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# The Design, Development and Formative Evaluation of a Multimedia-based Pediatric Patient Education Package: 'The BMT Voyage: All You Need To Know About Your Bone Marrow Transplant'

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A Thesis

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# ABSTRACT

## The Design, Development and Formative Evaluation of a Multimedia-based Pediatric Patient Education Package: 'The BMT Voyage: All You Need To Know About Your Bone Marrow Transplant'

Julie Daignault

The design, development and formative evaluation of a multimedia-based pediatric patient education package is described. The CD-ROM informs children about the bone marrow transplant process (presents declarative information) and helps to reduce pediatric patient and family stress and anxiety (attitude change) through the delivery of interactive multimedia instruction for self-paced instruction. A script covering the subject-matter and written in a question and answer format was produced. A storyboard depicting the overall concept as well as the navigational features of the application was produced. The scripts and storyboard were evaluated by several experts as well as by two end-users and their families in terms of the story-telling concept, accuracy of the content, language level used, appropriateness of the illustration/animation vis-à-vis the content and effectiveness of the spaceship/voyage metaphor. The results of these evaluation efforts were implemented in the subsequent development of the application. Two experts evaluated the application in terms of its design and navigation. The sponsor of the project and an end-user, evaluated the application in terms of its design, navigation and presentation of content. The application was modified and burnt onto a CD-ROM. Post-production evaluation efforts subsequently took place. The CD-ROM was evaluated by medical and educational technology experts as well as by patients and their families in terms of technical, pedagogical, psycho-social and medical aspects. The CD-ROM was also evaluated by four end-users in terms of knowledge gains, attitude change and reactions to the application. Results of all the evaluation efforts are presented. Overall, appeal to children, use of animation and appropriate presentation of information for children are the main strengths of the CD-ROM. Lack of interactivity and sophistication in animation are considered to be the main weaknesses. Evaluative comments and suggestions for the further design and development of the CD-ROM, as well as suggestions for further research, are discussed.

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'The BMT Voyage' was produced at Concordia University in collaboration with the Montreal Children's Hospital and the Lamplighters Leukemia-Childhood Cancer Association.

# Dedication

The work entailed in this project is dedicated to the wonderfully resilient children of the Hematology-Oncology Clinic of the Montreal Children's Hospital, particularly Nathan Beaulieu, Kenny Potvin, Ashley Winslett and Mark Anthony Maimone.

Thanks not only for contributing to the project, but for teaching me some of the most important lessons of all.

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# Chapter 1 - Introduction

The partner-clients of the project were the hematology-oncology clinic of the Montreal Children's Hospital and the Lamplighters Leukemia-Childhood Cancer Association. The staff of the MCH acted as subject-matter experts whereas the Lamplighters were sponsors.

## Context of the Problem

When a bone marrow transplant (BMT) is prescribed as the next step in the treatment of cancer, the patient is confronted with a situation about which she generally knows very little. When that patient is a child, apprehension and lack of knowledge may affect her both independently and through the reactions of parents. This lack of knowledge characteristically leads to much anxiety, as well as a feeling of powerlessness. Educational material for children about bone marrow transplant was lacking at the Montreal Children's Hospital. The need was identified by nursing staff in the hematology-oncology clinic. However, the Montreal Children's Hospital was strapped for funds, to support the production costs of this endeavor. The Lamplighters Leukemia Childhood Cancer Association, an independent support-group/charitable organisation which works with the Hospital, could provide this support.

The type of educational objectives usually addressed by nursing staff and child life specialists at the Montreal Children's Hospital include:

- Informing the child about the procedures which can be expected to occur;
- Creating a forum for discussion concerning the different things which the child and the family can do to best prepare for the procedure;
- Creating a forum for discussion of the emotions which come into play for the child and the family.

Most children who need a BMT have usually been treated for cancer already and thus hold previous knowledge with regards to cancer treatment (i.e. chemo- and radiation therapy). Generally, after a second relapse, the patient needs a BMT. Certain forms of cancer also call for the BMT protocol right away. Nonetheless, a BMT represents a new experience, and often a traumatic one.

### Limitations of existing educational materials

The problem was general and not specific to this Hospital. At the time of the project[1], not much educational material could be found for children concerning bone marrow transplants, except for a colouring book produced by the Leukemia Society of America (Shands Hospital at the University of Florida, 1989). Oncolink, based out of the University of Pennsylvania, had Internet discussion groups (mailing lists, or listservs) for children only, as well as World Wide Web pages directed to adult patients or parents of younger patients (editors@oncolink.upenn.edu, 1996a, 1996b, 1996c, 1996d). Other educational products aimed at patients and their families did not address children -- e.g. a mass-published book entitled Everybody's Guide to Cancer Therapy (Dollinger et al., 1995), the NYSERNet clearinghouse on cancer information on the World Wide Web (NYSERNet Inc., 1996a, 1996b, 1996c, 1996d), and other Web pages by the National Childhood Cancer Foundation (1996). Only one software package which was designed to "better prepare children with cancer about the possible side effects and symptoms they will be experiencing as a result of the myelosupression from their chemotherapy" ('What are blood counts?', Petersen, 1996, p. 23) was known of, but not available commercially. However, further research demonstrated that patient education software had been around since at least 1985 (Bell, 1986, Ellis, 1985, Vargo, 1991).

### Target audience

The audience targeted by the application consisted of school age children (6-12), diagnosed with cancer and who may undergo a bone marrow transplant at the Montreal Children's Hospital and other pediatric hospitals.

The application was originally going to be bilingual (French/English). In the context of the course for which it was produced, the decision was made to produce one version only. The English version was produced because potential adopters (Canadian and American pediatric hospitals) were more likely to need an English language application. However, the application was designed with a multicultural, multilingual audience in mind. Provisions were made in the design to quickly adapt the product into other languages. It was also designed to be used on-site, in clinics equipped with a micro-computer and CD-ROM drive. The machine does not need to be dedicated: for instance, it can be used to provide clinic patients with other educational and/or gaming software, access to the Internet, etc. The CD-ROM can also be lent out by clinic libraries.

### Rationale, Needs/Broad Objectives

The nursing staff at the Montreal Children's Hospital's hematology-oncology clinic recognized the need for educational material which would complement the only educational interventions available thus far:

- a two-hour meeting with the family, the child and the hematologist/oncologist who would perform the bone marrow transplant;
- answers provided by hospital staff to patient and parent questions.

The drawbacks of these approaches are:

- the two-hour meeting happens at a very difficult time and gives the family and patient too much to absorb at once;
- staff are not always available to answer questions;
- answers are not always comprehensible, or staff are not always patient;
- the parents or child may feel guilt (believing that cancer is due to something wrong they did), a general loss of control, and the fear of appearing stupid and ignorant when asking questions.

The purpose of the project was to design and develop an interactive multimedia application which would contribute to the quality of life of children being treated at the hematology-oncology clinic of the Montreal Children's Hospital and, possibly, other pediatric hospitals. In particular, the application addresses two broad objectives:

- to convey the information that bone marrow transplant protocols comprise, in a non-intimidating, self-paced manner to patients aged 6-12;
- to provide a medium which will facilitate this transfer of knowledge at a pace, and with the level of detail, which suits the patient and her family.

In other words, the product would have to inform children about BMT (present declarative knowledge) and reduce pediatric patient and family stress and anxiety (change attitude) through the delivery of interactive multimedia instruction for self-paced instruction.

These objectives were later refined, subsequently to the primary subject-matter expert interviews in the front-end analysis phase of the project (see Chapter 3).

Additionally, patients -- especially parents -- want to be informed and involved: Hannah et al. (1989) remarked the trend towards self-help and self-care, as well as the growing sophistication of knowledge grasp and the desire to participate in their own care. They also noticed that hospitals were putting more emphasis on prevention and maintenance, discharging patients earlier and changing the setting of care for chronic illnesses to home-care, therefore increasing the care responsibility for patients.

Cut-backs in staff and increasing workloads for remaining staff are also an important factor in this paradigm shift: a significant drawback and constraint of actual practice is that daily operations of a hospital get in the way, making patient education almost accidental, little less than an after-thought (Chan, 1992). It often amounts to being no more than dispensing information.

## Instructional media selection

### Pre-determined selection of media

This project stemmed in part from the fulfillment of final objectives of a multimedia design and development course in the MA program in Educational Technology at Concordia University. The final project had to be an educational, multimedia CD-ROM. Though high in quality, the resultant student project was subject to constraints of experience and time. This situation is not unlike those which educational technologists often find in the course of their work, where the instructional medium has already been selected and 'fixed' in design specifications, even before a needs assessment is conducted. Deliverables thus consisted of a self-contained application created with MacroMedia Director, version 4.0, on a Macintosh platform. The product was pressed onto a hybrid CD-ROM (IBM PC-compatible running Windows 3.1 or 95 and Macintosh 68K or PowerPC), and was produced in English only. It was completed in June 1996.

### Selection of the platform and authoring software

A PC platform was selected for delivery because of technical support specifications at the Montreal Children's Hospital, but the application was developed on a Macintosh platform. The end-result was a hybrid CD-ROM. The authoring software used was MacroMedia Director. Other software packages used were: Microsoft Word, Adobe Photoshop, MacroMedia SoundEdit Pro, Aldus Superpaint, and Eudora (email program) for team communication and exchange of documents over the Internet.

### Interactive media - Rationale for delivery medium

The product is an interactive multimedia application which was transferred onto a CD-ROM. Such applications typically incorporate a combination of text, sound, animation and video to present a variety of information. Through exposure at home or at school many children are familiar with the personal computer as a tool for recreation and education. Even without such exposure, children adapt easily to the computer environment; it seems intrinsically attractive to them and lends itself to self-paced learning.

The attraction of the computer for children and the ability to revisit the content appealed to the funders of the project, the Lamplighters. They liked the idea of a computer-based learning instrument, of an option for individual learning, as a supplement to the 2-hour meeting with the oncologist. The notion which appealed to them most was that of control: with a CD-ROM, mouse in hand, choosing what she wants to know, the child would regain a sense of control over the disease that affects her, as well as the treatment imposed on her. Advantages of computer-assisted instruction (CAI) in patient education will be further discussed in Chapter 2.

Given all this, the designers determined several factors and characteristics right away. The application would contain:

- no video (for technical reasons);
- animation (to provide dynamic movement, despite the lack of video);
- a narrative structure (to tell a story, rather than throw medical facts around).

## Resources and limitations

### Design/development Team

The team which participated in the design and development consisted of the author and two other graduate students in the Educational Technology Program at Concordia: Joanne Gaudreau and Wendy Lowe. The team members had varied, yet highly complementary academic backgrounds in the areas of communication studies, graphic arts, teaching and psychology, and were involved in the multimedia course. Project activities were delegated amongst the three team members and each was directly involved in the design and development of the application. The author took on the extra role of project coordinator by managing activities and functions related to the project, as well as being the main liaison with the Montreal Children's Hospital and the Lamplighters. This also translated in added responsibilities in the production phase. She further took on the evaluation tasks for the purpose of this thesis-equivalent. Agreement was secured from the teammates, the thesis-equivalent supervisor and course instructors as to the legitimacy of this approach.

### Technical advisors and SME's the Montreal Children's Hospital

The primary contact was Daniel Héon, senior audio visual technician at the Montreal Children's Hospital. The design team had the benefit of an extensive subject-matter expert team, including ward and clinic nurses, hematologists, child life specialists, a hospital teacher, etc. The primary contact to this end was Norma Auger, head nurse of oncology.

### Financial support and sponsor

The Montreal Children's Hospital had no money for the project and could only pay in kind, in ways of expert knowledge and time. The design team had to look outside for funding and this caused the biggest number of problems throughout the project. The client-consultant relationship was rocky, and communication channels were blurred. The sources of conflict arose mainly out of the stake the Lamplighters had in the implementation of the application at the Montreal Children's Hospital, as well as distribution of the CD-ROM to other BMT pediatric centres. Issues of ownership took a long time to settle. Dealing with this complicated everything and caused many delays. However, they did not seriously compromise the development of the application in English.

### Technical limitations

The CD-ROM was developed on a Macintosh platform, in the multimedia laboratory at Concordia University's Department of Education. Efforts were made to ensure that graphics would look as good on a PC platform as they did on the Macintosh. Navigation, programming, sound and graphics in general were not a problem across platforms. However, Director (v. 4) could not fully synchronize animation and sound (both are processor-dependent and require different resources), nor can playing speed of animation be predicted on different platforms, or with different CD-ROM drives. Access time to CD-ROM is also a problem which was impossible to control (e.g. once the test CD-ROM was burnt in 2X speed, it was checked on a Pentium with a 6X CD-ROM drive and the animation was extremely rapid, whereas it was lagging behind on an older Macintosh processor). The result was nonetheless a fully-functional hybrid CD-ROM. The graphic design was done by a professional. The animation was sometimes repetitive and/or choppy. The sound recording was good though in mono sound, at 11 kHz, and there was hiss. Production values were good considering it was the first CD-ROM development project for the design team. The extent of interactive features were also limited by the programming capabilities of the team.

## Scope of the project

### Project Activities and Timeline

The product became a self-contained, finished unit but was deemed a prototype in the sense that it needed further evaluation with end-users who have or simulate the characteristics of the intended audience, to check for: comprehension of content, ease of navigation, enjoyment, attitude change (less anxiety for both patient and family, increased sense of control over the BMT process and the illness), etc. Further expert reviews with medical and multimedia experts, as well as end users, would prove be beneficial. The scope of the project did not include a final development stage.

More details are provided in Chapters 3 and 4.

## Chapter 2 - Design and Development: Concepts and Methodology

The concepts involved in the production of multimedia-based instruments for pediatric patient education are many. They include:

- patient education;
- instructional design for patient education (declarative knowledge and attitude change) and strategies for children, especially;
- the use of narrative structures as a design strategy;
- implications from educational multimedia design:
    - information structuring and sequencing;
    - interactivity design;
    - interface design;
    - technical design;
- advantages and disadvantages of computer-assisted instruction in pediatric patient education.

### Concepts

#### Patient Education

Health education, in general, seeks to impart knowledge so as to equip the learners who receive it with the tools necessary to make decisions about the quality of their life. It can shape attitudes and reinforce the adoption of behaviours which will ultimately contribute to these learners' health status. As such, curricula, programs and interventions are designed and developed by health educators to achieve these goals (Greene, 1984). This taxonomy is often referred to as KAB, or:

- Knowledge acquisition;
- Attitude formation or change;
- Behaviour formation or change.

The process of improving health status is generally thought to take place in that order.

Health education can take many forms:

- non-formal education / popular education;
- preventative measures, (e.g. smoking cessation and safe-sex campaigns) or;
- patient education (e.g. pre- or post-treatment intervention to favour regimen compliance. i.e. pre-operation videos).

Patient education differs from health education in that it is given in hospital, clinic and other health care settings. More specifically, reported aims and goals of Patient Education are as follows:

| **Aims and goals of Patient Education** | **Author** |
|---|---|
| • increase knowledge about a disease and its treatment | Bluebond-Langner (1990) |
| • provide ideas and skills that help patients: | |
| - cope with and adapt to immediate medical problems | Gillispie and Ellis (1993), |
| - facilitate compliance to medical regimens | Chan (1992) |
| - avoid disease, maintain health, and enhance feelings of well-being | Gillispie and Ellis (1993),<br>Chan (1992) |
| • teach patients to support their abilities for self-care | Chan (1992) |

Table 1 - Aims and goals of Patient Education

As with the larger discipline of health education, patient education must reach cognitive, affective, psychomotor and behavioural aspects of learning (Annand, 1992). Some of its reported advantages have important consequences, running the gamut from increased quality of life to increased cost-effectiveness in the health care system:

- increased compliance with therapeutic regimens;
- decreased anxiety;
- decreased incidence of some illnesses or effects of illnesses, for example, decreased mortality from cardiovascular disease due to education regarding risk factors;
- enhanced self-care and less use of emergency rooms;
- reduction of time lost from daily activity because of illness;
- increased number of appointments kept;
- decreased postoperative complications and reduction of hospitalization time (adapted from a literature review, Bell, 1986).

Perrin and Gerrity (1981) further pointed out that teaching ill children, especially, about their illness and its management is assumed to contribute to improved compliance with treatment, control and coping. Guidelines for educational design for these children are especially necessary.

### Benefits in illnesses where anxiety can be pronounced

Cancer certainly brings about a lot of anxiety for the patient. Diagnosis, treatment, remission, relapses, and the issues of dying or surviving are laden with trepidation. This situation is even more traumatic when the patient is very young. Other illnesses and disorders, where anxiety may play a marked role (blood hypertension, acute and long-term depression, diabetes), have been the object of studies where positive outcomes -- no matter how slight -- were attributed to patient education:

A meta-analysis of 102 studies determined that the effects of blood hypertension patient education on blood pressure, knowledge about hypertension, medication compliance, weight, compliance with health care appointments and anxiety were significantly small to large (Devine and Reifschneider, 1995).

Brown's (1990) meta-analysis revealed that diabetes education slightly improved knowledge, self-care behavior and metabolic control among patients. She further found that age was negatively correlated with knowledge acquisition and cholesterol levels (the higher the mean age of the patients, the lower effects of patient education on these variables). She concluded that the studies' findings support the effectiveness of diabetes patient education in improving health-related outcomes. Another evaluation of an education program designed to improve the level of active self-care behavior of diabetes patients treated with insulin produced similar conclusions, with a twist: the program was found to be only marginally effective in changing self-care behavior, with positive outcomes being attributable to supervision by a health professional or a peer, while engaged in the program. Among these experimental groups, scores on knowledge and diabetes locus of control improved significantly, while attitude, social norm, and level of active self-care behavior improved partially (deWeerdt et al., 1989)

Stokes (1993) believes that to promote correct diagnosis and decreased morbidity and mortality associated with acute and long-term depression, patient education is necessary to explain:

- the medical nature of the disorder;
- its effective treatment through pharmacological intervention;
- the need to continue full-dose maintenance therapy for 6 to 9 months after complete remission of the depressive episode so as to prevent relapse;
- the need to recognise the recurrent nature of the disorder and that lifetime pharmacotherapy may be necessary to manage it.

### Environmental factors pointing to need for patient education/self-care

The general benefits attributable to patient education discussed above also combine with the constraints listed below to point to a growing need for patient education as a way of enhancing self-care and home-care, even in oncology:

| Constraint | Author |
|---|---|
| • move of cancer care to outpatient clinics and shorter hospital stays | Villejo (1991) |
| • increased consumer health awareness and demand for accurate and complete information | Bell (1986) |
| • increased demand from governments and third-parties for health care cost effectiveness, translating into mandatory accreditation and legal mandates | Bell (1986) |

Table 2 - Environmental factors pointing to need for patient education/self-care

Especially in response to this last constraint, Bell believes that patient education has shifted from "unplanned, fragmented, and incidental exchanges of information to programs purposefully designed, systematically supplied, and comprehensive in nature" (1986, p. 177). She suggested that these more formalized education efforts require:

- defined learner objectives;
- documentation of the learning activity;
- evaluation of its effectiveness and efficacy.

## Impediments to Patient Education

The stress and anxiety about diagnosis, disease and treatment (Villejo, 1991) can be a great impediment to patient education, regardless of the age of the patient. However, when the patient is a child, stress and anxiety may mix with an incomplete grasp of what is happening to her/him. Children can also be more resilient than adults in the face of dire circumstances -- again, partly because of the lack of conceptual understanding and lack of life experience.

### Conceptual understanding of illness in children

Notwithstanding the complexity of medical jargon, disease and illness are complex concepts which children of varying ages will understand to different degrees. According to a developmental, Piagetian framework, level of conceptual understanding of illness is generally determined in empirical studies to be correlated to age-related development in both healthy and sick children (Perrin and Gerrity, 1981; Schvaneveldt et al., 1990; Rasnake, 1989). Perrin and Gerrity (1981), for instance, put forward that conceptual understanding of illness-related knowledge is parallel to developmental progression. Their empirical study used a scale corresponding to Piaget's theoretical framework of cognitive development. The results, they reported, were consistent with developmental progression in understanding complex concepts. The participants were healthy children, from kindergarten to grade 8, and their beliefs regarding illness causation were as follows:

- K = magical, result of transgression of (parental) rules;
- 4 = all illness caused by germs;
- 8 = complexity of inter-related mechanisms begins to be understood.

They finally remind the reader that "we should remember that at least until adolescence a child cannot be expected (...) to understand the progression of his illness through different phases" (Perrin & Gerrity, 1981).

Rasnake (1989) suggests that when health education material regarding hospitalization and medical procedures is designed to cater to age-related conceptual abilities of patients, cooperation with health care providers in treatment increases and anxiety decreases. These conclusions are based on an empirical study of children aged 3 to 5 and 7 to 10 (N=48), assigned to conditions of control, developmentally-appropriate material and developmentally-advanced material. Only one study (Eiser et al., 1990), contradicting these conclusions, was found.

Further investigation is needed to determine whether sick children develop more sophisticated conceptual understanding than healthy children or whether the affective aspects of their illnesses impede this development. Perrin and Gerrity suggest that "determinants of such a difference have not been explored, but may include cognitive regression due to the stress and anxiety of acute illness and/or hospitalization" (1981, p. 848). They conclude that educational interventions -- short of not being offered -- "be (...) further scaled down in their level of cognitive sophistication". However, some education may be better than none. Relatively unstructured, peer patient education in a controlled social situation can also be beneficial. Through open-ended interview and observation, Bluebond-Langner (1990) noted significant increases in knowledge gain about cancer and its treatment in children who attended a pediatric oncology camp, and this despite the lack of formal instruction. This suggests that an informal, anecdotal approach works to increase knowledge among children.

Other findings suggest that:

- increased conceptual understanding leads to higher health locus of control (Shagena, 1988);
- young children and parents of children with chronic physical illnesses tend to have lower health locus of control and consequently rely more heavily on care providers (Perrin, 1985).

One could hypothesize that increased conceptual understanding leads to increased health locus of control and thus enhances self-care, and possibly feelings of competency, too. Lowered anxiety thus would decrease as conceptual understanding increases. The hypothesis that children afflicted with chronic or terminal illness develop complex understanding regarding illness faster than healthy children also remains to be determined.

### Lack of planning

Another significant impediment to effective patient education is rampant in hospital settings: lack of proper planning. Delivery of education comes as an afterthought to physical care, often taking the form of "the distribution of printed materials or the incidental type of teaching that is provided the morning of the discharge" (Chan, 1992 p. 20). Neither is it thought out to maximize the learning potential of the patient (Armstrong, 1989).

Chan recognizes the need "to plan, implement and evaluate in-hospital education programs" (idem). Armstrong recommends taking advantage of the "patient's pathways during his 'usual' route of care for the type of service delivered" (601). In pre-planning, nursing and other staff can anticipate various times and places of educational contact. Armstrong goes on to describe interventions which can be implemented at every stage, from the meeting in the nurse's office to the operating room in the case of a same-day surgical patient -- in short, a multi-faceted, multi-modal approach to patient education. Says Armstrong: "Attempting to deliver all the required content during 'one-shot delivery', while the patient in under distress, is like assuming that nursing student can learn all about a topic in one sitting" (1989, p.601).

Armstrong also believes that use of computers in the education process is another way to maximize patient learning. Ellis documents cases where computer-based patient education packages were used to gather data about a specific population frequenting clinics. The computer was in the waiting room, thus keeping patients busy while waiting and optimizing data-collection to better serve the population.

The dangers of not planning may lead to drop-out, and hence increased morbidity and/or mortality: "if potential consumers of healthcare services do not feel that they are in partnership with health professionals, they may choose to function independently of the health care system" (Bell, 1986, p. 256).

## Implications for design

Knowledge acquisition, beyond obviously informing, often holds the accessory role of providing facts, ideas and concepts in helping to change health-related beliefs and attitudes. Behaviour change is thought to result from enough intervention at the first two levels. It is a longer-term outcome and therefore harder to measure -- longitudinal studies are necessary for this. These were not possible in the timeframe of the present project, nor in the context of multimedia development in general.

The most direct implication for this project is that a change in knowledge should affect a change in attitude; likewise a change in attitude should affect a change in behaviour:

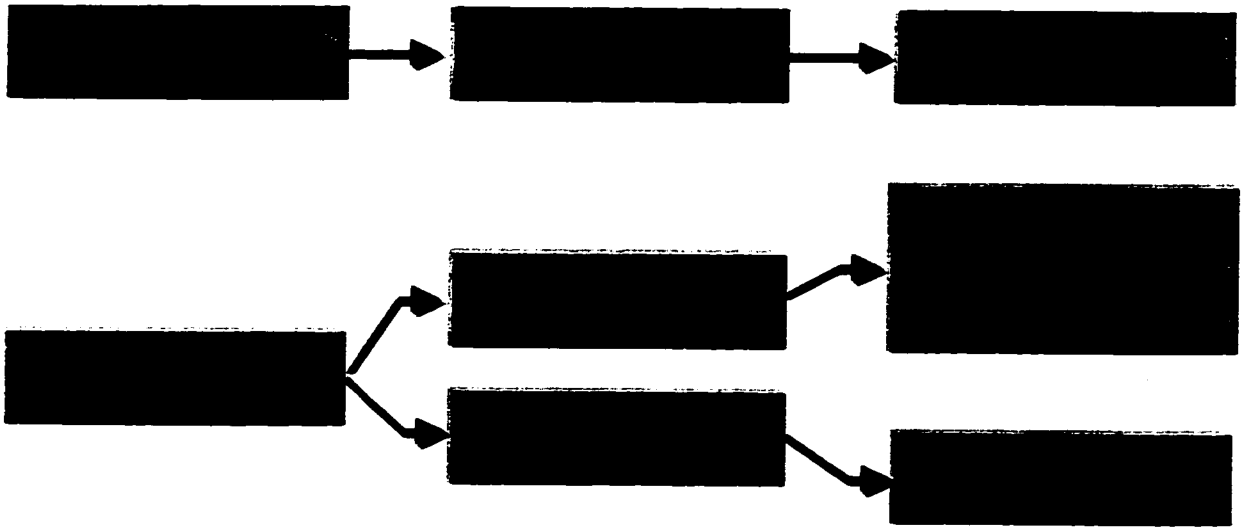


Figure 1. KAB taxonomy

The following table further summarizes certain implications to consider in the design of pediatric patient education:

| **Implications for design** | **Author** |
|---|---|
| • Design for aims and goals of patient education; | Bluebond-Langner (1990),<br>Gillispie and Ellis (1993),<br>Chan (1992) |
| • Learning objectives must be realistic, measurable, and focus on positive behaviour;<br>• Options must be given when goals cannot be achieved or need to be revised;<br>• Rewards must be incorporated into the plan; | Armstrong (1989) |
| • Education must use strategies which help reduce anxiety; | Villejo (1991) |
| • Materials for children should preferably be developmentally-appropriate (also tied to internal locus of control in health); | Perrin (1985)<br>Shagena (1988)<br>Schvaneveldt et al. (1990) |
| • Informal, anecdotal approach works to increase knowledge in children/pediatric patients; | Bluebond-Langner (1990) |
| • Planning a multimodal approach, optimizing pathways of patient along route of care, is better. | Armstrong (1989) |

Table 3 - Implications to consider in the design of pediatric patient education

Armstrong maintains that the ultimate variable affecting outcomes is the patient's involvement, believing that it is directly proportional to the amount of change in the patient's knowledge, skill, and behaviour.

## Instructional Systems Design for Pediatric Patient Education

Although several alternative ID models have been offered in recent years, the author feels that they more accurately represent the methodology which the designer employs when actually carrying out the design activities, rather than the model. The discussion at hand warrants the presentation of a more conventional model, although authors doubt that systematic ID models designed for military and industry instruction are appropriate for material directed at children (Abrams, 1996). Hienich, Molenda and Russell (1993), for instance, propose their ASSURE model for developing instructional media, adapted from conventional models:

- Analyse learner characteristics;
- Specify learning objectives;
- Select, design and modify materials;
- Utilise good 'showmanship' techniques to present it;
- Require learner response, giving them a chance to practice;
- Evaluate students' achievement of the objectives.

This process is further discussed, in the context of the project at hand, in Chapters 3 and 4.

The formulation of design guidelines for pediatric patient education also needs to be informed by:

- recommended instructional strategies to enhance the types of learning involved in patient education (organizational strategies such as organized discourse - i.e. narrative structures - and associative strategies such as the use of metaphors and images for declarative knowledge; social learning theory / human modeling, and conditions and components of attitude learning);
- the theory behind attitude formation and change: the discussion will center especially around human modeling and Bandura's social learning theory, and the Krathwohl taxonomy of affective learning.

### Theory behind attitude formation and change

Bandura's social learning theory helps to explain how humans may form and changes their beliefs, values and attitudes. Special importance is given to the influence of human modeling. Smith and Ragan (1994) report three forms which human modeling can take:

- actual experience;
- vicarious experience (observation of a model);
- emotional associations.

Another useful tool to understand and classify the process of attitude formation is Krathwohl's taxonomy, or Affective learning hierarchy. In designing instruction, the designer would have to select the objective level of final attainment which the learner would ideally reach. In health education contexts, this is typically level 3.0

Valuing, more specifically: 3.2 preference of a value, and 3.3 commitment to the value. In other words, given a choice of values, a patient would ideally prefer the value of good health and commit to this value by taking active steps toward achieving it.

## Instructional strategies for types of learning involved

### **Declarative knowledge strategies**

Declarative knowledge strategies reported by Smith and Ragan (1994) include:

- relating instructional goals to personal life goals and making them personally relevant;
- presenting the goal in an interesting, dynamic format;
- using organizational strategies:
    - organized discourse, e.g. narrative structures;
    - clustering and chunking;
- using associative strategies:
    - metaphoric devices;
    - images and imagery.

Of special interest to the design of multimedia-based instruction are the use of narrative structures, metaphoric devices and images. Clustering and chunking also seems to be a staple of conventional CBT and CAI: most packages are divided in lessons and modules.

### Performance objectives

Smith and Ragan finally point out the need for spaced practice. Specific performances which the learner should be able to attain are paraphrased recall and, with organized discourse, “understanding”.

### Attitude formation and change strategies

#### Components and conditions of attitude learning

Components of attitude learning are closely matched with the concerns of patient education:

| *Learning components for attitude change vs.* | *Learning components for patient education* |
|---|---|
| • cognitive component (knowing how) | • (K) knowledge acquisition |
| • affective component (knowing why) | • (A) attitude formation or change |
| • behavioural component (opportunity to practice and feedback) | • (B) behaviour formation or change |

Table 4 - Learning components for attitude change and Learning components for patient education compared

#### Writing attitudinal objectives

Attitudinal objectives, rather than performance objectives, are the goal of attitude-forming instruction. They are behavioural objectives, not in sense of performance but because, for lack of better measurement, attitude of others can be gauged by their behaviour, e.g. what they reportedly think, believe, value - either by saying it or demonstrating it. Obviously, if an emphysema patient values preventative measures to stop his illness from worsening, and yet still smokes, the incongruency in his behaviour leads us to doubt the attitude he allegedly holds.

Attitudinal objectives can be used in all sorts of instruction, as long as the main objectives deal with forming or changing beliefs, values and/or attitudes.

### A design strategy familiar to children: narrative structures

Perhaps the best known approach to micro-design strategy is Gagné and Briggs' Events of Instruction. Lockard et al. adapted them for CAI in their 1994 publication.

However, the author's literature review led her to the story-telling model proposed by Egan, and thus found that narrative structures work for affective learning as well. Egan questions the principle, supported by Piagetian theory, that children's understanding proceeds from the simple to the complex. He believes that this is an inadequate account of the development of children's understanding. Egan proposes that stories evoke "high emotional colouring" and "make whatever is to be learned into something meaningful". He further maintains that curriculum in general should be taught through stories, rather than in the logico-mathematical, content-oriented, approaches à la Dewey and Piaget (i.e. from unknown to known, from abstract to concrete). The model he proposes is illustrated in the following table:

The Story Form Model (Kieran Egan)

1. Identifying importance:
- What is most important about this topic?
- Why should it matter to children?
- What is affectively engaging about it?

2. Finding binary opposites:
- What powerful binary opposites best catch the importance of the topic?

3. Organizing content into story form:
- What content most dramatically embodies, the binary opposites, in order to provide access to the topic?
- What content best articulates the topic into a developing story form?

4. Conclusion:
- What is the best way of resolving the dramatic conflict inherent in the binary opposites?
- What degree of mediation of those opposites is it appropriate to seek?

5. Evaluation:
- How can one know whether the topic has been understood, its importance grasped, and the content learned?

Table 5 - The Story Form Model

Egan believes that the most profound and important aspects of a story need to be brought to the fore, if we want young children to understand the story. In a patient education intervention, for instance, the binary opposites of health/illness coupled with feeling better/pain could come into play. Incorporating the notion of binary opposites, to colour instructional content with high emotional contrast, concords with learning conditions and components of affective learning. Apart from emotional associations, other aspects of social learning theory and human modeling which come into play are vicarious experience and observation of models through the story's characters.

Another advantage of the narrative structure is that it may aid comprehension of complex subject-matter in children (Clarke and Smyth, 1993, Sharp et al., 1995). Some authors (Buckley, 1994) lend Egan support, even endorsing his schema of child development (opposed to Piaget's), and suggesting that the school curriculum must be adapted to correspond more closely to these views. Clarke and Smyth (1993) also support the narrative approach in teaching elementary school age children. They describe a project that uses children's literature to teach social studies and history in elementary classrooms and review research which suggests that students at this level prefer to read narrative literature rather than traditional textbooks. Sharp et al. (1995) propose that this would appear to be effective. They describe another application of story-telling, with children at risk and conclude that multimedia technology is a valuable tool for development of story comprehension and literacy. Their empirical study compares results of story-telling to kindergarten students using text-only, helpful video, and minimal video. Results indicate that multimedia technologies are valuable tools for supporting the development of story comprehension, mental model building, and literacy in young children who are at-risk for school failure.

Other risks which face children, such as life-threatening illnesses, are not discussed. There is certainly ground for further research concerning these issues.

### Multimedia design/educational computing design issues

Just as film has cinematic language, multimedia is a medium, with its own set of design principles and constraints, and its own emergent language. This comparison with film is adequate: Plowman (1994) likened the results from fieldwork which examined children's use of four interactive multimedia programs to those of early film features as well as the problems which a nascent medium may pose to users. The cinematic metaphors don't stop there: we often speak of a scene when developing a segment of a multimedia application. The CD-ROM discussed in this report was made with MacroMedia Director, a software package taking the film-making analogy to its farthest: objects in the screen environment are cast members, they are placed on the stage for on-screen display and on the score - which looks like cell animation - for internal control, etc. (MacroMedia, 1995).

Nelson (1990) defines the essential quality of multimedia as 'virtuality', a two-fold characteristic, comprising conceptual structure and feel. For instance, if we revert to the film analogy, the conceptual structure is the plot and characters, and the feel is atmosphere, suspense and style. In multimedia products, the conceptual structure can include content, rules and strategies, and feel, dynamic characteristics, colors and "other sensory aspects" (Nelson, p. 239). The challenge, Nelson believes, is to "conceive and realize a unifying vision" (Nelson, p. 238). In a nutshell, consistency, continuity and integrity on all levels of design.

For the specific business of educational multimedia design, the author decided on four components:

- Information structuring and sequencing;
- Interactivity design;
- Screen design;
- Technical design.

Concepts and implications which apply to design of educational multimedia come from Apple and Scheafermeyer, as well as from an extensive literature review by Park and Hannafin of empirical research in psychology, pedagogy and technology. From these bases Park and Hannafin elaborated educational multimedia design principles. The principles concern the many sub-components which belong to one or more of the afore-mentioned components. Combined with strategies for declarative knowledge and affective learning, as well as design implications from patient education, they spell out a model which designers may follow when designing multimedia pediatric patient education.

## Information structuring and sequencing

Application and content should be user-centered (Apple, 1987), specified to a given target audience, and should also state entry-level competencies and performance objectives (Schaefermeyer, 1990). The principles from Park and Hannafin most applicable to the structuring and sequencing of information are:

- embedding structural aids to facilitate selection, organization and integration;
- reflecting the diverse ways in which the system will be used through linkages between and among nodes;
- using familiar metaphors both in conveying lesson content and designing the system interface;
- anchoring knowledge in realistic contexts and settings;
- providing methods that help learners acquire knowledge from multiple perspectives and cross-reference knowledge in multiple ways.

The bases for these principles are the use of hierarchical cognitive structure or learning hierarchies (Gagné, 1985), conceptual models and metaphors (Mayer, 1989, Ortony, 1975), feedback (Tennyson & Christensen, 1988), and interaction strategies (Hannafin, 1989) to organise declarative knowledge and content, as well as anchored instruction (Cognition and Technology Group at Vanderbilt, 1990, 1991), situated learning (Brown, Collins, & Duguid, 1989), generative learning (Wittrock, 1974), and cognitive flexibility (Spiro & Feltovitch, 1991), (quoted in Park and Hannafin (1993)).

Park and Hannafin especially believe that interactive multimedia has the ability to "promote greater flexibility" (p. 75), exactly because it provides opportunities to give learners access to ill-structured knowledge from multiple points of view, to construct its meaning by building multiple representations. This is best illustrated by Don, below.

### Strategy: Narrative structures and story-telling

With narrative structures, multiple representations are possible through means of re-arranging content according to different organizing criteria, or indexes, (e.g. chronological, topical, associative, etc.). Don (1990) calls these indexes "context gears". Characters of the story can serve as gears or interfaces to different topics. Characters also are vehicles for human modeling through vicarious experience.

Don (1990) talks of the interdependent nature of content and context in multimedia narrative. 'Context gears' can be provided through navigation aids and other interface features to "generate stories". She gives an example with oral story-telling: to tell the story of the women in her family, she used the 'gears' of common interests, generation and social context to interface the stories of each of the characters with each other. The user can thus compare and contrast a common interest held in two different generations (e.g. the political activism of the grandmother and granddaughter in their respective eras), or the challenges of motherhood in different epochs. The user can also follow one character throughout her life. In this case, multiple representations are possible through means of re-arranging content along chronological, topical and associative lines. Characters of the story can stand as interfaces - or context gears - between topics (Don, 389).

The multimedia design strategies to retain from this are basically: multiple representations of events and information, using a multiple characters as a means of representing contextualized information within the full span of diversity which the information can come to represent, etc.

This also is the basic idea behind hypertext, to which Spiro and Feltovitch applied their theory of cognitive flexibility. It consists of a database model, a way of indexing data. Its reconstitution is made according to criteria chosen by the user and is an attempt at building knowledge. 'Paths' - or story-lines - may be pre-thought-out, thus generating a more linear feel to this otherwise non-linear medium.

Gay (1992), on the other hand, proposes the model put forth by Nielsen (1990) where interactive narrative structures (especially fiction) require episodes (or 'hypertext nodes') and decision points (or 'links') between episodes. Structure and rhythm is determined by the length of the episodes. At the end of an episode, the user encounters a decision point and influences the deroulement of the narrative by selecting an option. In the case of a multimedia patient education package, the influence may be how much the patient wants to know, how much s/he cares about knowing certain topics.

Gay further proposes three models of interactive narrative structures, listed in the table below, on a continuum of user control:

| Guided stories | Free exploration | User as author |
|---|---|---|
| User is reader with little control, follows one of several predetermined paths through a story. Author has control over presentation, number of choices, and frequency of choices. | User has control over order of presentation and is able to augment information presented. | User is an author with ability to create own stories using multimedia tools and resources (text, graphics, movies, etc.). |

Table 6 - Gay's three models of interactive narrative structures (Gay, 1992)

### Narrative structure in computer- and multimedia-based training

Applications of narrative strategies abound in educational software, especially software designed for pure training purposes. By far, the most widely-used narrative structures used for training purposes in multimedia are case-based scenarios and case studies, both also forms of role playing/human modeling.

Schank (1990) is perhaps the better-known advocate of these with his case-based tutors, such as:

- VICTOR, a voice and image courtesy tutor;
- DUSTIN, a language training system for non-English speaking employees;
- TAXOPS, a tax opportunity advisor;
- CREANIMATE, a biology tutor for students.

Edelson (1993) further elaborated on the case-based teaching architecture of CREANIMATE. The program asks learners to create a new animal while the narrator/storyteller looks out for opportunities to present stories and questions that will prompt learning in the creation of the animal.

Stories and anecdotes can also blend with case studies in adult training for complex social skills (Burke, 1993), such as with the Guided Social Simulation (GuSS) architecture, for teaching ill-defined skills such as managing, handling diplomatic relations, or selling. A multimedia retrieval system for anecdotes with an educational flavor, Story Producer for InteractivE Learning (SPIEL), is integrated within the architecture.

Other characteristics pertaining in part to information structuring and sequencing are discussed in following sections.

### Interactivity design

Using a narrative structure to organize information structure and sequence also undeniably shapes interactivity. Most of the principles elaborated by Park and Hannafin discussed above are thus applicable to interactivity design. Other principles pertaining to specific characteristics which will be covered in depth in the thesis-equivalent report and include user control and navigational aids, and feedback. Narration will be discussed in the next section.

Some of the principles underlying the different characteristics are as follows:

Navigation and user control:

- Providing tactical, instructional and procedural assistance;
- Providing clearly defined procedures for navigating within the system and accessing on-line support (Navigational aids (graphical browser, audit trails, orientation instruction, guidance, advice), Edwards & Hardman (1989), Instructional control in CBI, Merrill (1980), Laurilard (1987), Disorientation, Tripp & Roby (1990), quoted in Park and Hannafin (1993));
- Providing for user control through direct manipulation, forgiveness, and event loops (Apple, 1987);
- Providing navigation aids (branching, cues and prompts through help of menus and other navigation items such as buttons so the user doesn't have to rely on recall to deal with a command-line interface) (Scheafermeyer, 1990).

Feedback:

- Providing appropriate feedback (Scheafermeyer, 1990);
- Use of feedback and 'dialog' to provide immediate feedback and keep user informed (Apple, 1987);
- Providing opportunities to respond and receive response-differentiated feedback where critical information is involved, but avoid excessive response focusing when incidental learning is expected;
- Interactive multimedia must adapt dynamically to both learner and content characteristics (Feedback in CBI, Tennyson & Christensen, 1988, Feedback and emerging technologies, Hannafin, Hannafin & Dalton, 1993, Adaptive CBI, Roos & Morrison, 1988, quoted in Park and Hannafin, 1993).

### **Strategy: Metaphors**

The use of metaphors seems natural with a narrative structure - another 'literary' device, a theme to carry the story. Metaphors are important to organize many aspects of educational multimedia design (interactivity design, as organisational strategy for declarative knowledge, etc.). Most importantly:

- Familiar metaphors should be used in both in conveying lesson content and designing the system interface (Mayer, 1989, Ortony, 1975, quoted in Park and Hannafin, 1993).

Another advantage of this strategy is the memorability of metaphorical language (Tripp, 1990). Tripp reports that modern views of the metaphor suggest that they are psychological mechanisms which not only promote retention, but conceptual understanding of complex aspects of scientific theory. The choice of an appropriate metaphor can even help avoid confusion and conceptual difficulties for users (Cates, 1994).

#### Drawbacks of metaphors

According to a Piagetian framework, metaphors would work as an instructional device for formal reasoners and possibly preoperational reasoners as compared to literal language. If tied to developmental level, would metaphors not be good for all children? One would assume that any developmentally-appropriate metaphor would work as an instructional device for its intended audience. However, Flynn proposes that metaphors are effective for certain levels, not for others (Flynn, 1995). Research around this issue seems inconclusive.

## Screen Design: dynamic displays

Scheafermeyer (1990) stresses the importance of instructional text formatting/screen display and embedded graphics. Apple includes in screen design: interface design, the importance of WYSIWYG and aesthetic integrity (no visual confusion, informative design, simple and clear layouts of screens), as well as consistency. Principles from Park and Hannafin include:

- Complying screen design and procedural conventions that require minimal cognitive resources, are familiar or can be readily understood, and are consonant with learning requirements (Human factors, Baker, 1989, quoted in Park and Hannafin, 1993);
- Presenting information using multiple, complementary symbols, formats, and perspectives (Paivio, 1971, Symbol systems, Salomon, 1979, Learning from pictures vs. text, Levie & Lentz, 1982, quoted in Park and Hannafin, 1993).

One of the greatest benefits from multimedia is the integration of many media to convey one message, under the hospices of dual coding theory, including:

- combining illustrations and text (Mayer and Gallini, 1990);
- combining illustrations and narration (Mayer, 1992);
- animation with or without narration (Windschilt, 1996);
- dynamic visual displays (Howson and Davis, 1992, Mayer, 1992, Park, 1994, Park and Gittelman, 1992, 1995).

Park and Hannafin believe that memory functions best when both semantic and image representations can be cross-referenced and that multiple representations improve both encoding and retrieval. This view clearly assumes an information processing model of cognition. According to the dual coding hypothesis, knowledge is represented in semantic (meaning), imaginal (pictures), or dual formats (Paivio, 1971). These representations are not literal copies of events, but emphasize dominant properties such as shape, size, and detail.

### Animation

Animation could thus arguably represent a form of dual coding. Animation has been linked to better procedural/problem-solving comprehension (especially involving mechanical devices - Mayer and Gallini, 1990, Mayer, 1992), scientific knowledge (Howson and Davis, 1992, Windschitl, 1996) and higher education (Park and Gittelman, 1992).

Some evidence was found that adolescents may prefer realistic illustrations over cartoons (Dirr and Katz, 1991).

### Technical design

Among characteristics of technical design are quick response time and quick loading (Scheafermeyer, 1990) as well as consistency (Apple, 1987). Apple also raises the issue of designing for disabilities such as illiteracy and recommends ways of dealing with them:

- limit number of keystrokes and mouse movements;
- limit cognitive load;
- limit amount of things to remember.

### Overall guidelines for D&D of interactive narrative - an example from second language learning

An application in second language learning furnished design guidelines for narrative-based interactive learning tools. The following list of recommendations was generated from a series of interviews, observations, and discussions with users of *El Avión Hispano* during the development of the program:

- provide ambiguous story elements;
- authors should create many ambiguous story elements so that the stories are not too predictable. They must provide story elements which allow for creative flexibility, and multiple interpretations and uses. Authors should include suggestions of stories, development of plot, characterization, etc.;
- give readers many choices throughout the program. The experience of using hypermedia systems should be a rewarding, entertaining, and enriching experience;
- incorporate spatial anchors. Interactive fiction allows readers to move through time and space. Authors should incorporate into the program orientation devices and familiar elements such as a home card, metaphors or fixed bases in case the reader becomes lost or disoriented;
- non-sequential story elements. The author should construct the fiction as a network of ambiguous story elements or episodes. Since readers are bale to structure their own stories or follow their own paths throughout the program, the individual story elements need to make sense no matter how they are put together (but there is a limit to how free they're able to do this);
- consistent user interface. authors must make certain that the tools and program have a consistent, clean and clear look. The user interface should be transparent and easy to follow.

## Advantages of computer-assisted instruction (CAI)

In a survey of studies about benefits the of CAI in general, Cartwright found that CAI was reported to be equal or superior to conventional instruction on such variables as achievement, attitude toward the subject matter and the instructor, and time to complete the task (1993). Hannah et al. echoed the same, stating that "twenty years of school-oriented research in CAI have substantiated its value" (1989, p. 263), and further stating that CAI demands active participation in the learning process. It only seems natural to establish what the advantages and disadvantages of CAI are, especially for this domain.

### Advantages of computer-assisted instruction (CAI) in patient education

At a time where a survey of American Academy of family physicians members indicated that less than 4 percent of computers in nonfederal office-based practices (USA) were used for patient education (Ellis, 1985), it could be nonetheless noted that patient educational software existed and was available. In fact, packages marketed covered various topics (allergies, cancer, cardiology, diabetes, etc., Bell, 1986; breast self-exam, stress, arthritis, etc., Vargo, 1991).

The primary specific advantage of CAI for children can best be summed up this way:

> "(CAI) has a special appeal to the young client who is comfortable with the technologies because computers are used in their formal educational programs. This method could be another choice when the 'patients don't read our patient education pamphlets anymore'" (Armstrong, 1989, p. 603).

Other specific advantages include:

| | |
|---|---|
| Improved health indices (health indices generally show that computer assisted patient education does have an effect on the KAB components): | |
| • improved patient's (and family's) ability to cope more effectively with health related problems | • Hannah et al. (1989) |
| • improved use of medical resources by patients | • Bell (1986) |
| Pedagogical advantages: | |
| **Enhanced learning** | |
| • increased knowledge and learner performance | • Hannah et al. 1989, Petersen 1996 |
| • self-paced instruction, accommodates a variety of learners | • Vargo 1991, Ellis 1985, Bell 1986, Petersen 1996, Hannah et al. 1989 |
| **Enhanced instructional delivery** | |
| • method of delivery more entertaining than didactic education from nursing staff | • Petersen 1996 |
| • non-threatening environment, non-intimidating | • Bell 1986, Fos 1988 |
| **Assessment and feedback** | |
| • maintains records of educational activities completed | • Vargo 1991, Bell 1986 |
| • immediate feedback | • Ellis 1985 |
| • assessment of patient learning for legal and accreditation purposes | • Bell 1986 |

Table 7 - Advantages of computer-assisted instruction (CAI) in patient education

### Time and money

In times of cuts in social spending, it might also be timely to point out that computer-assisted patient education is thought to be a cost-effective measure. Though admittedly more recognized in the USA than here, return on investment (ROI) quickly becomes a factor which can be noticed in a number of ways. Armstrong quotes research by Kulik, Kulik, and Cohen (1985) on the use of computer-assisted patient education which demonstrated that achievement of educational objectives took about one-third the time required by conventional teaching methods (i.e. self-paced vs. teacher-led classroom). The same research further stated that costs for computerized patient education were also recouped via savings in staff time, increased patient satisfaction with care, increased referrals, fees for educational services, and direct third-party reimbursement for provision of patient education.

## Disadvantages of (CAI) in patient education and nursing practice

### Time and money

The other side of the cost-effectiveness coin are the large investments which may prevent hospitals and clinics to adopt CAI in the first place:

| **Large initial outlay of time and money:** | |
|---|---|
| • purchase, installation, maintenance of hardware and software | Hannah et al. 1989, Bell 1986 |
| • time of nurse managers with energy and expertise to select most suitable products | |
| • physical space availability | |
| • training needed | |

Table 8 - Disadvantages of (CAI) in patient education and nursing practice - time and money

### Software, technophobia, literacy and hype

These are other disadvantages with CAI:

| | |
|---|---|
| • limited availability of appropriate software | Vargo, Hannah et al. 1989 |
| • only literate patients can benefit from the programs | Vargo, Hannah et al. 1989 |
| • fear of computers | Vargo, Hannah et al. 1989 |
| • misuse of tool (attempt to replace rather than supplement human interaction during education process) | Chan, 1992 |
| • dangers in comparing delivery modes (explain) | Ellis, 1985, Clark, 1992 |
| • newness of media - therefore temporary heightened interest | Ellis, 1985 |

Table 9 - Disadvantages of (CAI) in patient education and nursing practice - other factors

Furthermore, CAI can be, and often is, badly designed. Nibley (1993) states six common problems that can interfere with the effectiveness of multimedia information delivery, especially when combining narrated word and still images:

- including pictures which do not translate well to the screen;
- putting more information than the screen can display;
- distracting elements;
- contradicting messages;
- not enough pictures;
- script difficulties.

## Methodology

Conventional ISD development was covered in the previous section. The discussion for this section will focus on more recent models.

### Alternative development approaches

The team started work with Rapid Prototyping (Tripp and Bichelmeyer, 1990) in mind as a production model. Jones defines rapid prototyping as a process in which formative evaluation is implemented using prototypes which emulate the end-product inasmuch as possible (Jones, 1992). As will be outlined in Chapter 4, it was however difficult to implement formative evaluation as thoroughly as rapid prototyping may call for.

Tessmer (1995) also proposed a new way of approaching the process, which approximates real-world practice, especially in instructional multimedia development. He calls this the 'Layers of Necessity' model: analysis, design, development and evaluation happen concurrently. To speed-up the design/development process, instructional scenarios are developed. From the evaluation of these scenarios comes more analysis data which goes into the building of two competing prototypes. And again, until the designers get to a negotiated prototype.

### Instructional development for multimedia in health education

Production ratios reported by design teams involved in computer-assisted patient education vary widely: some products boasted a 60:1 ratio (60 hours of development for 1 hour of instructional material) (Vargo, 1991) while others took ten times longer (600:1, Ellis, 1985). Vargo also stated that programs written at an 8th grade reading level best meet the needs of their patients. Most packages also include pretest-posttest to gather data on patient learning.

### Team composition

Ellis reported that the team overseeing lesson development is generally coordinated by an health educator, and includes a physician with expertise in computer programming as well as other health professionals. Their team also often includes a university researcher (1985). In contrast, the design team involved in this project, was a small team of instructional designers, using clinical staff and patients as subject-matter experts.

# Chapter 3 - Analysis, Design and Development

This chapter details the actual analysis, design and development of the CD-ROM project. The whole process took place over 6 months, from January to June 1996, and included formative evaluation within that timeframe. Further formative evaluation took place after June 1996. These efforts will be the focus of Chapter 4.

The design team took a primarily intuitive approach to the whole process, armed with its knowledge and experience, and relied heavily on: reference materials, results of the staff interviews, common sense, and hands-on knowledge of children.

## Front-End Analysis (January 30-April 30, 1996)

### Project identification (January 30-February 19)

Initial discussion of the idea for this project started in late January 1996, with the Montreal Children Hospital's senior audio-visual technician, Daniel Héon. An initial meeting between clinic nurses and two of the three designer/developers of the CD-ROM application, as well as identification of the project and material needed ensued in mid-February 1996. The need for educational material concerned with bone marrow transplants and designed for children was identified during this meeting, as discussed in Chapter 1.

### Development and presentation of project proposal (February 20-March 10)

#### Research and development of project proposal (February 20-March 24)

An Internet search was conducted to look for similar, already-existing applications. As mentioned in Chapter 1, nothing much was found.

The bone marrow transplant procedure was researched (Armitage and Messner, in Dollinger et al., 1995, NYSERNet Inc., 1996a, 1996b, 1996c). Content outlines were drafted and subject-matter interviews would fill in the gaps.

Other efforts were devoted to looking for and negotiating funding from the Lamplighters and settling the various issues brought about by the collaboration of the design team, Montreal Children's Hospital and the Lamplighters.

In these very early stages of the CD-ROM project, it was decided that the product would have to:

- present declarative knowledge to inform children about BMT;
- reduce pediatric patient and family stress and anxiety, i.e. change attitude;
- use delivery of interactive multimedia instruction for self-paced instruction;
- have as characteristics:
  - no video but animation (for technical reasons and for appeal to children);
  - narrative approach to content delivery (for appeal to children and to lessen cognitive load).

Further aspects are as follows.

### Teaching strategy and Learner evaluation

There would be no quizzes - the stress of performance would not be added to the stress inherent to the situation. The application had to give the learner a sense of control, had to inform and increase comfort. Children and families react in individual ways, but their reaction is characterised by shock and anxiety.

### Information structure and sequencing

Narrative structure/story-telling approach: A narrative approach would be applied to represent the experiences of patients who had gone through the bone marrow transplantation procedure. The content would focus on issues related to the preparative regimen, the actual transplant, the engrafment and post-transplant. The narrative would be told from the children's point-of-view, in a language appropriate to them and to their conceptualization of pain, illness, cancer and treatment. Its unfolding would follow the conventions of story-telling.

### Interactivity

Multiple user capabilities: The tool would serve as an impetus for group discussion, either: between patients; between patients and their families; between patients and hospital staff; and so on.

Other common features of interactivity, such as navigational aids (forward button, back button, stop button, quit button, quit screen requiring confirmation, help, start over), would be implemented.

### Screen and technical design

Animation: The use of animation would be the over-riding feature of the application's screen design. This form of presentation would engage the child's interest into the information and render the characters, with whom the child can identify, attaching.

Sound & Text Minimization: Given that the target group for this application would primarily consist of young school-age children, designers/developers must be careful not to present the material beyond the reading capabilities of its intended audience. Narration would minimize the reading of text, complex concepts could be illustrated graphically, and interaction with the application would not require extensive knowledge of keyboard or mouse functions. This strategy also allows the application to circumvent difficulties posed by linguistic differences.

### Other considerations

Multicultural perspective: The Montreal Children's Hospital is located in a large, multicultural, metropolitan city. Designers/developers of the application tried to transcend the limitations of language by minimizing the amount of text, and by providing for the easy implementation of different linguistic options (notably French and Spanish). However, the end-product was made in English only, for that was all that time could allow.

### Presentation of project proposal and preliminary project plan (March 13)

The final project proposal and preliminary project plan were presented to the Lamplighters and Montreal Children's Hospital on March 13, 1996.

### Extra negotiations and project kick-off (March 14-24)

It was originally proposed that the application would be developed in both French and English. However, when time came to formalize a production plan -- with all the assurances which the Lamplighters wanted -- it became clear that the original kick-off date would be postponed. The author then had to tell the Lamplighters that the CD-ROM would be made in English only. The Lamplighters' president also insisted during this time, that official project approval be given by the head of Hematology, Dr. Whitehead. Until then, the design team was under the impression that head nurse Norma Auger's permission to release clinic and ward nurse time to the project was sufficient. Presenting the project yet again to Dr. Whitehead and obtaining his official approval delayed the kick-off of the project and several tasks thereafeter.

## Needs assessment (March 25-April 24)

The objective of the needs assessment was to determine what was most important for the children to know, from their point of view, especially. Instruments used in this phase, as well as results and their implications for subsequent phases of the project, are discussed below.

### Subject matter expert interviews (March 25-28)

The questionnaire for needs assessment interviews (see Appendix A, results reported below) was developed from March 25-28, in view of subject-matter interviews with hospital staff (clinic and ward nurses, and BMT units housekeeper). One of the team members drafted up a questionnaire. The others added their input for interview methodology over email. One of the challenges was the small amount of time the staff could take off their schedules to meet with the design team. Often, staff members would come and go from meetings with the team to their patients. The decision was made to have an open group discussion (45 minutes), leaving nurses and other staff to give ideas about the project for the initial part of the meeting, and then break off into smaller groups. Each of the three team members would then follow the questionnaire for more precise information with 1 to 3 staff members (1 hour). Many questions had been answered in the course of the larger group interview, but this provided the opportunity of going in depth over such issues as telling the patient and the family that the patient needs a bone marrow transplant, and how they generally deal with the highly charged feelings which often arise. However, the following three tables contain a summary of the important points which directly contributed to design and development:

- What is the profile (i.e. age range, mindset, physical strength, etc..) of the children in the ward ?

There is no typical patient. Age is a big factor. Teenagers are more anxious:
- 2-6 yr. old: little comprehension, only short term
- 79 yr. old: comprehension, fear of pain
- 10-16 yr. old: fear of unknown

Roughly, nurse will deal with parent for 4-9 year olds, with the patient directly with 10-16 year olds. Patients are anxious about: isolation, pain, time in the BMT unit, limited contact (only with adults, no other kids). Most of these children are already familiar with chemo or radiation therapy.

- How do these children find out about their cancer diagnosis ? Parents ? Doctors ? Nurses ?

The physician announces the diagnosis and the treatment options to the parents. Sometimes the child is told by the parents who may or may not filter out information. Parents have different approaches. Upon admission to the hospital, 2 nurses are assigned to the family.

- What is their initial reaction ? How does their reaction change over time ?

Initial reaction depends on the patient's age. The younger ones do not understand mortality as much as the older ones. The adolescents are really affected differently because they're at an age where they think they're indestructible and then they realize they have a life-threatening disease. The younger ones seem to take one day at a time.

- Do they understand what their disease is and the consequences of their ailment?

Technical information is explained to the parents by the physician and by the nurses. Some of the information to the children is given by their parents, some by the nurses -- depends on their age.

- When BMT is first mentioned, who explains this procedure to the children ? To the parents ?

BMT is decided on when there's no more choice, sequence is generally:
- cancer diagnostic
- chemo-therapy
- remission: wait and see how long they are well
- more chemo, if needed
- If there is a relapse, the child gets more chemo until the 2nd remission
- If there is a 2nd relapse: BMT or palliation

- Are psychological and emotional issues addressed or is the focus primarily on the physical component of the BMT ?

Patients need to be told about the isolation. They may not always be able to see the ones they love, like siblings, and they need to be in a special room... This is very difficult for them.

Table 10 - Learner analysis - Needs assessment interview with nurses

Typical sequence from Doctor's decision to use BMT for treatment:

- Physician announces BMT, leaves family with info for a week
- Start testing family for donor typing, if not already done
- A donor needs to be identified and matched on schedule with time that child
- needs it
- Donor can be the child himself (autologous), if external to family, donor
- is anonymous

- Child admitted to hospital

- Child put on a low bacteria diet (all food sterilized), install central line by surgery with 3 tubes to give food, blood/bone marrow transfusion and medications, medications make kids sick (nausea, diarrhea) at this point, but they're used to it, if they've had chemo

- Put in isolated room (BMT unit) prepared 24 hours in advance, cleaned, equipped with all medical equipment that won't go out of the room anymore (BP, heart monitor, etc.)

- Chemotherapy for 2-3 days (depends on protocol) - mouth sores usually develop (others in the food tract also). Total body irradiation done (2-3 days - depend on protocol) : need to go to Montreal General Hospital, 2 special transports/day, child covered up and wears a mask

- Comes back to MCH, given a bath, goes back to room, rest day

- Transplant day: bone marrow harvested at the same time when donor is a relative

- Wait 2 weeks to see if they'll make it through: side effects show up here the 2 weeks after the transplant is hard especially on the parents. If the child breaks into a fever, 1st sign of anxiety (the chemo and irradiation has destroyed the immune system - bone marrow given to regenerate it, waiting for cells to appear again. If cells re-form, marrow is producing, shown in print outs of blood samples taken every day at 6am. Parents often ask for them (tangible proof of the child's health status). Often become ecstatic if one cell shows, but still not sure that transplant won't be rejected.

Table 11 - Chronological sequence of a bone marrow transplant - Needs assessment interview with nurses (content/task analysis)

Nurses' suggested approach for the CD-ROM:

Our approach is positive. At the beginning, explain everything summarily, then it's day by day:
- try to not provoke anxiety.
- "you can come visit your room and visit your nurses before"
- "you'll take a bath every morning in a pink liquid with bubbles"
- "your bandages around the central line will be changed"
- "we'll sample your blood every day at 6am"
- "you might lose you hair"

Our belief is: 'Honesty is the best policy', within the limits of the child's capacity to understand and what should be discussed by the family.

Specific issues

- Pain: The children are told they do not need to be in pain (i.e. mouth sores). One of the central line tubes is for medication to alleviate the pain. Tell the patient that it will soon pass. The bone marrow transplant itself, is not painful to the receiver, it is transfused like blood, through a central line tube on the chest. The number of needles and punctures to the skin is reduced to minimize the risk of infection so the central line is used for retrieving blood samples (daily), etc....

- Isolation: They are in isolation (limited direct, physical contact with others, no direct contact with children) for about 4 to 6 weeks and then they need to be isolated when they go back home for about 6 to 9 months. They may not be able to have direct contact with some of their siblings (younger siblings are usually not allowed). They can't always have the toys they want (everything has to be sterilized and some toys carry more bacteria than others). Parents might not be able to come in if they are sick. However, the nurses and medical team will be there for them. They can play and read and watch TV. but sometimes they are too sick.

- Food: the patients might not feel like eating because they're too sick (i.e. nausea, diarrhea...). Food is sterilized and they are given a low-bacteria diet. If they don't feel hungry, they are given liquid food by IV but they should really eat solid food before going back home. If they are hungry for a certain kind of food, they may have to wait a while - they might not be able to get it right away - the food must be sterilized and specially treated.

- Mortality: Addressing the issue of mortality depends on the parents. This should not be discussed on a CD-ROM. The younger children think in the present - the consequences of their illness is not always concrete - although they see their parents crying and relatives suddenly visit and bring them gifts - they are aware that something is up. The adolescents react more like adults - given that adolescents concentrate very much on the future, they are now faced with their own mortality.

