Objective To evaluate the effectiveness of the STARRIGHT FITTING CYSTIC FIBROSIS INTO YOUR LIFE EVERYDAY CD-ROM. Data were analyzed to evaluate the effectiveness of the program as an educational tool for children and adolescents with cystic fibrosis (CF). Methods Forty-seven children and adolescents with CF between the ages of 7 and 17 years were enrolled in the study. Participants completed an initial evaluation of CF-related knowledge and coping skills and were then randomly assigned to one of two groups: the treatment group or the wait-list control group. Participants then viewed the CD-ROM, and researchers completed posttest measures. Results Analyses indicated that both disease-related knowledge and coping strategies generated by children and adolescents with CF improved as a result of the intervention and that this effect was replicated in the wait-list group. Conclusions In sum, the results of the current study indicate that the STARRIGHT CD-ROM program is a promising intervention for increasing CF-related knowledge and the competence of children’s and adolescents’ coping strategies. These positive results are enhanced by the brief, inexpensive, and portable nature of this educational program.

Key words cystic fibrosis; STARRIGHT; educational intervention; coping skills.

Approximately 18% of children living in the United States have a serious chronic condition that significantly affects their daily functioning (Newacheck, McManus, Fox, Hung, & Halfon, 2000). Although these conditions vary in terms of symptomatology and severity, most require extensive treatment regimens that must be performed each day. High rates of noncompliance have been documented for many pediatric conditions, due to the extensive treatment regimens that must be performed each day (Quittner et al., 2000; Rapoff, 1999). Problems with adherence have been associated with inadequate knowledge about the disease and its treatments, as well as developmental and family factors (Rapoff, 1999). Although health care providers typically make specific recommendations, patients often lack the knowledge and coping skills necessary to follow through with these recommendations. In chronic-illness populations, long-term management of the disease and successful psychosocial adaptation may be positively influenced by educational programs that increase knowledge and teach effective coping skills. The central purpose of this study was to evaluate the effects of a newly developed educational CD-ROM for children and adolescents with cystic fibrosis (CF; Davis, Quittner, & Stack, 2002).

Cystic fibrosis is the most common terminal genetic disease of Caucasian populations, and it affects approximately 1 in 3,400 live births (Korosok, Wei, & Farrell, 1996). It is a complex autosomal recessive disorder affecting the exocrine glands in several major organ systems, including the respiratory, digestive, and re-
productive. Over the past several decades, reductions in morbidity and mortality in patients with CF have been a result of earlier diagnosis as well as arduous and aggressive treatment regimens that assist in slowing the cycle of pulmonary infections and physical decline. However, the regimen for patients with CF is both complex and time consuming, including airway clearance, oral and nebulized medications, and increased calorie intake (Orenstein, Rosenstein, & Stern, 2000). Due to the progressive nature of this disease, the prescribed treatment regimen often increases in complexity over time. Thus, patients with CF need to acquire and maintain the skill set necessary to manage this chronic condition throughout their lifetime.

Disease-Related Knowledge

As is true for other pediatric conditions, the factors that influence adaptation to CF are multidimensional and include psychological, developmental, and educational factors (Gudas, Koocher, & Wypiz, 1991; Lorenz & Wysocki, 1991; Quittner & DiGirolamo, 1995). To date, most research on adaptation to CF has been descriptive, comparing psychological and behavioral adjustment of children with and without CF. More recently, there has been a call for the development and evaluation of interventions that increase the knowledge, skills, and coping strategies needed by children and adolescents to manage this disease (Quittner et al., 2000).

The need for educational programs for children and adolescents with CF is highlighted by extensive literature citing significant errors, gaps, and misconceptions in disease-related knowledge by patients and their parents. Specifically, Conway, Pond, Watson, and Hamnett (1996) reported that a sample of adolescents and adults had not only inadequate knowledge of genetics but also misconceptions about respiratory and gastrointestinal problems. Other studies have documented inadequate understanding of the treatment regimen for CF. For example, Gudas and colleagues (1991) found that despite the specific dietary recommendations made by the health care team, a majority of parents and children were not aware that dietary alterations were part of the treatment regimen for CF. More recently, levers and colleagues (1999) found a strong relationship between an accurate understanding of the treatment regimen and rates of adherence. Thus, children with CF may need specific and accurate information about their disease in order to manage it on a daily basis.

