

# **The Experience Journal: A Computer-Based Intervention For Families Facing Congenital Heart Disease**

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## **Abstract**

This study tested the feasibility and safety of a computer-based application designed to facilitate the healthy coping of children and their families who must contend with significant congenital heart disease (CHD). The application, called the Experience Journal (EJ), is a psychoeducational intervention based upon a narrative model involving the sharing of personal stories about an illness. Testing was conducted in two phases. In Phase 1, 9 parents of children with CHD and 1 adult with CHD were asked to use the EJ. After utilization, semistructured interviews assessed EJ usability and safety. In Phase 2, 40 mothers of children with CHD used the EJ during a hospitalization. Assessment of feasibility and safety was measured through the use of semistructured interviews prior to EJ utilization and 2-4 weeks after hospital discharge. Results revealed that the EJ was safe and useful for decreasing social isolation, increasing understanding of familial feelings about cardiac illness, and fostering positive reactions in mothers. Computer-based interventions that present psychoeducational and medical information closely connected to "one's own story" may open up new possibilities for families facing pediatric illnesses.

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### **Abstract**

**Objective:** This study tested the feasibility and safety of a computer-based application designed to facilitate the healthy coping of children and their families who must contend with significant congenital heart disease (CHD). The application, called the Experience Journal (EJ), is a psychoeducational intervention based upon a narrative model involving the sharing of personal stories about an illness. **Method:** Testing was conducted in two phases. In Phase 1, 9 parents of children with CHD and 1 adult with CHD were asked to use the EJ. After utilization, semistructured interviews assessed EJ usability and safety. In Phase 2, 40 mothers of children with CHD used the EJ during a hospitalization. Assessment of feasibility and safety was measured through the use of semistructured interviews prior to EJ utilization and 2-4 weeks after hospital discharge. **Results:** Results revealed that the EJ was safe and useful for decreasing social isolation, increasing understanding of familial feelings about cardiac illness, and fostering positive reactions in mothers. **Conclusions:** Computer-based interventions that present psychoeducational and medical information closely connected to "one's own story" may open up new possibilities for families facing pediatric illnesses.

**Key Words:** prevention, pediatric, computer, safety, heart disease.

Improvements in the management of congenital heart disease have enabled children to survive who in the past would have died, and allowed others to avoid debilitating effects. However, many youngsters continue to experience a chronic illness with repeated operations, hospitalizations, and invasive outpatient procedures. Studies show evidence of psychological resiliency, but also constraints and burdens on patients facing pediatric cardiac illness (DeMaso et al., 1990; DeMaso et al., 1991; DeMaso et al., 1995; Peterson & Harbaugh, 1995). Parental functioning, along with adaptive parent-child relationships, are important predictors in the emotional functioning and distress in these children (DeMaso et al., 1990; DeMaso et al., 1991; DeMaso et al., 1995).

There has been a consensus supporting the need for preventative intervention strategies for children and parents (Institute of Medicine, 1989). For families confronting physical illnesses, the focus has either been on identifying risk factors (DeMaso et al., 1990; DeMaso et al., 1991; DeMaso et al., 1995) or on preparing patients for procedures or hospitalizations (Campbell et al., 1995; Campis et al., 1990; Hunsberger et al., 1984; Kain et al., 1996; Pearson, 1980; Pinto & Hollandsworth, 1989; Rasnake & Linschied, 1989; Schmidt, 1990; Vernon & Thompson, 1993). The preparatory interventions generally include cognitive strategies (e.g., pre-admission programs, bibliotherapy, support groups) designed to provide families with educational information regarding their illnesses combined with the modeling of and permission for adverse affective responses (e.g., fear, anger). While difficult to measure, all interventions have been generally viewed as helpful to families (Campbell et al., 1995; Kain et al., 1996; Kennedy & Riddle, 1989; Recker, 1994; Schmidt, 1990; Zastowny et al., 1986).