Table 12 - Nurses' approach to children during the bone marrow transplant treatment- Needs assessment interview with nurses (content/task analysis)

One team member was also given more educational material used at the clinic, specifically geared for children. Current material utilized at the hospital was reviewed (Bombeck, 1989, Canadian Cancer Society, 1993, Morin, 1989, Murray, 1991, Pomminville and Demers, 1984, Peterkin, 1992, Schulz, 1990, Shands Hospital at the University of Florida, 1989, The Center for Attitudinal Healing, 1979). Of particular help was the Shands Hospital at the University of Florida's colouring book about bone marrow transplant, featuring drawings by young patients about their experience. Most of the drawings centered around the child's view of their own coping with the emotional hardship inherent to the isolation involved in the BMT process (see Figure 2 - 'It's just fine to cry'), or the support they can get when their reaction to medication leads them to feel weak and sick.

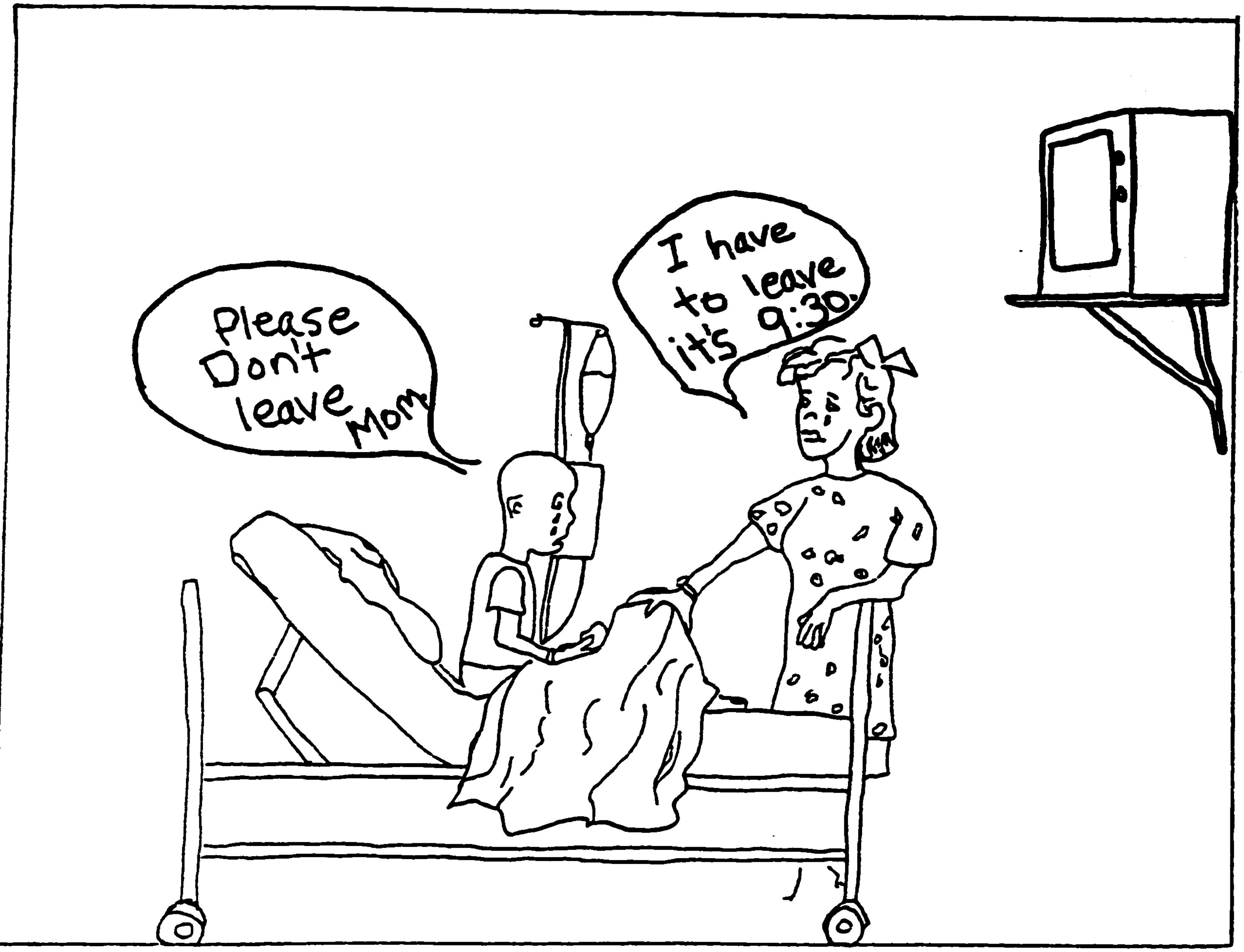
Another round of subject-matter interviews with child life educators and the hospital teacher (April 24), followed. They will be discussed shortly.

### Learner analysis

As part of the interviews, the developers could establish certain criteria about the audience, as indicated in Table 10 - Learner analysis - Needs assessment interview with nurses, above. Another important characteristic also came up: illiteracy was a problem for many patients and families, thus making the importance of our oral narrative take on a different dimension.

### Content and task analyses

These were made from March 29 on, from cancer and BMT literature for children and adult laypersons collected since the beginning, and results of the staff interviews. It became clear, as indicated in the tables above, that a bone marrow transplant was a chronological process comprising several steps. Content is further discussed in the design phase.



**It's just fine to cry!**

Ricky

Figure 2 - "It's just fine to cry!" (Shands Hospital at the University of Florida)

## Design

Instruments used in this phase, as well as results and their implications for subsequent phases of the project, are further discussed in this section.

### Design, development and evaluation of instructional content and strategy

#### Identification and design of content (March 29-April 8)

Broad themes and specific concerns were designed from the results of the needs assessment interviews, as discussed above.

After exchanging transcripts and summaries of other educational material, the team met to establish the scope of the content, as well as its tentative sequence. The content/task analysis was broken down into a Question & Answer format (see Figure 3 - Content map) which was refined through later stages of design.

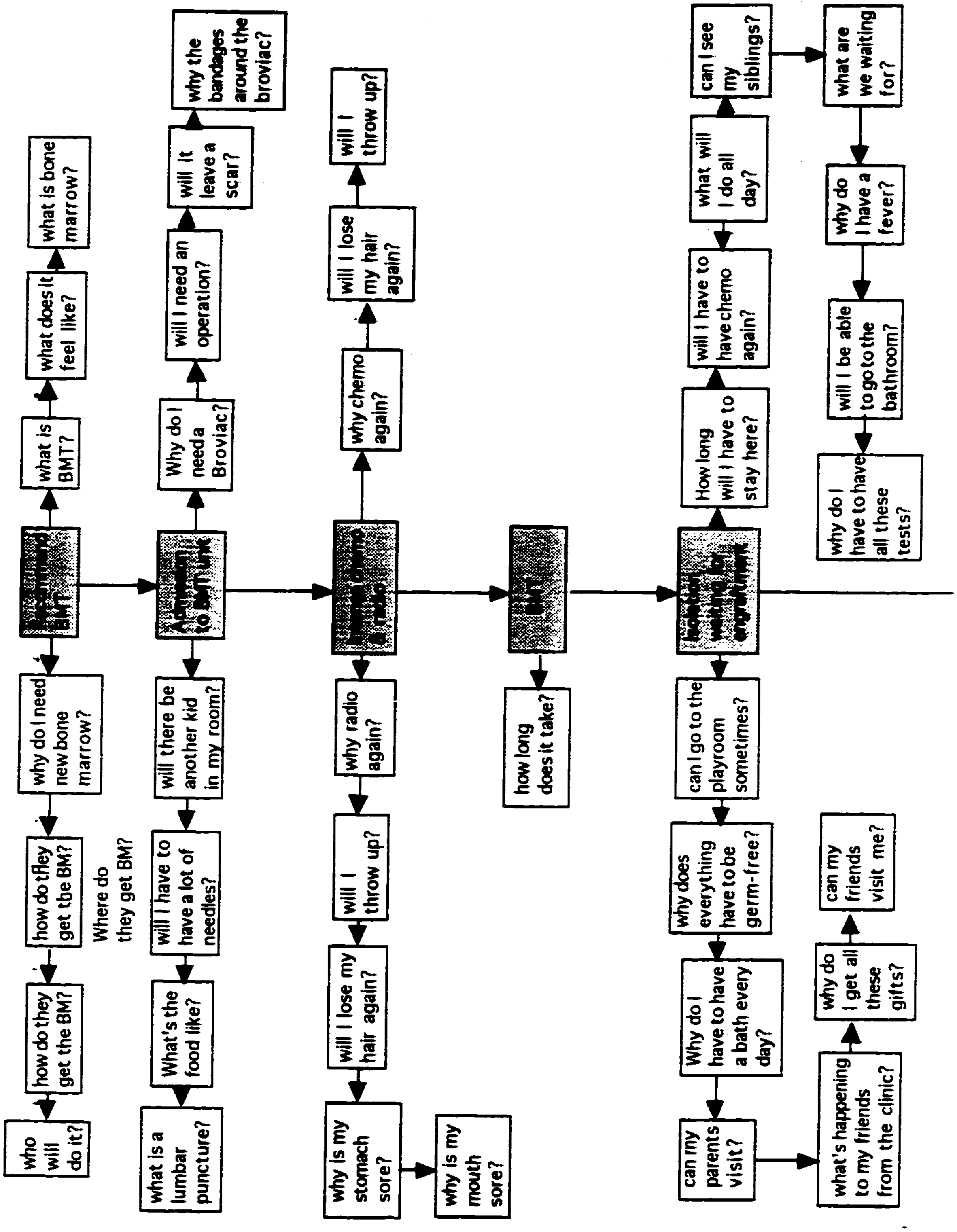


Figure 3 - Content Map

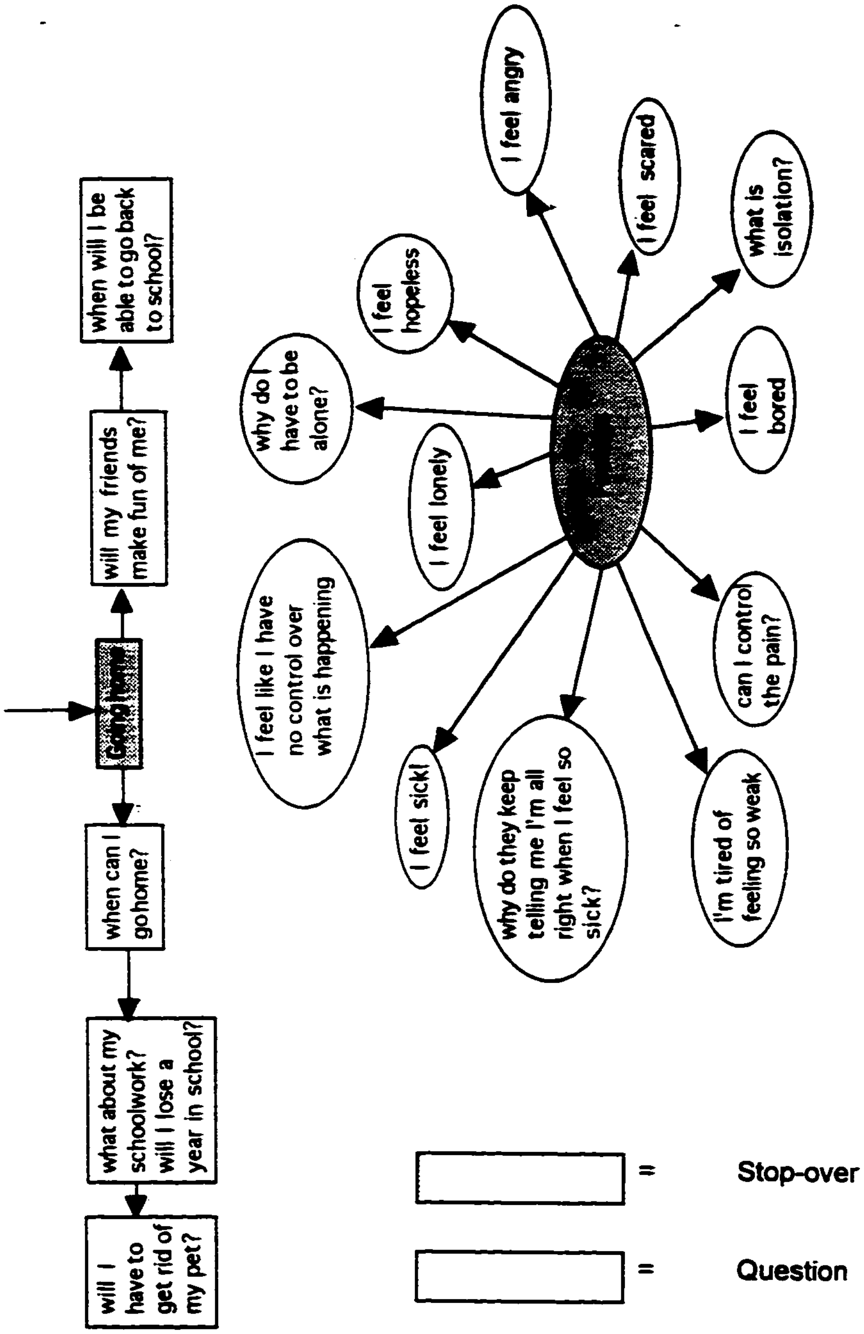


Figure 3 - Content Map (cont.)

### Development of instructional strategies (March 30 -April 15)

The Q&A format and narrative approach started taking shape into character dialogue after the content map was drafted up. The metaphor of a voyage, which would give the narrative and animation a theme, was elaborated by the team during a brainstorming session. The voyage would comprise 7 'stop-over's' which represent the 7 steps of the bone marrow transplant procedure (refer to Figure 3. Content map), preceded by a section on navigation and other instructions to use the CD-ROM. Though the narrative structure would be somewhat linear (partly to lessen cognitive load, but mostly to follow the story's chronological progression), the user would be given a choice of questions (and therefore answers), to reclaim a sense of control and empowerment. At this point, the team had identified the use of characters as an interface to a database of cases, a repository of experience, since it had been established early on that the story of a bone marrow transplant is as different as the patient who receives it. Initially, the idea of 6 characters was discussed, as well as the possibility for the patient/end-user to add her own story to the repository. This idea was soon discarded because it posed technical challenges beyond the experience of the design team. It would, however, have provided maximum levels of interactivity, as in the case of 'user as author, interactive fiction scenarios reported by Gay (1992). The patient depositing her story would have benefited from sharing the information and articulating her story, as well as providing added content, view points (again, the idea of multiple points of view) and added value.

Other functions and elements, such as music and sound effects, were being discussed between the team-members as well. A lot was still up in the air, but the team finally settled on four characters, two females and two males, representing different origins (Oriental, Latino, African-Canadian and Caucasian), and the different ages within the 6-12 age range

### Expert review/formative evaluation of initial content (April 9-April 15)

An extensive review of the initial content brought the multidisciplinary team together at the Montreal Children's Hospital into an extraordinary meeting (three child life specialists, six ward and clinic nurses, oncology head nurse, hematologist, hospital teacher), shortly after content identification, to make sure the design team had understood the scope and breadth of information the patient/end-user would benefit from. It also occurred as the team worked on instructional strategies. Methodology and results of this expert review will be discussed in Chapter 4. Basically, the script was submitted to the team, along with the questionnaire, just mentioned above.

The ward nurses, as well as the hematologist/BMT specialist identified former BMT patients who could help with learner verification efforts. They contacted the families. Meetings would be set up with two families, which are discussed below.

## Design concepts of CD-ROM (April 15- May 18, 1996)

### Development of script (April 20 - May 14)

The script was to go through the following stages of writing, evaluation and re-writing:

1. 'The script'
2. Content validation (expert review)
3. First re-write + storyboard
4. Script and storyboard validation (expert review and learner verification)
5. Post-validation script
6. Rehearsals and sound-recording
7. 'Final as the kids said it' script

Each team member was responsible for her third of the script.

### Extra subject matter expert interviews (April 24)

The author felt that the psychological and emotional aspects of the BMT procedure were still missing from the content. Another needs assessment / interview meeting was set, this time with those staff-members whose specific purpose was to look after the child's quality of life and well-being while at the hospital. The director of Child Life Services, as well as her staff member on the oncology ward, and the hospital school teacher sat for about an hour with the author at the hospital. The questionnaire was developed by the author, from previous rounds of needs assessment.

### Development of storyboard (April 24 - May 15)

After the second round of needs assessment, and with the first round of revisions made, the team met to start working on the storyboard. The voyage metaphor lent itself to a spaceship as a vehicle, both literally and figuratively. The team thought that an outer-space voyage had a 'cool' appeal to children and young teenagers - it also represented the 'out-of-this-world' aspect of the BMT experience. Spending the four to eight weeks in isolation after the transplant is as close as these children would have ever come to 'leaving the earth'. The transition of the spaceship, from planet to planet (i.e. each of the 7 stop-over's), would mark the chronological progression. The scenes of the stop-over's, where the characters would relay each other with bits of the narrative, would be the control room of the spaceship. This would be the literal vehicle, the graphical-user interface where navigational aids would be displayed. Since complex concepts would come up in the narratives, and the team wanted to exploit the power of animation and illustration to this end, the decision was immediately made to include a projection screen on the 'dash-board' of the control room. Buttons alongside the projection screen would represent the questions which the patient/end-user could choose to ask and then hear and 'see' the answer.

The metaphors are also easily recognized, since they are a mainstay of popular culture (e.g. Star Trek, etc.). The decision, however, was also made to make the characters - though animated - as lifelike as possible. The narrators would be real children. Too many other educational materials used animal or fantastic characters (Morin, 1989; Pomminville and Demers, 1984) which may hold a special appeal to very young children and draw parallels with fairy tales. However, they seemed to dilute the message to triviality, and some of them were quite simply idiotic. The design team thought that 'honesty' being 'the best policy', real characters, with whom the children could readily identify, was the option of choice.

The identity of the characters, their gender, ethnic origin, age, appearance, and names were also decided on to make the task of allocating dialogue easier to manage. Illustrations started being produced by the team member who was a graphic artist. The child-actors who would lend their voices to them were selected. Alasdair Lowe, 10 years old, played Alex, the 12 year-old African-Canadian boy (see Figure 4). Dinah Weldon, 11 years old, played Suzanne, the 11 year-old Caucasian girl (see Figure 5). Jessica Abrami, 10 years old, played 'captain' Maya, the 8 year-old Latino girl (see Figure 6). Daniel Paradis, 9 years old, played Robert, the 6 year-old Asian boy (see Figure 7).

A decision was made to force the user through an introduction at each stop-over and to select one of the characters to be the 'captain'. The design team consisting of women made the selection of the captain easy - it would be one of the female characters! The team also chose the younger female character - Maya - to further diverge from the traditional idea of an older, male, authority figure.

Along with each third of the script, each team-member was responsible for her part of the storyboard, deciding to divide the dialogue related to various aspects of the topics and allocate them to a different character, customizing them to the specific attributes of the character (i.e. Robert, the 6-year old, would contribute simple, ingenuous anecdotes while Maya, the captain, would cheerfully and knowledgeably introduce each topic, etc.), and deciding on the illustration and/or animation which would go into the projection screen to explain the concept being discussed.

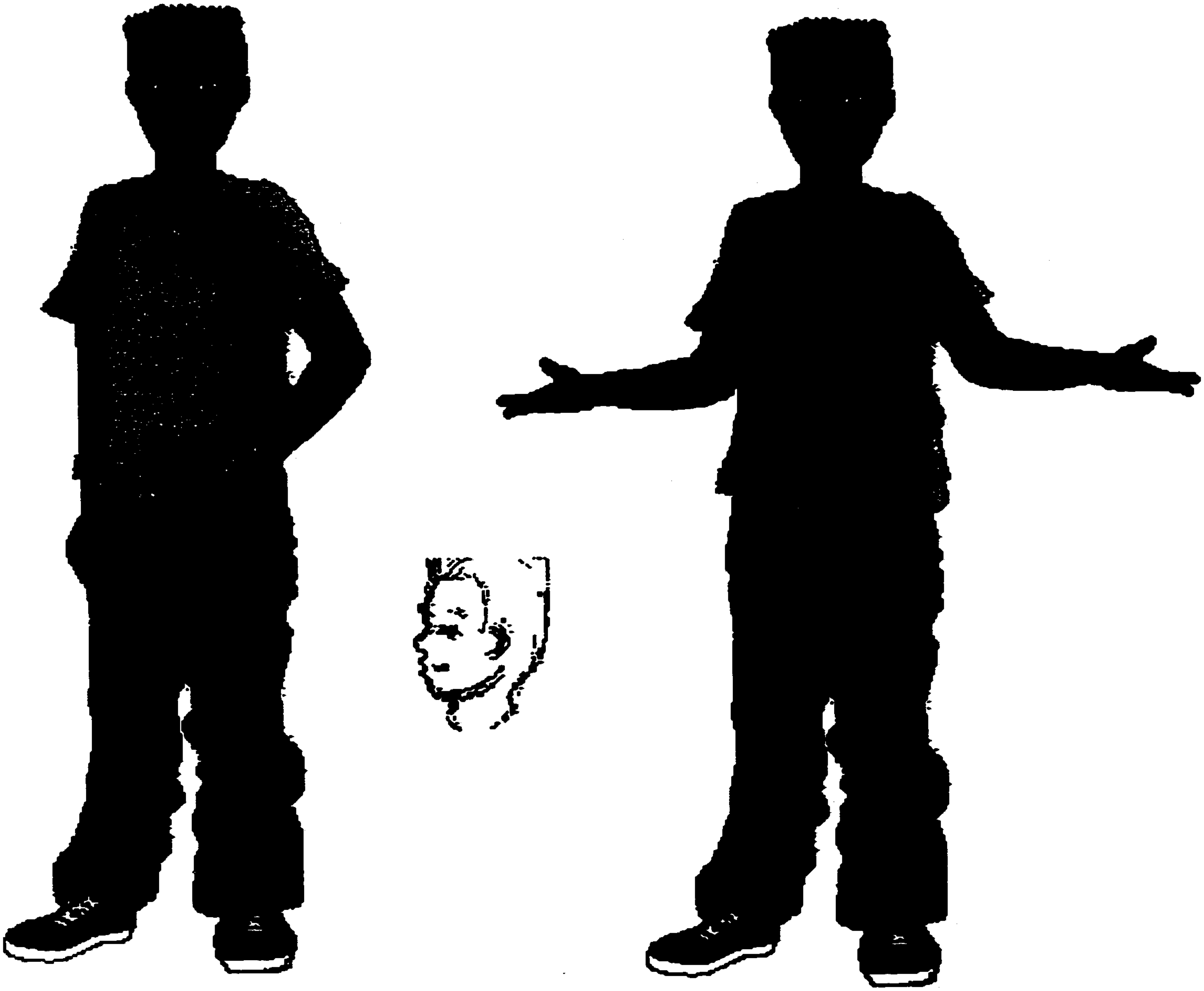


Figure 4 - Alex

Figure 5 - Suzanne

Figure 6 - Maya

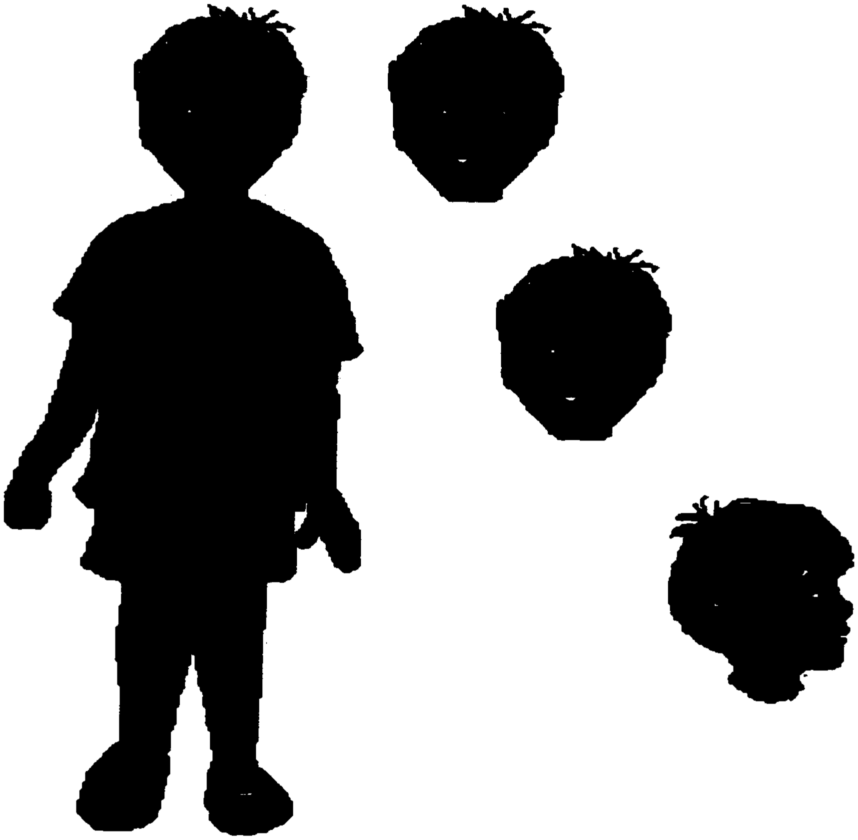


Figure 7 - Robert

The scenes were numbered during storyboarding to ease the management of the development phase. There were 7 stop-over's or scenes, comprising many scenes within. The introductory animation with the title and logos became Scene 1. The characters' introduction became Scene 2. The navigation demonstration became Scene 3. The rest of the scenes are as follows:

You need a bone marrow transplant -> Scene 4 (stop-over 1)
Admission to BMT unit -> Scene 5 (stop-over 2)
Central line -> Scene 6 (stop-over 3)
Chemotherapy and radiation -> Scene 7 (stop-over 4)
Bone Marrow Transplant -> Scene 8 (stop-over 5)
Engrafment -> Scene 9 (stop-over 6)
Going home -> Scene 10 (stop-over 7)

Within these BMT treatment related-scenes, Scene x.1 would be the introduction to that particular scene/topic. Scenes x.2 to x.n would represent the different questions related to the scene/topic. The Voyage would finish with Scene 11 - 'Bon Voyage!'.

The team met several times to further refine the storyboard and script, as well as make decisions about animation and illustrations. Changes were brought especially after the next round of evaluation. Parts of the storyboard can be found in Appendix B.

### Learner verification/Formative evaluation and Expert review/validation of storyboard and script (May 6-13)

Learner verification/Formative evaluation was conducted from May 9-11 with 2 former BMT patients and their families (a 13 year-old boy and his mother, and an 11 year-old boy and his father, mother and older, donor brother) to gauge the level of language, appropriateness of graphics, conceptual understanding of content and strategies, story-telling concept, accuracy of the content, and effectiveness of the spaceship/voyage metaphor. This was conducted with the script and storyboard. Results and their implications will be discussed in Chapter 4.

Expert review/validation of the storyboard and script was conducted from May 6-13. The review was done with the help of the head nurse, clinic and ward nurses and a hematologist to validate the form, accompanying graphics and the storyboard. Results and their implications will also be discussed in Chapter 4.

### Development of final script

Following the last bit of evaluation, the final touches were brought to the script as the child-actors were being rehearsed.

### "Expert review"/validation of script

Further adjustments were brought to the script throughout the process of recording the narrators, from May 15-18. The actors were all around 10 years of age and helped put the script into language which could be easily understood by children, to the extent that the scriptwriters had not achieved this despite efforts to do so.

## Development

### Production of CD-ROM (May 1 - June 25, 1996)

The production of the CD-ROM took place in the last stages of the project.

### Outline according to the 4-component model

This model was introduced in Chapter 2 and consists of the following parts.

#### Information structuring and sequencing

These activities included determining scope, breadth and sequence of the content, script writing, storyboarding, etc. They were covered in the Analysis and Design sections. During script-writing and storyboarding, the different steps of the BMT treatment became the voyage stop-over's, as discussed above.

#### Interactivity

Navigational aids were conceived along with the application's main metaphor (voyage in a spaceship) and interface (control room of the spaceship). Flowcharting was a great help in determining hyper-links.

#### Screen Design

Graphic design was quite extensive for this project and included cross-platform testing from the Macintosh platform to the PC-compatible platform. All of the four characters were created in different body positions to create the animations. Components of other explanatory animations, as well as illustrations, were also created throughout the month of May. The child actors were rehearsed and sound-recorded from May 15-18. Sound editing was done as the recording took place. Shortly after, the author started putting together the basic animation of the characters and a prototype module which the other team-members started developing other modules from, adding other animation, linking screens and scripting navigation buttons.

#### Technical Design

More advanced programming required the help of the multimedia course teaching assistant, as well as that of a Technical Services staffperson. The team started cross-platform testing as soon as one module was up and running to ensure the integrity of the application from the development platform (Macintosh) to one of the playback platform (PC - the platform of interest to the Hospital). Debugging was done as needed. A test CD-ROM burn took place in the last month of production to ensure the integrity of the application from the development medium (local hard disk) to CD-ROM, as well as to test it on both playback platforms. The final CD-ROM burns were made June 25, 1996, following the last adjustment and client validation.

### Discussion of the production process

#### Layout, graphics and photos

The huge number of illustrations were created by the team member who was also by training a graphic artist. Wendy Lowe sketched most of the illustrations by hand, using pencil on drawing paper. Wither she or the two other members of the team would then scan them into graphic files with the help of Adobe Photoshop. Wendy would then use Aldus Supertpaint to colour the illustrations. Most of the illustrations used in the animations were also created this way. Some illustrations, particularly the geometrical forms in the control room/application interface (e.g. navigation buttons, 'dashboard', planet backgrounds - see Appendices C to L) were created directly with Superpaint. Some of these were also created with the bitmap drawing tool included in the authoring software used to develop the application, MacroMedia Director, v. 4. All these illustrations were developed on the Macintosh platform.

It soon became apparent that many pictures would be needed. As the scenes were numbered during storyboarding, the different illustrations were also numbered accordingly: 'Scene x.y - description'.

### Cross-platform testing

The characters were the first illustrations to be created. Cross-platform testing (from Macintosh to PC) started with them. It took about a week to adjust to the different system colour palettes used by the Macintosh and Windows OS.

### Digitizing slides (BMT Unit "Virtual Tour")

The only illustrations which were photos were the 13 different shots shown during the 'Walk Thru' (Scene 5.2 - Admission to the BMT unit - virtual tour of the unit). The head nurse of Oncology gave the team a tour of the BMT unit during one of the team's first visits to the ward. Daniel Héon of AV had also assured the team that he could provide any photographic work necessary. The sequence of shot was as follows:

1. shot of 1st door (corridor to BMT unit/nursing station and bath)
2. 1st door open
3. look at nursing station
4. look at bath
5. shot of 2nd door (nursing station and bath to ante-room)
6. 2nd door open
7. look at sink in ante-room
8. shot of 3rd door (ante-room to bedroom)
9. 3rd door open
10. look at bed
11. look at outside window from bed
12. look at fun centre (Nintendo and VCR with TV) from bed
13. look at hall window with walkie talkie from bed

Once Mr. Héon was finished taking the photos, he gave the author the slide film. She then took it to Champion Lab to have the film digitized directly onto a CD-ROM.

### Narration

One of the team members was in charge of looking for young actors who could lend their voice to the characters. She got her youngest son and his schoolmates involved, rehearsed them at her home about a week before the recording. Ad-hoc script revisions happened throughout this process. Time was booked in the lab over a weekend during which the children were recorded for all the excerpts assigned to them, one after the other. They would rehearse each excerpt, then record two takes (or more if necessary). The narration was recorded straight to the computer's processor and hard disk with the help of a uni-directional mono microphone. The three team members were present for the recording sessions. One made revisions to the script as the children encountered difficulties or made suggestions. The other made sure the microphone and child were well positioned and gave the go-ahead to the young actor to start talking. Upon that cue, the third member would start recording the excerpt to the computer with the help of a digital sound-editing package (SoundEdit Pro). She would then select the better of the two excerpts and edit it as needed. All the excerpts were saved in AIFF format, so they would essentially be ready to use into Director once the recording was finished.

### Prototype module

When enough elements were ready to start integration and production of a prototype module - or scene - this part of the project got underway.

#### Animation

The first element to be created was the animation of the characters. Creating animation in Director is very much like building traditional cell-animation. The advantage with digital technology, however, is that certain sequences of movement can be repeated at will through the use of code. In this case, the characters' animations were looped until such a time as the narration excerpt assigned to them would finish. The overall animation of the characters to be used in all scenes was thus created. For the prototype module, all the others animations had to be created, too. These would be different from one scene to another and would represent to heaviest time-labour investment.

### Integration and programming

Several different 'movies' (Director files) were easier to manage than one gigantic file, especially since there could be up to three team-members working on the application at the same time. Director applications also obligatorily work with at least one file called the 'shared cast', which became necessary to any one developing any one of the modules. This 'shared' file would contain the elements common to all the 'movies' which would constitute the entire application. It was time to start up each of the different movies which were needed by the application. It was also time to flowchart the entire structure of the application so it would run smoothly, as one file. Scene one would link to Scene 2, and so on. It seemed clumsy to have one scene lead into another without a segue, so a new movie, called 'Transit', was created. Different parts of 'transit' would link one scene to another. For instance, the first part of transit would link Scenes 1 and 2: scene 1 ends on a 'Let's go' button which launches the voyage; the button activates a link to a label in 'Transit' which would play the part of that movie where the user can see the ship leaving earth and going into space; upon exiting this sequence of 'Transit', the application links to Scene 2, opening on the characters in the control room, dark space in the background. This movie, called 'Intro', contains Scenes 2 and 3. At the end of 'Intro', the application links to 'Transit', at a label where the ship can be seen moving on through space and eventually landing on the first stop-over planet. Upon exiting this sequence of 'Transit', the application links to Scene 4, opening on the characters in the control room, with a different, planet background. This movie, called 'NeedBMT', is Scene 4, where the characters talk about the need for a bone marrow transplant. This is where the user is finally presented with a choice of question buttons. The linking goes on along the same lines. A last movie, called 'Aloha', was added at the end: we see the ship go back to earth, and the credits are then displayed. See Appendix M, Flowcharts for each of the movie/scenes.

## Further evaluation within timeline of development

### Learner verification/Formative evaluation of CD-ROM

A learner verification/formative evaluation of the application before it was burnt onto a test CD-ROM was conducted, June 10-13, mostly for debugging and navigation clarification. The participants were two adults who had not seen the project in any of the previous stages. One was an educational technology graduate student and the other was an automation engineer. Results may not have brought much validity, since the participants were adults and also biased (highly technology-literate people, unlike some of the children who may end up using the CD-ROM), but will be reported nonetheless.

### Learner verification pilot/Formative evaluation of CD-ROM

A pilot for the learner verification/formative evaluation of the application to come was conducted, June 21, with the test CD-ROM. The participant was a 14 year old boy, and though not a cancer patient himself, the brother of a neuroblastoma patient. Client approval by the president of the Lamplighters also took place on June 21.

The rest of the evaluation (post-production) as well as during production will be explained in more detail in Chapter 4.

# Chapter 4: Evaluation

This chapter details the evaluation of the CD-ROM project. Formative evaluation efforts were incorporated into the analysis, design and development phases, between March and June 1996, as mentioned before (concurrent evaluation). The post-production evaluation process, conducted after thelast buurning of the CDROM, took place sporadically over 8 months, from October 1996 to May 1997. These efforts all described here, after a literature review of formative evaluation.

## Concepts

### Formative evaluation of computer-based patient education

#### Formative evaluation in educational technology

Broadly speaking, educational evaluation is a "formal appraisal of the quality of educational phenomena" (Popham, 1988, p. 7), in other words, of its effectiveness in reaching its objectives, in affecting knowledge, attitudes and/or behaviour -- something that is not unheard of in health education.

Borich and Jemelka report that Stufflebeam et al. defined educational evaluation as "the process of delineating, obtaining, and providing useful information for judging decision alternatives" (Stufflebeam et al., 1971, quoted in Borich and Jemelka, 1982). Arguably, in this process a second objective is fulfilled: that of finding ways to improve the design.

Cambre attributes the origin of the term, and its differentiation from 'summative evaluation' to Scriven, stressing that formative evaluation is so called because it happens during the "developmental or 'formative' stages" (Cambre, 1981, p. 3). She makes sure, however, to clearly trace the origin of the practice to the 1920s, back to the early days of the use of audio-visual instruments for educational purposes. Recalling the earliest efforts to conduct a formative evaluation, Cambre maintains that the tools used for its purposes can be traced back to Lashley and Watson and their methodology for evaluating educational films, such as expert judgment, target audience tests, and interviews (Cambre, 1981).

Most influential, perhaps were film appraisal checklists such as the checklist developed by Devereux in 1933 for Educational Research Products Inc. It used a semantic scale of five points that ranged from 'excellent' to 'objectionable' rating major areas of concern from objectives, content and technical concerns to how effective the movie was (idem). This is not unlike the typical 7-point semantic scale and 5-point Likert scale instruments being used in most evaluation and assessment situations nowadays.

Dick and Carey elaborate further and include in their definition the notion of classical educational evaluation models. They make sure to point out what formative evaluation features which other types of educational evaluation do not, namely that formative evaluation:

- is conducted during the development of instruction;
- is undertaken for the purpose of refining the instruction;
- includes the collection and interpretation of learner performance data (Dick and Carey, 1991, p. 261).

In a rapid prototyping context, research and design co-exist as "processes [that] do not occur in a linear fashion" (Tripp and Bichelmeyer, 1990, p. 36). See Figure 8 below.

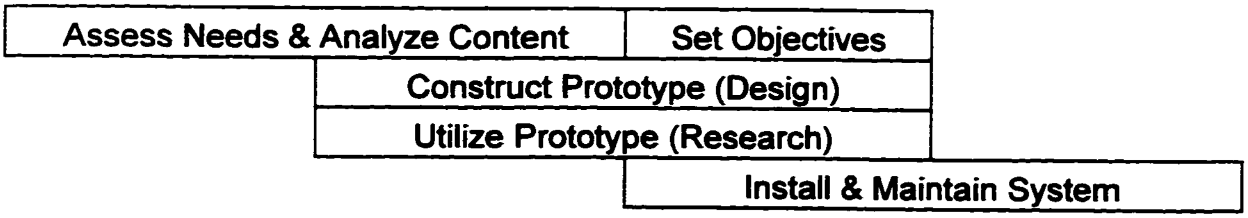


Figure 8 - The Rapid Prototyping ISD Model (Tripp and Bichelmeyer, 1990)

Tripp and Bichelmeyer are not the only proponents of this approach. They quote Reigeluth as suggesting that a sound theory for developing educational technology products should not keep research and design from happening at the same time.

Flagg (1990) is another proponent of the concurrent approach whereby phases of program development are paralleled with phases of evaluation. Her model, as follows, seems to make a more formal distinction between research and evaluation:

| Phases of Product Development | Phases of Evaluation |
|---|---|
| Phase 1: Planning | Needs assessment |
| Phase 2: Design | Pre-production formative evaluation |
| Phase 3: Production | Productive formative evaluation |
| Phase 4: Implementation | Implementation formative evaluation/<br>Summative evaluation |

### Multimedia evaluation

Northrup agrees, quoting the approach proposed by Flagg (above), especially in the context of multimedia evaluation (1995). She further proposes guidelines for formative evaluation and data collection criteria, including guidelines for participants to involve at each stage, recommended strategies for gathering data and the type of information to be gathered, particularly the various multimedia components and attributes discussed earlier in Chapter 2. They are summarized in the following table, and within the full analysis-development cycle:

| **Guideline** | **Group involvement** | **Data collection strategies** | **Information to be gathered** |
|---|---|---|---|
| ANALYSIS<br>Review findings with customers to verify correctness | SMEs, key stakeholders, policy makers | INTERVIEWS<br>one-to-one<br>two-to-one<br>panel discussions<br>focus groups<br>mass mailouts | Findings with:<br>• accuracy<br>• currency<br>• relevance<br>• comprehensiveness<br>• lack of bias |
| DESIGN<br>Create a rapid prototype of design approach | customers, key stakeholders, end users | think-aloud protocol | • attitudes regarding approach<br>• metaphor<br>• screen layout and design<br>• button placement<br>• colour<br>• font<br>• general interactivity<br>• user interface |
| Conduct paper-based content evaluation | key stakeholders, SMEs | guidelines for review instrument or checklist<br>written feedback directly on instructional strategies | • content<br>• accuracy<br>• currency<br>• relevance<br>• comprehensiveness<br>• lack of bias |
| Conduct a storyboard evaluation | target audience | one-to-one by interacting with user using paper-based or computer-generated storyboards<br>complete assessment sequence | • clarity of information instructional strategies and procedures<br>• logic<br>• currency<br>• accuracy<br>• relevance<br>• ease of use<br>• lack of bias |

Table 13. Concurrent formative evaluation and data collection criteria (adapted from Northrup, 1995)

| Guideline | Group involvement | Data collection strategies | Information to be gathered |
|---|---|---|---|
| DEVELOPMENT<br>Conduct a prototype evaluation | target audience | small-group try-out | • user performance-prototype assessment, paper/pencil task, online questions, problem-solving, or some authentic measure<br>• attitude-questions about the product itself: navigation, clarity, learner-control |
| Conduct a product evaluation | target audience | instrument to measure organizational data | • user perceptions of instructional, technical and cosmetic adequacy including:<br>• motivation<br>• interactivity<br>• learner control<br>• user interface<br>• screen layout |
|  |  | outcome data, field trial | • confirmatory user performance and attitudes |

Table 13. Concurrent formative evaluation and data collection criteria (Continued) (adapted from Northrup, 1995)

Preece et al. (1993) provide a more precise definition of formative evaluation when it applies to multimedia. The term they use is that used in the software industry - usability testing or; "gathering information about the usability or potential usability of a system in order to improve features within an interface and its supporting material, or to assess a completed interface" (p. 108).

Nelson (1990) believes the objectives of multimedia evaluation depend on the quality he names 'virtuality', i.e. the conceptual structure and feel. The evaluation must then be concerned with:

- gauging if the end user understands the structure and its elements, as well as determining if this information is clear and useful to them;
- checking that the overall feel as well as details of the design are pleasing and easy to use.

### Evaluation in Health education

As mentioned before, health education seeks to: improve the learners' knowledge and/or attitudes; to improve their health behaviour; to improve their health status. Evaluative studies are necessary to measure this improvement. Types of evaluative studies are reviews or trials. Designs can broadly be divided into 2 types: descriptive and causal. Descriptive designs are characteristic of reviews - which focus on making decisions about interventions, regarding necessary modification, renewal and discontinuation. Causal designs are characteristic of trials, which seek to generalize findings to other programs and interventions. The objects and purposes of evaluative studies are: diagnostic, formative and summative. Formative evaluation is conducted in the process of intervention to gauge effectiveness in reaching objectives and make modifications as needed. It does not seek to generalize findings so much, therefore they are more descriptive in nature. Approaches to conducting formative evaluation are: process, impact, and outcome. The process approach looks at the effectiveness of the implementation of the intervention itself. The impact approach looks at changes in knowledge, attitudes and behaviour and generates more tangible measures of the effects of the intervention. The outcome approach uncovers the reason for these changes in knowledge, attitudes and behaviour and how these are reflected in indicators of health status. The use of formative evaluation in health education can ensure that interventions are more effective (Abramson, 1979, Baggaley, 1988, Glanz, et al., 1991, Greene, 1984, Turner et al., 1989). The preferred model is a thus a descriptive design, or review, which takes an impact approach, to evaluate whether changes in knowledge, attitude or behaviour have occurred

### Evaluation of attitudes about illness

Knowledge and attitude are the two elements of the KAB equation which seem most often to be the object of study when an educational intervention is assessed. Standardized instruments also seem to often be used in studies where, among other variables, patients' attitudes and feelings (e.g. anxiety level) and locus of control are evaluated.

Beisecker et al. (1994) administered the Beisecker locus of authority in decision making in a breast cancer survey of 67 oncologists, 94 oncology nurses and 288 patients from a women's clinic. Results showed that while all participants believed that physicians should have a dominant role in decision making, nurses seemed to think that patients should have more input than patients themselves or physicians felt they should.

Walker et al. (1990) used the PARS III (Personal adjustment and role skills scale) to assess the psychosocial adjustment of children suffering from chronic physical illnesses (orthopedic conditions, etc.) but no mental nor cognitive impairments. The instrument comprises 28 items, divided into six areas, among them dependency, and tendency to anxiety-depression. They concluded that their study provided evidence that the PARS III can be used successfully to assess psychosocial adjustment of children with chronic illnesses and no cognitive impairments.

De Weerdt et al. (1989, 1996) used the State Trait Anxiety Inventory and Multidimensional Health Locus of Control Scale for diabetes for two studies. The 1989 one - education program for insulin treated patients with diabetes, designed to improve the level of active self-care behavior of the participants - surveyed over 500 adult diabetes patients from 15 hospitals. Those in the experimental groups completed the program under the guidance of a health care professional or a fellow patient. The control group completed the program on their own.

Through the use of the Multidimensional Health Locus of Control Scale for diabetes, they were able to ascertain that diabetes locus of control improved significantly among the experimental groups.

Standardized instruments may provide more reliable results, but they also require large numbers of participants which will provide sufficient numbers to account for that reliability. Does this suggest that a standardised instrument is a must, especially when one attempts to assess change in attitudes and anxiety?

It seems that one can conclude something with relatively small numbers of participants, and no apparent use of standardized instruments. Bordieri et al. (1992) surveyed 32 individuals with cancer who were asked to rate 15 psychosocial needs in terms of importance to themselves. Their family members (n=41), oncology nurses (n=45), hospital social support staff (n=40), and rehabilitation counselors (n=41) were also asked to rank those needs. Differences were reported among groups in nine need areas indicating that perceptual discrepancies existed.

A lot of projects also only include subjective patient evaluation of lesson effectiveness, including comments from patients to computer-generated evaluation questions. A few projects also include outcome measures (Chan, 1992, Ellis , 1985, Petersen, 1996).

### Formative evaluation procedures and models

Smith and Ragan report suggested procedures and models by Dick and Carey:

- design review;
- expert review;
- one-to-one;
- small group.

These are the data collection strategies described in Table 13 (Northrup, 1995), above.

Stake's Countenance model (pretest - treatment - posttest) is a commonly used, formal model. According to Borich and Jemelka's discussion of decision-oriented models, Stake's early work draws on the tradition of educational psychology models. Its methodology is straightforward and consists of:

- identifying objectives
- stating objectives in measurable behavioural terms
- devising and administering measurement instruments
- comparing obtained results with the pre-specified objectives (Stake, 1967, quoted in Borich and Jemelka, 1981, p. 7).

Another model heavily inspired from educational psychology is Provus' Discrepancy model (1971, in Borich and Jemelka, 1981). It consists of "before and after", or multiple products, comparisons. This approach is quite reminiscent of classical measurement, where both control and experimental groups are used.

Newer, more flexible models have emerged in recent years which take a more global view. These are reminiscent of ethnographic models used in anthropology. They are holistic approaches that are as free of judgment as possible. Two basic types of methods are available to the evaluator: interactive and non-interactive. Interactive methods include participant observation, interviews with key informants and surveys. Non-interactive methods include nonparticipant observation, consulting documents and archives (extant data analysis) and artifacts analysis (Popham, 1982, Ott, 1989).

The Center for Disease Control's model, too, is quite liberal and flexible. It states that formative evaluation can happen at any stage and feed forward or back at any moment during the production cycle: concept development, concept testing, message and materials development, draft message and/or channel testing.

Other proponents of formal models of evaluation have also made distinctions between approaches. Dick and Carey (1991) suggest three: one-on-one, small group and large group. Each has a different purpose. One-on-one evaluations serve to approximately measure the effectiveness and clarity of the instruction for the individual learner. Small group evaluation chiefly provides the first idea of how learners are likely to perform and react to the instruction. It will also give a real-world test with regards to feasibility. Finally, large group evaluation will confirm the performance, attitudinal response to, and feasibility of the instruction once it is implemented. Cambre also makes a distinction between "expert opinion ('appraisal') and student performance ('learner verification') as sources of evaluation data" (1981, p.4)" - or what most instructional design and human performance technology practitioners refer to as subject matter expert review and/or validation, and one-on-one, small group or field testing.

One can conclude that there are no fast, hard rules when it comes to choosing a model for formative evaluation. There are a few good rules: a model should be chosen according to the preference of the practitioner and to how appropriate it is for the given situation. One constant where thoroughness must be demonstrated, however, is the gathering of data. After all, the fact remains that objectives (change in knowledge, attitude or behaviour) should be measurable in order to determine the product's effectiveness.

## Formative evaluation techniques and criteria

### Methods and tools for multimedia evaluation

The different methods and tools for multimedia evaluation include: self-report instruments (continuous reaction/think-aloud protocol, questionnaires, interviews, two-on-one evaluation, computer interviewing, self-evaluation (Flagg, 1990, Tessmer, 1994); panel reviews (Tessmer, 1994); tests and observation (Flagg, 1990); storyboards and prototypes (Northrup, 1995 - see Table x, above).

Preece et al. (1993) recommend among others:

- observational evaluation (observing end-users using an interface/application, taking notes on navigation and performance, sometimes timing);
- software logging, or 'tracking' (used to record timed log of end-user interaction with the interface, has the advantage of being unobtrusive);
- verbal protocols, such as think-aloud protocol (video or audio recording of end-user's spoken observations and thoughts while she interacts with the interface);
- survey evaluation (probing for end-users' opinions, mostly through interviews).

Preece et al. (1993) identified interviews as survey tools. There are two types:

- structured interviews, with a set sequence of predetermined questions, such as public opinion surveys. These instruments do not provide much option for probing individual attitudes;
- flexible interviews, with a few set topics but no set sequence. These instruments provide for individual attitudes, leaving the field wide open for diversion from set topics, based on end-users' responses.

### Guidelines for the evaluation of patient education software

Posel established software evaluation guidelines specifically designed for nursing staff called the 'Hospital Oriented Instructional Software Evaluation' guidelines (1993):

- Identification: title, author, publisher, price;
- Product description: type (tutorial, drill or simulation), duration, purpose (inservice, client teaching, orientation, continuing education), similar material already available in-house, target audience(s), stated objective(s);
- Hardware: hardware requirements, network capabilities, specification of present hardware status in-house, discrepancies and comments;
- Software / technological overview: appropriate use of instructional strategies, foolproofness, record-keeping facilities if necessary, provision of lesson control options or user control, ease of use, security procedures, freedom from programming bugs;
- Software / system information: visual appeal, resolution and clarity, animation, graphics / grain size, pacing, step size, sound / audio, back-up policy, warranty, preview and update policy, support after purchase, site licensing;
- Nursing specifications: use of nursing theory in content presentation, incorporation and support of nursing philosophical objectives;
- Content: accuracy, comprehensiveness, currency, organization, relevance, validity, assessment of objectives and outcomes;
- Instructional design and strategies: description of software, incorporation of teaching and learning principles relevant to the type of package and audience;

- Plan for assessment of effectiveness: facility for student evaluation included within the program;
- Final evaluation: limitations, support maintenance required, overall assessment, potential uses, special considerations, recommendations, date of next review.

(adapted from Posel, 1993, pp. 274-5)

### Rationale for evaluation

The evaluation efforts for this project were three-fold:

- learner verification;
- expert review;
- design review.

#### Learner verification

The main goals of the learner verification were to evaluate acquisition of knowledge and evaluate attitudinal change with end-users. This procedure is typically conducted to gauge the effectiveness of an educational intervention. To this end, it was worthwhile looking into some literature which investigated attitudes and locus of control towards illness, especially dealing with cancer or children. 'The BMT Voyage' also being a multimedia piece, it became important to conduct usability testing as well, to see if the users felt comfortable with the interface, the navigation and reacted well to the technical design (quality of animation and sound, etc.), in other words, this part of the evaluation was concerned with the CD-ROM's 'virtuality' (Nelson, 1990).

#### Expert and design reviews

To further assess effectiveness, as well as to determine overall quality of the product, expert reviews and a design review - to assess the extent to which implications for design that came to light after an examination of relevant literature were incorporated into the actual design - were conducted.

##### Aspects evaluated

The application, in all of its stages, needed to be reviewed through this three-fold approach to check on each of these four major aspects of the application:

Technical:
- user attitudes/perceptions of technical and cosmetic adequacy including:
  - interactivity
  - learner control
  - user interface
  - metaphor
  - screen layout and design
  - button placement
  - colour

Pedagogical:
- user attitudes/perceptions of instructional adequacy including:
  - clarity of information, instructional strategies and procedures
  - logic
  - accuracy
  - relevance
  - ease of use
- user performance assessment

Medical:
- content
- accuracy
- currency
- relevance
- comprehensiveness

Psychosocial:
- change in user attitudes (toward treatment, reduced anxiety, etc.)
- assessment by professionals (adequacy, accuracy, etc.)

Table 14 - Aspects evaluated during post-prodution evaluation

Particularly in the case of the four end-users with whom the CD-ROM (post-production) was evaluated, the author was seeking to find out as many of the criteria listed below:

**1 - Current state of health**

**2 - Affective assessment**

Attitude

- tendency to anxiety-depression
- anxiety level (for both patient and family)
- dependency
- health locus of control
- sense of control over the BMT process
- sense of control over the illness

Psychosocial adjustment

- feelings with regards to peers
- feelings with regards to hospital staff
- feelings with regards to hospitalization
- feelings with regards to family (parents and siblings)
- feelings with regards to mortality
- feelings with regards to unknown
- feelings with regards to isolation
- feelings with regards to 'special status'
- feelings with regards to treatment

**3 - Knowledge assessment**

Previous experience

- with computers
- with CD-ROM's and multimedia (e.g. Web)
- with cancer and its treatment (from patient education received through experience and nurses)

Comprehension of content

- conceptual understanding of illness causation
- conceptual understanding of treatment and effects on illness
- conceptual understanding of treatment and effects on physical appearance
- level of language
- appropriateness of graphics
- conceptual understanding of content
- conceptual understanding of narrative approach
- accuracy of content

**4 - Reactions to CD-ROM**

Enjoyment

- weaknesses
- strengths
- suggestions for change

Ease of navigation

- navigational path
- confusion/difficulty with interface
- metaphor (planets - chapters, space voyage, ship)

**5 - Modified behaviour**

- compliance with therapeutic regimen, including cooperation with health care providers in treatment (younger children can identify painful side-effects of some treatment with the nurse i.e. the administrator of the treatment)
- decreased postoperative complications and reduction of hospitalization time
- enhanced, active self-care behavior

Table 15 - Post-production evaluation criteria, end-users

## Methodology

### Participants

Expert reviewers (medical and para-medical professionals) and end-users for learner verification who participated in the evaluations which took place during the design and development included:

| # | Participant group |
|---|---|
| 1 | Multidisciplinary team (3 child life specialists, 6 ward and clinic nurses, oncology head nurse, hematologist, hospital teacher) |
| 2 | Former BMT patients and their families (a 13 year-old boy and his mother, and; an 11 year-old boy and his father, mother and older, donor brother) |
| 3 | Oncology head nurse, hematologist, clinic nurses |
| 4 | Educational technology graduate student and an automation engineer |
| 5 | Fourteen year old boy, and though not a cancer patient himself, the brother of a neuroblastoma patient |
| 6 | President of the Lamplighters |

Table 16 - Concurrent Evaluation Participants

Participants for the rest of the evaluation, after June 1996, included the following medical and para-medical professionals, educational technology professionals and end-users:

| **#** | **Participant group** |
|---|---|
| 7. | Head of Audio-Visual, Montreal Children's/Montreal General Hospitals and Senior Audio-Visual technician, Montreal Children's Hospital; |
| 8. | Over 15 persons who ranged from being Lamplighters members, Montreal Children's Hospital staff as diverse as student nurses, nurses, child life specialists, the hospital teacher, a psychiatrist, the head of hematology, MCH public relations head, patients and their parents; |
| 9. | Staff psychiatrist at the Hospital for Sick Children in Toronto; |
| 10. | Over 11 educational technologists who were part of the crowd to whom the design team presented the CD-ROM during a symposium session; |
| 11. | Four children ranging in age from 6 to 11, both non-patient and patients, and their mothers, including an educational technologist specialising in instructional design; |
| 12. | Professor of educational psychology at McGill University specialising in applied cognitive science; |
| 13. | Three educational technology/ training specialists who interacted with the CD-ROM at a technarium/trade fair during a local professional conference. |

Table 17 - Post-production Evaluation Participants

### Design

The team tried to conduct concurrent formative evaluation, which took place after different stages of the design and development phases, as outlined previously in Chapter 3.

After client approval, copies of the CD-ROM were burnt and the team did not change anything to the application anymore. From this point on, the author conducted post-production formative evaluation, in the eventuality that modifications would be brought to the application, were the client to choose so.

See Tables x - Concurrent Formative Evaluation During Design and Development, and x - Post-Production Formative Evaluation, for cross-referenced lists of designs, techniques, participants and instruments, used in each of the evaluation efforts.

### Constraints

The evaluation efforts were never meant to be clinical trials or truly experimental designs. In fact, most of them belong to 'qualitative' kind of research, and the author believes these to be the most common way to conduct evaluation in practice, within the context of multimedia development. Perhaps invoking practicality is futile, or the point cannot be made. Most of the instruments used in these evaluation efforts were not standardized instruments. Standardized instruments simply did not fulfill the needs of the author, nor - in the case of end-user evaluation - was the sample large enough to warrant the use of a standardized instruments, such as the PARS III or Trait Anxiety Inventory. Most instruments were thus created for the specific purposes at hand. They were not put through rigorous checks for validity or reliability. Nonetheless, it was the intent of the author to draw up instruments and procedures which would reliably and validly gauge changes in knowledge and attitudes and otherwise achieve the objectives sought by the particular evaluation effort.

| Stage | Group involved | Design | Technique/instrument | Aspect(s) to evaluate |
|---|---|---|---|---|
| 1. Instructional content and organization | 1 | -- | Expert review, paper-based initial script and guidelines for review, focus group and flexible interview | medical, psychosocial |
| 2. Storyboard and script | 2 | -- | Learner verification, small-group, pre-selected portions of paper-based storyboard and semi-structured interview | pedagogical, medical, psychosocial, technical |
| 3. Storyboard and script | 3 | -- | Expert review/validation, paper-based revised script, full storyboard and guidelines for review | medical, psychosocial |
| 4. Formative evaluation of CD-ROM | 4 | one-shot case study | Learner verification/navigation, one-to-one direct observation and think-aloud protocol | technical |
| 5. Formative evaluation of CD-ROM | 5 | one-shot case study | Learner verification pilot, one-to-one direct observation and think-aloud protocol | pedagogical, medical, psychosocial, technical |
| 6. Formative evaluation of CD-ROM | 6 | -- | Client approval, one-to-one direct observation and think-aloud protocol | pedagogical, medical, psychosocial, technical |

Table 18. Concurrent formative evaluation during design and development

| Stage | Group involved | Design | Procedure/instrument | Aspect to evaluate |
|---|---|---|---|---|
| 7. Formative evaluation of CD-ROM | 7 | -- | Expert review, small group direct observation and think-aloud protocol | technical |
| 8. Formative evaluation of CD-ROM | 8 | one-shot case study | Expert and learner review, client approval, small group direct observation and semantic differential scale questionnaire | medical, pedagogical, psychosocial, technical |
| 9. Formative evaluation of CD-ROM | 9 | -- | Expert review, one-to-one open interview | psychosocial |
| 10. Formative evaluation of CD-ROM | 10 | -- | Expert review, small group semantic differential scale questionnaire | pedagogical, technical |
| 11/1. Formative evaluation of CD-ROM | 11 | one group pretest-posttest | Learner verification, one-to-one flexible interview, direct observation and think-aloud protocol | pedagogical, medical, psychosocial, technical |
| 11/2. Formative evaluation of CD-ROM | 11 | -- | Expert review, one-to-one semantic differential scale questionnaire, flexible interview | pedagogical, technical |
| 11/2. Formative evaluation of CD-ROM | 11 | one group pretest-posttest | Learner verification, small-group flexible interview, direct observation and think-aloud protocol | pedagogical, medical, psychosocial, technical |
| 11/3. Formative evaluation of CD-ROM | 11 | one group pretest-posttest | Learner verification, small-group flexible interview, direct observation and think-aloud protocol | pedagogical, medical, psychosocial, technical |

| Stage | Group involved | Design | Procedure/instrument | Aspect to evaluate |
|---|---|---|---|---|
| 12. Formative evaluation of CD-ROM | 12 | case study | Expert review, one-to-one flexible interview | pedagogical, technical |
| 11/4. Formative evaluation of CD-ROM | 11 | one group pretest-posttest | Learner verification, small-group flexible interview, direct observation and think-aloud protocol | pedagogical, medical, psychosocial, technical |
| 13. Formative evaluation of CD-ROM | 13 | case study | Expert review, small group and one-to-one semantic differential scale questionnaire, flexible interview | pedagogical, technical |

Table 19. Post-production formative evaluation

Likewise, it seems silly to mention Campbell and Stanley inspired classical threats inherent to pre-experimental designs. The efforts were often haphazard: the author had to seize the opportunity and conduct evaluation when she could. Threats include: convenience sampling, and self-selection - again, not unlike real-world practice. Undeniably, random selection of participants and their random assignment to different conditions were not only unfeasible - they were quite simply silly objectives to attain.

However, the author feels compelled to mention constraints on the pre-experimental designs used in the evaluation efforts, according to Campbell and Stanley. With the one-shot case study, the threats of history, maturation, selection and mortality, as well as the interaction of selection and the treatment are distinct possibilities. With one-group pretest-posttest designs, the threats to validity include the ones mentioned above, safe for selection and mortality . They also include those of instrumentation and interaction of testing and the treatment.

The author considers these to be minor. Reservations about the results she obtained will be discussed in the conclusion. Moreover, the lack of comparison with a control group - typically not receiving the treatment or receiving it through a different media - is perhaps moot. Clark (1992) maintains that most evaluations of technology-based instruction, such as multimedia-based and computer-based learning and training packages, are poorly designed because of general failure to control three common confounding variables: the use of different instructional methods in different treatments; the presentation of different content in different treatments; and the novelty of new media, which tends to increase interest, motivation, and persistence for a relatively short period of time after its introduction to learners. The author would most likely have fallen into one of these traps, had she planned for control groups.

Yet, examples of such approaches seem to abound in patient education. Concoli and Jean (1994) determined that, ISIS, their patient education computer program about hypertension, improved knowledge about hypertension among the patients out of a sample which were assigned to the experimental group. The acquisition of knowledge was measured by a retention test. The control group received the treatment through 'the habitual educational techniques', hence the possibility of presentation of different content in different treatments. Moreover, the experimental group received the 'habitual' treatment <u>and</u> the computer program treatment! Needless to say, improved retention of knowledge often results from repeated exposure to a given educational intervention.

Horan et al. (1990) reported statistically and clinical significantly changes in the behaviour diabetic adolescents in their study comparing CBT vs. conventional conditions. We face, again, the possibility of presentation of different content in different treatments. Note that clinical significance was observed. Would the nurse be right in opting for the CBT because of its apparent effectiveness, vis-à-vis the conventional methods, if the results could be considered possibly invalid?

The author had no other educational intervention, conventional or otherwise to compare the CD-ROM to. The sole concern was whether this tool was effective or not.

### Instruments

Most evaluation instruments were developed expressly for their given purpose (e.g. the guidelines for review which accompanied the two versions of the script given to the Montreal Children's Hospital for review, etc.).

The only instrument which generated quantitative data was the semantic differential scale questionnaire used in evaluations 8, 10, 11 and 13. Altogether, 32 participants filled out the questionnaire during these four evaluation efforts. The participants could further be divided into three categories for analysis purposes: medical and para-medical professionals; patients and support system; educational technology / training professionals.

Instruments and techniques which generated qualitative data were:

- flexible and semi-structured interviews (one-to-one, small group, focus group), with a few set topics but no set sequence. These instruments provide for individual attitudes, leaving the field wide open for diversion from set topics, based on end-users' responses (Preece et al., 1993);
- paper-based initial and revised scripts, storyboard, and guidelines for review;
- direct observation and/or think-aloud protocol (one-to-one, small group);
- navigation chart.

### Procedure

To assess end-user reaction to the application, an impact approach was primarily needed. In health education terms, an impact approach looks at changes in knowledge, attitudes and behaviour and generates more tangible measures of the effects of the intervention (Greene, 1984). The procedures for the different instances of evaluation are described one by one in this section.

## Concurrent evaluation procedures

### 1. Expert review/formative evaluation of initial content (April 9-15, 1996)

An extensive review of the initial content brought the multidisciplinary team together at the Montreal Children's Hospital into an extraordinary meeting (3 child life specialists, 6 ward and clinic nurses, oncology head nurse, hematologist, hospital teacher) shortly after content identification, to make sure the design team had understood the scope and breadth of information a patient would benefit from (medical and psychosocial aspects). The members of the team were given the paper-based initial script with guidelines for review a few days before a focus group meeting. They were left to do this individually, on their own time. The meeting was then held to gather their impressions and opinions within the context of a flexible interview, guided by extra questions to further clarify doubts of the design team.

The meeting was held with almost all, on the oncology ward floor. The answers were mostly provided by Dr. Koch. One child life specialist and one assistant head ward nurse were not there, but filled out the questionnaire and sent it to the team after the meeting.

### 2. Learner verification/Formative evaluation (May 9-11, 1996)

Two learner verifications were conducted from May 9-11 with 2 former BMT patients and their families (a 13 year-old boy and his mother, and an 11 year-old boy and his father, mother and older, donor brother) to gauge the level of language, appropriateness of graphics, conceptual understanding of content and strategies, story-telling concept, accuracy of the content, and effectiveness of the spaceship/voyage metaphor (pedagogical, medical, psychosocial, and technical aspects). This was conducted small-group style, with pre-selected portions of the paper-based script storyboard and semi-structured interview. Members of the family were present to give background information to the design team and relate anecdotes. One was done at the clinic, while the other was held in the home of one the designers.

### 3. Expert review/validation of storyboard and script (May 6-13, 1996)

This review was done with the help of the head nurse, a few clinic and ward nurses and a hematologist to validate the revised version of the script and accompanying graphics (medical, psychosocial aspects) as well as the storyboard. They were given this with guidelines for review (see Appendix x). They were left to do this individually, on their own time. A few days later, the author collected the completed questionnaires and annotated storyboards.

### 4. Learner verification/Formative evaluation of CD-ROM (June 10-13, 1996)

A learner verification of the application was conducted before it was burnt onto a test CD-ROM, mostly for debugging and navigation clarification (technical aspect). The participants were two adults who had not seen the project in any of the previous stages. One was an educational technology graduate student and the other was an automation engineer. They were left free to navigate the application and were encouraged to give their opinions. Both came to the university lab where the CD-ROM was being developed, on separate occasions. The procedure utilised was one-to-one direct observation with a think-aloud protocol.

### 5. Learner verification pilot/Formative evaluation of CD-ROM (June 21, 1996)

A pilot for the learner verification of the application to come was conducted with the test CD-ROM. The participant was a 14 year old boy, and though not a cancer patient himself, the brother of a neuroblastoma patient. He was left free to navigate the application and was encouraged to give his opinions (pedagogical, medical, psychosocial, and technical aspects). The procedure used was one-to-one direct observation with a think-aloud protocol, and it took place at the university laboratory where the application was developed. This learner verification was totally open.

### 6. Client approval/Formative evaluation of CD-ROM

Client approval by the president of the Lamplighters also took place at the university lab on June 21. The procedure, again, was one-to-one direct observation and think-aloud protocol.

## Post-Production evaluation procedures

After copies of the CD-ROM were burnt, other expert reviewers were typically given a short introduction to the CD-ROM, its objectives and raison-d'être. They were then shown the CD-ROM and sometimes left free to navigate it as an end user would. They were also left free to comment in an open interview, or were given a questionnaire (see Appendix N) to fill out and were finally engaged in a semi-structured interview based on their answers to the questionnaire. In the case of presentation to groups of experts, they were only asked to fill out the questionnaire: in one case, qualitative observation of navigation and reaction was made (group # 8, presentation to the Montreal Children's Hospital). A much more structured approach was used with end users, typically mixing the use of the questionnaire, the use of a semi-structured interview and free navigation of the CD-ROM with annotated observation of use of application and navigation.

### 7. Expert review/technical (November 1, 1996)

The author took the CD-ROM to the Montreal Children's Hospital Medical Library to ensure that it would run smoothly on the computer which would be used for the presentation of the CD-ROM to the staff and patients of the Hospital. While the dry-run was being made, the head of the Montreal Children's/Montreal General Hospitals AV departments, as well as his senior technician at the Children's looked on and made comments which pertained to the technical quality of the CD-ROM. As it happened, a small group direct observation and think-aloud protocol took place unexpectedly.

### 8. Expert and learner review/client approval (November 29, 1996)

The presentation of the CD-ROM to Montreal Children's Hospital brought together over 15 persons who ranged from being Lamplighters members, Montreal Children's Hospital staff as diverse as student nurses, nurses, child life specialists, hospital teacher, psychiatrist, head of hematology, public relations, patients and their parents, etc. The computer and CD-ROM were on display for all to interact with in a meeting on the floor of the temporary oncology ward (renovations were being made to the original floor by then), for about three hours. People dropped by and took turns at navigating the application. Meanwhile, the author also took advantage of the occasion to conduct small group direct observation, looking especially for navigation difficulties. Throughout the three hours, fifteen semantic differential scale questionnaires were also filled out.

#### 9. Expert review (January 30, 1997)

In an effort to expand avenues for 'The BMT Voyage', the author and one of the design team colleagues took it to one of the staff psychiatrists at the Hospital for Sick Children in Toronto. Dr. Arlette Lefebvre is herself at the head of an effort to ameliorate quality of life for ill and disabled children, using information technology: a conferencing network called Ability Online. The CD-ROM was briefly presented to her, in her office. The setting was a one-to-one open interview, to assess psychosocial aspects of the CD-ROM. Dr. Lefebvre was in a hurry and made pertinent, if few, comments.

#### 10. Expert review (March 14, 1997)

During a presentation to educational technologists at a local education symposium, the CD-ROM was presented to the audience. One volunteer came up to the computer to navigate it at her will and let the rest of the audience look on. At the end of the presentation, the author asked people in attendance to fill out the semantic differential scale questionnaire which had been left on their chairs. Eleven questionnaires were filled out and returned. The author was looking for feedback on the pedagogical and technical aspects of the CD-ROM.

#### 11/1. Learner verification pilot (April 28, 1997)

A pilot for the learner verification of the CD-ROM was conducted. The participant was an 11 year old boy, and though not a cancer patient himself, well acquainted with the bone marrow transplant treatment. He was left free to navigate the application and was encouraged to give his opinions (pedagogical, medical, psychosocial, technical aspects). The procedure used was one-to-one direct observation with a think-aloud protocol, and it took place in his home, using a Macintosh LC 575 (68K processor, 2X CD-ROM drive, 14" colour monitor). This time, the author used a flexible interview approach, with a tentative script for later evaluations with end users. The procedure basically consisted in:

- asking the end-user: "You've been told you have to have a BMT: Do you know what a BMT is? Do you know what happens? What do you think? What do you feel? What do you want to know?";
- letting the end-user navigate the CD-ROM at will: timing the duration of the navigation; observing reactions and navigational path; telling the end-user to voice his opinions ('What you like, what you don't like, what you would change... don't be shy, just tell me!") as he navigates the CD-ROM;
- asking the end-user: "Now that you've looked at the CD-ROM, can you tell me: three things you learned; how you would feel about having a BMT."

Notes were taken by the author throughout the process. For reporting purposes, we will call him Alfred.

### 11/2. Learner verification (May 6, 1997)

From the pilot with Alfred, the author used the same loose script, but this time chose to audio-tape the evaluation, because taking notes while interacting with the end-user and observing him was too cumbersome. The author also decided to make a navigational chart for the same reason.

The learner verification of the CD-ROM proper started with a 6 year old boy. For reporting purposes, we will call him Dan. Dan was not a cancer patient himself, and although his grandmother passed away from cancer in the year preceding his participation in this evaluation, he had very little knowledge of the illness itself. He was left free to navigate the application and was encouraged to give his opinions (pedagogical, medical, psychosocial, technical aspects). The procedure used was a small-group (he was accompanied by his mother) flexible interview, direct observation and think-aloud protocol. Dan was timed, too, but the author asked him to stop after 20 minutes. One of the design assumptions was that children - especially younger ones - would lose interest after 15-20 minutes on the CD-ROM, hence the modularity of the stop-over's, and the restricted time for this 6 year-old. Furthermore, Dan was audio-taped. The evaluation took place at the university laboratory where the application was developed, on a PowerPC

Macintosh (PCI chip, 4X CD-ROM drive, 17" colour monitor). The author used a flexible interview approach, with the script from the pilot evaluation with Alfred.

#### 11/2. Expert review (May 6, 1997)

Dan's mother sat through the evaluation with her son and intervened every now and then, giving him some prompting. She also happened to be an educational technologist, specialising in instructional design. After the 20 minutes had gone by with her son, and after some questions asked of him, the author started querying the expert with the aid of the semantic differential scale questionnaire about various technical and pedagogical aspects. She, too, was audio-taped. Meanwhile, Dan kept on playing with the CD-ROM.

#### 11/3. Learner verification (May 13, 1997)

It was then time to evaluate the CD-ROM with an end-user more representative of the intended audience. Allison is an 11 year-old girl, a leukemia patient, undergoing treatment for her first relapse. She had been diagnosed with leukemia when she was 6 years old and was treated successfully. Her mother and sister have been tested, alas their bone marrow is no match for her. She is now in remission, but should she relapse a second time, she will have to have a bone marrow transplant.

Allison was accompanied by her mother during the evaluation. The setting was a small-group flexible interview, with direct observation and think-aloud protocol to gauge pedagogical, medical, psychosocial, and technical aspects. The same procedure was used as that with Dan, save for the timing: Allison was left free to navigate the whole CD-ROM, with no time constraints. Allison and her mother also filled out the questionnaire and made comments, as Dan's mom did. This evaluation took place at the Montreal Children's Hospital's Medical Library, using a multimedia Pentium PC-compatible running Windows 95 (6X CD-ROM drive, 15" colour monitor, sound card). Because this computer was located in a library, the author, Allison and her mother all had to wear earphones.

### 12. Expert review (May 14, 1997)

Another chance expert review happened while the author was demonstrating the CD-ROM for other purposes. Both pedagogical and technical aspects were quickly assessed by Dr. Suzanne Lajoie, professor of educational psychology at McGill University and renowned specialist in the cognitive aspects of computer-based instruction. The procedure consisted of a very spontaneous small group flexible interview (two graduate students/research assistants working with Dr. Lajoie sat in on the demonstration). This took place in Dr. Lajoie's McGill office, using a PowerPC Macintosh with a 15" colour monitor.

### 11/4. Learner verification (May 22, 1997)

The last of the end users was Marty, an 11 year-old boy and leukemia patient. He, too, was accompanied by his mother. Marty was diagnosed just at the end of 1996 and has been responding successfully to chemotherapy, although he was also scheduled to undergo radiation therapy when the author met him. The procedure was the same as with other end users (small-group flexible interview, direct observation and think-aloud protocol, evaluating pedagogical, medical, psychosocial, technical aspects), though the author forgot to bring the questionnaire and her interview script. The questions were asked to the best of her recollection. This situation also saw an added participant: a friend of the author's kindly came along with his PowerPC Powerbook (PCI-based laptop Macintosh, with colour 10" LCD display, 8X speed CD-ROM) so the evaluation may be held in a room of the hematology clinic, where Marty had to remain while he received blood transfusions.

### 13. Expert review (May 30, 1997)

The CD-ROM was once again presented to educational technologists in a trade fair setting at a local ISPI conference, May 30, 1997. The questionnaire was on hand for volunteers. The computer and CD-ROM were on display for all conference participants to interact with in a room adjacent to others where the conference was taking place, for about two hours. People dropped by and took turns at navigating the application. The author was too busy responding to inquiries to conduct any kind of direct observation, but throughout the two hours, three semantic differential scale questionnaires were also filled out, including one by Dr. Steve Yelon of Michigan State University.

### Data analysis

The only instrument which generated quantitative data was the semantic differential scale questionnaire. The scale allowed for descriptive statistics (frequencies, mean, medians and standard deviations) to be gathered, as well as mean comparisons according to certain classifying criteria (Chi-square test). The statistical analyses were made with the help of Minitab for Windows, version 10.

Instruments and techniques which generated qualitative data were:

- flexible and semi-structured interviews (one-to-one, small group, focus group);
- paper-based, initial and revised scripts, storyboard, and guidelines for review;
- direct observation and/or think-aloud protocol (one-to-one, small group);
- navigation chart.

Results obtained through these instrument are reported in the results section and help to interpret the quantitative data.

## Results

### Concurrent evaluation results and resulting modifications

#### 1. Expert review/formative evaluation of initial content (April 9-15, 1996)

Shortly after content identification, an extensive review of the initial content was conducted with the multidisciplinary team of the Montreal Children's Hospital (participant group #1 - 3 child life specialists, 6 ward and clinic nurses, oncology head nurse, hematologist, hospital teacher). The members of the team were given the paper-based initial script with an embedded questionnaire and guidelines for review. The filled-out questionnaires and transcripts from the meeting with the multidisciplinary team from the hospital are far too voluminous to annex to this report.

Many corrections were made for accuracy. The nurses and child life specialists, especially, also provided many anecdotal suggestions and made their content modifications in narrative, as if addressing a child (no explicit instructions had been given to them concerning this).

One of the areas which received the most comments for corrections and additions was the section about the preparative regimen, specifically, the effects of chemotherapy on the blood system. The nurses set the team straight on the nature of bone marrow stem cells, as well as the function of white blood cells. The section about the actual transplant also received attention, especially concerning the infections and accompanying fever which patients often suffer after receiving the new marrow.

The waiting period after the transplant also got many corrections, as it turned out to be the longest, with 8 questions. Almost all evaluators pointed out that the team's use of 'immune system' was probably inappropriate for the children targeted by the CD-ROM. They all suggested using 'blood counts' instead, which refers to the print-out which the patient and her parents receive every morning. Most BMT patients would already be familiar with their 'blood counts', because they receive them also during prior treatment (chemotherapy before BMT is recommended). Another segment which drew a lot of comments was that concerning visits of siblings. The team had understood that siblings aged 10 and over could visit the patient in the BMT unit. This was corrected to no one under 12 years of age, and only healthy ones. One question in the original document was going to allude to the issue of mortality ("What's happening to my friends from the clinic?"), but was dropped entirely as the general reaction was one of disapproval. Most evaluators thought it inappropriate: they believed that the parents should address this issue with their child, only if they wished so.

The meeting also provided a forum for feedback on this initial effort. The author conducted a focus group interview which brought the following issues forward:

- from Dr. Koch, hematologist, head of the BMT unit:
    - content is vague;
    - too much adult vocabulary;
    - inaccuracies;
    - general concept is good;
    - leave out autologous transplants (where donor is the patient herself);
    - don't get too specific - varying levels of sophistication.

- from Kathie Moffat, director of Child Life Services:
    - use humour, lighten it up;
    - good to include chemotherapy: comfort in what they already know.

- general feedback from everyone:
    - as pain or other negative aspects are mentioned give reassurance that something can be done to make the situation better.

Revisions were made by the design team bearing all of this in mind. The script was revised, and storyboarding would be the next step. Some of the participants of this evaluation would be asked to review the re-write and storyboard later on.

Overall, the design team found this an extremely efficient, effective and manageable way of conducting expert review for such complex subject matter.

## 2. Learner verification/Formative evaluation (May 9-11, 1996)

Two learner verifications were conducted, with the re-written script and parts of the storyboard, from May 9-11, 1996, with 2 BMT survivors and their families to gauge the level of language, appropriateness of graphics, conceptual understanding of content and strategies, story-telling concept, accuracy of the content, and effectiveness of the spaceship/voyage metaphor (pedagogical, medical, psychosocial, technical aspects). This would be the reality check: did the team's plans sound true to children who had been there?

### 2.1 Jon

Two members of the design team met with Jon, 13 years old, and his mother at the hematology clinic. The author conducted a small-group interview with Jon and his mother, with pre-selected portions of the paper-based script storyboard and semi-structured interview. The other design team member took notes. Results which provoked further changes to the script are summarised in the following table:

| Reaction / suggestion / correction | Change to Scene(s) #* |
|---|---|
| Medications such as Benadryl are given to fight reactions along with sedatives which make them sleep a lot (Jon slept much of his time in isolation) | 8.2 |
| Food is wrapped in aluminum foil and your mouth is very dry so it's hard to eat (you salivate less because of the radiation lasts about 3-4 months); sense of taste changes | 5.4, 6.2 |
| Chemotherapy and radiation - heavy doses for 3 days prior to BMT (radiation 2 times per day for three days) | 7.1 |
| Radiation - it is cold in the room; can bring a radio to listen to music while getting the radiation (prior to radiation the children are fitted for special capes to protect their lungs and so on...) - the machine is scary at first | 7.3, 7.4 |
| BMT day - Jon was sleeping, it doesn't hurt - he suggested mentioning "you fall asleep and then it's over" - parents and doctor beside you at all times; the nurse does not come in and out of the room, she stays there the whole time and so does the doctor - it doesn't take 3-4 hours, it takes about one hour | 8.3 |
| Isolation and waiting for engrafment - 2 persons can be in the room at the same time but usually the kids must be older than 12 and must not have colds or illnesses. Parents can sleep in the room with the child - a cot is set up next to the child's bed. There is a telephone to call people and you can bring your favourite stuff to decorate your room - the room belongs to you for the time your in there. When the child begins to feel lonely, it may be a sign that he/she is getting better. | 9.3, 9.6 |
| Two weeks prior to entering the BMT unit, a series of tests need to be run - dentist, heart, lungs, ultrasound. | 7.4 |
| Going home - you may be able to play with your friends but you won't much feel like it sometimes. You can get visitors at home but only 2 at a time and you can't go to places where there are crowds of people (i.e. shopping mall) - for a while you will have to wear a protective mask on your face when you go to places with lots of people. | 10.3 |
| School - school is usually warned about the child's situation and nurses can go to the school to help other kids understand - also have a private tutor at home (5 hours/day) | 10.4, 10.5 |
| Show a visual of the BMT unit or the room you will stay in | 5.2 |
| Cyclosporin - given to the child so that he/she doesn't reject the new bone marrow (organs etc..) - it serves to prevent rejection - immune system is affected by this medication - don't want the child to get too strong too fast to cause her/him to reject the new bone marrow. | 9.5 |
| * See Appendix O for a list of the scene titles | |

Table 20 - Formative Evaluation (pre-selected parts of script and storyboard), Jon, BMT survivor, 13 years old

General reactions:

- Jon liked the multiple images on the screen.

Suggestions not implemented:

- Jon suggested that words such as "therapy" might be difficult for the younger children to understand.

Suggestions implemented:

- Jon suggested provide visual representation of "good cells vs. bad cells" when talking about chemo and radiation (like the Pac-Man video game to represent the battle inside the body).

### 2.2 Kevin

The author and the other member of the design team met with Kevin, an 11 year-old boy, his father, mother and older, donor brother. This interview was held in the home of one the designers. This time, both team members participated in the interview and took notes. Results and contributions from Kevin, his mother and father are summarised in the following table:

| Reaction / suggestion / correction | Change to Scene(s) #* |
|---|---|
| Kevin got Benadryl, too. He got hives from his brother's bone marrow | 8.2 |
| Use the children's answers to express the strain on the family | general |
| The patients get popsicles instead of jello to calm mouth sores | 7.1 |
| Bags of sand surround the patient when he gets radiation therapy to keep him immobilized, they play the radio in the room. Kevin fell asleep during his treatment | 7.3, 7.4 |
| * See Appendix O for a list of the scene titles | |

Table 21 - Formative Evaluation (pre-selected parts of script and storyboard), Kevin, BMT survivor, 11 years old

General reactions:

- Kevin's father recommended giving more of a sense that it's really not fun to have a BMT;
- The spaceship leaving earth gives a sense of leaving regular life.

Suggestions not implemented:

- Kevin suggested that the CD-ROM remind doctors to wash their hands before coming into the room (BMT unit).

Kevin's donor brother also pointed out that the spinal tap procedure used to harvest the bone marrow made him feel as though "a horse kicked me in the back" the day after the transplant.

Both instances proved very enriching for the anecdotal quality of the script: many of the incidents related were transformed into an answer from one of the characters to the questions/scenes indicated in the two tables above. Somehow, the story was coming alive because it started taking on a more personal flavour. The focus was shifting from the patient who happens to be a child to the child who happens to be a patient. Because the storyboard was paper-based, however, nothing much could be said about the functionality and usability of the interface.

### 3. Expert review/validation of storyboard and script (May 6-13)

This review was done with the help of the head nurse, a few clinic and ward nurses and Dr. Bond, another hematologist, to validate the revised version of the script and accompanying graphics (medical, psychosocial aspects) as well as the storyboard. Guidelines for review were also included. They essentially got the complete version of the tools used with Jon and Kevin.

The main changes brought to the script and storyboard from this review were:

| **Reaction / suggestion / correction** | **Change to Scene(s) #*** |
|---|---|
| Doctor: BMT patients don't always get radiation therapy - say 'sometimes' | 4.2 |
| Doctor: Use 'central line' instead of 'Central line' (Central line is a brand name) | 4.3 |
| Head nurse: Try this for an answer: "A central line is put it by a doctor. You are asleep when they do this so you don't feel any pain. The tube comes out of your body on your chest. The nurses this special tube to take blood specimens and to give you your medications." | 4.3 |
| Doctor: I don't see why you would tell the kids to absolutely eat during their stay. If the patient can eat, she will - why not something about starting to eat before going home | 5.4 |
| Head nurse: Jello is never given, use frozen juice instead | 5.4 |
| Doctor: Don't mention that some patients stay only 2 weeks in the BMT unit - that's very rare | 5.5 |
| Head nurse: toys must be brought in before child comes, and handed over to the nurse to be specially cleaned | 5.5 |
| Head nurse: explain the tubes hanging out from the central line this way: "At the end of the tube, you'll see 2 or 3 separate rubber lines - sort of like fingers on the end of your hand" | 6.1 |
| Doctor: Mom and dad can go inside the BMT unit at any time, not just 'sometimes' | 9.6 |
| Head nurse: try this: "My mom and dad stayed with me. We'd watch TV or play video games. My little sister was not allowed in my room but I could see her through the window of my room and we talked using a walkie talkie" | 9.6 |

* See Appendix O for a list of the scene titles

Table 22 - Expert review (re-written script and storyboard)

The changes which the hematologist suggested concerned accuracy. The head nurse made many suggestions which concerned both accuracy and making the story anecdotal and child-like.

### 4. Learner verification/Formative evaluation of CD-ROM (June 10-13, 1996)

A learner verification of the application was conducted before it was burnt onto a test CD-ROM, mostly for debugging and navigation clarification (technical aspect). The participants were two adults who had not seen the project in any of the previous stages. One was an educational technology graduate student and the other was an automation engineer. They were left free to navigate the application and were encouraged to give their opinions. Both came to the university lab where the CD-ROM was being developed on separate occasions. The procedure utilised was one-to-one direct observation with a think-aloud protocol. The following table summarises their comments and corresponding changes to the interface:

| **Ed. tech. grad. student** | **Engineer** | **Change made** |
|---|---|---|
| Alert message ("Go on!) popped out of nowhere during navigation | Implement a function to help learner keep track of which questions are asked | Correction was brought, alert messages were eliminated altogether and replaced by check-marks |
| Add a sound to the help button | Make the help hypertext | Sound, help screen added |
| Start over and quit buttons and too close to back and forward arrows - they make the arrows look bigger | | Colours of arrows matched the respective buttons, colours were switched to kill the longer arrow effect |
| | Add a stop button to stop the answers once they are started | Done |

Table 23 - Formative evaluation/prototype - navigation

### 5. Learner verification pilot/Formative evaluation of CD-ROM (June 21, 1996)
### 6. Client approval/Formative evaluation of CD-ROM (June 21, 1996)

A 14 year old boy, the brother of a neuroblastoma patient, was left free to navigate the application/test CD-ROM and was encouraged to give his opinions during one-to-one direct observation and think-aloud protocol at the university laboratory where the application was developed. Client approval by the president of the Lamplighters also took place at the same time. Some of the suggestions regarding the interface were made by both as the client looked on while the boy navigated the application. The boy thought the content was adequate and accurate, though not detailed enough to his liking. Chances are the amount of detail he required reflected his above-average knowledge of cancer treatment due to his brother's illness. Such an amount of detail would however overwhelm the end-user who was just getting acquainted with cancer and its treatment. In any case, this was the team's assumption.

The president of the Lamplighters had not seen anything since the beginning of the project, but a first draft of the script. She was pleasantly surprised by the CD-ROM.

Both detected a design decision which could have confused the end-user in her navigation. The 'Walk thru' button (Scene 5.2 - Virtual BMT unit tour) was placed second from the top, on the left panel. Yet, in her introduction to the stop-over (Admission to BMT unit/ADMUNIT.DIR), Maya 'the captain' mentions this option a great deal, putting on it more emphasis than the three other questions. Most users would then delay in locating the button if it were not the first one to be noticed, at the very top, on the left panel.

The following table summarises the comments and corresponding changes to the interface and CD-ROM packaging of both participants:

| Boy | President | Change made |
|---|---|---|
| Place the Walk Through button at top left in ADMUNIT | Place the Walk Through button at top left in ADMUNIT | Done |
| Want more detail in the answer the kids gave | | Impossible to implement at that point in time |
| "It's OK... it's not lame lame, but it's not Nintendo" | | Very hard to implement, probably a good idea |
| | Include written instructions in jewel case on how to start up the CD-ROM | Done |

Table 24 - Formative evaluation pilot/Client approval results and modifications

Other suggestions which the Lamplighters president had included:

- include instruction booklet for parents about sitting with their child at the computer and discussing any issues the child might want to bring up, and assisting her in navigation or reading if needed;
- include bibliography of educational materials which were consulted to produce the CD-ROM for further reference for interested parents.

They were very good suggestions, but were not implemented.

### Post-Production evaluation results and discussion

At this point, the evaluation efforts were conducted for potential revisions to the CD-ROM. Computer-based instruction is often thought to be in an ever-changing state, with new versions of software coming out ever so often. The changes suggested in the following pages may not have been implemented, but they help to extrapolate principles of design for this kind of educational intervention.

Evaluation efforts conducted for the purpose of this thesis-equivalent document included: Expert review; Learner verification, and; Design review.

The application, in all of its stages, needed to be reviewed through this three-fold approach to check on each of the afore-mentioned four major aspects of the application (technical, pedagogical, medical and psychosocial).

The Design Review (essentially a reflective process on part of the author) is part and parcel of the Conclusion to this thesis-equivalent document.

Table 25- Overall evaluation results from questionnaire

| | | **Medical professionals and para-medical staff (n=10)** | | **Patients and support system (n=7)** | | **Educational technology professionals (n=15)** | | **All (N=32)** | |
|---|---|---|---|---|---|---|---|---|---|
| **Statement:** | $\chi^2$ | **mean** | **SD** | **mean** | **SD** | **mean** | **SD** | **mean** | **SD** |
| **I use multimedia programs:** | p<0.01 | 1.70 (2 = not very often) | 0.48 | 2.29 (2 = not very often) | 0.76 | 2.80 (3 = often) | 0.77 | 2.34 (2 = not very often) | 0.77 |
| **I could 'move' around the CD-ROM (e.g. could locate the buttons, etc.):** | | 3.50 (3 = easily) | 0.71 | 3.57 (4 = very easily) | 0.53 | 3.73 (4 = very easily) | 0.46 | 3.63 (4 = very easily) | 0.55 |
| **The level of detail on the screen was:** | | 3.00 (3 = just right) | 0.00 | 3.00 (3 = just right) | 0.58 | 2.93 (3 = just right) | 0.26 | 2.97 (3 = just right) | 0.31 |
| **The animations were:** | | 3.90 (4 = very useful) | 0.32 | 3.71 (4 = very useful) | 0.48 | 3.27 (3 = useful) | 0.70 | 3.56 (4 = very useful) | 0.62 |
| **The voices and pronunciation of the characters were:** | | 3.80 (4 = very sincere and clear) | 0.42 | 3.57 (4 = very sincere and clear) | 0.53 | 3.27 (3 = somewhat sincere and clear) | 1.44 | 3.50 (3 = somewhat sincere and clear) | 1.05 |
| **The answers that the characters gave to the questions were:** | | 3.60 (4 = very accurate) | 0.52 | 3.33 (3 = accurate) | 0.52 | 2.76 (3 = accurate) | 1.58 | 3.17 (3 = accurate) | 1.18 |
| **For ease of use, the CD-ROM needs:** | | 1.50 (1 = no explanation at all) | 0.53 | 1.43 (1 = no explanation at all) | 0.53 | 1.73 (2 = some explanation) | 0.88 | 1.59 (2 = some explanation) | 0.71 |
| **For children, the characters are:** | | 3.70 (4 = very appealing) | 0.48 | 3.57 (4 = very appealing) | 0.53 | 3.07 (3 = appealing) | 1.07 | 3.39 (3 = appealing) | 0.84 |

**Table 26 - Overall evaluation results from questionnaire - comments/strengths**

| Medical and para-medical professionals | Patients and support system | Education professionals |
|---|---|---|
| Animation | Good explanations | Visual appeal of space scenes |
| Accuracy | Clear information | Sound effects |
| Keeps person interested | Not boring | Diversity of characters and perspectives |
| Appealing to children | Useful for siblings | Color and motion |
| Provides developmentally-appropriate information | Excellent graphics | Clear and simple content |
| Good model for future projects | Appropriate content for children | Children as survivors |
| Colourful | Quick and esy to use | Self-paced |
| Animated | Easy for children to relate to | Appropriate level of language |
| Exciting follow-up | Answers children's questions | Animation appealing to kids |
| Diversity of characters (ethnic, gender) | Fun | Good questions, appropriate length for exaplanation |
| Interactive and user-controlled | Complete - a lot of info | Appealing to kids |
| Lively and positive | Colourful | Good use of voyage metaphor |
| Reassuring, comforting and infromative | Nice pcitures | Quality of intro and metaphor |
| Very complete but simple | Good variety of questions | Original treatment |
| Very appealing | Not complicated | Just enough info |
| User-friendly | | Animation |
| Children will love it | | Design |
| Can repeat | | Commands |
| Very visual and fun | | Gives info to the patients and others |
| Easy to use | | Easy to use |
| Will be appealing to children | | Characters are extremely likeable |
| | | Very interactive |
| | | Answers individual concerns |
| | | Graphics excellent |
| | | Animation and action |
| | | Today's technology |
| | | Go through it at your own speed |
| | | Easy to use |
| | | Has kids in it - can relate |
| | | Nice way of dealing with heavy subject |
| | | Friendly |

**Table 27 - Overall evaluation results from questionnaire - comments/ weaknesses**

| Medical and para-medical professionals | Patients and support system | Education professionals |
|---|---|---|
| Didn't understand how to choose sound level | Include a game | Not good for poor readers |
| Not quite 'Toy Story' graphics | Wish it were for sale already | Some repsonses too quick |
| Need computer which is not available yet | Not boring | Face movement not always synchronised with face |
| Wish it were available in French | More realistic drawings of medical equipment (before BMT) needed | Add a quizz at the end of each chapter |
| Some facial movements of the characters | | Not enough variety in sounds |
| Unilingual | | Music could have been fun |
| Not in both languages yet | | Colours |
| | | Needs more work on the sound and colours |
| | | Needs to be more exiting |
| | | Would be better to change of the body positions of the characters |
| | | Facial expression, especially mouth |
| | | Some of the graphics |
| | | Uneven sound levels |
| | | Ship crashing |
| | | Graphics a bit rough |
| | | Language: anti-chamber scary! |

### Expert review

There were two types of expert review: concurrent and post-production[2]. In the previous section, the outcomes of concurrent evaluation were reported, along with subsequent changes to the application. Post-production evaluation has not yet had an effect on the application. However, from the combined results of the questionnaire instrument and various interviews, the author can discuss the following potential repercussions on subsequent production.

#### Results of the questionnaire

Answers to the questionnaire were provided by groups 8, 10 and 13 (please refer to Table 17 - Post-Production Evaluation Participants).

#### Semantic differential scale responses

Overall, there was little variance in rated responses, except for Question 1, concerning the use of multimedia: as expected, educational technology experts had more experience with this than medical experts, or patients and their support systems.

##### *Technical (questions 2, 3, 4 and 5)*

Medical and educational technology professionals rated navigation as easy to very easy. They also thought that the interface was not overcharged with details. They found the animations useful to very useful. They finally thought that the characters expressed themselves somewhat to very clearly and with some to much sincerity.

It would seem that the design team had thus succeeded in building a technically-sound application.

##### *Pedagogical (questions 6, 7 and 8)*

Medical and educational technology professionals rated the content as accurate to very accurate. They also thought that the CD-ROM's use was fairly to very self-explanatory. They finally found that the characters were appealing to children.

It would seem that the design team had thus succeeded in building an application with some pedagogical merit.

#### *Remarks*

In all cases, it would also appear that the slight difference in mean rating between medical and educational technology professionals points directly to their respective areas of expertise.

### Open-ended comment responses

#### *Technical weaknesses*

There was a common theme among medical and educational technology professionals' comments concerning graphics. Comments concerned the quality (e.g. "not quite *Toy Story*"), the lack of synchronization between the narration and the animation, and the limited facial expressions and body positions of the characters. One educational expert also did not like the colour scheme.

Educational experts also noticed that recording levels for narration were not always even. One wondered why there was no music.

#### *Pedagogical weaknesses*

In this case, there was no commonality among medical and educational technology professionals' comments. The only comment from medical professionals concerned the unilingual nature of the tool (a significant percentage of patients do not have English as their mother tongue at MCH). Comments from educational professionals concerned the lack of an alternative to reading buttons for poor readers; the lack of quizzes and other learning activities; some scary features, like the ship crashing and the use of the word 'anti-chamber'.

### *Technical strengths*

There was an equally common perspective among medical and educational technology professionals' comments concerning animation, interactivity and user-friendliness. Both groups thought both to be high points. Medical experts also appreciated the fact that the application was colourful and user-controlled. Educational experts appreciated the fact that the application was well designed, using a Voyage metaphor well.

### *Pedagogical strengths*

The pedagogical strengths noted by medical and educational technology professionals were very similar. Both groups thought that the CD-ROM: was lively and positive (including visual appeal); was developmentally appropriate and informative, complete yet simple; provided diversity in characters; allowed repetition and self-pacing.

Educational experts further noted that the application was good for patients and parents, proposed an original treatment, and included appropriate questions which address the concerns of children.

### *Psycho-social strengths*

The pedagogical strengths denoted by medical and educational technology professionals were also very similar. Both groups thought that the CD-ROM was very appealing to children (especially the characters), and offered reassuring and comforting information in a positive manner about a serious subject.

### *Medical strengths*

Medical experts also commented that the application's content was medically accurate.

### *Remarks*

The overall consistency in positive comments leads the author to believe that the generally high rating attributed to the technical and pedagogical aspects identified in the questionnaire and assigned by these groups, substantiate the technical and pedagogical effectiveness of the CD-ROM. Comments about the psycho-social and medical strengths of the application also lead the author to believe that the application reached an important educational goal: reducing anxiety among potential BMT patients and their families.

As well, the overall consistency in the identification of weaknesses leads the author to believe that there is room for improvement, especially at the technical level (better production values, more interactivity needed).

### Observation notes

Interaction between users and the CD-ROM was observed while the application was on hand for three hours at the MCH. The most striking observations of medical professional users are the following:

- Voyage metaphor was understood
- “Next” button (scene 5.2, walk through the BMT unit)
- Forward arrow made intuitive sense
- Navigation was mostly linear
- Anecdotes and animation were met with goodhearted laughter
- Characters appealed to the adults in the room; they recognized the appeal they would have to children;
- No comments were made concerning lack of accuracy
- Sound effects were a hit

Except for one design flaw - the "Next" button - all around pedagogical and technical design seemed to be sound, appeal was strong and content was accurate.

### Reservations

Reservations about the instrument should be stated: the same questionnaire was used in all instances, but from one circumstance to another, the setting was different - environmental differences imply different interaction with the object of the evaluation (i.e. direct vs. vicarious experience with the application) and may affect the results. For the benefit of comparison, according to point of view (patient, education professional, medical professional), the results were grouped as such. The little amount of range in opinion differences lead the author to believe that variability attributed to the different settings of the evaluation may be negligible.

## Results of the interviews

These results concern participants: Head of Audio-Visual, Montreal Children's/Montreal General Hospitals and Senior Audio-Visual technician, Montreal Children's Hospital; Staff psychiatrist at the Hospital for Sick Children in Toronto; An educational technologist specialising in instructional design, and; Professor of educational psychology at McGill University specialising in applied cognitive science.

### Technical aspects

The head of Audio-Visual, Montreal Children's/Montreal General Hospitals and senior Audio-Visual technician, Montreal Children's Hospital, noticed lighting flaws in the photos taken by the technician. They were also surprised to see the heightened granularity of the images, once processed and imported into the application. The head of AV also noticed uneven sounds levels in the narration. However, they were favourably impressed with the quality of the graphics and the fun factor of the animation.

Dr. Lefebvre, Ms Brown and Dr. Lajoie wished that the application were more interactive (e.g. add hot spots: click the door; door opens) ant its flow less linear, although Ms. Brown appreciated that the chronological nature of the process required a linear story. This very characteristic lead Dr. Lajoie to believe that a video would have been better. She questioned the reason for choosing animation: was it more realistic than video? Ms. Brown, however, found that the animation was great: it added to comprehension. However, she thought that some narrators spoke too fast (Suzanne). Dr. Lajoie liked the Help function, and thought that navigation was clear. Ms. Brown thought that the characters sounded sincere and their fictitious age, though she deplored the lack of synchronization of the words with their mouths.

### Pedagogical aspects

Dr. Lefebvre, Ms Brown and Dr. Lajoie wished that the application had included learner evaluation (add fun quizzes throughout voyage, to check knowledge gains). Ms Brown thought that poor readers would not be able to read buttons/questions and wondered whether there could be a way around that. Along with the AV people from MCH, she thought that the CD-ROM featured a good diversity in characters. Ms. Brown especially appreciated that the CD-ROM provided a wealth of information in an accessible way.

### Psycho-social aspects

Ms Brown thought that using terms like 'vomit' and 'diarrhea' was an appropriate use of language because it was realistic. She also thought that being informed helps anxiety reduction.

### Remarks

Results of the expert interviews echo those of the of the questionnaire.

### Learner verification

There were two types of learner verification: concurrent and post-production[3]. In the results section, the outcomes of concurrent evaluation were reported, along with subsequent changes to the application. Post-production evaluation has not yet had an effect on the application. However, from the combined results of the questionnaire instrument and various interviews, the author can discuss the following potential repercussions on subsequent production.

#### Results of the questionnaire

Results of the questionnaire discussed above concerned the specific comments of experts. Patients and people from their support systems - who are defined as learners - also answered the questionnaire and made comments.

Patients and their support systems were: Jon and Kevin, with their respective families, plus a few Lamplighters members, i.e. a subset of participant group 10, presentation at the MCH.

#### Semantic differential scale responses

##### *Technical (questions 2, 3, 4 and 5)*

Navigation was rated as very easy. Patients thought that the screen/ interface contained just the right amount of information, that animations were very useful and that the characters were very clear and sincere.

##### *Pedagogical (questions 6, 7 and 8)*

Patients furthermore thought that the content was accurate, that the CD-ROM very easy to use and that the characters were very appealing.

##### *Remarks*

This overall enthusiastic response - very close in high ratings to medical experts - is perhaps the most important. This was the population to please with technically and pedagogically-sound design.

### Open-ended comment responses

#### *Technical weaknesses*

Patients wished that drawings of medical equipment were more realistic.

#### *Pedagogical weaknesses*

Comments from patients echoed those of educational professionals, concerning the lack of learning activities, in guise of games.

#### *Technical strengths*

Patients and their support system echo the same sentiments as the expert groups about the user-friendliness of the application. Contrary to these, however, patients thought the graphics to be excellent and the overall design to be colourful.

#### *Pedagogical strengths*

The pedagogical strengths denoted by patients and their support system echo again the feedback from the expert groups. They, too, thought that the CD-ROM contained information that was complete yet simple. They also thought, like educational technology experts, that the content was appropriate for children and answered their questions. Above all else, they liked the fact that it was fun for children.

#### *Psycho-social strengths*

The pedagogical strengths denoted by patients and their support system included the fact that the CD-ROM could also be useful for non-patient siblings.

#### *Remarks*

The overall consistency in positive comments leads the author to believe that the generally high rating attributed to the technical and pedagogical aspects identified in the questionnaire and assigned by this group, substantiate the technical and pedagogical effectiveness of the CD-ROM. Comments about the psycho-social strength of the application also lead the author to believe that the application reached an important educational goal: reducing anxiety among potential BMT patients and their families. Shortcomings identified by patients and their support system are mostly technical and concerning multimedia design: the lack of interactivity. They also pointed to a certain lack of realism with illustrations of medical equipment, which in turn may have pedagogical implications. Since the CD-ROM is a tool for familiarization of kids with their environment at the hospital. It is therefore important to give them a sense of comfort and control by preparing them with realistic depictions of equipment (perhaps the photo of the Walk Thru of the BMT unit where instruments are shown could have been used again).

### Learner verification interviews with potential end-users

The main goals of the post-production learner verification were to evaluate acquisition of knowledge and evaluate attitudinal change with end-users. This procedure is typically conducted to gauge the effectiveness of an educational intervention. To this end, it was worthwhile looking into some literature which investigated attitudes and locus of control towards illness, especially dealing with cancer or children. 'The BMT Voyage' also being a multimedia piece, it became important to conduct usability testing as well, to see if the users felt comfortable with the interface, the navigation and reacted well to the technical design (quality of animation and sound, etc.), in other words, this part of the evaluation was concerned with the CD-ROM's 'virtuality' (Nelson, 1990).

Essentially, this part of the evaluation concerned: Alfred; Dan; Allison, and; Marty. Several tables summarising results of these efforts follow.

## Table 27 : Affective assessment before exposure to CD-ROM - Non-patients

| | **Dan, male, 6 years old (accompanied by his mother)** | **Alfred, male, 11 years old (alone)** |
|---|---|---|
| **Current state of health** | • Articulate, healthy | • Articulate, healthy |
| | • Never was a cancer patient | • Never was a cancer patient |
| **Attitude** | | |
| • tendency to anxiety-depression | • none detected | • some detected |
| • anxiety level (for both patient and family) | • not very high | • very negative view of cancer based on ill-conceived notions of illness causation |
| • health locus of control | • hard to evaluate | • hard to evaluate |
| • sense of control over the BMT process | • hard to evaluate | • anticipates fear with pain |
| • sense of control over the illness | • hard to evaluate | • would make him feel sad, mad and scared if he had cancer |
| **Psychosocial adjustment** | | |
| • feelings with regards to peers | • seems to get along with peers | • would make him feel like an outsider, "like you can't have a normal life"<br>• would be concerned about repercussions of time away on schooling |
| • feelings with regards to hospital staff | • not discussed | • afraid they would think he is weird because if he were ill |
| • feelings with regards to hospitalization | • would be scared of going to the hospital because this means injections to him (fear of needles) | • would be afraid of the new people he would meet at the hospital |
| • feelings with regards to family (parents and siblings) | • not discussed | • would be afraid of the repercussions on his family if he had cancer (parents would need cunselling, siblings would hate him, he would feel guilt, kids would tease his siblings, etc.) |
| • feelings with regards to mortality | • sees cancer as a precursor to death, because of his grandmother's battle with cancer | • sees cancer as a precursor to death |
| • feelings with regards to unknown | • does not seem to scare him | • does seem to scare him |
| • feelings with regards to isolation | • not discussed | • would not like it |
| • feelings with regards to 'special status' | • not discussed | • would be very concerned with other people's opinions |

## Table 28 : Affective assessment before exposure to CD-ROM - Cancer patients

| | **Allison, female, 11 years old (accompanied by mother)** | **Marty, male, 11 years old (accompanied by mother)** |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| **Attitude** | | |
| • tendency to anxiety-depression | • none detected | • none detected |
| • anxiety level (for both patient and family) | • not very high | • both mother and son were tense throughout the interview (could be attributed to the fact that Marty was in between blood transfusions) |
| • health locus of control | • internal, both daughter and mother displayed very positive attitudes about treatment and possible cure | • external, both son and mother displayed resigned attitude to submitting to treatment to get better |
| • sense of control over the BMT process | • knew what length of the treatment to expect and for this reason did not look forward to the possibility of a BMT<br>• Both mother and daughter look at BMT as a way to avoid chemontherapy for the rest of Allison's life, rather than a life-saving procedure. | • anticipates transplant to hurt<br>• recognizes that treatment is necessary to get better |
| • sense of control over the illness | • both are confident that Allyson will be cured one day | • Marty feels angry about having to undergo treatments for 2 years |
| **Psychosocial adjustment** | | |
| • feelings with regards to peers | • seems to get along with other patients of the clinic | • seems to get along with other patients of the clinic |
| • feelings with regards to hospital staff | • seems to enjoy good relationship with staff, trusts them | • seems to enjoy good relationship with staff, trusts them |
| • feelings with regards to hospitalization | • already has been hospitalised, does not like the isolation | |
| • feelings with regards to family (parents and siblings) | • very attached to mother, older sister and other family members | • did not elaborate on feelings of anticipated loneliness at the thought of isolation |
| • feelings with regards to mortality | • not discussed | • not discussed |
| • feelings with regards to unknown | • does not seem to scare her | • does not seem to scare him |
| • feelings with regards to isolation | • does not like it | • not discussed |
| • feelings with regards to 'special status' | • feisty and assertive with people who stare at her because of wheelchair or loss of hair | • not discussed |

## Table 29 : Knowledge assessment before exposure to the CD-ROM - Non-patients

| | **Dan, male, 6 years old (accompanied by his mother)** | **Alfred, male, 11 years old (alone)** |
|---|---|---|
| **Current state of health** | • Articulate, healthy | • Articulate, healthy, sociable and outgoing but prefers to keep to himself |
| | • Never was a cancer patient | • Never was a cancer patient |
| **General aptitudes and abilities** | • problems reading some questions on the buttons<br>• seemed like a brighter-than-average youngster, very articulate<br>• 1st grade student, attends French school | • bright youngster, 6th grade |
| **Previous experience** | | |
| • with computers | • no problems with the mouse, knew how to click on buttons | • no problems with the mouse, knew how to click on buttons<br>• word processing |
| • with CD-ROM's and multimedia (e.g. Web) | • plays with CD-ROMs and games on a Macintosh computer at home | • plays with CD-ROMs and games on a Macintosh computer at home and at school<br>• surfs the Web regularly |
| • of cancer and treatment | • none | • has been exposed to information about BMT |
| **Comprehension of content** | | |
| • conceptual understanding of illness causation | • equates cancer with hospitalisation, pain and dying because this is what happened to his grandmother | • attributes cause of illness to germs and lack of hygiene (implication - repeat that we don't know the cause of cancer - it's not a cause and effect thing) |
| • conceptual understanding of treatment and effects on illness | • must be painful, because his grandmother was in pain when she was dying | • none discussed |
| • conceptual understanding of treatment and effects on physical appearance | • none | • one of his main concerns because he associates cancer with hair loss<br>• knows about "getting a tube in the chest" |
| • conceptual understanding of BMT as treatment | • did not know what a BMT was | • did not offer an explanation |

## Table 30 : Knowledge assessment before exposure to the CD-ROM - Cancer patients

| | **Allison, female, 11 years old** | **Marty, male, 11 years old** |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| **General aptitudes and abilities** | • some problems with reading some questions on the buttons<br>• seemed like a brighter-than-average youngster, very articulte<br>• 4th grade student, repeated grade 2 from missing 5 months of school the first time she was diagnosed and treated for leukemia.<br>• receives home schooling and a home teacher (too sick to be in school) | • seemed like a brighter-than-average youngster, not a talker<br>• sees a home teacher (too sick to be in school) |
| **Previous experience** | | |
| • with computers | • no problems with the mouse, knew how to click on buttons | • word processing |
| • with CD-ROM's and multimedia (eg Web) | • plays with CD-ROMs and games on a PC computer at home | • plays with CD-ROMs and games on a PC computer at home and at school |
| • of cancer and treatment | • cancer patient for 6 years, considerable knowledge of the illness<br>• already acquainted with the concept and reality of isolation and familiar with the preparation for one of those stays (bringing toys and other comforts from home)<br>• had also been told about bone marrow transplants, could explain them very well<br>• knew what length of the treatment to expect<br>• wears a Portapak, did not know what a central line was | • cancer patient for 5 months, well acquainted with side effects of treament<br>• already acquainted with the concept and reality of isolation<br>• had also been told about bone marrow transplants, could explain to a certain degree<br>• was told what to expect from radiotherapy<br>• wears a Portapak, knew what a central line is |
| **Comprehension of content** | | |
| • conceptual understanding of illness causation | • knew what being neutropenic meant ("You have low low counts and you can catch viruses easily.")<br>• too sick to be in school and knows how to explain this bit of illness caussation: "'Cause there's like too many germs and stuff like that." | |

## Table 30 : Knowledge assessment before exposure to the CD-ROM - Cancer patients

| | **Allison, female, 11 years old** | **Marty, male, 11 years old** |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| • conceptual understanding of treatment and effects on illness | | • recognizes that treatments like chemo can make him sick and tired, in which cases "it's hard to get to the hospital" |
| • conceptual understanding of treatment and effects on physical appearance | • Allyson was wearing a beret to conceal her loss of hair | |
| • conceptual understanding of BMT as treatment | • execellent: "It's another person to- another person... ... takes out- bone-marrow from them... and, hmm... if it's a match for you they give it to you in bags, but if it has to be sterile, your stuff- no-one can visit you, only through plate-glass, and stuff like that. So the risk for infection is very high." | • did not offer an explanation |

## Table 31 : Affective assessment after exposure to CD-ROM - Non-cancer patients

| | **Dan, male, 6 years old (accompanied by his mother)** | **Alfred, male, 11 years old (alone)** |
|---|---|---|
| **Current state of health** | • Articulate, healthy | • Articulate, healthy |
| | • Never was a cancer patient | • Never was a cancer patient |
| **Attitude** | | |
| • tendency to anxiety-depression | • none detected | • no indication that negative view of cancer based on ill-conceived notions of illness causation changed<br>• overall tone more optimistic than before seeing CD-ROM |
| • anxiety level (for both patient and family) | • would be "just a little bit scared (...) 'cause ... maybe I can get some needles, but maybe one or two" | • would still feel scared, mad and sad |
| • health locus of control | • hard to evaluate | • hard to evaluate |
| • sense of control over the BMT process | • see anxiety level, above | • reports not feeling as scared as before because of new knowledge<br>• would still feel scared of waking up in the middle of the central line operation, feeling pain and "freaking out because of the tubes" |
| • sense of control over the illness | • hard to evaluate | • hard to evaluate |
| **Psychosocial adjustment** | | |
| • feelings with regards to peers | • not discussed | • would be afraid of being teased by them if he were ill<br>• concerned of peers' opinion of him upon his return to school |
| • feelings with regards to hospital staff | • not discussed | • did not mention whether he would still be afraid of staff's opinion of him |
| • feelings with regards to hospitalization | • would be "just a little bit scared (...) 'cause ... maybe I can get some needles, but maybe one or two" | • did not mention whether he would still be afraid of people at the hospital |
| • feelings with regards to family (parents and siblings) | • not discussed | • would be afraid of siblings jealousy because of extra attention paid to him |
| • feelings with regards to mortality | • not discussed | • not discussed |
| • feelings with regards to unknown | • not discussed | • not discussed |
| • feelings with regards to isolation | • not discussed | • not discussed |
| • feelings with regards to 'special status' | • not discussed | • would be concerned with his physical appearance<br>• would still be concerned other people's opinions |

Table 32 : Affective assessment after exposure to CD-ROM - Cancer patients

| | Allison, female, 11 years old | Marty, male, 11 years old |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| **Attitude** | | |
| • tendency to anxiety-depression | • none observed, very optimistic | • none observed, just resignation |
| • anxiety level (for both patient and family) | • when prompted to describe any feelings of anxiety ('Would you use words like nervous, or scared, or anxious?'), Allyson pointed out that it was the inconveniences which she wouldn't appreciate, rather than the fear.<br>• anxious about possible separation from her family | • none expressed, but feels reassured about lack of pain during BMT itself |
| • health locus of control | • internal, both daughter and mother displayed very positive attitudes about treatment and possible cure | • external, both son and mother displayed resigned attitude to submitting to treatment to get better |
| • sense of control over the BMT process | • Allison had concerns about the possibility parents would have for visits and stay-over's: clarified in discussion<br>• had strong objections to having some of the toys from home cleaned - especially her Barbie dolls<br>• strong reaction about food restrictions (do not apply when she is neutropenic): particulalry did not like the fact that she would have to be off meat and lettuce for at lesat 6 weeks<br>• she would not like the length of time in relative isolation, in the BMT unit; lack of social contact her over-riding concern<br>• said she would fight the isolation by means of communication available to her (phone, walkie talkie, etc.) | • it won't hurt!: "...If I had to get one, I would be more confident about getting one, 'cause I know it doesn't hurt now."<br>• could already tell e would not enjoy liquid food |

## Table 32 : Affective assessment after exposure to CD-ROM - Cancer patients

| | Allison, female, 11 years old | Marty, male, 11 years old |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| • sense of control over the BMT process (cont.) | • would rather receive injections and have blood samples taken through needles then getting a central line: would not like the rubber tubes coming out of her body<br>• she thought it would be 'OK' to go in and have a BMT and staying in the room all this time now that she knew that she could bring her own movies and toys, as she already has in her treatment to date | |
| • **Psychosocial adjustment** | | |
| • feelings with regards to peers | • not discussed | • not discussed |
| • feelings with regards to hospital staff | • not discussed | • not discussed |
| • feelings with regards to hospitalization | • would not enjoy the isolation, feels anxious about possible separation from her family<br>• woried about losing her toys when they must be cleaned prior to being admitted into BMT unit<br>• she wouldn't appreciate inconveniences, rather than the fear ('I wouldn't like because I don't get the food I want and I don't get the stuff I want') | • was surposed to find out that a BMT means a sojourn of at least 6 weeks at the hospital<br>• could already tell e would not enjoy liquid food<br>• likes knowing about comforts of the BMT unit (walkie talkies, video games, etc.) |
| • feelings with regards to family (parents and siblings) | • greatest assurance : knowledge that she could maintain direct contact with her mother, older sister, and older cousins | • did not elaborate on feelings of anticipated loneliness at the thought of isolation, though he could think ahead tothe use of walkie talkies to stay in touch with loved ones "without being really close to them" |
| • feelings with regards to mortality | • not discussed | • not discussed |
| • feelings with regards to unknown | • not discussed | • not discussed |
| • feelings with regards to isolation | • would not enjoy the isolation, feels anxious about possible separation from her family | • not discussed |
| • feelings with regards to 'special status' | • assertive about her difference, though at first it would upset her | • none in particular |

## Table 33 : Knowledge assessment after exposure to the CD-ROM - Non-patients

| | **Dan, male, 6 years old (accompanied by his mother)** | **Alfred, male, 11 years old (alone)** |
|---|---|---|
| **Current state of health** | • Articulate, healthy | • Articulate, healthy |
| | • Never was a cancer patient | • Never was a cancer patient |
| **Comprehension of content** | | |
| • conceptual understanding of illness causation | • not discussed | • no indication given that Alfred had changed his misconception of illness causation |
| • conceptual understanding of treatment and effects on illness | • central line appealed to Dan because it meant no needles<br>• understood by the 3rd stop-over that there would not be as much pain as anticipated<br>• learned that bone marrow is like blood<br>• learned "how it goes in the hospital" | • "I know what chemo and radiotherapy will be like"<br>• "I know how they find the bone marrow and do the transplant" |
| • conceptual understanding of treatment and effects on physical appearance | • does not like the idea of facial hair as a side effect of treatment | • "When you come home, people might stare at you in strange ways but the nurse told them, so they know" |
| **Conceptual understanding** | | |
| • level of language | • did not ask for clarification about meaning of words | • did not ask for clarification about meaning of words |
| • appropriateness of graphics | • liked the space images | • thought some medical illustrations (equipment) lacked realism |
| • conceptual understanding of content | • seemed to have no problem<br>• see: conceptual understanding of illness causation, and; conceptual understanding of treatment and effects on physical appearance, above | • seemed to have no problem<br>• see: conceptual understanding of illness causation, and; conceptual understanding of treatment and effects on physical appearance, above |
| • conceptual understanding of narrative approach | • got carried away into story-telling mode, understood that he was traveling through space | • understood story-telling mode |
| • accuracy of content | • not applicable | • not applicable |

## Table 34 : Knowledge assessment after exposure to the CD-ROM - Cancer patients

| | Allison, female, 11 years old | Marty, male, 11 years old |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| **Comprehension of content** | | |
| • conceptual understanding of illness causation | • not stated specifically, but had prior knowledge | • "Well I guess I understand it takes that long 'cause they gotta make sure that you don't get sick again or you don't get bacterias, that you don't get around bacterias... And I know everything's gotta be really clean... 'Cause dust and stuff, if you got allergies, or... anything can make you start feeling nauseous or get a cold, different things..." |
| • conceptual understanding of treatment and effects on illness | • "Hmm... Yeah... It's like- hmm... OK, somebody gets a bone-marrow from them... and then they put in a bag just like the ones when they're given blood... and then, like what they do is they sterilize it and all that stuff and make sure they have no cells or anything in it... and then what they do is they give it to you... after they kill all your cells and stuff like that.."<br>• both mother and daugter re-iterated that she "knew a bit about it"<br>• learned about central line, isolation,cleaning of toys and food restrictions | • "I don't wanna... be getting headaches or anything... Headaches or be nauseous... I like to keep from being nauseous as much as possible 'cause I really hate throwing up, and stuff...!":<br>• wanted to know if the BMT would make him feel nauseous<br>• found out about the BMT room. Two issues of real concern regarded the amount of time Marty would have to spend in there, were he to get a BMT, and why it seemed to take so long<br>• had a false pre-conception of the time necessary for complete BMT process (6 weeks minimum): "That's a long time! I thought you would have to stay... about a week!" |
| • conceptual understanding of treatment and effects on physical appearance | • does not like the idea of facial hair as a side effect of treatment | • not discussed |

## Table 34 : Knowledge assessment after exposure to the CD-ROM - Cancer patients

| | **Allison, female, 11 years old** | **Marty, male, 11 years old** |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| **Conceptual understanding** | | |
| • level of language | • did not ask for clarification about meaning of words | • did not ask for clarification about meaning of words |
| • appropriateness of graphics | • liked the spacecraft | • thought some medical illustrations (equipment) lacked realism |
| • conceptual understanding of content | • knows from experience about pain involved in BMT sampling to find a match | • said he knew the answer to 'Where do they get the bone marrow?' (question 4.4).<br>• said he already knew what a central line was |
| • conceptual understanding of narrative approach | • understood story-telling mode | • understood story-telling mode<br>• thought it caused too much linearity in the application: "...*maybe it could have a list of which places to go, so you wouldn't have to go to every different place*" |
| • accuracy of content | • Allison affirmed that explanation given to question 7.2 "What is chemotherapy" was accurate | • made no specific comments |

## Table 35 : Reactions to CD-ROM - Non-patients

| | **Dan, male, 6 years old (accompanied by his mother)** | **Alfred, male, 11 years old (alone)** |
|---|---|---|
| **Current state of health** | • Articulate, healthy | • Articulate, healthy |
| | • Never was a cancer patient | • Never was a cancer patient |
| **Ease of navigation** | • 20 minutes on CD-ROM (timed and stopped) | • 36 minutes |
| • navigational path | • needed a bit of prompting form the author and his mother at first<br>• randomly selected questions, at first mostly concerned with "getting all the clicks" | • randomly selected questions<br>• had no problems with navigation<br>• navigated quietly |
| • confusion/difficulty with interface | • needed reading assistance from his mother for question buttons<br>• had some difficulty locating the 'Next' button for virtual tour of BMT unit (Scene 5.2, Stop-over #2) | • had no difficulty locating the 'Next' button for virtual tour of BMT unit (Scene 5.2, Stop-over #2) |
| • metaphor (planets - chapters, space voyage, ship) | • a bit startled by the transitions into the 'virtual tour'<br>• enjoyed the BMT Unit tour otherwise<br>• talked back to the characters and mimicked them<br>• recognized leaving earth and traveling through space | • wished there were more photos of the BMT unit, thought some shots were superfluous |
| **Enjoyment** | • loved it, mostly for the animations | • made several suggestions for change, but, when asked, would say he thought CD-ROM was good |
| • weaknesses | • thought ship crash was funny<br>• stop-over #5 (Scene 8/BMT.DIR) too short | • stop-over #5 (Scene 8/BMT.DIR) too short<br>• did not like Maya: thought she had too strong a lead<br>• crash landing is weird<br>• some illustrations of medical equipment was not realistic<br>• some of the introductions are redundant |
| • strengths | • general enthusiasm for the whole product<br>• enjoyed travel through space<br>• liked Alex, because he told stories and was funny | • general enthusiasm for the whole product<br>• likes animations |
| • suggestions for change | • none made | • objected to characters using words like diarrhea<br>• have other characters give introductions to stop-overs<br>• would like more than 13 photos of the BMT unit |

## Table 36 : Reactions to CD-ROM - Cancer patients

| | Allison, female, 11 years old (accompanied by mother) | Marty, male, 11 years old (accompanied by mother) |
|---|---|---|
| **Current state of health** | • Leukemia, dignosed when she was 5, currently getting out of her 2nd relapse, potential BMT candidate | • Leukemia, dignosed late 1996, currently in remission, possibility of BMT not an issue for now |
| | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised | • Currently receiving chemo, has been neutropenic and put in isolation while hospitalised, will receive radiotherapy soon |
| **Ease of navigation** | | |
| • navigational path | • needed a bit of prompting form the author and her mother at first<br>• followed a linear path | • chose questions ccording to a pre-conceived notion of the answer that would be forthcoming<br>• randomly selected a few questions per stop-over<br>• had no problems with navigation |
| • confusion/difficulty with interface | • needed reading assistance from her mother for question buttons<br>• had some difficulty locating the 'Next' button for virtual tour of BMT unit (Scene 5.2, Stop-over #2) | • had some difficulty locating the 'Next' button for virtual tour of BMT unit (Scene 5.2, Stop-over #2) |
| • metaphor (planets - chapters, space voyage, ship) | • a bit startled by the transitions into the 'virtual tour' (meant to represent dimming lights when a slide show starts): Allison expexted the room to turn into a dungeon after the fade to black.<br>• Allison rejoiced in seing the cushy comforts of home could be found in the BMT Unit | • talked back to the characters |
| **Enjoyment** | • both mother and daughter expressed their enjoyment profusely | • reported not feeling bored because "I was learning new stuff"<br>• generally low-key response, but, when asked, would say he thought CD-ROM was good |
| • weaknesses | • thought ship crash was funny<br>• stop-over #5 (Scene 8/BMT.DIR) too short | • too much linearity "...maybe it could have a list of which places to go, so you wouldn't have to go to every different place"<br>• worried by the ship exploding on landing |
| • strengths | • general enthusiam for the whole product | • found the animation useful and not distracting |
| • suggestions for change | • none made | • wanted a game or quiz to "challenge" him<br>• thought that some of the grpahics were not realistic<br>• would have liked a feature to tell his own story and retrieve the stories of other children |

### Current state of health

The particulars of this category are detailed in each of the preceding tables concerning the results of the interviews with the end-users.

### Affective assessment

#### *Attitude before exposure to CD-ROM*

Dan had a fear of needles which he transposed onto going to the hospital. Alfred anticipated pain and fear, as well as death (based on ill-conceived notion of cause of cancer). He stated that he would feel angry that he had cancer. Allison demonstrated an internal health locus of control, and a positive view of treatment as cure, but would not like having a BMT because of the length of the treatment and relative separation from her family. Marty displayed an external health locus of control, and a tense and resigned attitude towards the illness and its treatment. He anticipated the BMT to be painful.

#### *Attitude after exposure to CD-ROM*

Dan stated feeling less scared about the possibility of hospitalization. Alfred would still feel angry that he had cancer, thought reassured about the treatment. Allison sounded optimistic though still anxious about separation from her family. With stay-over's for her mother were clarified, she felt a little better. She could think ahead of visits and phone conversations with other family members. She was especially annoyed at the inconveniences a possible stay in the BMT unit would impose (toys cleaned, liquid food, etc.). Marty still felt resigned but reassured about a lesser amount of pain than anticipated. He would not like liquid food, either.

#### *Attitude: before vs. after exposure to CD-ROM*

It would seem, per user attitude change - however slight - that the CD-ROM effectively helps users feel reassured about their concerns. Among the patients an inkling of a trend seemed apparent: the attitude of the child was shared with the parent's (mother): could parent's attitude be a determinant of child attitude?

### *Psychosocial adjustment before exposure to CD-ROM*

Dan has fear of needles which he transferred into a fear of hospitalization. Alfred would be very concerned with everyone's opinion and of the repercussions on his family if he were ill. Both Dan and Alfred thought of cancer as a precursor to death. Allison did not like the idea of isolation when hospitalized. She is very attached to her immediate family and assertive with people who stare at her. Marty did not talk about feeling of loneliness or isolation. Both Allison and Marty seem to enjoy good relationships with people they meet at the MCH (staff, peers, etc.).

### *Psychosocial adjustment before exposure to CD-ROM*

Dan still had feelings concerning the issue of hospitalization, though he stated being less scared by the prospect, because the CD-ROM had somehow convinced him that he would only have to submit to one or two injections (the insertion of needles is in fact totally avoided by the installation of a central line). Alfred stood out again, with enduring feelings concerning the issues of peers, family and physical appearance, though they seemed 'softer' than prior to navigating the CD-ROM. He would very much be concerned with other people's opinion, especially that of peers (teasing) and that of siblings (jealousy). Allison still had feelings concerning the issues of hospitalization, family (parents and siblings) and isolation. her greatest assurance from the CD-ROM was that she could maintain direct contact with her mother, older sister and cousin, if she were to have a BMT. Marty still had feelings concerning the issues of hospitalization and family. He was surprised by the length of stay a BMT would entail. He would not liquid food. He never mentioned fears of loneliness or isolation but could already think ahead to using the walkie talkies to stay in touch with loved ones.

### *Psychosocial adjustment: before vs. after exposure to CD-ROM*

Allison, Marty and Dan seem to share the same concerns, as opposed to Alfred who has a distinct set. The difference between Alfred and Dan could reside in the age difference, whereas that between Alfred and Allison and Marty could stem from Allison's and Marty's experiences as cancer patients who have already had to deal with the issues which bother Alfred.

## Knowledge assessment

### *Previous experience*

Aside from experience with computer and games, as well as a generally high level of abilities (except for reading; the author cannot explain Allison's difficulties), important variations in learner characteristics include:

- experience with illness (both non-patient vs. patient, and, within the patient sub-group, Allison vs. Marty. However, both patients' non-experiential knowledge of the illness and treatments is comparable);
- age (Dan was younger, whereas Allison, Alfred and Marty were all the same age).

### *Comprehension of content before exposure to the CD-ROM*

Dan's and Alfred's lack of experience with the illness explain why they recognized mostly the possibilities of pain, death and hair loss. Allison's extended experience with the illness explains perhaps why she was the only one who had a correct conceptual understanding of illness causation. Marty's experience talks to his knowledge of the effects of the treatment on him.

### *Comprehension of content after exposure to the CD-ROM*

All four were able to state in their own ways that they had learned about the whole, or part of, the BMT process. Marty was able to offer his conceptual understanding of illness causation. Other gains in knowledge mostly had to do with the effects of treatment on illness and on physical appearance. All four also learned lots about the hospitalization process and its spin-off subjects.

### *Comprehension of content: before vs. after exposure to the CD-ROM*

Per user-testing of knowledge gains, it would seem that the CD-ROM accomplished its pedagogical goals.

### Reactions to CD-ROM

#### *Ease of navigation*

Dan and Allison needed prompting at first, as well as assistance in reading buttons. Dan, Allison and Marty all had difficulty locating the "Next button" in Scene 5.2, as did most experts. Allison followed a linear pattern of navigation while the boys all selected questions more or less randomly. The author would be hard-pressed to explain a difference based on gender. Dan and Marty talked back to the characters. All seemed to understand and go along with the metaphor of the Voyage.

#### *Enjoyment*

All users generally enjoyed the CD-ROM. Commonly identified weaknesses include: the ship crash on every planet; the short duration of stop-over #5 (BMT.DIR/Bone Marrow Transplant). The most commonly identified strength was the animation. Suggestions for change included: some graphics could be more realistic; more interactivity, games and quizzes are required. Marty, specifically, was asked whether he would like the original idea of the design team, to make this CD-ROM also a living repository of stories written up by former patients. Marty answered affirmatively.

### Modified behaviour

This topic would have concerned specifically: compliance with therapeutic regimen, including cooperation with health care providers; decreased postoperative complications and reduction of hospitalization time, and; enhanced, active self-care behavior. These changes are hard to evaluate without the benefit of a longitudinal study.

## Conclusion

The original intent behind this CD-ROM was to inform children about BMT (present declarative knowledge) and reduce pediatric patient and family stress and anxiety (change attitude) through the delivery of interactive multimedia instruction for self-paced instruction. Results of different evaluation efforts point to the design team's relative success in accomplishing these goals.

### Changes to make in next version of CD-ROM

#### Changes to make based on feedback from experts:

Technical

- implement better synchronization between the narration and the animation
- augment range of facial expressions and body positions of the characters
- implement better recording levels for narration were not always even
- change "Next" button (scene 5.2, walk through the BMT unit) to something more noticeable
- make application more interactive (add hot spots, etc.) and its flow less linear

Pedagogical

- translate application to French
- provide an alternative to reading buttons for poor readers
- add quizzes, games and other learning activities/evaluation

Other

- do not leave ship crashing

#### Changes to make based on feedback from learners:

Technical

- make drawings of medical equipment were more realistic
- change "Next" button (scene 5.2, walk through the BMT unit) to something more noticeable
- more interactivity

Pedagogical

- add learning activities, in guise of games, quizzes, etc.

Other

- do not leave ship crashing
- augment duration of stop-over #5 (BMT.DIR/Bone Marrow Transplant)

## Design Review

Of the many implications to consider in the design of pediatric patient education which the literature featured, the following were actively implemented in the CD-ROM:

| Implications for design | Author |
|---|---|
| • Design for aims and goals of patient education; | Bluebond-Langner (1990),<br>Gillispie and Ellis (1993),<br>Chan (1992) |
| • Education must use strategies which help reduce anxiety; | Villejo (1991) |
| • Informal, anecdotal approach works to increase knowledge in children/pediatric patients; | Bluebond-Langner (1990) |

Table 37 - Implemented implcations for design - pediatric patient education

The author's literature review lead her to the story-telling model proposed by Egan, and thus found that narrative structures work for affective learning as well. Egan questions the principle, supported by Piagetian theory, that children's understanding proceeds from the simple to the complex. He believes that this is an inadequate account of the development of children's understanding. Egan proposes that stories evoke "high emotional colouring" and "make whatever is to be learned into something meaningful". He further maintains that curriculum in general should be taught through stories, rather than in the logico-mathematical, content-oriented, approaches à la Dewey and Piaget (i.e. from unknown to known, from abstract to concrete).

However, the story-telling approach intuitively appealed to the design team because:

- children are familiar with it and like it;
- it lends itself naturally to educational multimedia:
    - allows for use of animation, narration, illustrations, etc.
    - aids the design process (particularly information structuring and sequencing) immensely;
- it circumvents the difficulties posed by the heavy use of medical jargon.

The story format used was more conventional than what Egan proposes. The , value of binary opposites and the use of high emotional colouring are questionable: the goal of the application was to not alarm patients, and certainly not to heighten the drama of the situation they were going through.

The decision to go with a conventional story format was perhaps detrimental. In their discussion of Rapid Prototyping, Tripp and Bichelmeyer enumerate among this method's disadvantages the early committal to a design. The Q&A format gave the design team a static design which left interactivity to a minimum. Although several arguments were made in favour of this approach as an appropriate design decision (even the main instructor of the multimedia production class thought it was), the author still feels that the product could have been more interactive. The results of the evaluation concur with this.

A noteworthy phenomenon was that patients and their predominant take-caring parent tended to share the same outlook and attitude towards the illness and all that it implies, therefore giving real impact to one of the things the expert team at the Montreal Children's Hospital had pointed out: that they trusted the parents to take on the role of educator. It was clear to the team that we were not so much addressing the children - but their immediate family, too. However, if further research were to demonstrate or suggest what common sense tells us about parenting, the educational efforts - even when directed to children - must incorporate a strong component to orient and familiarize the parent as well, for the child will see the facts and reality through their foremost authority figure.

Allison and her mother had the same kind of outlook on the illness, trusting that everything would be fine despite the relapse and the current lack of a match. Likewise, Marty and his mother were both more 'stressed out' about the situation - their reaction was marked by resignation, almost seemed like passive anger. Again, the fact that the diagnosis had taken place only a few months before certainly plays a lot with this.

The similarity noticed in the parent-child dynamic leads the author to think that standardized instruments of the family stresses and relationship inventory-types could be useful indicators of the important variable that the parent's attitude represents in the formation of anxiety in the child regarding her condition.

However, such an investigation would require trained psychologists, a more numerous team, and certainly a bigger sample - perhaps a clinical trial.

The literature (Armstrong) maintains that the ultimate variable affecting outcomes in health education is the patient's involvement, believing that it is directly proportional to the amount of change in the patient's knowledge, skill, and behaviour. Certainly, the experience of evaluation leads the author to believe that parents and family play a big role in the well-being of the patient in pediatric settings.

## Further research

Further investigation is needed to determine whether sick children develop more sophisticated conceptual understanding than healthy children or whether the affective aspects of their illnesses impede this development. Perrin and Gerrity suggest that "determinants of such a difference have not been explored, but may include cognitive regression due to the stress and anxiety of acute illness and/or hospitalization" (1981, p. 848). They conclude that educational interventions -- short of not being offered -- "be (...) further scaled down in their level of cognitive sophistication". However, some education may be better than none. Relatively unstructured, peer patient education in a controlled social situation can also be beneficial. Through open-ended interview and observation, Bluebond-Langner (1990) noted significant increases in knowledge gain about cancer and its treatment in children who attended a pediatric oncology camp, and this despite the lack of formal instruction. This suggests that an informal, anecdotal approach works to increase knowledge among children.

Other findings suggest that:

- increased conceptual understanding leads to higher health locus of control (Shagena, 1988);
- young children and parents of children with chronic physical illnesses tend to have lower health locus of control and consequently rely more heavily on care providers (Perrin, 1985).

One could hypothesize that increased conceptual understanding leads to increased health locus of control and thus enhances self-care, and possibly feelings of competency, too. Lowered anxiety thus would decrease as conceptual understanding increases. The hypothesis that children afflicted with chronic or terminal illness develop complex understanding regarding illness faster than healthy children also remains to be determined.

As the reader may recall from Chapter 2, Brown's (1990) meta-analysis revealed that diabetes education slightly improved knowledge, self-care behavior and metabolic control among patients. Brown further found that age was negatively correlated with knowledge acquisition and cholesterol levels (the higher the mean age of the patients, the lower effects of patient education on these variables). She concluded that the studies' findings support the effectiveness of diabetes patient education in improving health-related outcomes. Another evaluation of an education program designed to improve the level of active self-care behavior of diabetes patients treated with insulin produced similar conclusions, with a twist: the program was found to be only marginally effective in changing self-care behavior, with positive outcomes being attributable to supervision by a health professional or a peer, while engaged in the program. Among these experimental groups, scores on knowledge and diabetes locus of control improved significantly, while attitude, social norm, and level of active self-care behavior improved partially (deWeerdt et al., 1989).

The results of the evaluation of "The BMT Voyage" can only lead the author to similar conclusions with a *very limited degree of confidence*. Further research to establish the direct link between educational interventions and their impact on health-related outcomes is necessary.

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## Endnotes

[1] Since then, the author became aware of similar efforts to the design team's. In the USA, the Starbright Foundation, chaired by Steven Spielberg, is producing a title about leukemia geared towards children. In Canada, the email/conferencing network, Ability Online, based in Toronto, brings together children and sympathetic adults in different forums for discussion which deal or not with a disability or life-challenging illness.

[2] They can both classify as formative evaluation because the post-production evaluation efforts were very much undertaken within the mindset of continuous improvement, i.e. anticipating modification to both the French and English version in the process of translation.

[3] They can both classify as formative evaluation becasue the post-production evaluation efforts were very much undertaken within the mindset of continuous improvement, i.e. anticipating modification to both the French and English version in the process of translation.

# REFERENCES

Abrams, A. (1996). Multimedia Magic. Needham Heights, Mass.: Allyn and Bacon.

Abramson, J. H. (1979). Survey Methods in Community Medicine, 2nd ed. Edinburgh: Churchill Livingstone.

American Society for Training and Development. (1986) Essentials for evaluation.

Annand, F. (1992). A challenge for the 1990s: Patient Education. Journal of Ophtalmologic Nursing and Technology, 11(5): 206-210.

Apple Computers (1987). Human Interface Guidelines. Reading, Mass.: Addison Wesley (Chapter 1).

Armitage, J.O. and Messner, H. (1995). Bone Marrow Transplantation in Dollinger, M. et al. Everyone's Guide to Cancer Therapy. Toronto: Somerville House Publishing.

Armstrong, M.L. (1989). Orchestrating the process of patient education. Methods and approaches. Nursing Clinics of North America. 24(3): 597-604.

Baggaley, J. (1986) Formative evaluation on educational television. Canadian Journal of Educational Communication, 15(1), 41-48.

Baggaley, J. (1988). Perceived effectiveness of international AIDS campaigns. Health Education Research, 3(1) 7-17.

Beisecker, A. E. et al. (1994). Attitudes of oncologists, oncology nurses, and patients from a women's clinic regarding medical decision making for older and younger breast cancer patients. Gerontologist, 34(4), 505-512.

Bell, J.A. (1986). The role of microcomputers in patient education. Computers in Nursing, 4 (6), 255-258.

Billings, D. (1986). Computer-assisted instruction for health professionals. Norwalk, CT: Appleton-Century Crofts.

Bluebond-Langner, M. (1990). Children's knowledge of cancer and its treatment: impact of an oncology camp experience. Journal of Pediatrics, 116(2): 207-213.

Bombeck, E. (1989). I want to grow hair, I want to grow up, I want to go to Boise. New York: Harper & Row, Publishers.

Bordieri, J.E. et al. (1992). Congruity of perceived psychosocial needs of individuals with cancer. Rehabilitation Counseling Bulletin, 36(2), 120-125.

Borich G. and Jemelka, R. (1982). Programs and systems: An evaluation perspective. London, UK: Academic Press.

Brown, S. A. (1990). Studies of educational interventions and outcomes in diabetic adults: A meta-analysis revisited. Patient Education and Counseling, 16(3), 189-215.

Buckley, J. (1994). A critique of Kieran Egan's Theory of educational development. Journal of curriculum Studies: 26(1): 31-43

Burke, R. (1993). Intelligent retrieval of video stories in a social simulation. Journal of Educational Multimedia and Hypermedia: 2(4):381-92.

Cambre,M.(1981) Historical overview of formative evaluation of instructional media products. Educational Communication and Technology Journal, 29 (1), 3-25.

Campbell D.T. & Stanley, J.C.(1966) Experimental and quasi-experimental designs for research. Boston: Houghton Mifflin Co.

Canadian Cancer Society (1993). I Found Seashells on the Beach. Calgary: Canadian Cancer Society, Alberta/N.W.T. Division.

Cartwright, P. (1993). Teaching with dynamic technologies. Change, 25(6).

Cates, W. M. (1994). Designing Hypermedia is Hell: Metaphor's role in Instructional Design (ED373706)

Chan, V. (1992).. Closed-circuit TV: an effective patient education tool. Canadian Journal of Nursing. 5(3): 20-22.

Chen, M. (1995). A methodology for characterizing computer-based learning environments. Instructional Science: 23(1-3): 183-220.

Clark, R. E. (1992). Dangers in the evaluation of instructional media. Academic Medicine, 67(12), 819-820.

Concoli, S. and Jean, J. (1994). Comparative study between a computer-aided education (ISIS) and habitual education techniques for hypertensive patients. Proceedings of the ?? Annual Symposium on Computer Applications in Medical Care: 10-14.

Cooper, P. A. (1993). Paradigm shifts in designed instruction: from behaviourism to cognitivism to constructivism. Educational Technology: 33(5): 12-19.

Council of Ministers of Education, Canada (1985). Criteria for educational computer software evaluation.

de Weerdt, I. et al. (1989). A meta-analysis of the effects of psychoeducational care in adults with hypertension. Patient Education and Counseling, 14(3), 191-215.

Devine, E. C and Reifschneider, E. (1995) Randomized controlled evaluation of an education program for insulin treated patients with diabetes: Effects on psychosocial variables. Nursing Research, 44(4), 237-245.

Dick, W. and Carey, L. (1991). "Formative evaluation". In Briggs et al. (Eds.), *Instructional Design Principles and Applications.* New Jersey: Educational Technology Publications.

Dick, W. and Carey, L. (1991). "Summative evaluation". In Briggs et al. (Eds.), *Instructional Design Principles and Applications.* New Jersey: Educational Technology Publications.

Dirr, K.L. and Katz, A.A. (1989). Cartoons vs. realistic illustration: picture preferences of adolescents patients. Journal of Biocommunication, 16(4), 2-7.

Don, A. (1990). Narrative and the Interface, in Laurel, B., ed. The Art of human-computer interface design. pages 383-391.

Dwyer, C. (1993). Multimedia in Education. Educational Media International: 30(4): 193-98.

Edelson, D. C. (1993) Socrates, Aesops and the computer: questioning and storytelling with multimedia. Journal of Educational Multimedia and Hypermedia: 2(4): 393-404.

editors@oncolink.upenn.edu, Helping People Cope - If you need individual or family counselling, reprinted with permission of Pennsylvania Department of Health, Hermann, J.F. et al. (1988). [Online] Available http://cancer.med.upenn.edu/psycho_stuff/cope/33.html, March 12, 1996 (a).

editors@oncolink.upenn.edu, Helping People Cope - If you need support from others who have had cancer, reprinted with permission of Pennsylvania Department of Health, Hermann, J.F. et al. (1988). [Online] Available http://cancer.med.upenn.edu/psycho_stuff/cope/37.html, March 12, 1996 (b).

editors@oncolink.upenn.edu, Helping People Cope - Pain Control, reprinted with permission of Pennsylvania Department of Health, Hermann, J.F. et al. (1988). [Online] Available http://cancer.med.upenn.edu/psycho_stuff/cope/23.html, March 12, 1996 (d).

editors@oncolink.upenn.edu, Helping People Cope - Questions about cancer treatment, reprinted with permission of Pennsylvania Department of Health, Hermann, J.F. et al. (1988). [Online] Available http://cancer.med.upenn.edu/psycho_stuff/cope/19.html, March 12, 1996 (c).

editors@oncolink.upenn.edu, Introduction to pain, reprinted with permission of The Trustees of the University of Pennsylvania, Buhle, E. L. Jr. (1994). [Online] Available http://oncolink.upenn.edu/med_onc/intro_pain.html, March 12, 1996 (d).

Eiser, C. et al. (1990). What children's stories tell us about their understanding of illness. Early Child Development and Care, 57(?): 1-7.

Ellis, L.B., Petxel, S.V. and Asp, E.H. (1983). Computer-assisted instruction for the chronically-ill child. In R.E. Dayhoff (Ed.), Proceedings of the Seventh Annual Symposium on Computer Applications in Medical Care (pp. 366-369). Silver Spring, MD: IEEE Computer Society Press.

Ellis, L.B.M., Raines, J.R. and Hakanson, N. (1981). Health Education Using Microcomputers, I: Initial Acceptability. Preventive Medicine, 10, 123-456.

Ellis, L.B.M., Raines, J.R. and Hakanson, N. (1982). Health Education Using Microcomputers, II: One Year in the Clinic. Preventive Medicine, 11, 123-456.

Ellis,L.B. (1985). Computer-based patient education. Primary care: Clinics in Office Practice. 12(3): 547-55.

Flagg, B. (1991) *Formative evaluation of educational technologies*. Englewood Cliffs, New Jersey: Educational Technology Publications.

Flynn, L.L. et al. (1995). Learning New Concepts Independently through Metaphor. Reading Improvement, 32(4): 200-219.

Fos, P.J. (1988). An alternative approach to prevention: computer-assisted patient education. ASDC Journal of Dentistry for Children, 55(1): 43-6.

Gay, G. (1992). Structuring Interactive Multimedia Fiction, source unknown.

Gillispie, M.A. and Ellis, L.B. (1993). Computer-based patient education revisited. Journal of Medical Systems. 17(3-4): 119-25.

Glanz, K. et al., eds. (1991) Health behaviour and health education: Theory, Research and Practice. San Francisco: Jossey-Bass Publishers.

Greene, W. J. (1984). Introduction to health education. Prospect Heights, Illinois: Waveland Press.

Hannah, K.J., Conley-Price, P., Fenty,. D., McKiel, E., Soltes, D. Hogan, T. and Wiens, D. (1989a). Computer-assisted self-control of diabetes by adolescents. The Diabetes Educator, 16 (3), 205-211.

Hannah, K.J.et al. (1989b). Computer applications for staff development and patient education. Methods of Information in Medicine. 28(4): 261-6.

Heller, R.S. (1991). Evaluating software: A review of the options. Computers & Education, 17 (4), 285-291.

hem-onc@uokhsc.edu. Bone Marrow Transplant Resource Netmarks. [Online] Available http://www.uokhsc.edu/sections, January 14, 1996.

Hienich, Molenda and Russell (1993). Instructional Media, 3th ed. New York: MacMillan.

Horan, P. P. et al. (1990). Computer assisted self-control of diabetes by adolescents. Diabetes Educator: 16(3): 205-211.

Howson, B. A. and Davis, H. (1992). Enhancing comprehension with videodiscs. Media and Methods: 28(3): 12-14.

Jones, M.K. (1992). Rapid Prototyping in automated instructional design. Educational Technology, Research and Development. 40(4), 95-100

Keller, J. M. & Suzuki, K. (1988). "Use of the ARCS motivation model in courseware design" in Jonassen, D. H., ed. Instructional designs for microcomputer courseware. Hillsdale, NJ; Lawrence Erlbaum and associates.

Laurel, B. (1993). Computers as Theater. Reading, Mass: Addison Wesley.

Lockard, Abrams and Many. (1994) Microcomputers for 21st century educators. New York: Harper Collins.

MacroMedia (1995) MacroMedia Director, version 4.0 (Macintosh)

Mayer, R. and Anderson, R. B. (1992). The instructive animation: helping students build connections between words and pictures in multimedia learning. Journal of Educational Psychology: 84(4): 444-52.

Mayer, R. E. and Gallini, J.K. (1990). When is an illustration worth a thousand words? Journal of Educational Psychology: 82(4): 715-26.

McDermott, T.J. (1989). Cartooning: a humorous approach to medical and health education. Journal of Biocommunication, 16(4), 20-27.

McLellan, H. (1992). Hyper Stories: some guidelines for instructional designers. Journal of research on computing in Education, 25(1): 28-49.

Mielke, K. W. and Swineheart, J. W. (1976) Evaluation of the Feeling Good series. New York: Children's Television Workshop.

Morin, S. (1989). Le Coquin Petit Bernard. Montreal: Hôpital Sainte-Justine.

Mory, E.H. (1992). The use of informational feedback in instruction: Implications for future research. Educational Technology Research and Development, 40 (3), 5-20.

Murray, S. (1991). Fuzzy and Frankie. Washington, D.C.: Children's National Medical Center.

National Childhood Cancer Foundation, Facts about childhood cancer. [Online] Available http://www.nccf.org/nccf/facts.htm, March 12, 1996.

Nelson, T. H. (1990). The right way to think about software design, in Laurel, B., ed. The Art of human-computer interface design.

Nibley, M. (1993). Words and pictures: scripting and producing the multimedia educational program. Journal of Interactive Instruction Development; 6(2): 10-13.

Noble, C. (1991). Are nurses good patient educators? Journal of Advanced Nursing, 16(10): 1185-1189.

Northrup, P. T. (1995). Concurrent Formative Evaluation: Guidelines and Implications for Multimedia Designers. Educational Technology, 35 (6), 24-31.

NYSERNet Inc., Chapter 1 - The Nuts and Bolts of Bone Marrow Transplants, from Bone Marrow Transplants - A Book of Basics for Patients, reprinted with permission of BMT Newsletter. [Online] Available http://nysernet.org/bcic/bmt/bmt.book/chapter.1.html, January 14, 1996 (a).

NYSERNet Inc., Chapter 6 - Emotional and Psychological Considerations, from Bone Marrow Transplants - A Book of Basics for Patients, reprinted with permission of BMT Newsletter. [Online] Available http://nysernet.org/bcic/bmt/bmt.book/chapter.1.html, March 12, 1996 (b).

NYSERNet Inc., Chapter 7 - When Your Child Needs a Bone Marrow Transplant, from Bone Marrow Transplants - A Book of Basics for Patients, reprinted with permission of BMT Newsletter. [Online] Available http://nysernet.org/bcic/bmt/bmt.book/chapter.7.html, January 14, 1996 (c).

NYSERNet Inc., I Can Cope Program: A Series of Education Classes for People Facing Cancer, reprinted with permission of American Cancer Society (1993). [Online] Available http://nysernet.org/bcic/acs2/pat.fam/i.can.cope.html, March 12, 1996 (d).

Park, I. and Hannafin, M.J. (1993). Empirically-based guidelines for the design of interactive multimedia. Educational Technology Research and Development, 41 (3), 63-85.

Park, O and Gittelman, S. S. (1992). Selective use of animation and feedback in CBI. Educational Technology, Research and Developemtn, 40(4): 27-38.

Park, O. and Hopkins, R. (1993). Instructional conditions for using dynamic visual displays. Instructional Science, 22: 1-24.

Patterson, A.C. and Bloch, B. (1987). Formative evaluation: A process required in computer-assisted instruction. Educational Technology, 27 (11): 26-30.

Perrin, E.C. (1985). Health locus of control beliefs of healthy children, children with a chronic physical illness, and their mothers. Journal of Pediatrics, 107(4): 627-633.

Perrin, E.C. and Gerrity, P.S. (1981). There's a demon in your belly: Children's understanding of illness. Pediatrics 67:841-849.

Peterkin, A. (1992). What About Me? When Brothers and Sisters Get Sick. New York: Maginaiton Press.

Petersen, M. (1996). What are blood counts? A computer-assisted program for pediatric patients. Pediatric Nursing, 22 (1), 21-25.

Plowman, L. (1994). The primitive mode of representation and the evolution of interactive multimedia. Journal of Educational Multimedia and Hypermedia, 3(3-40, 275-293.

Pomminville, L. and Demers, J. (1984). Pomme raconte... Le cancer: une grosse tempête dans le jardin de ta vie. Montreal: Leucan - Association pour les Enfants atteints de leucémie-cancer.

Popham, W. J. (1975). *Educational Evaluation* (2nd ed.). New Jersey: Prentice Hall.

Posel, N. (1993). Guidelines for the Evaluation of Instructional Software. Computers in nursing, 11(6) (1993 Nov-Dec) :273-6

Rasnake, L. K. (1989). Anxiety reduction in children receiving medical care: Developmental considerations. Journal of Developmental and Behavioral Pediatrics, 10(4): 169-175.

Rubin,D.H. et al. (1986). Educational intervention by computer in childhood asthma: a randomized clinical trial testing the use of a new teaching intervention in childhood asthma. Pediatrics: 77(1): 1-10

Schaefermeyer, S. (1990), Standards for Instructional Computing Software Design and Development. Educational Technology, 30 (6), 9-15.

Schank, R. C. (1990). Case-based teaching: Four experiences in educational software design. Interactive Learning Environments, 1(4): 231-53.

Schofer, K.K. and Ward, C.J. (1990). The computerization of the patient education process. Computers in Nursing, 8 (3), 116-122.

Schulz, C. M. (1990). Why, Charlie Brown, Why? A Story About What Happens When a Friend is Very Ill. New York: Topper Books.

Schvaneveldt, J. et al. (1990). Children's understanding of AIDS: A developmental viewpoint. Family Relations, 39(3): 330-335.

Shagena, M. M. (1989). Concepts of illness and perception of control in healthy children and in children with chronic illnesses. Journal of Developmental and Behavioral Pediatrics, 9(5): 252-256.

Shands Hospital at the University of Florida. (1989). I'm Having a Bone Marrow Transplant. New York: The Leukemia Society of America.

Sharp, D. L.M. et al. (1995). Dynamic visual support for story comprehension and mental model building by young at-risk children. Educational Technology Research and Development: 43(4): 25-42.

Shuell, T.J. (1992). Designing instructional computing systems for meaningful learning. In M.Jones and P.H. Winne (Eds.), Adaptive learning environments (pp. 19-54). NATO ASI Series (Vol. 85). Berlin: Springer-Verlag.

Sinclair, V.G. (1985). The computer as partner in health care instruction. Computers in Nursing, 3 (5), 212-216.

Sneed, L. C. (1992). Make your video tell a story. Training: 29(9): 58-63.

Stokes, P.E. (1993). A primary care perspective on management of acute and long-term depression. Journal of Clinical Psychiatry, 54(8, Suppl), 74-84.

Team Oncology, Healing Path Newsletters - Pain and Cancer, pt. 2. [Online] Available http://www.entrepreneurs.net/hall/nws2.html, March 12, 1996.

The Center for Attitudinal Healing (1979). There is a rainbow behind every cloud. Millbrae, California: Celestial Arts.

Thomas, B.S. (1991). Computer-assisted patient education in the ambulatory care setting. Computers in Nursing, 9 (5), 168-169.

Tripp, S. D. (1990). Metaphor and Instruction. Unpublished paper (conference?)

Tripp, S. D. and Bichelmeyer, B. (1990). "Rapid Prototyping: an alternative instructional design strategy". *Educational Technology Research and Development*, 38(1), 31-44.

Turner, C. F. et al., eds. (1989). AIDS: Sexual behaviour and intravenous drug use. Washington DC: National Academy Press.

Vargo, G. (19910. Computer-assisted patient education in the ambulatory care setting. Computers in Nursing, 3(5), 212-216.

Villejo, L. (1991). Brain function, learning styles, and cancer patient education. Seminars in Oncology Nursing, 7(2): 97-104.

Wager, W. and Gagné, R.M. (1988). Designing computer-assisted instruction. In D.H. Jonassen (Ed.), Instructional designs for microcomputer courseware (pp. 35-60). Hillsdale, NJ: Lawrence Erlbaum Associates, Publishers.

Walker, D.K. et al. (1990). Assessing psychosocial adjustment of children with chronic illnesses: a review of the technical properties of PARS III. Journal of Development and Behavioural Pediatrics, 11(3), 116-121.

Whitten, J. L. et al. (1989). *Systems analysis and design methods* (2nd ed.). Homewood, Illinois: Irwin.

Windsschitl, M. (1996). Instructional animations: the in-house production of biology software. Journal of computing in higher education: 7(2): 78-94.

# Appendix A. Questionnaire for needs assessment interviews

# CD-ROM / BONE MARROW TRANSPLANT PROJECT
# EVALUATION OF THE CONTENT

PRESENTED BY:
JULIE DAIGNAULT
JOANNE GAUDREAU
WENDY B. LOWE

TO:
HAEMATO-ONCOLOGY CLINIC/
MONTREAL CHILDREN'S HOSPITAL &
LAMPLIGHTERS (MONTREAL)

APRIL 9, 1996

Expert review/formative
end analysis/design

Dear haemato-oncology clinic staff member,

The following several pages outline the instructional content which we think, so far, needs to be included on the CD-ROM which we are producing about bone marrow transplant. This content is in narrative form, as if it were told to a child. It comes from interviewing clinic and ward nurses and other staff, as well as consulting many books from the clinic's patient library and our own research.

We will meet with you on Wednesday, April 10 (tomorrow) to get your feedback.

Your help at this stage is crucial. Being very new to this subject-matter, we know that there are many inaccuracies and omissions. We would be extremely grateful if you could take a few moments out of your day to look at this document and write down any thoughts you may have. To make this task easier, we have:

- included a "map" of this content (2 pages, attached);
- divided sections of the document to correspond with different sections of this map;
- included evaluation forms after each section with specific questions and directions.

We would encourage you to:

- jot down any corrections, comments and thoughts anywhere on the document as they go through your mind when you are reading;
- answer all questions in square brackets [ ] in the text; on the evaluation forms after each section, and; at the end of the document;
- use point form, if this is more convenient and quick for you.

We know that you are very busy, however, taking a few moments to do this will ensure that the information for young patients about bone marrow transplant, as we understand and explain it on the CD-ROM, will be accurate before we start producing the materials.

Thank you for your collaboration,

The Production Team (Joanne, Julie and Wendy)

## 1) Recommend Bone Marrow Transplant

**Note: Please refer to this section on the accompanying map to guide you. Please jot down any corrections or comments that may occur to you anywhere on the document (margins, back of the previous page, etc.)**

Your doctor thinks you should have a bone marrow transplant. You have a lot of questions.

*What is a bone marrow transplant?*

It's a treatment where chemotherapy and irradiation are used to get rid of all the white blood cells in your body, in case some of them are cancer cells. Then they give you new bone marrow that has healthy white blood cells.

*What does it feel like? Is that an operation?*

A bone marrow transplant is not an operation. It's like a blood transfusion. Healthy bone marrow is taken from a donor and then it's given to you through a special tube, called a central line or Broviac, that goes into a vein in your body. The transfusion doesn't hurt and takes about one hour.

*What is bone marrow?*

It's a jelly-like liquid, sort of the same color as blood which is found inside your bones. It makes new blood cells for your body continuously. Some people think it smells like garlic.

*Why do I need new bone marrow? Why from a donor?*

The reason you need new bone marrow is to replace any cancer cells that may still be in your body with new healthy cells. They usually get the new bone marrow from a donor. The donor could be anyone who has the kind of blood type that matches yours - either a family member or it might even be someone you've never met.

*How do they get the bone marrow?*

Usually you get the bone marrow from donor - someone who has very similar blood to yours. This can either be a member of your family or sometimes it can be from someone you have never met before.

*Who will do it?*

There is a team of people who specialize in bone marrow transplants at the hospital that will make sure that all the steps in the bone marrow transplant are carefully carried out. Of course your doctor (oncologist) is the head of the team, and you will see all the other members almost everyday in the BMT unit - each playing an important role in making you better again.

## Evaluation - section 1

*Are you a nurse? If not, what is your position?*

*Are there questions which children (6-12 years old) ask that we haven't included? If so, what are they and what are their answers?*

*Is the information in this section accurate?*

*Have we omitted important, vital or necessary information? What is it?*

*If the information told in vocabulary that can easily be understood by patients aged 6 to 12?*

*Is it told properly (is it honest? realistic? too optimistic? too negative? etc.)? Why / why not?*

*Are the feelings described in the different answers representative of what children feel in these situations? If not, why? Can you a share a few examples?*

## 2) Admission to BMT Unit

**Note: Please refer to this section on the accompanying map to guide you. Please jot down any corrections or comments that may occur to you anywhere on the document (margins, back of the previous page, etc.)**

Once your doctor has recommended that you undergo a bone marrow transplant, you will be admitted to the BMT unit - a place that is specialized for children, like you who receive healthy bone marrow.

[What is the daily routine of hospital personnel that children may expect, and what do they each do... housekeeper, nurses, doctor, child life educator - what is the role of others? nutritionist, psychologist, social worker, etc.]

*Will there be another kid in my room?*

At this point, you will be in a room all to yourself - this may be for 6-8 weeks which feels kind of long - this can feel really lonely sometimes but it keeps away the bacteria and germs which can make you sick.

*Why do I need a Broviac? Will I have to have a lot of needles?*

Once you enter the unit, the doctor will place a Broviac on your chest - it kind of looks like a square with three tubes. This will be painless for you and although it can be a nuisance, it prevents all those awful needle pokes to test your blood. Your chemotherapy and other medicines are given to you from a tube. When you're feeling yucky and you don't feel much like eating, liquid food filled with nutrients is given to you from one of the tubes; and finally, the new healthy bone marrow you will receive from your donor will transplanted painlessly through another of the tubes.

*Will I need an operation? Why the bandages around the?*

The Broviac is inserted into your chest either a few days before or on the day of your bone marrow transplant, but the doctor puts something on your skin and puts you to sleep so that you don't feel anything - no pain. The bandages around your will protect your skin from bacteria and germs which can cause infection.

*What is the food like?*

Like any hospital, the food doesn't taste so good. You'll need to be placed on a special low bacteria diet - it needs to be specially prepared for you so you may have to wait a while when you ask for your favorite dish, like French fries. Although you might not always feel like eating solid food either because you feel sick or because the food tastes kind of bad, it's important that you try to eat as much solid food as you can to make you stronger.

*What is a lumbar puncture?*

[What is it? How is it different from spinal tap?]

## Evaluation - section 2

*Are there questions which children (6-12 years old) ask that we haven't included? If so, what are they and what are their answers?*

*Is the information in this section accurate?*

*Have we omitted important, vital or necessary information? What is it?*

*If the information told in vocabulary that can easily be understood by patients aged 6 to 12?*

*Is it told properly (is it honest? realistic? too optimistic? too negative? etc.)? Why / why not?*

*Are the feelings described in the different answers representative of what children feel in these situations? If not, why? Can you a share a few examples?*

## 3) Chemotherapy and Radiation

**Note: Please refer to this section on the accompanying map to guide you. Please jot down any corrections or comments that may occur to you anywhere on the document (margins, back of the previous page, etc.)**

When you first found out that you had cancer, the doctor told you that you would need to have chemotherapy and, possibly, radiation treatments.

*What is chemotherapy? Why do I need it?*

Chemotherapy is a treatment where you are given strong medication to help kill the bad cancer cells in your body. You have to go to the hospital to have chemotherapy, and they give you the medication from a little tube attached to a needle in your arm.

*Will it hurt? Will I lose my hair?*

The needle may prick a little when it first goes in, but you'll get used to it being there and after a while, you won't even feel it anymore. You won't feel the medication, but the bad part is that sometimes it makes you feel sick, or sometimes, it can make you look fat. The good part is that the medication is to try to make you better by destroying the bad cells. You might also lose your hair but it will grow back as healthy as it was before you lost it.

*What is radiation therapy? Why do I need it?*

Radiation is a treatment which you may or may not need. The doctor will tell you whether you need to have this treatment. It's like having an X-ray machine that sends special rays into your body which will help get rid of the bad cells. The big machine can be scary the first time, but it's not as scary after that.

*Will it hurt? Will I lose my hair?*

Radiation is not painful - it's like someone taking a picture of your body. The bad part is that afterwards, you might feel sick to your stomach, like throwing up, but the good news is that there are medicines to help you feel a little better. You can lose your hair but before you know it, you'll start to feel fuzz again.

### *Radiation and Chemotherapy again?*

Before you can receive new bone marrow, they have to get rid of all the bad cancer cells in your body. Sometimes these bad cells need to be destroyed with radiation and chemotherapy so that the good cells can rebuild themselves when you receive healthy bone marrow. The difference between the radiation and chemotherapy you receive before your bone marrow transplant and what you've received in the past is that the treatments will be stronger.

### *Will it hurt? Will I lose my hair?*

At this point, since the doses are higher and stronger, you may feel sick, like throwing up, you may experience diarrhea, and you might feel like sleeping all the time. You may also develop mouth sores which can be really uncomfortable. If you feel sick or you experience any pain - remember to tell a member of the team, such as the nurses or doctor, and they will give you something to make you feel better. The bad part is that you will lose your hair again, but it will grow back just like it did the last time! Hair always grows back.

## Evaluation - section 3

*Are there questions which children (6-12 years old) ask that we haven't included? If so, what are they and what are their answers?*

*Is the information in this section accurate?*

*Have we omitted important, vital or necessary information? What is it?*

*If the information told in vocabulary that can easily be understood by patients aged 6 to 12?*

*Is it told properly (is it honest? realistic? too optimistic? too negative? etc.)? Why / why not?*

*Are the feelings described in the different answers representative of what children feel in these situations? If not, why? Can you a share a few examples?*

## 4) Bone Marrow Transplant

**Note: Please refer to this section on the accompanying map to guide you. Please jot down any corrections or comments that may occur to you anywhere on the document (margins, back of the previous page, etc.)**

*Will it hurt? How long does it take? What does it feel like?*

Once you have received strong doses of chemo and radiation therapy, your body will be ready to receive the healthy new bone marrow from your donor. This part is painless because you receive this through a tube in your Broviac. It usually takes about one hour. Once you have received the new marrow, doctors and nurses will carefully monitor your blood. You may get a fever, but your body is trying to fight off any infection - whenever you feel any discomfort or pain - just tell the nurses and doctors and they will give you medication to help make you feel better. You may also feel weak and tired, but you' ve been through a lot and it' s OK to feel tired. From two to four weeks after you have received your bone marrow, everyone will be waiting for your good cells to appear.

*Why does it smell funny?*

[Any explanations why bone marrow smells like garlic?]

## Evaluation - section 4

*Are there questions which children (6-12 years old) ask that we haven't included? If so, what are they and what are their answers?*

*Is the information in this section accurate?*

*Have we omitted important, vital or necessary information? What is it?*

*If the information told in vocabulary that can easily be understood by patients aged 6 to 12?*

*Is it told properly (is it honest? realistic? too optimistic? too negative? etc.)? Why / why not?*

*Are the feelings described in the different answers representative of what children feel in these situations? If not, why? Can you a share a few examples?*

## 5) Isolation / waiting for engrafment

**Note: Please refer to this section on the accompanying map to guide you. Please jot down any corrections or comments that may occur to you anywhere on the document (margins, back of the previous page, etc.)**

After the new bone marrow is given to you, you'll have to wait and see if your blood starts to produce new cells again. Just before the transplant, you had chemotherapy and radiation so your old, sick immune system could make way for a brand new one which would help you get rid of the cancer. You're now waiting for that new immune system to show up - this is called "engrafment". Because your body is so busy rebuilding it, you will feel very weak, but "engrafment" itself is not very painful.

[How is immune system defined to children?]

*How long will I have to stay?*

What's hard about being in the hospital is feeling alone - especially at night when Mom and Dad have to go home. Sometimes, time drags on in the hospital. You have to be in something called "isolation" which means being alone in your room for a long time. You have to be the only one living in that room because everything in your room has to be really clean and free from germs. Sometimes it gets boring. You really wish you were home playing Nintendo. It smells funny in the hospital and you wish you were sleeping in your own bed.

The first 2 weeks are going to be tough. It takes at least 2 weeks to see that the new bone marrow is finding a new place in your body, starts producing new cells in your blood and building a new immune system. But waiting to see that you're going to have a brand new immune system will take longer than 2 weeks. You should be there for about 4- 6 weeks. You can try to imagine the good cells in your body beating up or destroying the bad cells.

*Will I have to have chemo again?*

You won't have chemo again while you wait for the new bone marrow to grow in your body.

*What will I do all day?*

All this time can seem long to you. Do you know how long 2 weeks is? It's how long mom or dad gets for a vacation every year - maybe the same time that you spent on vacation at camp, at the beach or camping.

For the first few days - maybe a week - you'll probably spend most of the time sleeping. It takes a lot of strength to build a new immune system. You'll feel weak, like you a have a bad cold all the time. You might feel really yucky and feel sick, like throwing up and sometimes having diarrhea.

If it hurts, tell the nurse right away to give you something to help take the pain away. If you feel too sick to say how much it hurts, you can point to a face on a piece of paper which shows how much pain you're having.

You might get sores in your mouth, and they're painful, but you can ask the nurse to give you something to take the pain away. They may hurt so much that you won't feel like eating. You may also not feel like eating because you feel sick or because the food really tastes bad, but it's important that you try to eat food to make you stronger. You may not be able to have any kind of food you want, cause your food has to be free from bacteria but you have to eat.

When you start feeling a little better, you'll be able to play with the games and toys in your room, watch TV, talk on the phone with your friends or play with the child life educator (other term?). People in the hospital are really nice - sometimes they will play with you.

*Can I see my siblings?*

If you have a sister or brother who is 10 years old, or older, they could come visit you in your room, but they have to be very clean and they can't be sick. Your room needs to be extra clean, because if there are too many bacteria and germs, it could make you very sick. If you sister or brother is sick, or if they are younger than 10 years old, they won't come in the room but you'll be able to see them through the window of your room and could talk to them on the walkie talkie.

*What are we waiting for?* - see: what will I do all day?

*Why do I have a fever?*

[Why indeed? Fighting infection?]

*Will I be able to go to the bathroom?*

[Needs to be clarified]

*Why all these tests?*

[What are all the tests? blood, stool/urine, etc......]
[Reasons for the tests?]

*Can I go to the playroom sometimes?*

You won't be able to leave your room for the whole time that you will wait for a new immune system to help you defend yourself against cancer and keep you from being sick again. But you can play in your room. Your mom or dad may come into your room, as well as some of your older sisters or brothers. You will be able to talk to other people you know on the phone or through the window of your room. People who work at the hospital will also come visit you every day. Some of them will be glad to play with you, or bring you toys or movies.

*Why does everything have to be germ-free?*

Your room needs to be very clean. When you had the chemo and radiation before the day you got the new bone marrow, your cancer, your bad cells, and your immune system were sort of erased, taken away... that leaves you very weak and it would be easy for you to get very sick if the room wasn't this clean. If it was very dirty, like when your room at home is messy, or if it's just like your house or school may be when it's clean, you would get very sick. Do your parents wash the floors with soap that smells very strong sometimes? That's to kill germs because germs and bacteria grow anywhere where there is a little bit of dirt... your body is usually strong enough to fight them but not now.

*Why do I have to take a bath every day?*

For the same reason, you have to take a bath with a special soap every day... you may not like it, especially if you feel too sick to play with the water, but the nurse will help you clean yourself and the soap is pink and makes bubbles so you can have a little bit of fun.

*Can my parents visit?* - see other questions dealing with visits

*What's happening to my friends from the clinic?*

Some of the people who may visit you are other kids who you made friends with at the clinic. Maybe some of them have to have a bone marrow transplant, too, and they want to see how you're doing because they'll do the same thing later. Maybe the kid in the room next to yours had a bone marrow transplant just before you did. It's only natural to wonder how everyone is doing. You may see other kids through the window and feel angry that they seem to be feeling well when you feel so sick. It's OK. But your friends must feel very happy to see that you had a bone marrow transplant to get rid of your cancer. If you ask how other friends are doing and the nurse, social worker or one of your parents tells you, you may feel very sad and angry to hear that they are very sick. It's OK.

If you want to cry, it's OK. Cry. And talk to your mom or dad, or the nurse or anybody else who works at the hospital. They will be happy to listen to you, to hold you if you cry. If you feel strong enough, you may want to draw on a piece of paper a picture of yourself and show how sad or mad you are.

*Why do I get all these gifts?*

All of a sudden, you may receive visits from all sorts of relatives you haven't seen for a while, or aunts, uncles and cousins who live very far away and who you don't usually see very often. They may bring you all sorts of gifts - a teddy bear, some toys. It might seem strange to get all of these gifts and see all these people all of a sudden. It's not even a holiday or your birthday! It may make you wonder what is going on. If you feel funny about this, talk to the nurse or to your parents and they will try to understand what's bothering you.

## Evaluation - section 5

*Are there questions which children (6-12 years old) ask that we haven't included? If so, what are they and what are their answers?*

*Is the information in this section accurate?*

*Have we omitted important, vital or necessary information? What is it?*

*If the information told in vocabulary that can easily be understood by patients aged 6 to 12?*

*Is it told properly (is it honest? realistic? too optimistic? too negative? etc.)? Why / why not?*

*Are the feelings described in the different answers representative of what children feel in these situations? If not, why? Can you a share a few examples?*

## 6) Going Home

**Note: Please refer to this section on the accompanying map to guide you. Please jot down any corrections or comments that may occur to you anywhere on the document (margins, back of the previous page, etc.)**

You'd like to know when you can go home! When you first get home, it is sort of a surprise not to be in the BMT unit. You can roam around inside the house, but you need to be careful about bacteria and germs and you may not be able to play outside as soon as you get back home. It may take many months. Once your body has built up healthy cells to fight infections, you can run around and play outside with your friends all you like.

*When can I go home?*

It's nice going back home to your family, your friends and best of all - your own bed. Most of the time, BMT patients can go home about 6 or 8 weeks after the transplant.

*Will I have to get rid of my pet?*

When you get back home, you will need to be careful not to be exposed to any germs or bacteria. You might have to send your pet away for a while if it is furry, because pets carry germs. Your doctor will tell you when you can bring your pet back home.

*Will my friends make fun of me?*

If your Mom and Dad have talked to your friends, then it will help them understand what you have gone through. At first they might be surprised at your appearance, especially if you had long hair and now it's just growing back, but you haven't changed as a person, so once they realize that you're the same, they'll be fine and happy to see you again.

*What about schoolwork? Will I lose a year in school? When will I be able to go back to school?*

Going back to school can be scary, and you might have some catching up to do on your school work, but your teachers and your parents will help you and soon you'll be back on track.

[What can generally be said of school teachers in the hospital?]

## Evaluation - section 6

*Are there questions which children (6-12 years old) ask that we haven't included? If so, what are they and what are their answers?*

*Is the information in this section accurate?*

*Have we omitted important, vital or necessary information? What is it?*

*If the information told in vocabulary that can easily be understood by patients aged 6 to 12?*

*Is it told properly (is it honest? realistic? too optimistic? too negative? etc.)? Why / why not?*

*Are the feelings described in the different answers representative of what children feel in these situations? If not, why? Can you a share a few examples?*

## 7) Feelings

**Note: Please refer to this section on the accompanying map to guide you. Please jot down any corrections or comments that may occur to you anywhere on the document (margins, back of the previous page, etc.)**

When you first find out you have cancer, you need to remember that you didn't get cancer because of something you did wrong, it just happens sometimes. When you find out that you are going to have a special procedure, like a bone marrow transplant, you might have lots of feelings that may be hard to talk about. Some of these questions may have crossed your mind:

Can they take the pain away?
I feel angry that this is happening to me.
I feel bored in the hospital.
I feel scared about what is going to happen.
I feel lonely in this unit, it's hard to be away from my family and friends.
I'm tired of feeling sick and of being sick.
Can Mom and Dad be with me?
Do I look funny?
I feel frustrated because I can't do anything myself.
I feel as if I have no control over what's happening to me.
Why do I have to be alone all the time?

## Evaluation - section 7

*Are there questions which children (6-12 years old) ask that we haven't included? If so, what are they and what are their answers?*

*Is the information in this section accurate?*

*Have we omitted important, vital or necessary information? What is it?*

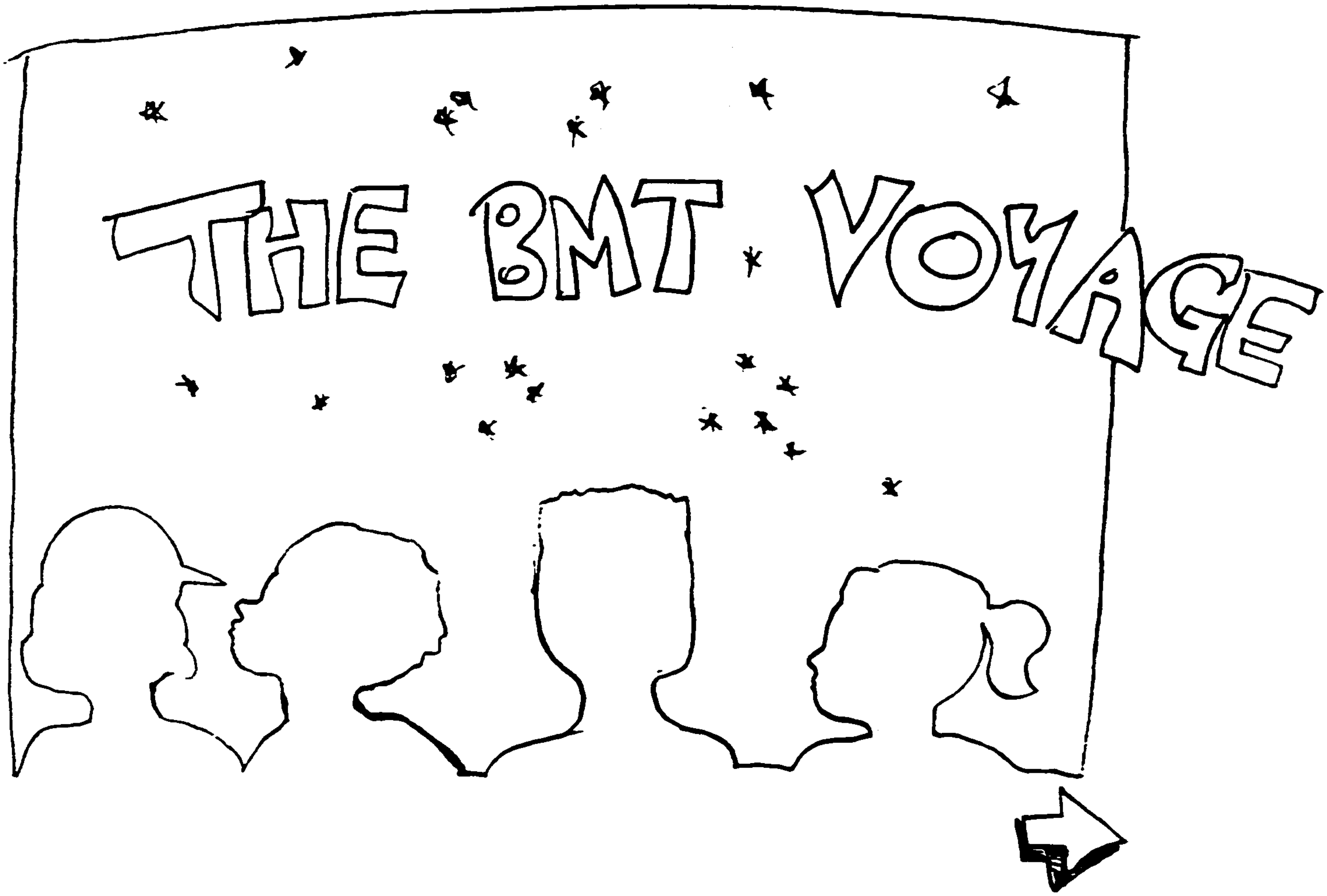
*If the information told in vocabulary that can easily be understood by patients aged 6 to 12?*

*Is it told properly (is it honest? realistic? too optimistic? too negative? etc.)? Why / why not?*

*Are the feelings described in the different answers representative of what children feel in these situations? If not, why? Can you a share a few examples?*

# Appendix B. Parts of the storyboard

①



☐ what you see on the main screen above the children

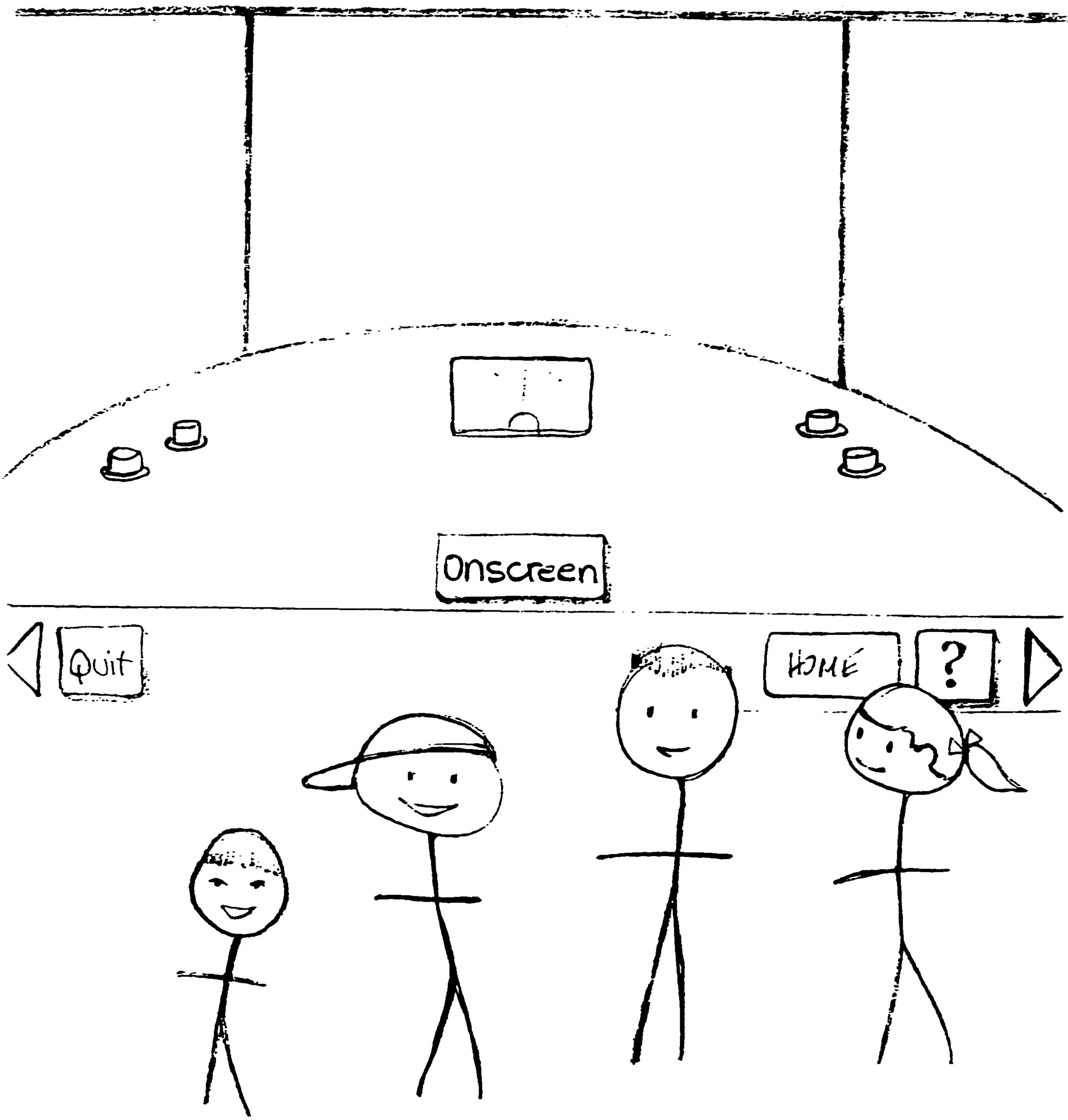
what you hear.

☐ Questions to click on

SCENE ___ TOPIC ______________

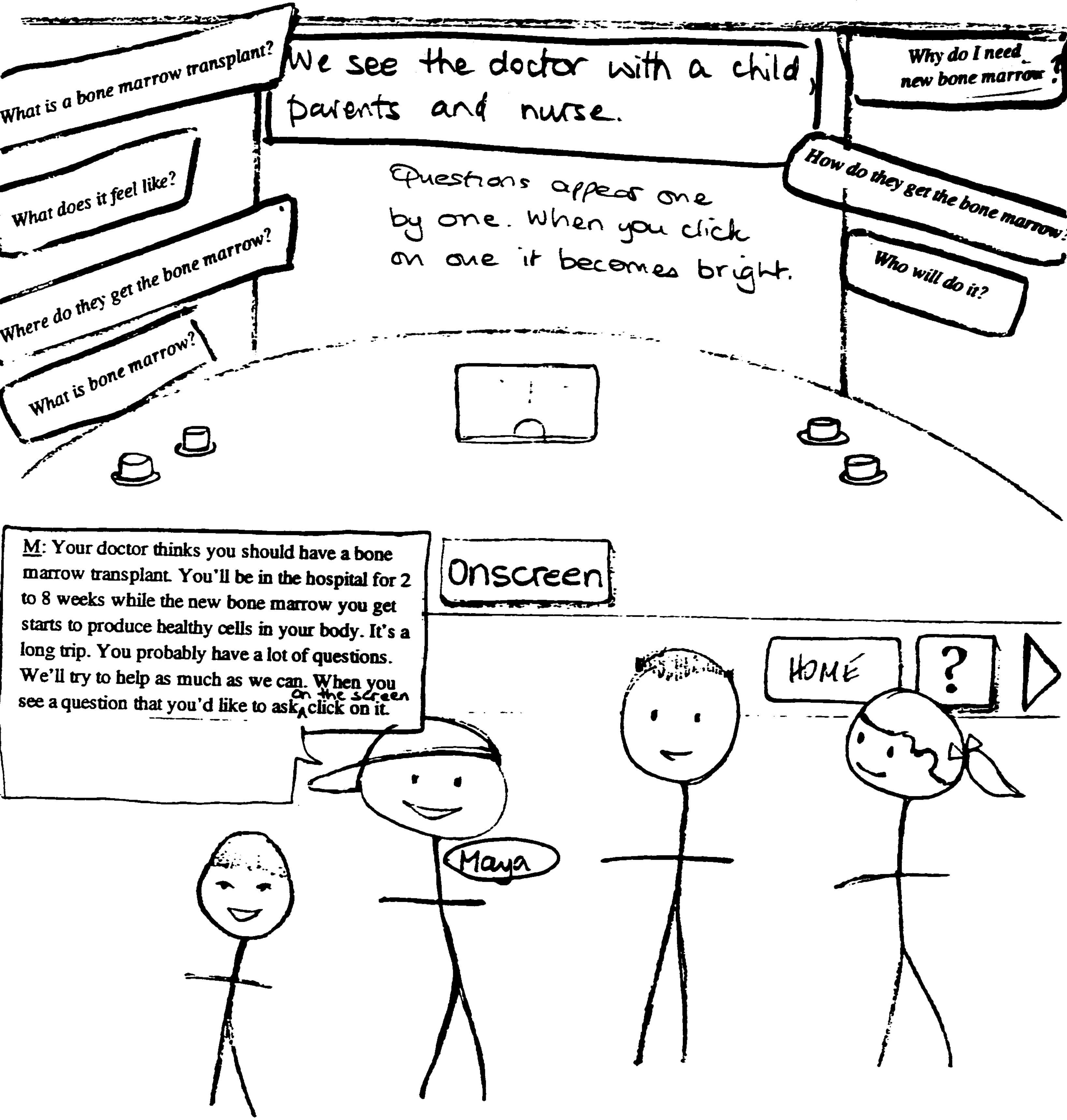
SCREEN ______________

EFII
VOYAG



SCENE 4.1 TOPIC You need a Bone Marrow Transplant. EFI VOYAG

SCREEN ____________



We see the doctor with a child, parents and nurse.