Coping Skills and Chronic Illness

Given the extensive physical and psychological challenges imposed by a chronic illness, it is reasonable to assume that children and adolescents with CF will experience increased levels of stress (Thompson, Gustafson, Hamlett, & Spock, 1992). Sources of stress may include altered physical appearance, lack of social relationships, and conflicts with parents and siblings (Charron-Prochownik, 2002; DiGirolamo, Quittner, Ackerman, & Stevens, 1997). Furthermore, extensive treatment demands often affect aspects of daily life, including recreation time, family interactions, and peer relationships (Quittner & DiGirolamo, 1998; Quittner, Tolbert, Orenstein, Hollingsworth, & Eigen, 1996). To manage these situations, children and adolescents must develop effective coping strategies.

As adolescents make the transition into adulthood and attempt to master important developmental tasks (e.g., greater independence, increased responsibility for disease management), they often display poorer adherence to treatment, less competent coping strategies, and increased conflict with parents (Coupey & Cohen, 1981; DiGirolamo et al., 1997; Lazarus & Folkman, 1984). Interestingly, in a study of adolescents ranging in age from 11 to 20, all participants stated they would like additional information on how to cope with their disease on a daily basis and on potential health problems they may encounter in the future (Hames, Beesley, & Nelson, 1991). These teens and young adults also indicated that they would prefer to obtain this type of information from medical staff rather than from their parents. An educational CD-ROM that focuses on increased knowledge and improved coping strategies might be well received by this population.

Educational Programs for Children and Adolescents with CF

Despite the well-documented need for educational programs for patients with CF and their parents, few programs to date have been developed and evaluated. In one of the few studies of a systematic educational program, Bartholomew et al. (1991) found that the CF Family Education Program increased knowledge of CF and that it was associated with improved adaptation. In a second, more comprehensive evaluation of this program, investigators found that improvements in knowledge and management of CF were related to the ability of caretakers to cope successfully with problems
related to disease management, such as adjusting enzymes and increasing caloric intake (Parcel et al., 1994). It is important to note, however, that the CF Family Education Program required a substantial time commitment from study personnel and the participants’ families. For this reason, it may not be feasible to implement this type of intervention in a clinical setting in which nurses may already be overburdened.

In an ongoing randomized trial, a more comprehensive educational intervention is being evaluated and compared to a family therapy intervention for adolescents with CF and their parents. The primary outcome of this study is improved adherence to medical regimens, with secondary outcomes focused on increased disease-related knowledge, coping skills, and family functioning. Preliminary results have indicated positive effects for both interventions; however, these interventions require families to travel long distances to the medical center, to attend 10 sessions of treatment over a period of 5 months. Thus, the time commitment and resources involved in these interventions may limit their feasibility and generalizability (Quittner et al., 2000).

Recently, a new educational CD-ROM titled *Fitting CF Into Your Life Everyday* was developed by the STARBRIGHT Foundation, with the aims of educating children and adolescents about their illness as well as teaching them how to cope successfully with such related stressors as hospitalizations, chronic pain, and complex treatment regimens. If the CD-ROM program is shown to be effective, it has the advantages of being brief, cost-effective, and easily transportable.

The purpose of the current study was to evaluate the effectiveness of the STARBRIGHT Foundation’s new CD-ROM program designed for children and adolescents with CF. The study utilized a randomized wait-list control design, which allowed participants in the wait-list group to serve as controls for both time and maturation, but to eventually have the opportunity to participate in the intervention. Specific hypotheses were generated about how the program would affect children’s knowledge; experience of common, problematic situations; and coping skills. First, researchers hypothesized that participants in the treatment group, who viewed the CD-ROM, would demonstrate increases in disease-related knowledge and decreases in the frequency and difficulty of problematic situations, and would generate more competent coping strategies than would participants in the wait-list group. Next, they hypothesized that similar results would be found for the wait-list group after they received the intervention.

