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An Information Model for Cystic Fibrosis (CF) Patients and Carers

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Abstract

“...it is often forgotten that most healthcare is self care...” **Vickery & Lynch (1995:551)**

In Australia, Cystic Fibrosis (CF) is the most common serious genetic condition in children today affecting one in every 2,500 births. The nature of chronic diseases requires collaborative care from a team of professionally qualified clinical staff and family carers. To meet the challenge of CF a family carer and patient need the knowledge and training to participate in the daily treatment regimen. In the last five years, the Internet has also been gaining ground as a source of information for chronic conditions (Harris 2004). However, people are suffering from an overload of information that is being made available on the Internet. This research presents a model that illustrates the many information sources required to support CF patients and carers over the stages of the disease, and provides a framework for dissemination of information by healthcare providers.

Keywords

Chronic disease, Cystic Fibrosis, Internet, Information Model

Introduction

An increasing number of people are turning to the Internet for health-related information (Sammer 2000). There are literally thousands upon thousands of articles that are available to assist consumers and health professionals with information, that can empower patients and carers of patients with chronic illnesses to become involved in the self-management of that disease (Lorig & Holman 2000). The preparedness of informed patients prior to a clinical consultation may provide cost savings by reducing consultation time and/or the number of visits, and should also result in more satisfied consumers as they are more aware of the information required to treat themselves or their family member. This preparedness can also assist a traumatised person to feel more in control of the options with which they may be faced when their specialist discusses a future of living with a chronic illness.

Since chronic diseases are now the main cause of mortality and morbidity (Cheah 2001), and approximately 75 per cent of health budgets are allocated to costs associated with chronic diseases (Wagner 1998), more economic and alternative methods of treating patients need to be considered. This is required to reduce the incidence of episodes of care and the subsequent cost of the provision of healthcare services. Healthcare can be

delivered more effectively and efficiently if patients with chronic diseases take an active role in their own care, and programs are being established to assist patients in self-management by providing information for people living with a chronic illness.

Chronic diseases normally cannot be easily cured and last over long periods of time. In all chronic diseases, but especially those that affect a person throughout their life, there will always be a close relationship with a range of health professionals. They provide the ongoing support to ensure, for example, that a child continues to develop and remains in good health into adulthood for as long as possible. There are questions, however, that are not necessarily clinical in nature that people need to ask and would like to be able to discuss with like-sufferers.

Cystic Fibrosis (CF) is a major and terminal chronic disease, which has not received the same high profile focus as other chronic illnesses such as cancer, arthritis and diabetes. Cystic Fibrosis is a genetic disorder, which is inherited through both parents being carriers of the CF gene. Patients with CF, and their carers, are particularly dependent upon their own care initiatives and regimens for the treatment of this chronic disease. For most cases of this inherited condition, this is so from birth to a premature death at an indeterminate and often young age.

Cystic Fibrosis is a serious, lifelong condition (Super, Barnes & Greg 2001). The diagnosis of a person with CF in recent years has occurred more frequently at birth in Australia, although a number of people are still diagnosed as adults. In the US newborn screening is only occurring in less than ten states. The patients or carers of the person diagnosed, invariably go into the shock cycle, often as a result of a lack of understanding of what CF means. How people deal with post diagnosis shock, and how information regarding CF is acquired and its sources, varies. However, there is an increasing percentage of the population that go on-line to the Internet to gain a better understanding of what CF is, and the treatment options available.

As with many other conditions there is often a period of time when CF is suspected from various symptoms, but without a firm diagnosis. The prospective patient and/or carer may seek information on the disease for support and guidance at such a time, particularly those living in remote areas or a distance from clinicians who specialise in CF. The virtual communities, or disease-related support groups that transcend geographical constraints, can be a life-saver to the carer.

At the time of diagnosis, in Australia, patients and parents are briefed by hospital clinical staff, and are provided with leaflets explaining the different aspects of the disease, such as physical and mental impacts, the daily treatment regimen, and the medications to be applied. Advice on managing the family and psychosocial or emotional issues is also made available. The information is comprehensive, but people diagnosed with a disease such as CF, and the family supporting the patient, have their own specific questions that need to be answered. These invariably come later, and often at a time when relevant CF specialist support is not always available.

The Internet is a media that is being used to seek advice prior to any visit to a health professional, often as a means of preparing a list of relevant questions that may be addressed with the general practitioner or medical specialist. The empowerment of patients, and the carers of people with a chronic disease, is a focus for Internet-based Web sites providing support and advice for chronic disease management (<http://www.healthservices.gov.bc.ca/cdm/patients/index.html>). Chronic disease management sites are designed to assist patients and carers to manage their treatment regimens, find appropriate community support, cope with psychosocial issues, and receive advice regarding how to communicate with family and friends, and medical and other healthcare professionals (<http://www.healthservices.gov.bc.ca/cdm/patients/index.html>).

The information needs of people change as the disease progresses, and also at different stages of the patient's life; for example at adolescence, prior to and during organ transplantation, and close to death. People's thirst for information and knowledge tends to be consistent with their requirement for patient or carer empowerment, and the Internet increasingly provides a medium for patients and carers to search on their own initiative for information relevant to their condition and circumstances.

Empowerment of Patients and the Changing Role of the Carer

Patient empowerment means "that patients have the right to make their own choices about their health care" (<http://pages.hosting.Domain direct.com/>), and to facilitate that empowerment requires that patients be provided with the most appropriate information services, at the right time, in a convenient place and in an appropriate format (http://www.nelh.nhs.uk/nsf/inprimarycare/chronic_disease/self_care.ntm). The amount of information available on the Internet is extensive, and during times of trauma, people need to be able to locate disease information that is relevant, both quickly and easily.

With health funding availability consistently a challenge and, the cost of the treatment of the chronically ill expected to continue to increase, Lewis and Dixon (2004) stress the importance for health organisations to provide support to patients with complex case management needs. They further advocate empowering patients to manage their own health care planning. For this to occur, it requires a collaborative effort between the healthcare provider and patient (Von Korff et al. 1997; Holman & Lorig 2000; Lewis & Dixon 2004).

The ageing population and the move to a model that supports the treatment of patients in the home, has seen a need for the changing role of the family or informal carer. The term 'carer' came into common usage in the 1970s (Heaton 1999), with the emergence of more people living with a chronic illness at home, and being cared for by an informal, family or primary carer. Informal carer has been shortened over time to be recognised as 'carer', which is defined as "those who are providing regular and substantial care"

(Department of Health and Social Services Inspectorate 1996:15). The person performing this role may be a family member, relative or a friend of the person suffering the chronic disease. In most cases of CF, the carer is the mother of the child or children suffering from CF. Siblings often provide assistance with treatment regimens, relieving the carer of arduous daily activities.

Chronic diseases, such as Cystic Fibrosis, that have a daily treatment routine, require patient and family carers to have sufficient knowledge of the disease to assist with the physiotherapy to be given several times a day, medications and dietary needs with every meal. This is essential to ensure that the child sufferer is receiving sufficient nutritional support, exercise and relief to combat the effects of the disease.

Information Availability

Generally, patients and the carers of the patient diagnosed with Cystic Fibrosis are provided with booklets explaining in simple terms what CF is, the dietary, medication and treatment requirements, and the frequently asked questions about the disease. Videos are also available and are provided to people who are interested in learning more about the disease. These materials are prepared by the CF Association or Trust, hospitals and CF clinics. CF associations in each State of Australia are a major source of information for patients and carers, with regularly produced newsletters, patient leaflets, guidance to relevant references and Web sites, and general articles regarding the disease.

Increasing Importance of the Internet for Health Consumers

Internet communities provide a means for a group of peers to communicate with each other. They include discussion boards on Web sites, mailing lists, chat rooms, or newsgroups (Eysenbach & Till 2001). These Internet-based communication facilities are available for people to express emotions, to seek answers to questions, to find information and to provide advice to others 24 hours a day.

