions*. New York : New York University Press.
- Leydon, Geraldine M., et al. 2000. Cancer patients information needs and information seeking behaviour : in-depth interview study. *British Medical Journal* April1, Vol.320, no.7239: 909. Available full text in UM Expanded Academic ASAP Int'l Ed. (online database).



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- Malaysia. 1999. *The Telemedicine Act 1997*. Act 564. Kuala Lumpur : Percetakan Nasional Malaysia.
- Marshall, Joanne G. 1993. Issues in clinical information delivery. *Library Trends*, Vol.42, no.1:83-107.
- Nayga, Rodolfo M. 2000. Nutrition knowledge, gender, and food label use. *Journal of Consumer Affairs*, Vol.34:97. Available full text in UM Expanded Academic ASAP Int'l Ed. [online database].
- Patrick, Kevin. and Shannah Koss. 1995. *Consumer health information "White Paper"*. Information Infrastructure Taskforce, Working Draft 15 May. Available at <http://nii.nist.gov/pubs/chi.html>.
- Pennbridge, Julia; Rita Moya and Lakeshia Rodrigues. 1999. Questionnaire survey of California consumer's use and rating of sources of health care information including the Internet. *The Western Journal of Medicine*:302. Available full text in UM Expanded Academic ASAP Int'l Ed. [online database].
- Valente, Thomas W. and Saba, Walter P. 1998. Mass media and interpersonal influence in a reproductive health communication campaign in Bolivia. *Communication Research*, Vol25, no1: 96-124.
- Williamson, Kirsty. 1997. *I can tell you a remedy for migraines. Telecommunications and the information and communications needs of older adults*. Information and Telecommunications Needs Research (SIMS), Monash University, 1997. Available at: <http://www.infotech.monash.edu.au/itnr/reports/remedy.html>.
- Wollin, Judy, et al. 2000. What people with newly diagnosed MS (and their families and friends) need to know. *International Journal of MS Care* [serial online], Vol.2, no.3. Available at: [http://www.ms-care.com/a0009/page\\_04.htm](http://www.ms-care.com/a0009/page_04.htm).