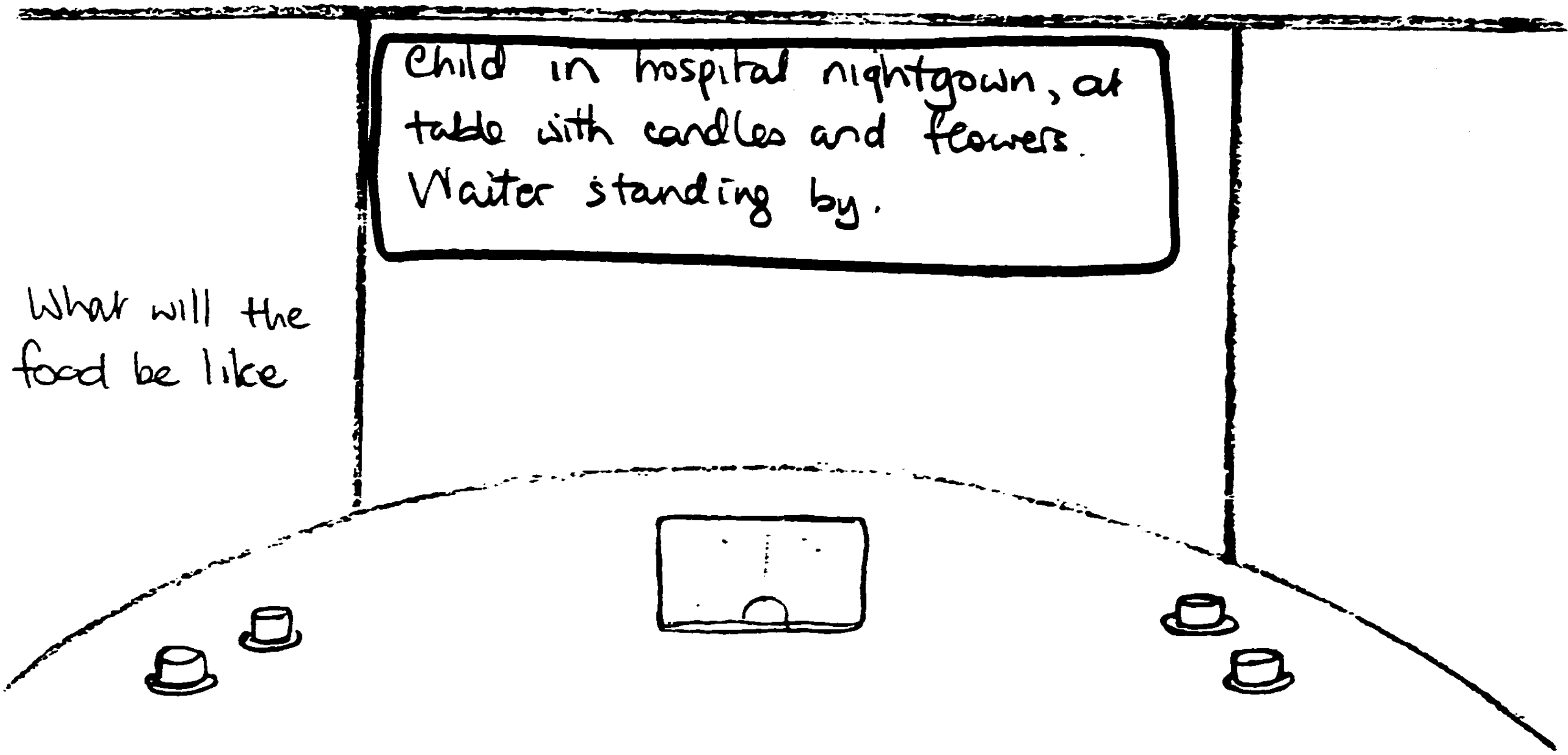
Questions appear one by one. When you click on one it becomes bright.

M: Your doctor thinks you should have a bone marrow transplant. You'll be in the hospital for 2 to 8 weeks while the new bone marrow you get starts to produce healthy cells in your body. It's a long trip. You probably have a lot of questions. We'll try to help as much as we can. When you see a question that you'd like to ask on the screen click on it.

BMT VOYAG

SCENE 5.4 TOPIC BMT unit.

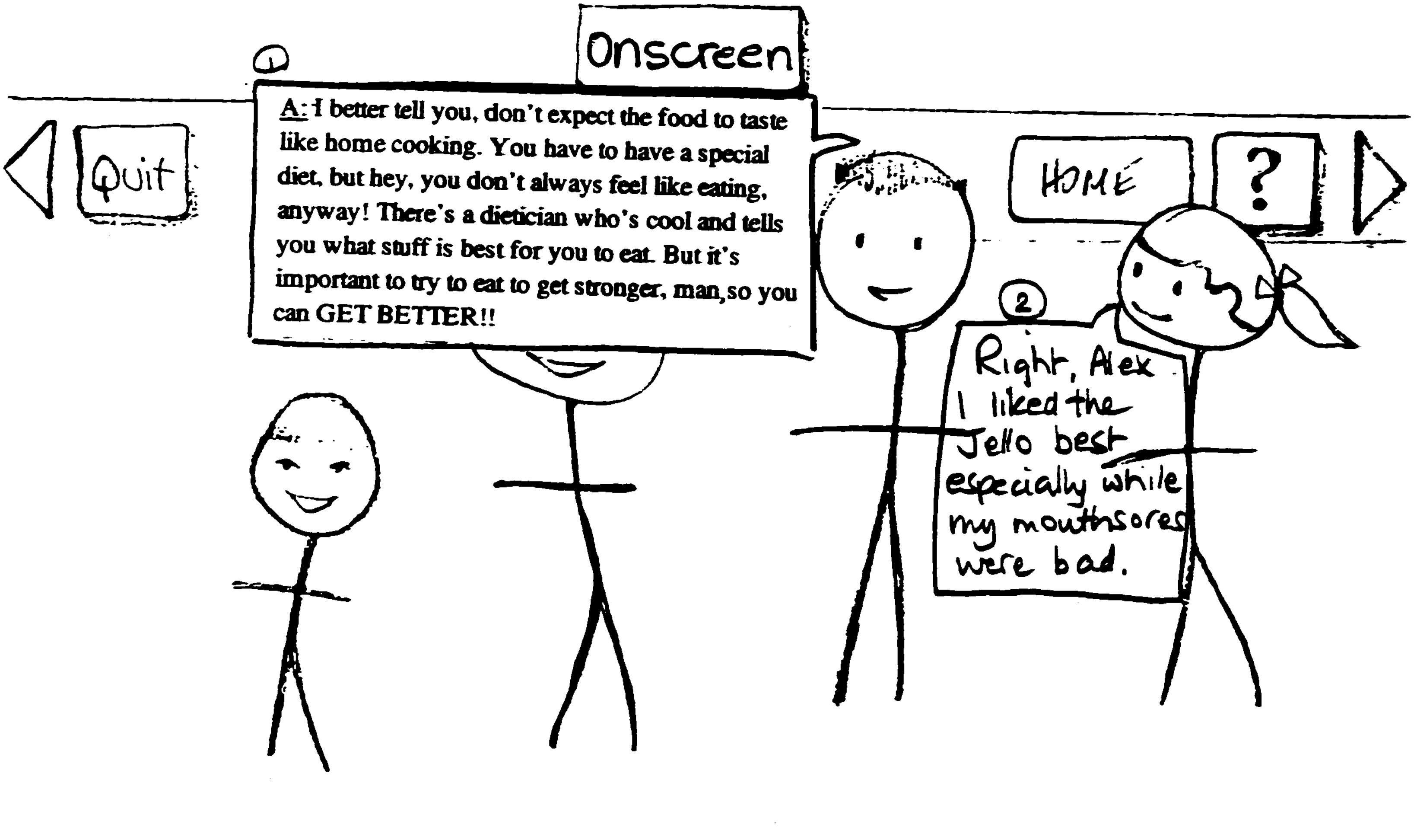
SCREEN



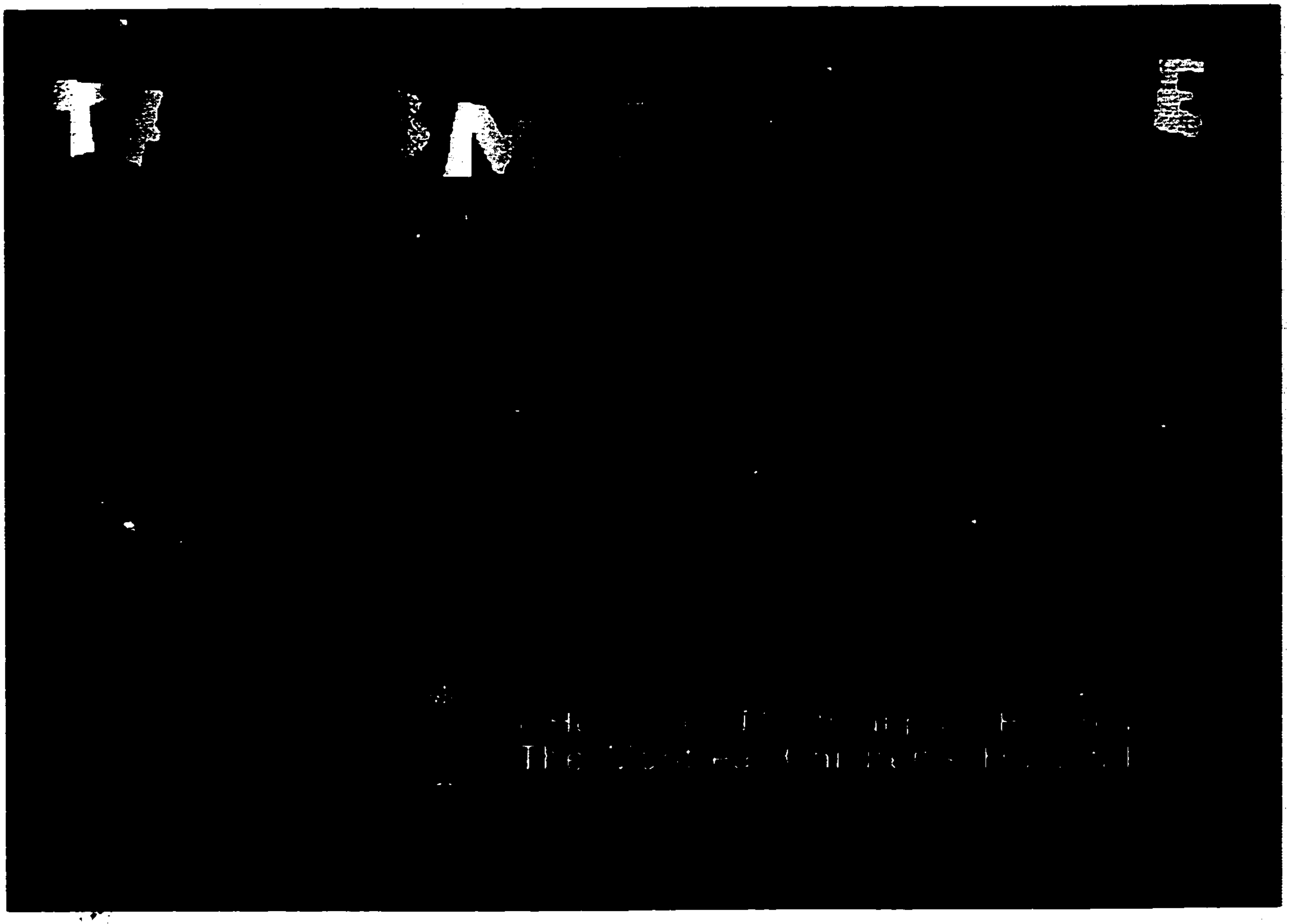
Child in hospital nightgown, at table with candles and flowers. Waiter standing by.

What will the food be like

Onscreen



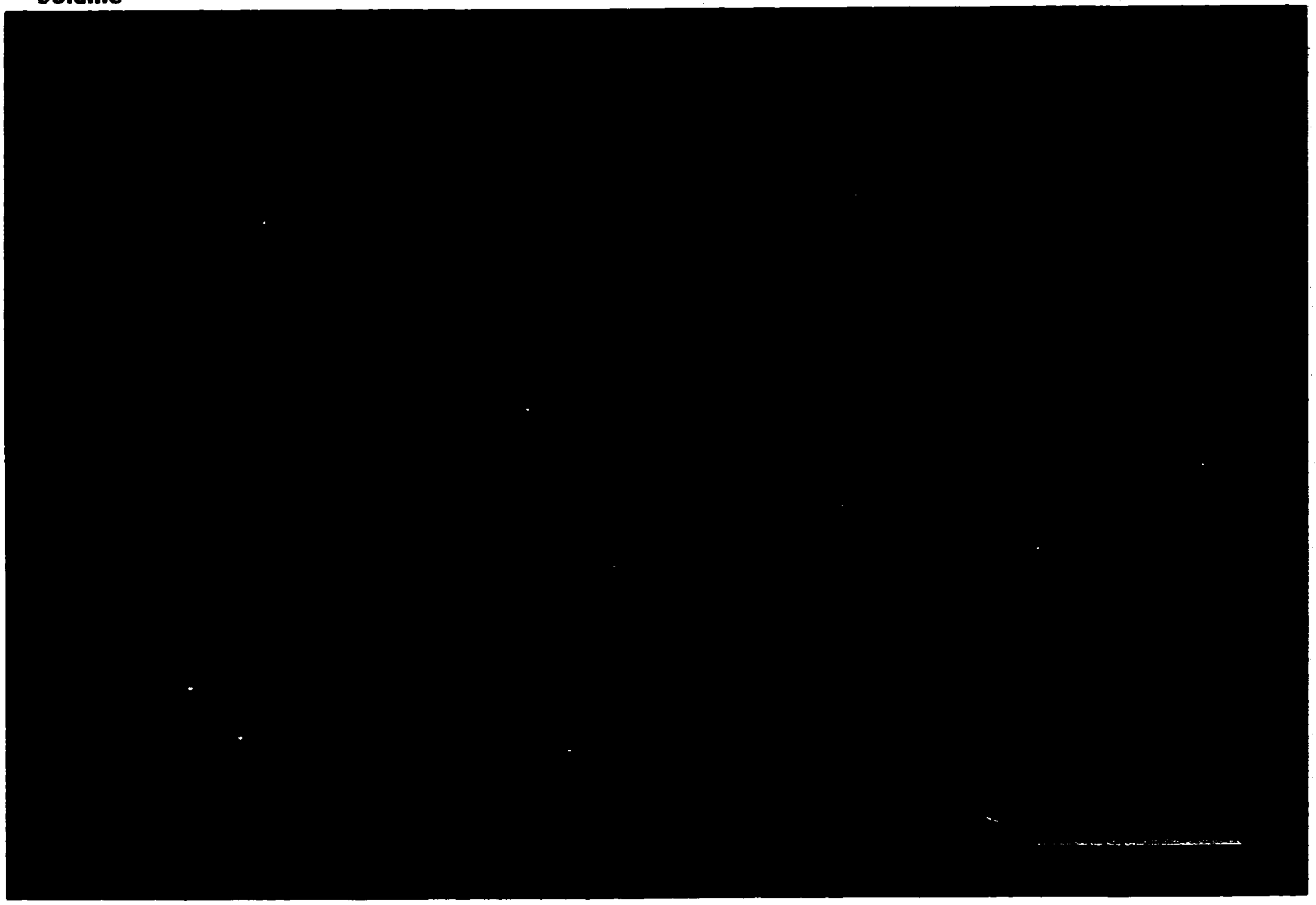
# Appendix C. Introduction to CD-ROM



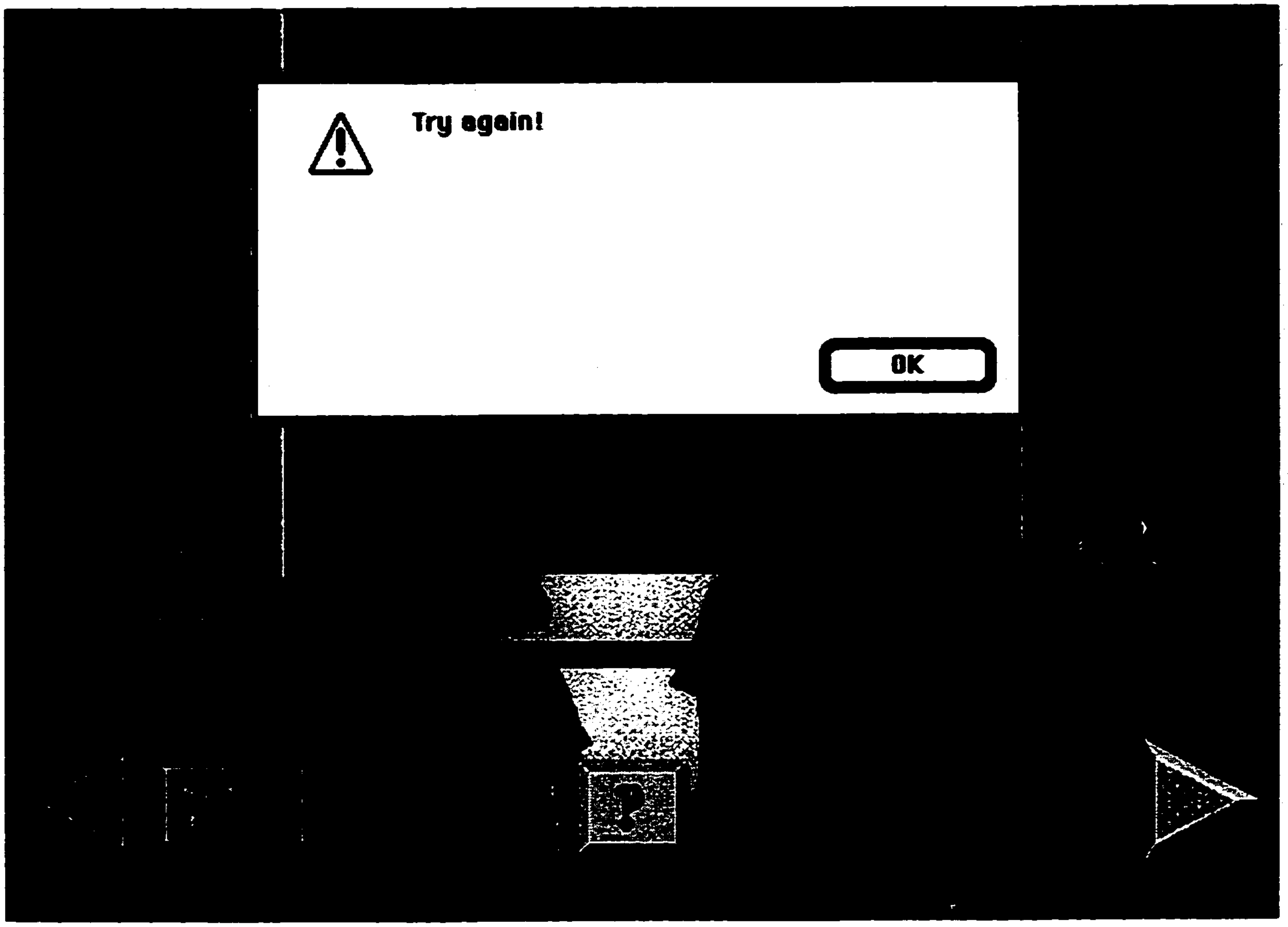
[illegible]

The [illegible] Children's Hospital

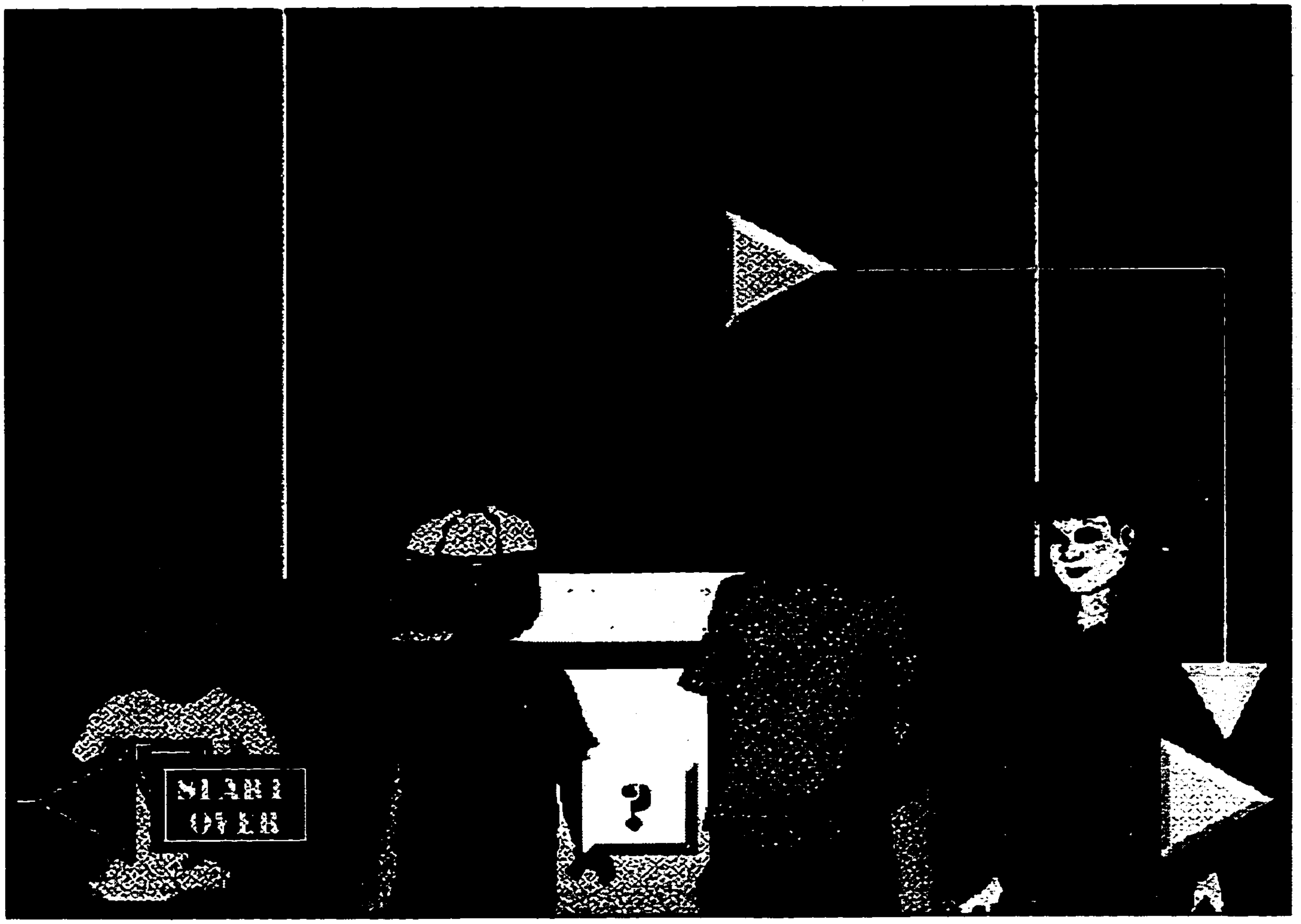
**Volume**



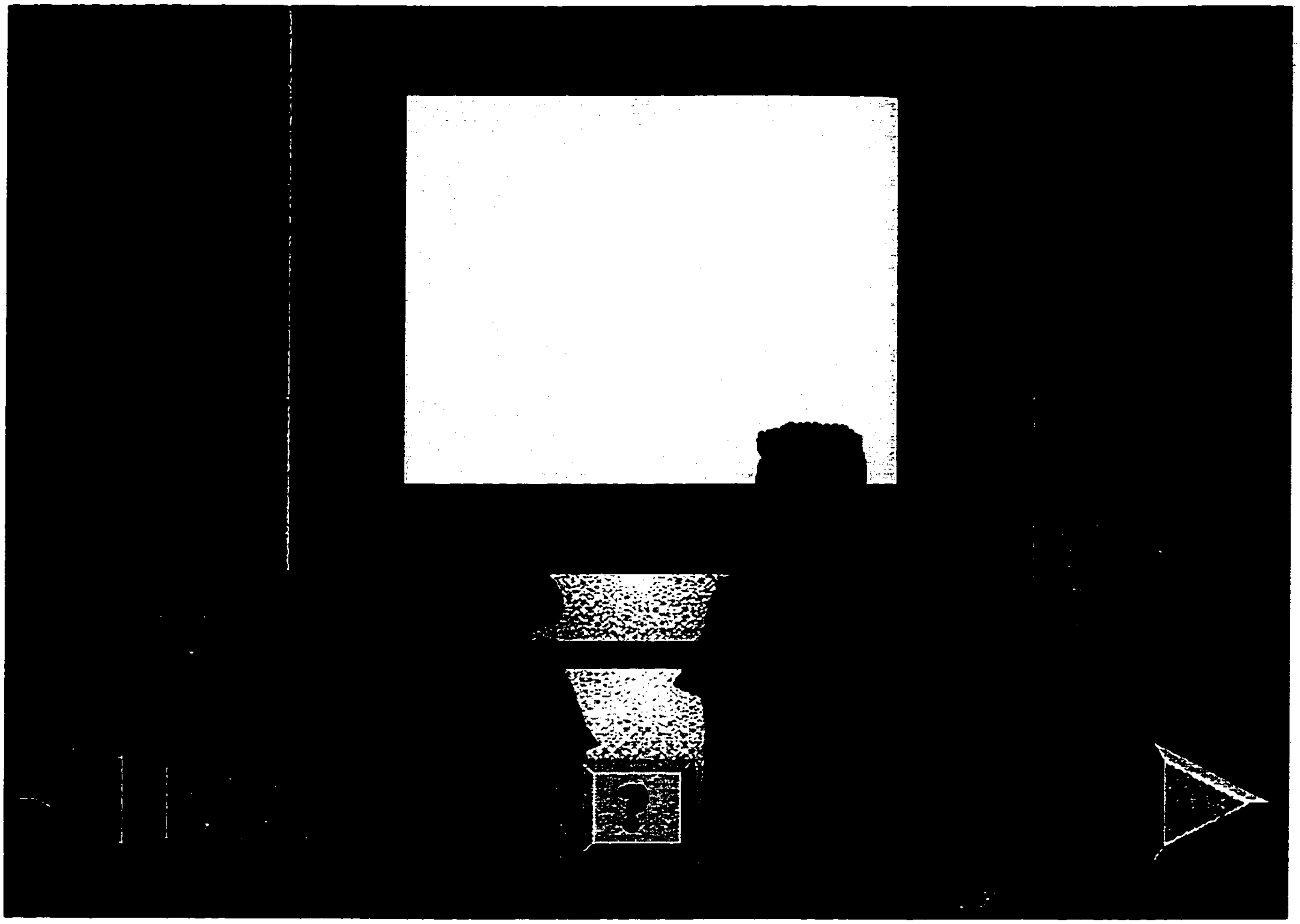
# Appendix D. Navigation demo



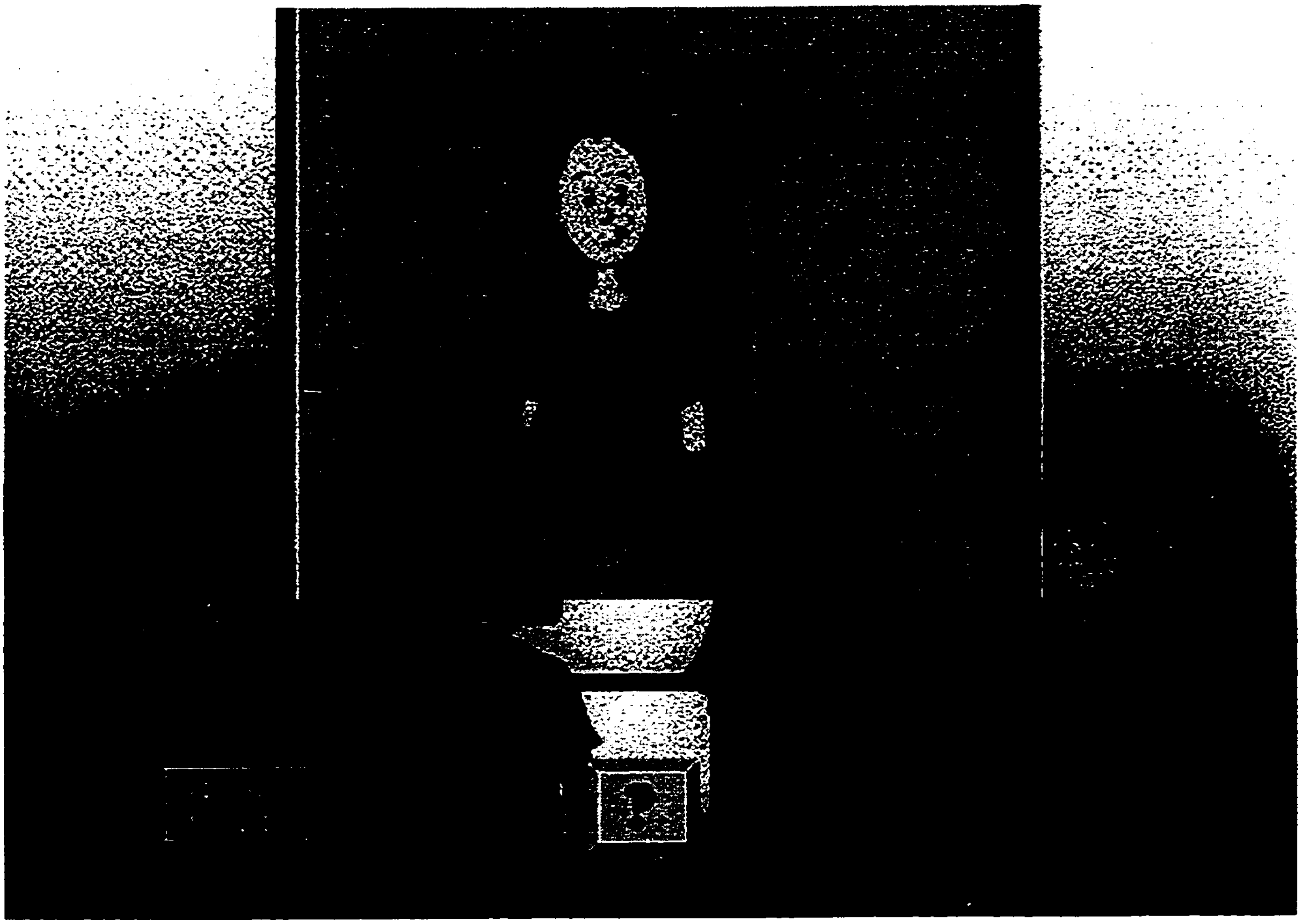
Try again!

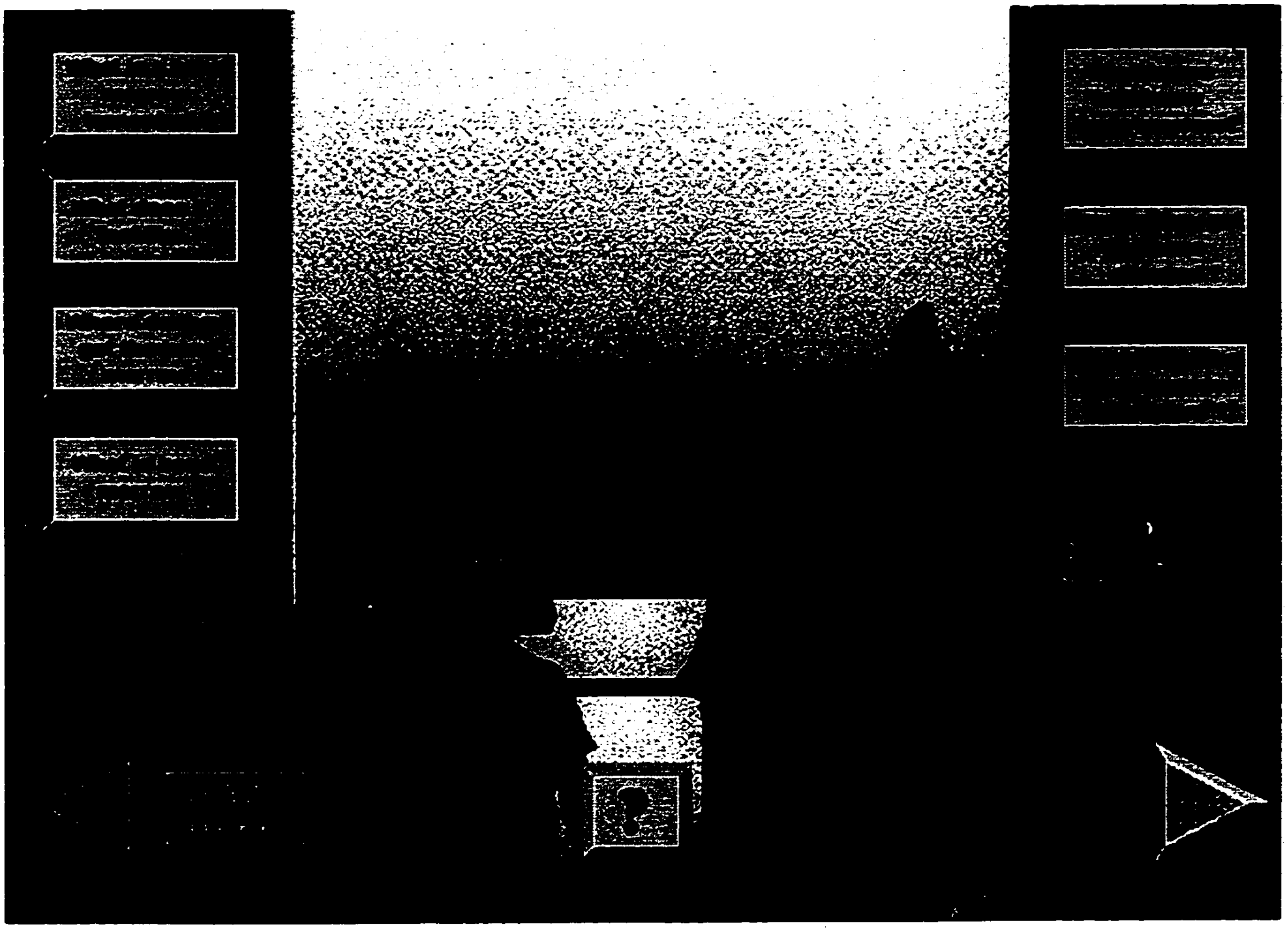

START OVER
?

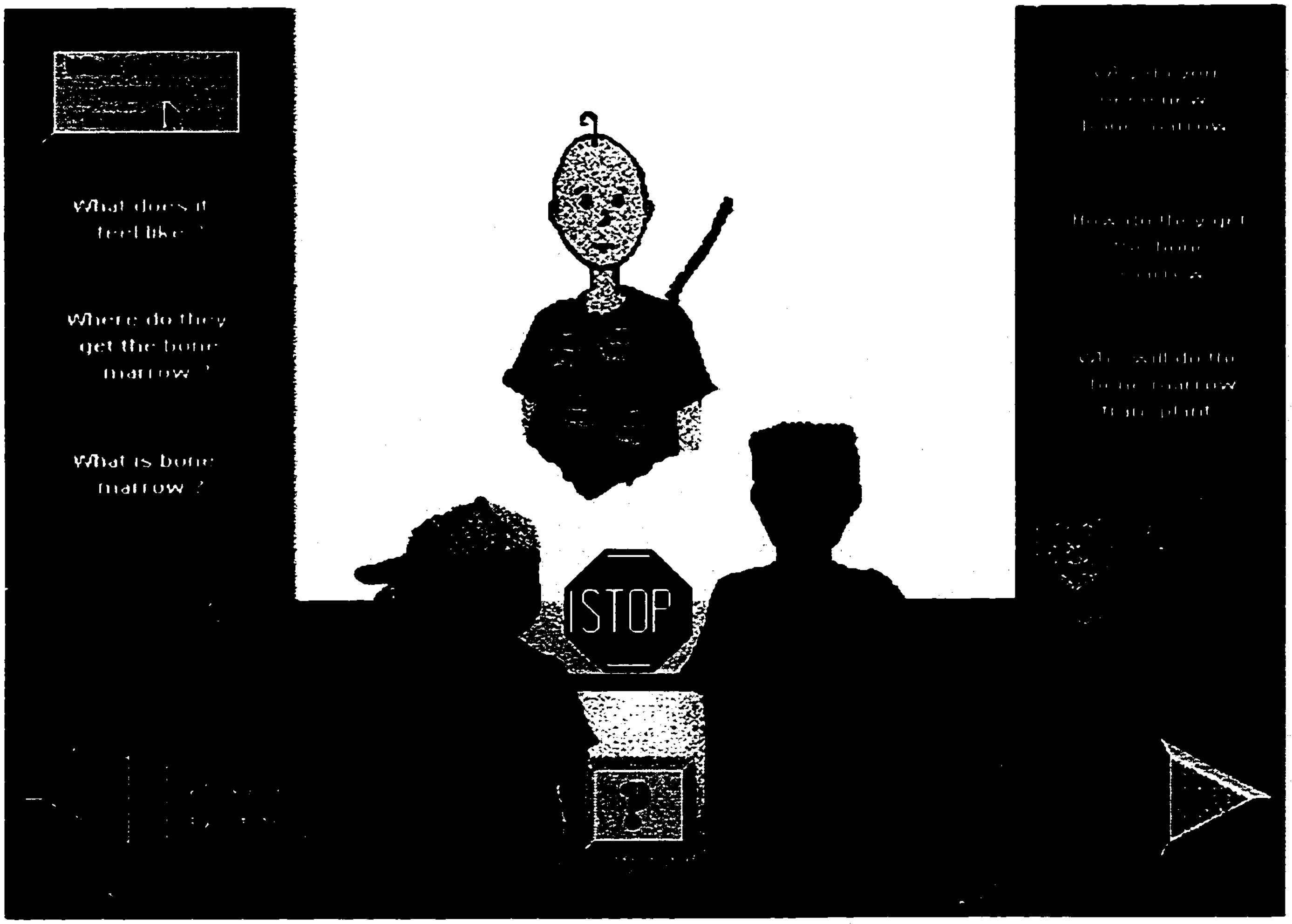

START
OVER
?

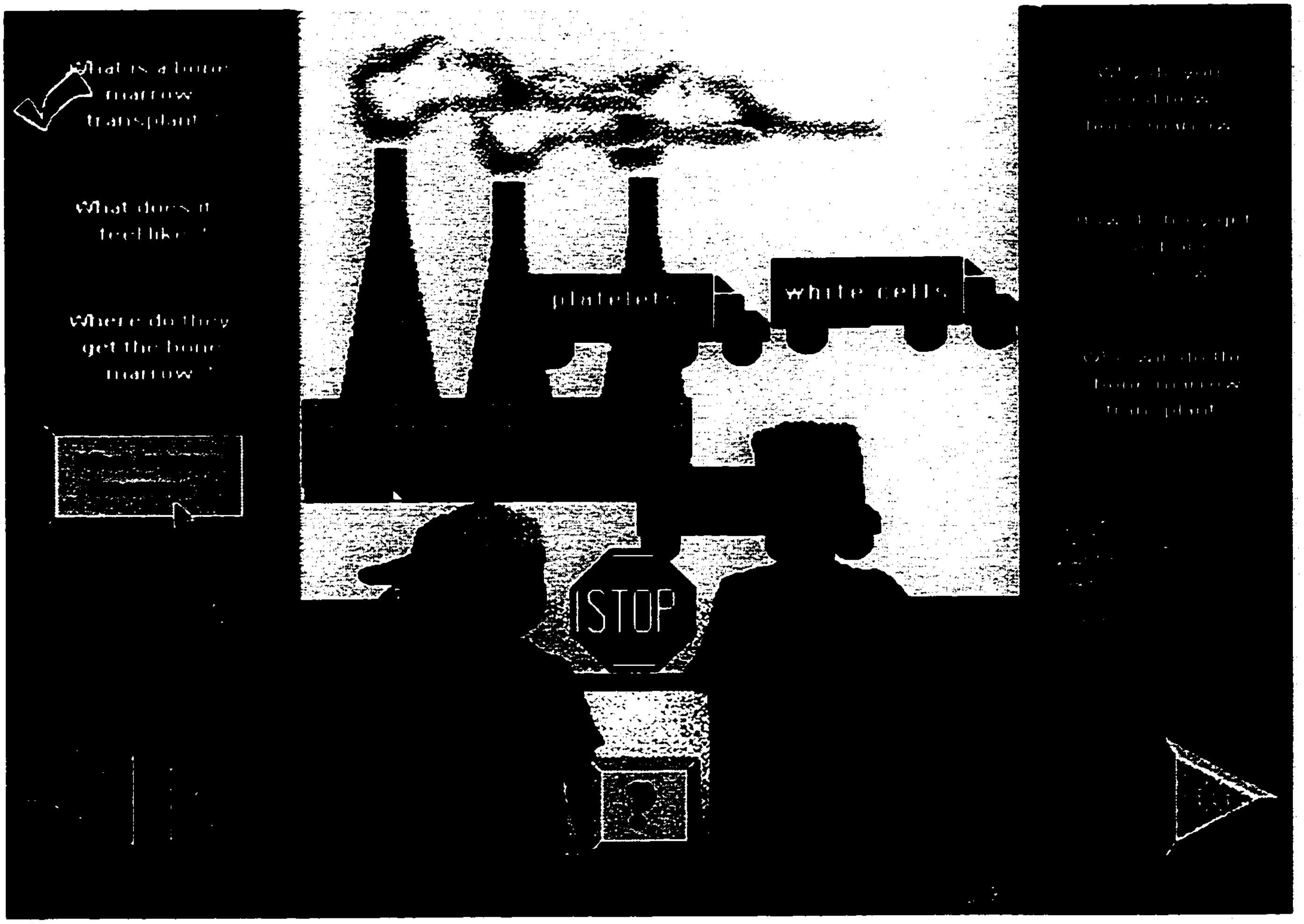


## Appendix E. Stop-Over #1 : You need a BMT

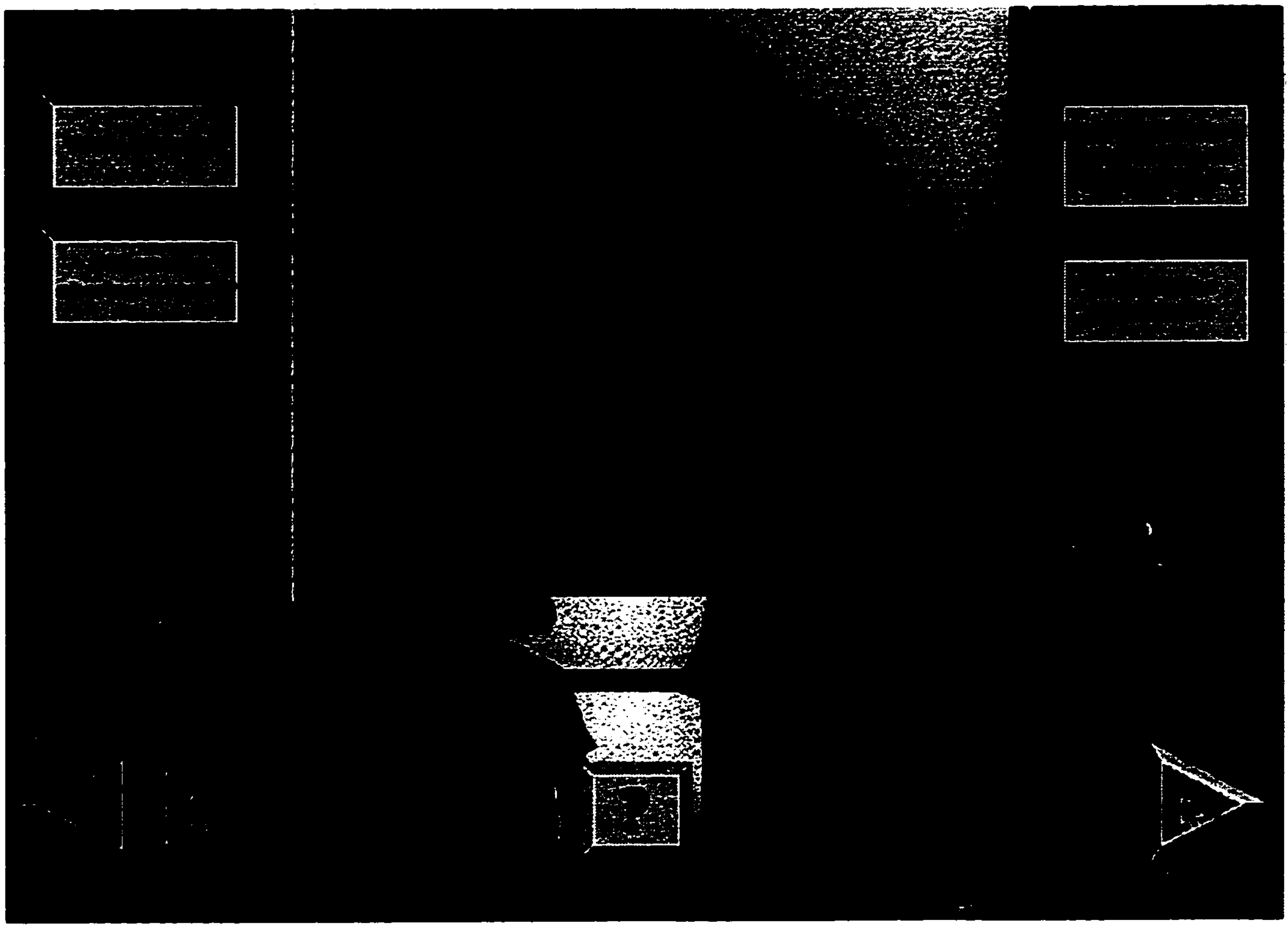


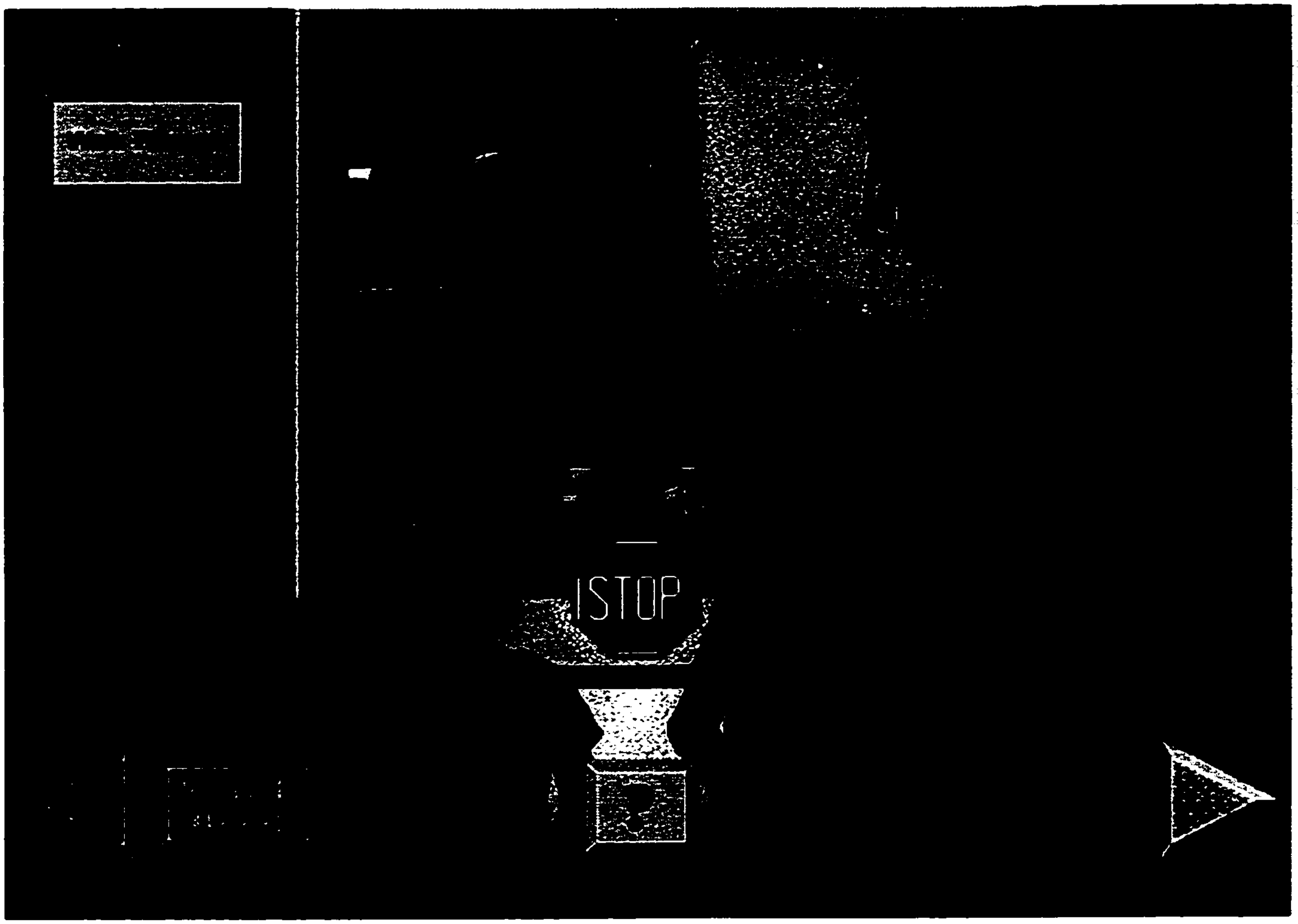



What does it feel like ?
Where do they get the bone marrow ?
What is bone marrow ?
STOP

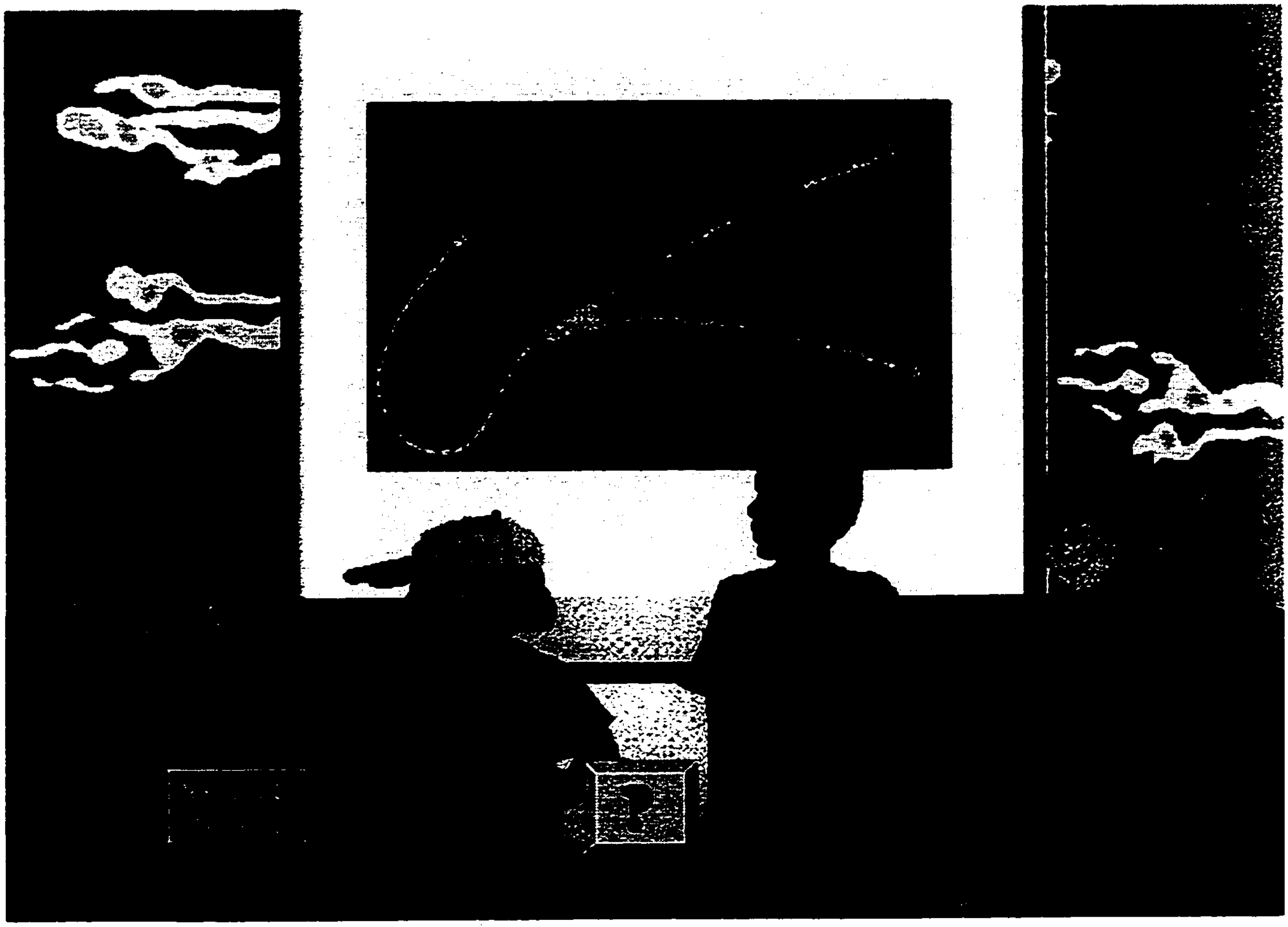

What is a bone marrow transplant?
What does it feel like?
Where do they get the bone marrow?
platelets
white cells
STOP
[illegible]
[illegible]
[illegible] bone marrow transplant

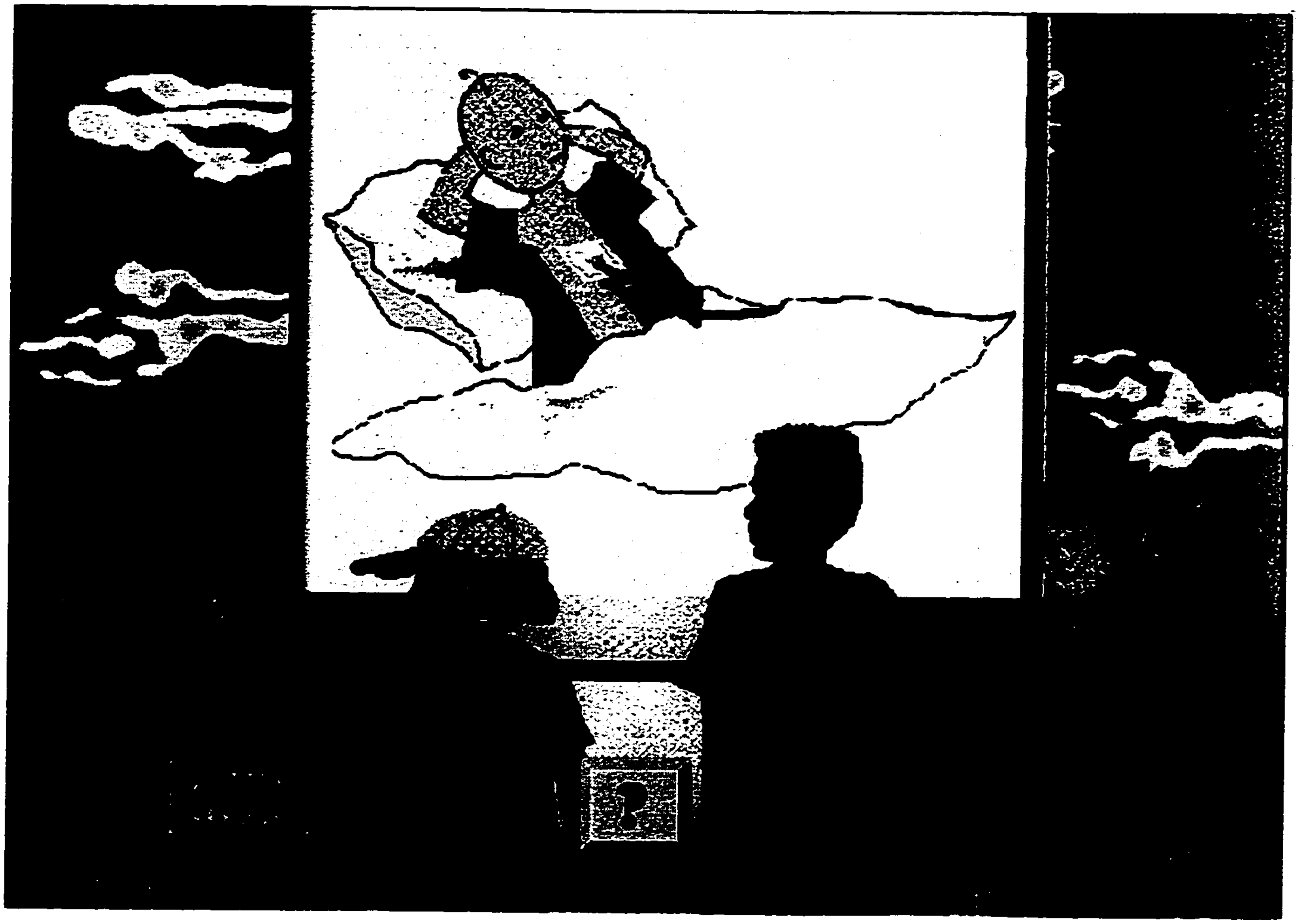
# Appendix F. Stop-Over #2 : Admission to BMT unit

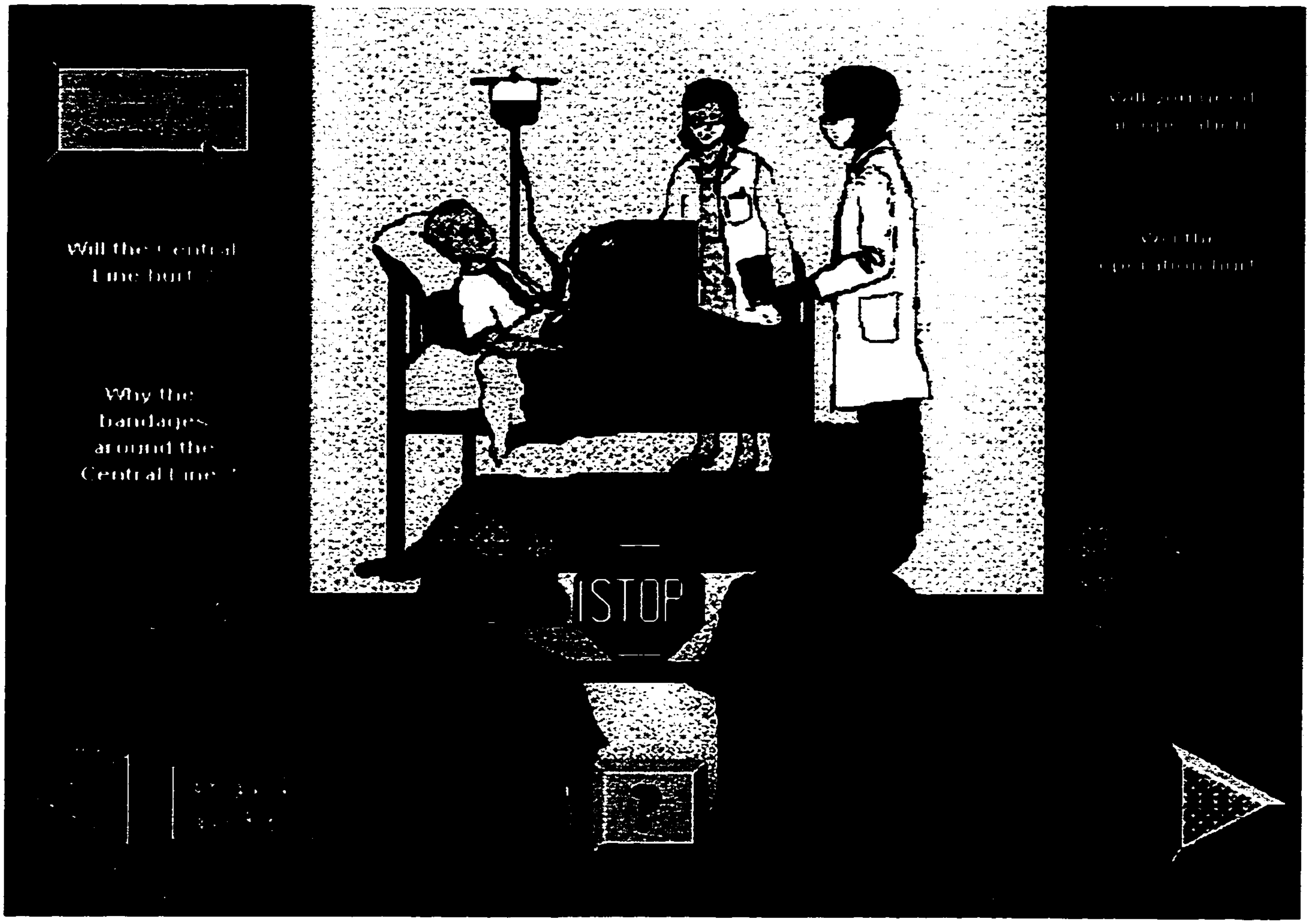



STOP

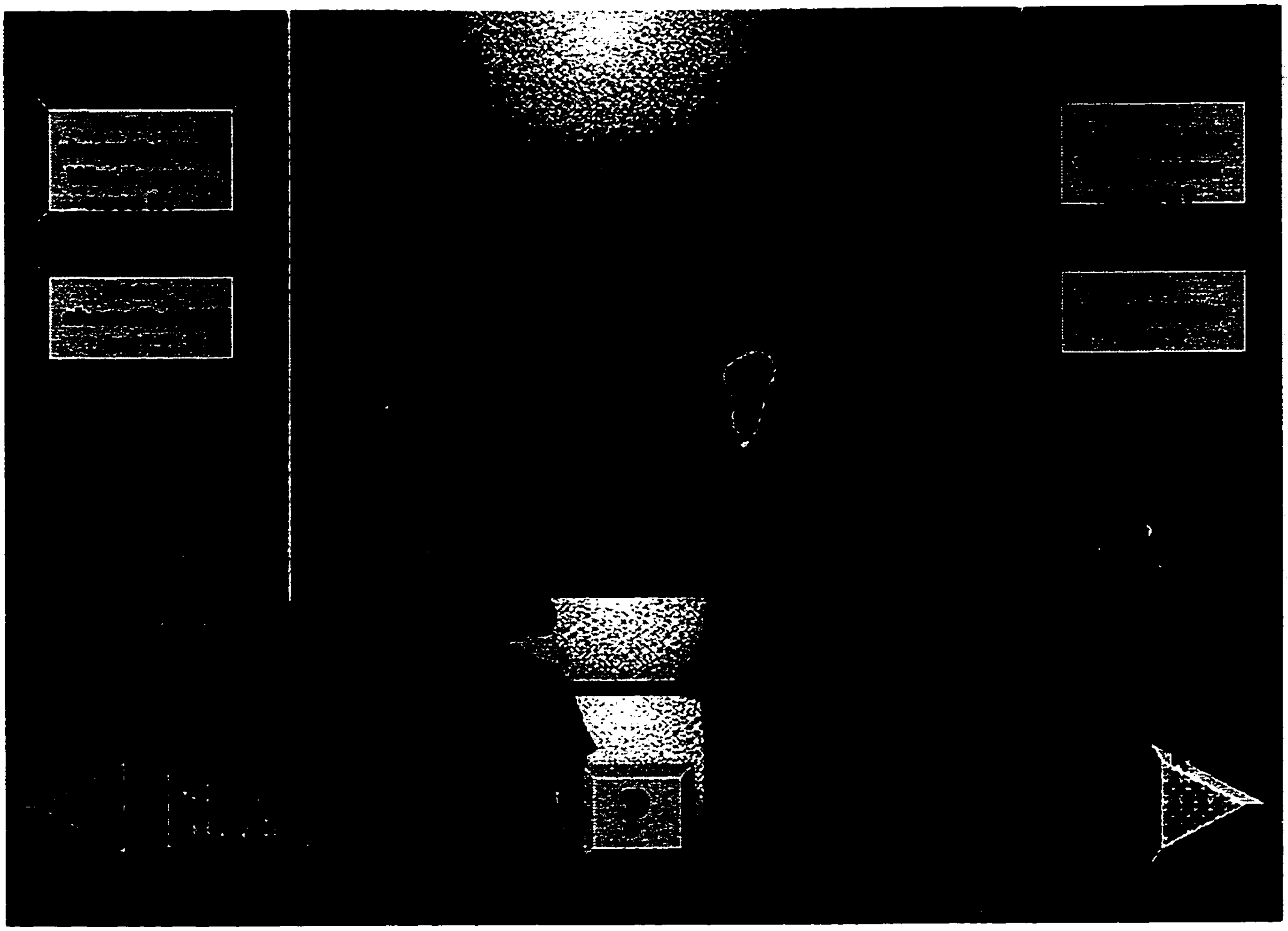
## Appendix G. Stop-Over #3 : Central Line