Internet postings are accessible for quantitative and qualitative research. Eysenbach and Wyatt (2002) explain that there are three different types of Internet-based research methods. The first is passive analysis such as “studies of information patterns on Web sites or interactions on discussion groups” (Eysenbach & Till 2001: 1103). The second method of online research is through active analysis in which researchers participate in communications (Seabold & Kuiper 1997). Finally, the third type of Internet-based research gathers information in the form of online semi-structured interviews, online focus groups, Internet based surveys, or by using the Internet to recruit participants for ‘traditional’ research (Eysenbach & Till 2001).

People normally under-estimate the value that is gained by asking other patients and their carers about how their illness affects them. By comparing these findings with existing data sources, this can yield useful information (Baker 2000). It needs to be remembered that the use of the Internet for communicating and sharing healthcare information is little more than ten years old. In the coming years it will become feasible to undertake investigative research that evaluates the effect of Internet and web information on the long term care of CF patients.

Research Objectives

The aim of this research has been to explore the information needs from a lay-person's perspective, of adult patients and carers of children with CF. A particular emphasis has been to investigate the increasing use of the Internet by patients and carers.

The problems explored and analysed in this research have involved the challenges that adults with CF, and carers of children with CF face when trying to find information regarding this disease. The model of information needs that has been developed may also be equated with many other chronic diseases from the perspective of a patient or carer. Chronic disease generally affects people other than the patient, has differing requirements during the different stages of the illness, and has many available sources of information. The reliance of both adults and carers of children with CF on undertaking so much of their own treatment also critically rests upon their access to appropriate CF healthcare information.

Families have to cope, and all seem to seek advice from other people who have experienced similar worries, regarding how to manage the daily treatment regimen, or how to ensure that other siblings receive sufficient attention, when so much focus is being placed on the child newly diagnosed with CF. They have to learn how to communicate with family and friends about the impact that Cystic Fibrosis is likely to have on the child, and how it will change the daily routines of the family. At these challenging times, people turn to a range of sources for information, and these include CF specialists, the CF Association and the Internet. Depending on the problem to be addressed, for example, the need to understand medication directions, and any side-effects of a medication, people will search the Internet for information. Where the issue is emotional or psycho-social, sufferers prefer the opportunity to talk to others in person.

As an alternative to hard-copy, information on CF on the Internet is increasing at a prolific rate, perhaps even exponentially. In the context of this research study, the Internet exhibits advantages for CF patients and carers over hard-copy information such as:

- Accessible instantly 24 hours a day, and 7 days a week (assuming availability of a PC and an Internet connection).
- Not constrained by a geographic locality, that is, information is available from almost anywhere in the world.
- Information on the latest diagnosis and treatment techniques occurring in the world (compared to those of local service providers).
- Communication with other CF patients and carers (anonymously, if desired) anywhere in the world, who otherwise would remain unknown.

- Fast search capability that is unavailable with hard-copy information.

Information on the Internet can be easily updated by health service providers and at minimal cost, compared with the time and cost to re-print hard-copy materials.

At the same time people are suffering from over-load from the amount of information that is being made available on the Internet, and Cystic Fibrosis is no exception.

Research Findings

The research determined that there is a need for an information model that is structured to mirror the needs of patients and carers through the disease's various stages. The axis of the structure in the form of the different stages of the CF patient's struggle for life is derived from a consolidation of the literature research, and the content analysis of bulletin boards, and the informant interviews. It is a structure that reflects a CF patient and carer's demand for relevant information, of a certain type and category, and at times when it is most needed. The format of this more standardised structure will make it easier for patients and carers to access and interpret. In essence, the model attempts to provide a consolidated view, from a lay-person's perspective of the differing information needs during the phases of the CF disease. The model also emphasises that patients and carers may require this information either on-line, or in hard-copy from an alternative source to the Internet.

By encouraging the chronically ill to participate in their own health care through keeping patients and carers better informed, it will not only ensure that the future will see more collaborative and better informed healthcare, but should also result in cost efficiencies in healthcare delivery.

A synopsis of the information model, and the research's conclusions and recommendations will be presented at the conference.

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