Lastly, they predicted that children and teens would view the intervention positively, giving the CD-ROM program high satisfaction ratings and indicating a willingness to share it with others.

**Procedure**

All patients who met the inclusion criteria and who were scheduled for a regular clinic visit during the 9-month recruitment phase were approached for inclusion in the current study. A total of 49 children with CF and their parents were approached, and approximately 96% (N = 47) agreed to participate. Reasons for nonparticipation were the lack of access to a computer and a misdiagnosis of CF. Once parents and children agreed to participate, informed consent was obtained in accordance with the University of Florida Institutional Review Board, and the psychosocial measures were completed.

Participants completed an initial evaluation (Time I) of their knowledge of CF and their coping skills. They were then randomly assigned to one of two groups: treatment or wait-list (see Figure 1). This design offered several advantages. First, it allowed all participants to participate in, as well as potentially benefit from, the CD-ROM intervention. Second, the use of a wait-list group provided a methodologically rigorous test of the impact of the educational program, controlling for maturity, seasonal differences, and other developmental variables. Finally, this design also increased the sample size for the treatment outcome analyses (Yang, Wu, Tang, & Quittner, 2003).
**Active Treatment Group**

After the Time I evaluation, participants assigned to the treatment group viewed the CD-ROM while being supervised by a trained researcher at their next clinic visit (Time II), which occurred two to three months later. Immediately after viewing the CD-ROM, participants completed a set of posttest measures to assess their knowledge of CF and coping skills, with the addition of a consumer satisfaction questionnaire.

**Wait-List Control Group**

Participants randomized to the wait-list group completed the initial evaluation (Time I) and the same set of measures at Time II, 2 to 3 months later. During their third visit (Time III), participants in this group viewed the CD-ROM while being supervised by a trained researcher, and then completed the same posttest measures described earlier.

After the completion of each assessment, participants were given a $5 gift certificate as reimbursement for their time and effort. In addition, once participants completed all of the assessment points, they were given a copy of the STARBRIGHT CD-ROM, which had additional educational modules.

**Materials**

**STARBRIGHT Fitting Cystic Fibrosis Into Your Life Everyday CD-ROM.** This new CD-ROM features three modules: Eating, Breathing, and CF Questions and Answers. Completion of the CD-ROM takes approximately 30 min. Topics covered in the Eating module include a description of the digestive system, a set of dietary recommendations, and information on the importance of taking enzymes. In the Breathing module, topics include the reasons for respiratory treatments, the consequences of smoking, the importance of exercise, and adherence to treatments. The last module, CF Questions and Answers, presents hypothetical problems that may be encountered by children and adolescents with CF, as well as suggestions for coping with these problems. The CD-ROM discusses several common issues, including peer relationships, the importance of doing treatment, and coping with hospitalizations.

**Cystic Fibrosis Knowledge Questionnaire (CFK; Quittner & Drotar, 1997).** The CFK was used to assess participants' CF-related knowledge at each assessment point. It consists of 27 multiple-choice items, with scores reported as percentage correct. This measure was adapted from a more comprehensive knowledge measure, to focus on the topics covered in the STARBRIGHT CD-ROM program (Quittner et al., 2000). Adequate reliability was found for the current sample (Cronbach's alpha = .91).

**Role Play Inventory of Situations and Coping Skills (school-age and adolescent versions) (DiGirolamo et al., 1997).** Both versions of the Role Play Inventory of Situations and Coping Skills (RISCS) developed by Quittner and colleagues (DiGirolamo et al., 1997; Quittner et al., 1996) are context-specific vignettes designed to assess the frequency and difficulty of problematic situations encountered by school-age children and adolescents with CF, and the competence of their coping strategies. Audiotaped vignettes are presented to the participant, who is then asked to rate, on a 5-point scale, the frequency of these problematic situations (1, not at all frequent; 5, a lot) as well as their difficulty (1, not at all difficult; 5, extremely difficult). Finally, participants are asked to generate a coping strategy for each problematic situation. Coping responses are tape-recorded and transcribed, and then rated for competence using empirically derived criteria on a 4-point scale (1, extremely incompetent/ineffective; 4, extremely competent/effective). Coping responses were rated by judges who were blind to group assignment. Internal consistency coefficients for the Frequency and Difficulty scales have ranged from .63 to .80 and from .67 to .85, respectively (Quittner & DiGirolamo, 1995). Interrater reliability was assessed across two judges for half of the responses, with percentage agreement calculated at 98%. In the current study, four items from the RISCS measure were selected because of their relevance to the topics presented in the CD-ROM program. In addition, two generalization probes (i.e., new situations that the participant had not heard before) were administered at the posttest to determine whether participants could apply both their knowledge and coping skills to novel situations.

**Consumer Satisfaction Questionnaire.** Participants were asked to complete a measure of their overall satisfaction with the CD-ROM program, including any additional information they would like to obtain. This questionnaire was administered only after participants viewed the CD-ROM.

**Participants**

Enrolled in the study were 47 children and adolescents between the ages of 7 and 17 years (29 males, 18
females) with a proven diagnosis of CF (see Table I). All of the participants were receiving medical treatment at an accredited CF center in the southeastern U.S. Participants were excluded from enrollment if they were unable to comprehend English or if a medical chart review indicated they had psychiatric or cognitive difficulties that would preclude their understanding of the questionnaires or the CD-ROM.

Participants were then randomly assigned to either the treatment (n = 25) or wait-list control (n = 22) group, using a computer-generated randomization procedure. An independent statistician who did not interact with the children or their families performed the randomization. Further, investigators were blind to the randomization process and had no influence over allocation of participants to conditions.

In the treatment group, children’s mean age was 13.6, with a range of 8 to 16 years, and mean Forced Expiratory Volume in one second (FEV1% predicted) was 87.0%. Median grade level was 8, with 96% of children enrolled in public or private school and with 4% homeschooled. A little over half (56%) of the participants were male. On average, parents had 13 years of education.

In the wait-list group, children’s mean age was 12.5 years, with a range of 7 to 17 years, and mean FEV1% predicted was 85.2%. Median grade level was 7, with 77.3% enrolled in public or private school and with 22.7% being homeschooled. Parents had on average 13 years of education.

Statistical Analyses

Data were analyzed to evaluate the effectiveness of the STARBRIGHT CD-ROM program as an educational tool for children and adolescents with CF. Several types of analyses were conducted, including the following:

1. descriptive analyses on the demographic characteristics of participants;
2. between-group analyses comparing scores on the dependent measures at Time I to ensure equivalence of the two groups prior to intervention;
3. within-subject analyses comparing scores on dependent measures for the treatment group across assessment points;
4. an ANOVA of change scores on the dependent measures comparing the treatment (Time I to Time II) and wait-list groups (Time I to Time II) to test for carryover effects (Kenward & Jones, 1987), followed by within-subject analyses of treatment effects in the wait-list group after the intervention (Time II to Time III; Yang et al., 2003); and
5. descriptive analyses of the consumer satisfaction data, including ratings of which aspects of the program participants enjoyed and input on how this type of educational tool could be used (e.g., shared with peers, shown at school).

Results

Descriptive Statistics

Comparisons of the demographic characteristics of the two groups were made to determine whether the randomization procedure produced similar groups at Time I. An independent t test was used to compare participant age, grade level, and pulmonary functioning. No differences were found between the groups on these characteristics (see Table I). In addition, chi-square analyses were conducted to compare the gender distribution of each group, $\chi^2 (df = 46) = 0.74$, $p = ns$; the child’s current school environment $\chi^2 (df = 46) = 3.67$, $p = ns$; and their prior computer usage, $\chi^2 (df = 46) = 0.50$, $p = ns$. No significant differences were found between the groups on any of these variables. Finally, t tests revealed no significant differences between the groups in disease-related knowledge or in any of the coping variables measured by the RISCS (see Table II).

