

# Effect of Computer Support on Younger Women with Breast Cancer

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**OBJECTIVE:** Assess impact of a computer-based patient support system on quality of life in younger women with breast cancer, with particular emphasis on assisting the underserved.

**DESIGN:** Randomized controlled trial conducted between 1995 and 1998.

**SETTING:** Five sites: two teaching hospitals (Madison, Wis, and Chicago, Ill), two nonteaching hospitals (Chicago, Ill), and a cancer resource center (Indianapolis, Ind). The latter three sites treat many underserved patients.

**PARTICIPANTS:** Newly diagnosed breast cancer patients (N = 246) under age 60.

**INTERVENTIONS:** Experimental group received Comprehensive Health Enhancement Support System (CHESS), a home-based computer system providing information, decision-making, and emotional support.

**MEASUREMENTS AND MAIN RESULTS:** Pretest and two post-test surveys (at two- and five-month follow-up) measured aspects of participation in care, social/information support, and quality of life. At two-month follow-up, the CHESS group was significantly more competent at seeking information, more comfortable participating in care, and had greater confidence in doctor(s). At five-month follow-up, the CHESS group had significantly better social support and also greater information competence. In addition, experimental assignment interacted with several indicators of medical underservice (race, education, and lack of insurance), such that CHESS benefits were greater for the disadvantaged than the advantaged group.

**CONCLUSIONS:** Computer-based patient support systems such as CHESS may benefit patients by providing information and

social support, and increasing their participation in health care. These benefits may be largest for currently underserved populations.

**KEY WORDS:** breast cancer; quality of life; patient participation; computer; patient education; disadvantaged; Digital Divide.

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Breast cancer, the most common cancer among women, accounts for 29% of all new cancer diagnoses in the United States, and is the leading cause of cancer death among women between 20 and 59 years old. The physical effects of breast cancer and its treatment (depression, fatigue, hair loss, weight gain, and changes in physical appearance) can have a devastating impact on quality of life,<sup>1-4</sup> affecting women's self image and ability to carry out roles within and outside the home. Ability to deal with complex information, obtain social support, and participate (as desired) in one's care become crucial in minimizing that devastation.<sup>5,6</sup>

The impact of breast cancer is even more serious among African-American women, whose breast cancer-related mortality rates are higher than for Caucasians.<sup>1,7</sup> Moreover, medical underservice (often associated with minority status and with less health insurance, income and formal education) leads to fewer opportunities to participate in care or obtain needed information and social support.<sup>8-10</sup>

An intervention that improved information seeking skills, social support, and patient participation in health care might improve psychosocial aspects of quality of life.<sup>11-13</sup> Computer-based systems provide a venue for such an intervention, because multiple services (e.g., rapid access to information, support groups, and decision support systems) can be integrated to support each other. Furthermore, in-home systems are available to patients when and where needed. Because the medically underserved often lack other resources, such services should have greater impact for them than for traditionally better-served groups.

This paper reports on a randomized controlled evaluation of one such system, Comprehensive Health Enhancement Support System (CHESS), developed at the University of Wisconsin-Madison. In a previous randomized trial, HIV-infected patients used CHESS extensively, and access to CHESS reduced mood distress and improved cognitive functioning, social support, and active involvement in life.<sup>14</sup> Unpublished anecdotal comments by clinicians suggested that CHESS users also participated

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more effectively in their care. Qualitative analyses found that those who improved most had done so by using the CHES information and decision components in thoughtful and connected ways for moderate amounts of time, rather than by spending large amounts of time in discussions with other patients.<sup>15</sup> Underserved minority HIV patients used CHES overall as much as middle class Caucasians, but participated less in discussions, while making heavier use of information and decision services.<sup>16,17</sup> Although CHES effects did not show significant interactions with race for HIV patients, these two findings suggest that such interactions might occur.

Pilot tests of CHES with breast cancer patients indicated widespread acceptance and use of CHES, including by low-income African-American women.<sup>18,19</sup> Thus, we proposed that:

- A. CHES would affect breast cancer patients' perceptions of six outcomes: 1) social support, 2) unmet need for information, 3) competence dealing with that information, 4) participation in health care, 5) confidence in doctor(s), and 6) psychosocial quality of life.
- B. Effects of CHES would be greater for the medically underserved, primarily indexed by race.

## METHODS

### Subjects and Recruitment

Between April 1995 and May 1997, this randomized controlled trial accrued younger (age 60 years or less) breast cancer patients treated at two large teaching hospitals in Madison, Wis, and Chicago, Ill, two other hospitals in Chicago, and a community-based cancer resource center in Indianapolis, Ind. The last three treated mostly low-income minorities and were sought out to meet study goals of including 100 minority patients (mostly African American with lower income, less education, and no health insurance) among the total sample of 300.

Nurses and doctors at the participating organizations introduced the study to breast cancer patients at a clinic visit following diagnosis. Eligible patients were within six months of diagnosis, not homeless, not active illegal drug users, able to give informed consent, and able to understand and answer sample questions from the pretest survey. All qualifying patients were encouraged to speak with a study representative who described the study. Consent was documented by obtaining signed, University of Wisconsin IRB-approved consent forms.