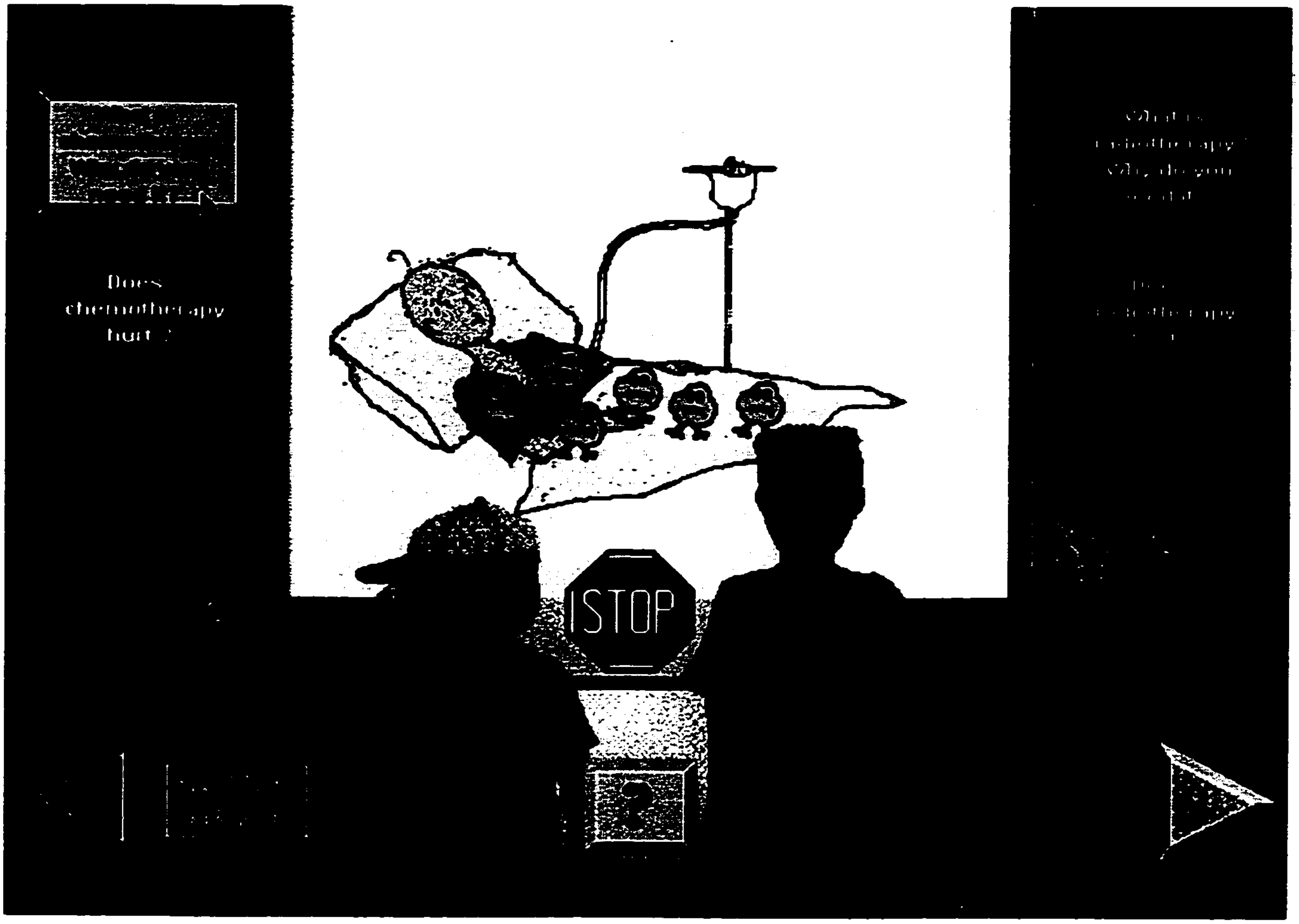




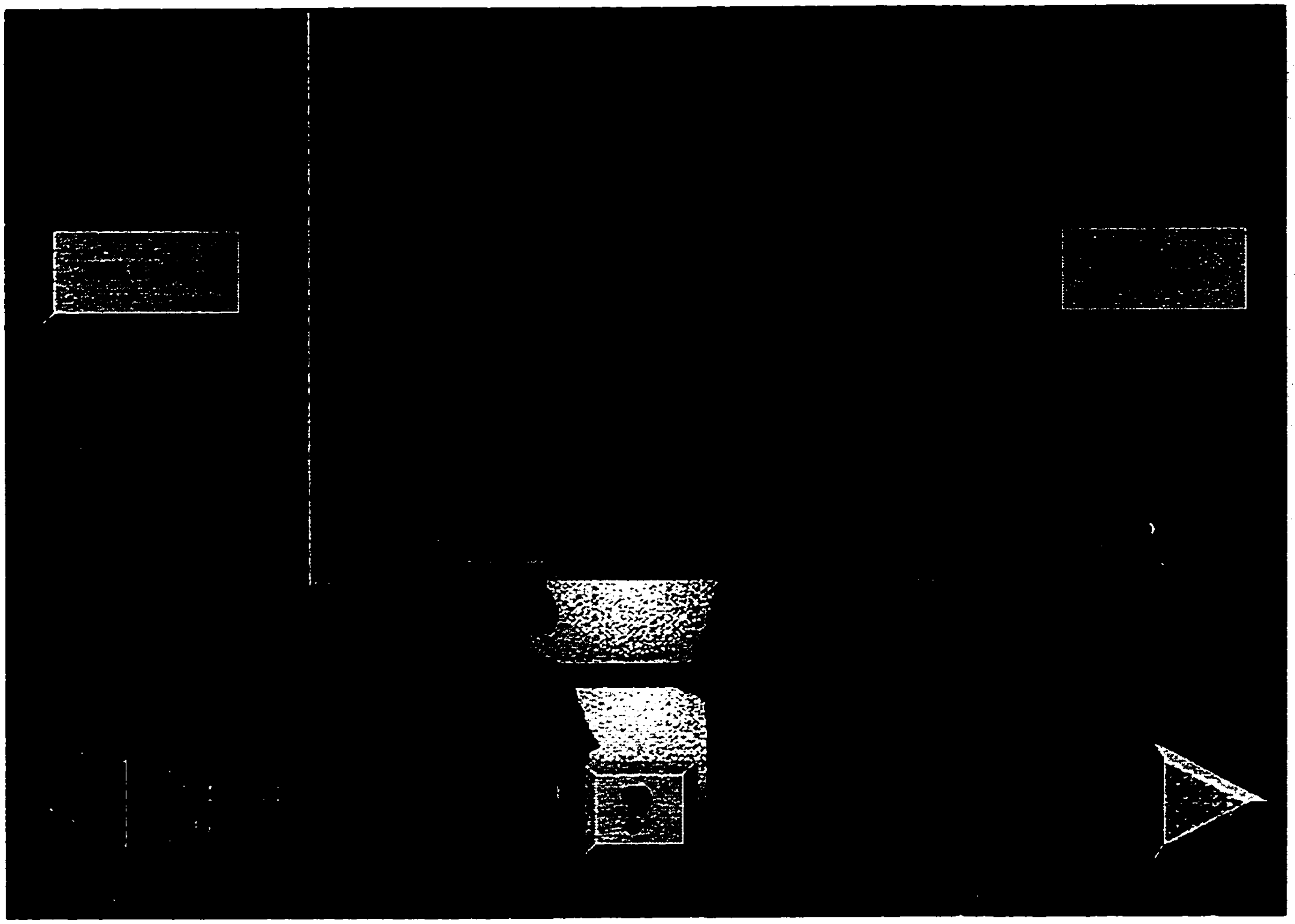

Will the Central Line hurt?
Why the bandages around the Central Line?
Will you need an operation?
Will the operation hurt?
STOP

# Appendix H. Stop-Over #4 : Chemo and radiation therapy

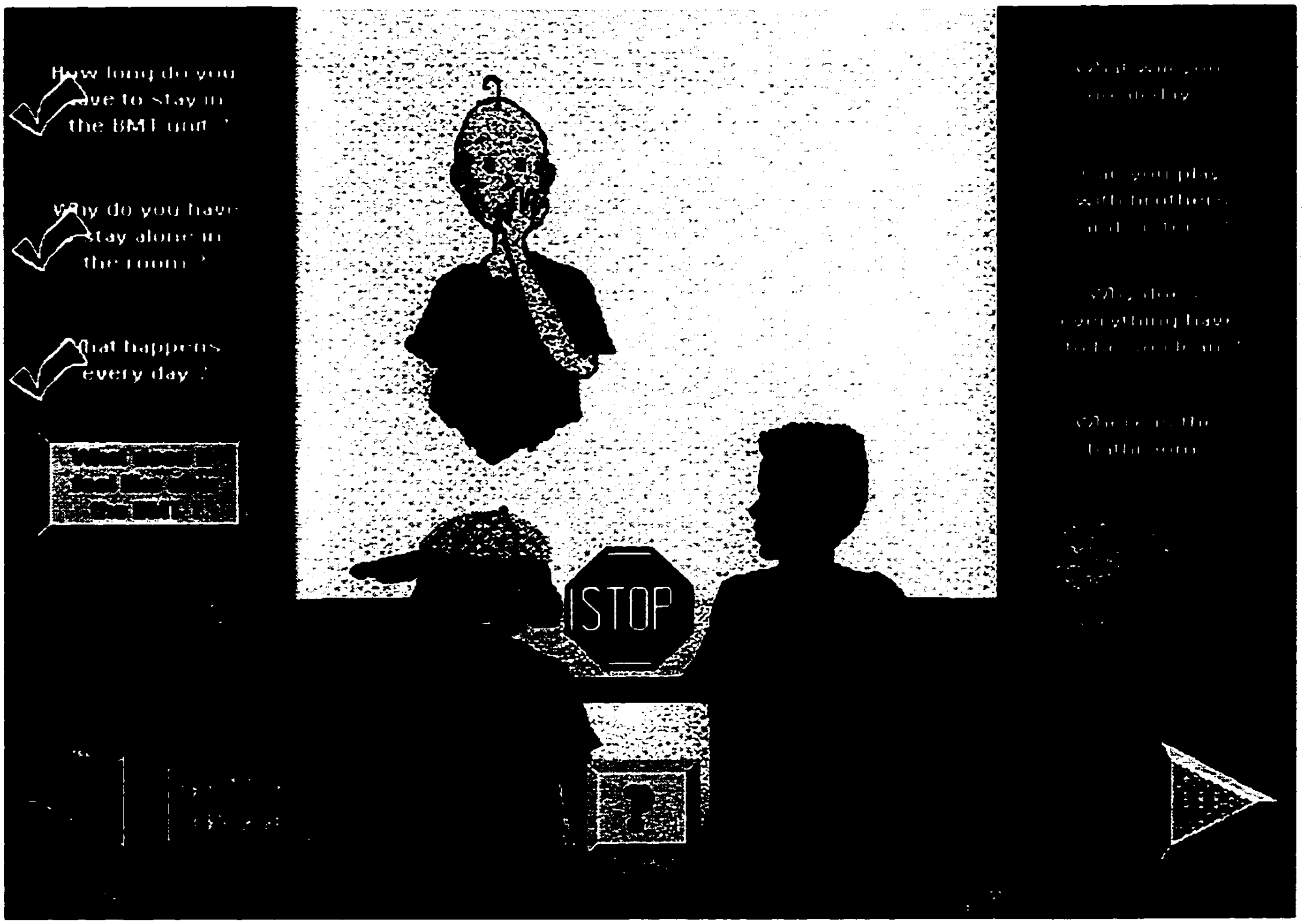


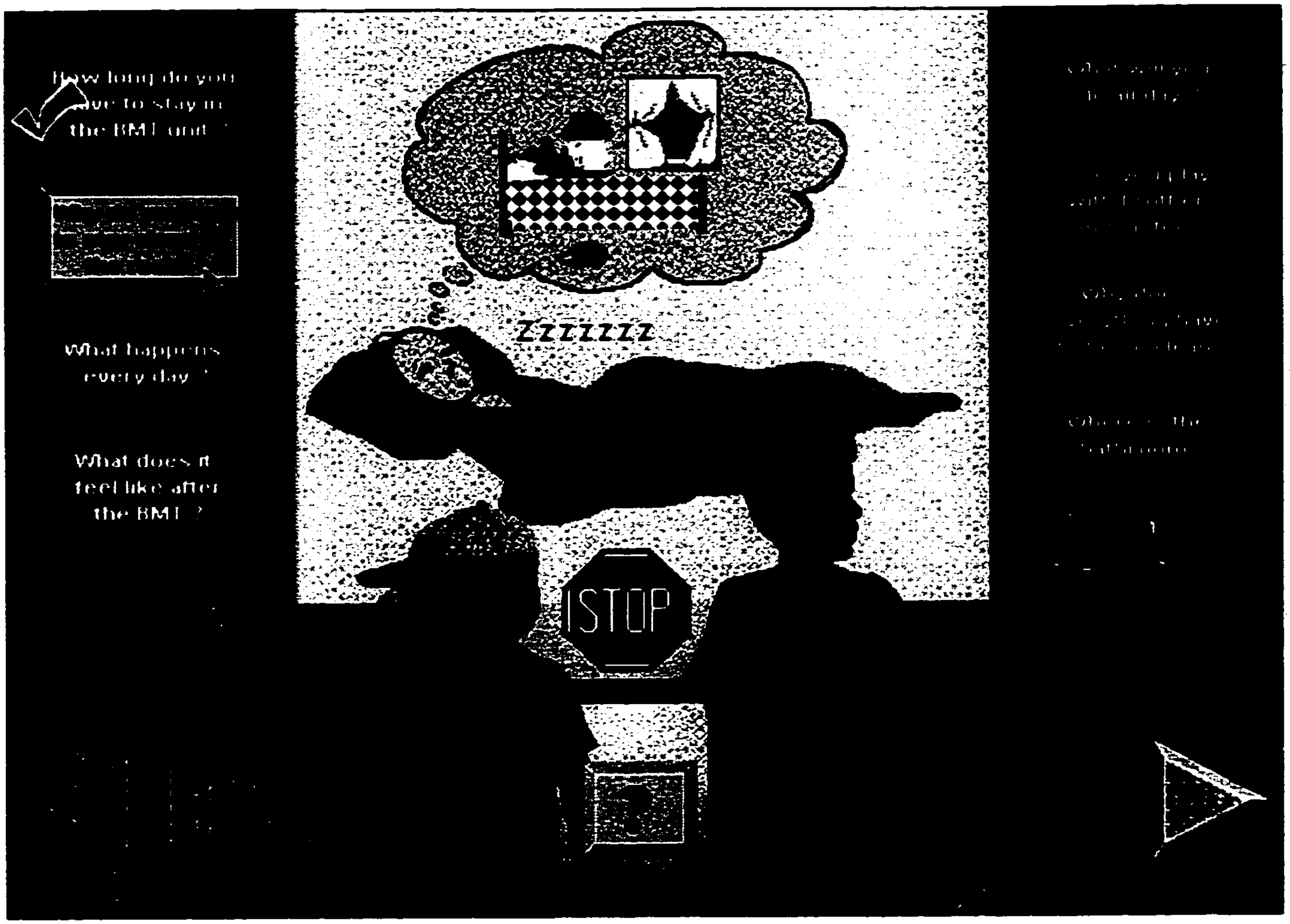

Does chemotherapy hurt ?
What is radiotherapy? Why do you need it
Does radiotherapy hurt
STOP
?

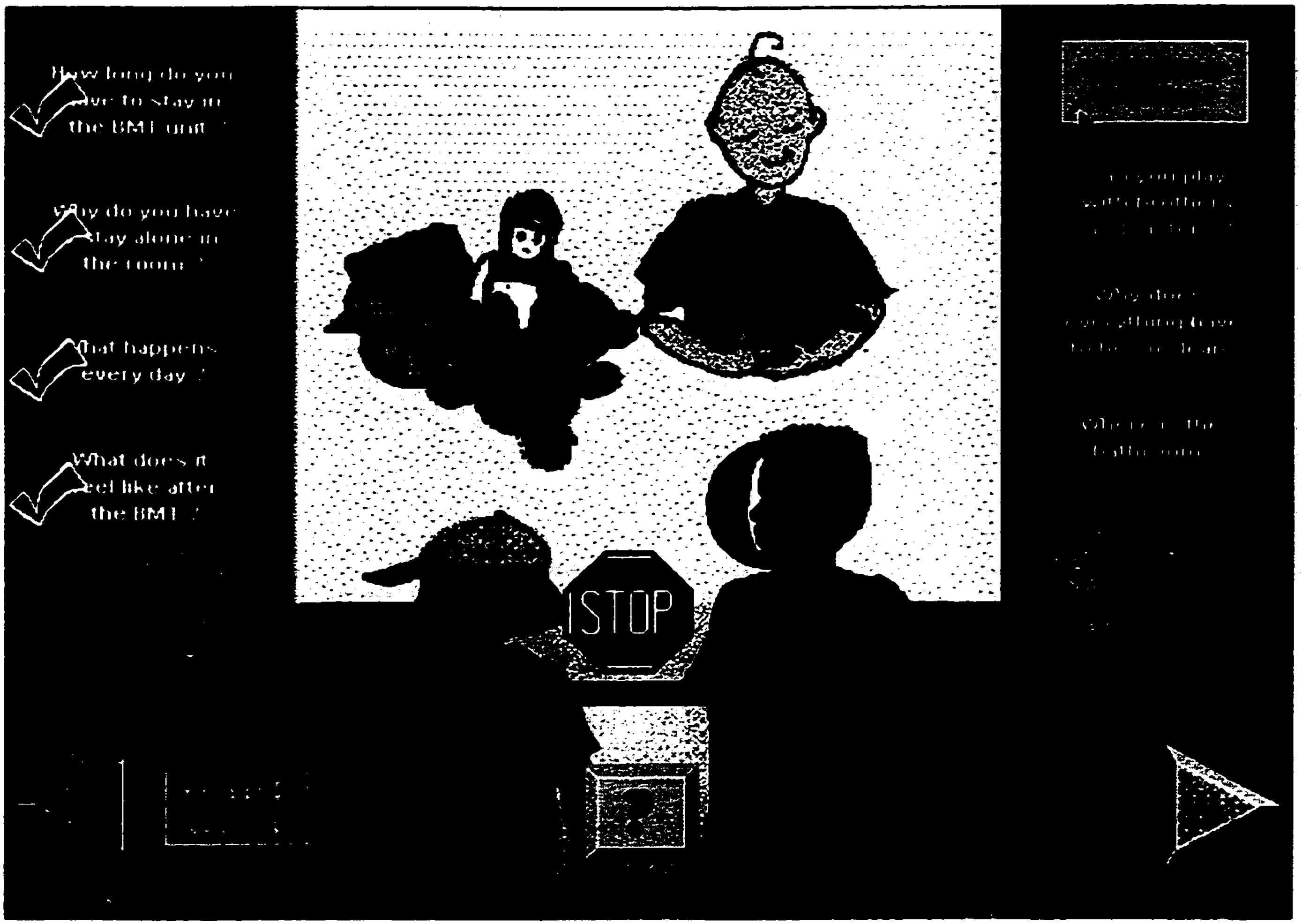
# Appendix I. Stop-Over #5 : BMT

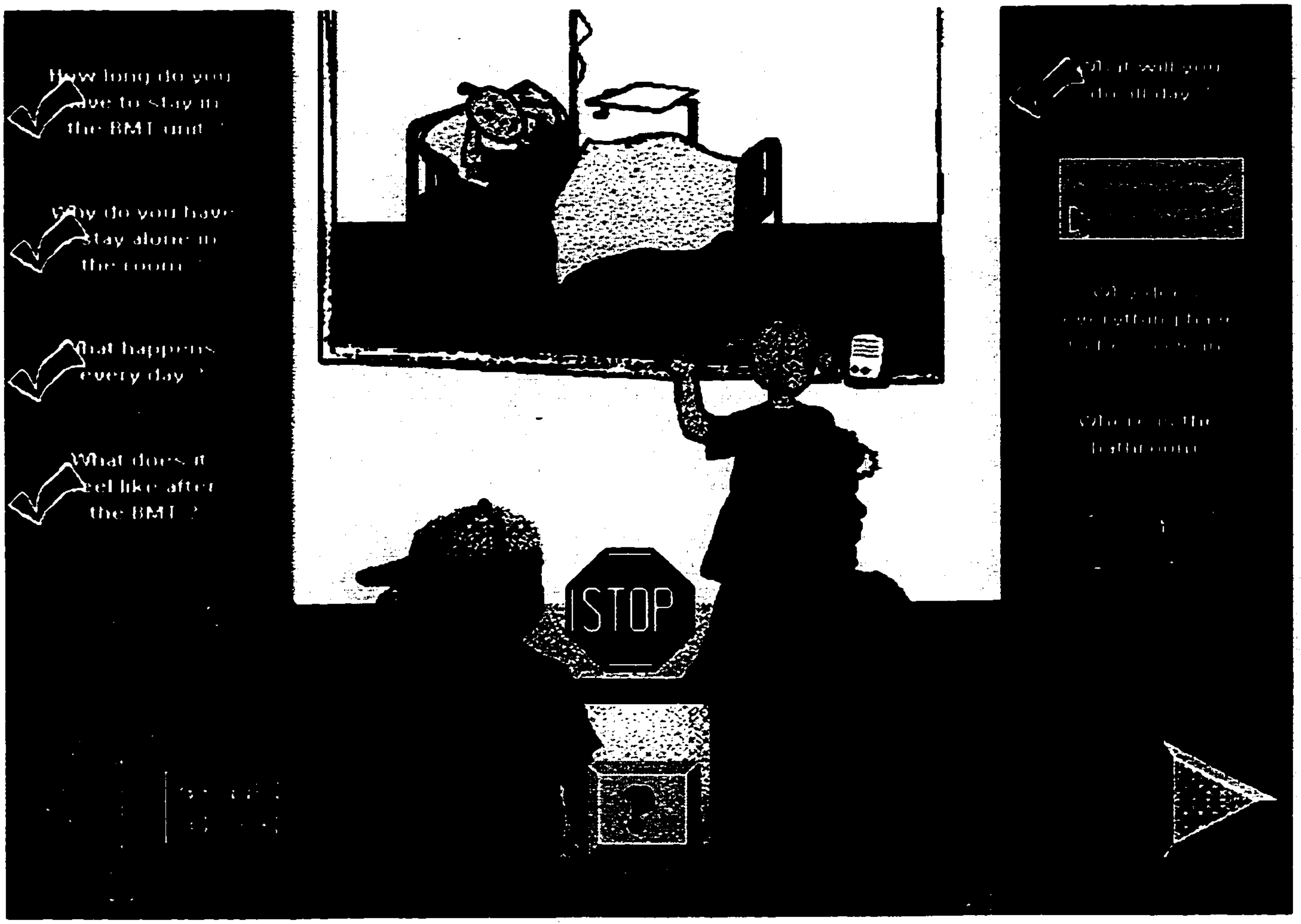


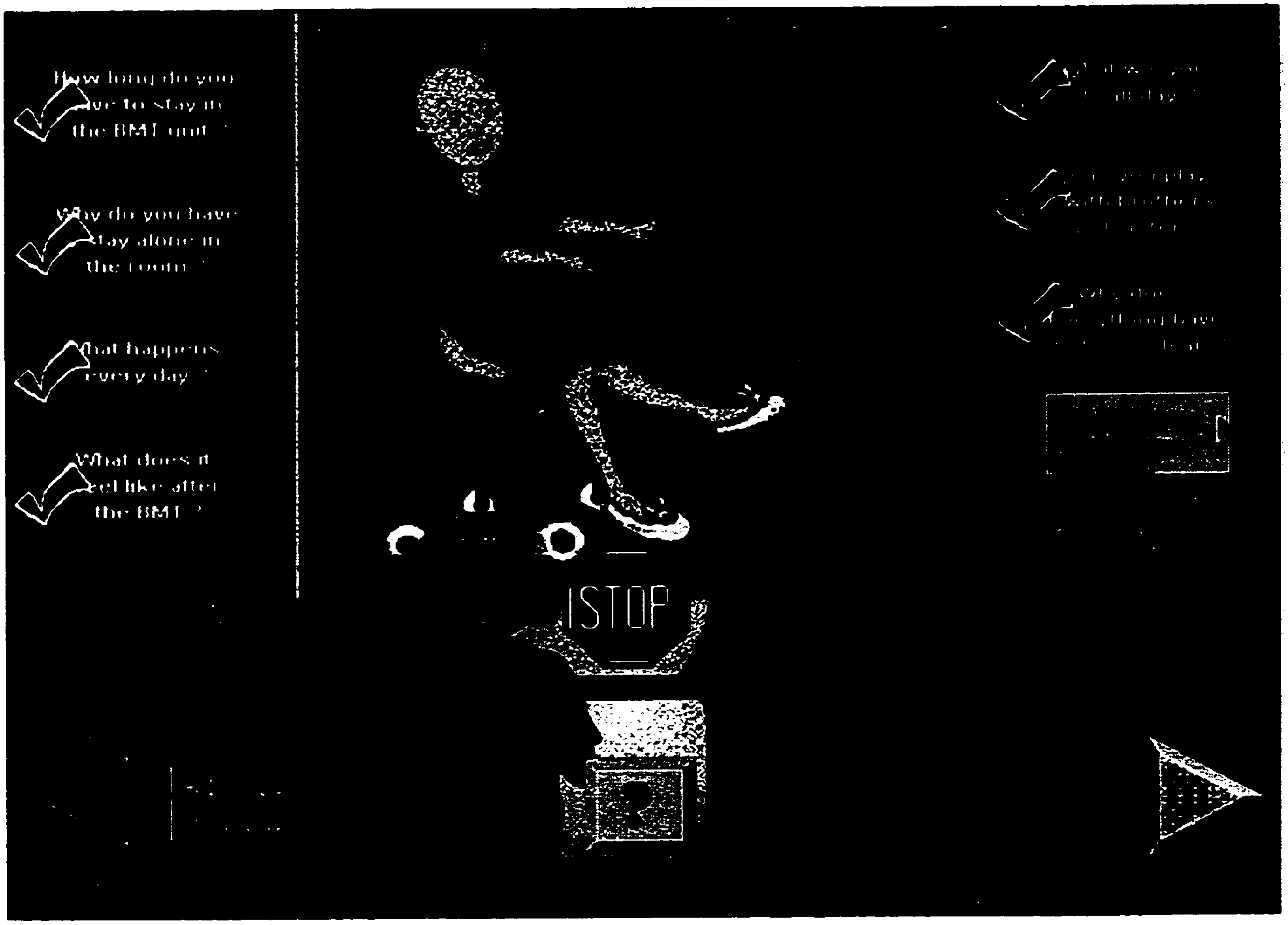
# Appendix J. Stop-Over #6 : Engrafment


How long do you have to stay in the BMT unit ?
Why do you have to stay alone in the room ?
What happens every day ?
STOP
What can you do all day
Can you play with brothers and sisters ?
Why does everything have to be so clean ?
Where is the bathroom

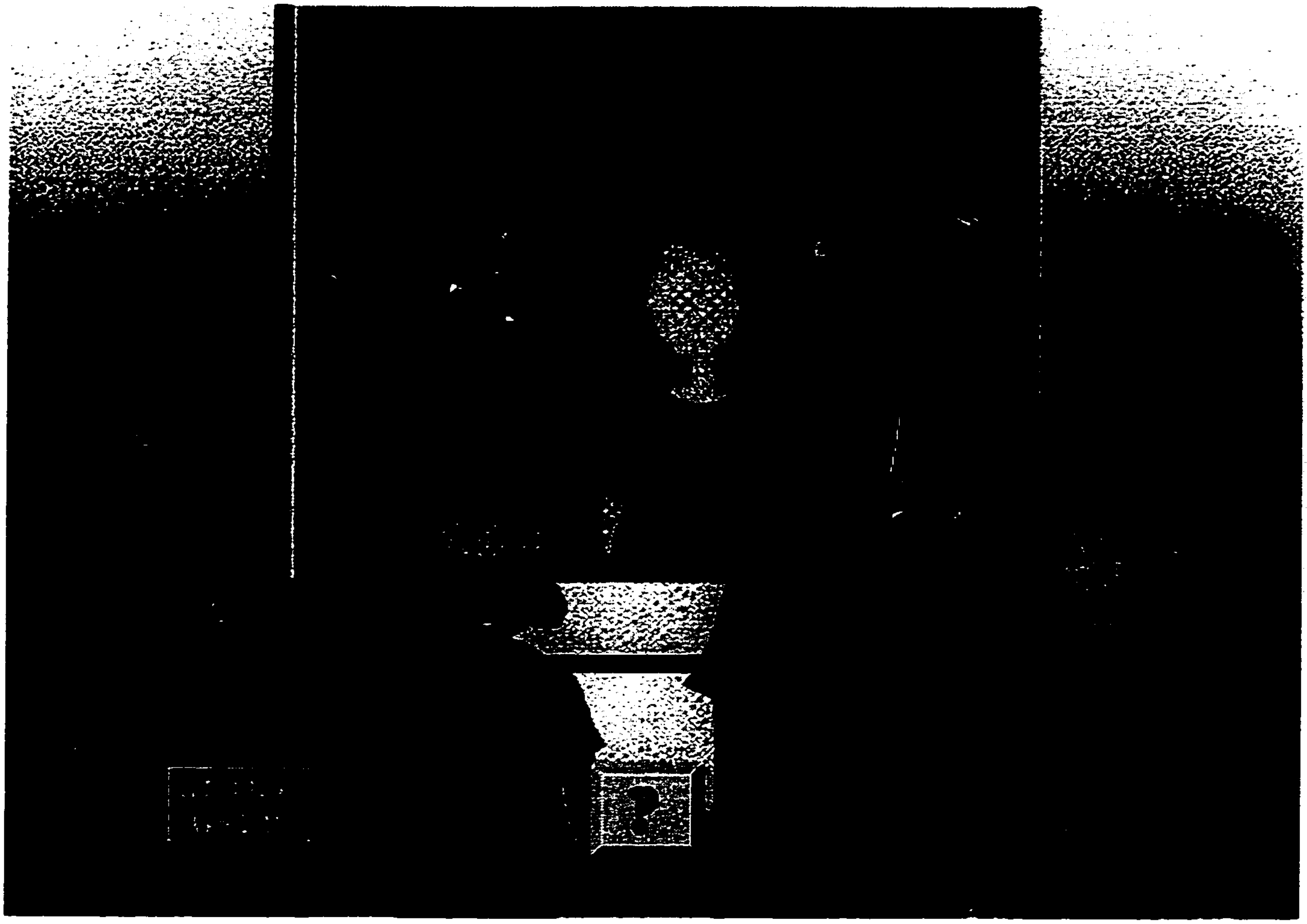

How long do you have to stay in the BMT unit ?
What happens every day ?
What does it feel like after the BMT ?
Zzzzzzz
STOP

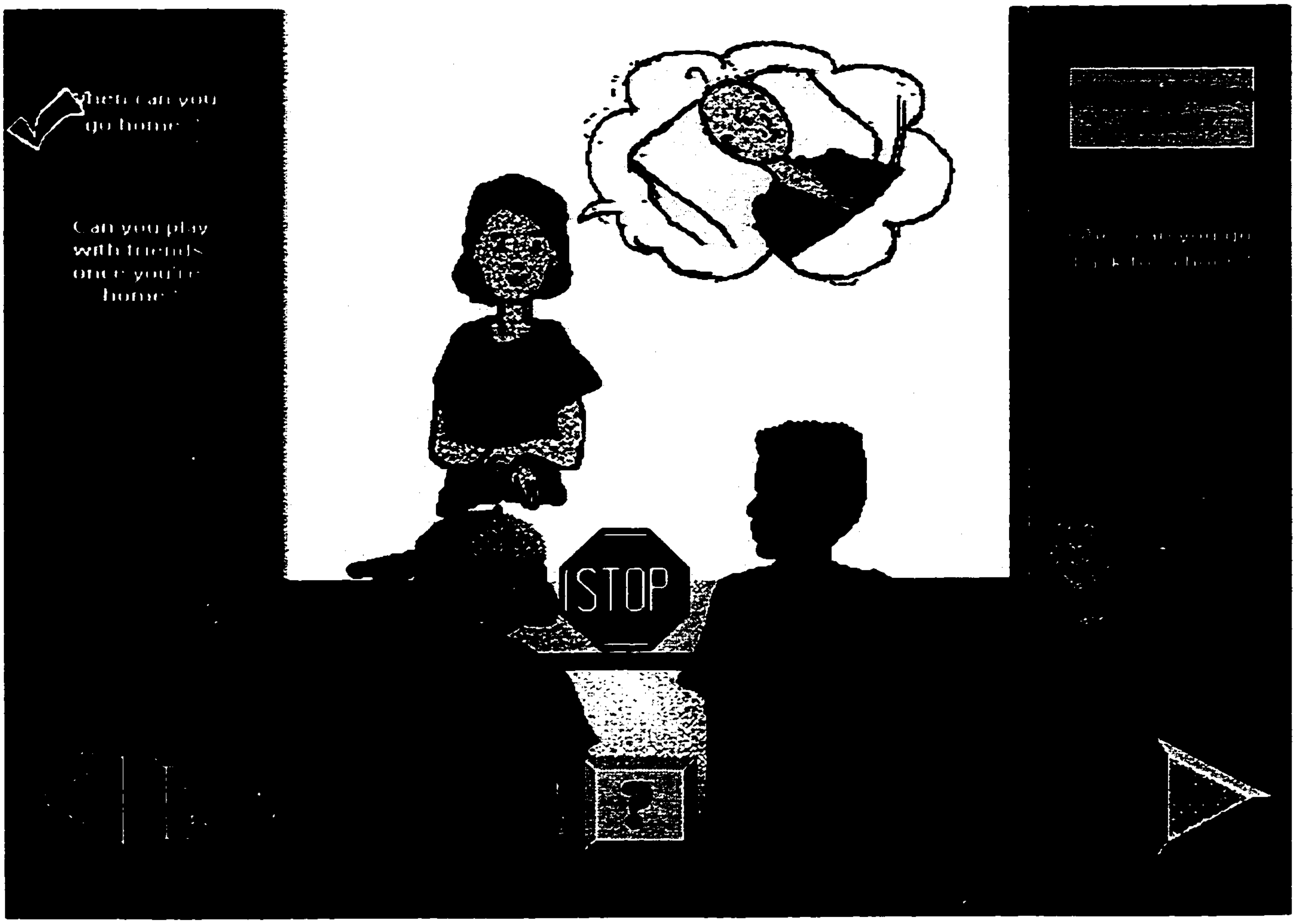

How long do you have to stay in the BMT unit ?
Why do you have to stay alone in the room ?
What happens every day ?
What does it feel like after the BMT ?
STOP
[illegible] you play with brothers [illegible] ?
Why does everything have to be [illegible] clean
Where is the bathroom

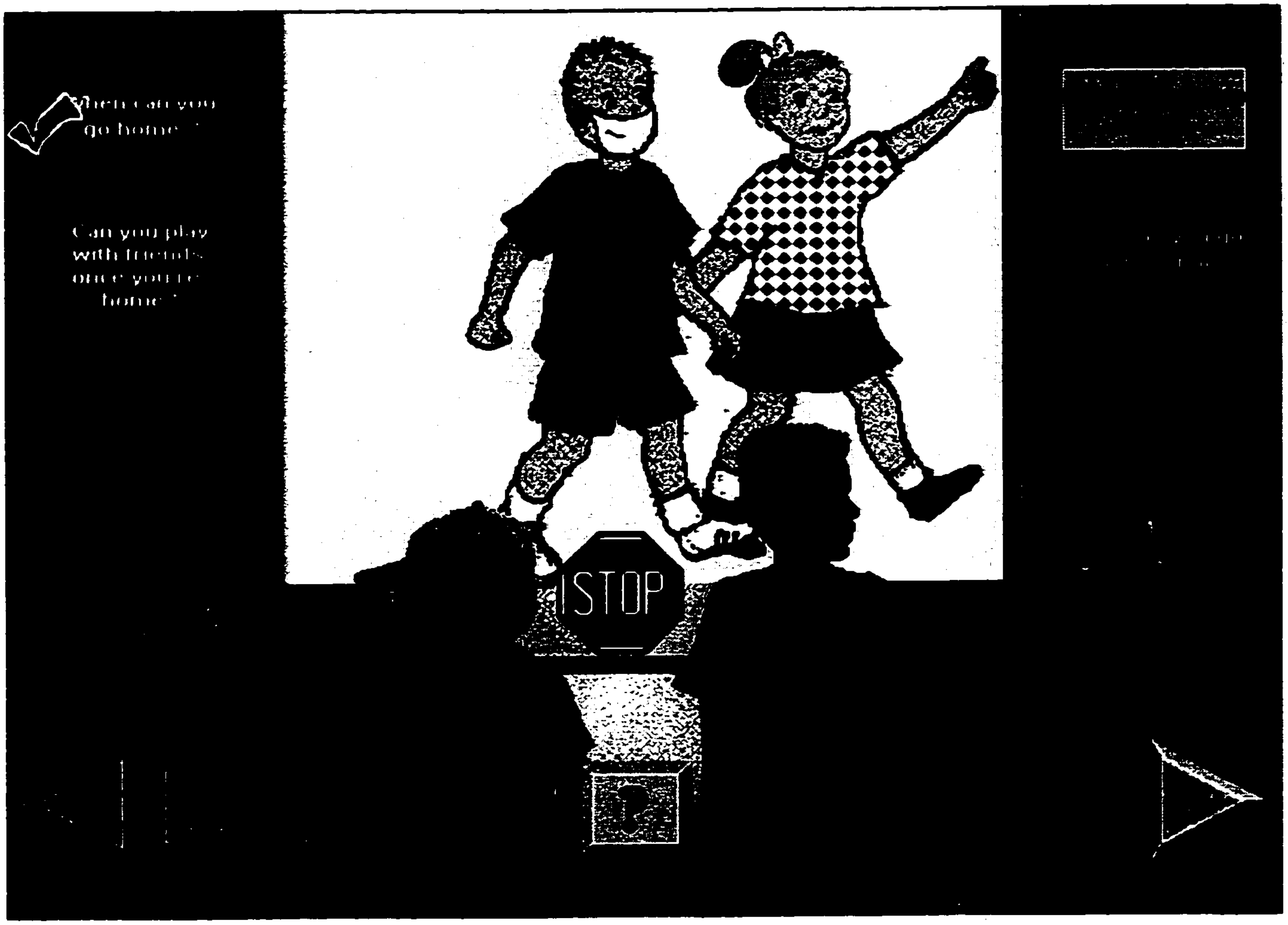

How long do you have to stay in the BMT unit ?
Why do you have to stay alone in the room ?
What happens every day ?
What does it feel like after the BMT ?
What will you do all day ?
Where is the bathroom
STOP


How long do you have to stay in the BMT unit?
Why do you have to stay alone in the room?
What happens every day?
What does it feel like after the BMT?
STOP

## Appendix K. Stop-Over #7 : Going Home



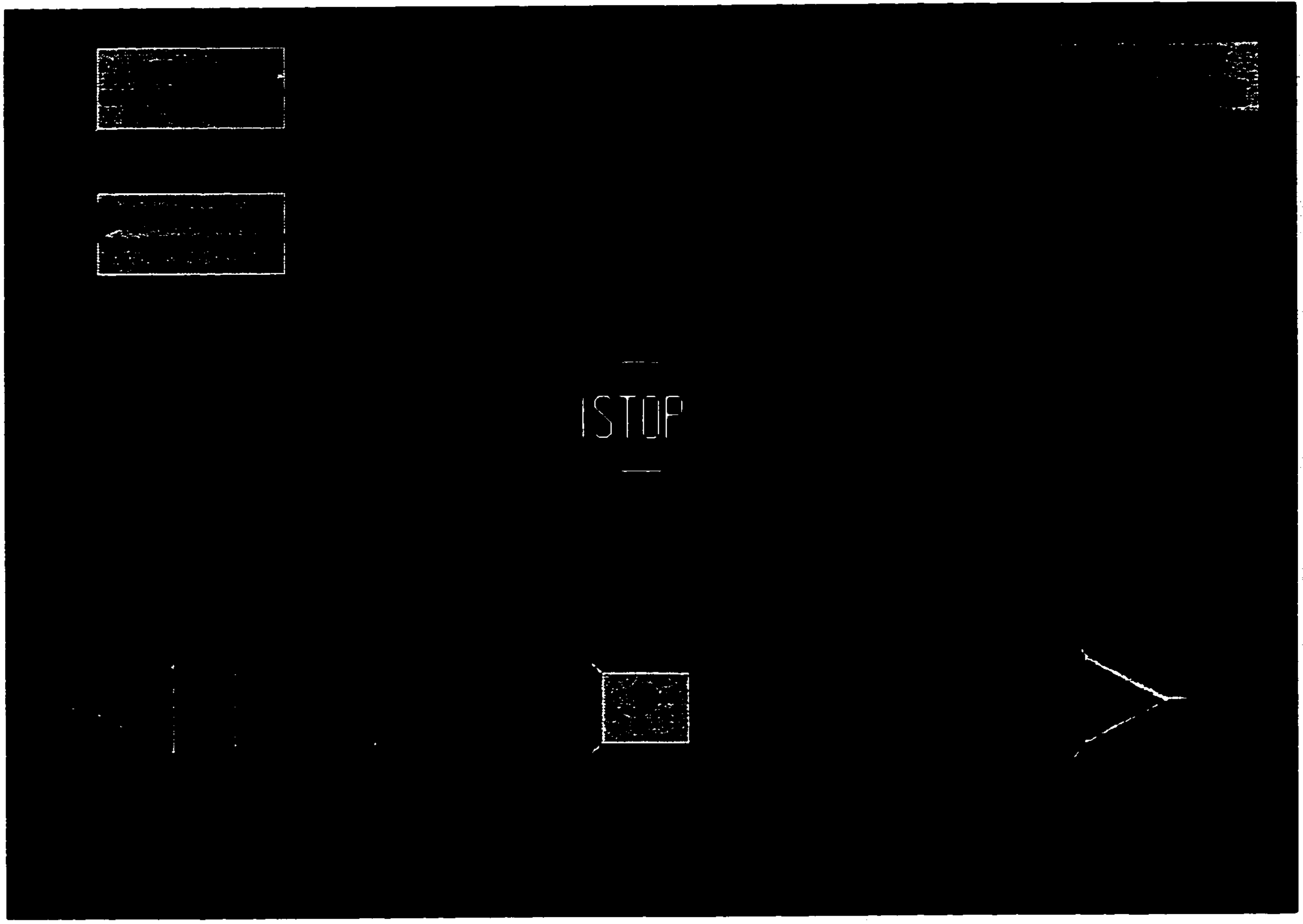

When can you go home?
Can you play with friends once you're home?
When can you go back to school?
STOP



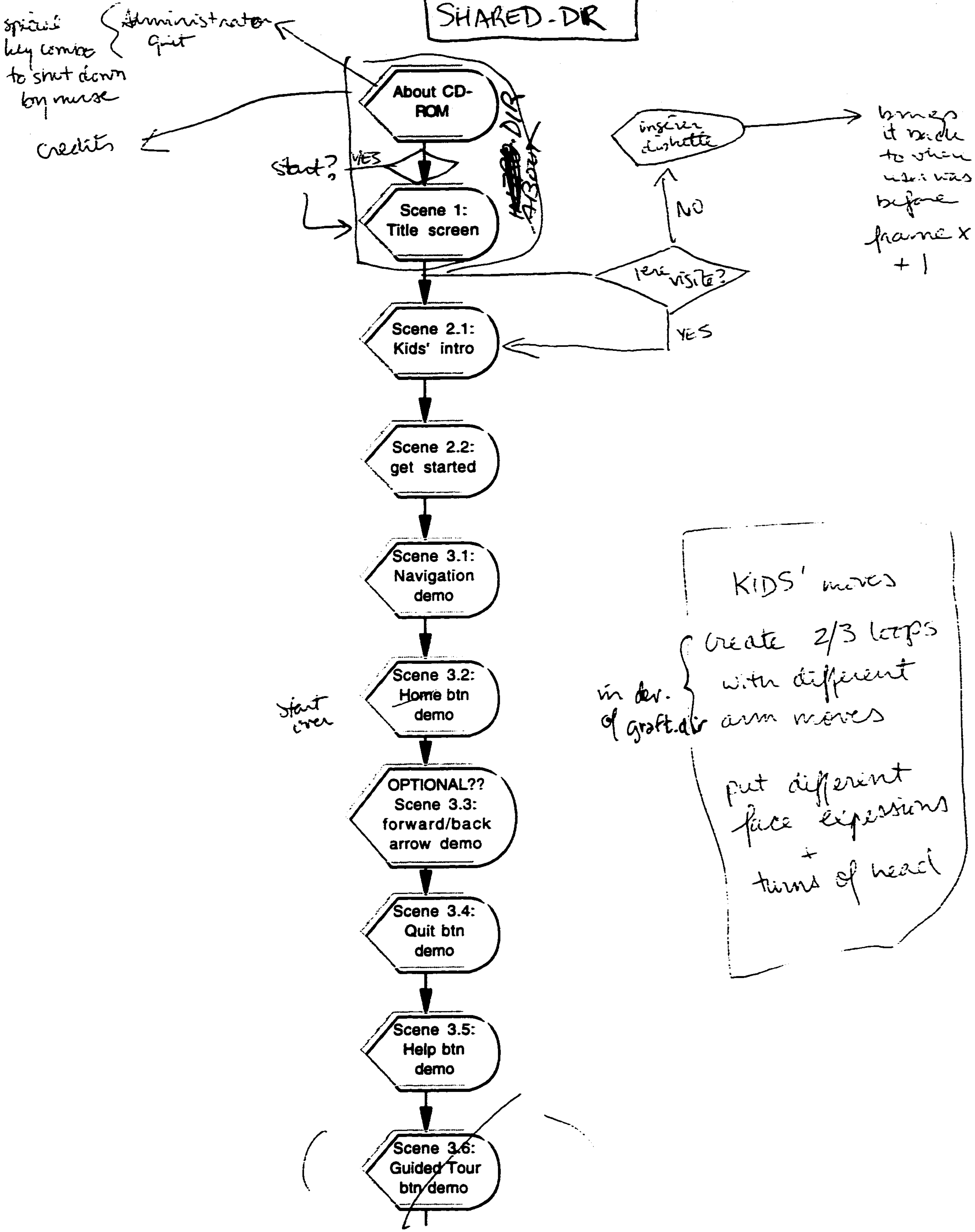
When can you go home?

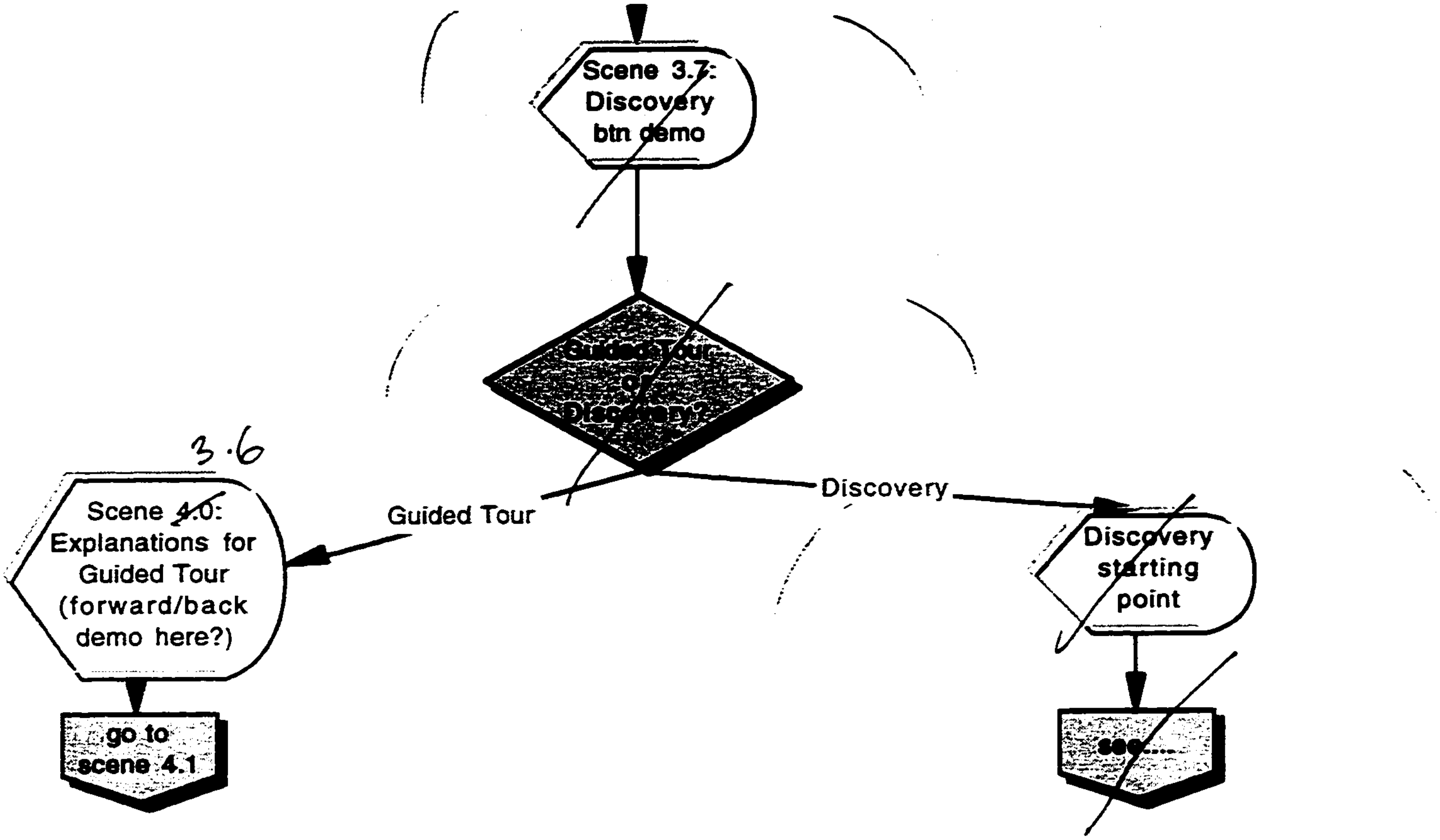
Can you play with friends once you're home?

# Appendix L. Help screen


!STOP

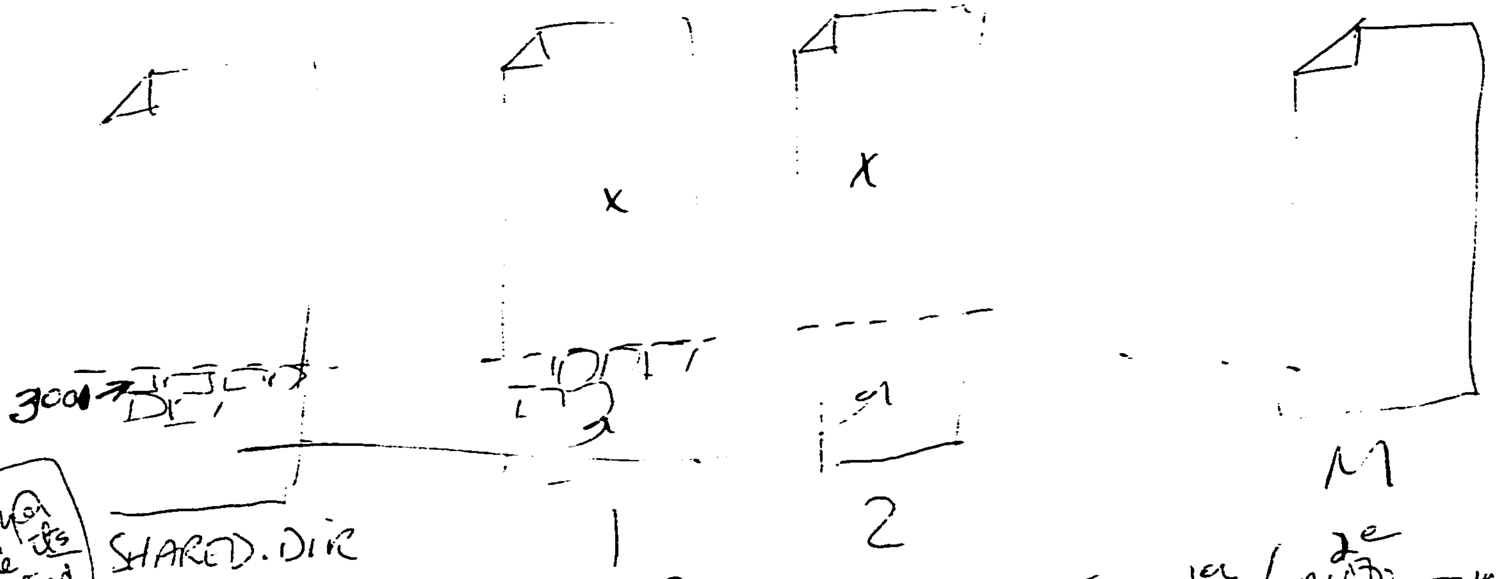
# Appendix M. Flowcharts for each of the movie/scenes


SHARED-DIR
special key combo to shut down by nurse
Administrator quit
credits
About CD-ROM
~~ABOUT~~ DIR
start?
YES
Scene 1: Title screen
insert diskette
brings it back to where user was before
frame x + 1
NO
1ere visite?
YES
Scene 2.1: Kids' intro
Scene 2.2: get started
Scene 3.1: Navigation demo
start over
Scene 3.2: ~~Home~~ btn demo
OPTIONAL?? Scene 3.3: forward/back arrow demo
Scene 3.4: Quit btn demo
Scene 3.5: Help btn demo
Scene 3.6: Guided Tour btn demo
in dev. of graft.dir
KIDS' moves
create 2/3 loops with different arm moves
put different face expressions + turns of head



in 6GS BMT (shared...)
when working on
it on hard disk / local disk

Shared. dir → Shared cast

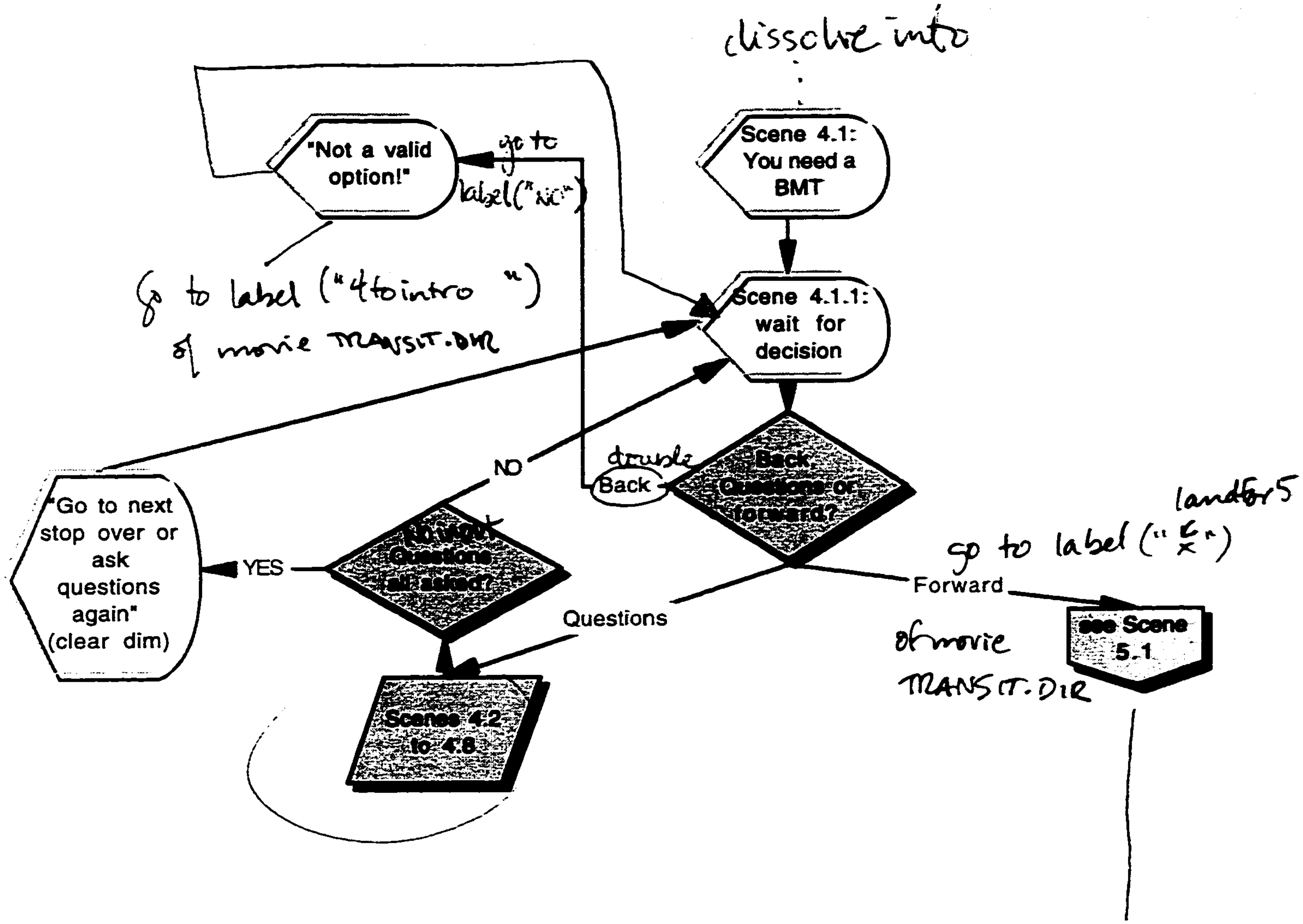


ntifyor
its
ime
modified

créer 1er / 2e photo — module 6

liste d'éléments pour SHARED
pour @ des fichiers

↳ what elements in what channels?



TRANSIT. DIR

- dissolve
- spaceship flying across new sky (7?)

or

through galaxy going farther & farther (metaphor of isolation)

- go to 5.1 (adminit.dir)

go to label("xyz") of movie TRANSIT. DIR

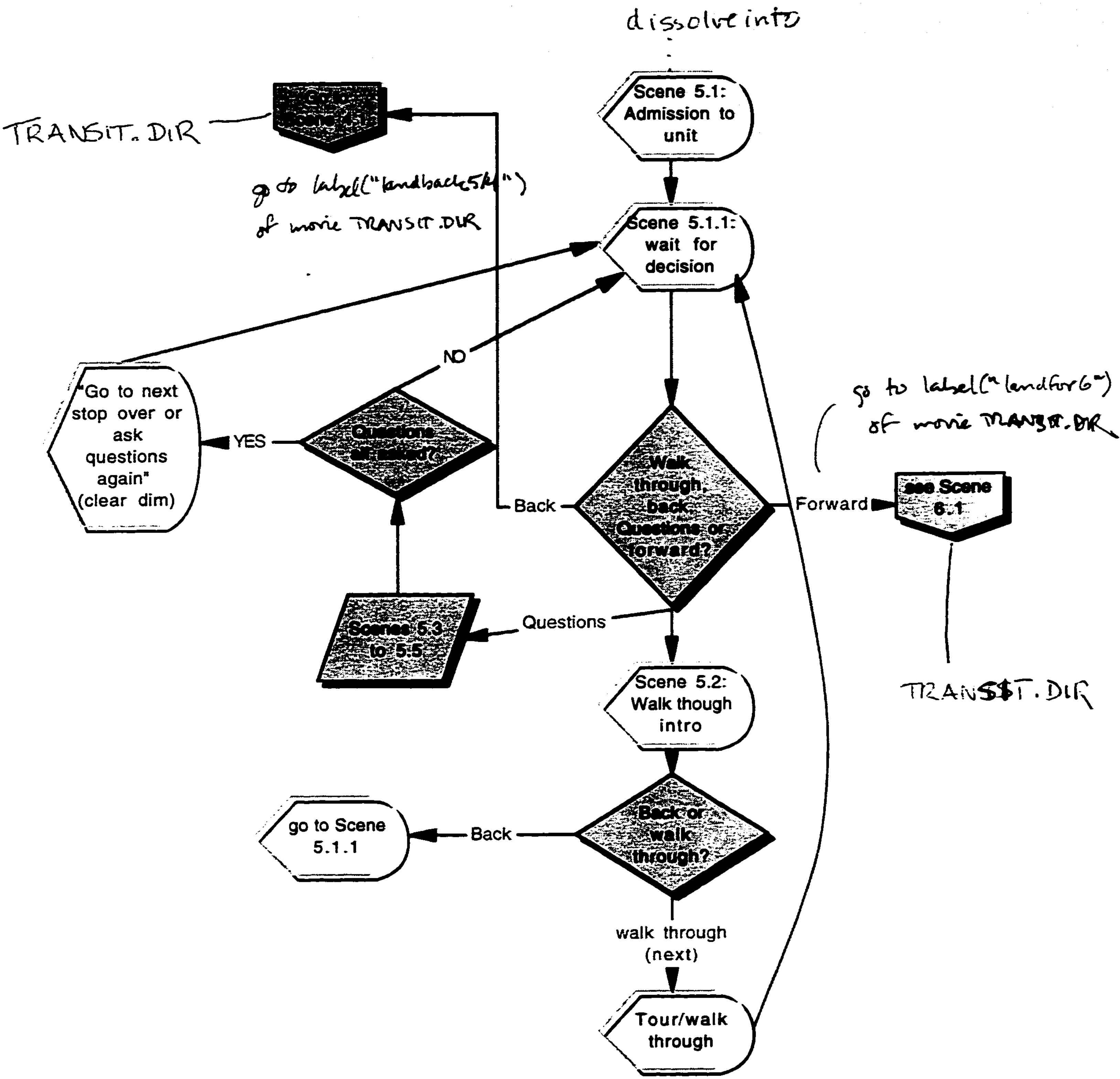
or back

17 labels ?