Intervention Effects

Knowledge of Cystic Fibrosis

It was hypothesized that participants who viewed the CD-ROM program would show increases in disease-related knowledge when compared to controls.

Paired t tests were conducted within each group to assess changes in knowledge scores from Time I to Time II. As predicted, knowledge increased in the treatment
group (see Table III). However, no change in knowledge was found for the wait-list group between Time I and Time II (Time I, $M = 52.9, SD = 22.1$; Time II, $M = 52.7, SD = 21.7$; $t(21) = 0.7, p = ns$). Next, ANOVA was conducted to assess possible carryover effects for the wait-list group. No carryover effects were found. However, as predicted, significant treatment effects were found for the treatment group, as evidenced by improvements in CF knowledge. In addition, paired $t$ tests were conducted within the wait-list group from Time II to Time III to see if the intervention effect was replicated. Significant increases in CF knowledge were also found for the wait-list group following the intervention (Time II, $M = 52.7, SD = 21.7$; Time II, $M = 89.2, SD = 8.5$; $t(21) = 8.2, p < .001$; effect size = 2.41) (see Table IV).

### Role-Play Inventory of Situations and Coping Skills (RISCS)

Participants who viewed the CD-ROM were expected to report less frequent and less difficult problematic situations on the RISCS and generate more effective coping strategies than those in the wait-list group. Paired $t$ tests were conducted on the RISCS measures for the treatment group. No differences were found on the Frequency and Difficulty scales on the RISCS; however, as expected, children and teens in this group generated more competent coping strategies after completing the CD-ROM intervention (see Table III). As expected no changes were found for the wait-list group following the intervention (see Table IV).

Next, an ANOVA was conducted between change scores for the treatment group during Time I to Time II and for the wait-list group during Time I to Time II and after the intervention (Time II to Time III). No carryover effects were found on any of the coping measures. Although no changes were found for the treatment group on the RISCS Frequency and Difficulty scales, improvements were found in the competence of coping strategies generated by this group (see Table III). Paired $t$ tests were then conducted for the wait-list group from Time II to Time III, with similar results. No differences were found on the Frequency and Difficulty scales; however, improvements in coping strategies were found after participants completed the intervention (see Table IV).

An additional analysis was conducted to determine whether participants were able to generate competent coping strategies to the new generalization vignettes. Mean competency scores on these vignettes compared favorably with the postintervention scores for both groups, $M = 2.72, 2.69$, respectively, $t(46) = .65, p = ns$, suggesting that they could generalize what they had learned to new vignettes.

### Consumer Satisfaction

Descriptive analyses were conducted to determine participants’ satisfaction with the CD-ROM program. All participants who completed the program ($N = 47$) reported that they enjoyed it and learned new information. Several participants noted that some topics were missing from the CD-ROM, such as attending college, dating, school issues, and death and dying. Furthermore, when asked how they would utilize the CD-ROM program, a majority reported they would play it alone (85%); in addition, 57% would play it with friends, 31% with classmates, 26% with siblings, and 26% with parents.

### Conclusion

Overall, the STARBRIGH CD-ROM program appeared to be an effective tool for improving disease-related knowledge and coping strategies for children and adolescents with CF. The greatest effects were found...
for changes in knowledge, with small effects found for changes in coping strategies generated in response to the audiotaped vignettes.

Increases in knowledge are important for several reasons. First, several studies have shown that knowledge is an important component of effective disease management and is associated with increased self-efficacy (Bartholomew et al., 1991). Although knowledge is not sufficient to produce behavioral changes, it appears to be a necessary step in the change process (Henley & Hill, 1990; Hinton, Watson, Chesson, & Mathers, 2002; Ievers et al., 1999). Although changes in knowledge were found immediately following the intervention, it is unclear how long children and adolescents were able to maintain this information. Future studies should focus on assessing the longitudinal effects of the intervention.