Recruitment rates were 93% in Madison, Wis, 84% in Indianapolis, Ind, and 61% in Chicago, Ill, where CHES was less integrated into normal practice at the two nonteaching hospitals and staff may have been less able to take time to offer CHES to patients. Among patients contacted, the most frequent reasons for refusal to

participate included 1) no time, 2) didn't want to make another decision, 3) no interest in using a computer, 4) didn't want more information, and 5) unwilling to be randomized.

We accrued 295 women with newly diagnosed breast cancer. After dropouts, 246 women remained, including 55 African Americans and 9 other minorities (see Figure 1 for the study flowchart). We called dropouts and found that being too busy and feeling too ill were the most frequent reasons for dropping out after randomization. Other reasons included wanting to move beyond breast cancer, disappointment at not being assigned to receive CHES, and just changing their mind.

### Intervention

At the time of the study, CHES programs resided on a home computer, with modem connections to a central server for communication. (See [chess.chsra.wisc.edu](http://chess.chsra.wisc.edu) for a demonstration of the system, since migrated to the Internet.) CHES content was developed by clinician and patient panels to respond to needs identified by interviews and prioritized with surveys of 400 breast cancer patients and families.<sup>20</sup> Designed to be attractive and easy to use, CHES integrates eleven services to provide breast cancer information, decision-making tools, and support services.

- Information Services: Questions & Answers (short answers to hundreds of frequently asked breast cancer questions); Instant Library (full articles drawn from the scientific and popular press); Consumer Guide (descriptions of health services, identifying good providers and being an effective consumer); and Referral Directory (descriptions of and ways to contact local and national breast cancer services).
- Support Services: Discussion Groups (limited-access, facilitated bulletin boards for sharing information and support); Ask an Expert (patients receive a confidential response from experts); and Personal Stories (how others facing breast cancer coped).
- Decision Services: Assessment (measures a person's emotional status and offers coping advice); Health Charts (patients record and track health changes); Decision Aid (learn about options, clarify values and understand consequences of choices); and Action Plan (plan successful changes by identifying goals, resources and ways to overcome obstacles).

### Study Administration

After completing the consent form and pretest, patients were randomly assigned to the control or

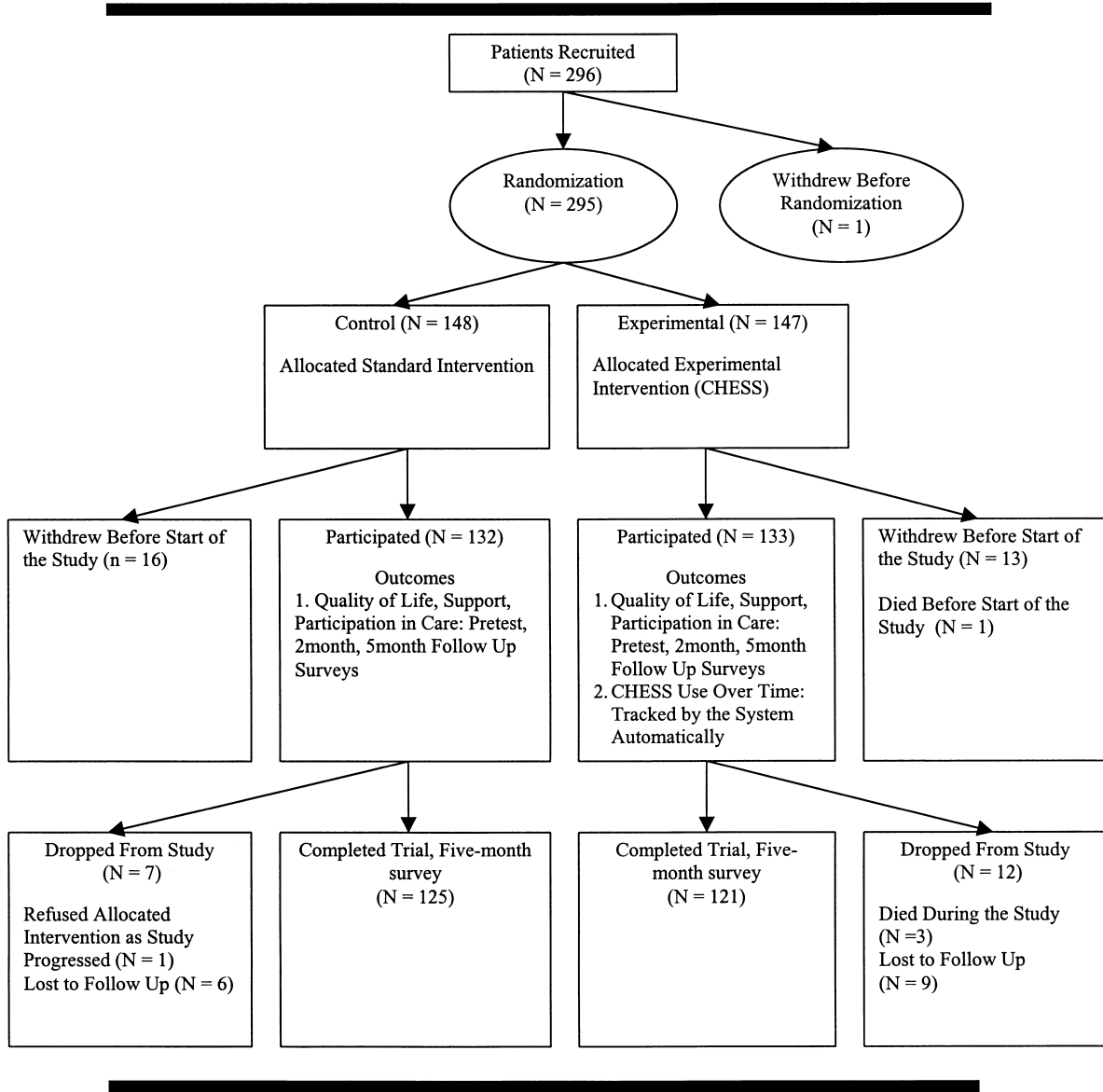


FIGURE 1. Study profile.