Nearly all interventions target children primarily despite the identified importance of parental functioning to child outcome. There has also been significant concern about the

availability of these interventions to families. In a survey (Gonzalez-Heydrich et al., 1998) of 27 consecutive families admitted to Children's Hospital in Boston, 58% had no formal psychoeducational or emotional preoperative preparation. Nearly 50% of families had not spoken with other parents with similar illnesses, despite 89% being interested in hearing their experiences. These results occur even though the hospital provides a formal pre-admission program and most of the cardiology staff attempts to provide education and support to families. Over 90% of families were interested in passing on their experiences to others, with 89% interested in a computer-based application that would make this easily accessible.

Both cardiac surgery and catheterization are known to be associated with emotional distress, pain, and anxiety (Peterson & Harbaugh, 1995). At the same time, health care has seen reductions in the lengths of hospitalizations, along with increases in ambulatory surgery and same day admissions for surgery. The need for timely information and preparation remains at least the same, if not increased, in the face of these changes. The Experience Journal (EJ), a computer-based application designed to facilitate the healthy coping of families facing pediatric illness, was designed to be an innovative technique in the face of these dilemmas (Gonzalez-Heydrich et al., 1998). The areas of preventive intervention, medical crisis counseling, narrative therapy, and computer utilization guided the design and implementation of the EJ.

Offord (1982) noted that it is essential to establish that a preventive intervention does more good than harm. The need to establish safety is particularly important for a computer application where parents are not seeking treatment for their children and there is no readily available clinician. Thus, the establishment of safety for participants using the EJ was one of the main goals of the study.

In the design of an effective intervention for medical crises, Shapiro and Koocher (1996) outlined the importance of expression of emotion, working on relationships, examination of meaning, being involved in meaningful activity, seeking others with similar experiences, and medical proactivism in addressing these impediments. Parents have been found to informally talk with other parents about their experiences, often finding support and reduced isolation from others sharing the same experience (Gonzalez-Heydrich et al., 1998). A computer application for parents could bring together a wide audience of those seeking others with similar experiences.

Narrative therapy is an orientation that emphasizes the construction of meaning as a central concept and goal. An individual's personal explanation and beliefs as to how and why his or her illness developed usually encapsulate that person's deepest convictions and confusions (Shapiro & Koocher, 1996). Based upon this work, an effective preventive intervention needs to include a focus on self-understanding and shared understanding. Self-understanding has proven an important component of resiliency in previous studies (Beardslee, 1989; Focht & Beardslee, 1996). The design of a computer program as a preventive intervention needs to go beyond the simple expression of factual information to one that allows an individual to not only read the stories of others, but also allow them the opportunity to tell their own story. Studies have shown significant positive effects in patients who have the opportunity to either tell their stories (Adler, 1997; Clark & Standard, 1997; Suedfeld & Pennebaker, 1997) or write them (McGihon, 1996). Research has also noted the value of linking information to personal experience to bring about sustained change in understanding and behavior (Beardslee et al., 1996; Beardslee et al., 1997).

There are a significant number of "virtual" support groups in cyberspace for a wide variety of physical illnesses as well as numerous sites for obtaining factual information about

pediatric illnesses. There are a number of computer projects in various stages of development to help ill children communicate with one another on-line. These include The National Cristina Foundation, Express Link-Up, and The Starbright Foundation (Greenman, 1998). While there is little data existing on the efficacy of these interventions, their popularity and impressive growth would seem to support their value to participants (Shapiro & Koocher, 1996).

The EJ takes the experiences of contributing children, parents, and health care professionals and makes these experiences available via computer access to families who may be facing similar issues. The program was designed to foster the creation of an electronic community that enhances family and self-understanding. Its goal is to move the narrative process from private meaning to a shared and often more accurate meaning of the experience. In the EJ similar stories are linked and saved so that they can be easily explored and re-visited, rather than depending on the "at the moment" experience of an on-line "chat room." This project is unique in its linking of personal experiences and information together in a computer application that can be used by families facing congenital heart disease. We examined the hypothesis that the EJ will be safe, helpful, and useful to mothers of children facing cardiac illness.