↓

1 label per going forward/back

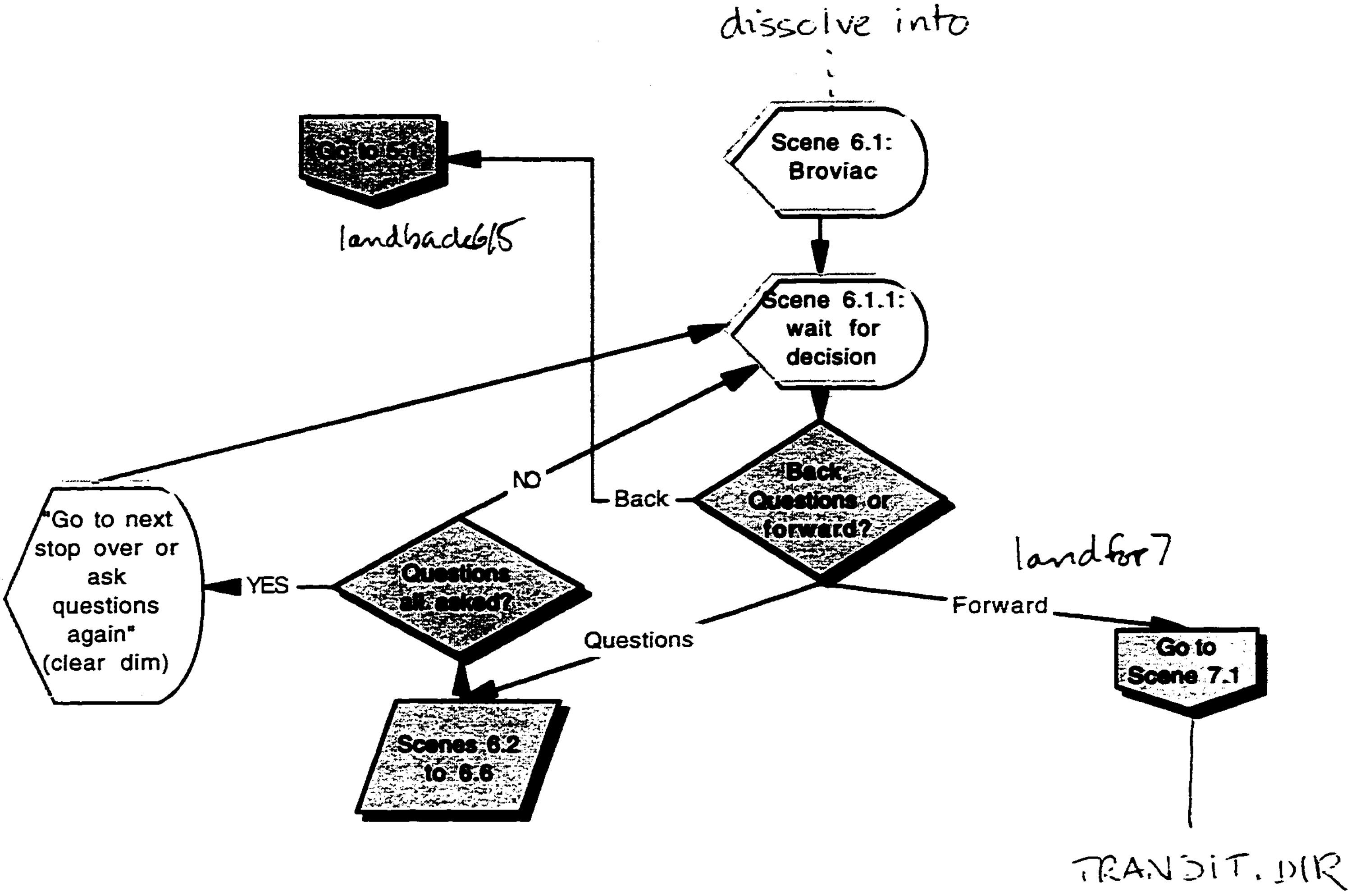
needBMT.dir



go to label("landback5k")
of movie TRANSIT.DIR

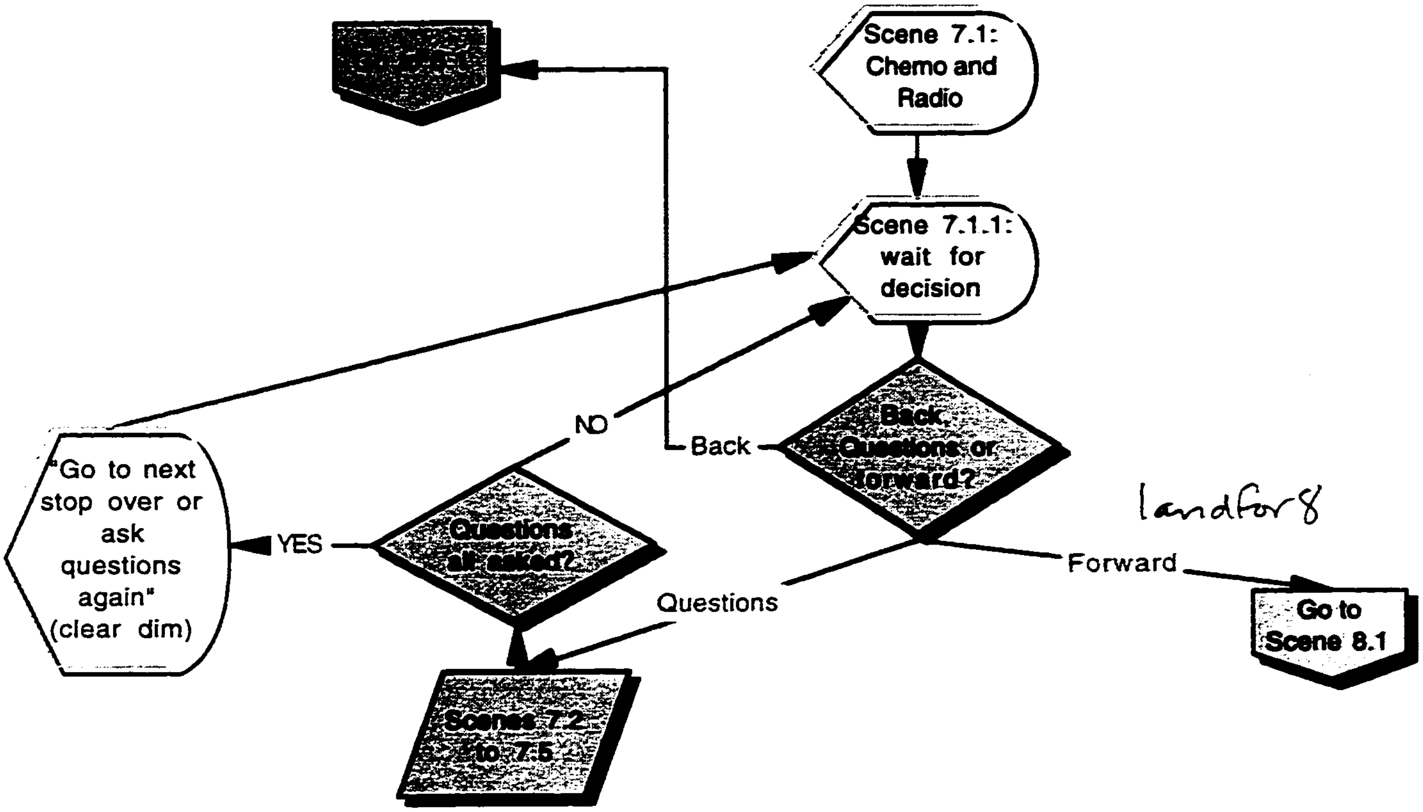
go to label("landfor6")
of movie TRANSIT.DIR

admunit.dir


dissolve into
Scene 6.1: Broviac
Go to 5.1
landback6/5
Scene 6.1.1: wait for decision
Back, Questions or forward?
Back
NO
Questions all asked?
YES
"Go to next stop over or ask questions again" (clear dim)
Questions
Scenes 6.2 to 6.6
Forward
landfor7
Go to Scene 7.1
TRANSIT.DIR

broviac.dir

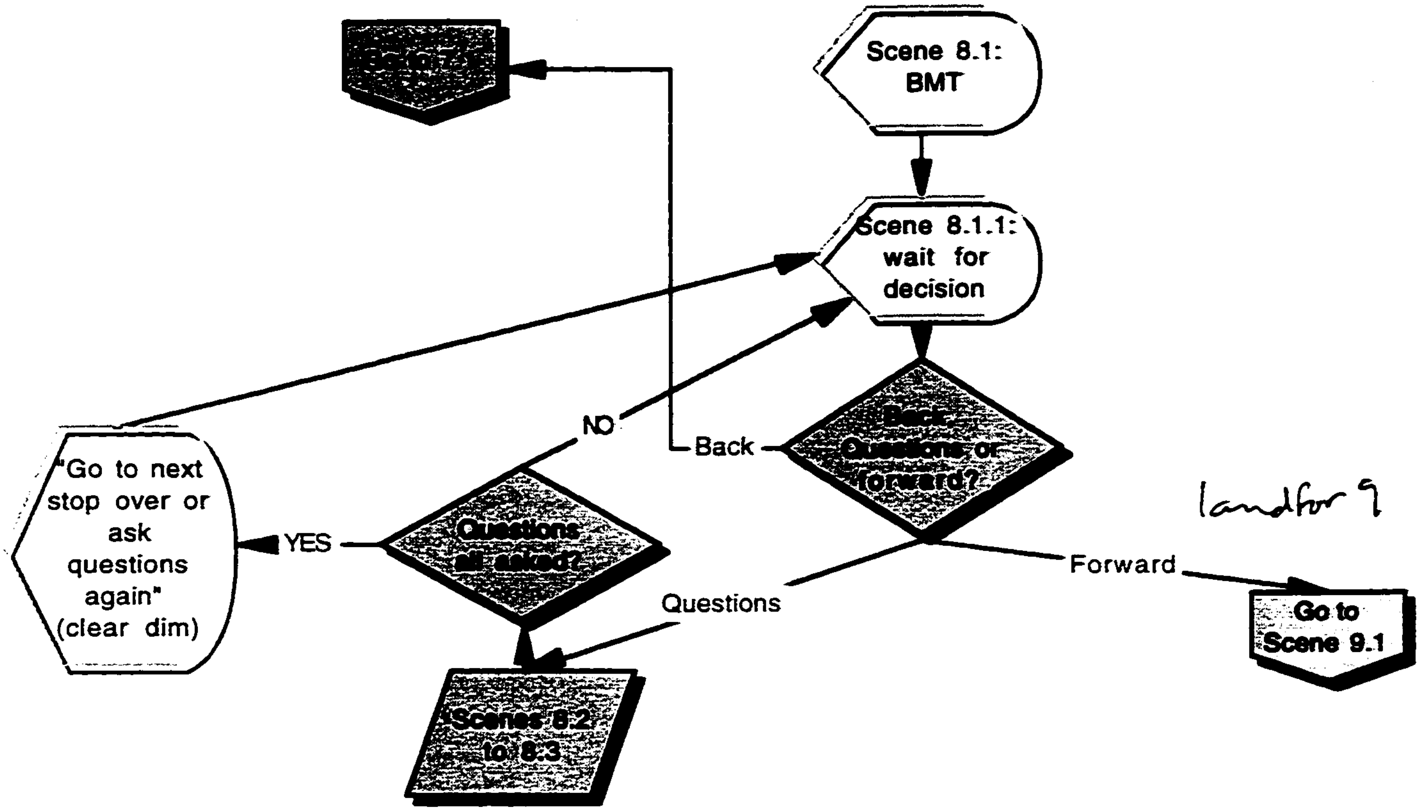
landback 7/6



landfor 8

CHEMRAD · DIR

landback 8/7

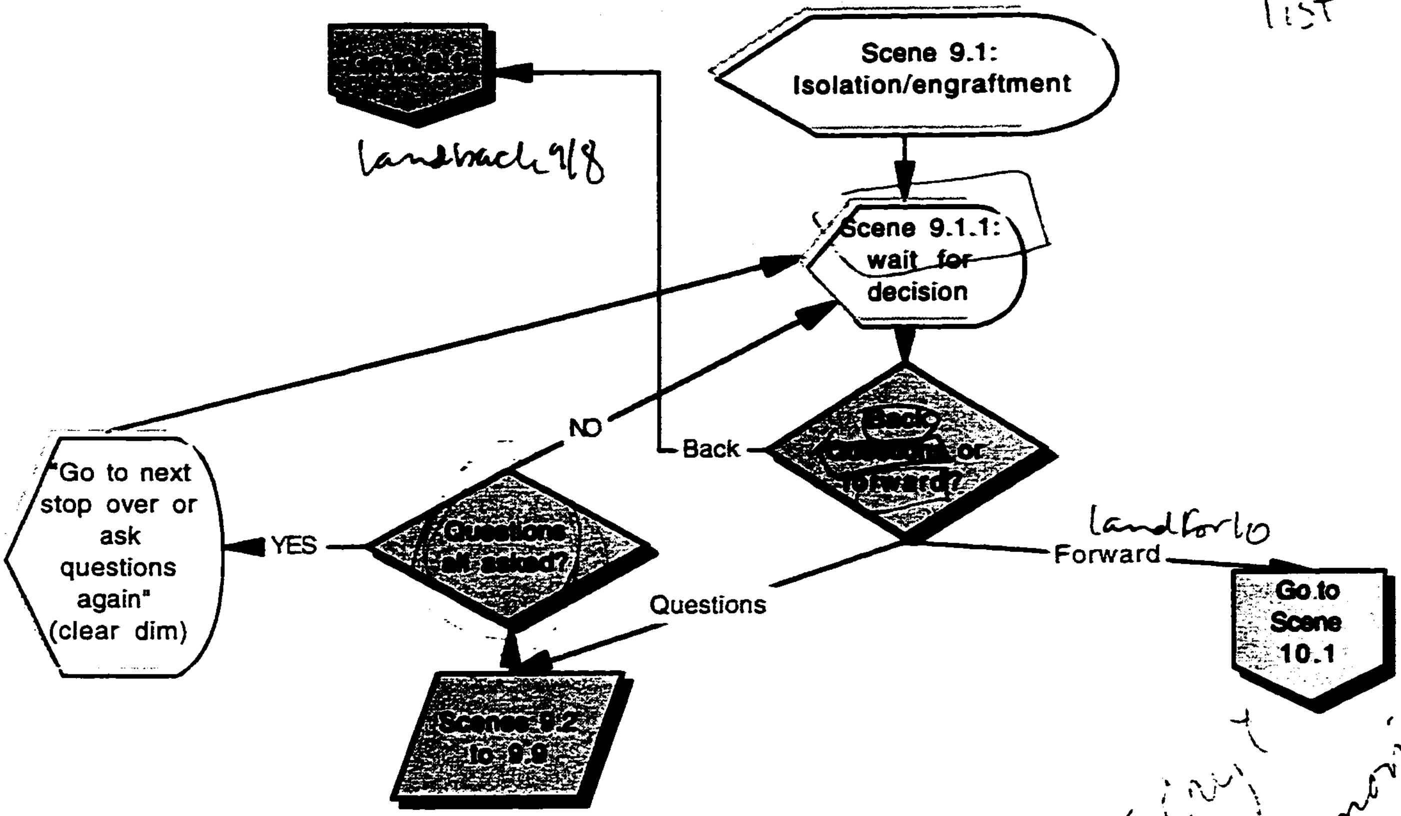


landfor 9

BMT.DIR

set gScene9 = [0,0,0,0,0,0,0,0]

list

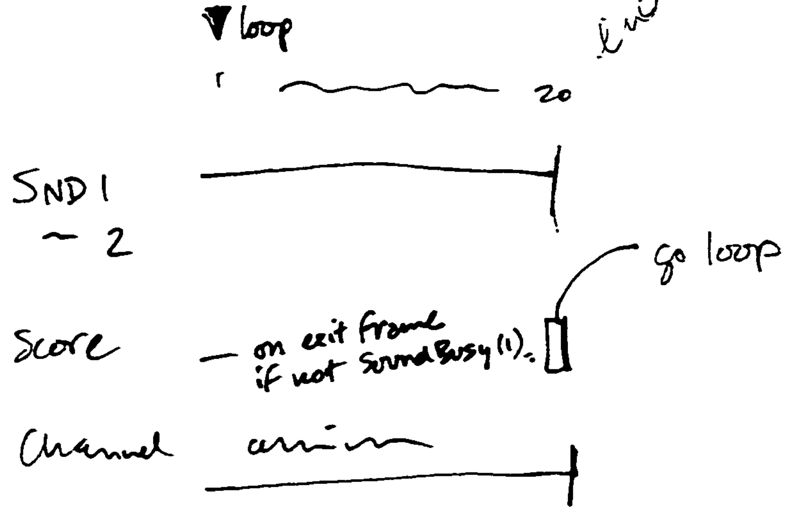


[illegible] movie script

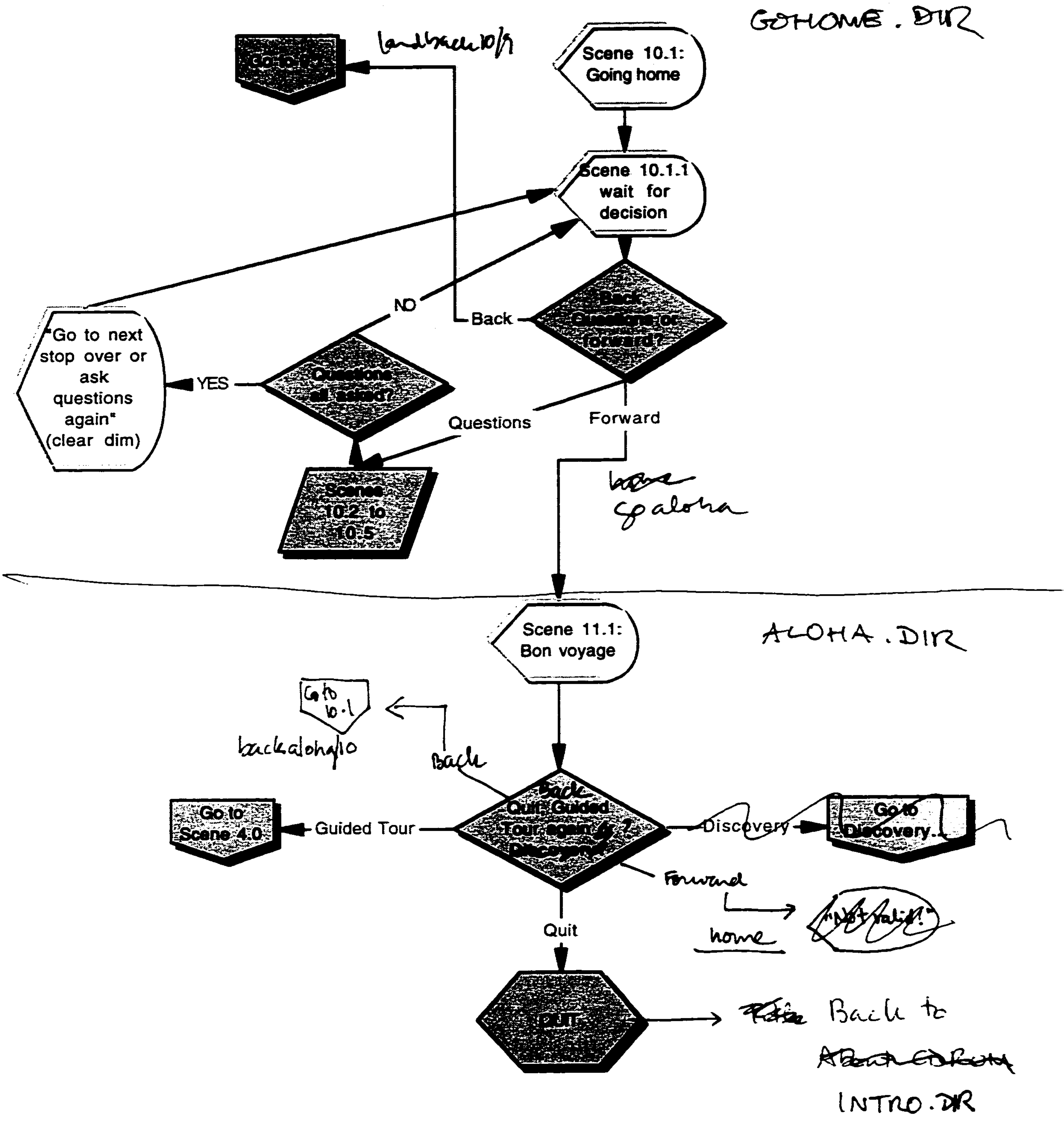
on startmovie

initvariables

end



GRAFT.DIR

GOHOME.DIR
landback10/9
Scene 10.1: Going home
Scene 10.1.1 wait for decision
Back Questions or forward?
Back
NO
"Go to next stop over or ask questions again" (clear dim)
YES
Questions all asked?
Questions
Forward
Scenes 10.2 to 10.5
go aloha
ALOHA.DIR
Scene 11.1: Bon voyage
Go to 10.1
backaloha10
Back
Back Quit, Guided Tour again or ? Discovery
Go to Scene 4.0
Guided Tour
Discovery
Go to Discovery.
Forward
home
"Not valid!"
Quit
QUIT
Back to
INTRO.DIR

# Appendix N. Evaluation questionnaire

# The BMT Voyage - Formative evaluation questionnaire

**Please answer all of the following questions. You need not reveal your identity.**

**Indicate your opinion about the following statements by circling the number representing the opinion closest to yours. Where none of the opinions apply, please circle "0 - Other", and explain on the line below the scale:**

I use multimedia programs:

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| Very often | Often | Not very often | Never | Other |

I could "move" around the CD-ROM (e.g. could locate the buttons, knew where I was "going"):

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| Very easily | Easily | With difficulty | With much difficulty | Other |

If "0 - Other", explain: ____________________

The level of detail on the screen was:

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| Overwhelming | Just right | Not sufficient | Not sufficient at all | Other |

If "0 - Other", explain: ____________________

The animations were:

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| Very useful | Useful | Somewhat useful | Not useful at all | Other |

If "0 - Other", explain: ____________________

The voices and pronunciation of the characters were:

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| Very sincere and clear | Somewhat sincere and clear | Not sincere nor clear | Not sincere or clear at all | Other |

If "0 - Other", explain: ____________________

The answers that the characters gave to the questions were:

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| Very accurate | Accurate | Somewhat accurate | Not accurate at all | Other |

If "0 - Other", explain: ____________________

For ease of use, the CD-ROM needs:

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| A lot more explanation | More explanation | Some explanation | No explanation at all | Other |

If "0 - Other", explain: ____________________

For children, the characters are:

| | | | | |
|---|---|---|---|---|
| 4 | 3 | 2 | 1 | 0 |
| Very appealing | Appealing | Somewhat appealing | Not appealing at all | Other |

If "0 - Other", explain: ____________________

Please list:

| 3 major strengths of the CD-ROM | 3 major weaknesses of the CD-ROM |
|---|---|
| 1- | 1- |
| 2- | 2- |
| 3- | 3- |

I am:

A specialist (hematologist, etc.) __ Nurse __ A patient __
A Child Life Services staff member __ A parent __ Other __

ANY SUGGESTIONS? Please write your suggestions for improvement at the back. Thank you! -->

# Appendix O. Script and titles of scenes

| VISUALS | SOUND |
|---|---|
| Kids' silhouettes against a dark sky | Scene 1 Title page: The BMT Voyage |
| The 4 kids are in the control room through the windows we see outer space, sky with stars | Scene 2.1 Kids' intro<br>Maya: Hi! I'm Maya! My friends and I are taking you on a voyage. It's called a bone marrow transplant. Why is it a voyage? 'Cause it's going to be a real challenge to reach your goal, the goal of getting better!<br>Robert: My name is Robert and I'm six! I had my bone marrow transplant on my fifth birthday!<br>Suzanne: I'm Suzanne and I'll be eleven in January. I had a BMT two years ago. BMT means bone marrow transplant and it's something you don't forget!<br>Alex: Hey! Alex is my name, I'm 12, and I can tell you lots of stuff about, like, the hospital and , all the stuff that happens when you get a bone marrow transplant ! |
| Same as above | Scene 3.1 Navigation demo<br>Maya: Before we go too far, better get used to the controls of this ship! Here we go! |
| Home button flies to Suzanne's hands<br>She holds it while talking then it flies back into place | Scene 3.2 Navigation demo<br>Suzanne: First, the Start Over button. When you click on it, you come back here! |
| The forward arrow flies to Alex, then back again to its place, as he explains it.<br>Then the backward arrow does the same. | Scene 3.3 Navigation demo<br>Alex: The arrows are neat! When you're ready to go on with the voyage, click on the forward one. If you want to go back to see something again, click on the back one! Try the forward button first!<br>Maya: Way to go! Now go back!<br>Alex: You got it! Cool! |
| The help button flies to Maya, and back again<br>Help screen appears with a display of all the buttons and printed instructions - OR runs 3.2 to 3.5 | Scene 3.4 Navigation demo<br>Maya: The Help button is in case you forget how to use the other buttons! Just press it and we'll help you find your way. |

| VISUALS | SOUND |
|---|---|
| The Quit button flies into Robert's hands, then back, as he explains it<br>When the user clicks on Quit, “Do you really want to quit? Yes No” alert box appears and waits for action | Scene 3.5 Navigation demo<br>Robert: The Quit button is for when you're finished! Or maybe when you've had enough! Try it<br>Maya: Okay, now choose No! |
| | |
| | TRANSITION INTO GUIDED TOUR (TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars<br>Map of the seven stopovers appears in the main window<br>Examples of question buttons appear<br>Robert points to the main window<br>Forward flies into his hands<br>Back flies into his hands<br>Forward arrow lights up | GUIDED TOUR<br>Scene 4.0<br>Maya: This whole tour is divided into 7 different stopovers. Each time we land at a destination, I'll give you some new information. There will be some question buttons in case you want to find out more about what I say. Click on the questions you want and we'll answer them.<br>Robert: And you'll see pictures on the big screen!<br>Alex: You can click on as many questions as you like before we take off again. When you're ready to take off, you click on the forward arrow. If you think we should go back to the last stopover, click on the back arrow. OK?<br>Maya: Let's go to our first stopover now! |
| | TRANSITION INTO NEED A BMT (TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars<br>In the main window, we see the doctor with a child, parents and nurse.<br>Question (4.2 to 4.8) buttons appear in the two side windows one after another | Scene 4.1 You Need A Bone Marrow Transplant<br>Maya: Your doctor thinks you should have a bone marrow transplant. You'll need to stay in the hospital for 4 to 8 weeks while the new bone marrow you get starts to produce healthy cells in your body. It's a long trip. You probably have a lot of questions. We'll try to help as much as we can.<br>Remember, if you see a question on the screen that you'd like to ask, click on it. |
| | IF THE USER CLICKS ON QUESTIONS, IT GOES TO ANY OF 4.2 TO 4.8, DEPENDING ON CHOICE. IF THE USER CLICKS ON BACK ARROW, ALERT BOX “NOT VALID”. IF USER CLICKS ON FORWARD ARROW, GO TO SCENE 5.1 |

| **VISUALS** | **SOUND** |
|---|---|
| show an infusion (same as in 8)<br>???????<br>In the main window, animation of chemo and radio warriors fighting cells, some good ones get destroyed | Scene 4.2 You Need A Bone Marrow Transplant<br>*What is a bone marrow transplant?*<br>Alex: Hey! that's a basic question, right? It's a treatment where they use big doses of chemotherapy and sometimes radiation therapy to get rid of certain dangerous cells in your body.<br>Suzanne: But the big doses of chemotherapy and radio therapy get rid of healthy cells as well as sick cells, especially in your bone marrow. And you NEED that bone marrow to stay in shape! That's why they give you new bone marrow. |
| In the main window, a picture of a child receiving bone marrow, in bed with IV unit connected to Central line | Scene 4.3 You Need A Bone Marrow Transplant<br>*What does it feel like?*<br>Robert: It doesn't hurt to get the new bone marrow, 'cause they put it in a central line that's going to be put in your chest by a doctor. |
| In the main window, animation of technicians comparing blood samples to find a good match. | Scene 4.4 You Need A Bone Marrow Transplant<br>*Where do they get the bone marrow?*<br>Suzanne: Usually they get the bone marrow from a donor - someone who has cells that are like yours. The donor will be either a member of your family or maybe someone you have never met before. They can use your own bone marrow sometimes. |
| In the main window, a simple diagram showing bone marrow... or a little factory | Scene 4.5 You Need A Bone Marrow Transplant<br>*What is bone marrow?*<br>Alex: It's like jelly, sort of the same color as blood, and it's inside your bones. It makes new blood cells for your body all the time. It's like a factory for white cells, red cells and platelets, the important cells you need to be healthy. |

| **VISUALS** | **SOUND** |
|---|---|
| In the main window, animation: kid comes up to a wicket that says "Bone marrow". Another one says "Hats", another one says "Video games". | Scene 4.6 You Need A Bone Marrow Transplant<br>*Why do I need new bone marrow*<br>Robert: I needed a bone marrow transplant because I had something called a relapse - my cancer wasn't going away.<br>Suzanne: You need new bone marrow because the big doses of chemo and radio therapy they give you to get rid of the cancer also get rid of the important, healthy cells. |
| In the main window, a picture of a doctor taking a bone marrow sample from a donor. | Scene 4.7 You Need A Bone Marrow Transplant<br>*How do they get the bone marrow?*<br>Maya: Whoever is donating it is put to sleep in the operating room so the doctors can collect the marrow from the donor's hip bones. The person is asleep so it's not scary or painful. |
| In the main window, a dream cloud with a picture of Alex getting a sample taken | Alex: I was my own donor! |
| In the main window, a dream cloud with a picture of Lucie getting a sample taken | Suzanne: My donor was my sister Lucie. She's only six years old, like Robert. |
| In the main window, a picture of hospital staff, name tags identifying them, with patient | Scene 4.8 You Need A Bone Marrow Transplant<br>*Who will do it?*<br>Robert: There's a bunch of really great people at the hospital who do all the stuff to make you better! There was Dr. Brown, and then Marie, my nurse and then John, my teacher and Sophie; she's the Child Life Specialist. |

| VISUALS | SOUND |
|---|---|
| | TRANSITION TO 5.1<br>(TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars<br>In the main window, one view of the BMT unit<br>Walk through button pops up<br>Question (5.3 to 5.5) buttons appear in the two side windows one after another | Scene 5.1 Admission to BMT Unit<br>Maya: Of course there's a special place in the hospital for kids like us. It's the Bone Marrow Transplant Room. It is different from a regular hospital room: Boy is it different! If you want to see it, click on the walk through button. |
| | IF THE USER CLICKS ON WALK THROUGH, IT GOES TO 5.2. IF CLICKS ON QUESTIONS, IT GOES TO ANY OF 5.3 TO 5.5, DEPENDING ON CHOICE. IF THE USER CLICKS ON BACK ARROW, GOES TO SCENE 4.1. IF USER CLICKS ON FORWARD ARROW, GO TO SCENE 6.1 |
| In the main window, a series of photographs of a walk through the BMT unit, virtual tour, from a kid's point of view: | Scene 5.2 Admission to BMT Unit<br>Walk through the BMT Unit<br>Maya: Now you can have a closer look at what's in store. Click on the Next button to walk through. Then we'll go back to the other kids. |
| - shot of 1st door | Scene 5.2.1 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Welcome to the BMT Unit. You'll be spending a lot of time here, so let me show you what it's like. |
| - 1st door open | Scene 5.2.2 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Let's go in to the BMT Unit. |
| - look at nursing station | Scene 5.2.3 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Right after you walk through the first door, you'll see the nursing station. Niurses who will take care of you work here. |

| VISUALS | SOUND |
|---|---|
| - look at bath | Scene 5.2.4 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: If you look to the side of the nursing station, you'll see the special bathtub where you'll take a bath everyday. THis is the only place you can go to outside of your room while you're in the hospital. |
| - shot of 2nd door | Scene 5.2.5 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Now, if you turn to the other side of the unrsing station, you'll see the ante-chamber. |
| - 2nd door open | Scene 5.2.6 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Let's go in to the ante-chamber. |
| - look at sink in ante-rrom | Scene 5.2.7 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Every person who will come into your room will need to stop in the ante-chamber first, to wash their hands. |
| - shot of 3rd door | Scene 5.2.8 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Now, they're ready to go into your room. |
| - 3rd door open | Scene 5.2.9 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: Okay, now it's time to go into your room! |
| - look at bed | Scene 5.2.10 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: So this is your room! All the things you see above the bed are instruments that will help us make sure that everything is fine with you. |

| VISUALS | SOUND |
|---|---|
| - look at outside window from bed | Scene 5.2.11 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: When you're lying in bed, you'll still get to see outside through your window. |
| - look at hall window with walkie talkie from bed | Scene 5.2.12 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: You'll also be able to look through another window in your room. This is where people can talk to you using a walkie-talkie. |
| - look at fun centre from bed | Scene 5.2.13 Admission to BMT Unit<br>Walk through the BMT Unit<br>Nurse: And of course, here's your fun centre, with a TV and video games. Hope you like your room! |
| In the main window, a picture of a child alone in the the room, through the window with the walkie talkie | Scene 5.3 Admission to BMT Unit<br>*Will there be another kid in my room?*<br>Alex: Hey, no problem, man. You get a room all to yourself! At first I was really glad, you know, to be by myself. I didn't feel so good, know what I mean! But later on I got kind of fed up. It's sort of a long time, see?<br>Robert: I hated being alone! At home, I share a room with my brother. It's a lot more fun! |
| In the main window, a picture of a child with her stuff. | Scene 5.4 Admission to BMT Unit<br>*How long do I have to stay here?*<br>Suzanne: The time in the BMT unit can seem really long. I had to stay 6 weeks! Sometimes it seems like you're never going to get out of there!<br>Maya: You can bring your own books and toys to help keep you busy. They have to be given specially cleaned before it comes in the room. |

| VISUALS | SOUND |
|---|---|
| In the main window, a picture of a child in hospital nightgown, at table with candles and flowers, waiter standing by.<br>inflated hot dog?<br>father tripping over and spaghetti on the floor | Scene 5.5 Admission to BMT Unit<br>*What is the food like?*<br>Alex: I better tell you, don't expect the food to taste like home cooking. You have to have a special diet. There's a dietitian who's cool and tells you what stuff is best for you to eat. The food is sterilized and it's all wrapped in foil.<br>Robert: There's a lot of food you can't eat after the transplant: no chocolate, no nuts, no meat, no letttuce... a lot of the stuff I like!<br>Maya: It's because of bacteria. But hey, you don't always feel like eating, anyway! Then, they put liquid food through the IV into the central line.<br>Suzanne: I liked the popsicles they made in the hospital, especially while my mouthsores were bad. |
| | |

| VISUALS | SOUND |
|---|---|
|  | TRANSITION TO 6.1<br>(TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars<br>In the main window, an illustration of a Central line<br>Question (6.2 to 6.6) buttons appear in the two side windows one after another | Scene 6.1 Central line<br>Maya: Before you enter the bone marrow transplant room, you have to get something called a central line in your chest. A central line is a special tube that the nurses can put medecine in, instead of giving it to you in a needle! After you get it, you'll see a tube peeking out from under a bandage on your chest. At the end of the tube, you'll see 2 or 3 separate rubber lines - sort of like fingers on the end of your hand |
|  | IF THE USER CLICKS ONQUESTIONS, IT GOES TO ANY OF 6.2 TO 6.6, DEPENDING ON CHOICE. IF THE USER CLICKS ON BACK ARROW, GOES TO SCENE 5.1. IF USER CLICKS ON FORWARD ARROW, GO TO SCENE 7.1 |
| In the main window, child with central line (from another scene)<br>animation of the waiter (from 5.4 ?) one of the Central line tubes hooked up to blender | Scene 6.2 Central line<br>*Why do I need a Central line?*<br>Alex: Well, the medicine for the chemotherapy and other medicines are given to you through one of the tubes. And the nurses take blood specimens through another tube.<br>Maya: Also, when you're feeling yucky and you don't feel like eating, liquid food is given to you through one of these tubes. They also give you the new healthy bone marrow through another tube. |
| In the main window, a picture of a child with Central line peeking out of the hospital nightgown: the kid holds a sign with the red circle and bar symbol for "no" over a syringe, meaning "needles prohibited" | Scene 6.3 Central line<br>*Will the Central line hurt?*<br>Maya: The central line doesn't hurt but it's going to be in your chest the whole time you're in the unit. Sometimes it's uncomfortable if you try to sleep on your stomach. But anyway, it's better than having a whole lot of needles all the time! |

| VISUALS | SOUND |
|---|---|
| In the main window, close up of a Central line on a child's chest with bandages | Scene 6.4 Central line<br>***Why the bandages around the Central line?***<br>Alex: My doctor told me that the bandages would help protect me from getting an infection so you have to leave them on.<br>Robert: Yeah, Marie, my nurse, changed mine often. It didn't hurt a bit! |
| In the main window, a picture of a child dreaming of a Central line | Scene 6.5 Central line<br>***Will I need an operation?***<br>Robert: You need an operation to get the central line but you'll be asleep so you don't feel any pain. When you wake up, you see the tube peeking out from the bandage on your chest. |
| In the main window, a picture of a child dreaming of anything but a Central line | Scene 6.6 Central line<br>***Will the operation hurt?***<br>Mava: My operation didn't hurt because I was asleep when the surgeon put in the Central line. It hurt a little after the operation, but they gave me some medication to take away some of the pain. When you feel bad, you always ask your nurse for help at any time. That's what they're there for! |

| VISUALS | SOUND |
|---|---|
| | TRANSITION TO 7.1<br>(TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars<br>In the main window, animation of the chemo agents going in body, pacman style, and radio rays<br>Question (7.2 to 7.5) buttons appear in the two side windows one after another | Scene 7.1 Chemotherapy and Radiation<br>Maya: When I first found out that I had cancer, the doctor told me that I would need to have chemotherapy and, maybe, radiation treatments. You may have had either chemotherapy or radiation before, but now you have to have much stronger doses to destroy your own marrow. Then you get new bone marrow.<br>We'll try to help answer your questions. When you see one on the screen that you'd like to ask, click on it. |
| | IF THE USER CLICKS QUESTIONS, IT GOES TO ANY OF 7.2 TO 7.5, DEPENDING ON CHOICE. IF THE USER CLICKS ON BACK ARROW, GOES TO SCENE 6.1. IF USER CLICKS ON FORWARD ARROW, GO TO SCENE 8.1 |
| In the main window, animation of chemo agents walking around inside a child's body, kicking cells around<br>Mouth sores pop up on kid's face IN THEIR MOUTH | Scene 7.2 Chemotherapy and Radiation<br>*What is chemotherapy and why do I need it?*<br>Alex: Well, hey, --you've probably had chemotherapy before. You know it's a treatment where they get strong medication to help kill cancer cells. Right before your bone marrow transplant, they get rid of all the unhealthy cells to make room for new healthy ones. You get the medication through one of the tubes in your Central line.<br>Robert: Guess what? You're going to lose your hair!<br>Suzanne: I had bad mouthsores after the chemo, but they gave me stuff to help with the pain. |

| VISUALS | SOUND |
|---|---|
| In the main window, animation of a kis looking sad and gradually smiling...<br>... as kid starts juggling with hats | Scene 7.3 Chemotherapy and Radiation<br>*Does chemotherapy hurt?*<br><u>Maya:</u> You don't feel the medication, but sometimes it makes you feel sick. I threw up and I didn't feel like doing anything. I tried to think chemo would make me be better.<br><u>Suzanne:</u> My hair had started to grow again before I had the transplant, but I lost it again. The medication is strong and that's why you lose your hair, but it grows back eventually.<br><u>Robert:</u> So I guess it's time you started your hat collection!<br><u>Alex:</u> My favourite hat was my Mets cap! |
| In the main window, a picture of a kid and the radiation machine | Scene 7.4 Chemotherapy and Radiation<br>*What is radiation therapy and why do I need it?*<br><u>Suzanne:</u> Radiation is a treatment where they send special rays into your body to help get rid of the cancer. The doctor will tell you if you need it or not. The machine can be scary the first time, but it's not as scary after that.<br><u>Maya:</u> It doesn't feel like anything! But 2 weeks before you go into the hospital, you have to have a bunch of tests for your heart, your lungs, and other stuff.<br><u>Robert:</u> They measure you to make shields to protect your lungs. They put sand bags all around you and a kind of mould for your head so you don't move. Well, you can't move. I fell asleep listening to the radio while I was in the room. Hey - is that why they call it radiotherapy? |

| VISUALS | SOUND |
|---|---|
| In the main window, animation of a kid getting a picture taken of stomach with a camera | Scene 7.5 Chemotherapy and Radiation<br>*Does radiation hurt?* |
| kid starts grimacing, as if stomach hurts...<br>...gradually starts smiling again | Alex: Nah, radiation is not painful - it's like someone taking a picture of your body for a loooong time! And the room is cold! But a week later, you might feel sick to your stomach, like throwing up, or have diarrhea. Boy, did I ever feel sick! |
| | Suzanne: Ten days after my radiation therapy, my mouth was so dry... I didn't have any spit. At least there are medicines to help you feel a little better. |

| **VISUALS** | **SOUND** |
|---|---|
|  | TRANSITION TO 8.1<br>(TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars In the main window, picture of a child receiving bone marrow infusion<br>Question (8.2 to 8.3) buttons appear in the two side windows one after another | Scene 8.1 Bone Marrow Transplant<br><u>Maya:</u> OK! You've finished the chemo or the radiation therapy - now you're ready for the bone marrow transplant. |
|  | IF THE USER CLICKS QUESTIONS, IT GOES TO ANY OF 8.2 TO 8.3, DEPENDING ON CHOICE. IF THE USER CLICKS ON BACK ARROW, GOES TO SCENE 7.1. IF USER CLICKS ON FORWARD ARROW, GO TO SCENE 9.1 |
| In the main window, close up animation of bone marrow infusing into the central line of a smiling kid | Scene 8.2 Bone Marrow Transplant<br>*What does it feel like - will it hurt?*<br><u>Alex</u> The bone marrow transplant is not painful because you get the marrow through your Central line. It's like a blood transfusion. |
| NOT!<br>In the main window, animation accelerated pace - like silent movie - clock needles swirling around and a nurse walking in and out of the room, checking something everytime | Scene 8.3 Bone Marrow Transplant<br>*Will I feel sick??*<br><u>Maya:</u> I got a reaction to the bone marrow- like an allergy. But they gave me medicine to fight the reactions. I just felt really sleepy. |

| VISUALS | SOUND |
|---|---|
|  | TRANSITION TO 9.1<br>(TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars<br>In the main window, 3 adults - hospital personnel and parent - talk to each other and say "engraftment" in speech bubbles, next to a giant blood count printout<br>Question (9.2 to 9.9) buttons appear in the two side windows one after another | Scene 9.1 Isolation / waiting for engraftment<br>Maya: After you get the new bone marrow, you have to wait until it starts to produce new cells again. It can take a while. You're waiting for your blood counts to come back to normal - you'll hear all the adults around you call this "engraftment". |
|  | IF THE USER CLICKS QUESTIONS, IT GOES TO ANY OF 9.2 TO 9.9, DEPENDING ON CHOICE. IF THE USER CLICKS ON BACK ARROW, GOES TO SCENE 8.1. IF USER CLICKS ON FORWARD ARROW, GO TO SCENE 10.1 |
| In the main window, animation of monthly leaves of calendar flying around<br>....close up of one months with marks appearing on each successively | Scene 9.2 Isolation / waiting for engraftment<br>*How long will I have to stay?*<br>Suzanne The first 2 weeks after the transplant, I sat up in bed doing nothing - I felt too weak! It can take 4 weeks for the new bone marrow to find its place in your body and start producing cells.<br>Alex: All of us were in the special unit for different lengths of time. You could be in there for 4, 6 or even 8 weeks - it depends on each kid. If you get sick, you stay a little bit longer.<br>Robert My Mom made a calendar and every day I put little check marks and a sticker face on the squares to count the days I was in the unit. |

| **VISUALS** | **SOUND** |
|---|---|
| In the main window, picture of Alex in his BMT unit bed dreaming of his own bed at home, mom sits next to him | Scene 9.3 Isolation / waiting for engraftment<br>*Why do I have to stay alone in the room?*<br>Alex It can get to be a drag, having to stay in the hospital all this time, especially being alone in that room. But you have to be the only one in that room because everything has to be really clean.<br>Suzanne: Sometimes it was boring. When I was there, I wished I was home sleeping in my own bed. But my parents kept me company - grown ups can visit you, if they're not sick. |
| In the main window, illustrations of each member of the team and what they do | Scene 9.4 Isolation / waiting for engraftment<br>*What's going to happen every day?*<br>Suzanne: Well, after the transplant, the doctor and nurses keep coming in, checking a bunch of things, most of all the blood counts. When I was there, there was the heart monitor and a bunch of pumps that I was attached to.<br>Maya: Everyone wants to make sure that your counts are up and stable: then, your new bone marrow is OK! I got a lot of platelet transfusions before my counts were OK.<br>Robert: And the housekeeper comes to clean the room every day - it has to be so clean! I'm glad it wasn't my job! |

| VISUALS | SOUND |
|---|---|
| In the main window, animation of pained expression appearing on each kids' faces as each appears when s/he talks... | Scene 9.5 Isolation / waiting for engraftment<br>***What does it feel like? Will it hurt?*** |
| | Alex For a while, it feels like you have the flu all the time. I felt like throwing up and I had diarrhea. |
| | Robert: I had a fever and some infections. |
| | Suzanne: And I had sores in my mouth. It hurt to talk or eat, or even swallow! But I always asked the nurse for something to take the pain away. |
| ...all the faces start smiling | Maya: I also got medicine after the transplant, to make sure my body accepted the new bone marrow - it made hair grow on my face! But after a while, that funny hair went away. |
| In the main window, : | Scene 9.6 Isolation / waiting for engraftment<br>***What will I do all day when I start feeling a little better*** |
| picture of Suzanne talking to her sister | Suzanne: I'd watch tv or play video games with my mom and dad. I talked to lots of people on the phone. |
| picture of Maya choosing her toys | Maya: And people who work at the hospital come visit you all the time. Like Sophie, the child life specialist - well, they're there to play with you, or just talk. That's their job! |
| | Robert: My doctor and Sophie told me to choose my favourite toys and bring them to the hospital before my BMT. They have to sterilize them to get them really clean. |
| Alex with teacher | Alex: John was my teacher at the hospital. He's a great guy. When I felt good enough to do a little school work, he helped me and he kept in touch with my teacher back at school to see if I was doing the same things as the other kids. |

| VISUALS | SOUND |
|---|---|
| In the main window, split screen | Scene 9.7 Isolation / waiting for engraftment<br>*Can I play with my brothers and sisters?* |
| right: picture of Suzanne talking to her sister | Suzanne: I couldn't play with my sister Lucie but I could see her through the window and I used a walkie talkie to talk to her. |
| left: Robert seeing his brother on tv | Robert: Yeah, my doctor told me that kids couldn't come in the room: they have too many germs! My family made home videos of my baby brother, so I saw him on tv. |
| In the main window, animation of bacterias and germs getting cleaned off of a toy | Scene 9.8 Isolation / waiting for engraftment<br>*Why does everything have to be germ-free?*<br>Alex: Your room needs to be extra clean, because if there are too many bacteria and germs, it could make you really sick. Everything that goes into your room needs to be sterilized: usually, your body is strong enough to fight germs but not now.<br>Suzanne: Even the food has to be sterilized. They wrap it in aluminum foil and they cook it a lot. You should see how the hot dogs come out! |
| In the main window, | Scene 9.9 Isolation / waiting for engraftment<br>*Where is the bathroom?* |
| picture of Robert, not feeling so great, being helped by his dad | Robert: You have to take a bath with special soap every day... I hate baths, especially when I feel sick. Anyway, my nurse or my dad helped me. |
| picture of Alex, soaking contently, nursing station in background<br>CRANE TO GET KID OUT OF BATH? THEY ARE WEAK | Alex: Hey! Sometimes it feels nice to enjoy a nice soak in the tub. But the tub won't be in your room - it's in another part of the bone marrow transplant room, close to the nurses. |
| picture of a bedpan?...... | Maya: That's right... There is no bathroom in your room, you get a bedpan and a special toilet on wheels! Yeah, I know it's not the best, but... |

| VISUALS | SOUND |
|---|---|
| | TRANSITION TO 10.1<br>(TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars In the main window, animation of a kid running to a house with arms open<br>then picture of a kid looking out window, at other kids playing...sad, can'T play with them<br>Question (10.2 to 10.5) buttons appear in the two side windows one after another | Scene 10.1 Going Home<br>Maya I bet you'd like to know when you can go home! When you first get home, it's a bit wierd not to be in the BMT unit anymore. You can go all over your house, but you need to be careful of bacteria and germs and you may not be able to play outside right away. It can take a whole year before you can do everything you used to do |
| | IF THE USER CLICKS QUESTIONS, IT GOES TO ANY OF 10.2 TO 10.5, DEPENDING ON CHOICE. IF THE USER CLICKS ON BACK ARROW, GOES TO SCENE 9.1. IF USER CLICKS ON FORWARD ARROW, GO TO SCENE 11.1 |
| In the main window, animation of a kids jumping on a kids' bed (not a hospital one) | Scene 10.2 Going Home<br>*When can I go home?*<br>Alex: It's great going back home to your family and best of all - your own bed! Most of the time, BMT patients go home between 4 to 8 weeks after the transplant. It could be more, it could be less. It's different for each person. |
| In the main window, picture of one of the four kids speaking to a sick friend (eg with chiken pox) on the phone | Scene 10.3 Going Home<br>*Can I play with friends once I'm home?*<br>Robert: It might be a while until your friends can come over to your house. It depends on your blood counts. Nobody who's sick can come over to see you. |

| VISUALS | SOUND |
|---|---|
| In the main window, animation of mean kids laughing... | Scene 10.4 Going Home<br>*Will my friends make fun of me?* |
| ???????? | Maya: My nurse went to school to explain what happened to me. This helps other kids understand what I went through. |
|  | Suzanne: At first, your friends might be surprised at the way you look. My face was swollen. You feel a bit embarassed but you feel normal pretty soon. |
|  | Robert: I had to wear a mask on my face when I went to places with lots of people. It was weird but I got used to it. Sometimes people you don't know stare at you - that's not very polite! |
| In the main window, Alex fooling around... then worried... | Scene 10.5 Going Home<br>*When will I be able to go back to school?* |
| then working on school stuff | Alex: I never thought I'd worry about missing school, heh, heh... but I did! Actually, going back to school was kinda scary. I had some catching up to do, but my teachers and my parents helped me get back on track. |
| Animation of a teacher going home to Maya...<br>...home teacher speaks to real teacher on the phone | Maya: You have a home teacher, sorta like the hospital teacher, who comes to your house 'cause you won't be able to go back to school for about 9 months. |
|  | Suzanne: They always keep in touch with your school and your teachers there so that when you go back, you can do all the same work as the other kids. |

| VISUALS | SOUND |
|---|---|
|  | TRANSITION TO 10.1<br>(TRANSIT.DIR) |
| The 4 kids are in the control room through the windows we see outer space, another skyscape with stars Animation: spaceship starts moving... | Scene 11.1 Bon Voyage!<br>Suzanne: Hurray! You made the trip with us! Now, you're all set!<br>Robert: If you want to come back and see us again, in case you forget a question, we'll be here!<br>Alex: You still have to really go on the real trip now, so...Good Luck from all of us who know what you will be going through.<br>Maya: Remember that everyone wants to help you get better! Talk to your parents, doctors and nurses and all the other people who are on the staff, whenever you feel down. It really helps. |
| TRANSIT.DIR | All: Bon Voyage!! |

# Appendix P. Detailed post-production evaluation results

## Detailed results from post-production evaluation

### *Group 7. Expert review/technical (November 1, 1996)*[1]

The head of the Montreal Children's/Montreal General Hospitals AV departments, Irwin Haberman, navigated the CD-ROM during a test/dry-run on a computer at the library in preparation for a presentation of the CD-ROM to the hospital staff in hematology. His senior technician at the Children's, Daniel Héon, looked on. Both made comments which pertained to the technical quality of the CD-ROM. They looked at the CD-ROM in its entirety, going through every single question. They noticed particularly lighting flaws in the slide photos Mr. Héon had taken of the BMT unit for the virtual tour or 'Walk Thru' in the 'Admission to BMT unit' stop-over (Scene 5), as well as the heightened granularity of the images brought on by the digitizing and conversion processes required to get the celluloid into numeric format, and then changed from millions of colours to an 8-bit PICT file. Mr. Haberman remarked that there was hiss on the sound excerpts where the children spoke. He guessed by ear that they were recorded at 11kHz, in mono. Sound quality differed from one playback platform to another - this multimedia PC was particularly bad in replaying sounds. Mr. Haberman also noticed that some answers given by the children on the CD-ROM implied previous experience or knowledge of certain cancer treatments such as chemotherapy. The author told him that these were purposeful design decisions, given the background of most potential end-users. Both Mr. Haberman and Mr. Héon were otherwise favourably impressed with the work of the design team, remarking especially the quality of the graphic work, the fun factor which the animation brought to the whole, and the thought put into making the characters diverse in all categories (age, gender, ethnicity).

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[1] The number preceding the headline refers to the participant group number.

### *Group 8. Expert and learner review/client approval (November 29, 1996)*

The much anticipated presentation of the CD-ROM to the Montreal Children's Hospital finally took place four weeks later. It brought together over 15 persons who ranged from being Lamplighters members, to Montreal Children's Hospital staff, patients and their parents, etc. The computer and CD-ROM were on display for all to interact with in a meeting on the floor of the temporary oncology ward for about three hours. People dropped by and took turns at navigating the application. Meanwhile, the author conducted direct observation, looking especially for navigation difficulties.

*Navigation difficulties:*

- The first person to try out the CD-ROM was the manager nurse from the clinic. It seemed as though she had problems with the mouse and as if it were confusing to her at first, but she figured out navigation little by little;
- One of the hematologists asked, when the manager nurse got to Scene 8 - BMT stop-over, "how many chapters are there ?" ;
- Later the manager nurse explained to another nurse that the voyage functions as a series of "tableaux". The metaphor seemed to be recognized by all;
- The "Next" button in the 'Walk Thru' the BMT unit (Scene 5.2) was not apparent to the second nurse who tried out the CD-ROM, and again with the third navigator;
- The author witnessed a nurse explaining to the head nurse who came in a bit later how the CD-ROM works (navigation, asking questions, checkmarks);
- All seemed to understand the forward arrow intuitively;
- All tended to click on questions sequentially;
- By the second hour of the presentation, the CD-ROM was being navigated for the third time by another nurse.

*Credibility/humour:*

- Anecdotes about children/patients were being discussed by the nurses as they listened to the stories of the characters (they recognized patients to whom the anecdotes might be linked).

- Animations in the 'Waiting for engrafment/isolation' stop-over (Scene 9/GRAFT.DIR) of the over-inflated hot dogs (sterilised food), rubber ducky (necessity to take bath everyday while in the unit), bed pan ('Where is the bathroom?') were greeted by laughter from all.
- Anecdotes in the 'Going home' stop-over (Scene 10/GOHOME.DIR) about people staring ('That's not very polite!" says Robert) and about missing school ('I never thought I'd worry about missing school, ha, ha... but I did!' says Alex) got laughs, too.
- Many other animations and anecdotes got laughter as well.

*Technical difficulties of the CD-ROM (slow access speed, etc.):*

- Delays in accessing data on the CD-ROM didn't seem to bother adults
- By the third run of the CD-ROM, body parts of the characters started disappearing after the virtual tour of the BMT unit. It was later determined that this was because of a visual effect inserted at the tour which did not translate well to a Windows platform.

*Reaction to characters*

- Alex was seen as cool, Maya as smart.
- Alex got many laughs - use of humour obviously worked.
- Robert was seen as 'cute'.

*Accuracy of content:*

- There were no comments concerning inaccuracies.

*Multiple points of view*

- The Hospital teacher liked the fact that different children are answering different questions: "Children will like this".

*Reaction to aesthetics, 'feel' and screen design:*

- They liked the buttons and the 'pop' sounds with the question buttons.
- The Hospital teacher thought the graphics were excellent.

The overall reaction from the director of Child Life Services and her case worker in the clinic, as well as the head of Public Relations, was that the CD-ROM was marketable and could be presented at conferences. Two clinic nurses said that they loved it. Everyone was generally impressed, including the head of hematology, Dr. Whitehead, whose permission to go ahead with the project was required by the Lamplighters president.

This was perhaps the most gratifying experience for the design team: feeling tangibly the satisfaction of the work accomplished and witnessing the delight which the hospital staff expressed (said Norma Auger, head nurse: "You had better get 200% out of 100% on this project!"), as well as watching Jon and Kevin navigate the finished product.

Throughout the three hours, fifteen semantic differential scale questionnaires were also filled out. The results are discussed in the thesis document

### *Group 9. Expert review (January 30, 1997)*

The CD-ROM was briefly presented to Dr. Arlette Lefebvre, staff psychiatrist at the Hospital for Sick Children in Toronto. Dr. Lefebvre is the founder of Ability Online, a conferencing network for ill and disabled children. The author and one of her colleagues met Dr. Lefebvre in her office. The setting was a one-to-one open interview, to assess psychosocial aspects of the CD-ROM. Dr. Lefebvre was in a hurry and made pertinent, if few, comments. She sat through the navigation demonstration impatiently, wished aloud that there was some way to skip it. She navigated briefly through Scenes 4 and 5. Her over-riding concern was that of a lack of learner evaluation: she wished that there would have been tests all along the voyage to give the children an opportunity to check their knowledge gains. She also thought that these would have been simple devices which would have brought more interactivity to the application, which she thought was generally lacking.

### *Group 10. Expert review (March 14, 1997)*

During a presentation to educational technologists at a local education symposium, the CD-ROM was presented to the audience. One volunteer came up to the computer to navigate it at her will and let the rest of the audience look on. At the end of the presentation, the author asked people in attendance to fill out the same questionnaire filled out at the Montreal Children's Hospital. Eleven questionnaires were filled out and returned. The author was looking for feedback on the pedagogical and technical aspects of the CD-ROM. The results are discussed in the thesis document.

### *Group 11/1. Learner verification pilot (April 28, 1997)*

Alfred provided the author with the opportunity to try out her planned procedure for end-user evaluation. This procedure basically consisted of

- asking the end-user: "You've been told you have to have a BMT: Do you know what a BMT is? Do you know what happens? What do you think? What do you feel? what do you want to know?" (pre-test);
- letting the end-user navigate the CD-ROM at will: timing the duration of the navigation; observing reactions and navigational path; telling the end-user to voice his opinions ('What you like, what you don't like, what you would change... don't be shy, just tell me!") as he navigates the CD-ROM;
- asking the end-user: "Now that you've looked at the CD-ROM, can you tell me: three things you learned; how you would feel about having a BMT."

#### Background

The author met Alfred at his home. Alfred does not suffer from cancer, but has been exposed to information about the bone marrow transplant treatment. Alfred is a very bright young man, in the 6th grade at a local public school. He likes to play with CD-ROM's and surf the Internet. He also loves to watch the Simpsons, Star Trek, and is an avid reader. He is very articulate, sociable and outgoing, but prefers to keep to himself.

### Knowledge pre-assessment

"Do you know what a BMT is? Do you know what happens?", Alfred was then asked. He mentioned:

- getting a tube in the chest;
- oncologist telling him he had gotten cancer by accident, because he wasn't careful, and "not sanitary".

"If you don't take care and clean yourself enough you'll get cancer", he concluded. The author was quite surprised by these answers from Alfred and tried to see, if with some probing, he could rectify his false assumptions about the causes of cancer. However, Alfred started talking about his feelings: he would feel scared, he would be afraid of dying, he would also be afraid because the BMT procedure was not appealing. "The chemotherapy gets heavier - it's not fun, you go through hell". Alfred even stated something quite dramatic for a boy his age: "I would rather die because I'm afraid of the pain".

Again, to rectify this dramatic view of things, the author proposed a scenario where the oncologist would give a realistic, objective view of the facts: that the BMT can save your life and that there 45% of chances that it will do so. Alfred insisted: 45% of chances you survive also means there are chances you will die.

The author then asked Alfred what he would want to know, were he to go into the hospital for a BMT. He answered that he would want to know about the room he would get, what treatments he would receive, where the bathroom would be, how heavy the treatments would be and whether the effects from the treatment would be the same as with regular treatment for remission.

### Affective pre-assessment

The scenario was proposed: "You've been told you have cancer: how do you feel about that?". Alfred indicated that it would make him feel sad, mad and scared because it would make him think he would die. And on: "You've been told you have to have a BMT: how do you feel about that?". He pointed out that it would make him feel different, like an outsider, "like you can't have a normal life".

When the author asked Alfred what words he would use to describe the emotions he would feel, he mentioned feeling sorry for his family, because he thought that people would tease his siblings ("He's got cancer, he's a loser"), that they would have to go through "bad stuff", that his parents would probably have to go see a counselor and that he would feel guilty about the trouble he would cause his family. He also said he would feel mad about the isolation from family and friends during the treatment, and that he would feel afraid of the new people he would meet at the hospital. He was also concerned about the repercussion this time away would have on his schooling, especially about being held back a year while his friends would move on. When the author pointed out that if he were to have a BMT, he would keep up with his work with the hospital and home teachers and join his friends the next, he took some comfort but thought it would still pose a disadvantage.

### Navigation and reactions

Alfred then proceeded to navigate the CD-ROM, checking almost all the questions. It took him 36 minutes in all. Alfred navigated quietly, and did not click madly all over the screen as the author expected out of a boy his age, though he followed the kids with the mouse pointer at first. He had no problems with the navigation demo at the beginning of the application.

Somehow, during production, the animation of the spaceship, traveling from planet to planet, was made to look as though the spaceship was crash-landing on every single planet on its route. Alfred thought that was weird.

He thought that when Maya turned towards Robert when he spoke, she looked as though she was looking down at him. The rictus on her face in that position (looking to her right) could easily lead someone to think this. Alfred, however, was the only user out of almost 50 to notice.

### Stop-over #1

During the first stop-over (Scene 4/NEEDBMT.DIR - You need a bone marrow transplant), Alfred clicked on 3 out of 7 questions. After listening to the answer to question 4.2, "What is a bone marrow transplant?", he had one of the most ingenuous and ingenious responses an end-user could have: he asked whether it would be possible, with cloning technology, to mechanically duplicate bone marrow so as to not have to find a donor. He pursued this theme after listening to the answer to question 4.4, "Where do they get the bone marrow?".

### Stop-over #2

During the second stop-over (Scene 5/ADMUNIT.DIR - Admission to the BMT unit), ALFRED thought that the change in the background environment seen through the dashboard of the ship (which is the planet), was "neat". He thought it provided continuity to the story. He went through all the questions of this stop-over. Alfred first chose question 5.2, the 'Walk Thru', and had no problems navigating this part of Scene 5. It should be pointed out here, that scene 5.2 differs from all the other scenes in the Voyage: because it is a 'slide show' of sorts, a slide white screen drops down, the kids turn around, the lights are dimmed (we see the back silhouettes of the kids), and a 'Next' button is provided just below the slide screen to navigate through the 13 pictures which constitute the tour of the unit. Most end-users had a hard time locating the 'Next' button and tended to confound it with the forward button, which lets the end-user navigate from one stop-over to another. Alfred noticed the button while it was being explained by the Maya character and clicked on it right away to go on the 'Walk Thru'. He then said he would have liked to have seen more than 13 photos and that some of the shots were superfluous, notably the shots where each of the three doors leading to the room are shown closed and then opened (they were put in that sequence to give the impression of an animation). The only remaining question Alfred had was about the make-up of the popsicles mentioned in question 5.5, 'What is the food like?'.

### Stop-over #3

During the third stop-over (Scene 6/BROVIAC.DIR - Central Line), Alfred asked 3 out of the 5 available questions. By then, he had realised that Maya was the character who would give the introduction at the beginning of each stop-over. He thought this task could have been shared between the different 'members of the crew'. In fact, he seemed to resent the Maya character: "It's like she's the best person, El Supremo, or something". He also thought that the explanations at the beginning were superfluous: "you don't need it 'cause you'll hear about it again in the question". After he chose to listen to his third choice, question 6.4, 'Why the bandages around the central line?', he came back to this point, saying that Robert offered a fresh perspective and "said new stuff" (Robert, adds an anecdote to the answer which goes: "Marie, my nurse, changed mine [my bandages] all the time. It didn't hurt a bit!").

### Stop-over #4

During the fourth stop-over (Scene 7/CHEMRAD.DIR - Chemotherapy and radiation), Alfred asked all the questions available. He reiterated his reservations about having Maya introduce the topic. During scene 7.3, 'Does chemotherapy hurt?', Alfred liked the sequences featuring Robert and Alex, discussing side effects of chemotherapy, namely hair loss. Robert says: "So, I guess it's time you started working on your hat collection!", while the animation on the big screen behind the characters shows a collection of hats twirling around, as if they were being juggled. Alex adds: "My favourite hat was my Mets cap!", as one of the hats - a baseball cap - dropped out of the twirl and landed on his head. Alex also raised his arms when the cap landed on his head, a change of pace, because we always see Alex with his hands in his pockets. His third choice was question 7.4, 'What is radiotherapy?'. The illustration on the big screen for the answer features the patient character being examined by a doctor and hooked-up to a bizarre looking machine (the feedback from MCH was the same). Alfred thought that the machine looked funny. Finally, with the mention of diarrhea a few times during this stop-over, Alfred thought it would have been better if the characters had used a euphemism, such as 'poop'.

### Stop-over #5

Upon arriving at the 5th stop-over (Scene 8/BMT.DIR - Bone marrow transplant), Alfred said "Some stop-over!" when he saw that here were 2 questions instead of the usual 4 to 7. He looked at both and because there were only the two of them, he thought that they would have been better placed on another stop-over.

### Stop-over #6

Alfred then navigated to the longest stop-over (Scene 9/GRAFT.DIR - Isolation/Waiting for Engrafment), where he chose 5 out of the 8 questions. Here he had no comments or suggestions for change, but just positive reactions to different animations used in the questions.

### Stop-over #7

At the last stop-over (Scene 10/GOHOME.DIR - Going Home), Alfred asked all of the 4 questions. Here, too, Alfred had no suggestions for change. He had an attitudinal reaction to the question dealing with returning to school: "I wouldn't want to go back to school - kids would tease me, after being away for a year. They'd say 'What's his problem?'". Once again, Alfred was demonstrating his concern with other people's opinion.