experimental group. To ensure consistency across sites and provide subjects some benefit for participation, the control group received a copy of *Dr. Susan Love's Breast Book*.<sup>21</sup> Those in the experimental group had CHESS at home for six months (a period long enough for most patients to finish treatment). CHESS staff delivered a computer, installed it, gave brief training (less than one hour), and left a user's manual.

Subjects completed a pretest at the clinic and two- and five-month post-tests and were compensated \$25 for each. Post-test surveys were mailed to subjects and returned in pre-addressed stamped envelopes. If a subject did not respond within two weeks, a follow-up phone call was made and a second copy of the survey mailed. Surveys were usually entered into the database within a week of arrival at

the central office. If missing data were found, site coordinators phoned to obtain remaining answers.

**Measures**

**Patient Characteristics.** Sociodemographic characteristics (age, race, income, education, and insurance status) were assessed at the pretest survey; disease-related information (diagnosis date, type and date of surgery, and schedule for radiation and chemotherapy) was collected on post-test surveys and validated by medical record reviews conducted by trained research staff. All surveys collected Karnofsky Performance Status<sup>22,23</sup> to assess impairment of normal activities. Staging data (tumor size, nodal status, and metastasis) were abstracted from medical

record reviews, and the TNM classification scheme applied. For analysis, we classified patients with breast cancer at stage 0, I, and II as early and those at stage III and IV as late stage.

**Patient Outcomes.** For convenience here and in tables, patient outcomes are presented in three groupings, with explanation of conceptual independence or nonindependence for multiple comparison purposes.<sup>24</sup>

**Social Support and Information Measures.** A six-item social support scale (Cronbach's  $\alpha = 0.89$ )<sup>14</sup> assessed a woman's perception of available emotional and instrumental support (see Appendix for sample items). A three-item unmet information need scale ( $\alpha = 0.83$ ) assessed the extent to which a woman lacked information about her health or health care. A five-item information competence scale ( $\alpha = 0.80$ )<sup>25</sup> assessed a woman's level of competence seeking information.

**Participation-related Measures.** A four-item scale ( $\alpha = 0.77$ )<sup>14</sup> assessed how much a woman perceived herself involved in her health care. Two items ( $\alpha = 0.68$ )<sup>25</sup> assessed comfort asking clinicians questions and confidence making major decisions about her health. These two scales are closely related outcomes and will divide  $\alpha$  in analyses. Level of confidence in her doctor(s) came from a single item in the Functional Assessment of Cancer Therapy-Breast (FACT-B) instrument.<sup>26-29</sup>

**Quality of Life Measures.** The FACT-B instrument satisfied assessment guidelines<sup>30</sup> by tapping several psychosocial dimensions of QOL with test-retest reliability and sensitivity to change.<sup>26-29</sup> Six items assessed social/family well-being ( $\alpha = 0.79$ ). Six other items assessed emotional well-being ( $\alpha = 0.80$ ). And seven items assessed functional well-being in everyday life ( $\alpha = 0.84$ ). The FACT-B also includes a measure of nine breast-cancer-specific concerns. While these assess potentially independent problems (and thus have lower scale reliability;  $\alpha = 0.66$ ), a scale of them reflects the degree to which a patient was worried about treatments, side effects, and recurrence. These four QOL measures are closely related and will divide  $\alpha$  (0.05) in analyses.

All scale scores were linearly transformed to a 0–100 scale with a higher score indicating more positive outcomes, e.g., more support, greater participation, less unmet information need, and fewer concerns.

## Analyses

Tests of intervention effects used an intention-to-treat approach that compared the original randomized groups regardless of individuals' amount of use of the experimental intervention. To test whether CHESS enhanced patient outcomes over time, separate multiple linear regression models<sup>31,32</sup> predicted the two- and five-month post-test

scores with experimental assignment (CHESS or control) as the main predictor, controlling for the pretest score. In addition, because health outcomes may be affected by time since diagnosis, stage of disease, and recent (within one month) chemotherapy, we also controlled for these and the individual's Karnofsky score. Finally, because sociodemographic variables may influence a patient's quality of life scores and access to services, we controlled for patient's level of education, race, and whether the patient had private health insurance.

To test whether medically underserved patients benefited more for each outcome variable, a subsequent model tested the interaction of experimental assignment (CHESS or control) with race. Although study design and sampling treated race as the primary indicator of medical underservice, some African-American women in this sample were not socioeconomically disadvantaged, while some Caucasian women were. Therefore, we also tested two additional interactions with insurance (private insurance vs no insurance) and education. Because race, education, and insurance status were moderately correlated (average  $R = .33$ ), their interactions were added separately to the main effects model.