## **Method**

### **Procedure**

The EJ was described to the participants as a research project designed to facilitate the healthy coping of children and their families who must contend with congenital heart disease. Appropriate human studies permission was obtained.

**Phase 1.** Each participant was asked to use the EJ under the direction of the project's research assistant and was then asked a series of semistructured questions about the application.

The purpose was to identify any obvious problems or concerns in the EJ (e.g., problems using it, application "bugs") that would prevent the completion of Phase 2.

**Phase 2.** Each mother completed a semistructured interview prior to use of the EJ. Mothers were asked to use the EJ for at least 30 minutes. Mothers were interviewed a second time 2-4 weeks ( $M = 2.4$  weeks) following the initial interview. Each mother was interviewed at her child's follow-up appointment at the hospital ( $n = 1$ ) or by telephone ( $n = 39$ ) if her child received follow-up cardiology care by an outside physician. Each mother was offered a \$20 payment following the completion of the second interview. The project's research assistant conducted the interviews.

## **Participants**

The participants were mothers who had children hospitalized for cardiac disease at a pediatric medical center. Participants in Phase 1 included 9 mothers of children ranging in age from 6 weeks to 25 years ( $M = 8.8$  years) who were admitted for cardiac surgery ( $n = 8$ ) or medical concerns ( $n = 1$ ). One adult female patient (age 25 years) also participated in Phase 1. One mother declined to participate in the study resulting in a 91% rate of participation.

Participants in Phase 2 included 40 mothers (ages 19 - 46;  $M = 36$  years) of children ages 3-16 years ( $M = 7.6$ ). Mothers needed to be available to complete interviews in English in the hospital and at home. The majority of the mothers were Caucasian ( $n = 36$ ) and married ( $n = 32$ ). Roughly equal numbers of male ( $n = 17$ ) and female ( $n = 23$ ) children were included. Eighty percent of the families fell within the top two socioeconomic levels on the Hollingshead Four Factor Index of Social Status (Hollingshead, 1975). The majority of the children were hospitalized for cardiac surgery ( $n = 31$ ) and the remainder were hospitalized for cardiac medical reasons ( $n = 9$ ). A total of 16 mothers (11 surgical, 5 medical admissions) declined to participate



in the study citing reasons such as lack of time and high level of stress resulting in a 74% rate of participation. Three mothers who completed the initial interview in Phase 2 did not complete the follow-up interview due to lack of time ( $\underline{n} = 2$ ) and death of family member ( $\underline{n} = 1$ ).

### **Computer Application: Experience Journal (EJ)**

The EJ is a psychoeducational intervention based upon a narrative model involving the sharing of personal stories about an illness (Umaschi et al., 1998; Gonzalez-Heydrich et al., 1998). The EJ works by accepting descriptions from families about what it has been like to live and cope with a medical condition or illness (ranging from short written explanations of an experience to pictures, poems, stories, and videos). The computer program organizes these contributions in a way that makes it easy for families to access information that is of interest to them. A committee of parents and health care providers reviews and edits all contributions for appropriateness prior to including them in the EJ.

Unlike most collections of related World Wide Web pages which are relatively static, "link-managed" by one person, and organized to facilitate retrieval of specifically sought data, the EJ is dynamic and continuously evolving as new contributions are added. The EJ software organizes the entries based on their similarity of word frequencies. It then presents the entries, represented as "flowers on a pond." These "flowers" are arranged so that those close to each other represent entries that are close in content. The user clicks a "flower" to read, look at, or watch the entry (Figure 1). A copy of the EJ was placed on a laptop computer and taken to patient rooms; the EJ was also accessible on a desktop computer on the inpatient cardiac unit.

Insert Figure 1 about here.

To date, over 130 entries have been gathered, though the task of soliciting more entries continues. A consent for the use of information/materials has been developed in collaboration

with the hospital's legal office. The child life, psychiatry, and social work staff in hospital, along with parent representatives have collected contributions from patients and their families.

Children's entries were also obtained using a version of the Storytelling Agent Generation Environment which is an interactive computer program that helps children write stories and listen to stories that others have written (Umaschi et al., 1998). In addition, a computer was available on the cardiology unit in which anonymous contributions could be written.

## **Measures**

**Phase 1.** A semistructured interview form was developed for Phase 1 of the present study to elicit initial feedback regarding the use of the EJ. In addition to background information, participants were asked to rate the application regarding satisfaction and potential hurtfulness using a 7-point scale anchored at one end by "1 = not at all" and at the other end by "7 = extremely satisfied." They were also asked several open-ended questions regarding feasibility of the program as well as benefits from using the EJ.

**Phase 2.** A review of existing assessment literature found that the semistructured interviews developed by Beardslee et al. (1992) to assess the safety and feasibility of his preventive intervention for families with parental affective disorders covered the main dimensions targeted for the present study. Both the initial and the follow-up interviews were modified for the present study including the specific questions regarding the child's cardiac illness.

These interviews elicit both quantitative ratings and qualitative data. All interview ratings were determined by using a 7-point scale anchored at one end by "1 = not at all" and at the other end by "7 = a great deal" or "extremely satisfied." The following categories of ratings were obtained in these interviews:

1. **Satisfaction and Safety**. Ratings of “satisfaction and safety” along with “specific impacts” of the EJ were obtained in the follow-up interview (see Table 1). In addition, open-ended questions regarding satisfaction and safety of the EJ were included.

Insert Table 1 about here.

2. **Coping Response**. Seven open-ended questions regarding effects of the EJ on parent and child’s perceived coping responses to the heart problem were asked in the follow-up interview (see Table 2).

Insert Table 2 about here.

3. **Attitude Change**. Ratings of attitude changes that the mothers attributed to the EJ were elicited. Specifically, mothers were asked to rate the effect of the EJ on understanding their own, family’s, spouse’s, and children’s feelings about the heart disease. They were also asked to rate the impact of the EJ on how supportive their family, spouse, and children were of each other.
4. **Illness-related Concerns**. Identification of illness-related concerns before and after utilization of the EJ.
5. **Family Functioning**. Self-ratings of functioning in family relationships before and after utilization of the EJ.

The ratings of mother’s illness-related concerns and family functioning are not included in this analysis given the focus on feasibility and safety. These questions were included assist in future intervention modifications of the application.

## Analysis of the Data

Descriptive statistics were calculated for each of the rating scales. Each of the responses to the open-ended questions in the Coping Response category was reviewed and coded based on the frequency and similarity to other responses.

## Results

### Phase 1

The participants reported that they were very satisfied ( $M = 6.4$ ) with the way that stories were presented in the EJ. Similarly, they rated overall satisfaction of the EJ positively with a mean of 5.8. The mean rating was 1.6 when participants were asked if the EJ was hurtful. With regard to negative aspects of the EJ, 6 of the 10 participants reported that the EJ was not hurtful at all. All four participants who commented on this question reported that they felt sad and/or uncomfortable feelings as they related to the stories, but that their feelings did not stop them from continuing to use the EJ. Finally, although participants generated a number of suggestions for how to improve the EJ, none of the problems that were identified prohibited the use of the EJ in its current form in Phase 2 of the study.

### Phase 2

**Satisfaction and Safety.** The means and standard deviation scores for the rating of satisfaction and safety are reported in Table 1. The mean overall satisfaction ( $M = 5.7$ ) was quite high as was the satisfaction ( $M = 6.0$ ) with the presentation of the stories in the EJ. Parents reported minimal harm from using the EJ with scores ranging from 1 ( $n = 36$ ) to 4 ( $n = 1$ ) when asked if they felt the EJ was hurtful at all.

Mean satisfaction ( $M = 4.2$ ) with the presentation of factual information was moderate. Of note, only 28 mothers responded to this question as 12 reported that they did not learn factual

information from using the EJ and therefore declined to answer this question. However, most mothers who declined to respond reported informally that they did not intend to learn factual information from the EJ and were therefore satisfied with this.

Analyses of the “specific impacts” of the EJ are noteworthy for the very high rating regarding the “sense of other facing same issues” ( $M = 6.7$ ). Table 1 details similar high ratings for “helpful to read about other experiences, understand children with heart problems and their families, decrease extent to which you felt alone, and increase sense of hope.”

In an open-ended question, 37 mothers answered "no" when asked if there were aspects of the EJ that were not helpful. The remaining 3 mothers were dissatisfied with the lack of specific information about children's reactions to hospitalization. Finally, when asked to comment on the aspects of the EJ they found most helpful, mothers generated the following types of responses: related to the experience of others and felt less alone ( $n = 21$ ), exposure to child/patient perspective ( $n = 12$ ), ideas for coping skills ( $n = 6$ ), and gaining perspective ( $n = 5$ ).

Review of the responses to open-ended questions given by four mothers who acknowledged some hurtfulness (all moderate or less) indicated that they felt overwhelmed by empathizing with the families that they were reading about. However none of these mothers desired to stop using the EJ as a result of their discomfort; they all reported that the EJ was useful and helpful. All 40 mothers unanimously reported that using the EJ did not make their relationship with their child worse nor did it make it more difficult for them to talk to their family about their child's heart disease.

**Coping Response.** Table 2 presents the number of mothers who responded to each question. Four recurrent themes emerged repeatedly in the analysis of their responses. Across the seven questions, 21 comments regarded mothers feeling fortunate in comparison to other

families. A total of 18 comments were generated regarding mothers' increased understanding of their child's experiences. Mothers also reported that the EJ assisted in decreasing social isolation (15 comments) and improving communication regarding heart disease (15 comments).

**Attitude Change.** Mothers reported moderate increases in their understanding of their own ( $M = 5.0$ ,  $SD = 1.9$ ), their whole family's ( $M = 4.8$ ,  $SD = 1.9$ ), their spouse's ( $M = 4.1$ ,  $SD = 2.3$ ), and their children's ( $M = 4.3$ ,  $SD = 2.0$ ) feelings about their child's heart disease that they attributed to using the EJ. Similarly, mothers also reported that the EJ moderately increased how supportive their whole family ( $M = 4.0$ ,  $SD = 2.3$ ), their spouse ( $M = 4.0$ ,  $SD = 2.3$ ), and their children ( $M = 4.2$ ,  $SD = 2.4$ ) were of each other.

### **Discussion**

The findings of this study support the premise that a computer-based intervention theoretically derived from preventive intervention, medical crisis counseling, and narrative therapy is not only safe and feasible, but also beneficial to mothers of children with cardiac illness. The EJ had high satisfaction ratings along with very low ratings of harmfulness. Over 70% of the mothers spontaneously requested increased access to the EJ before, during, and after hospitalization suggesting that the computer is a viable medium for providing preventive interventions for these families.

Based on the “specific impact” rating scales, mothers found the EJ helpful in decreasing social isolation, understanding children with heart conditions, and increasing hopefulness. These results were paralleled in the recurrent themes identified from the open-ended “coping response” questions. The EJ was described as helpful to mothers through expanding their perspective (i.e., things could be worse), increasing their understanding of their own child, improving communication regarding heart disease, and reducing social isolation. The “attitude

change” question regarding increases in understanding of feelings about their child’s heart disease and inter-family supportiveness further bolster the use of the EJ as a sounding board for mothers to compare and contrast their own experiences and their child's feelings/behavior. All of these factors have all been identified as important to both successfully navigating medical crises (Shapiro & Koocher, 1996) and in developing self-understanding (Focht & Beardslee, 1996).

