



University Health Network

Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

One Size Doesn't Fit All: Tailoring Information to Cancer Patients

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Librarian, Patient Education, Princess Margaret Hospital

Agenda

- The Program
 - What are we providing?
- The People
 - Who is providing the service?
 - How are they trained?
- The Projects
 - What types of projects support our services?



Princess Margaret Hospital

- Largest comprehensive cancer centre in Canada devoted exclusively to cancer research, treatment and education.
- Cancer care is organized by disease-sites
- Over 311,500 annual outpatients visits for diagnosis, treatment and follow-up
- Large, diverse, multicultural community



Patient Education



Expressed Needs of Cancer Patients and Their Families

- Ever increasing demand by consumers for information about their disease and treatment.
- Patients and their families express the need to communicate and understand the events that occur throughout the course of their cancer¹.

- 1.Hannah KJ, Conley-Price P, Fenty D, McKiel E, Soltes D, Hogan T, Wiens D. Computer applications for staff development and patient education. *Methods Inf Med* 1989; 28: 261-6.



Educating for Patient-Centred Care

- Considering not only the disease itself, but also the “whole person”
- Tailoring to individual needs ensures patients are educated about their options
- Empowering patients to become full participants in their care through enhanced communication and a strong patient-provider relationship
- Encouraging patients to share in decision-making according to their own needs and desires



Tailoring Cancer Information

- Tailoring information to meet individual learning needs is becoming an integral part of patient-centered cancer care
- Developing accessible education for patients, tailored for each individual learner, has become more feasible with the emergence of information and computer technologies
- To effectively partner with patients and their families, strategies for providing tailored health information are being implemented at Princess Margaret Hospital (PMH)



Client Factors: The Patient Education Challenge

- To ensure consistent, evidence-based cancer information that recognizes the unique attributes and learning needs of the heterogeneous clientele
 - Age
 - Education
 - Language and culture
 - Information preferences
 - Disability



Coping Styles & Information Seeking

- People deal with stressful situations in one of two ways:

Monitors

- Information seekers
 - Prefer a high information input before a stressful event and suffer less psycho-physiological distress when they have information



Blunters

- Information avoiders or distractors
 - Prefer less information and suffer more distress when they have a high information input.

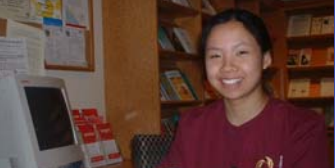


Major Learning Needs

- Cognitive
 - More factual information about cancer prevention, detection, and/or treatment
- Affective
 - Information which will aid in dealing with cancer emotionally
- Psychomotor
 - Information to help them manage the physical aspects of their illness



The People



Volunteer Assisted Program



- Patient Education Volunteers are recruited to provide support to users
- Volunteers range in age, background and educational level; many are cancer survivors or family members of patients
- Comprehensive training program provides necessary technical and psychosocial skills.



Environment

- One main Patient and Family Resource Center and 17 satellite centres established in clinical waiting areas.
- Visitors have easy access to computers, printers, multimedia resources and volunteer support.



The Role of the “VOLUNTEER”



- In cancer centers volunteers are often used to supplement the work of professional staff in the provision of emotional support to families and patients.*
- The "good-will" of volunteers must be integrated with competence.

- * Wares C, McGill A, Huchcroft S. Patient perceptions of volunteer support. Dimensions in Health Service 1988; 65:22-24.



Developing a “Professional Volunteer”

The main tasks of an organization in the development of a volunteer program is to:

- identify social needs
- carefully evaluate all available resources
- determine the targets
- recruit, select, educate, and manage teams of volunteers.*

Fusco-Karmann C, Gangeri L, Tamburini, M, Tinini, G. Italian consensus on a curriculum for volunteer training in oncology. *Journal of pain and symptom management* 1995; 12:39-46.



PMH Computer-based Education Volunteer Training Program

- Potential volunteers attended a general information session where a variety of volunteer opportunities are outlined.
- Persons who expressed interest in volunteering for the Patient and Family Resource Centres were provided with a position description that identified:

- *the general and specific program objectives.*
- *the desirable skill-set.*
- *program training components.*
- *commitment expectations.*
- *duties and related tasks.*
- *the rewards of becoming a Resource Centre volunteer.*



PMH Computer-based Education Volunteer-Assisted Program

“PMH Resource Centre
Volunteers are trained
to provide computer
assistance, manage
resources and support
the patient and family
in a manner that
demonstrates,
compassion, respect
and empathy.” *