### User-defined gains in knowledge

The author then proceeded to ask Alfred what three things he had learned from navigating the CD-ROM. He answered:

- "When you come home, people might stare at you in strange ways but the nurse told them so they know"
- "I know what chemo and radio will be like"
- "I know how they find bone marrow and how they do the transplant"

### User-defined changes in feelings

The author then asked him if anything about the way he felt had changed: he mentioned not feeling as scared because he knew what would happen, but he would still feel scared for the following reasons:

- he would be asleep during the operation to install the central line, but he would be afraid of waking up in immense pain during the operation and "freak out because of the tubes";
- his feelings would be calmed, but he would still feel scared, mad and sad.

Alfred also felt that the issue of siblings' feelings had been forgotten about in the Voyage. "If kids made fun of your siblings and they didn't like you anymore or if they're jealous that you're getting lots of attention, what do you do?", he asked.

### General reactions

Overall Alfred's navigation seemed rather easy and strayed from asking questions in the sequence which might have been implied by the layout of the buttons (left column, top to bottom; right column, top to bottom). However, he did not use any of the navigational helpers, nor did he backtrack to a previous stop-over with the back button.

## *Group 11/2. Learner verification (May 6, 1997)*

From the pilot with Alfred, the author developed the approach to be used with other end-users. With Dan, however, the evaluation was audio-taped, and a navigational chart was used.

### Background

Dan was not a cancer patient himself, and although his grandmother passed away from cancer in the year preceding his participation in this evaluation, he had very little knowledge of the illness itself. Being only 6 years old, he was not yet a sophisticated reader and had some problems with reading the questions on the buttons - a difficulty no doubt compounded by the fact that Dan attends school in French, even though he masters spoken English. However, Dan proved to be the perfect participant to test the use of the CD-ROM with users from the lower age range it targets. Dan seemed like a brighter-than-average youngster. He is very articulate, plays with CD-ROMs on a Macintosh computer at home. He had no problems with the mouse and knew how to click on buttons. He was accompanied by his mother, who was later interviewed as an expert, because she is an educational technologist.

### Affective pre-assessment

The scenario was proposed: "You've been told you have cancer. You've also been told you have to have a BMT: how do you feel about that?". Dan indicated that it would make him scared because going to the hospital meant having injections given to him. He indicated very clearly that needles and shots hurt and scare him.

### Knowledge pre-assessment

"Do you know what a cancer is? Do you know what happens?", Dan was then asked. He mentioned that it hurt and that this is what his grandmother had. To him, this meant going to the hospital and dying.

### Navigation and reactions

Dan then proceeded to navigate the CD-ROM. Dan's navigation was timed to last about 20 minutes in all.

With the beginning animation of the ship leaving a planet meant to represent the earth, Dan assessed the situation correctly by recognizing it as such. He then had problems understanding what the volume control was about. The ship was then seen traveling through space, which Dan again identified as such.

With Scene 3 (Navigation demo), Dan needed a bit of prompting form the author and his mother. He asked his mother to help him identify the forward button. He managed fine with the back button. He then had to be prompted to try the 'Quit' button. He also took to repeating what the characters were saying, mimicking them. when the navigation demo was over and the application was waiting for user input (clicking forward to move on to Scene 4), Dan sat still. The author prompted him, asking him if he remembered what to do. To this, Dan replied that "it's a little bit too much to remember!". The author gave him a hint: "Remember... you want to go forward". Dan then clicked on the forward button.

As mentioned above, during production, the animation of the spaceship, traveling from planet to planet, ended up looking as though the spaceship was crash-landing on every single planet on its route. Dan reacted to this by saying "Oh no!", or "Oh my gosh!" while finding this amusing.

### Stop-over #1

During the first stop-over (Scene 4/NEEDBMT.DIR - You need a bone marrow transplant), Dan clicked on 7 out of 7 questions. It soon became apparent that Dan would require assistance in reading the questions on the buttons. Hence his choice in sequence was quite arbitrary. After listening to the answer to question 4.7, "How do they get the bone marrow", Dan saw the check-mark appear, as after the answer to any question. He recognized the convention behind this visual signal right away: "Right! I did one!". He repeated this response after listening to the answer to question 4.3, 'What does it feel like?'. The author started worrying that Dan would only be concerned with 'getting the questions right' at this point. Dan then clicked on question 4.6, 'Why do I need new bone marrow?'. After he listened to the response, the author asked him if he knew which question he had just asked. Dan said no. Maybe this seemed like a game to him. The author had further doubts about the significance of the material to a 6-year old when, in reaction to a simile made by Alex in question 4.5, 'What is bone marrow?' ("bone marrow is like jelly"), Dan laughed heartily. He also thought that the animation of the patient in his night-gown was funny. Dan finally had to receive some prompting for moving on to the next stop-over, once he had asked all the questions. He had not yet fully understood the idea that several planets meant different chapters.

### Stop-over #2

His first reaction upon 'landing' on the second stop-over (Scene 5/ADMUNIT.DIR - Admission to the BMT unit), however, was to recognize that he was indeed on another planet: "It's all green!" he said when he saw the background revealed through the ship's dashboard. He then mumbled "there's four clicks here". He decided to choose the Walk thru (Scene 5.2). Dan needed prompting to start navigating this part of Scene 5. AS mentioned before, scene 5.2 differs from all the other scenes in the Voyage: because it is a 'slide show' of sorts. A white slide screen drops down, the lights are dimmed, the kids turn around, we see the back silhouettes of the kids, and a 'Next' button appears just below the slide screen to navigate through the 13 pictures which constitute the tour of the unit. As most end-users, had some difficulty locating the 'Next' button. Dan had noticed the button while it was being explained by the Maya character but needed prompting before clicking on it to go on to the 'walk thru'. He was also a bit startled by the different look this question had, because of the transitions, especially the fade to black which makes the entire computer screen (even outside the application screen) go black. Said Dan, "It looks funny". That seemed to stall him and indicate a need for more prompting.

After seeing the first slide, Dan said "Oh, my gosh!". The author asked him what was on his mind. He replied that he didn't really want to ask that question. Upon immediate prompting from his mom, however, he resumed the slide show. He needed further prompting afterwards. By the 5th slide, his interest was piqued. This slide mentioned the anti-chamber (room previous to where visitors finally go into the child's room). David said: "What is in there?!!". Then he started mimicking again:

| **CD-ROM/narration** | | **Dan's response (verbatim)** |
|---|---|---|
| Scene 5.2.7 | Walk thru the BMT Unit | |
| Nurse: | Every person who will come into your room will need to stop in the ante-chamber first, to wash their hands. | They have to wash their hands?!! |
| Scene 5.2.8 | Walk thru the BMT Unit | |
| Nurse: | Now, they're ready to go into your room. | OK... go to the room! |
| Scene 5.2.9 | Walk thru the BMT Unit | |
| Nurse: | Okay, now it's time to go into your room! | (nothing) |
| Scene 5.2.10 | Walk thru the BMT Unit | |
| Nurse: | So this is your room! All the things you see above the bed are instruments that will help us make sure that everything is fine with you. | OK! |
| Scene 5.2.11 | Walk thru the BMT Unit | |
| Nurse: | When you're lying in bed, you'll still get to see outside through your window. | OK! |
| Scene 5.2.12 | Walk thru the BMT Unit | |
| Nurse: | You'll also be able to look through another window in your room. This is where people can talk to you using a walkie-talkie. | A walkie talkie?! |
| Scene 5.2.13 | Walk thru the BMT Unit | |
| Nurse: | And of course, here's your fun centre, with a TV and video games. Hope you like your room! | OK, Let's go in space!! |

Dan was ready to move on to the next stop-over. The author asked him if that was really what he wanted to do. He then proceeded to ask all the other questions. He then announced that he wanted to go into space again and clicked forward.

### Stop-over #3

During the third stop-over (Scene 6/BROVIAC.DIR - Central Line), Dan asked all questions available to him in quasi-sequential order. He first assessed the situation, as always: "OK... I have 5 questions". the first question he asked was question 6.3, 'Will the central line hurt?'. The answers of the characters especially emphasized that the central line made it possible to avoid having samples of blood retrieved and receiving medication through the insertion of needles in the skin. Dan reacted very positively, demonstrating that he was convinced by the characters' answers. His second to last choice was question 6.6, 'Will the operation hurt?'. Before he clicked on the button, the author - as always - read out the question to Dan:

| | |
|---|---|
| Author: | That's 'Will the operation hurt'. |
| Dan: | I don't think it will. |
| Author: | You don't think it will? |
| Dan: | No. |

It seemed that by the third stop-over, Dan's fears concerning pain had been alleviated somewhat.

### Stop-over #4

During the fourth stop-over (Scene 7/CHEMRAD.DIR - Chemotherapy and radiation), Dan asked all the questions available, an in sequential order. The background of this planet was red, and Dan ingenuously identified it as Mars:

| | |
|---|---|
| Dan | Oh we're on Mars! |
| Author | You know where you are? Where are we? |
| Dan | Yeah, we're on Mars 'cause it's a red planet |

The answer to the first question Dan asked (7.2, 'What is chemotherapy?'), surprised him so he had to ask it and listen to the answer again, the startling revelation concerned the loss of hair (a common side-effect of chemotherapy). Yet more proof that physical appearance is a big concern for children. By the time Dan was finished with this stop-over, the 20 minutes were up.

### User-defined gains in knowledge

The author then proceeded to ask Dan what three things he had learned from navigating the CD-ROM, after assurance that he could resume his 'play' with the CD-ROM afterwards. He answered:

- "I really learnt that it doesn't hurt when you do that";
- "I learnt that... the red thing - I don't remember what it's called... it's like, it's like blood" (Dan meant the bone marrow);
- "I learnt how it goes in the hospital (...) I would be just a little bit scared (...) 'cause... maybe I can get some needles, but maybe one or two".

The author then wanted to assess Dan's notion of time and asked him how long he thought he would have to stay in the hospital if he were a BMT patient. This was somewhat of an unfair question, because Dan had not come across a question concerning the length of time BMT patients may have to spend in the hospital during their 'voyage'. Still, Dan's assessment of 10 days was quite far from the actual time anyone must stay at the hospital for a bone marrow transplant.

### User-defined changes in feelings

The author then asked him if any thing about the way he felt had changed:

- continuing on the notion of time, Dan mentioned boredom as a possible 'evil' he would want to avoid;
- he liked Alex, because he told stories and was "really funny".

Strangely enough the youngest evaluation participant would identify with the oldest character, representing as it were the two opposite ends of the age range targeted by the CD-ROM.

### General reactions

The author hence proceeded to ask Dan about his recollections and impression of the characters:

- he remembered that Robert was 6 years-old from the introduction, though he did not remembered his name;
- he said he remembered the Maya was 7 or 8 (she is 8);
- he remembered that Alex was 12;
- he remembered that Suzanne was 10 but about to turn 11.

When asked how many planets there were in all, Dan answered 9 (there are 7, with the introduction and conclusion, which seem like two extra planets but are actually two sequences where the ship is traveling through space). He correctly identified that he had passed four stop-over's.

Probably by way of his 'young' and tender age, Dan seemed to have enjoyed the CD-ROM or at least seem taken away into the fantasy of space travel and the amusement of animation more so than other, older children, who intently paid more attention to the content. Dan learned, however - and he learned important lessons, namely that it would not hurt has much he anticipated.

### *Group 11/2. Expert review (May 6, 1997)*

Ms. Brown (her real name is concealed to protect the anonymity of her son), Dan's mother sat through the evaluation with her son. After the 20 minutes had gone by with her son, and after some questions asked of him, the author started querying the expert with the aid of the semantic differential scale questionnaire about various technical and pedagogical aspects. She, too, was audio-taped. the results of the questionnaire are discussed ahead. However, here is what she had to say otherwise:

To the statement "I use multimedia programs", Ms. Brown chose 'not very often', specifying that her experience with multimedia was mostly confined to browsing the World Wide Web with Netscape Navigator. She has seen educational products but has not used them. Yet she still felt competent and comfortable with the evaluation of these tools as educational interventions.

In reaction to the second statement ('I could "move" around the CD-ROM...'), she answered that she thought that the navigation was easy but first she ascertained whether the "actual information is just one-way?". She even said, "just going boom, boom", motioning to the right with her hand. the author pointed out that there were options (back, start over and quit button) to make the chronological progression less linear. The author also probed Ms. Brown about what she felt was the underlying concern - total random access:

| | |
|---|---|
| Ms. Brown | Well that's what we expect nowadays |
| Author | that's right |
| Ms. Brown | But you might want to control it that way because the child is getting information |

The author then ascertained that she understood the logical sequencing decisions from her brief exposure to the CD-ROM. the author still wanted to get to the depth of this issue:

| | |
|---|---|
| Ms. Brown | I think that this kind of information, you'd want... you'd want some kind of background information before they went forward to more detail |

Ms. Brown had suggestions to make the CD-ROM more interactive. She thought, for instance, during the Walk Thru (Scene 5.2), that hot spots could have been added. Of her son's experience with the CD-ROM, she said:

| | |
|---|---|
| Ms. Brown | That could have been... I think he wanted to click on the pictures cause that's what he's used to with the other CD's |
| Author | Right |
| Ms. Brown | Just click on the picture... you know click on the door |
| Author | OK, so like click on the door to open the door |
| Ms. Brown | Click, click |
| Author | ...things like that... |
| Ms. Brown | That was one part... |
| Author | hmmm hmm |
| Ms. Brown | ...that wasn't completely clear immediately, this sense of being able to control the image |

In response to the 'The animations were...' statement, Ms. Brown replied tat she thought they were great. The author asked whether they added to the comprehension or distracted from the meaning. Ms. Brown thought they added to the comprehension.

In response to the 'The voices and pronunciation of the characters were ...' statement, where the evaluator is asked to give her opinion about the sincerity and clarity of the characters, Ms. Brown replied that she thought the narrators talked too fast, especially the Suzanne character. However, she found that they sounded sincere and they sounded as old as their characters' ages. She also thought that this question really contained two different and distinct questions.

In response to the 'The answers that the characters gave to the questions were:...' statement, Ms. Brown replied that she thought they were accurate, or well formulated for children from that age range. The only thing that Ms. Brown worried about was that young readers wouldn't be able to read the questions on the buttons. She suggested repeating the question within the answer each time, short of having the questions narrated upon pressing the button[1] the designers had planned the script answers to do just what Ms. Brown suggested, but it seemed that this solution was not effective enough, if such feedback was coming forth from people such as this ID expert.

Ms. Brown thought that the real strength of the CD-ROM was the visual appeal, the space theme specifically[2], along with the sound effects. She also thought another strength was the diversity which the 4 characters gave to the CD-ROM.

The lack of synchronization between the faces of the characters and their speech was another thing that bothered Ms. Brown, though she recognized that it was most likely a difficult thing to accomplish.

She thought the navigation was clear since the buttons were always available at the bottom of the screen. To increase the interactivity and active learning, she suggested the addition of 'fun' quizzes, interspersed throughout the Voyage:

| | |
|---|---|
| Ms. Brown | Well just like 'what have you learned so far?' and they could just type in, I suppose and maybe you could get some expert feedback or something. |

The author rounded out the interview by asking Ms. Brown about anxiety reduction, the tone and realism of the CD-ROM's message and the characters' frank talk about topics which may be taboo.

| | |
|---|---|
| Author | ...what do you think it does for anxiety reduction. Does it work? |
| Ms. Brown | Well I think the more familiar you are with any process, you know, the whole business of being in that room all alone, maybe if you that there are more people... (mumbles can't hear) |
| Author | hmm hmm... (Dan mimics sound effects) That's obviously the fun element (referring to Dan - do you think that might be a distraction and detract from the seriousness of the topic? |
| Ms. Brown | I think that you need to make these things, you know,.... |
| Author | Somewhat fun? |
| Ms. Brown | Yeah |
| Author | Do you get the impression that the tine was too rosy, too optimistic, or do you think that it' s a good dose of realism? |
| Ms. Brown | For me, not knowing about the process beforehand... there's a lot there, there's a lot of information. It might as well be told in a way that makes it more accessible |
| Author | Hmmm.... a taboo subject of course was the topic of dying. |

| | |
|---|---|
| Ms. Brown | Hmmm hmm |
| Author | And the kids at the hospital are very aware that that's something that happens. We didn't touch on that, but other things we were frank about, like reactions to medicine and treatment and you hear things like 'vomit' and 'diarrhea'. Do you think that's objectionable? |
| Ms. Brown | Oh no, that's reality |
| Author | Do you think that's appropriate? |
| Ms. Brown | Yeah. That's the kind of information that's important.. to know that it's normal that this kind of thing is going to happen. |

This concluded the interview with Ms. Brown: Dan had to leave for a swimming lesson.

## ***Group 11/3. Learner verification (May 13, 1997)***

### Background

Allison is an 11 year-old girl, a leukemia patient, undergoing treatment for her first relapse. She had been diagnosed with leukemia when she was 5 years old and was treated successfully with chemotherapy. Her mother and sister were tested: alas their bone marrow was no match for her. She is now in remission, but should she relapse a second time, she will have to have a bone marrow transplant.

Allison was accompanied by her mother during the evaluation. Allison was left free to navigate the whole CD-ROM, with no time constraints. Her mother was encouraged to give her opinion but was asked to refrain from helping Allison unless the girl requested it. The evaluation was audio-taped, and a navigational chart was used.

### Knowledge pre-assessment

Allison, being a cancer patient, had considerable knowledge of the illness. Despite being 11 years old, she seemed to have some problems with reading some questions on the buttons. However, she also seemed like a brighter-than-average youngster.

She is in the 4th grade: she repeated grade 2 after missing five months of school the first time she was diagnosed and treated for leukemia. She also receives home schooling and a home teacher - she has been too sick to be in school and knows how to explain this bit of illness causation:

> Author: You can't go to school right now?
>
> Allison: Hmm-hmm. 'Cause there's like too many germs and stuff like that.

She is very articulate, plays with CD-ROMs and games on a PC computer at home. She had no problems with the mouse and knew how to click on buttons. She was the perfect participant who represented the user with a fair amount of previous knowledge. Particularly, Allison was already acquainted with the concept and reality of isolation. Allison has sojourned at the hospital when in a state of neutropenia[3]. Generally, on those occasions, she has stayed overnight but not in the same rooms as the BMT patients (BMT units). The room is generally small, two people are allowed in at a time, including children.

Allison knew what being neutropenic meant ("You have low low counts and you can catch viruses easily."). Depending on the blood counts, the patient can also go out on the ward. Allison was also familiar with the preparation for one of those stays (bringing toys and other comforts from home). On weekdays they also have access to VCR's, video and computer games and the hospital teacher. what did not come through during the design team's need assessment was that children like Allison existed, who have 'trained' for being a BMT patient - they know a lot of the people of the multidisciplinary team, are familiar with the surroundings of the hospital and with the equipment required to monitor their progress, as well as the invasive nature of the treatment.

In fact, Allison had also been told about bone marrow transplants, she could explain them very well:

| | |
|---|---|
| Allison | It's another person to- another person... |
| Author | Oh OK... |
| Allison | ... takes out- bone-marrow from them... |
| Author | Right... |
| Allison | and, hmm... if it's a match for you they give it to you in bags, but if it has to be sterile, your stuff- no-one can visit you, only through plate-glass, and stuff like that. |
| Author | Yeah... |
| Mother | Because they give you all the chemo first to kill everything. |
| Allison | Yeah. |
| Author | Hmm-hmm... |
| Allison | So the risk for infection is very high. |

When asked about the length of the treatment, she knew what to expect and for this reason did not look forward to the possibility of a BMT. Both mother and daughter look at BMT as a way to avoid chemotherapy for the rest of Allison's life, rather than a life-saving procedure.

### Affective pre-assessment

The author moved on to ask about feelings towards the possibility of a BMT. It soon became apparent that Allison knew about the isolation that getting a BMT involved, and this was her main concern:

| | |
|---|---|
| Mother | So it's really the isolation you wouldn't like... |
| Allison | Yeah. |
| Mother | And not being in contact with anyone... |
| Author | Yeah... Like, how do you feel about that? |
| Allison | Not good. I do not like it |

### Navigation and reactions

Allison then proceeded to navigate the CD-ROM. It took her about 40 minutes to go through the whole CD-ROM, asking every single question available to the user.

With Scene 3 (Navigation demo), Allison needed a bit of prompting from the author and her mother. She had to be prompted to try the 'Quit' button. When the navigation demo was over and the application was waiting for user input (clicking forward to move on to Scene 4), Allison clicked on the forward button.

### Stop-over #1

During the first stop-over (Scene 4/NEEDBMT.DIR - You need a bone marrow transplant), Allison clicked on 7 out of 7 questions. Her choice in sequence was linear. After listening to the answer to question 4.2, "What is a BMT?", the author asked Allison if she thought the answer made sense. Allison said yes. She than clicked on question 4.3, "What does it feel like?". Allison then asked if she could "try all the questions". The author re-enforced that she was free whatever she wanted. Allison moved on to question 4.4 ("Where do they get the bone marrow?") and 4.5 ("What is bone marrow?). The author then inquired about her opinion:

| | |
|---|---|
| Author | So what do you think so far? |
| Allison | It's good! |

Allison then asked the rest of the questions for this stop-over.

### Stop-over #2

Her first reaction upon 'landing' on the second stop-over (Scene 5/ADMUNIT.DIR - Admission to the BMT unit), was to think that the usual ship crash was funny. She chose the Walk thru (Scene 5.2) first. As mentioned before, scene 5.2 differs from all the other scenes in the Voyage: because it is a 'slide show' of sorts. A white slide screen drops down, the lights are dimmed, the kids turn around, we see the back silhouettes of the kids, and a 'Next' button appears just below the slide screen to navigate through the 13 pictures which constitute the tour of the unit. As most end-users, had some difficulty locating the 'Next' button. Allison had noticed the button while it was being explained by the Maya character but needed prompting before clicking on it to go on to the 'walk thru'. Se was also a bit startled by the transitions. Somehow, they failed to convey the intended effect. In fact, Allison expected the room to turn into a dungeon after the fade to black. However, Allison's over-riding reaction to this virtual tour was to rejoice in seeing the cushy comforts of home could be found in the BMT Unit:

> Mother It's the room. (Pause.)
> Allison Look it has a La-Z-Boy. (Laughter.) There's a telephone! (laughter). That's cool.

Allison moved on to ask question 5.3, 'Will there be another kid in the room?'. Allison had few concerns about the possibility parents would have for visits and stay-over's. The answer to this particular question may have misled Allison. The point was being made that the BMT patient could not expect to share the room with a sibling like they may do at home.

She then asked question 5.4 ('How long do I have to stay here?'). She reacted strongly with objections to having some of the toys from home cleaned - especially her Barbie dolls. She kept question 5.5 ('What is the food like?') for last. Allison reacted strongly again - she had no idea about the food restrictions, which do not apply when she is neutropenic. Allison particularly did not like the fact that she would have to be off meat and lettuce for at least 6 weeks ('I wouldn't have a salad for 6 weeks? I don't think so!').

Other reactions to this stop-over included her stating that she would not like:

- the length of time in relative isolation, in the BMT unit;
- the lack of social contact, in fact that's her over-riding concern;
- the pain involved (knows from experience) in BMT sampling to find a match.

She also affirmed that she would fight the isolation by means of communication available to her (phone, walkie talkie, etc.).

### Stop-over #3

During the third stop-over (Scene 6/BROVIAC.DIR - Central Line), Allison asked all questions available to her in sequential order. Her first reaction was a grimace at the idea of rubber tubes sticking out of her chest (attached to the central line), though she wears a Portapak. The first question she asked was question 6.2, 'Why do you need a central line?'. Allison remained undeterred in her opinion - did not want a central line sticking out of her chest. She than asked question 6.3, 'Will the central line hurt'. The answer to this question emphasized that the central line is important to avoid the insertion of needles, for they carry a great risk of infection, even sterilized, for the BMT patient. Allison's reaction was the opposite of Dan's: she would rather receive injections and have blood samples taken through needles. She then explained her disdain at the central line:

> Allison Because ... the way it looks like, it looks like a chicken foot sticking out of you!

The author pointed out that another, more realistic, medical illustration of the central line was more accurate. She still didn't warm up to the idea. However, it indicated tot he author that there may have been a lack of attention and care in this particular illustration.

Allison looked at the rest of the questions for this stop-over and maintained her opinion about the central line. She would rather "have needles". The operation to insert the central line did not scare her -- because she had the same procedure for the installation of the Portapak. It was just the appendage to her body which bothered her.

Also, during this stop-over, Allison started to rely more and more on her mother to read longer, plurisyllabic words from the question buttons to her, such as 'bandage'.

### Stop-over #4

During the fourth stop-over (Scene 7/CHEMRAD.DIR - Chemotherapy and radiation), Allison asked all the questions available, an in sequential order.

She first asked question (7.2, 'What is chemotherapy?'). Again, Allison asked her mother to read a long word to her - 'chemotherapy'. The author was able to re-check the accuracy of the answer to this question with regards to mouth sores:

| | |
|---|---|
| Author | Do you think the explanation they gave is accurate? Is that what happens with chemotherapy? |
| Allison | Yeah. |
| Author | Yeah? Is that how they explained also to you that they would cure cancer cells, and that kind of stuff? |
| Allison | Yup. |

Next, Allison asked question 7.3, 'Does chemotherapy hurt?'. She had no particular reaction. Then, she asked question 7.4, 'What is radiation therapy?'. The answer to this question gave the author a chance to realize that Allison had never had radiation therapy despite her experience with the illness. Despite her efforts to sound out Allison' opinion or attitude toward radiation, the author could not elicit much more than 'I don't know' from the girl. Allison finally asked question 7.5, 'Does radiation hurt?', to which she had no particular reaction either.

### Stop-over #5

Allison's reaction to the fifth stop-over (Scene 8/BMT.DIR) was the same as Alfred's and Dan's[4]. She thought it was too short to be a stop-over:

| | |
|---|---|
| Allison: | That was a short planet! |

She had no further reaction and moved on to the next stop-over, after having listened to the answers to the two questions of this one.

### Stop-over #6

During the sixth stop-over (Scene 9/GRAFT.DIR), Allison again asked all available questions in sequential order. she had no reaction to the first question (9.2, 'How long do I have to stay?'). the issue of parental visits came up again with question 9.2 ('Why do I have to stay alone in the room?'), but Allison's mother interjected before the author could further clarify with Allison:

| | |
|---|---|
| Allison | I thought you were... (Pause.) |
| Author | You had a question? |
| Allison | Yeah, what... Huh... |

Mother I think she sometimes- 'parent's Tuesday'- 'cause I know Rose-Mary did stay with Sarah, but now she probably slept in an ante-room, but she was there.
Allison OK
Author So what do you think of that?
Allison Nah...
Author Still doesn't...
Allison Still doesn't appeal to me.

With the answer to question 9.4 ('What's going to happen every day?'), however, Allison's anxiety about separation from her immediate family seemed alleviated a little. Allison's reaction to the answer to question 9.5 ('What does it feel like?') was the same as Dan's - she didn't like the idea of hair growing on her face (changes in physical appearance). with the answer to question 9.6 ('What will I do all day?'), Allison again was worried about losing her toys, having to have them cleaned, which meant not having them for a few days (stuffed animals which she takes to bed every night). She had a very real and immediate sense of the different difficulties she would have to face, were she to become a BMT patient. Allison went through the rest of this stop-over with no particularly noteworthy reactions.

### Stop-over #7

During the last stop-over (Scene 10/GOHOME.DIR), Allison again asked all questions in sequential order. Allison nodded all the way through Maya's introduction to this stop-over which dealt with restrictions on outdoors activities and going to school for post-transplant, discharged BMT patients. Allison then informed the author about the restrictions she faces now, even when not a BMT patient:

- can go play outside but is forbidden to ride her bike or play soccer in a team (she had started playing last year);
- cannot go to school, although she is allowed to visit her classmates.

She had no particular reactions to questions 10.2 or 10.3. With question 10.4, 'Will people stare at me?', Allison had a reaction because of previous experience. When she was diagnosed the second time, she had to get around in a wheelchair because she was weakened by the illness and was also wearing a hat to conceal her hair loss. The results that many people stared at her, which she did not appreciate:

| | |
|---|---|
| Author | Yeah... So how do you feel about that? |
| Allison | I don't like it. |
| Author | No... |
| Allison | I just stare right back at them... |
| Author | Oh, good! |
| Mother | That's her latest way, if someone stares, she'll stare right back, right in their eyes... |
| Author | And do you... |
| Allison | I'll go like this... Like, OK, say your staring at me? Well... (gives a mean look) |
| Author | (laughter) |
| Mother | They turn around quickly... |
| Author | So you look at them with that mean look, and it's like: 'What are you staring at?!...', type-a-thing... But at first, like how did it make you feel? |
| Allison | Upset. |

Allison went on to the last stop-over. Her voyage then ended.

### General reactions

Allison did not use any other buttons than the forward button for navigation. Both mother and daughter reported enjoying the CD-ROM very much and thinking it was very good. Allison needed to be told again about the help and back buttons. The author asked her whether she thought, in retrospect, she could have used the back button to revisit a question. Allison said she didn't know

### User-defined knowledge gains

Upon prompting from her mother started describing the different things she had learned through navigation the CD-ROM:

| | |
|---|---|
| Allison | Hmm... Yeah... It's like- hmm... OK, somebody gets a bone-marrow from them... |
| Author | Right... |
| Allison | ...and then they put in a bag just like the ones when they're given blood... |
| Author | Hmm-hmm... |

| | |
|---|---|
| Allison | ...and then, like what they do is they sterilize it and all that stuff and make sure they have no cells or anything in it... |
| Author | Hmm-hmm... |
| Allison | ...and then what they do is they give it to you... |
| Mother | After what... |
| Allison | After, hmm... |
| Mother | ...after they kill all your... |
| Allison | ...your cells and stuff like that... |
| Author | OK, OK... |
| Mother | She knew a bit about it... |
| Author | You knew a bit about it... |
| Allison | A bit... |

### User-defined change of feelings

The author then asked Allison if her feelings about the possibility of a BMT had changed. The comments were mixed, meaning that some referred to changes (or lack thereof) in opinion held before seeing the CD-ROM, and others to changes (or lack thereof) in opinion held during the navigation of the CD-ROM. Allison found out through her exposure to the CD-ROM that she would have to have a central line. Her feelings, formed upon receiving that information, had still not changed by the end of her navigation. She would not like the rubber tubes coming out of her body.

Allison had a good idea of what a BMT would represent for her before seeing the CD-ROM. She stated that she thought it would be 'OK' to go in and have a BMT and staying in the room all this time now that she knew that she could bring her own movies and toys, as she already has in her treatment to date.

The greatest assurance for her, however, seemed to stem from the knowledge that she would be able to maintain direct contact with her mother and older sister. She also started thinking ahead about visits from older cousins. Her greatest worry seemed to be alleviated:

| | |
|---|---|
| Allison | I guess it's OK if you can bring your own movies and stuff like that. |
| Author | Huh-huh. |
| Mother | And if someone lives with her. |
| Author | So you'd like it for your mom to... |
| Allison | But I wouldn't like to live without my sister. |

| | |
|---|---|
| Mother | She could visit through the glass. |
| Allison | Yeah but that's through glass! Like, not come in and hug me or anything... |
| Author | But she's 16, you said, almost 16, so I think she might allowed in. |
| Mother | Probably... It's basically young kids, actually, 'cause they tend to carry more germs, and stuff like that. |
| Allison | So Lori and John and stuff... And Gail, maybe... |
| Author | Who are Lori, John and Gail? |
| Allison | My cousins. And my sister's friend's Gail. |
| Author | OK |
| Mother | Probably just your sister. |
| Allison | Yeah, but my cousin too. |
| Author | How old's your cousin |
| Mother | 18. |
| Allison | 18. |
| Author | OK He probably could visit you in the room. |
| Allison | Maybe. If they were there, I wouldn't mind... Like my cousins. |
| Author | Huh-huh. How old are they? |
| Allison | One's 18, and the other one's about 16, same as my sister. |
| Author | Oh... I think they would be able to visit you in the room... |
| Allison | Whew... |

When prompted to describe any feelings of anxiety ('Would you use words like nervous, or scared, or anxious?'), Allison pointed out that it was the inconveniences which she wouldn't appreciate, rather than the fear ('I wouldn't like because I don't get the food I want and I don't get the stuff I want'). But both Allison and her mother had a palpable sense of optimism about the possibility of a BMT - she would even like to schedule it in the winter, so she would not miss out on the summer.

### ***Group 12. Expert review (May 14, 1997)***

Another chance expert review happened while the author was demonstrating the CD-ROM for other purposes. Both pedagogical and technical aspects were quickly assessed by Dr. Suzanne Lajoie, professor of educational psychology at McGill University. Two graduate research assistants, who were working on multimedia learning packages for children, looked on and made comments, too.

First, Dr. Lajoie questioned why video was not used, if there was a specific reason for using animated characters. Had it been determined that cartoon-type illustrations were better than more realistic video clips? The author answered that animation was faster to create. Digitizing video imposed a learning curve and a management of file size that no member of the design team was really willing to face, especially given that this was their first, big, multimedia project. She then asked if the question buttons represented the curriculum. To this the author responded that the CD-ROM was essentially a FAQ - Frequently asked questions list - of the bone marrow transplant treatment. The questions - or curriculum - were the results of a front-end analysis. The user had the choice of questions, of going back and forth. etc. However, the story format gave the whole Voyage a fairly linear structure. Dr. Lajoie thought this would have been ideal for a video. The Voyage should be more interactive, she thought. She liked the Help function and thought it was useful. She also had no problems with the navigation. She finished up by asking whether the users were given a test. To this the author responded that the evaluation was more casual, at least in the formative evaluation of the product. She then explained how knowledge and attitude, especially anxiety would be assessed through semi-structured interviews with potential end-users. She then informed Dr. Lajoie that users reported feeling less scared "because I know what is going to happen". Dr. Lajoie thought this was great. Her two assistants thought the design team had done a wonderful job. It gave one of them ideas on addressing the end-users of her package.

### *Group 11/4. Learner verification (May 22, 1997)*

#### Background

The last of the end users was Marty, an 11 year-old boy and leukemia patient. He, too, was accompanied by his mother. Marty was diagnosed just at the end of 1996 and has been responding successfully to chemotherapy, although he was also scheduled to undergo radiation therapy when the author met him. The evaluation was held in a room of the hematology clinic, where Marty had to remain in-between blood transfusions. Marty is currently in remission. Reactions to the treatment for Marty have included nausea and headaches.

### Affective pre-assessment

Marty was fairly articulate but tended to stick to one-word answers. Both mother and son did not come across as being as relaxed as Allison and her mother. One has to assume that the recent diagnosis, in this case, made the difference.

Author So this is pretty new for you and your family. What's it been like so far?
Marty Well, it's been hard...
Author Yeah..
Marty 'Cause you have to get a lot of different treatments... And you gotta know what you're taking...
Author Huh-huh... Right...
Marty And it's hard to get to the hospital when I'm in bed sleeping... 'Cause I'm tired.
Author Is it the treatments that make you feel tired?
Marty Yeah. Well some of the treatments. Some of them make me feel tired, some of them make me feel sick.

Despite the recent diagnosis, both mother and son expressed relief at finding out that Marty was suffering from a very treatable form of leukemia. The relief also seemed to mask a hint of resignation:

Mother ...the initial shock was a little difficult to get over, but when we found out that it looked very good, and that the doctors were very optimistic, that it's fortunately a very treatable type of leukemia, so... After that it was 'OK, Let's do it..., it's something we have to do...'

Marty more directly expressed some anger:

Author Oh, you have to do it for 2 years...
Mom It's a 104 -week treatment.
Author How do you feel about that?
Marty I'm... just really mad that I've gotta wait all that time just to get better

When asked if he talked about his illness with companions from the clinic:

| | |
|---|---|
| Author | OK. And do you guys talk about the chemo and how you feel, or you just wanna play and do normal kid stuff? |
| Marty | Well, I talk to some of the kids here, about some of the chemo take makes us sick, you have to talk about it. What else would you talk about? |

About the possibility of BMT, Marty shared these feelings and fears:

| | |
|---|---|
| Marty | Well, while I'm getting it I guess it would hurt, I guess, but it might be, probably, I'd be asleep or something. They'd give me something to sleep. |
| Author | OK. Right. |
| Marty | I guess it would hurt while I'm getting it. |
| Author | hmm hmmm |
| Marty | hmm hmmm |
| Author | So how would you feel about that? Would you be scared or would you think, 'Well I guess it's just like chemo, and I need that treatment!' or... |
| Marty | I'd rather not, like, have to have it, but if it's going to make me better I'll do it. |

### Knowledge pre-assessment

Marty reported that the staff at the hospital had given him a lot of information about the treatments and the reactions he could expect. He considered himself well-informed. He has had the experience of being neutropenic, just like Allison. He also receives schooling at home. Marty further knows what he can expect from radiation therapy because he was about to undergo his first treatment when the author met him. The author had a hard time assessing what Marty could make of the explanations that had been given to him by the nurses: when asked to explain it in his own words, his mother proceeded to explain it for him.

The author moved on to assess how Marty thought the illness had changed his life. Like Allison, he had to stop some athletic activities. Marty could also explain a little about the BMT procedure:

| | |
|---|---|
| Marty | Well... I think I got a thing... On my back, in my spine... the marrow is, I guess it's not good, it's not healthy, so they have to change it. |

Marty also had previous experience with computers and multimedia: he has played with CD-ROMs at home (*Carmen Sandiego*, spelling and math games, word processing for writing stories and computerised chess) and has a PC at home. He had no problems handling the mouse and knew how to click on buttons.

### Navigation and reactions

In terms of navigating the CD-ROM, Marty read the questions fast and decided quickly on which questions he would ask. As time went on, it became obvious that he chose them on a pre-conceived notion of the answer he was going to get and his presumed knowledge of the answer.

The character quirks seemed to grow on him as he navigated. Moreover, Marty navigated the CD-ROM on a laptop with a track-pad, but he managed fine. He even talked back to the characters, as the other children did - a sign to the author that they identified with them or at least liked them. He had no problems with the navigation

### Stop-over #1

At the first stop-over (Scene 4/NEEDBMT.DIR - You need a bone marrow transplant), Marty clicked on 6 out of 7 questions. He first chose, 'What is bone marrow' (question 4.5), which elicited no reaction from the young patient. The next question was 'Where do they get the bone marrow?' (question 4.4). To the answer, Marty responded 'I knew that!'. His mother added that he knew that he could get the bone marrow from a family member. Marty's third choice was 'What does it feel like?' (question 4.3). Marty nodded at what Robert said (check what he says). He went on to ask 'What is a bone marrow transplant?' (question 4.2). Marty's second to last choice for this stop-over was 'How do they get the bone marrow?' (question 4.7). Marty had no reaction to the answer. He finally asked 'Why do I need new bone marrow?' (question 4.6). In reaction to the generally low-key response, the author asked Marty about his thoughts of the CD-ROM so far. The patient simply answered "It's good". The author further inquired about

Marty's opinion of the usefulness of the animations. Marty replied that he liked them. When asked whether he thought they were distracting, he still answered no.

### Stop-over #2

Marty finally moved on to the second stop-over (Scene 5/ADMUNIT.DIR - Admission to the BMT unit). He, like most of the other children, was somewhat stuck after the introduction. The 'Next' button was being confused with the forward arrow yet again. Marty actually clicked on the forward arrow, 'landed' on stop-over 3, and clicked the backward arrow - with no prompting - to return to the second stop-over. Upon his 're-landing', Marty knew immediately to click on the 'Next' button. Marty decided to go on the virtual BMT Unit tour right away. He mumbled after each segment was over, as if he were acknowledging the answer. He just flew through the tour, making no comments, with the exceptions of the walkie talkie ('Cool!', he said) and the video games ('Hmm hmm', he appreciatively mumbled). The author asked whether he liked the part about the video games. While Marty said 'It's cool', his mother exclaimed: 'That's just what we need! More video games!'. Marty seemed favourably impressed with the cool stuff he would have access to. In fact, Marty could already think ahead to the use of walkie talkies to break the isolation :

> Marty Well, then, I could talk to people without being really close to them.

The author took advantage of this to move on more specifically to the theme of isolation. Marty had already had an idea of this experience because he had been constrained to a hospital room / isolated environment when he was neutropenic on two occasions. However, Marty never really elaborated about feelings of loneliness other than stating that his siblings were not allowed to visit him.

Marty then asked question 5.4 (How long will I have to stay here?). When the Suzanne character mentioned that she had stayed in the BMT unit for 6 weeks, Marty repeated "6 weeks!". The author probed for the meaning hidden behind his exclamation:

> Marty That's a long time! I thought you would have to stay... about a week!

Marty moved on to question 5.5 (What is the food like?). He thought he wouldn't enjoy liquid food. Despite being put in relative isolation when he was neutropenic, Marty had not had to face any diet restrictions, only avoiding any foods which the combined effects of his illness and the treatments would render intolerable.

**Stop-over #3**

Marty finally moved on to the third stop-over (SCENE 6/CENTRAL LINE Central Line) at which point the CD-ROM started to experience technical glitches. The head of the Maya character kept disappearing during the loops where she was animated, as it did when the CD-ROM was presented to staff at the MCH. Marty stared unperturbed and decided to move on immediately to the 4th stopover by pressing on the forward button. The author asked Marty if he did not want to look at any of the questions, to which he simply said no. When asked why he offered that he knew that the central line is "the tube thing".

**Stop-over #4**

At the fourth stop-over (SCENE 7/CHEMRAD.DIR - Chemo and radiation therapy), the author asked Marty to purposefully choose a question so she could verify whether the technical glitches had gone away. Marty chose Question 7.4 (What is radiation therapy and why do I need it?). He asked none of the other questions, had no comments to make on this stop over and moved on to the next.

**Stop-over #5**

At the fifth stop-over (SCENE 8/BMT.DIR - Bone Marrow Transplant), Marty asked question 8.3 (Will I feel sick?). He then clicked on the other question, 8.2 (What does it feel like?). Again, Marty had no comments.

**Stop-over #6**

During his sixth stop-over (SCENE 9/GRAFT.DIR - Engrafment), Marty only asked one question, "What happens every day?" (question 9.4). Again, Marty made no comments and moved on rapidly to the next step. The author asked him if he wanted to asked other questions:

Author There's nothing else that you wanted to know?
Marty Well, I sorta knew everything...

### Stop-over #7

Marty moved on to the last stop-over (SCENE 10 /GOHOME.DIR - Going home) where he asked question 10.4 ("Will people stare") upon prompting from his mother. At the end of the answer he asked:

Marty OK. Then, we're done, Yeah? Keep on jumping?
Author Just... you do what you want.

Marty had finally reached the end of the voyage and not a minute too soon: he seemed bored.

### User-defined Knowledge Gains

The author proceeded to ask Marty about three things he had learned from the CD-ROM. Marty stated first that he did not know prior to navigating the CD-ROM whether a BMT would hurt or not. The author probed by asking why this was important for Marty to know:

Marty Because, I don't wanna... be getting headaches or anything... Headaches or be nauseous... I like to keep from being nauseous as much as possible 'cause I really hate throwing up, and stuff...!

Marty concluded by saying he wanted to know if the BMT would make him feel nauseous.

The author asked whether he had learned anything else, to which Marty replied that he had found out about the BMT room. The two issues of real concern here regarded the amount of time Marty would have to spend in there, were he to get a BMT, and why it seemed to take so long:

| | |
|---|---|
| Marty | I'm really surprised that it takes about six weeks to do that... |
| Author | What surprised you about that? |
| Marty | I thought you would just get it and, you'd stay in the hospital for about just 1 week, just to recover or something... |
| Author | Huh-huh... |
| Marty | I didn't think it would be 6 weeks! |
| Author | So you don't like the idea of having to stay in the hospital for that long? |
| Marty | I don't really like the idea, but I know you have to if you really wanna stay OK... |
| Author | Hmm-hmm... But you were really surprised to see it takes that long... Did you understand why it takes that long? |
| Marty | Well... I don't think I did... |
| Author | That's OK... Just what you understand or what you know. |
| Marty | Well I guess I understand it takes that long 'cause they gotta make sure that you don't get sick again or you don't get bacterias, that you don't get around bacterias... And I know everything's gotta be really clean... 'Cause dust and stuff, if you got allergies, or... anything can make you start feeling nauseous or get a cold, different things... |

Marty could not think of any further things which he learned.

### General reactions

The conversation with Marty then diverted onto the topic of computer games. He explained that one of the spelling games he likes to play is hard and challenging because "you really gotta think". However, he thought that the graphics used in the game are "too babyish". The author took advantage of this to link it back to his impression of the CD-ROM. The first thing Marty noted was the lack of synchronization between the lips and faces of the animated characters with the narration. He then commented that the graphics could bit more realistic:

| | |
|---|---|
| Marty | Yeah, the kid standing with one hair, it's a little weird. |
| Author | Yeah?... You find it weird? |
| Marty | It's funny though, but- I think it would be a little better if it looked more- |
| Author | Realistic? |
| Marty | ...if it looked more like real people. |

Moving on to ask whether Marty would have liked to see a game inserted into the CD-ROM, the author first wanted to confirm if Marty felt bored with the application:

| | |
|---|---|
| Marty | Hmm... Not really, like- I was learning new stuff, so I wasn't really bored... |
| Author | Right... OK... Do you wish you had games or something to do, more than just click the buttons, and listen to the kids? |
| Marty | Yeah, I think I- if you could- I don't think you can really like play a game on anything like this. But, if somehow you could think up of a game to go with it. Maybe if you want, like a little test, like if you go thru all of it... |
| Author | Right... |
| Marty | ...like at the and you could challenge yourself on it, or something so you could remember. |
| Author | OK, so a test to see if you've learned what the kids have told you about... |
| Marty | Yeah. |
| Author | OK. Sort of like the same questions I was asking you afterwards, do you remember and that kind of stuff? |
| Marty | Hmm-hmm. |

Marty also liked the original goal of the CD-ROM (could not be implemented, because of complexity):

| | |
|---|---|
| Author | Would you like- like you we telling me that you use word processing at school to tell stories- Would you like to be able to have a button that could let you tell a story about what you think chemo is like, and look at stories of other kids that have entered their stories of what they think it's like... |
| Marty | Yeah. |
| Author | You'd like that? |
| Marty | Yeah, so that we exchange ideas- I mean exchange experiences, like- |
| Author | Yeah... |
| Marty | Of what happened to some kids... |

Marty said being able to judge the appropriateness of the characters with regards to age portrayed "based on how tall they are and how they look":

| | **Age of character** | **Age Marty gave them** |
|---|---|---|
| **Robert** | 6 | 6 |
| **Maya** | 8 | 10 |
| **Alex** | 12 | 12-13 |
| **Suzanne** | 11 | 11 |

Perhaps because of her preponderant role, Maya seemed older then she was meant to be.

Marty would also have liked to have more freedom of movement, a brake away from the linearity of the story format: "...maybe it could have a list of which places to go, so you wouldn't have to go to every different place". Marty also thought that the apparent explosion of the ship when it landed on each new planet seemed worrisome. He had this alternative to suggest:

| | |
|---|---|
| Marty | ... then you see it [the ship] like land on the place - and then you show the kids - little green men looking in... |
| Author | (Laughter) |
| Marty | And then you show the kids again. |
| Author | Right. Would you like to see the kids go out of their ship onto the planet? |
| Marty | Yeah, that's clever. |

### User-defined Change of feelings

On the topic of feelings, Marty affirmed feeling reassured about pain:

| | |
|---|---|
| Marty | Well, now that I know that it doesn't hurt... |
| Author | Huh-huh... |
| Marty | ...If I had to get one, I would be more confident about getting one, 'cause I know it doesn't hurt now. |
| Author | OK... So that was your main- Your big concern was like- 'Oh, I don't want anything that's gonna hurt...!' Right? |
| Marty | Yeah... |

Marty had nothing further to say about changed feelings.

### *Group 13. Expert review (May 30, 1997)*

The CD-ROM was once again presented to educational technologists in a trade fair setting at a local ISPI conference, May 30, 1997. The questionnaire (see Appendix D) was on hand for volunteers. Results of the questionnaire are discussed in the thesis document.

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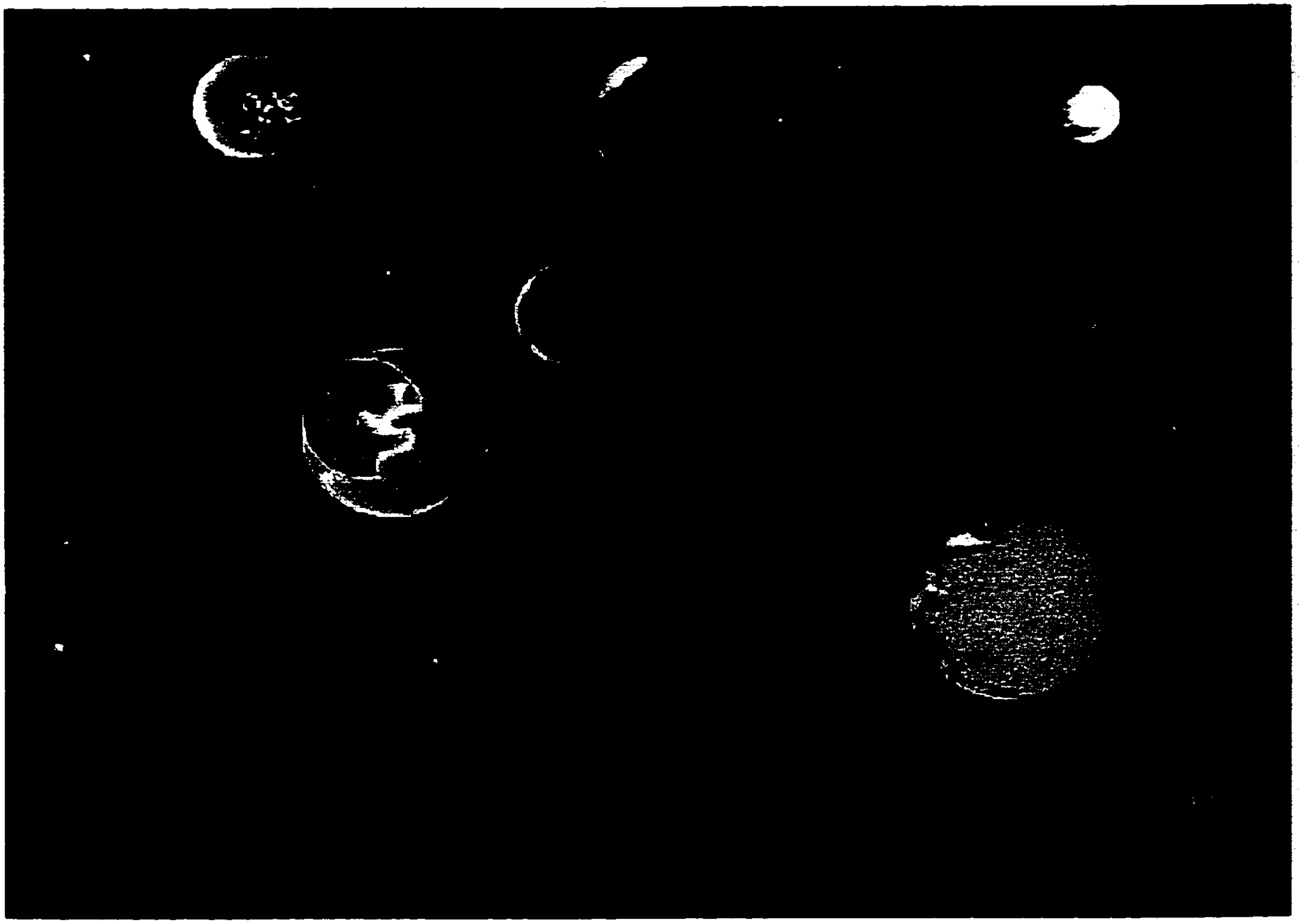
[1] This was a solution which the designers had discarded because it compromised the interactivity of the CD-ROM.

[2] It is good to note that these were Ms. Brown's immediate feedback after exposure not only through her eyes, but through her eyes as a mother and her son's reaction to the CD-ROM.

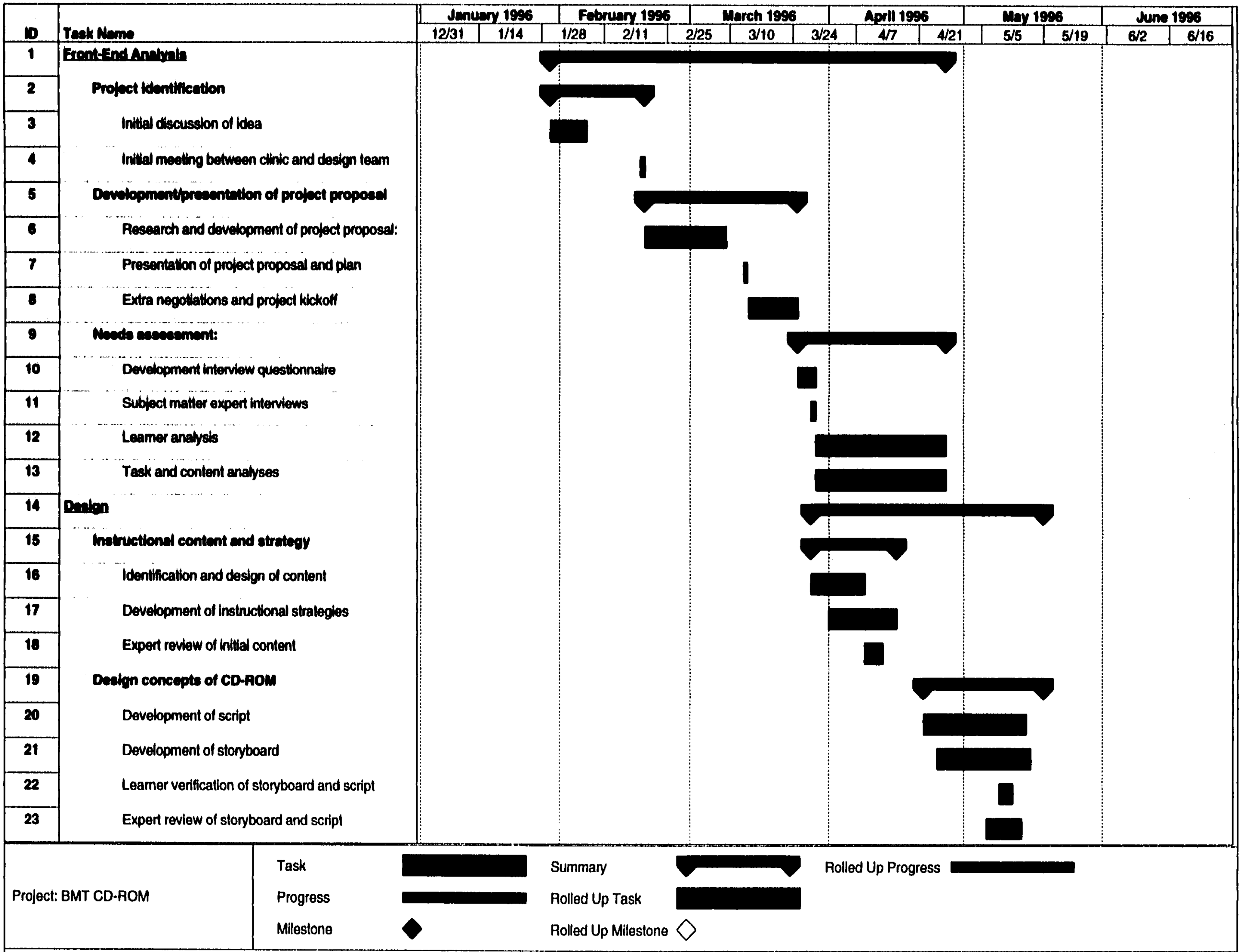
[3] Involves staying in a small room, in relative isolation, getting blood and platelet transfusions, getting chemotherapy on the ward instead of the clinic. give a definition of neutropenia.

[4] After the 20 minutes were up and the author interviewed Dan's mother, Dan kept on playing with the CD-ROM. His reaction to this stop-over was 'Just 2 questions!!'.

# Appendix Q. Ship crash-landing



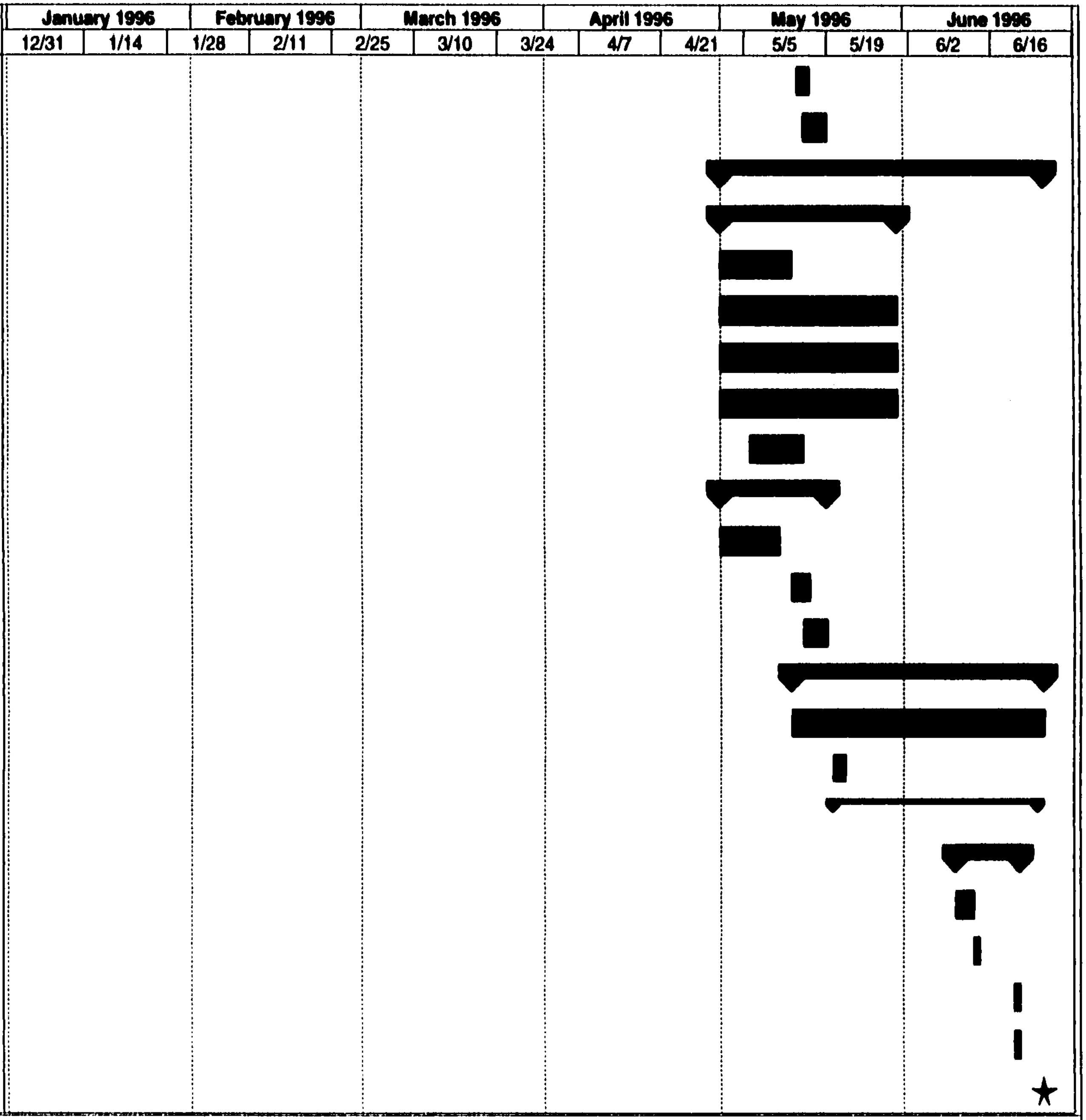
# Appendix R. Gantt chart: Production of CD-ROM timeline



| ID | Task Name |
|---|---|
| 1 | **Front-End Analysis** |
| 2 | **Project identification** |
| 3 | Initial discussion of idea |
| 4 | Initial meeting between clinic and design team |
| 5 | **Development/presentation of project proposal** |
| 6 | Research and development of project proposal: |
| 7 | Presentation of project proposal and plan |
| 8 | Extra negotiations and project kickoff |
| 9 | **Needs assessment:** |
| 10 | Development interview questionnaire |
| 11 | Subject matter expert interviews |
| 12 | Learner analysis |
| 13 | Task and content analyses |
| 14 | **Design** |
| 15 | **Instructional content and strategy** |
| 16 | Identification and design of content |
| 17 | Development of instructional strategies |
| 18 | Expert review of initial content |
| 19 | **Design concepts of CD-ROM** |
| 20 | Development of script |
| 21 | Development of storyboard |
| 22 | Learner verification of storyboard and script |
| 23 | Expert review of storyboard and script |

Project: BMT CD-ROM

| ID | Task Name |
|---|---|
| 24 | Development of final script |
| 25 | Adjustments to script |
| 26 | **Development** |
| 27 | **Layout, graphics and photos** |
| 28 | Characters |
| 29 | Other illustrations |
| 30 | Cross-platform testing |
| 31 | Interface |
| 32 | Slides (digitizing) |
| 33 | **Narration** |
| 34 | Selecting child actors |
| 35 | Rehersals and script revisions |
| 36 | Sound recording and editing |
| 37 | **Prototype module** |
| 38 | Animation |
| 39 | Flowcharting |
| 40 | **Integration and programming** |
| 41 | **Evaluation** |
| 42 | Navigation clarification |
| 43 | Test CD-ROM burn |
| 44 | Learner verification pilot |
| 45 | Client validation |
| 46 | **Project completion** |



Project: BMT CD-ROM

| | | | | | |
|---|---|---|---|---|---|
| Task | ■ | Summary | ▬ | Rolled Up Progress | ▬ |
| Progress | ▬ | Rolled Up Task | ■ | | |
| Milestone | ◆ | Rolled Up Milestone | ◇ | | |

# Appendix S. Letter of thanks from Lamplighters

**Association contre la leucémie et le cancer infantiles**
La Fondation des Lampistes contre le cancer infantile

L'Hôpital de Montréal pour enfants
Montreal Children's Hospital

LAMPLIGHTERS
LAMPISTES

**Children's Leukemia-Cancer Association**
Lamplighters Children's Cancer Foundation

**N° d'enregistrement fédéral**
**Federal Registration Number**
**0468215-13-06**

TY-1088

20 June 1997

→ Julie Daignault
Joanne Gaudreau
Wendy B. Lowe
The BMT Voyage Design Team

Dear Julie,

On behalf of the Lamplighters Children's Leukemia-Cancer Association, and in particular, our children, it gives me great pleasure to thank you for your generous donation of time and talent. You shared these with us in the production of THE BMT VOYAGE. I also want to express our heartfelt appreciation for your Copyright Assignment and Waiver of Moral Right related to this product. It is our turn now to ensure production and access of the CD-ROM to as many children and families that need it.

The inspiration of our existence, the children who have cancer, benefit from your support through a new and vitally needed educational resource. With the prospect of a CD-ROM, steps were also taken to obtain computers for the Bone Marrow Transplant units and the new LAMPLIGHTER HEMATOLOGY-ONCOLOGY WARD. You may not realize it, but you have been instrumental in a lot of changes.

My husband has accepted a new job in Toronto and my family will be leaving by the end of July. Your new LAMPLIGHTER contact will be Guy Groleau who can be reached at 285-2500(x394). Consider the various items in support of mass producing the CD-ROM's as follows:
a) Successful french translation of the text;
b) Design of a Lamplighter release form;
c) Contact of potential CD-ROM producers;
d) Budget for cost of translation and production; and
c) Search for a sponsor to cover these costs.

Guy will contact Julie, to determine if you have a role as we go from here. Again I thank you for your wonderful support. I hope you have great success in your chosen fields and best wishes for the summer.

Sincerely,
Suzanne Hétu-Eng
Suzanne Hétu-Eng
Representative

cc: David Wells

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