

The Use and Impact of a Computer-Based Support System for People Living with AIDS and HIV Infection

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ABSTRACT

CHES (the Comprehensive Health Enhancement Support System) is an interactive, computer-based system to support people facing AIDS/HIV Infection and other health-related crises or concerns. CHES provides information, referral to service providers, support in making tough decisions and networking to experts and others facing the same concerns. CHES is designed to improve access to health and human services for people who would otherwise face psychological, social, economic or geographic barriers to receiving services.

CHES has been evaluated in a random-assignment study with over 200 men and women living with AIDS and HIV infection. When CHES was placed in subjects' homes for 3-6 months, use of CHES was extremely heavy, with the average subject using CHES 138 times for 39 hours. Compared with a control group which did not receive CHES, subjects who used CHES reported significantly higher quality of life in several dimensions, including social support and cognitive functioning. Users also reported significant reductions in some types of health care costs, especially inpatient services (hospitalizations).

All segments of the study population used and benefited from CHES, including women, minorities and those subjects with lower levels of education. Thus, CHES appears to be an effective means of delivering education and support to the diverse populations which are affected by AIDS and HIV infection.

INTRODUCTION

CHES, the Comprehensive Health Enhancement Support System, is a multi-service system supporting HIV infected people, as well as people facing other major life crises [1,2]. CHES runs on a personal computer, typically placed in the home for three to six months; it can also be installed in health care settings or community sites. CHES' nine services offer a range of information, social and emotional support, and problem-solving tools

for people in health crises. The Information Services offer answers to commonly asked questions (*Questions and Answers*), detailed articles (*Instant Library*), communication with medical experts (*Ask an Expert*), and a tutorial on finding and using resources effectively (*Getting Help/Support*). The Support Services include programs that allow patients to communicate with each other (*Discussion Group*) and read personal accounts of people who have coped with the same crisis (*Personal Stories*). The Problem-Solving Services include programs to help people understand their lifestyle risks and patterns (*Assessment*), decision aids (*Decision Analysis*), and a guided program to implement decisions (*Action Plan*). CHES is now offered for six topics: AIDS/HIV, early stage breast cancer, acquaintance rape, academic failure (focusing on African American males), adult children of alcoholics, and stress management.

CHES was conceived following our experience with the BARN (Body Awareness Resource Network) system [3]. BARN is a widely-used, computer-based health promotion/behavior change system for 6th- to 12th-grade students, with information and skill-building activities on AIDS, alcohol and other drugs, body management, human sexuality, smoking and stress management. Compared with BARN, CHES provides more in-depth information, additional decision- and behavior-support services, and a communications link to other users. CHES design has been further shaped by various aspects of crisis [4,5] and change [6,7] theories. In situations fraught with irrationality and emotion, CHES is designed to provide: (1) an organized and systematic way for people in crisis to obtain good information, tailored to their needs, and delivered in an educationally sound way; (2) help in making and implementing decisions; and (3) social support from peers and professionals. People in crisis use CHES to anonymously ask potentially embarrassing questions of experts and communicate with people sharing the same problem. They can get the information and support they need at any time of the day.

The variety of services in CHES allows people to use it selectively to best meet their needs. Some use the expert systems for guidance in thinking through difficult issues. Others think through issues by exploring CHES databases of information. Still others seek advice from experts and peers through CHES computer mediated communication systems. Many will use all CHES services as they explore one particular issue. Regardless of how they use it, CHES is designed to reduce the asymmetry of knowledge between patients and health care providers, to increase patient and family sense of control, and to empower patients to be more active participants in their clinical care.

CHES has been developed over the last four years by a team of decision, information, education, communication, and medical scientists from the University of Wisconsin-Madison under a grant from the W.K. Kellogg Foundation. The AIDS/HIV module was evaluated with a grant from the Agency for Health Care Policy and Research.

THE RESEARCH DESIGN

The purpose of this research was to assess the impact of CHES on: (1) health status and quality of life; (2) risk behaviors and (3) health service utilization, of HIV-infected people. CHES was evaluated in a randomly-assigned experiment with 204 HIV-infected people from Madison and Milwaukee, Wisconsin. The 107 experimental subjects (who were given CHES for three or six months) and 97 control subjects, answered a pre-test and two or three post-tests; the first given two months after installation and the last given three months after removal of CHES. An additional nine women participated in the first cohort as a pilot test and were not randomly assigned. In addition to the outcome variables mentioned above, we also examined use of CHES and cost of operating CHES.

The computers used in this study were IBM-compatible personal computers assembled by local manufacturers, and had 386sx16 microprocessors (CHES will run acceptably on 286 machines), 40 MB hard drives, 1MB RAM, 3.5" floppy disk drives, color VGA monitors and 2400-baud modems. Communications were transmitted via modem to a central "host" computer (also a 386sx PC) with multiple modem connections. The computers were installed in subjects' homes by the project director, who also gave a 45-minute tutorial on CHES use. Whenever possible, the computers were locked down to immovable objects using a cable and padlock. No computers were lost or stolen from homes during this study. Equipment failure was very rare. Only 3 units needed to be replaced during the study. Most other service questions were handled

over the phone by the project director or programming staff.

The content of the AIDS/HIV module was initially developed in 1990-1991. Prior to the initiation of each cohort, the content was reviewed and updated to insure that the information was accurate and up-to-date. Late-breaking information was posted in Discussion Group. CHES content continues to be reviewed and updated annually.

RESULTS

CHES Use

Use of CHES was heavy. The 116 subjects (including the nine non-randomly assigned women) used CHES 15,966 times, an average of 138 uses per person (more than once per day on average) with a duration of 39 hours each. These figures do not include use of Health Charts (a program which users were required to use which routinely collects health status and health concerns data) or the Dictionary function (intended to help people understand complex medical terms). Nor does it include uses of less than one minute in duration. Over 34% of CHES uses occurred between 9:00 p.m. and 7:00 a.m., a time when most other sources of information and support are not available.

Social Support services accounted for 79% of all uses, 73% in *Discussion Group* alone. Information services accounted for 17% of all uses and Problem-Solving services just 4%. Subjects considered all services to be important, arguing that all but Social Support services could accomplish their goals with just one use. Even so, these findings raise important questions about the role and relative importance to the user of Information and Problem-Solving components in a support system of this type.

While making about as much overall use of CHES as whites, minorities allocated their use somewhat differently among CHES services. Minorities used *Discussion Group* a smaller proportion of their total use (68% versus 78%) than whites, while using Information services more (22% versus 15%) and Problem-Solving services more (6% versus 3%). Women used CHES 13% more frequently than men. In particular they were more likely to use the Information services, especially *Ask An Expert*.

Other demographics were also important predictors of use. People who had not yet developed AIDS symptoms used CHES more frequently, in particular the *Discussion Group* and *Personal Stories*. Younger people used CHES more frequently, especially *Questions and Answers*, *Personal Stories*, and *Discussion Group*. Thus, the results suggest possible reversals of traditional information use patterns that increase knowledge gaps between races, genders, etc. [8]

Quality of Life

Quality of life analyses, after the first two months of installation, found CHES users significantly higher on five of eight dimensions, and lower on none. CHES users reported improved cognitive functioning, an increased sense of social support, and leading a more active life, while controls stayed steady or got worse on each of these variables. CHES users also reported greater improvement than controls in actively participating in their health care, and they reported decreased levels of negative emotions while controls stayed the same. There were no significant differences at any time between the groups for depression, physical functioning, or reported level of energy.

If CHES was left in place only three months, its positive effects mostly disappeared once it was removed. However the results were more encouraging when CHES is left in the home for six months. Figure 1 portrays the average quality of life score as a percent of maximum for the Madison subjects over the four time periods. Even with a smaller sample size (30 experimental and 28 control), the positive effects of CHES were significant at five months (when CHES was still in the home) for active life, social support and participation in health care. And non-significant but still positive trends continued for cognitive function and negative emotions.

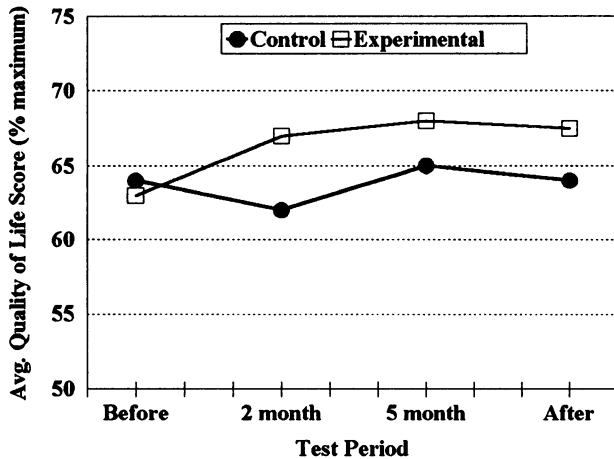


Figure 1. Average Percent Maximum Quality of Life Score -- Madison Cohort Only

Moreover, three months after CHES was removed from the longer-term (six month) implementation, CHES continued to have significant positive effects on social support and participation in health care. Non-significant positive trends continued in cognitive functioning and negative emotions but disappeared for active life. These results suggest a longer than 3-month implementation not only continues the beneficial effects

CHES has while it is in the home, but also has carryover effects after CHES is removed.

Risk Attitudes and Behaviors

CHES did not significantly change sexual risk behavior, but the six month implementation did, after CHES was removed, improve attitudes toward risk behavior and toward disclosure of HIV status to potential partners, compared to pre-test.

Health Services Utilization

CHES users self-reported number of visits to health care providers, time spent with providers, satisfaction with visits, number of admissions to hospitals and length of stay. We examined CHES effect on the reported utilization of health services and then monetized that effect by using average Madison area charges for the relevant health services.

Outpatient services There were no significant CHES effects on number of visits to various ambulatory care providers while CHES was in the home, although the number of phone contacts increased in the experimental group compared to the controls. Using an average charge figure for each service, the total charges for ambulatory care was reduced by 17% in the CHES group compared to a reduction of 7% in the control group, but this effect was also not statistically significant.

However, three months after removing CHES, the experimental group had (compared to pre-test) significantly fewer visits to dentists, primary care and alternative care providers, while the significant CHES effect on number of calls disappeared.

CHES had a statistically significant effect on the time spent with providers when a visit did occur. While CHES was in the home, significant reductions occurred (compared to the control group) in time spent with primary care, HIV and mental health providers. The experimental group's total time spent with non-emergency providers decreased 8% while control group time increased 13%. This difference was also significant. Hence, while it may not show in charges, since those figures are not based on time spent, the intensity of resource utilization was significantly lower in the CHES group, both during and after the period of CHES use.

Inpatient services CHES also had significant effects on in-patient care. While CHES was in the home, the average probability of admission in the control group increased 42% versus 16% in the CHES group. In the three months after CHES removal, the probability of admission increased another 25% in the control group while it decreased 2% in the CHES group. These results were not statistically significant.

However changes in length of stay were significant. If a person was admitted to the hospital, there was 61%

increase in average length of stay in the control group and a 29% reduction in the CHES group. After CHES was removed, average length of stay continued to be 35% higher than pre-test levels in the control group and 26% lower in the experimental group. As it turned out, there were pre-test differences between control and experimental groups that make the analysis of this data challenging. The analysis did take these differences into account as covariance. However, there is no way to completely remove the effect those differences have.

By combining admission rate and average length of stay it is possible to estimate the effect of CHES on the costs of inpatient care. One way to analyze the data would be to argue that while they had CHES, the experimental group costs went down \$148 at the same time that the control group costs went up \$457, for a total difference of \$605, a difference maintained (at a slightly lower level) even after CHES was removed (Figure 2A).

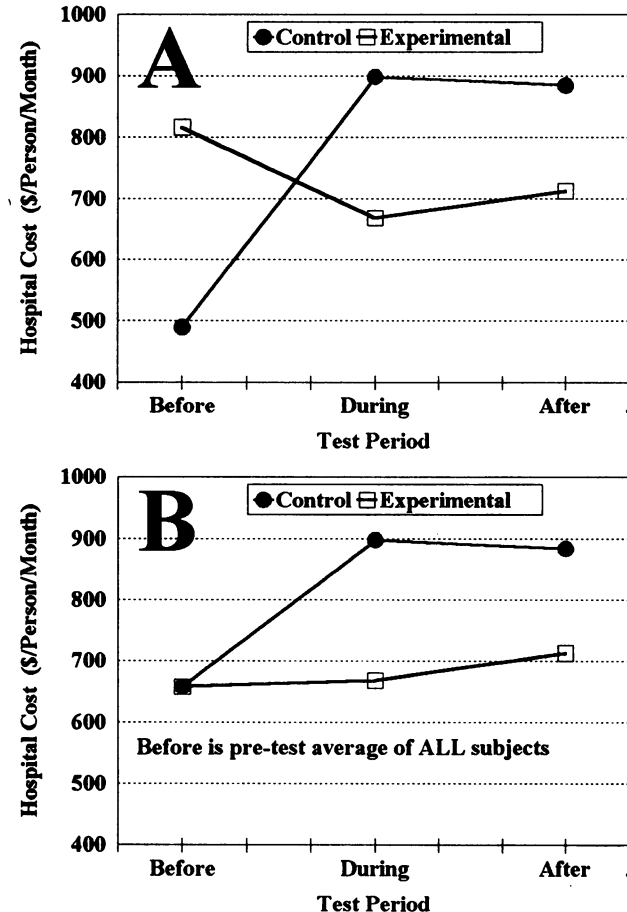


Figure 2. Average Hospital Cost Per Person Per Month

Because of the pre-test differences, a more conservative approach would be to average the pre-test costs of all subjects, and use this as a basis to compare

post-test differences between the two groups (Figure 2B). Using this approach, pre-tests costs of \$658 per person per month increased during the period of CHES use by \$240 for the controls, but only \$10 for the CHES group, a difference of \$230 (which decreased slightly to \$174 after CHES was removed).

At pre-test, approximately 30% of our subject population had AIDS, 35% symptomatic HIV infection, and 35% asymptomatic HIV infection. Using data obtained in the AIDS Cost and Service Utilization Study [9] on the average monthly costs for inpatient services for people at various stages of HIV infection, we calculated that our population would be expected to have an average monthly cost for inpatient services of \$685 per person per month, a value similar to the average we obtained for pre-test costs of all subjects in this study. The difference in inpatient costs between control and experimental subjects during the period of CHES use was thus at least 33% of the average total inpatient costs. Inpatient costs would be expected to account for about 60% of total health care costs in this population [9].

Effects of CHES on Minority Subjects

Thirty nine minority subjects were involved in the CHES study. At pre-test, we found that minorities were much more depressed than whites. Also, their utilization of health services was higher for primary care, HIV care, emergency care and dental care, but lower for mental health and other non-HIV specialty care.

Separate outcome analyses for minorities were hampered by the small sample size. However, interactions of experimental condition with minority group status and educational level were not significant. That is, CHES effects were not significantly larger or smaller for minorities than for whites.

In absolute numbers, although not significant, the experimental group of minorities showed a reduction (relative to the control group) in number of visits to dentists, primary care, mental health, and emergency care while CHES was in the home. The total number of visits for non-emergency care dropped 17% in the experimental group and increased 8% in the control, while CHES was in the home. After removal, the reduction compared to pre test was 42% for the experimental group and 3% for the control group.

CONCLUSION

The results of this evaluation are very encouraging. HIV-positive individuals (including minorities) used CHES frequently over a period of several months. CHES was highly valued by subjects as indicated in unsolicited letters of support as well as in formal evaluation. CHES improved quality of life and made

use of health services more efficient. No significant effects were detected on risk behaviors.

