Establishing Comprehensive Cancer Patient Education Programs: Standards of Practice

Note: Even though the standards of practice have been specifically written for cancer patient education, they can be adapted to meet the patient education needs of the general population as well.
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Part I: Introduction

History of Development

The *Guidelines for Establishing Comprehensive Cancer Patient Education Services* were developed by a task force of cancer patient educators from the National Cancer Institute’s (NCI) Cancer Patient Education Network (CPEN). The NCI Cancer Patient Education Network represented the cancer patient education leadership of NCI-designated cancer centers to promote excellence in patient education as an integral part of patient care.

The *Guidelines* were designed to serve as a model to help cancer centers, hospitals, clinics and teaching institutions develop and improve the delivery, management and quality of their cancer patient education services. The *Guidelines* are intended to guide healthcare providers - especially educators - with their program planning, development and evaluation responsibilities. While the *Guidelines* were developed by and for representatives of NCI-designated cancer centers, they may be adapted for use by any group or organization concerned with cancer patient education.

The *Guidelines* were originally developed in 1993 and were adapted from the *Standards for Healthcare Education and Training* developed by the American Society for Healthcare Education and Training (ASHET), American Hospital Association. In revising the *Guidelines*, the CPEN task force consulted the Second Edition of the ASHET standards. In addition, the task force reviewed patient and family education standards published by the Oncology Nursing Society, the Joint Commission on the Accreditation of Healthcare Organizations and the Association of Community Cancer Centers. This is the third edition of this publication and because of its increase in scope, it was renamed: *Establishing Comprehensive Cancer Patient Education Services: Standards of Practice*.

Methodology

The *Standards of Practice* provide cancer patient educators with a basic overview of the cancer patient education landscape, definitions, standards, pressing issues and recommendations regarding effective strategies to organize and structure patient education services, as well as assess, plan, develop, implement and evaluate cancer patient education in a variety of settings. The *Standards of Practice* are based on a systematic review of the literature, best practices, and the expertise of its project members.

Scope of Standards

Cancer is a leading cause of death worldwide, accounting for 7.6 million deaths (around 13% of all deaths). As one of the leading threats to health, cancer has touched millions of lives globally. As a result, education and the dissemination of information are essential at each stage along the continuum of care, from prevention through to survivorship and end of life care.

Our aim is to provide a framework for delivering standard cancer patient education approaches across all organizations responsible for these efforts. This framework includes, but is not limited to:

- Creating the provision of a framework for healthcare providers and decision makers for
planning, implementation, and evaluation of cancer patient education.
• Ensuring that evidence-based processes are used for the development and delivery of cancer education.
• Demonstrating value of patient-centered care and importance of patient education in their treatment pathway.

Patient Education Defined

Patient education is any set of planned, educational activities designed to improve patients’ health behaviors and/or health status. The purpose of patient education is to maintain or improve health or, in some cases, to slow deterioration. Health care providers may include doctors, nurses, dietitians, social workers, psychologists, discharge planners, pharmacists, occupational and physical therapists, respiratory therapists, health educators, community organizations and special interest groups. Patient education permeates all aspects of the health care experience and thus, is an essential component across the continuum of care – prevention, detection, diagnosis, treatment, research, survivorship and end-of-life.

Important elements of patient education are skill building and responsibility: patients need to know when, how, and why they need to make a change. Interdisciplinary coordination of care is equally important: each member of the patient’s health care team needs to be engaged.

Through assessment, planning, implementation and evaluation, patient education aims to:
• Improve patient understanding of their illness, diagnosis, disease, or disability.
• Improve patient understanding of how to manage multiple aspects of their illness.
• Improve patient self-advocacy for acting independently from, but in interdependence with their health care providers.
• Increase patient motivation to comply with treatment regimens through effective patient/provider communication.
• Improve patient outcomes and prevent or decrease complications.
• Assist the patient with making informed treatment decisions.
• Improve patient use of medical services by decreasing unnecessary phone calls and clinic/hospital visits.
• Increase patient satisfaction with health care service and lower risk of malpractice.

Benefits and Value of Patient Education

Whenever patients are asked about their priorities, most people want the security of knowing that they will be able to access timely, reliable, effective, and safe health care when they need it; that they will be given adequate information and support to participate in decisions that affect them; that clinical staff will accord them empathy, dignity, and respect; that they will be told about the options for treating or managing their condition and their preferences will be taken into account; and that they will not have to worry about the financial consequences of being ill. These attributes are important because it is hoped they will lead to better health outcomes. However, how do we bridge this divide between the clinician informing, advising and educating the patient and the patient taking an active role in making decisions.
about his or her health care?

Patients can play an active role in promoting the health of themselves, their families, and their communities by:

• Understanding the causes of disease and the factors that influence health
• Knowing when to seek advice and professional help
• Choosing appropriate healthcare providers
• Selecting appropriate treatments and self-managing their care
• Adopting health behaviors to prevent occurrence or recurrence of disease
• Providing feedback to enable assessment of the quality of care

However, how does the healthcare provider engage the patient in taking an active role? Several interventions have shown great promise in bridging this gap, highlighting the benefits of educating the patient in order to improve health literacy, support shared decision making and improve care processes.5

### Promising Interventions to Improve Health Literacy*

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Potential Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personalized patient information reinforced by professional or lay support</td>
<td>• Improvements in patients’ knowledge and understanding of their condition</td>
</tr>
<tr>
<td></td>
<td>• Increased sense of empowerment</td>
</tr>
<tr>
<td></td>
<td>• Greater ability to cope with the effects of illness</td>
</tr>
<tr>
<td></td>
<td>• Improved patient satisfaction</td>
</tr>
<tr>
<td></td>
<td>• May lead to improvements in health behavior</td>
</tr>
<tr>
<td></td>
<td>• May contribute to better health outcomes</td>
</tr>
<tr>
<td>Pre-operative and pre-discharge education materials</td>
<td>• May lead to shorter length of stay and fewer follow-up visits</td>
</tr>
<tr>
<td>Telephone counseling and helplines</td>
<td>• Less social isolation</td>
</tr>
<tr>
<td></td>
<td>• Improved self-efficacy and satisfaction</td>
</tr>
<tr>
<td></td>
<td>• Reduced mortality and fewer hospitalizations for some patient groups</td>
</tr>
<tr>
<td></td>
<td>• May improve diagnostic accuracy</td>
</tr>
<tr>
<td></td>
<td>• May contribute to improved health status and better quality of life</td>
</tr>
<tr>
<td>Motivational interviewing</td>
<td>• Better adherence to treatment recommendations</td>
</tr>
<tr>
<td></td>
<td>• Improved health behaviors</td>
</tr>
<tr>
<td></td>
<td>• Reduced risk factors</td>
</tr>
<tr>
<td></td>
<td>• Improved health outcomes</td>
</tr>
</tbody>
</table>

*The evidence is less strong when *May* is stated.
### Promising Interventions to Support Shared Decision Making*

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Potential Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient decision aids</td>
<td>• Increased patient involvement in decisions&lt;br&gt; • Better understanding of treatment options&lt;br&gt; • More accurate perception of risks&lt;br&gt; • Improved quality of decisions&lt;br&gt; • Appropriate impact on uptake of screening&lt;br&gt; • Does not increase patient’s anxiety&lt;br&gt; • Reduces use of elective surgical procedures&lt;br&gt; • <em>May</em> be cost effective</td>
</tr>
<tr>
<td>Health coaching</td>
<td>• Reduced mortality&lt;br&gt; • Reduced risk factors&lt;br&gt; • Improved health status&lt;br&gt; • <em>May</em> be cost effective</td>
</tr>
<tr>
<td>Question prompts</td>
<td>• Increased question asking in consultations&lt;br&gt; • <em>May</em> increase patient’s knowledge and understanding&lt;br&gt; • <em>May</em> empower patient’s and improve satisfaction&lt;br&gt; • Does not necessarily increase length of consultations</td>
</tr>
<tr>
<td>Self-management education and support</td>
<td>• Improved patient knowledge and understanding&lt;br&gt; • Improved confidence and coping ability&lt;br&gt; • Improved health behaviors&lt;br&gt; • Improved social support&lt;br&gt; • <em>May</em> improve adherence to treatment recommendations&lt;br&gt; • <em>May</em> improve health outcomes&lt;br&gt; • <em>May</em> reduce hospital admissions rates&lt;br&gt; • <em>May</em> be cost effective</td>
</tr>
</tbody>
</table>

*The evidence is less strong when *May* is stated.*
Promising Interventions to Improve Care Processes

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Potential Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient feedback (surveys, focus groups, complaints)</td>
<td>• Better understanding of priorities for quality improvement</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> help to stimulate change</td>
</tr>
<tr>
<td>Patient-reported outcomes measures</td>
<td>• Improvement in diagnosis and condition management</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> help patients choose providers</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> lead to improvement in patients’ knowledge and understanding of their condition</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> help to inform treatment choices</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> lead to improvements in health outcomes</td>
</tr>
<tr>
<td>Public reporting of performance data</td>
<td>• Stimulates change at the hospital level</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> help patients choose providers</td>
</tr>
<tr>
<td>Communications training for health professionals</td>
<td>• Better interactions between clinicians and patients</td>
</tr>
<tr>
<td></td>
<td>• Greater patient satisfaction</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> improve patient’s knowledge and understanding of their condition</td>
</tr>
<tr>
<td></td>
<td>• <em>May</em> lead to improvements in treatment adherence and health outcomes</td>
</tr>
</tbody>
</table>

*The evidence is less strong when *May* is stated.

The Future of Patient Education

Emerging evidence supports patient engagement can be a pathway toward achieving the goals of better quality care, greater cost efficiency and improved population health.6,7 However, there are multiple factors that influence whether and to what extent patients are able to engage at different levels and at different points along the continuum of care. These factors include, but are not limited to: a patient’s motivation, willingness, and ability to engage within and across different levels of the health care system; an organization’s policies, procedures and practices; and social, political and community norms.7 One such example is, the Affordable Care Act (ACA). For more information, go to:
http://www.healthcareandyou.org/?gclid=CluxsID_zrICFWaoPAod1kUAfg

Part II: Organizational Management

Part II summarizes how an organization can develop and manage a patient education program. This section illustrates:
• How to write a value proposition statement.
• How to write a mission and vision.
• How to structure a program within the organization.
• How to structure your strategic plan.
• The essential functions of the program staff.
• How to determine what facilities and equipment are needed.
• How a program is managed financially.
• Why policies and procedures are used.
• How to incorporate quality/performance improvement, evaluation and research.
• How to document program activities.
• Why professional development is imperative.

To assist you with developing and managing your patient education program, a Standards Checklist can be found in Appendix A.

Value Proposition

The value proposition represents the attributes that the supplying organization provides, through their programs, products and services, to create loyalty and satisfaction in targeted customer segments. In other words, it’s the implicit promise an organization makes to customers to deliver a particular combination of values, namely, price, quality, selection, convenience, service, brand, functionality, relationship. The value proposition clarifies the role that patient education plays as an intervention for achieving the organization’s goals.

Example: The Patient Education Office is a model of patient education excellence using a patient-centered approach by creating partnerships with staff, patient and family members. We develop and disseminate a broad array of innovative programs, products and services using our customer’s knowledge, experience and expertise and proven practice standards.

Mission and Vision

The mission statement defines what the patient education program is about - its purpose. The statement defines the direction of the program and the essential functions to be accomplished regarding what is achievable and given the resources available.

Example: To provide education that improves patient outcomes from prevention through survivorship.

The vision statement defines what the patient education program will accomplish in the future: a “picture of the future.”

Example: The Patient Education Office will be the foremost advocate and leader worldwide for advancing the science and practice of patient and health education.

Standard (Go to Appendix A for Standard Checklist)

These statements need to be in line with the organization’s mission and vision, written concisely, reviewed/revised annually and communicated to all staff affected by patient education and its outcomes (e.g., health care providers, educators, managers and administrative staff).
Organizational Structure and Culture

The biggest challenge an educator faces when they set out to establish or even maintain an effective patient education program, is the commitment of its organization’s leaders. An effective program cannot take place without it. This commitment includes:

- Establishing patient education as an organizational priority
- Standardizing processes to facilitate effective patient education
- Ensuring adequate resources are dedicated to patient education

Although there is no one best way to structure a patient education program (PEP), the key is to devise a structure that supports patient education and establishes authority and accountability to best meet patient education goals. In supporting this structure, communication and collaboration between departments/units is imperative and is best accomplished when relationships and lines of communication are clearly defined.

Standards

1. Institute policies and procedures, approved by the organization’s administrative, medical and education staff, that state the patient education program staff has the authority, responsibility and accountability for the development, implementation, administration, coordination and evaluation of the patient education program.

2. Document the roles and functions of the program as an interdisciplinary entity and emphasize the structural and collaborative relationships between the PEP and other departments/units within the organization. This documentation could be in the form of a PEP Welcome packet that highlights the various components of the program and supporting information (e.g., organizational charts, policies and procedures, staff resources, patient resources, etc.).

3. Write competency-based position descriptions delineating the minimum qualifications, authority, accountability and responsibility of the patient education program staff.

4. Hire qualified program staff and a sufficient number of staff to meet the needs of the organization’s patients, families and caregivers. Such staff will:
   - Be empowered and accountable to administer the program and its activities
   - Respect the religious, social, cultural and ethnic practices of patients and their families
   - Apply teaching-learning theories to the development, implementation and evaluation of patient/family education experiences
   - Ensure program materials are appropriate for varied ages, reading levels and languages and that there are mechanisms in place to assess the accuracy and applicability of program materials prior to endorsement and dissemination (e.g., review and approval every three years or as needed).
   - Ensure community resource information is available and current

5. Provide relevant documents in either print format, electronic format or both.
Strategic Plan

The PEP has a strategic plan, usually from 3-5 years, that defines the:
• Goals
• Performance measures
• Targets/outcomes, and
• Action plan

Standards

The strategic plan gives the program focus and is directly tied to the organization’s mission and vision. The plan should be reviewed and revised annually, based on feedback from program staff and appropriate interdisciplinary team members.

Essential Functions

PEP staff facilitates patient education in a variety of settings and with a variety of audiences. The PEP staff is integrally involved in the organization’s patient education activities through participation on committees, task forces and projects. This involvement ensures that the patient education needs are reflected in the broader mission of the organization and are developed based on specific population needs.

PEP staff plan, implement and evaluate education programs and activities for patients, family members and caregivers. Interdisciplinary collaboration is a vital part of the patient education program development process. This type of collaboration reinforces the role of patient education as an integral component of patient care.

Standards

1. Identify and define the various positions/roles within the PEP, their importance and priority for building the PEP.
2. PEP staff clearly defines scope of services, including its customers, functions and activities.
3. PEP staff provides patient education in an interdisciplinary and collaborative manner and provides training to all disciplines involved in the patient’s care, treatment, and services.
4. PEP staff provides patient education and training, based on patient’s assessed needs and abilities regarding cultural and religious beliefs, emotional barriers, desire and motivation to learn, physical or cognitive limitations and barriers to communication.
5. PEP staff serves as a resource to all members of the organization with regard to program development, implementation and evaluation (e.g., patient’s understanding of the education and training it provides).
6. PEP staff provides leadership to ensure the organization’s compliance with patient education standards from Joint Commission and other accrediting bodies.

For more information, visit:

Joint Commission
http://www.jointcommission.org/
Facilities and Equipment

The PEP provides facilities, equipment and resources to achieve its mission and vision, as well as support its essential functions. In order to achieve this aim, the following guidelines have been established.

Standards

1. An organizational environment, conducive to learning, is assessed and program plans are made accordingly.
2. Appropriate space, suitable for teaching patients and families, is identified and maintained.
3. Appropriate technical support, as well as print, graphic and audiovisual support, is established.
4. A research library and/or reference center is made available for PEP development.
5. A consumer health library/resource center is made available for patients, family members and caregivers.

Financial Management

Adequate financial resources are allocated for patient/family education. Funding is an essential component when providing the necessary staff and resources for an effective patient education program.

Standards

1. The PEP staff develops a budget to support the program’s mission and vision.
2. The PEP budget includes resources for staffing, operational expenses and materials/resources, as well as projected revenue.
3. Supplemental budgets items will require written proposals, grants and special funding, to cover special requests or additional program costs.

Policies and Procedures

Patient education programs are guided by written policies and procedures. Examples include:

• Patient-Family Education policy
• Interdisciplinary Plan of Care and Patient Teaching policy
• Patient Education for Food-Drug Interactions policy

Policies are the foundation on which organizations carry out a general course of action. Procedures define the specific steps for carrying out those actions and they highlight the tasks and responsibilities involved in the daily operations. Policies and procedures also provide evidence of performance for accrediting bodies.

Standards

1. Policies and procedures are clearly written and easily accessible in print or electronic format to the organization’s staff. They encompass interdisciplinary tasks and responsibilities, as well as outline the development and provision of patient and family education.
2. Policies and procedures can include:
   • The purpose of the policy
   • A policy statement(s) that outline the intentions of the policy
3. Policies and procedures are reviewed annually and revised as necessary.

Quality/Performance Improvement/Evaluation and Research

Evidence-based methodologies have become the cornerstone for quality/performance improvement. Methodologies such as the evidence-based practice process and the research process, give PEP staff the ability to assess, plan, implement and evaluate their patient education programs on an ongoing basis. Data from these processes assist the PEP staff to improve the current program, identify future program needs and determine how the program’s outcomes compare with its intended goals and objectives.

In addition, the PEP staff must keep up-to-date with the latest innovations and trends in cancer patient education, through a review of the literature and when appropriate, conduct research and publish findings in order to advance patient education practice.

Standards

1. The PEP staff utilizes the organization’s quality/performance improvement structure to modify program content or change how a program is delivered.
2. The PEP staff applies various methodologies (e.g., evidence-based practice process, research process) to address patient satisfaction, effectiveness of services and expected outcomes (e.g. pre-testing, post-testing, feedback questionnaires, focus groups, etc.). Based on results, practice changes are implemented and evaluated.
3. The PEP staff has mechanisms in place for obtaining feedback from patients, families and staff. When appropriate, patient follow-up is done to determine change in patient skill, knowledge and/or attitude.
4. The PEP staff utilizes the organization’s research structure to design research studies, prepare proposals or grants to fund a study and/or use standard research protocols to determine the effectiveness of patient education interventions.

For more information, go to:

Evidence-based Practice
http://www.biomed.lib.umn.edu/learn/ebp/
Documentation

Records of patient education programs and services are maintained to ensure the organization’s compliance with Joint Commission Standards and other accrediting/regulatory bodies. The records provide evidence that the PEP has provided an opportunity for the interdisciplinary team, patients, family members and caregivers, to take part in and benefit from patient education. Program records will be retained for at least five years or as required by the organization and/or regulatory agencies.

Standards

1. Records retained for accreditation/regulatory purposes include:
   • **Organization documentation**
     – Short and long-term strategic plans
     – Budget meeting minutes
     – Policy and procedure reports to committees or governing body (e.g., quality improvement documentation, annual reports)
     – Staff development documentation (e.g., may be maintained in another department, such as Human Resources)
     – Staff competency verification (e.g., may be maintained in another department, such as Human Resources)
     – Patient education material archives
   • **Patient teaching documentation**
     – Patient documentation and patient teaching records (e.g., the medical record)

Professional Development

PEP staff must possess appropriate credentials and competencies, by virtue of academic background, occupational experience and continuing education. Credentials and competencies are essential for several reasons. They:

• Enhance the level of performance
• Set a standard of quality for the profession
• Alert practitioners to new innovations and trends in patient education
• Provide a framework of merit and significance to the next generation of professionals
• Solidify commitment to the field and recognize a dedication to practice

Standards

1. The PEP staff has a minimum of a bachelor’s degree in education, nursing, health care administration, health education or related field.
2. New PEP staff receives an orientation of sufficient duration and content in preparation for their respective role.
3. The PEP staff demonstrates competency in the education process and related activities according to professional standards.
4. The PEP staff regularly participates in continuing education and in-service programs based on current
education needs in health care and in patient education specifically.

5. The PEP staff participates in an annual performance evaluation and identifies professional development goals, in collaboration with their supervisor.

6. The PEP staff is encouraged to demonstrate professional role responsibility by membership and active participation in professional organizations and by voluntary service in professional groups or community agencies.

7. The PEP staff has relevant texts and journals available to them and a mechanism in place to offer input into the purchase of applicable reference materials.

For additional information, go to:

**Age-specific Competencies**
http://library.med.utah.edu/Patient_Ed/

**Cultural Competencies**
http://nccc.georgetown.edu/

**Health Literacy**
Agency for healthcare Research and Quality Health Literacy Universal precautions Toolkit
http://www.ahrq.gov/qual/literacy/

The AHRQ Informed Consent and Authorization Toolkit
http://www.ahrq.gov/fund/informedconsent/ictoolkit2.htm

American Medical Association Health Literacy Kit

Implementing teach-back as a system-wide patient communication strategy.
Society of Hospital Medicine Webinar.
http://www.hospitalmedicine.org/AM/Template.cfm?Section=SHM_Webinars&Template=/CM/HTMLDisplay.cfm&ContentID=26964

Kripalani, S., Bengtzen, R., Henderson, L.E., & Jacobson, TA.
Clinical research in low-literacy populations: Using teach-back to assess comprehension of informed consent and privacy information.
http://www.jstor.org/stable/30033265

National Action Plan to Improve Health Literacy

North Carolina Program on Health Literacy
Health Literacy Universal Precautions Toolkit
http://nchealthliteracy.org/toolkit/
Part III: Program Development

Overview: Provision of Care, Treatment and Services

Care, treatment, and services are provided through the successful coordination and completion of a series of processes that include appropriate initial assessment of needs; development of a plan for care, treatment, and services; the provision of care, treatment, and services; ongoing assessment of whether the care, treatment, and services provided are meeting the patient’s needs; and either the successful discharge of the patient or referral or transfer of the patient for continuing care, treatment, and services.

The provision of care, treatment, and services to patients is composed of four core processes or elements:
• Assessing patient needs
• Planning care, treatment, and services
• Providing the care, treatment, and services based on the patient needs
• Evaluating the effectiveness of that care, treatment, or service including the use of teach-back with every patient encounter throughout their trajectory of care.

These core elements may also include the following activities:
• Providing access to the appropriate levels of care and/or disciplines for patients
• Teaching patients what they need to know about their care, treatment, and services
• Coordinating care, treatment, and services, when the patient is referred, transferred, or discharged

The elements that make up the provision of care, treatment, and services are related to each other through an integrated and cyclical process that may occur over minutes, hours, days, weeks, months, or years, depending on the setting and the patient’s needs. This cyclical process may occur among multiple organizations or within a single organization as they address patient populations with unique needs or patients receiving care, treatment or services that are problem prone.

The core processes or elements of the provision of care, treatment, and services should not be seen as separate steps, but rather as seamless interrelated activities in an integrated and ongoing care process. The activities related to the provision of care, treatment, and services should be capable of moving easily between elements as required to meet patients’ needs and maintain the continuity of care, treatment, and services.

**Health Education Theories, Models and Frameworks**

Theories and models play an essential role in the health education profession. They are among the health educator’s most useful tools as they tackle the challenges of assessing needs, assets and capacity for program planning, implementation and evaluation; administering and managing those programs; serving as an education resource and communicating and advocating for the needs of those they serve.

As a result, the following tables have been provided as an outline to identify the various individual (Table 1.), interpersonal (Table 2.), staged theories/models (Table 3.), as well as social systems theory (Table 4.) that can be used to assist the educator with understanding individual behavior, as well as the behaviors of the populations they serve.8

**Table 1. Individual Health Behavior Theories/Models**

<table>
<thead>
<tr>
<th>Theory</th>
<th>Originator(s)</th>
<th>Field of Study</th>
<th>Key Concepts/ Constructs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Belief Model</td>
<td>Hochbaum, G &amp; Rosenstock, I (1996)</td>
<td>Social psychology</td>
<td>Perceived threat</td>
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<td></td>
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Sources:
- Festinger, L (1957); Glanz, L & Rimer, B (1997)
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<td>House, J (1981);</td>
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Elaboration Likelihood Model

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| Piaget’s Child Development Theory  
**Source:** Jean Piaget Society | Piaget, J (1950s) | Biology Philosophy | **Stages**  
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Preoperational (2-7)  
Concrete operations (7-11)  
Formal operations (11-15) |
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Table 4. Social Systems Theory

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In addition to the aforementioned theories and models, there are several other frameworks worth noting when planning and developing effective education programs.

**Bloom’s Taxonomy** refers to a classification of the different objectives that educators set for students (learning objectives). Bloom’s Taxonomy divides educational objectives into three “domains” – cognitive, affective and psychomotor. Within the domains, learning at the higher levels is dependent on having attained prerequisite knowledge and skills at lower levels. For more information, go to: http://www.learningandteaching.info/learning/bloomtax.htm

**Evidence-based Practice (EBP)** is a multi-step, dynamic process that integrates the patient’s preferences or values, the evidence found in the literature and the clinician’s baseline expertise. The EBP process involves the following steps: selecting a topic; formulating a clinical question to assist in evidence retrieval; retrieving and analyze the evidence for strength, quality, and consistency; integrating best evidence with clinical expertise and patient values/beliefs; and recommending, implementing, and evaluating relevant education practice changes. For more information, go to: http://www.biomed.lib.umn.edu/learn/ebp/ http://www.us.elsevierhealth.com/Nursing/Research/book/9780323057431/Nursing-Research/

**Intervention Mapping** provides a powerful and practical tool for the planning and developing effective health education programs. The steps and tasks of Intervention Mapping offer a framework for making and documenting decisions for influencing change in behavior and environmental conditions to promote health and to prevent or improve a health problem. Intervention Mapping involves six steps:  
*Step 1. Needs Assessment;*
*Step 2. Preparing Matrices of Change Objectives;*
*Step 3. Selecting Theory-Informed Intervention Methods and Practical Applications;*
Step 4. Producing Program Components and Materials;
Step 5. Planning Program Adoption, Implementation and Sustainability; and,
For more information, go to:

Principles of Adult Learning is a theory that holds a set of assumptions about how adults learn. This theory emphasizes the value of the process of learning. The theory uses approaches to learning that are problem-based and collaborative rather than didactic and it emphasizes more equality between the teacher and learner. Malcolm Knowles (1980) identified six principles of adult learning. These principles include:

Principle 1. Adults are internally motivated and self-directed;
Principle 2. Adults bring life experiences and knowledge to learning experiences;
Principle 3. Adults are goal oriented;
Principle 4. Adults are relevancy oriented;
Principle 5. Adults are practical; and,
Principle 6. Adult learners like to be respected.
For more information, go to:

The Research Process uses systematic methodology to investigate any subject in order to discover facts, to establish or revise a theory, or to develop a plan of action based on the facts discovered. This systematic methodology is comprised of the following:
1. Develop the Research Question;
2. Define the Purpose, Aim, or Objectives;
3. Develop the Research Hypothesis;
4. Review the Literature;
5. Identify a Theoretical Framework;
6. Choose a Research Design;
7. Select a Sample;
8. Consider Legal and Ethical Issues;
9. Determine Data Collection Methods;
10. Determine Instrument Reliability and Validity;
11. Choose Data Analysis Methods;
12. Report the Results;
13. Discuss the Findings;
14. Make Practice Recommendations; and,
15. Communicate the Results.
For more information, go to:
Part IV: Key Patient Care Issues

The Role of the Patient Educator

Patient educators are responsible for designing, building and sustaining patient education programs. Patient educators work very closely with clinical staff to assess, plan, implement and evaluate their programs for patients and families. Patient educators also serve as a resource and advocate for patient education efforts that will subsequently lead to better health outcomes and quality of life. The depth and breadth of an educator’s responsibilities is vast - from cancer prevention to end-of-life, they are prepared to address today’s key patient care issues. These key issues and relevant resources, are as follows:

Cancer Prevention

According to the National Cancer Institute, a risk factor is anything that raises or lowers a person’s chance of developing a disease. Although doctors can seldom explain why one person develops the disease and another does not, researchers have identified specific factors that increase a person’s chances of developing certain types of cancers.

Cancer risk factors can be divided into four groups:

- **Behavioral** risk factors are things you do, such as smoking, drinking alcohol, using tanning beds, eating unhealthy foods, being overweight and not getting enough exercise.
- **Environmental** risk factors include things in the environment around you, such as UV radiation, secondhand smoke, pollution, pesticides and other toxins.
- **Biological** risk factors are physical characteristics such as your gender, race or ethnicity, age and skin complexion.
- **Hereditary** risk factors relate to specific mutated genes inherited from your parents. You have a higher likelihood of developing cancer if you inherit one of these mutated genes.

Most behavioral and environmental cancer risk factors can be avoided. Biological and hereditary risk factors are unavoidable, but it’s important to be aware of them so you can discuss them with your doctor and get screened for cancer, if necessary.

For more information, visit:

**The National Cancer Institute**
http://www.cancer.gov/cancertopics/prevention

Clinical Trials

Health care providers face a complex set of challenges when educating patients about clinical trials. These challenges are a result of factors that influence a patient’s understanding, participation, and satisfaction with clinical trials, the informed consent process, and their treatment decisions. These challenges include:

- Patient barriers and motivators to seeking information about and/or participating in clinical trials.
• Patient’s need for clear, easy-to-read information that accounts for race, ethnicity, and/or age.
• Staff’s ability to provide meaningful information and explanations to potential participants as early as possible.
• Staff’s ability to assess a patient’s understanding of the informed consent process and support patients in making their treatment decisions.
• Staff’s ability to validate children’s and their families’ perceptions about clinical trial participation and the consent process.
• Staff’s ability to help families understand the realistic expectations of a clinical trial.
• Staff’s ability to establish trust with patients and families.
• Staff’s awareness and utilization of formal standards, guidelines, and proven resources to effectively educate patients about clinical trials.

Based on these findings, the following clinical trial education recommendations for patients/families, clinicians and institutional leadership are outlined.⁹

Recommendations for Improving Patients’/Families’ Understanding of Clinical Trials
• Develop decision aids to support patients’ decisions about enrolling in clinical trials.
• Develop video/print resources designed specifically for children.
• Develop video/print resources for patients enrolling in phase I trials.
• Revise existing clinical trial resources to address lessons learned

Recommendations for Improving Clinicians’ Delivery of Clinical Trials Education
• Survey patients using a measure such as the Quality of Informed Consent questionnaire.
• Develop new resources such as age-specific booklets, videos, Internet-based tools, and consultation tapes and summary letters.
• Provide adequate time to make decisions about participating in clinical trials.
• Provide clear, concise information and explain in terms that are meaningful.
• Encourage patients to ask questions to ensure understanding of treatment options and the consequences of choosing one option over another.
• Educate staff on motivators/barriers that affect patients’ decisions about clinical trials.
• Educate staff to consider patients’ insurance coverage prior to making a decision.
• Tailor recruitment strategies to fit the study population and decrease participant burden.

Recommendations for Improving Clinical Trials Education at the Institutional Level
• Evaluate the reading level and ease of consent forms and translate them into appropriate languages.
• Utilize standardized resources such as teaching plans, decision aids, checklists, medical record forms, and video/audio-taped informed consent staff training sessions.
• Launch public service announcements to improve public awareness of clinical trials.

For more information, visit:

The National Cancer Institute
Complementary and Integrative Medicine

The terms complementary and alternative are often used interchangeably, however they are, two different approaches to the treatment of disease. Complementary medicine is used in addition to, or to complement, conventional medicine; alternative medicine replaces conventional treatment. Conventional medicine, also known as mainstream, western, allopathic, or regular, is practiced by medical doctors or doctors of osteopathy. While it is unlikely that a physician who practices conventional medicine would recommend a truly alternative treatment, some conventional doctors do practice complementary or alternative medicine, or may recommend a complementary treatment.

Combining conventional treatments options with complementary therapies may also be referred to as integrative medicine, as the two types of practices are both evaluated and may be utilized in a comprehensive treatment plan.

Treatments such as acupuncture, yoga, herbal medicines and nutritional supplements and homeopathy may not have been proven to work, but some have evidence supporting their use. The list of practices that are considered as complementary and integrative medicine (CIM) changes continually, as practices and therapies that are proven safe and effective become accepted as mainstream healthcare practices.

Patients may use complementary medicine for:
• Prevention of disease
• Managing symptoms
• Increasing wellness (quality of life, reported sense of well-being)
• Improving treatment effectiveness

Many patients report that complementary therapies are helpful, but others have found no effects or have reported problems. It is important that your doctor knows what therapies you are using, and that treatments you receive are from a qualified practitioner. Many cancer patients use complementary therapies, but they should not be the only source of treatment.

Before trying any CIM therapy, it is important to consider:
• Safety (appropriateness for your condition, quality control of herbal medicines and supplements, etc.)
• Effectiveness
• Cost in time and money
• Credentials of the practitioner

For more information, visit:

**National Center for Complementary and Alternative Medicine**
http://www.nih.gov/about/almanac/organization/NCCAM.htm

Digital Divide

The Digital Divide, or the digital split, is a social issue referring to the differing amount of information
between those who have access to the Internet (especially broadband access) and those who do not have access. The term became popular among concerned parties, such as scholars, policy makers, and advocacy groups, in the late 1990s.

The difference is not necessarily determined by the access to the Internet, however, but by access to ICT (Information and Communications Technologies) and to Media that the different segments of society can use. With regards to the Internet, access is only one aspect, other factors such as the quality of connection and related services should be considered. Today the most discussed issue is the availability of the access at an affordable cost.

The problem is often discussed in an international context, indicating certain countries such as the U.S. are far more equipped than other developing countries to exploit the benefits from the rapidly expanding Internet.

The digital divide is not a clear single gap which divides a society into two groups. Researchers report that disadvantage can take such forms as lower-performance computers, lower-quality or high price connections (i.e. narrowband or dialup connection), difficulty with obtaining technical assistance, and decreased access to subscription-based content.

For more information about bridging the gap, visit:

**Internet World Stats**

**Health Disparities**

Healthcare disparities are “population-specific inconsistencies in the incidence of disease, health outcomes and/or access to care”, and refer to gaps in the quality of healthcare across racial, ethnic, gender, sexual orientation, age, and socioeconomic groups. Inequalities in healthcare result in variations in the prevalence of chronic diseases, mortality and morbidity rates, and ultimately affecting patient outcomes. Measures, data and research on health disparities are widely available; however, challenges remain in the progress that’s been made and sustainable interventions developed to alleviate them.

These healthcare disparities can be attributed to socioeconomic and environmental characteristics of different ethnic and racial groups, access to care, barriers within the healthcare delivery system, and quality of healthcare. Healthcare Disparities persist due to reasons such as:

- Financial constraints
- Lack of regular point of care
- Structural barriers (e.g., poor transportation, inability to schedule appointments during convenient hours)
- Legal barriers (e.g., immigrant population)
- Health literacy
- Language differences
- Lack of diversity in the healthcare workforce
• Patient/provider communication gaps
• Provider discrimination
• Lack of preventive care
• Scarcity of providers in regions where there is a high concentration of minority populations
• Insurance coverage and healthcare financing system (e.g., limited coverage)

Personal patient barriers to care should be accounted for to allow for mechanisms to be put into place to alleviate those barriers. By customizing care based upon their income, age, transportation issues, lifestyle and behavior, eating and exercise habits, comorbidities, support network, and other limitations etc., we can begin to alleviate disparities in healthcare.

For more information, visit:

**The National Partnership for Action to End Health Disparities**
http://minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=11#mis

**Health Literacy**

Health literacy – the degree to which individuals have the capacity to obtain, process, and understand basic health information to make appropriate health decisions– is an emerging public health threat affecting all ages, races and income levels globally. It is an enormous cost burden on the healthcare system and annual health care costs are 4 times higher for individuals with low literacy skills. As per the IOM report on health literacy, 90 million adults have trouble understanding and acting on health information.

Health literacy can lead to lack of adherence to treatment regimens, an increase in medical errors, and an increased risk ofhospitalization because of poor understanding and self management of health care information. Limited health literacy increases healthcare disparities among vulnerable populations such as minorities and the elderly. For instance, over 66% of US adults age 60 and over have inadequate or marginal literacy skills. Improvements in these areas have been linked to extending longevity, improving quality of life and patient safety, reducing chronic disease prevalence and improving patient outcomes. Areas associated with health literacy include, but are not limited to the following areas:
• Communication between the patient and healthcare provider
• Medical instructions, drug labeling interpretation and adherence
• Patient education material and resources (e.g., written, oral, media [DVD, internet, in-house TV, etc.])
• Informed consent
• Medical and insurance forms
• Provision of accurate and relevant patient history

A few red flags for low literacy include:
• Frequently missed appointments
• Forgetting their glasses at home
• Incomplete registration forms
• Lack of adherence to treatment protocol
• Inability to name medications
• Inability to explain purpose or dosage requirements
• Inability to provide coherent and sequential history
• Lack of follow-through with tests and/or referrals
• Have fewer questions
• Identifies medication by appearance rather than reading labels

It is important that the health care team play an active role in enabling the patient. Enabling the patient can be accomplished by putting strategies and tactics in place to ensure the information being delivered is comprehended and that measures are taken to reinforce education throughout the treatment spectrum. Health care providers delivering the education should also be thoroughly trained on how to account for health literacy during the delivery of education.

The teach-back method has been used to ensure patients clearly understand what they need to do as part of their healthcare regimen by asking patients to explain their health instructions using their own words. This allows the healthcare provider to reinforce and clarify any misunderstandings and ask the patient to review it again to ensure they thoroughly understand. Examples of teach back method questions may include:
• How would you describe your health condition to a friend?
• Can you show me how many pills you should take each day?
• I want to be sure I explained everything clearly, so can you please explain it back to me to be sure I did?
• We’ve gone over a lot of information. In your own words, review for me what we talked about. How will you make it work at home?

For more information, visit:

**Centers for Disease Control and Prevention**

**Cancer Patient Education Network – Health Literacy Tool Kit**
http://www.cancerpatienteducation.org/

**SurroundHealth**

**Teaching Patients with Low Literacy Skills**
http://www.hsph.harvard.edu/healthliteracy/resources/doak-book/

**The U.S Department Health and Human Services**
http://www.health.gov/communication/hlactionplan/

**Teach-back Training Toolkit**
http://www.teachbacktraining.com/
Informed Decision-making

A growing body of research shows that both patients and providers benefit when patients are well informed and play a significant role in deciding how they are going to treat or manage their health conditions. Informed patients feel better about the decision process. Their decisions are more likely to match up with their preferences, values, and concerns. These patients are more likely to stick with the regimens the treatment requires, and they often end up rating their health after treatment as better.

Optimal medical decisions require fully informed patients who participate fully in a shared decision-making process, rather than delegating decisions to their doctors. One medical answer can never be right for all people. The decision that will best serve a particular patient often depends on the patient’s own preferences and values. And the treatment that is best for one patient may not be best for another in exactly the same situation.

For more information, visit:

Foundation for Informed Medical Decision Making
http://www.informedmedicaldecisions.org/what_is.html

National Cancer Institute – A Guide to Understanding Informed Consent
http://www.cancer.gov/clinicaltrials/conducting/informed-consent-guide/page1

Ottawa Health Research Institute – Patient Decision Aids
http://decisionaid.ohri.ca/AZsearch.php?criteria=cancer

The Society for Medical Decision Making
http://www.smdm.org/

Pain Management

According to the National Comprehensive Cancer Network (NCCN), pain is defined as an unpleasant, multidimensional, sensory, and emotional experience associated with actual or potential tissue damage, or described in relation to such damage. To assist in the clinical management of cancer pain, the NCCN has developed guidelines that outline the principles of cancer pain management including opioid management, universal screening and assessment tools, and psychosocial support and patient and family/caregiver education. For more information, visit:

National Comprehensive Cancer Network

Another useful resource is the Edmonton Symptom Assessment System (ESAS) for the assessment and evaluation of pain. This instrument can be found at:

National Palliative Care Research Center
http://www.npcrc.org/resources/resources_show.htm?doc_id=376168
Palliative Care/End-of-Life

Palliative care is care given to improve the quality of life of patients who have a serious or life-threatening disease, such as cancer. The goal of palliative care is to prevent or treat the symptoms and side effects of the disease and its treatment. This encompasses all aspects of treatment: physical, psychological, social, and spiritual. The goal is not to cure, but to supplement anti-cancer treatment, and/or offer supportive care once active treatment ceases. Palliative care begins at diagnosis and continues through treatment, follow-up care, and the end of life.

Research shows that palliative care and its many components are beneficial to patient and family health and well-being. A number of studies in recent years have shown that patients who have their symptoms controlled and also have their emotional needs met, have a better quality of life and improved physical symptoms. In addition, the Institute of Medicine 2007 report, *Cancer Care for the Whole Patient* cites many studies that show patients are less able to adhere to their treatment regimen and manage their illness when physical and emotional problems are present.

For more information, visit:  
**IOM – Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs**  

For patient educators and learning resource centers, in 2003, the Institute of Medicine recommended that organizations providing cancer treatment should “revise their inventories of patient-oriented material, as appropriate, to provide comprehensive, accurate information about palliative care throughout the course of disease.” This was in response to their environmental scan showing a lack of palliative care materials provided by the National Cancer Institute and other cancer education organizations.

For more information, visit:  
**IOM – Improving Palliative Care for Cancer**  

The National Consensus Project for Quality Palliative Care was established to build national consensus around the definition, philosophy, and principles of palliative care. They developed the *Clinical Practice Guidelines for Quality Palliative Care* to “serve as a description of what a comprehensive high-quality palliative care service contains, as well as a resource for practitioners addressing the palliative care needs of patients and families in primary treatment settings.” The guidelines were divided into eight domains of palliative care, and are as follows:

- Domain 1: Structure and Processes of Care
- Domain 2: Physical Aspects of Care
- Domain 3: Psychological and Psychiatric Aspects of Care
- Domain 4: Social Aspects of Care
- Domain 5: Spiritual, Religious and Existential Aspects of Care
- Domain 6: Cultural Aspects of Care
- Domain 7: Care of the Imminently Dying Patient
Domain 8: Ethical and Legal Aspects of Care

For more information, go to:

**National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines**
http://www.nationalconsensusproject.org

In addition to these resources, the National Comprehensive Cancer Network has developed palliative care guideline at:

**National Comprehensive Cancer Network (NCCN)**

**Patient/Family-Centered Care**

According to the Institute for Patient and Family Centered Care, patient/family centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships between health care providers, patients, and families. This approach shapes policies, programs, facility design, and staff day-to-day interactions and, leads to better health outcomes and wiser allocation of resources and greater patient/family satisfaction.

Patient/family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of family members of all ages. They acknowledge that emotional, social, and developmental support is integral components of health care, promoting the health and well-being of individuals and families and restoring dignity and control to them.

For more information, visit:
http://www.ipfcc.org/faq.html

Additional resources include:

**The Picker Institute**
http://pickerinstitute.org/about/picker-principles/

**St. Jude's Children’s Research Hospital**
http://www.stjude.org/stjude/v/index.jsp?vgnextoid=0342a1673e82f110VgnVCM1000001e0215acRCRD&vgnextchannel=6772fdd506543110VgnVCM1000001e0215acRCRD

**Patient Navigation**

The Association of Community Cancer Centers has developed a comprehensive framework for the role of patient navigator and navigator programs.
1. