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CHESS: Ten Years of Research and Development in Consumer Health Informatics for Broad Populations, Including the Underserved

David H. Gustafson, Robert P. Hawkins, Eric W. Boberg, Fiona McTavish, Betta Owens, Meg Wise, Haile Berhe, and Suzanne Pingree

Center for Health Systems Research and Analysis, University of Wisconsin, Madison, WI

Abstract

This paper reviews the research and development around a consumer health informatics system CHESS (The Comprehensive Health Enhancement Support System) developed and tested by the Center for Health Systems Research and Analysis at the University of Wisconsin. The review will place particular emphasis on what has been found with regard to the acceptance and use of such systems by high risk and underserved groups.

Keywords:

Computer Communications Networks, Medical Informatics, Internet, Patient Education, Social Support

Introduction

This paper reviews the research and development around CHESS (The Comprehensive Health Enhancement Support System) developed and tested by the Center for Health Systems Research and Analysis at the University of Wisconsin. The review will place particular emphasis on what has been found with regard to acceptance, use and impact of such systems by high risk and underserved groups.

Consumer Health Informatics Systems

Consumer Health Informatics Systems (CHIS) include computer programs providing information, decision, behavior change and emotional support for health issues [1]. CHIS operate on telephones, palm and Internet appliances, personal computers and public kiosks. Initially, CHIS were stand-alone systems. For example, BARN initially used Apple II computers placed in school libraries to help teens prevent smoking, drug abuse and sexual activity [2]. In the 1980s, these stand-alone systems began to add modems allowing users to communicate with each other and experts [3]. When the Internet could to rapidly transmit information, many CHIS migrated to it. However, some continue in a stand-alone format because they need more speed and processing than is available on the Internet.

CHIS services can range from simple applications such as a single article or discussion group to ones offering many services including information, communication, analysis, personalized web pages and computer based games designed to promote behavior change. CHESS is an example.

CHESS

First developed in 1989, CHESS has been tested in several research studies and is now Internet-based. CHESS programs are based on needs assessment surveys typically involving several hundred patients and families. Users test relevance and readability of content created by clinical experts. Patients access CHESS through home-based computers. Many organizations offering CHESS lend computers to patients who do not have their own. When logging on to CHESS users enter a code name and password to prove they are legitimate users. From main menu they choose a topic, pick a key word or enter into a service of interest. The services are described below using the prostate cancer module as an example.

Information Services. *Questions and Answers* include brief answers to 400 frequently asked prostate cancer questions. *Instant Library* links users to over 200 full-length articles drawn from the scientific and popular press available. *Consumer Guide* describes 150 services to help users visualize what it will be like to receive the service and learn to identify a good provider, and be an effective consumer. *WebLinks* connects users to other high quality websites specific to prostate cancer. *Resource Directory* describes local and/or national services and ways to contact them.

Communication Services offer information and emotional support. Patients and families use bulletin board style *Discussion Groups* to share information and support. Separate groups (e.g. for patients, partners, prayer) are limited to 50 and professionally facilitated. *Ask an Expert* provides confidential responses to questions by specialists at NCI'sregional Cancer Information Service. The responses are depersonalized and made available for all within *Open Expert*. *Journaling* provides a private place where users write their deepest thoughts and feelings about prostate cancer in a timed, controlled environment. *Personal Stories* show how people cope with prostate cancer. Professional writers interview patients and family and prepare stories to reflect priorities set by our needs assessment studies. *Video Gallery* shows prostate cancer patients and their spouses describing how they coped with the disease and treatment. Video is also used in other services (e.g. *Overview* and *Decisions)* to supplement text and graphics.

Analysis Services help users think through key issues. These collect data from users, process it and provide feedback). CHESS *Assessments* focus on specific issues of importance to prostate cancer patients (e.g. depression). *Health Tracking* collects data on health status every two weeks and displays graphs showing changes over time. CHESS uses that information to guide people to material relevant to their situation. CHESS does not currently share this information with clinicians although it could. *Decisions* helps users make important treatment decisions. Video clips show prostate cancer patients talking about their decision. Alternatively, they can use a decision analysis to learn about options, values, and consequences of choices. *Action Plan* employs a decision theory model build, evaluate and improve their behavior change strategies. A *Cognitive Behavior Therapy* program to address depression has been developed and is being tested.

While CHESS is quite comprehensive there are services it does not offer. CHESS could collect key health tracking data whenever a user logs on and triage the user to specific services. CHESS could monitor system use to guide users to particularly helpful but so far unused services. It could automatically collect and use health information (e.g. blood sugar level) to tailor messages or send information to clinicians. CHESS does not force people to use particular parts of the program, relying instead on providing information and support in several formats that allow the user to pick to presentation that best fits their learning style.

CHIS that focus on primary prevention or even chronic disease management have the challenging task of creating or maintaining "tension for change". CHESS focuses on life threatening diseases, such as a recent diagnosis of cancer, HIV and coronary artery disease where people are already motivated to obtain information and support.