The EJ was less useful in helping mothers understand their child's specific cardiac illness, improving communication with their child, and preparing them for future procedures or hospitalizations. For most mothers the EJ did not provide them with new information, warning signs, or specific coping skills. This fact was not surprising given that the EJ was not designed as a source of factual information and focuses primarily on personal experiences. In general, mothers were satisfied with the relatively small amount of factual information. However, several mothers were not satisfied with the lack of information about warning signs and specific coping skills; they requested additional contributions of this nature particularly from patients.

This study reports the unique use and assessment of a computer application to assist families of pediatric patients. The patients varied with regard to cardiac condition and were randomly selected from the children on the unit. The mothers were asked to use the EJ for at least 30 minutes while in the hospital; time of use ranged from approximately 30 to 75 minutes. In spite of the limited use of this program, the pilot findings regarding its potential impact on the mothers indicate that the EJ is worthy of further study to determine its effectiveness in comparison and/or conjunction with other interventions aimed at improving individual coping and family functioning of pediatric patients.

## **Limitations**

The following limitations warrant further investigation and an expanded effort to replicate these findings. First, the mothers in the sample were predominantly Caucasian, college-educated, upper-middle class, and married. Thus, generalizations to other groups of women are made with caution. Second, the responses of the mothers may have been positively biased due to social desirability. Although attempts were made to decrease this (e.g., telephone interviews), mothers may have felt pressure to rate the EJ positively because the interviewer was not an objective rater. In support for the validity of responses, ratings spanned the range of possible values and mothers rated the EJ low in several areas. It is recommended that future studies employ a research design in which the interviewers are blind to the intervention status.

A third limitation is the amount and type of exposure to the EJ stories that mothers experienced was not measured or controlled. In addition, mothers read various stories within the EJ (they are randomly presented) and therefore may have had quite disparate experiences with the EJ. For example, some mothers may have read contributions by mental health professionals regarding developmental expectations of pediatric patients whereas others only read personal experiences by parents and/or patients. This could have affected their satisfaction and ratings of the EJ and should be considered in future studies of computer-based interventions.

Numerous mothers suggested that their spouses, children, and extended family would benefit from reading the EJ. Making the EJ more accessible through a website would provide this access and again hopefully improve family functioning as a result of increased access by more family members. Similarly, numerous requests were reported by mothers for a comparable child/patient version of the EJ. Finally, there is reason to believe that similar “experience journals” would be beneficial to patients and their families with other diseases. It is possible to



create a journal for various diseases and for these journals to cross reference general information pertinent to children and families with pediatric illness (e.g., preparing a child for hospitalization).

Based on mothers' suggestions for improving the EJ, several recommendations for computer-based interventions for families of pediatric patients are warranted. First, mothers preferred a program with structure such that they would be able to identify the content most relevant to their situation. More than 50% of mothers recommended that the EJ stories be organized according to the child's diagnosis. Second, although mothers indicated that they found it helpful to read stories of children with diagnoses other than their child's, they requested more stories about patients similar to their own child (e.g., similar age, severity of illness, follow-up data). Many more contributions would be necessary to fill these requests. Third, the computer-based application needs to provide a great deal of background information. Mothers requested information such as an introduction (with education regarding cardiology and psychology) to the EJ, the history of each individual story, and specific coping strategies used by families. It appears that mothers wanted a greater context for the EJ in general and for individual stories in order to accurately compare and contrast their own experiences.

### **Clinical Implications**

Writing in the EJ was an optional opportunity for parents and family members. This aspect of the EJ, however, was not assessed or measured in the present study. Given previous findings by Smyth et al. (1999) showing that writing about a traumatic experience improves medical functioning, writing in the EJ about personal experiences with cardiac illness merits further research. It may be the case that writing in the journal is effective in different ways than reading the journal. For example, it may be that reading the EJ reduced social isolation but that

writing in it reduces anxiety or depression. It would be most interesting to attempt to replicate Smyth's findings with pediatric patients by having them draw or write about their experience with cardiac illness to determine any effects on their medical functioning.