Interacting with the CD-ROM program was also expected to increase the competence of coping strategies that children and teens generated for common problematic situations. Although viewing the CD-ROM program did not reduce the frequency or difficulty of these situations, it did lead to an increased ability to generate effective coping strategies. Note that these coping strategies were not measured using a self-report checklist but were generated verbally in response to common and difficult problematic vignettes as well as to new generalization probes. Responses generated by participants were scored by external raters who were blind to treatment condition and assessment point. Few studies to date have demonstrated positive changes in coping responses, and this finding seems especially important since the intervention was brief and cost-effective. Given that there is substantial data indicating an increased use of ineffective or maladaptive coping responses by adolescents as they move into adulthood, it will be important to develop interventions that are viewed as acceptable and useful by teens with CF (Coupey & Cohen, 1981). Thus, this CD-ROM program may be a simple and inexpensive way to promote more competent coping behaviors for those in a wide range of ages. However, additional studies are needed to address three key questions:

1. Do these verbally generated strategies lead to more effective behavioral and social interactions?
2. Are these modest improvements as measured on the RISCS clinically meaningful?
3. Do these effects last over time?

Results of the consumer satisfaction questionnaire indicated that all participants enjoyed the program and believed they had learned new information. Interestingly, over half of the participants reported that they would use the CD-ROM program with friends or classmates. This suggests that the CD-ROM program may not only be useful for patients with CF in a clinical setting but may also be an effective tool for teaching others. Thus, future studies should evaluate the impact of this CD-ROM on parents, siblings, and classmates. Currently there are few educational programs available for teachers and peers that provide basic information about CF in a format that is both fun and informative.

Despite the positive changes in knowledge and coping strategies observed in this study, the design precluded our ability to examine the maintenance of these effects over time. Future studies should include a follow-up assessment to determine the long-term impact of this innovative educational intervention on these outcomes as well as other potentially important variables, such as adherence behaviors and health-related quality of life. This intervention is worthy of additional efforts.

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Table IV. Mean Scores for the Treatment and Wait-List Groups Pre- to Postintervention

<table>
<thead>
<tr>
<th>Variables</th>
<th>Time I</th>
<th>Time II</th>
<th>Time III</th>
<th>Combined Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Active (n = 25)</td>
<td>Wait-List (n = 22)</td>
<td>Active (n = 25)</td>
<td>Wait-List (n = 22)</td>
</tr>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>CFK</td>
<td>57.0 (21.5)</td>
<td>52.9 (22.1)</td>
<td>83.0 (17.6)</td>
<td>52.7 (21.7)</td>
</tr>
<tr>
<td>Frequency</td>
<td>2.4 (0.79)</td>
<td>2.5 (0.94)</td>
<td>2.3 (0.68)</td>
<td>2.4 (0.90)</td>
</tr>
<tr>
<td>Difficulty</td>
<td>2.2 (0.87)</td>
<td>2.1 (0.78)</td>
<td>2.1 (0.81)</td>
<td>2.2 (0.84)</td>
</tr>
<tr>
<td>Competency</td>
<td>2.4 (0.80)</td>
<td>2.3 (0.76)</td>
<td>2.7 (0.64)</td>
<td>2.4 (0.86)</td>
</tr>
</tbody>
</table>

Note. CFK = Cystic Fibrosis Knowledge Questionnaire; RISCS = Role Play Inventory of Situations and Coping Strategies.

* Due to the nonsignificant carryover effects, the two groups were combined to examine change scores pre- and postintervention. This more sophisticated statistical analysis confirms the findings from the treatment group, that knowledge and coping efficacy increased significantly after viewing the STARBRIGHT CD-ROM program.
research given that it is inexpensive, portable, and well received by the children and adolescents in this study.

Authors’ Note

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The STARBRIGHT Fitting CF Into Your Life Everyday CD-ROM is available free of charge to children and teens with cystic fibrosis, their families, and healthcare professionals. The program can be ordered from STARBRIGHT’s website, www.STARBRIGHT.org, or by calling 1-800-315-2580.

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References


Kenward, M. G., & Jones, B. (1987). The analysis of data from 2 \times 2 cross-over trials with baseline measurements. Statistics in Medicine, 6, 911–926.