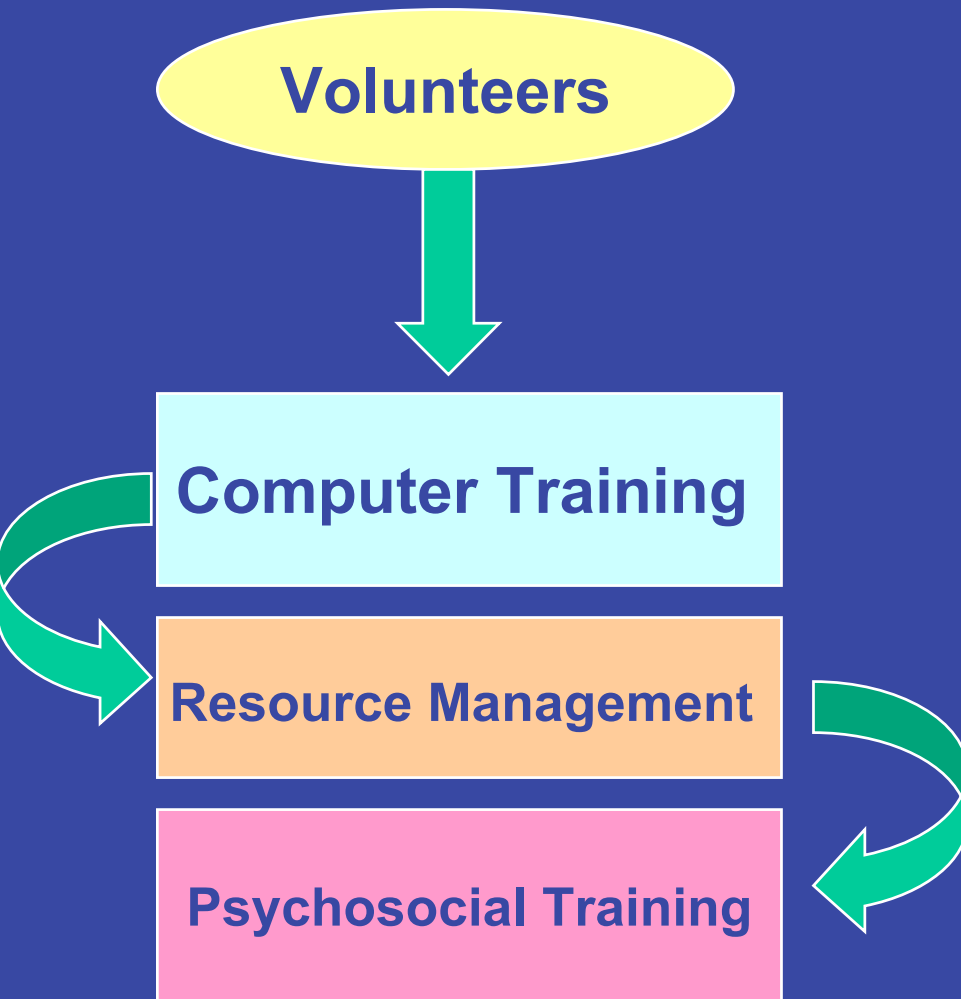


* PMH Patient Education, 1999



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PMH Computer-based Education Volunteer Training Program



30 Volunteers received:

- Comprehensive, easy to read, training manual
- Three half-day training seminars
- Computer practice / role play
- Evaluation and ongoing supervision



Comprehensive curriculum

Curriculum designed to:

Impart knowledge about:

- The mission and objectives of the program.
- The resources available.
- The challenges facing the cancer patient and family.

develop skills to:

- Support users of computer-based education program
- Manage resources in the Resource Centres
- Provide emotional support to the patient and family



Collaborators in Developing Volunteer Training Program

Volunteer Resources



Princess Margaret Hospital
University Health Network



Psychosocial
Oncology Program



Princess Margaret Hospital
University Health Network

The Princess Margaret
Hospital Foundation
University Health Network



University Health Network

Computer Training

- Enhancing computer skills
- Developing OIES expertise
- Providing Technical Support
- Using Electronic Library Catalogue



Library Management Training



- Understanding Call Numbers
- Completing Information Request Forms
- Lending Resources
- Using Electronic Library Catalogue
- Conducting Internet Searches



Psychosocial Training

- Resource Centre volunteers will be working closely with cancer patients and their families, in an autonomous environment.
- Patients may discuss emotionally sensitive issues and perceive volunteer as someone they can talk to about their illness

Training focuses on:

- Confidentiality
- Being Non-Judgmental
- Awareness to Content and feelings
- Cultural Sensitivity



Psychosocial Training

Full day Training

- Opportunity to reflect on interest in role
- Confidentiality
- Principles of Support
- Own Experience with Support
- Boundaries
- Beliefs and Baggage
- Elements of Communication
- Self Care



Program Evaluation

Information gathered helped us refine the volunteer training program in our efforts to provide responsive and immediate human support to users of the computer-based education program.

Quantitative and qualitative analysis:

- self-assessment questionnaire before training and and 6 months post training.
- focus groups



Dependent Variables of Interest

AFFECTIVE / ATTITUDINAL

- How do the volunteers feel about the training program and their competency?

COGNITIVE

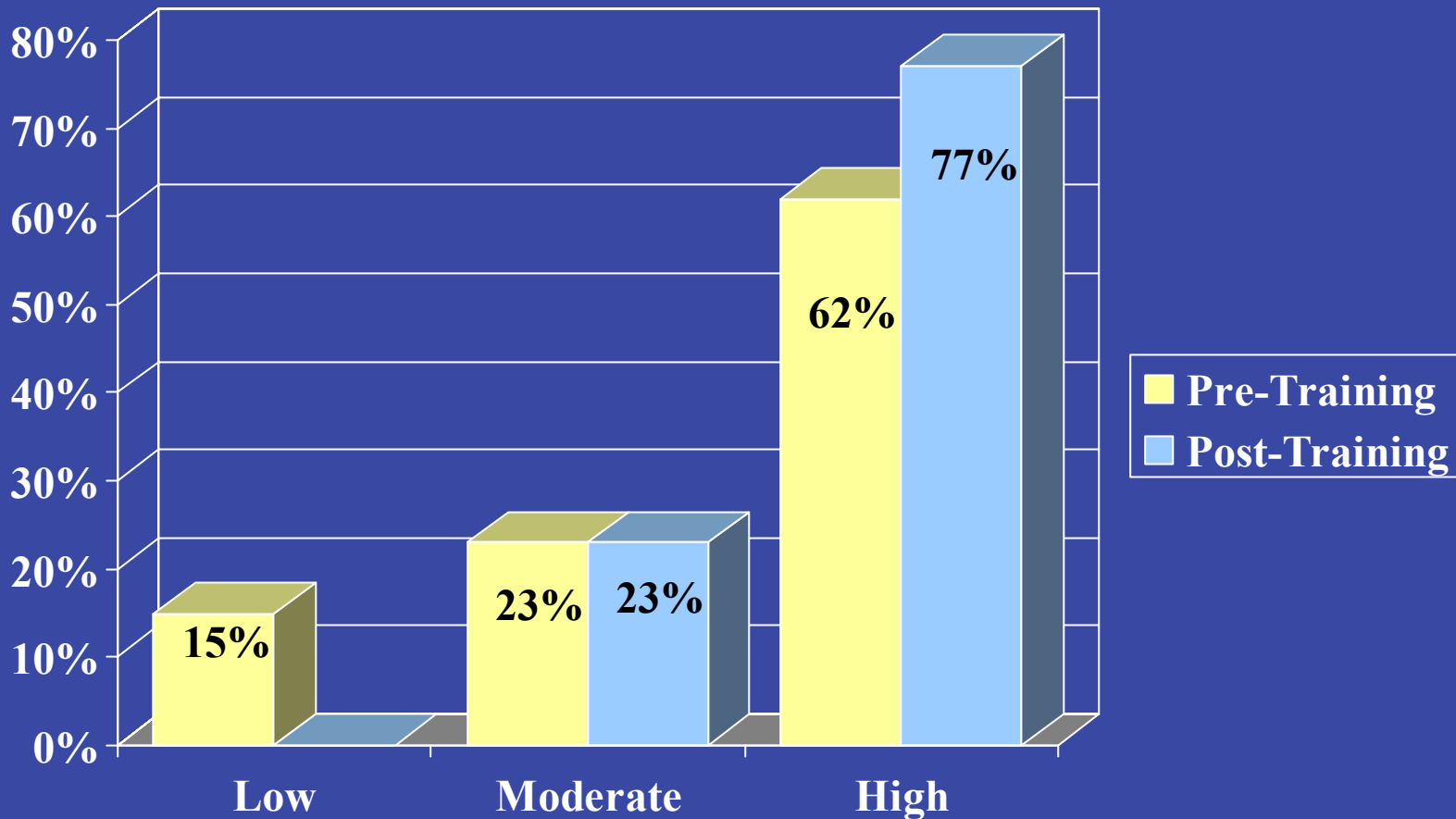
- What did the volunteers learn from the training program?

BEHAVIOURAL

- How are the volunteers able to support patients and their families?



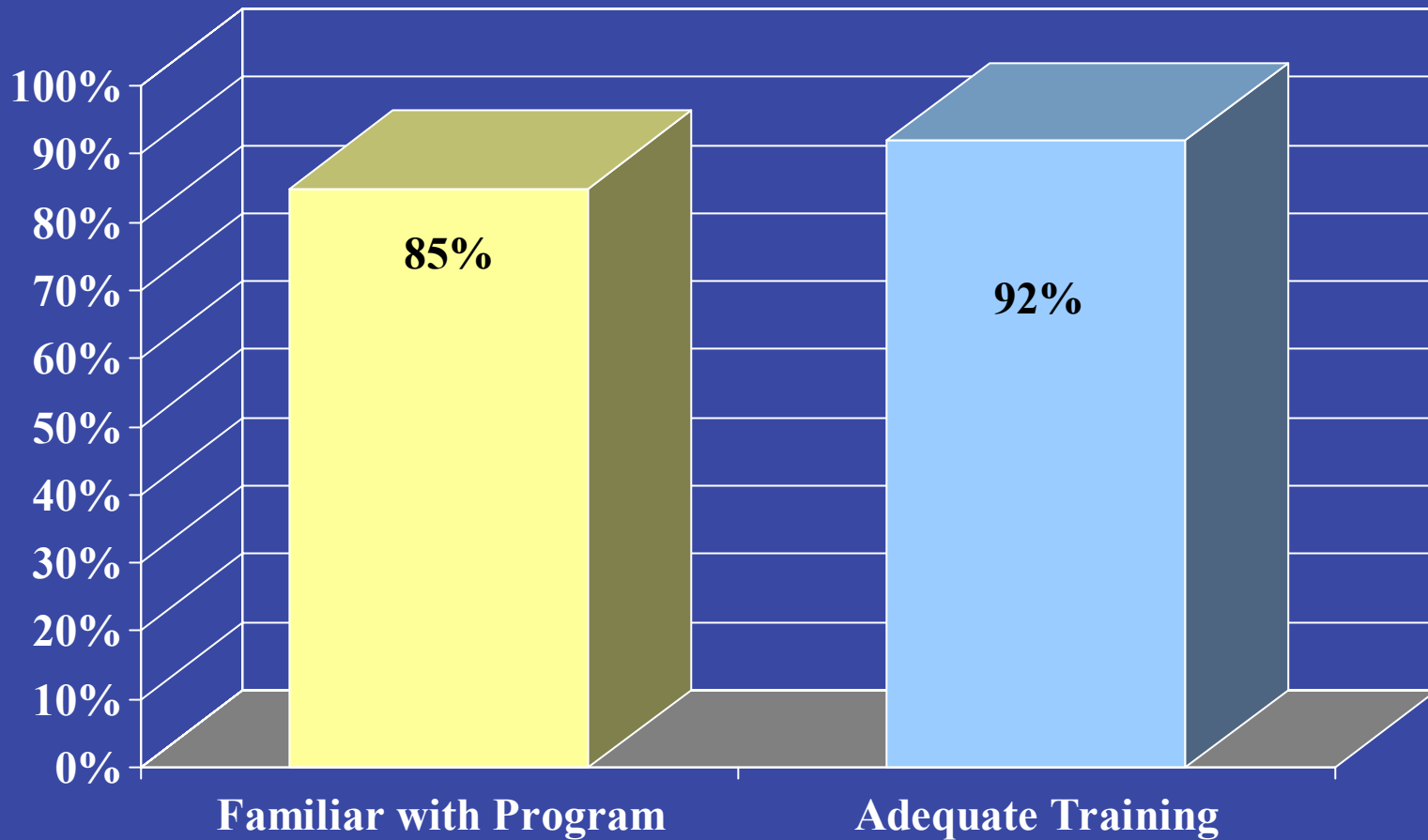
Computer Experience: Pre- and Post-Training



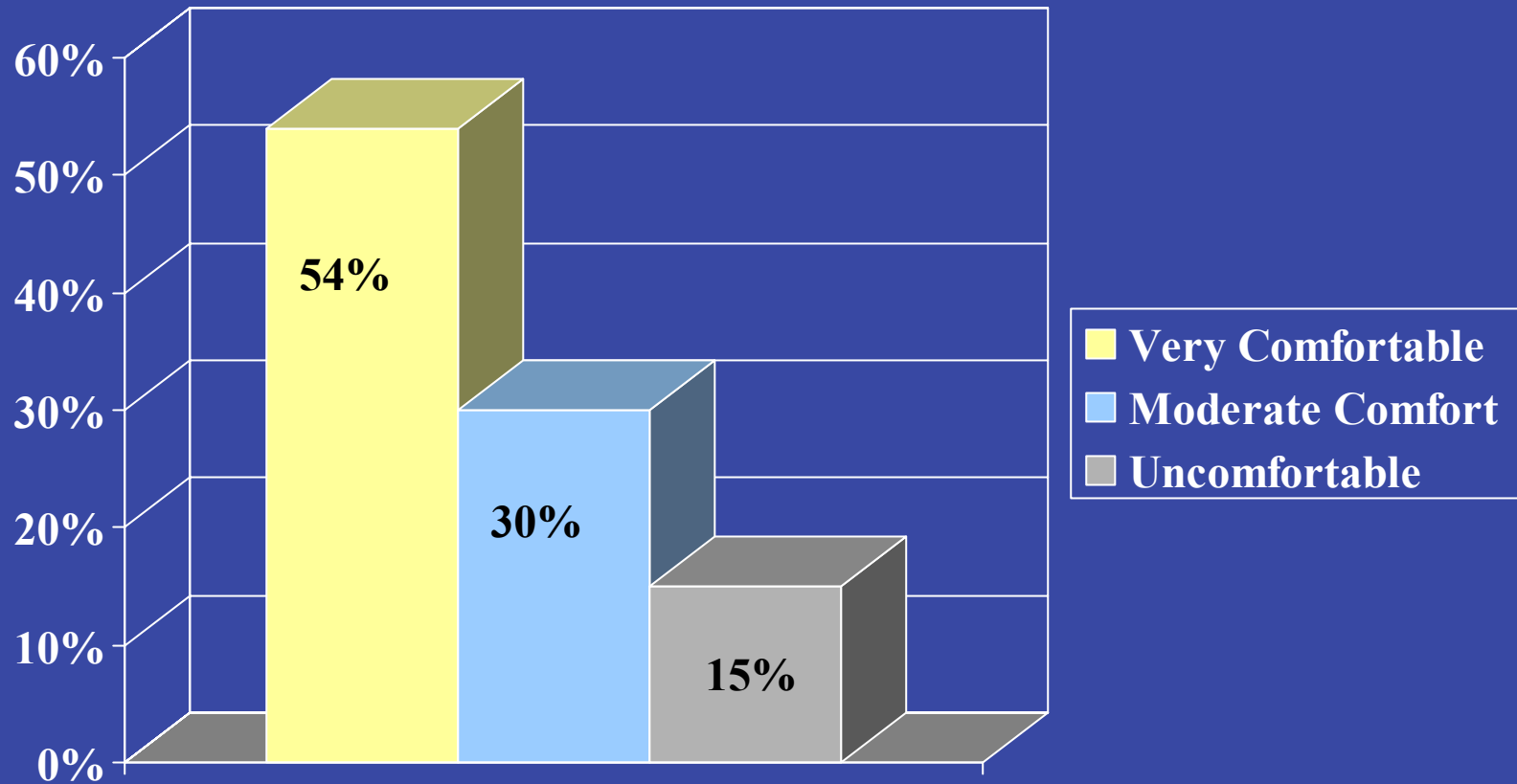
$p=0.05$



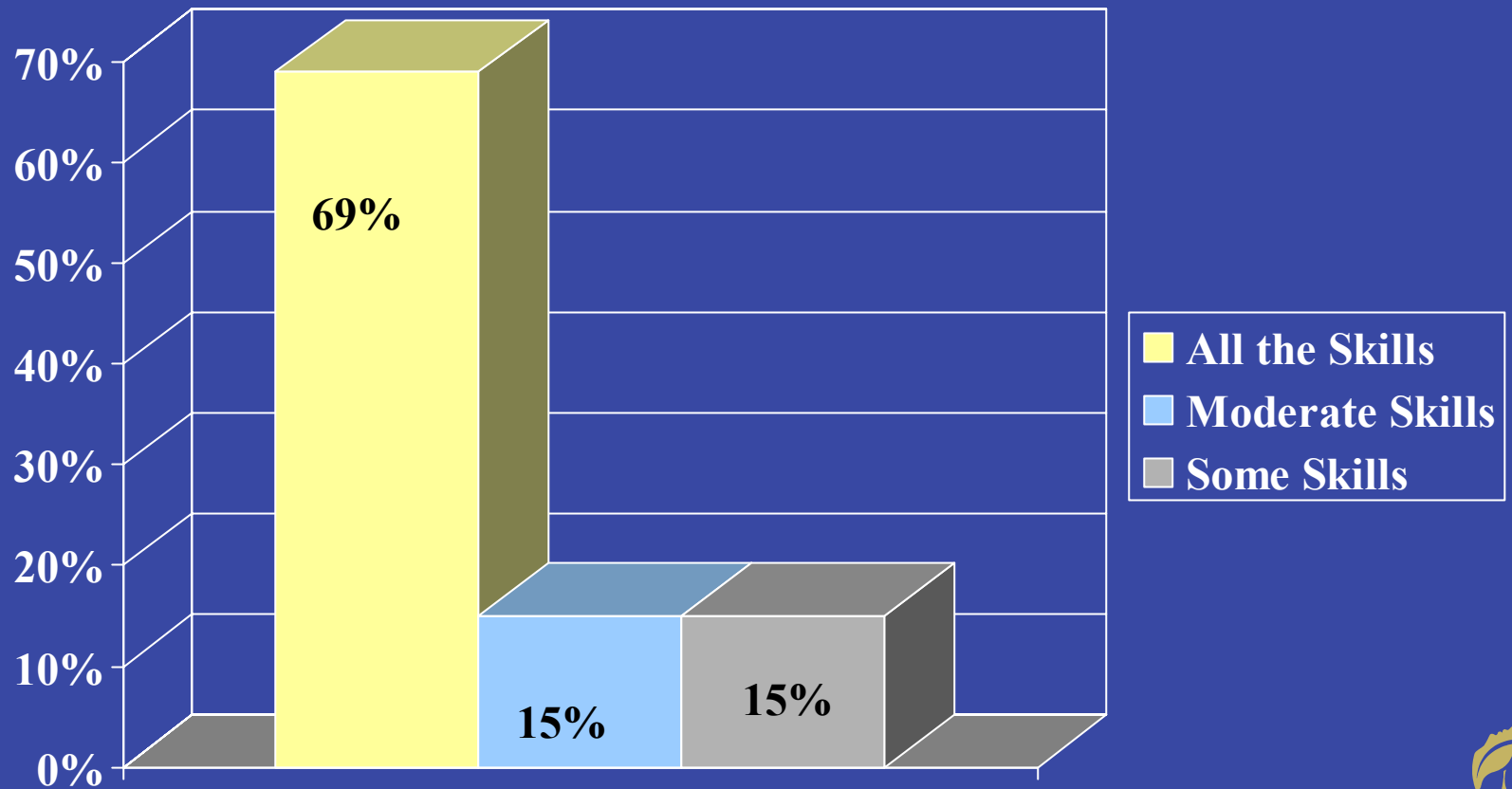
Post-Training: Familiarity and Training Ratings



Comfort Level Supporting Patients and Families



Post-Training Skill Rating



Less Computer-Literate User

I wanted to look at genetics, treatments and diagnoses. I did look at these, and [other] sites shown [to me] by the volunteer that I wouldn't have accessed otherwise. (Breast Cancer Patient)



Volunteer Debriefing

My primary role is patient support... I will get everything from what their immediate concern is, which may be a diagnosis they received 5 minutes ago, with full blown tears etc...to “I’m supporting my sister, and she’s been diagnosed, and she has a two year old child what should we do? What is there to read? ”



Dealing with Anger

I was confronted by a very angry man ... he didn't feel he was getting enough information about his illness.. I had to keep backing up a little bit. I was very nervous but then I realized there was nothing to be afraid of... Finally I said “I would make a list [of questions] and make an appointment and go through the list with him [his doctor].



Empowering Patients

One of the things that people really love is [when I show them] the personal stories [on the OIES]... They want those good news stories. They know that somebody else has made it.

You might [also] suggest that they go to support groups in the hospital.



