

Experience Journals: Using Computers to Share Personal Stories About Illness and Medical Intervention

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Abstract

Medical advances make it increasingly possible for children with previously fatal illness to live and thrive. However, a significant number still experience repeated operations, hospitalization, and invasive procedures, or need special care at home. Many do so with little or no intervention to help them and their families cope with the emotional stresses involved. One significant source of emotional and cognitive support is the community of patients and families who have experienced similar medical procedures. However, in spite of a general willingness to share experiences, communication among patients and families is usually limited. To facilitate this process, we are investigating the use of computer technology to record, organize, and display stories about the experiences of families with children who have been treated for cardiac and neurological illness at Children's Hospital, Boston. We are asking children and their families to record text and multimedia vignettes describing some aspect of their illness, coping strategies, or care that might be useful to others. These contributions will be available for browsing at a secure World-Wide-Web site. However, economic realities preclude reliance on a professional site administrator to organize and monitor what we hope to be a rapidly growing Web site with a large, distributed authorship. The need to make the Web site fully accessible to users who have varying familiarity with computers and Web browsing imposes further constraints. We are therefore developing software to automate the process of managing and organizing an easily accessed Web site that contains an "Experience Journal." We describe this software, the rationale for its development, and our plans for its use in the coming year.

Keywords

Hypertext; Hypermedia; Networked Information; Information retrieval; World Wide Web; Patient Communities.

Introduction and Motivation

In the USA alone, three million children are estimated to live with a chronic illness. The range of psychological adaptation that these children exhibit is very broad, but problems with self-esteem and peer relationships are prevalent. Serious medical illness is therefore increasingly recognized as an important early

risk factor for emotional disturbance [1].

A variety of interventions have been developed to assist patients and their families in the hopes of improving the resiliency of both. These include preadmission hospital preparatory programs, meetings between families and physicians, books and videos for children of different ages, and psychiatric consultation. Yet it is clear that the majority of families are not able to avail themselves of these resources before coming into the hospital [2].

One additional and potentially underutilized source of psychological support is the community of patients and families who have experienced hospitalization. We conducted a survey of 27 consecutive families with children admitted to the cardiac inpatient service at Children's Hospital (CH), Boston, to gauge pre-hospitalization preparation in general, and in particular the role of other patients and families in that preparation. The salient findings from this survey are:

- 58% of families had no preadmission preparation;
- 49% had not spoken to other families with similar hospital experiences prior to admission;
- 89% wanted to hear other families' experiences;
- 93% were willing to share their hospital experiences with others; and
- 89% were interested in computer-based preparation activities.

In addition to this survey, we were motivated by study of relevant literature and existing software (e.g., [3]), on-site hospital observations, and in-depth interviews with patients, families, and medical professionals. We identified four areas where current interventions could be augmented: preparing children and families for hospitalization, alleviating the hospital experience by providing more information, advising parents on how to care for their children when they return home, and providing a forum for families to exchange experiences and learn from each other.

Currently we are investigating the use of computer technology to assemble a journal of personal experiences of CH patients and families dealing with cardiac and neurological illnesses. Our aim is to create a World-Wide-Web site to facilitate sharing of family-authored vignettes. The nature of experience data, privacy and liability considerations, economic constraints, and the need to cater to all levels of computer sophistication among the

potential user population, pose several unique technical problems that make this more than just the trivial task of creating an ordinary Web site.

Excerpts from Example Vignettes

Sadly Alone

Jeff, age 16

My name is Jeff Smith, and I have a problem. I'm 16 years old and I have a real bad heart problem and I'm getting ready to have a heart transplant really soon but the hardest thing is my mother just had 2 strokes and a seizure and a little brother. so it's so hard to leave them alone so I just stay strong and do what I have to do and if you ever have this kind of problem just stay strong for your family and think of me.

Blumb, Blumb, Blumb

Sharon, age 4

I have a new heart now. It goes blumb, blumb, blumb. I used to go wish, swish, swish, swish. My blood goes round and round and round in big circles. It didn't do that before. The worst thing about being in the hospital is getting the chest tube out. It hurts a lot. I thought it might hurt, but I didn't know just then.

Eileen's Story

Peggy, Eileen's mom

Eileen was born with a heart defect. Her parents told her that her doctor wanted her to go to the hospital to have her heart fixed. Eileen hoped that after her operation she will be able to run and to play like her friends do. Eileen was scared about going to the hospital, but it helped Eileen to know that her parents would be with her when she goes to the hospital for her heart operation. So Eileen packed her favourite toys, her toothbrush and some of her clothes and went to the hospital with her parents.

Eileen's parents took her up to the second floor of the hospital to have a chest x-ray done. Her mom described it as taking a picture of her chest with a special camera. That didn't hurt at all.

Susan told Eileen that her parents would be able to go down to the "holding area" of the operating room when she went for surgery. Eileen was very happy about that because then she wouldn't be so scared. Eileen would also be able to take her favourite doll or toy down with her as well.

On the day of Eileen's surgery, she was not allowed to eat or drink anything. She was given a medication that would make her sleepy. Her parents carried her down to the holding area.

The surgeons who were doing the operation came to see Eileen. The surgeons were wearing funny scrub suits. They wore masks over their mouths and noses.

A few weeks after Eileen was home, she was able to do her favourite things like her friends. That made Eileen and her parents very happy.

Basic Premises

Personal-Experience Data is Different

Our purpose is to provide a way for a community to gather, organize, and share the community's collective wisdom. In our context, the community comprises the families of children who have been through the cardiac and neurology units at CH. Families can contribute to what we call an *Experience Journal* (EJ) by submitting personal narratives about their experiences, helpful information, poems, stories, and (eventually) pictures and video about the experience of coping with a serious illness. Some sample vignettes are shown in the sidebar.

The first thing to notice about these personal stories is that they are quite unlike the logically structured and uniform text that one finds in media such as encyclopedia articles and newspaper stories. Much of the accepted wisdom about text-based information retrieval (IR) has been developed for this latter kind of text data [4]. For example, in these media, researchers have found that a priori specification of an indexing or classification scheme can be useful. However, in an EJ it may be difficult to predict the topics that contributors will want to address, and restricting contributions to a predefined set of topics may not be an acceptable constraint.

Another key distinction is that experience data lends itself well to browsing. The type and degree of organization needed to support effective browsing is very different from that which is needed to support effective querying. Therefore, the fundamental operation in an EJ tends not to be "Find an entry with the following key words," so much as "Find an entry that is related to the one I just read."

A Dynamic Corpus

An important characteristic of an EJ is that it will grow and evolve continuously over time, even while people are reading it. For this reason, a preset limit on the size of an EJ is unacceptable. Furthermore, contributors will hope to see an entry included within an EJ soon after writing it. Therefore a model whereby successive EJ versions are produced and released at intervals would be unacceptable.

Distributed Authorship

Contributions to an EJ will come from many individuals in many styles and forms. In order to make the authoring and submission as easy as possible, we make minimal assumptions about the form of an EJ entry.

No Webmaster

Web sites that contain experience data or something like it can be organized and maintained by a human webmaster. However, we may not be able to guarantee funds to pay a professional webmaster, nor can we assume the availability (or reliability) of an unpaid volunteer. Therefore, our vision is of an EJ that is a self-organizing and self-evolving system, capable of operating indefinitely without the supervision or intervention of specifically trained people.

Extreme Ease of Access

In addition to being able to browse an EJ within the hospital,

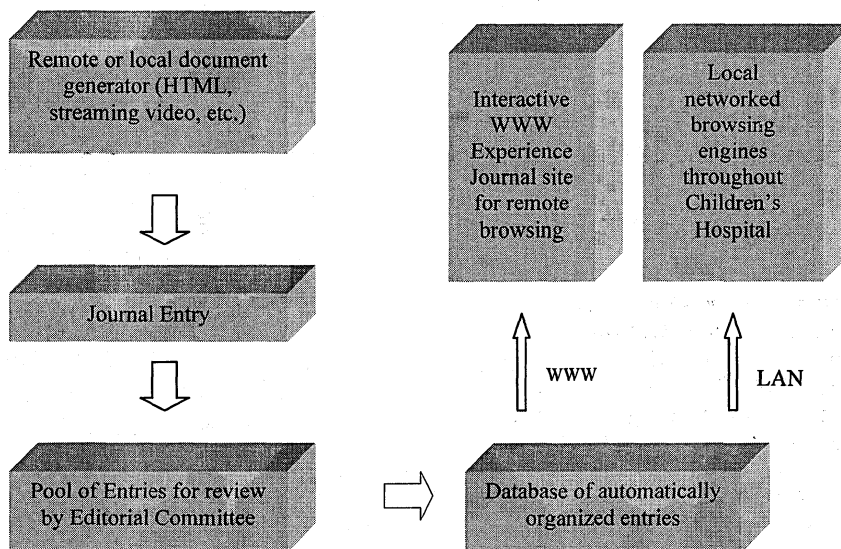


Figure 1 - EJ support software, architecture, and information flow

participating families must also be able to access it over the Internet, using a variety of different Web browsers. Furthermore, users with only the most basic computer skills should be able to browse an EJ. For this reason, we focus on an interface that uses simple point-and-click actions rather than more sophisticated access and browsing models such as Boolean queries or tailored databases.

EJ Support-Software Architecture

The requirements detailed in the preceding section are quite demanding. In this section we describe the architecture of the EJ support software, and explain how it tries to satisfy these requirements.

The EJ support system is illustrated in Figure 1. An EJ entry can be an HTML document (created with Netscape Navigator Gold or Microsoft Front Page, for example), an ASCII text file, or a URL for either type of file. Once composed by a contributing patient or family, an EJ entry is communicated via e-mail to the members of a screening committee, which is composed of members of the hospital staff and parents of present and former CH patients. The task of the committee is to determine whether a submission should be published as is in an EJ or whether it should be edited to eliminate material that could be medically harmful or legally compromising. Once committee approval is given, an EJ entry is then translated automatically into HTML, if necessary, and the Web page is incorporated into the EJ. Incorporating a new entry into an EJ is the main technical challenge. The relationship of the new entry to existing EJ entries must be established, and vice versa. The EJ can then be browsed locally or remotely with a variety of browsing software, including a customized EJ browser that we are developing ourselves (Figure 2).

The notion of an EJ as a set of automatically organized Web pages addresses the requirements noted in the previous section: in our design, browsing is potentially easy, since the user can be

guided visually to related entry pages; continuous growth and distributed authorship are inherently accommodated; and the typical webmaster's main task of site organization is handled automatically. The trick is to perform the automatic entry organization effectively.

Automatic Entry Organization

In spite of recent efforts [4], researchers still consider automatic organization of textual information a difficult and unsolved problem. However, personal-experience stories are very different from the kinds of documents studied by most IR researchers. The fact that an EJ is designed to be casually browsed, and not queried specifically, means some organizational anomalies can be tolerated. Our hypothesis is that useful organization of an EJ can be achieved with a combination of existing IR methods, even though they might not be adequate for other kinds of text data.

In our organizational strategy, a word vector is computed for each EJ entry by removing stop words (e.g., "the," "and," "is," etc.), stripping suffixes (e.g., "ly," "ing," etc.), and weighting the remaining word stems according to the inverse of their occurrence frequency in a large text corpus (i.e., rare words are weighted heavily, and common words discounted). A similarity score for a pair of entries can then be calculated by taking the dot product of the two associated word vectors. The foregoing is an amalgam of standard IR techniques [4].

The remaining problem is how to communicate visually the entry similarities.¹ We use the well-known technique of multi-dimensional scaling (MDS) to position entry icons so that similar entries are near each other in the visual display, and dissimilar ones are far apart. In other words, proximity, rather than coordinate location, is the measure of similarity. Thus clusters of similar entries form naturally [5].