Statistical significance is reported for  $P \leq .05$ , two tailed. For the conceptually-related measures identified above, the Holm procedure will be employed to divide  $\alpha$  among multiple comparisons.<sup>33,34</sup> Our sample size of 246 subjects (121 CHESS, 125 control) at an  $\alpha = 0.05$ , provided a 0.80 power to detect a 0.36 SD difference between the CHESS and control groups (between small and medium effect sizes, as defined by Cohen<sup>35</sup>). For the interaction of experimental assignment with race, we have 0.80 power to detect an interaction in which the women of color benefit more than Caucasians by 0.82 standard deviations (a large effect).

## RESULTS

Table 1 shows that the CHESS and control groups did not differ significantly on any sociodemographic and clinical characteristics. Women in the CHESS group averaged 155 uses of the system during the 26 weeks, or almost 6 times per week, with an average of 13 minutes per use. Caucasian women and women of color used CHESS equally frequently (5.9 and 6.2 times a week, respectively), but the average duration of use per episode was much higher for Caucasian women (14.6 vs 7.7 minutes). This difference came from Caucasians' greater use of Discussion Group (the bulletin board exchanges with fellow patients), which accounted for 68% of Caucasian women's use, but only 38% for women of color. Use of CHESS information services was equal for the groups, although women of color used the self-tracking and decision services considerably more than Caucasian women (over four hours during the study vs just under one hour). Because decision services demand more of users and are most directly linked to behavior changes,<sup>15</sup> the use of this service by women of color could provide a mechanism for stronger CHESS effects.

**Table 1. Characteristics of Patients Who Completed the Clinical Trial (N = 246)**

Patient Characteristics*	CHES (n = 121)	Control (n = 125)
<b>Sociodemographics</b>		
Mean age, y (SD)	44.3 (6.6)	44.4 (7.1)
Caucasian, %	76.0	72.0
Income (annual):		
\$40,000 or more, %	58.1	50.8
Education:		
Bachelor's degree, %	45.8	40.2
Living status:		
Living with partner, %	71.9	72.6
Insurance:		
Private insurance, %	86.0	84.7
<b>Clinical</b>		
Days since diagnosis at pretest: mean (SD)	55.0 (36.3)	47.4 (32.6)
Stage: early (I or II), % <sup>†</sup>	81.9	78.9
Surgery: Mastectomy, % <sup>‡</sup>	55.4	60.0
Chemotherapy, %	54.5	51.2
Radiation, %	38.0	40.8

\* Group differences were not significant ( $P \geq 0.05$ ) for all patient characteristics.

<sup>†</sup> Stage data were unavailable for 21 (8.5%) women.

<sup>‡</sup> 11 (4.5%) women did not have surgery (4 control, 7 CHES).

## Main Effects

After two months of implementation, the CHES group scored 4.8 points (95% confidence interval [CI], 1.5 to 8.1) higher on competence dealing with information than controls (Table 2). Similarly, the CHES group scored significantly higher than controls on two of three measures of interactions with the health care system: 6.4 points (95% CI, 2.1 to 10.7) on level of comfort with their participation (for which the multiple comparison significance level is 0.025) and 5.7 points higher (95% CI, 1.0 to 11.3) on confidence in their doctor. However, there were no significant main effects of CHES among the four quality of life measures.

Five months after the study began (Table 3), CHES subjects scored 4.9 points (95% CI, 1.4 to 8.4) higher than controls on social support and, similar to results at two months, 3.5 points higher (95% CI, 0 to 6.9) on information competence. While differences on the three participation measures were all still positive, none was significant. Again, there were no significant main effects for quality of life indicators.

## Interactions with Indicators of Medical Underservice

Although the limited number of women with color only provided sufficient power to reliably detect large interactions, several were found, and a number of others presented similar patterns. Thus, Figures 2 and 3 plot all interactions with  $P < .05$  to allow examination of a consistent pattern, even though some are not statistically

significant after controlling for multiple comparisons. After two months, significant interactions with race and education were present for two variables for which there had not been significant main effects: information need and behavioral involvement in one's health care. For overcoming the perception of unmet information needs, CHES helped minority women more than Caucasians (Figure 2). This interaction was repeated when education was substituted for race, with education more strongly related to information need for controls than for the CHES group. Similarly, for women participating in their own health care, CHES again helped minority women more than Caucasians, and education was related to participation more for controls than for the CHES group (Figure 2).

For interactions involving quality of life measures (Figure 3), access to private health insurance appeared more important than race or education, although controls for multiple comparisons across four QOL variables meant that these interactions did not reach significance. Being assigned to CHES was more related to functional well-being for women without private insurance than those with private insurance ( $P = .02$ , where significance required .0125). Women who were assigned to CHES reported fewer breast cancer concerns than did controls, particularly for those without insurance ( $P = .025$ , where significance required .0167). Two additional interactions for quality of life variables (with race for breast cancer concerns, and with insurance for emotional well-being) had similar shapes and  $P$  values less than .10 (.06 and .065, respectively), and perhaps widen the pattern to potentially involve three of the four QOL variables.

At five months, there was only one significant interaction (Figure 3), but it was again similar to the above. Education was related more strongly to information competence for controls than for the CHES group. And women who had CHES reported better functional well-being, particularly for those without insurance ( $P = .036$ , where significance required .0125).

## DISCUSSION

Based on needs assessment studies,<sup>13</sup> CHES was designed to help breast cancer patients and their families deal with information, be more active and confident participants in their health care, increase social support, and better maintain their socio-emotional quality of life against the impact of a breast cancer diagnosis and its treatment. And because minority women may have limited access to health care information and other resources, benefits for them are potentially even greater.

Our results indicate that CHES improved social support, information competence, participation in health care, and quality of life in this group of patients. After two months of implementation, there was either a significant main effect or interaction with an indicator of medical underservice for information needs and competence, and

**Table 2. Group Differences on Support, Participation, and Quality-of-life Variables at Two-month Follow-up — Results from Regression Models (N = 246)\***

Outcome Variables	Means (Covariate Adjusted)		Difference Between Means CHES–Control	95% CI† of Difference		Main Effect P Value‡	Interaction
	CHES	Control		Lower	Upper		
Social/information support							
1. Social support	80.8	78.4	2.4	–1.2	5.9		
2. Information competence	70.4	65.6	4.8	1.5	8.1	<.01	
3. Unmet information need¶	70.0	67.2	2.8	–2.7	8.4		Race,§ Education§
Participation in health care							
1. Participation: behavioral involvement	75.6	73.1	2.5	–1.1	6.1		Race,§ Education§
2. Participation: level of comfort	80.7	74.3	6.4	2.1	10.7	<.01	
3. Confidence in doctor(s)	83.0	77.3	5.7	1.0	11.3	<.05	
Quality of life							
1. Social/family well-being	79.3	78.2	1.1	–3.0	5.4		
2. Emotional well-being	73.9	72.8	1.1	–3.1	5.2		
3. Functional well-being	62.2	63.0	–0.8	–5.3	3.6		Insurance
4. Breast cancer concerns¶	65.1	63.3	1.8	–1.9	5.5		Insurance

\* Follow-up scores were statistically adjusted for pretest scores, days since diagnosis, stage of breast cancer, race, education, insurance status, chemotherapy status, and Karnofsky's performance status using the method of recycled predictions.<sup>32</sup> All scores were linearly transformed to a 0–100 scale.

† CI, confidence interval.

‡ Only P values smaller than .05 are shown. For behavioral involvement and level of comfort, Holm's method requires the smallest P value to be less than .025 and the next to exceed .05. For the four quality-of-life measures, Holm's method requires the smallest P value to be less than .0125, the next smallest to be less than .0167, the third .025, and the fourth .05.

§ Indicates a significant interaction (using same multiple comparison corrections as for main effects) between experimental condition and patient characteristics. See Figures 2 and 3 for details.

|| Indicates an interaction whose P value was less than .05, but was not significant because of the correction for multiple comparisons. The trend in these cases was always in the same direction as that in effects reported as significant: greater CHES benefit for the underserved.

¶ High scores indicate less breast cancer-related concerns and less unmet information need.

all three measures of health care participation. No significant main effects were found among four quality of life measures, but there was a consistent pattern among the interactions matching significant ones found elsewhere. CHES' mixture of disease information, self-monitoring and decision tools, along with shared experiences and support from other patients, may help patients tolerate treatment better, have more positive feelings about treatment, and therefore may improve outcomes as well.

The benefits of CHES were stronger in the short run. Five months after implementation, benefits of CHES were considerably less consistent. There were still significant increases in information competence and social support measures, but no difference for health care participation (possibly because there is less contact with the health system at this time) or quality of life. Thus, the benefits of a consumer support tool like CHES may dissipate over time. However, inspection of group means in Tables 2 and 3 suggests instead that control subjects eventually improved on their own between two and five months, as time since diagnosis and treatment passed, while the CHES group changed little beyond their two-month scores. Given the strains on breast cancer patients around the times of diagnosis and treatment (corresponding to the first

post-test), CHES appeared to help patients when they most need it.

There were several interactions of indicators of medical underservice with the CHES intervention: greater benefits for women of color, the uninsured, and those with less education. Note that race was not always the best locator of these interactions; low education and lack of health insurance were equally or more germane in identifying women who benefited most. Because the underserved have fewer resources, any incremental resource may have the potential to make a bigger difference for them.

Although we predicted such interactions, what is always at issue is whether the disadvantaged will have the ability and motivation to take advantage of that potential.<sup>17</sup> Because CHES (and other consumer health support services) relies heavily on written information, literacy and ease of reading are potential barriers for the underserved. In addition, the disadvantaged may be less experienced and comfortable with computers. Our results encourage optimism that computer technologies can assist the disadvantaged, because motivation provided by a life-threatening disease may overcome barriers to use. Disadvantaged women gain relatively more benefit because alternative resources are equally available to advantaged women in both experimental and control

**Table 3. Group Differences on Support, Participation, and Quality-of-life Variables at Five-month Follow-up—Results from Regression Models (N = 246)\***

Outcome Variables	Means (Covariate Adjusted)		Difference Between Means CHESS–Control	95% CI† of Difference		Main Effect P Value‡	Interaction
	CHESS	Control		Lower	Upper		
Social/information support							
1. Social support	84.2	79.3	4.9	1.4	8.4	<.01	
2. Information competence	69.3	65.8	3.5	0.0	6.9	.05	Education§
3. Unmet information need¶	67.0	69.6	–2.6	–8.2	2.9		
Participation in health care							
1. Participation: behavioral involvement	74.5	72.8	1.7	–2.3	5.6		
2. Participation: level of comfort	79.1	76.5	2.6	–1.4	6.7		
3. Confidence in doctor(s)	82.8	79.0	3.8	–2.2	9.8		
Quality of life							
1. Social/family well-being	75.8	74.7	1.1	–3.3	5.5		
2. Emotional well-being	76.3	75.3	1.0	–3.0	5.0		
3. Functional well-being	70.4	69.9	0.5	–3.5	4.4		Insurance
4. Breast cancer concerns¶	67.6	64.7	2.9	–0.6	6.4		

\* Follow-up scores were statistically adjusted for pretest scores, days since diagnosis, stage of breast cancer, race, education, insurance status, chemotherapy status, and Karnofsky's performance status using the method of recycled predictions.<sup>32</sup> All scores were linearly transformed to a 0–100 scale.

† CI, confidence interval.

‡ Only P values smaller than .05 are shown. For behavioral involvement and level of comfort, Holm's method requires the smallest P value to be less than .025 and the next to be less than .05. For the four quality-of-life measures, Holm's method requires the smallest P value to be less than .0125, the next smallest to be less than .0167, the third .025, and the fourth .05.

§ Indicates a significant interaction (using same multiple comparison corrections as for main effects) between experimental condition and patient characteristics. See Figures 2 and 3 for details.

|| Indicates a main effect or interaction whose P value was less than .05, but was not significant because of the correction for multiple comparisons. The trend in these cases was always in the same direction as that in effects reported as significant: a CHESS benefit or greater CHESS benefit for the underserved.

¶ High scores indicate less breast cancer-related concerns and less unmet information need.

groups. Moreover, minority women made less use of the Discussion Group, but more use of self-monitoring, planning and decision services, which we argued earlier may be more beneficial.

The clinical or personal importance of the changes reported here is a more complex issue, because no clear benchmarks exist for the information or health care participation variables. For the quality of life variables, however, two studies have demonstrated that 7.1–10.7 unit (translating to the 0–100 scale used here) changes in the functional well-being scale were associated with meaningful improvements in hemoglobin for patients treated for a variety of cancers.<sup>36,37</sup> None of the main effects for this measure or the other quality of life measures developed in the same way by the same researchers<sup>26–29</sup> were significant. If the same standard were applied to the information and health care participation measures for which significant main effects were observed, one could say that those main effects ranged in size from one-half to the lower bound of the clinically important range. More importantly, although the estimates are less reliable for the smaller sample size, the size of effects for the medically underserved (women of color, lower education, no private insurance) are consistently in or larger than this range, including two effects on functional well-being and one other measure of quality

of life. Thus, it would appear that the effects observed here for the medically underserved probably are personally and clinically, as well as statistically, significant.

Our results are probably generalizable to the U.S. population of younger women with breast cancer, although there are some remaining limitations. The ethnic diversity of the patients in the study (74% Caucasian, 22.4% African American, and 3.6% other minorities) is similar to that of the U.S. (72.2% Caucasian, 12.5% African American, and 15.3% other minorities).<sup>38</sup> The study sites included both public and private hospitals, some of which were teaching hospitals. Patients came from urban, small-city, and rural areas and included all socioeconomic strata, although all were from the Midwest. We did not include older women with breast cancer in this study. However, a recent CHESS evaluation in Medicare women found similar levels of acceptance and use.<sup>39</sup> In addition, patients treated in small, rural general surgeries were excluded, because including many clinics with few patients each would have been prohibitively expensive. Nonetheless, reactions to CHESS by patients at small clinics could conceivably be different from those at the specialized clinics studied here.

Our decision to compare CHESS to a control condition employing *Dr. Susan Love's Breast Book* creates a potential limitation to generalizability. Although we did this so that control-group patients from five different clinics would have

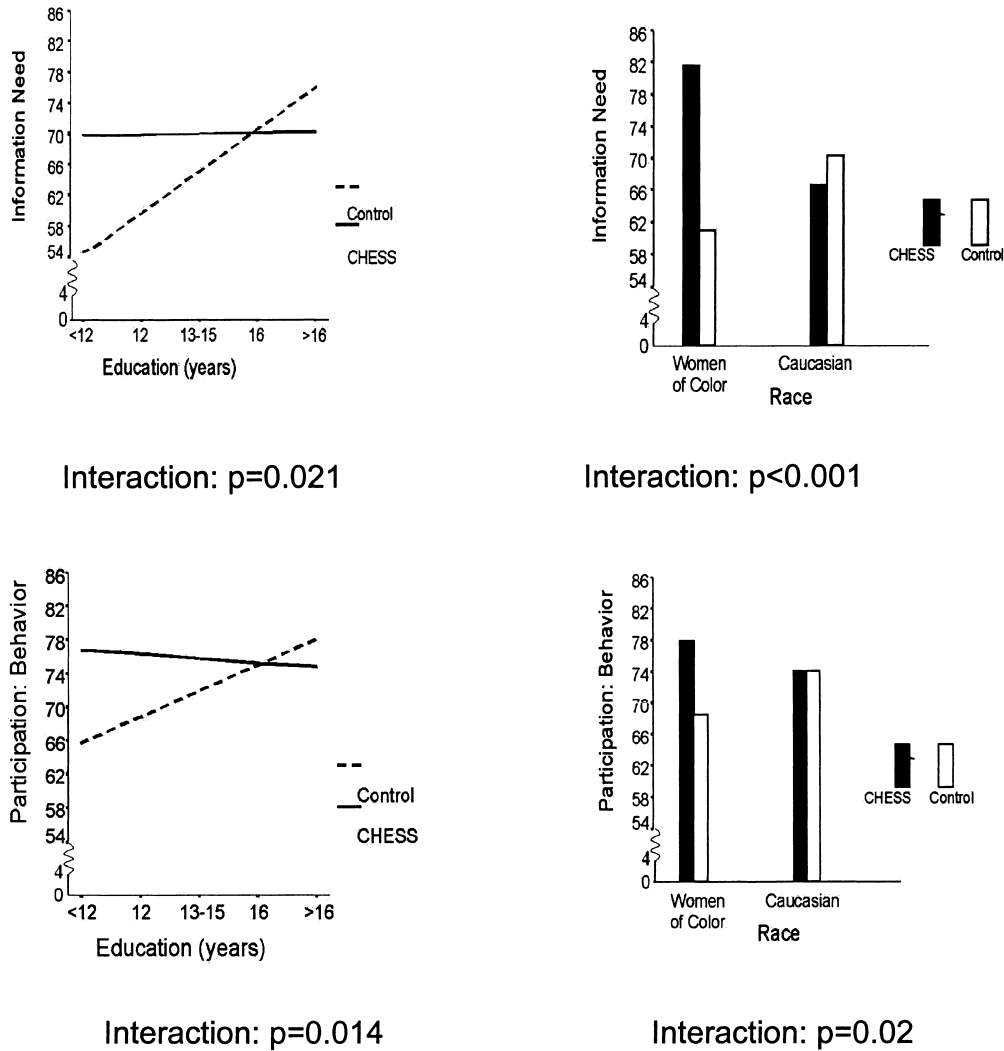
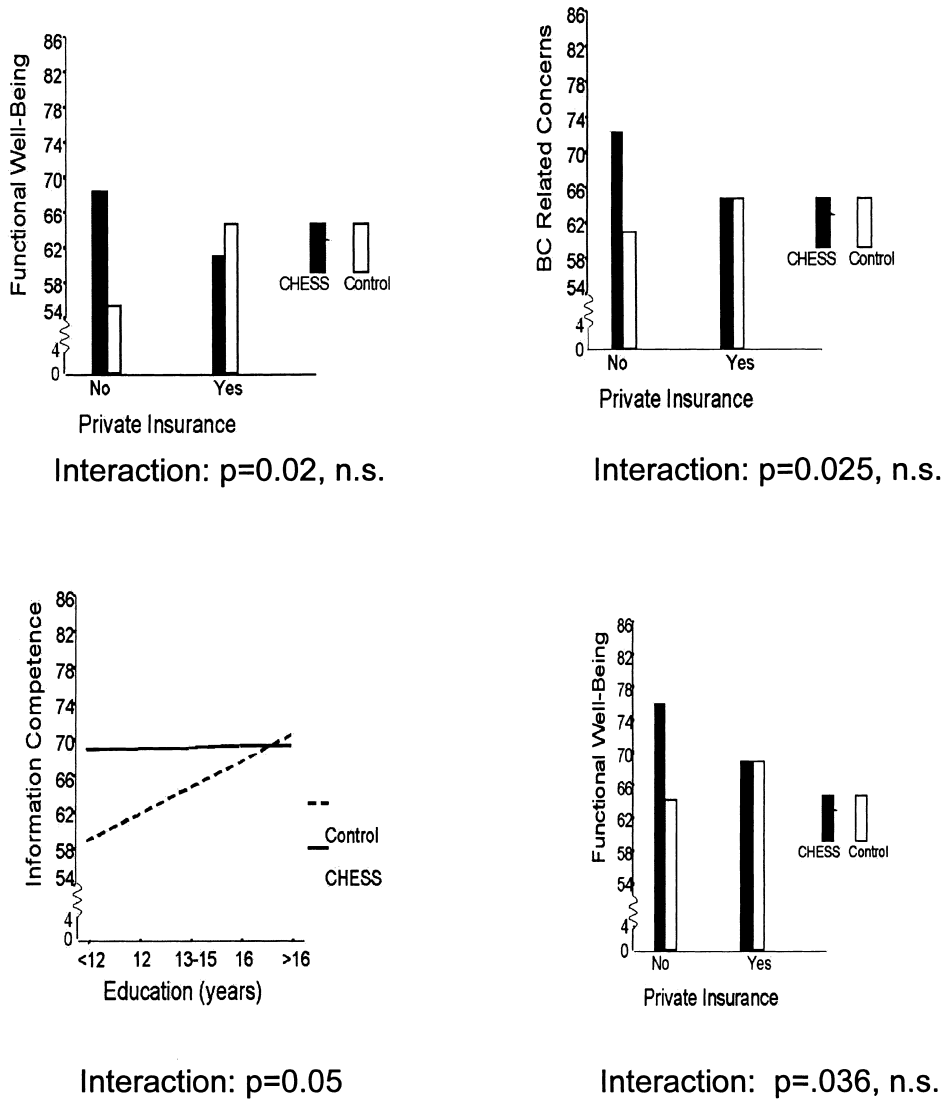


FIGURE 2. Interactions for participation and information need at two-month follow-up.

access to a comparable base of information, this could produce a conservative bias in experimental group comparisons. If so, actual implementations of CHES might produce slightly larger effects than those seen here. Conversely, one could argue that some benefits (particularly social and information support) could result simply from being loaned a computer, rather than the particular content it contained. We are skeptical of that explanation, given the heavy use of CHES, but a current study is comparing CHES to mere Internet access.