Supporting the Healthcare Providers

[our efforts] take a lot of pressure off the doctors, because otherwise they're [patients] going to go in and unload on the doctors. And the nurses get a lot of it too. So if they can do it with one of us, it certainly takes [some of the] pressure off.



Conclusions of Training

- Volunteers were able to develop an overall understanding of the education program including: Computer program, OIES, and Resource management.
- However, those with little prior computer experience were not as comfortable providing computer assistance to others.
- Volunteers were comfortable in their role as supports to patients. Volunteers found the psychosocial training most helpful but too short.



Lessons Learned

In order to develop a team of volunteers equipped to meet the needs of the patient and family using computer-based education programs training must include:

- well-defined requirements for service.
- a curriculum for volunteer service.
- Structured and informal training sessions and ongoing supervision.



Today: Volunteer-assisted for the PMH Computer-based Education

- Integration of technology and human resources
- facilitates self-directed learning and autonomy
- Provides informal support and referral as needed




The Projects

PRINCESS MARGARET HOSPITAL - UNIVERSITY HEALTH NETWORK

Welcome to the Patient Education Website


About Your Cancer




About Your PMH Treatment



Patient & Family Resource Centres



Patient Programs & Calendar of Events



PMH Patient Education Department About the PMH Foundation

Click on an area above to continue.

Princess Margaret Hospital
University Health Network

Subject: _____

Patient and Family Library
Search Request Form

Requestor Information: (Please print clearly)

Name: _____ Date: _____
Tel: _____ How will the information be picked up:
You are a: Patient Library pick-up
 Family Member Email
 Other Mail
Address: _____
Date Needed: _____

Search Information

What is the primary cancer diagnosis:

<input type="checkbox"/> Brain Tumor	<input type="checkbox"/> Malignant Hematology
<input type="checkbox"/> Breast Cancer	<input type="checkbox"/> Hodgkin's Lymphoma
<input type="checkbox"/> Gastrointestinal Cancer	<input type="checkbox"/> Leukemia
<input type="checkbox"/> Gynecological Cancer	<input type="checkbox"/> Non-Hodgkin's Lymphoma
<input type="checkbox"/> Pancreatic Cancer	<input type="checkbox"/> Other:
<input type="checkbox"/> Bone/Lymphatic Cancer	_____
<input type="checkbox"/> Bladder Cancer	Type: _____
<input type="checkbox"/> Prostate Cancer	_____
<input type="checkbox"/> Gynaecological Cancer	<input type="checkbox"/> Melanoma
<input type="checkbox"/> Cervical Cancer	Type: _____
<input type="checkbox"/> Ovarian Cancer	_____
<input type="checkbox"/> Head and Neck Cancer	<input type="checkbox"/> Other:
<input type="checkbox"/> Skin and Mouth Cancer	_____
<input type="checkbox"/> Cancer of the Larynx	_____
<input type="checkbox"/> Cancer of the Nasopharynx	_____
<input type="checkbox"/> Cancer of the Oropharynx	_____
<input type="checkbox"/> Cancer of the Hypopharynx	_____
<input type="checkbox"/> Paranasal Sinuses and Nasal Cavity Cancer	_____
<input type="checkbox"/> Salivary Glands Cancer	_____
<input type="checkbox"/> Thyroid Cancer	_____
<input type="checkbox"/> Lung Cancer	_____

Are you looking for information on metastasis? Yes No

Where is the metastasis? _____

What part of the body is affected? (if relevant): _____

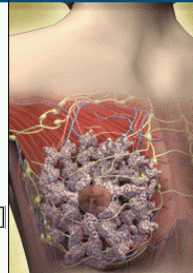
Patient Education 06/08/2002 v.4 1/2

ONCOLOGY INTERACTIVE EDUCATION SERIES, LAN EDITION
Princess Margaret Hospital Log In Feedback Quit

Breast Settings Bookmarks User Notes

Understanding Breast Cancer v1.00

Oncology Interactive EDUCATION SERIES



- What is Breast Cancer?
- Diagnosis
- Treatments
- Supportive Care
- Prevention and Early Detection
- Genetics**
- Common Questions and Answers
- Art Gallery
- Resources

Objectives
Credits
License

Guide to Using the Program Internet Update

Directories & Resources | For Health Professionals | For Media | For Staff | Contact Us | Site Map

University Health Network

Achieving Global Impact

Home Patient & Visitor Info Programs & Services Teaching & Education Research Careers Foundations

About UHN Princess Margaret Hospital Toronto General Hospital Toronto Western Hospital

General Information
Visiting Hours
Directions
TTC/Parking
Patient Education Network

PMH
TGH
TWH

Privacy & Confidentiality
Patient Relations
Wait Times



PATIENT EDUCATION AT PMH

Cancer Information

[Overview](#) | [Patient Education Program](#) | [Patient Guide](#) | [Cancer Information](#) | [Community Resources](#)

Frequently Asked Questions about Breast Cancer

- What is breast cancer?
- Why does breast cancer occur?
- What are the symptoms of breast cancer?
- Is mammography used only for screening?
- What is breast self-examination (BSE)?
- Can breast cancer be cured?
- Are there different types of breast cancer?
- Are my daughters at risk?
- What do lymph nodes have to do with breast cancer?
- Where should I go for additional information and reading materials?
- What should I ask my health care team?

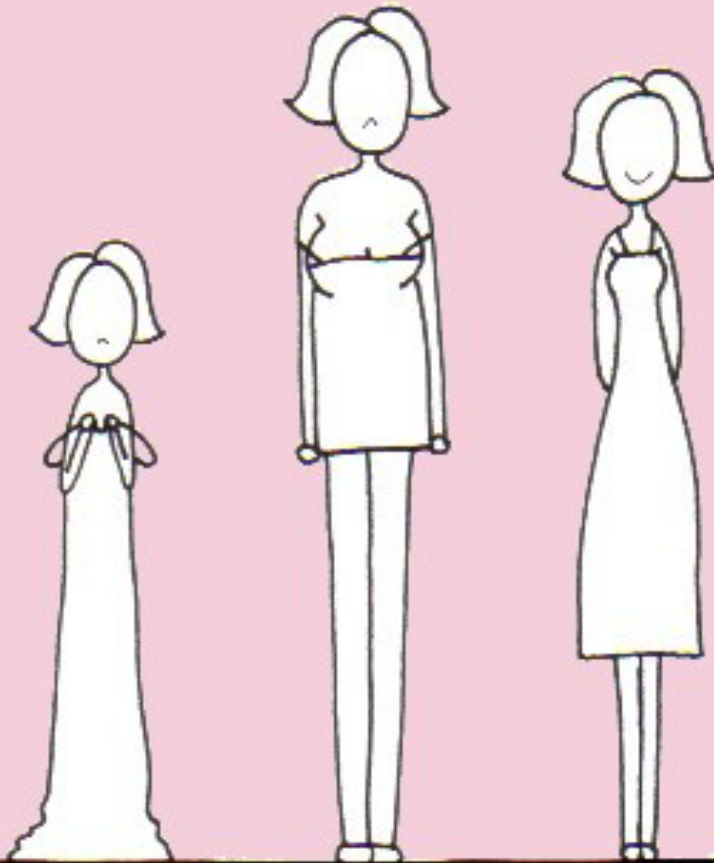
1. What is breast cancer?
Breast cancer is the uncontrolled growth of cells located in the breast. All cancer cells have the ability to spread. If breast cancer is not treated, the cancer cells can invade local tissues and eventually spread to distant organs (metastasize).

This text has been adapted from the [Oncology Interactive Education Series](#). [Click here for a demo of this unique and innovation series.](#)



University Health Network

Cathy Thorne © www.everydaypeoplecartoons.com



ONE SIZE NEVER FITS ALL.

Why Not Off The Rack??

- Some information seekers want information on subjects beyond the scope of our collection
- Lack of information affects quality of care, patient satisfaction levels
- Physicians and other health care providers may need additional resources to support their clinical encounters
- Need to respond to individual patients in a format suitable to his/her individual learning preferences.



Patient Education Teaching Methods

- Individual & group teaching
- Independent self-study
- Verbal instruction
- Written material
- Audiotapes & audiovisual Aids
- Computer-assisted programs



PMH Internal Site for Patients

- Oncology Interactive Education Series
- Calendar of Events
- Ongoing Programs
- Resource Catalogue
- Links to Web Sites





Resource Centres

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 [Programs & Events](#)

 [Oncology Interactive™](#)

Title

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Author

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Subject

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Publication Date

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Any Word

AND

Resource Centre

AND

Material Type

AND

Language

Resource Centres

General Health and Cancer Links

[Reference](#) | [General Medicine](#) | [General Cancer](#)
[Cancer Centres](#) | [Clinical Trials](#) | [Drug Information](#)
[Alternative Therapies](#) | [Journals and Newsletters](#)
[How to Evaluate Health Information on the Web](#)

Specific Types of Cancer

[Brain and Central Nervous System Cancers](#)
[Breast Cancer](#) | [Gastrointestinal Cancers](#)
[Gynecologic Cancers](#) | [Head and Neck Cancers](#)
[Hematologic Cancers](#) | [Lung Cancer](#)
[Prostate and Genitourinary Cancers](#)
[Sarcoma](#) | [Skin Cancer](#)

[List of All Web Site Resources](#)

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Resource
Centres



Programs
& Events



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
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Programs & Events

Click on a date to find out about programs running that day, or see a [listing of all ongoing patient programs](#).

 Return to Home Page

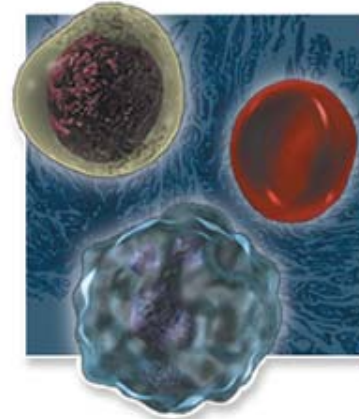
 Resource Centres

 Programs & Events

 Oncology Interactive™

◀ November 2003 ▶						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
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2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30						

Advanced Prostate
Bladder
Blood & Marrow Transplants
Brain
Breast
Cervical
Colorectal
Dysplasia
Hodgkin's Lymphoma
Hypopharynx
Larynx
Leukemia
Lip & Mouth
Lung
Melanoma
Nasopharynx
Non-Hodgkin's Lymphoma
Oropharynx
Ovarian
Pancreatic
Paranasal Sinuses & Nasal Cavity
Prostate
Salivary Glands
Sarcoma
Thyroid



Understanding **Leukemia**

English

Français



Understanding Advanced Prostate Cancer



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search

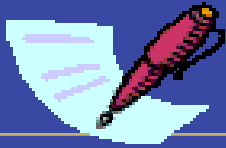


- ▶ What is Prostate Cancer?
- ▶ Recognizing Advanced Disease
- ▶ Making Treatment Decisions
- ▶ Treatment Options
- ▶ Clinical Trials
- ▶ Living with Advanced Prostate Cancer
- ▶ Controversies
- ▶ Resources

- ▶ Objectives
- ▶ Credits
- ▶ License



Guide to Using the Program



Search Request Form

- Filled the need for a structured process with well defined steps
- Allowed library volunteers and support staff to conduct a significant number of search requests
- Allowed for tracking of requests and information dispensed



Designing the Form

- SRF was designed to meet this need by containing:
 - A simple check box format for easy data capture of subjects necessary to complete a thorough search.
 - Standard format to define diagnosis, treatment and specific questions to be researched



Designing the Form cont.

- A series of steps to guide volunteers through an initial search for reliable sources of information
- An area to record the material that was given out to the patient or family member.

Peterborough Memorial Hospital
University Health Network

Subject: _____

Patient and Family Library Search Request Form

Requestor Information: (Please print clearly)

Name: _____ Date: _____
Tel: _____ How will the information be picked up:
You are a: Patient Library pick-up
 Family Member Email
 Other Mail
Address: _____
Date Needed: _____

Search Information

What is the **primary cancer diagnosis**:

<input type="checkbox"/> Brain Tumor	<input type="checkbox"/> Malignant Hematology
<input type="checkbox"/> Breast Cancer	<input type="checkbox"/> Hodgkin's Lymphoma
<input type="checkbox"/> Gastrointestinal Cancer	<input type="checkbox"/> Leukemia
<input type="checkbox"/> Colorectal Cancer	<input type="checkbox"/> Non-Hodgkin's Lymphoma
<input type="checkbox"/> Pancreatic Cancer	<input type="checkbox"/> Other:
<input type="checkbox"/> Gonadal/Urinary Cancer	<input type="checkbox"/> Sarcoma
<input type="checkbox"/> Bladder Cancer	Type: _____
<input type="checkbox"/> Prostate Cancer	<input type="checkbox"/> Melanoma
<input type="checkbox"/> Gynecological Cancer	Type: _____
<input type="checkbox"/> Cervical Cancer	<input type="checkbox"/> Other:
<input type="checkbox"/> Ovarian Cancer	Type: _____
<input type="checkbox"/> Head and Neck Cancer	<input type="checkbox"/> Other:
<input type="checkbox"/> Lip and Mouth Cancer	Type: _____
<input type="checkbox"/> Cancer of the Larynx	What part of the body is affected? (if relevant):
<input type="checkbox"/> Cancer of the Nasopharynx	_____
<input type="checkbox"/> Cancer of the Oropharynx	_____
<input type="checkbox"/> Cancer of the Hypopharynx	_____
<input type="checkbox"/> Paranasal Sinuses and Nasal Cavity Cancer	_____
<input type="checkbox"/> Salivary Glands Cancer	_____
<input type="checkbox"/> Thyroid Cancer	_____
<input type="checkbox"/> Lung Cancer	_____