To better understand CHESS we will contrast it with typical access to the Internet. 1) The Internet is a vast but unfocussed repository of cancer information of varying quality. CHESS is a non-commercial system, owned by the University of Wisconsin, whose content and presentation is developed and updated by clinicians and patients. CHESS Research Consortium members [Allina Medical Group, Dana Farber Cancer Institute, Fletcher Allen Health Care, Hartford Hospital, Harvard Pilgrim Health Care, Mayo Clinic, Merck Outcomes Research Department, St Paul's Hospital (BC), and the University of Wisconsin] contribute to its content, design and testing. 2) The Internet provides support through chat groups involving many people, some of whom can be pretenders. CHESS limits discussion and chat group access to a comparatively small number of approved people in a facilitated environment. 3) The Internet's interfaces vary substantially between programs and can be cumbersome. CHESS provides one easy-to-use interface that takes users to important materials within its own boundaries and to specific pages within other websites without having to learn to navigate each site. 4) The most important strength of CHESS may be its closed, guided universe of information and support options; an integrated package where everything points to everything else, instead of requiring search and discovery.

CHESS is one of the most thoroughly studied CHIS, including three randomized clinical trials [4-7]. and several field tests [8,9]. Five randomized trials are currently examining the CHESS impact on decision-making, behavior change and quality of life. We will review some key study results below.

The Digital Divide

Much of the research around CHESS has been focused on its impact on underserved populations. The Kaiser Family Foundation, Harvard University and NPR [10] and the National Telecommunications and Information Administration (NTIA) [11] study the extent of the digital divide. NTIA found that only 25% of people over age 55 have computers compared to 50% for younger adults. Only 13% of people over age 65 use the Internet and 64% have no interest in using it. NTIA also found that the gap between white and other non-Hispanics and the other two groups has widened since 1998 [11].

Rural areas are also disadvantaged regarding the Internet. Only 2% of rural people with elementary educations access Internet versus 4% in the central city. Many features that enhance the effectiveness of CHIS will use broadband. While 56% of cities over 250,000 have DSL and 65% have cable modems, less than 5% of towns under 10,000 have them [11].

There are many faces to the digital divide including race, poverty and disability. But the prime indicator is poverty. About 3% of Hispanics and black non-Hispanics with incomes below $15,000 use the Internet compared to 25% of the same ethnic groups with incomes between $35,000 and $75,000. Again, the gap seems to be increasing [11].

With the limited resources available to solve society's problems, does it make sense to use them to close the digital divide [1]? Would health behavior change? Would health improve? Would costs be reduced? The paper will examine what CHESS research tells us about these questions.

Acceptance and Use of CHIS

Measuring use of CHIS is a complex process. The number of hits indicates how often a person enters a site but does not indicate how long the user spent on the site and what they were doing while there. A person who lands on a site by accident and leaves immediately is counted as equivalent to a person spending hours in the site. Measuring the minutes spent in a program (or in a service) indicates intensity of use. But, some services are properly used in seconds; others require minutes. But this measure is complicated because we do not know whether a person is using the site for those minutes or eating lunch. How the service is used is important. A person who spends 45 minutes on a live chat group discussing his/her fears gets one set of benefits. A user gets different benefits by first reviewing frequently asked questions about pain, then reading articles on pain, then writing to an expert on pain, and then raising cancer pain in a discussion group. Measuring delay is important. But the Internet, especially from a modem, can have large delays and make people stop using it.

In our research use of CHESS is measured by the number of services used beyond a minimum time threshold and minutes of use within a service.

One key finding is that many stereotypes are wrong regarding who will accept and use CHIS. When CHIS were first developed many wondered whether age, gender and race would affect acceptance and use? CHESS studies suggest that underserved use CHESS as much as more affluent Caucasians. One study, with HIV patients, found little association of total use with any demographic [12]. Another population-based study attempted to recruit elderly Medicare women with breast cancer to CHESS. Those who were offered CHESS accepted and used it with about the same frequency as women with breast cancer who were under the age of 60 [9]. Similarly, in a randomized trial of younger women with breast cancer, the one-third of subjects who were underserved inner-city African American women used CHESS as much as more affluent white women with breast cancer [8].

While total amount of use is about the same across populations, different populations used CHESS very differently (Table 1). In particular, the underserved used computer-mediated communication services (such as electronic discussion groups) less frequently and information services (e.g., frequently-asked questions and library) and analysis services (e.g. decision analysis and health tracking) more. This is particularly important because a growing body of research discussed below, suggests that using CHIS for information and analysis is more important to quality of life than using CHIS for emotional support [5,13]. However, one of the important features of communication services is that they tend to be more "color blind" than face-to-face contacts. Underserved and affluent people interact with each other quite well in the anonymous environment of CHIS.

Table 1: CHESS Use by Caucasian, Minority and Elderly Women with Breast Cancer [Ref. 8]

	Elderly Caucasian	**Younger Caucasian**	**Younger Minority**
Total Weekly Use	6.8	5.9	6.2
% Communication	56	75	48
% Information	33	19	32
% Analysis	11	4	16

Impact of CHIS

A tentative picture is beginning to emerge about the impact of CHESS on diverse populations and the underserved people with life threatening illnesses. Several research studies have been conducted on the impact with underserved African Americans.