A final limitation is that the study reports aggregate effects for a support system, having many components designed to work together. While this approach was deliberate, and derived from the variation of patient needs,<sup>18,20</sup> we cannot say whether specific portions of CHES were responsible for these effects. Assigning each of a dozen or so CHES components to different groups could address this. However, we feel this would be a disservice to the patients involved by depriving each of the majority of services, and the ability to integrate material





**FIGURE 3.** Interactions for quality of life measures at two months and for information competence and functional well-being at five months. Due to multiple comparisons, significance required  $P < .0125$  for the two functional well-being interactions and  $P < .0167$  for breast cancer-related concerns.

from different services. However, given interactions with indicators of medical underservice, lower use of Discussion Group by women of color, and the match this presents with prior work on HIV-CHES,<sup>15</sup> one might wonder whether CHES could function effectively without the Discussion Groups (which accounted for 55% of all use). The ongoing study mentioned above includes a reduced-CHES condition without the Discussion Group and Ask an Expert components.

Future research should compare CHES against alternative support services of comparable or less cost.

Many professional programs (such as group psychotherapy for women with breast cancer) exist for people with life threatening illnesses. How would they compare to CHES and how would a combination of CHES and such programs affect women with breast cancer?

Although this study was conducted while CHES was a stand-alone program, it has now migrated to the Internet, potentially changing its accessibility and cost. More people are now gaining access and using the unregulated and possibly overwhelming world-wide web.<sup>40</sup> In fact, nearly 75% of all breast cancer patients

now offered CHES already have Internet access. However, although this research suggests that the underserved may benefit most, they currently are least likely to have such access.<sup>41,42</sup>

Costs of a wide scale dissemination of any interactive health communication (IHC) system depend on the implementation strategy employed. One could provide the system in the same way as most web sites: offering it to anyone with Internet access. Alternatively patients could be actively recruited to and supported in their use of the IHC.

In that case, costs would be divided into those associated with "marketing" the IHC to patients and costs of operating the IHC once patients accept it. Assuming three-month access, we estimate that a system like CHES

might be delivered for approximately \$150 per patient, including purchasing computers to loan. Delivery would be cheaper for patients who have Internet access, but relying on this strategy would exacerbate digital divide problems. An aggressive recruiting effort would increase costs. However, given the benefits observed here, and their concentration among those most in need of help, we believe an aggressive strategy is justified.

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## APPENDIX

### Patient Outcome Measures (With Example Items)

#### Social and Information Support

1. A six-item scale of perceived emotional and instrumental support (Cronbach's  $\alpha = 0.89$ ).<sup>14</sup>  
 "There are people I can count on for emotional support."  
 "There are people I can rely on when I need help doing something."
2. A five-item scale of competence at seeking information (Cronbach's  $\alpha = 0.80$ ).<sup>25</sup>  
 "At this time, I can figure out how and where to get the information I need."  
 "I feel that I am in control over how and what I learn about my health."
3. A three-item unmet information need scale (Cronbach's  $\alpha = 0.83$ ).  
 "There is information I need but don't know how to get."

#### Participation in Own Health Care

1. A four-item scale of perceiving oneself involved in one's health care (Cronbach's  $\alpha = 0.77$ ).<sup>14</sup>  
 "I went to the right provider at the right time."  
 "I thought about what was going to happen ahead of time."
2. A two-item level of comfort participating in one's own health care scale (Cronbach's  $\alpha = 0.68$ ).<sup>25</sup>  
 "I feel comfortable asking my doctor questions about my care."  
 "I feel confident about my ability to make major decisions about my health."
3. A single item assessed a woman's level of confidence in her doctor(s).<sup>26</sup>  
 "I have confidence in my doctor(s)."

#### Psychosocial Quality of Life<sup>26</sup>

1. A six-item scale of social/family well-being (Cronbach's  $\alpha = 0.79$ ).  
 "Family communication about my illness was poor."  
 "I felt close to my partner."
2. A six-item scale of emotional well-being (Cronbach's  $\alpha = 0.80$ ).  
 "I worried about dying."  
 "I felt nervous."
3. A seven-item scale of functional well-being in everyday life (Cronbach's  $\alpha = 0.84$ ).  
 "I was enjoying my usual leisure pursuits."  
 "My work was fulfilling."
4. A nine-item scale of the extent a woman was concerned about side effects and risks (Cronbach's  $\alpha = 0.66$ ).  
 "I felt self-conscious about the way I dressed."  
 "I felt sexually attractive."  
 "I worried about the effect of stress on my illness."

A complete set of items is available from the authors.

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