Additional research should examine the effects of CHES in greater detail. One study should compare CHES against other non-technology-based interventions costing about the same. We also need to conduct studies on the specific utility of various CHES components (i.e., which CHES services make the most difference, for whom, and under what conditions?). In addition, further study of CHES impact on costs of care is needed. The pre-test differences in length of stay between control and experimental groups, as well as the self-report nature of the data make further study of health service use desirable. Toward that end, a study has been funded by the Agency for Health Care Policy and Research to further examine effects of CHES on costs of care. This study will include aspects of care not addressed in this study (drugs and home care) and will supplement self reports with data from medical and billing records.

Of course, CHES has important implications for crises other than AIDS. CHES currently has programs addressing breast cancer, rape, adult children of alcoholics, academic failure and stress management. New programs are planned on diabetes, depression, and substance abuse. Some of these programs (e.g. diabetes) are likely to have positive effects on costs and quality of life. The primary benefit of others may center on quality of life. The effect of CHES on these other areas deserves careful evaluation.

In addition to studying the impact of CHES, work is needed to identify the most cost-effective means for its deployment. CHES computers could be loaned by clinics and HMO's, CHES could be placed in the National Information Infrastructure (the "Information Superhighway"), or made available through interactive television systems. These efforts are particularly important if CHES is to reach populations and providers that do not have access to personal computers.

Finally, the potential of CHES for collecting data means that a wide array of research issues can be addressed. The decision analysis program collects data on the importance people place on different decision criteria and the utility they assign to different options. Hence, we have an almost unique means of analyzing data on the values and perceptions of people in crisis. The dialogue taking place in the discussion groups can offer us important insights into the group dynamic of computer mediated communication systems and can also help us understand the issues being faced by people in crisis. The CHES use data offers an opportunity to learn how CHES has its effects, by telling us not only what services are being used, but also the styles or patterns with which people seek help, and even (for instance) what article in the Instant library is being read

most frequently. These are just a few of the examples of the rich data that are available to give us new insights into crisis and the means to address it.

References

- [1]. Gustafson, D.H., Bosworth K., Hawkins R.P., Boberg E.W., & Bricker E., 1992, "CHES: A Computer-Based Support System for Providing Information, Referrals, Decision Support and Social Support To People Facing Medical and Other Health-Related Crises," *Proceedings of the 16th Annual Symposium on Computer Applications in Medical Care*, 16, 161-165.
- [2]. Gustafson, D.H., Wise, M., McTavish, F., Taylor, J.O., Wolberg, W., Stewart, J., Smalley, R.V., & Bosworth, K., 1994, "Development and Pilot Evaluation of a Computer Based Support System for Women with Breast Cancer," *Journal of Psychosocial Oncology*, 11(4), 69-93.
- [3]. Bosworth, K., Gustafson, D., & Hawkins, R., 1994, "The BARN System: Use and Impact of Adolescent Health Education Via Computer," *Computers in Human Behavior*, (in press).
- [4] Moos R.H., & Schaeffer J., 1984, "The Crisis of Physical Illness: An Overview and Conceptual Approach," In: R.H. Moos (Ed.), *Coping With Physical Illness II: New Perspectives*. New York: Plenum Medical Book Company.
- [5] Aguilera, D., 1990, *Crisis Intervention: Theory and Methodology*. St. Louis: CV Mosby Company.
- [6] Bandura, A., 1977, "Self-Efficacy: Toward a Unifying Theory of Behavioral Change," *Psychological Review*, 84, 191-215.
- [7]. Strecher V.J., McEvoy-DeVellis B., Becker M.H., & Rosenstock I.M., 1986, "The Role of Self-Efficacy in Achieving Health Behavior Change," *Health Education Quarterly*, 13, 73-91.
- [8]. Pingree, S., Hawkins, R.P., Gustafson, D.H., Boberg, E.W., Bricker, E., Wise, M., and Tiillotson, T., 1993, "Will HIV-Positive People Use an Interactive Computer Support System for Information and Support? A Study of CHES in Two Communities," *Proceedings of the 17th Annual Symposium on Computer Applications in Medical Care*, 17, 22-26.
- [9]. Hellinger, F., 1993, "The Lifetime Cost of Treating a Person With HIV," *Journal of the American Medical Association*, 270(4), 474-478.