The use of a computer-based preventive intervention opens up a world of possibilities with regard to communication with medical populations. As shown in the present study, a virtual support system may have effects on parental as well as patient psychosocial functioning. Increasingly, interventions focused on linking cognitive information to one's unique personal experiences appears a critical variable to change in understanding and behavior (Beardslee et al., 1997). The creation of computer-based interventions presenting psychoeducational and medical information closely connected to "one's own story" could supplement traditional interventions such as self-help books, support groups, and meetings with mental health professionals.

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**Table 1.** Mean ratings<sup>1</sup> and standard deviations for Satisfaction, Safety, and Specific Impacts of the Experience Journal (EJ).

<b>Satisfaction and Safety</b>	<b>Mean (SD)</b>
Overall, how satisfied are you with the EJ?	5.7 (1.8)
How satisfied are you with the way 'people's stories regarding heart problems' were presented?	6.0 (1.4)
How satisfied are you with the way factual information was presented?	4.2 (2.3)
Overall, did you feel the EJ was hurtful at all?	1.2 (0.7)
Is your relationship with your child worse now that you have used the EJ?	1.0 (0.0)
Did the EJ make it more difficult to talk to your family about your child's heart disease?	1.0 (0.0)
<b>Specific Impacts</b>	<b>Mean (SD)</b>
Did the EJ give you any sense that there are others who are also facing the same issues of raising a child with a heart problem?	6.7 (0.7)
Did you find it helpful to read about other families' experiences or stories about living with their child's heart problem?	5.7 (1.5)
Did the EJ help you understand children with heart problems and their families?	5.6 (1.5)
Did the EJ decrease the extent to which you felt alone?	5.3 (1.7)
Did the EJ increase your sense of hope?	5.1 (1.9)
Did the EJ help you gain perspective about your child's illness?	5.0 (1.9)
Did the EJ increase your understanding of your experience?	4.8 (1.8)
Did the EJ relate to your own experiences?	4.5 (2.1)
Did the EJ help you understand your child's feelings or behavior about his/her heart problem?	4.3 (2.2)
Did the EJ increase your understanding of your child's experience?	4.1 (2.0)
How effective was the EJ in helping you understand your child's reactions?	3.9 (2.1)
Did the EJ help prepare you for the future?	3.5 (2.1)
Did the EJ give you help or ideas for the future regarding preparing your child for coming to the hospital?	3.5 (2.3)
Did the EJ improve communication between you and your child?	3.3 (2.0)
Did the EJ help you understand your own child's heart problem?	2.9 (2.1)
How effective was the EJ in helping you understand your child's heart problem?	2.7 (2.1)

<sup>1</sup> = Ratings were determined by using a 7-point scale anchored at one end by "1 = not at all" and at the other end by "7 = a great deal" or "extremely satisfied."

**Table 2.** Percentage of Mothers (n = 40) responding in the affirmative to the opened-ended Coping Response Questions regarding the Experience Journal (EJ).

Question	%Yes
Has the EJ affected how you think or feel about your child's heart problem? If so, how?	60
Having used the EJ, do you think of yourself or your experience with childhood heart disease differently? If so, how?	48
Did the EJ help you identify any skills, characteristics, or actions that help children or families cope well under stressful circumstances?	43
Did the EJ alert you to any specific issues about heart disease? If so, what issues?	20
Did the EJ give you any ideas about what you might do if problems come up?	20
Have you obtained any new information from the EJ about your child regarding how he/she feels about his/her heart problem or how it has affected him/her?	15
Has the EJ helped you to identify any warning signs in your child, indications that he/she is having trouble coping or managing in response to his/her heart problem?	15



Figure 1. The Experience Journal as viewed on the computer with each “flower” on the right screen representing an individual entry and the content from one entry viewed on the left screen.

