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Breast Cancer Treatment

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FOREWORD

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INTRODUCTION

The proposed work brings an innovative approach to clinical decision-making activities by placing state-of-the art interactive computer technologies in the hands of women facing treatment for breast cancer. By providing an individualized approach to treatment decisions we will be able to determine in future studies if decision support influences patient satisfaction with treatment and if satisfaction, in turn, influences well being. Ultimately, our objective is to enhance the quality of life of women facing breast cancer treatment by providing quality decision support that is effective, practical, and empowering.

This project was developed to address the stress, conflict, and uncertainty surrounding breast cancer treatment decisions that is so pervasive in our current health care delivery systems. Patient and provider relationships do not always provide for the level of support, information, and counsel that is required by women attempting to sort out the intricacies of decision options placed before them. Many patients are turning to books, videos, the Internet and various media technologies to help them through this difficult period. A shortfall of many of these sources is that they do not individualize the information to a particular woman, nor do they have the capacity to take into account, and tailor, the way the information is presented to optimize her reasoning capacity. Therefore, the specific aims of this project are to assist women and their families: (1) make active decisions about breast cancer treatment that reflect their goals, values, and personal decision making style, (2) in making more informed decisions by providing readily accessible information, and (3) avoid common decision errors by rehearsing various outcome scenarios and making the necessary corrections to increase satisfaction with choice.

The scope and significance of this project rests on the potential it holds to enhance the quality of patient's decisions and potentially the outcomes of those decisions. Greater involvement, in partnership with tailored decision support, may also optimize the decision-making process by which treatments are chosen thereby reducing untoward decision outcomes such as disappointment, regret, or depression.

RESEARCH ACCOMPLISHMENT

Statement of Work

Our Statement of Work is outlined in Figure 1 and describes the original plan to develop a prototype of an interactive decision support system for use by women diagnosed with early stage breast cancer. During Year 3 of the project, during prototype testing, the team enthusiastically identified additional components that could be developed that would enhance the quality and uniqueness of the program. At that point we requested an extension (please refer to this request of June 1999) to complete **additional components** that were not originally included in our schedule of activities.

For the original prototype we included the following components: (1) decision style assessment, (2) value assessment, (3) decision support, (4) pre-decision rehearsal, and (5) analysis, feedback, and communication. In the midst of developing these modules, the team realized the potential for providing more elaborated decision support and added additional components to the program. In addition, for the value assessment module (#2 above), we developed two separate methods for eliciting values and have tested women's ease of use and preferences for the two methods. This item was beyond the original scope of the project but it addresses one of the major issues in decision science, which is to assess personal values without the burden of complex mathematical models, which are currently prevalent in the field. Patients, in particular, find these much too cumbersome to use and we have devoted a great deal of attention to the development of alternative models that are more user friendly and still yield important information. We have also developed individualized interventions based on the assessment of decision style that promises to provide more specific and tailored information than any other system currently available.

Figure 1. Schedule of Activities

Project Period From January 1, 1997 to June 30, 1999¹

Quarter	Year 1 1997				Year 2 1998				Year 3 1999	
	1	2	3	4	1	2	3	4	1	2
PROTOTYPE DEVELOPMENT										
Assemble advisory and technical panels										
Purchase equipment & supplies										
Develop systems plan for prototype										
Write and edit text for program modules			■	■	■	■	■	■	■	■
Programming		■	■	■	■	■	■	■	■	■
Laboratory testing of components			■	■	■	■	■	■		
Review of prototype by advisory panel(s)				■		■		■	■	■
Preliminary field testing							■	■	■	
Prepare Interim and Final reports										
Prepare Papers for Presentation and Publication										

¹ In June 1999, we requested a one-year extension to complete additional components of the project, which will be addressed in further detail within this report.

The program now uses the decision style information and creates individualized action plans that are composed of a number of additional components including: (1) My Plan (describes basic decision procedures; helps the decision maker understand the steps involved and ways in which decision support improves the process), (2) Selecting a Doctor and/or Treatment Facility, (3) Building a Support Team, (4) Gathering Information, (5) Communication Tools (the program is designed to help women easily communicate by preparing letters, lists of questions, reminders, "to do" lists, etc.), (6) Emotional and Physical Support, (7) Entailment and Reactive Costs (interventions to reduce potential post-decision regret by anticipating future setbacks and emotional reactions), (8) Reflection and Restoration, and (9) Declaring a Choice. The addition of these 9 components, as well as the development of two versions of the values assessment were beyond the scope of the proposed project and will frame the Statement of Work for the year's extension.

KEY RESEARCH ACCOMPLISHMENTS

- Task 4 Months 13-15; 19-21 Completed
- Task 5 Months 16-18; 21-24 Completed
- Task 6 Months 16-21 Completed

Additional tasks to be completed during the extension to June 2000:

- Task 7 Months 24-26 Design format of 9 additional components
- Task 8 Month 25 Plan programming flow chart
- Task 9 Months 26-30 Write text for new components
- Task 10 Months 26-36 Write new program language/edit/revise
- Task 11 Months 33-36 Edit and revise new material
- Task 12 Months 35-36 Refine final prototype

REPORTABLE OUTCOMES

- Decision Support Prototype of originally-planned work is complete
- Presentations
 - Addressing the Psychological Needs of Women Diagnosed with Breast Cancer: Providing Decision Support. World Conference on Breast Cancer (1999). Ottawa, Canada.
 - Value-Based Decision Support for Early Stage Breast Cancer. World Conference on Breast Cancer (1999). Ottawa, Canada.
 - Development of an Instrument to Measure Decision-Making Behavior in a Clinical Setting. 22nd Annual Research Conference of the Midwest Nursing Research Society (1999). Columbus, Ohio.

- Papers in Progress
 - “Decision Support Interventions for Breast Cancer Treatment”
 - “Elicitation of Breast Cancer Treatment Values”

CONCLUSIONS

Building on the work completed during the first phase of this project, *Choices* promises to address fill the gap regarding access to quality decision support that is critical to empowered and informed choice that is currently lacking in both our scientific understanding as well as our clinical care. This project represents an important first step in the effort to define optimal strategies for providing personalized decision support to empower women’s self-determination and participation in cancer treatment decisions. One of the most illuminating findings of our prototype testing was the importance of determining women’s values regarding treatment options. This finding led us to develop two versions of the value elicitation (simple vs. complex) which has not been done in previous work. Again, this points to the vital importance of individualizing decision support systems to assure their relevance at the time of treatment and ultimately their satisfaction with the outcomes of those choices. At the conclusion of the study it is anticipated that the second and more elaborated prototype will provide a robust decision support product that has the capacity to individualize and tailor women’s decision-making experiences. In the future, *Choices* will provide a mechanism by which decision processes and outcomes can be evaluated.