Impact on Underserved African Americans

An NICHD/NCI funded randomized trial [6] of younger women with breast cancer (30% underserved minorities) involved placing CHESS in the homes of experimental subjects for six months while controls received standard care plus a book on breast cancer. CHESS patients improved more than controls in confidence in physician, comfort in posing questions to clinicians, decision confidence and information competence. Four of six quality of life measures showed significant interactions with characteristics associated with being underserved. Underserved minority women with CHESS moved to outcome levels similar to middle class whites.

Impact on the Elderly

This HCFA-funded study [9] examined the ability to get a full population of Medicare eligible women with breast cancer to accept and use CHESS. Surgeons in a five-county region (94% of them agreed to refer) referred 70% of the patients they could have referred and 73% of those patients accepted CHESS. CHESS was used as much by this group as younger women (under 60 yr) with breast cancer. As a population-based study no control group was available. However, quality of life and cognitive functioning improved more for the heaviest users of CHESS than for those who used it least. The changes in quality of life scores were similar to the findings for younger women with breast cancer. Using physicians and clinical staff as the only referral source gave nearly 50% penetration.

Impact on HIV+ patients

HIV infected people at all stages of disease (12% minorities) were randomly assigned to either no intervention (control) or CHESS in their homes [8]. Experimental subjects used CHESS extensively. No significant differences in use total use rates were found between minority patients and others. However, minority patients were more likely to use information and analysis services and less likely to use discussion group services [6]. Five of eight quality of life measures (activity, reduced negative emotions, social support, cognition, and participation in health care) significantly improved in those having CHESS access compared to the controls [6]. Average time spent with physicians dropped significantly for CHESS users, as did average length of hospital stay.

Impact on AIDS patients

A randomized trial of 261 patients (35% minority) with advanced HIV disease (a CD4 count of <500), is notable because CHESS had little impact. Use rates were similar to the previous HIV+ study. Minority women used it most. But quality of life changes, while statistically significant, were modest. Health service use improved only between 8 and 12 months. Minority status had no effect on any results. One possible explanations for the relative lack of effect is that the discussion group was flourishing as usual when two subjects began an extended and heated argument (over religion). Many users dropped out of the discussion group and overall CHESS use dropped dramatically. This suggests discussion groups are fragile; requiring careful monitoring and facilitation.

Use that Makes a Difference

One qualitative study examined how men and women with HIV used CHESS. Because of the intensity of analysis only 14 subjects were used. Half of these subjects made substantial improvements in quality of life and half did not. Transcripts were analyzed to determine whether the discussion involved communicating information versus emotional support messages. Similarly, other services uses were divided into information versus support content. People who use CHESS most were not those who benefit the most. Instead, quality of life improvements were greatest in those who were most involved in information tools [13]. Similar results have been found by Brennan in a study of caregivers of Alzheimer's patients [1]. Hence, although computer services are frequently used to provide emotional support [13], this may not be their most important role.

These studies are beginning to demonstrate a pattern for people using CHESS to cope with serious disease. 1) Undersreved minorities (African Americans in particular) and the elderly (two key groups often on the wrong side of the Digital Divide) are as likely to accept and will use CHIS as much as the younger, more affluent majority. 2) While they use CHESS services as frequently, they use them very differently. (less use in discussion groups and more information and analysis services. 3) Underserved groups benefit from CHIS more, partly because they have more to gain and partly because of the different style of use.

Other results simply raise questions. One is what happens if CHESS and pyschotherapy are combined. A small pilot test (24 adult children of alcoholics) were randomly assigned to receive CHESS for ten weeks or group psychotherapy for the same time period or receive both CHESS and psychotherapy. Average attendance at psychotherapy-only sessions was 39% vs. 82% for those who also had CHESS. Total use of CHESS services increased by 20% when psychotherapy was combined with CHESS.

Summary

Based on current data, one would conclude the underserved use CHIS differently from more affluent counterparts. This conclusion might change as one moves to other cultures. Studies are needed of how CHIS are used in different cultures and problems.

It appears that the different use patterns have worked the to the advantage of the underserved because they tend to use information and analysis services more and that use is most associated with improvements in outcome measures. But, what if communication services were easier to use for those of lower literacy (e.g. when voice recognition software is reliable without training) and if information were communicated verbally rather than in writing? Would underserved use the communication services more? Would that work to their detriment?

We know little about how the Internet is used by the patient. Unpublished data suggests that training people to use the Internet and giving them URLs for high quality websites, leads to less use and impact than training them to navigate one comprehensive website (CHESS) with links to specific pages on other sites so they need not learn how to navigate a variety of sites. But do these results hold as well for prevention, disease management and disease coping programs? How do the underserved use the Internet? Can they discriminate high from low quality sites? What effect does access have on quality of life and behavior change? CHIS may have important interactive effects with existing treatments. Those effects need to be studied in depth.

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Address for correspondence

David Gustafson

<dhgustaf@facstaff.wisc.edu>