The interface to the EJ browser is shown in Figure 2. The three

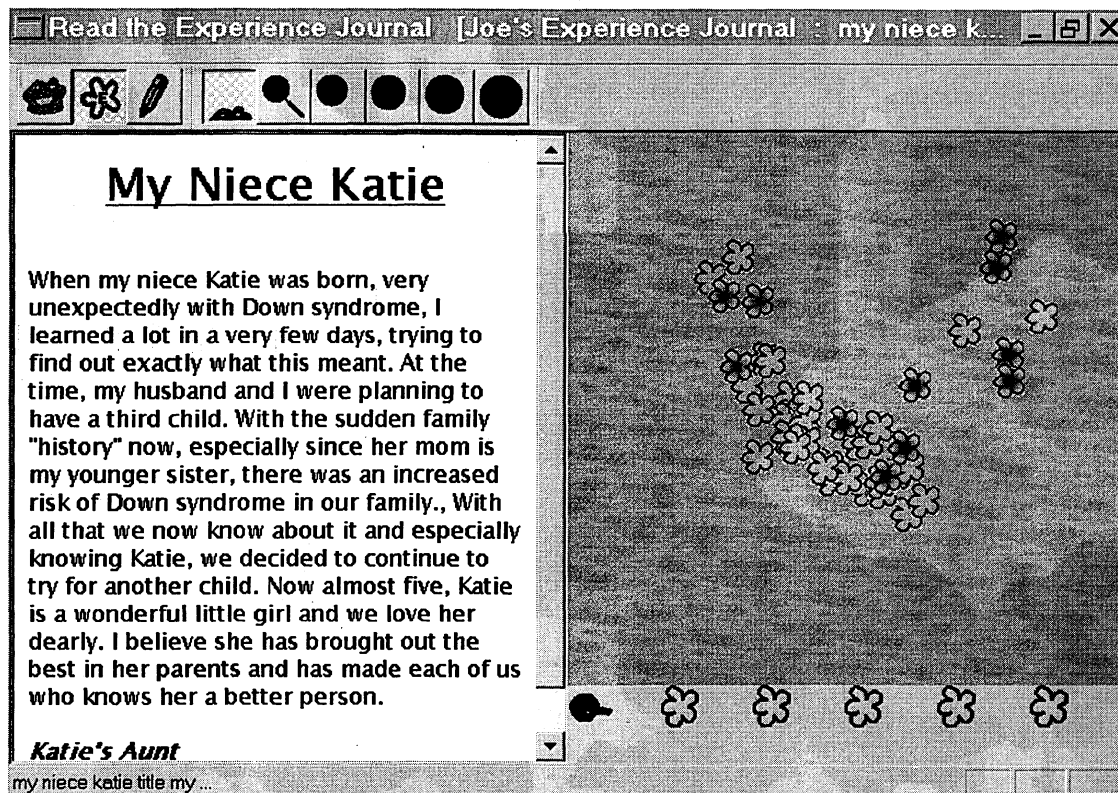


Figure 2 - A screen shot of the Experience Journal browser. Each flower represents a journal entry

buttons at the top-left of the EJ browser move between the Welcome screen, the Read screen, and the Add screen. The Read screen is shown above. On the right is the visual display of entries, whose layout has been calculated by the MDS algorithm. Each entry is represented visually by a flower in a pond. Clusters of flowers represent similar entries. Mouse-clicking on a particular flower will load the corresponding journal entry into the integrated web browser on the left. The five magnifying glass buttons cause a magnifying glass to follow the mouse, allowing the user to focus effectively on a possibly congested area of interest. The frog button removes the magnifying glass. The Add screen (not shown) allows a user to compose and submit a new EJ entry. Previously constructed entries, using any available web technology, may also be included easily.

1. In an earlier version of the EJ, we experimented with a strategy for automatically connecting related entries with hyperlinks. This strategy balanced the desire to connect all similar entries with the need to avoid redundancy and simplify the linking structure. While this capability is still in the EJ (the flowers in the bottom right-hand corner of the EJ browser represent linked entries that are accessible from the current entry), the current spatial browsing metaphor effectively subsumes this automatic linking functionality.

Project Status and Future Plans

The EJ support software has been implemented in C++, and is currently being tested and refined. A team at CH, consisting of a clinical social worker, a child life therapist, and a parent of a former cardiac patient, has begun the process of content solicitation for the first EJ. In addition, two of the authors (EA and MU) are collecting stories using the SAGE program an interactive story-telling and authoring tool for children [6,7].

As the EJ becomes populated, we plan to conduct a series of experiments to study its utility in a variety of contexts. These will include using the EJ at home or from the hospital, alone or with the help of medical professionals, to access information only (read only) or to share experiences (read and write), to tell/hear a story versus reading/writing [7].

We plan to test use of the EJ in facilitating the psychological adjustment of children with heart disease. A prescribed program of using the EJ would be given to a series of families and this program compared to the traditional hospital preparation programs. Participants in both groups will be matched for age, severity of diagnosis, and family characteristics. Pre and post measures of psychological adjustment will be used to assess the efficacy of the interventions.

Conclusion

As medicine advances many more children are being saved who otherwise might have died. Many of these children have complex needs for home care that extend to every aspect of their lives. These needs range from needing home-based invasive medical treatments to help explaining to peers and siblings about their illness and its consequences. Families often have no friends or extended family members who have direct experience of dealing with these issues. Traditional attempts to connect families facing a newly diagnosed illness with families who have faced similar issues have often had a profound effect. Often however, large geographic distances, busy schedules, and social inhibitions to calling strangers hamper these family-to-family connections. Moreover, even when these connections are made they can usually be only between a very small number of families.

The EJ is meant to facilitate family-to-family and patient-to-patient teaching so that the wealth of knowledge that a family acquires while caring for a sick child can benefit another family. Unlike Internet discussion groups, entries in an EJ will be actively solicited to help engage more families in contributing and to ensure that the EJ contains a broader and deeper representation of families' experiences. In addition, a committee of medical staff and parents to help prevent medically or legally harmful content from becoming part of the EJ will screen entries. Automatic organization of the EJ will provide a loosely structured system suitable for casual browsing. We believe that the combination of human solicitation and committee-based entry screening coupled with automatic structuring of the contributions will make the EJ an economically, medically, and legally viable tool to make the collective wisdom of families who have gone before them available to new patients and families.

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