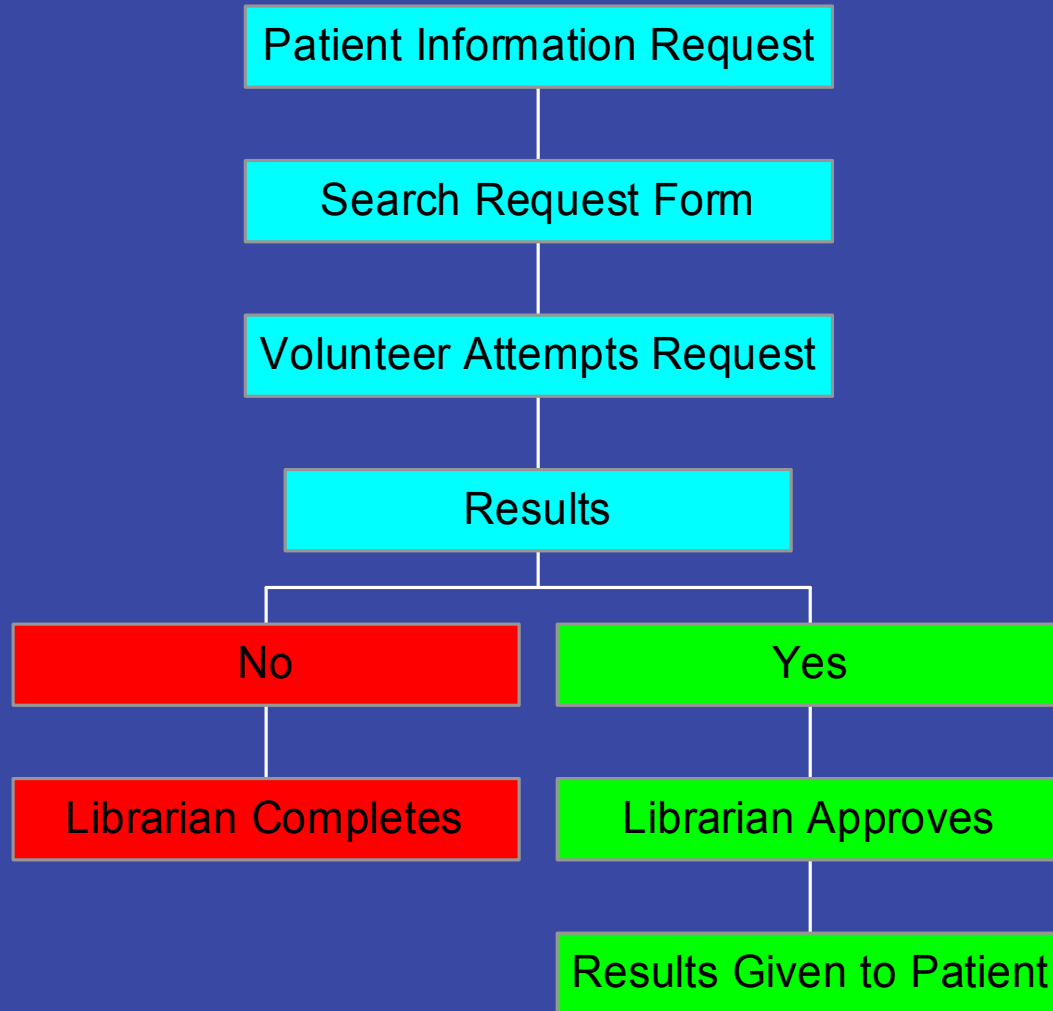
Are you looking for information on metastasis? Yes No

Where is the metastasis? _____

Patient Education 06/08/2002 v.4 1/2



Search Process



DIY: An Example

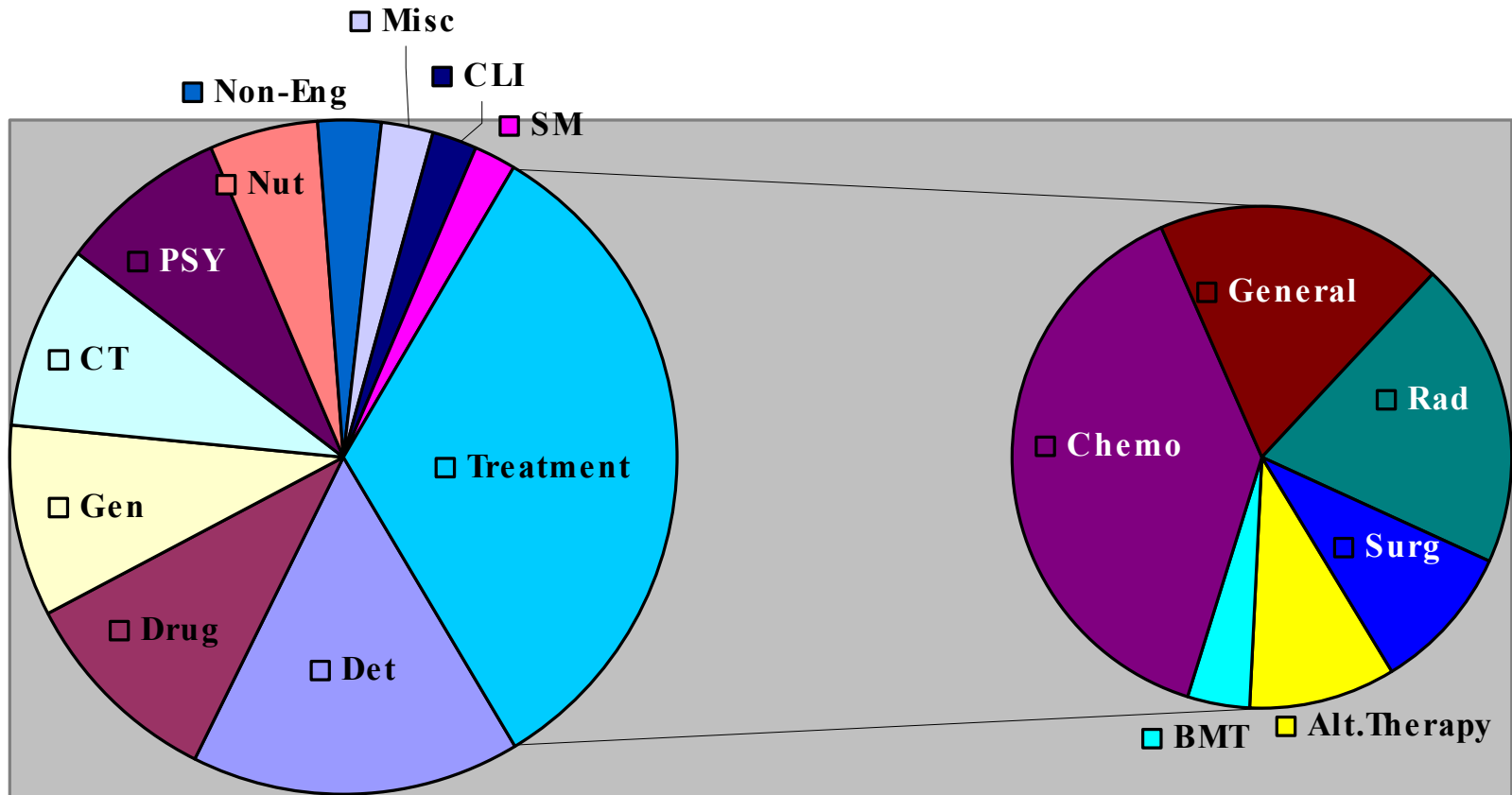
Request: How do I talk to my children about my husband's palliative condition?

Resources: PMH Psychosocial package, list of books and materials available in the library, recommended websites, list of community support groups

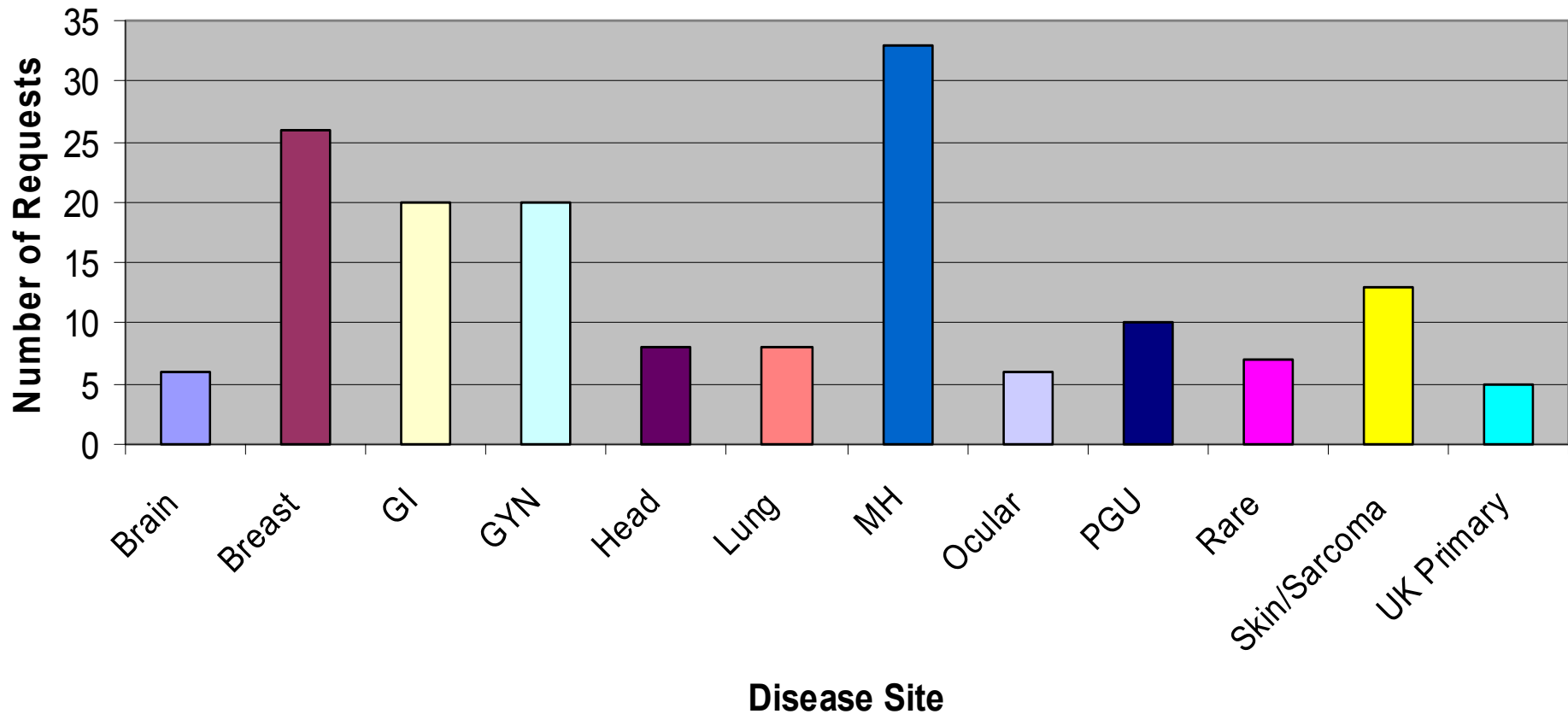
Personalized: Format (books, websites); Situation (father's condition); Location (support groups); Literacy level and age appropriate (child and parent)



Subjects Requested



Requests Breakdown by Disease Site



Evaluation

Ongoing evaluation of the SRF has enabled us to:

- Identify information gaps in our resources
- Increase the collection with new tools and materials
- Improve the turnaround time of request completion
- Use our tools to assist with other PEN projects.



Evaluation – Patient Satisfaction

- 100% thought the service was easy or very easy to use
- 94% would strongly recommend the service to others
- 88% thought the service was prompt or very prompt
- 83% understood the results of the search well or very well.

* Data collected through DOCH student project, Kevin Sui, 2004.



Evaluation – Patient Satisfaction

- 81% said the service helped them cope, understand illness, treatment, prognosis, deal with side effects, helps them communicate with family and HCP
- 72% said that library volunteers were friendly, positive and listened well
- 63% mentioned the accessibility of the service, they were able to walk-in, phone or email their requests
- 63% said that the information led them to ask more questions. They felt they needed follow-up.



Future Research Directions

- An electronic version of the search request form is now available on the UHN Internet site, evaluation of this is ongoing
- Getting clinical staff more involved in the process and opening up a dialogue with the creation of the Patient Education Consult.



Thank you!



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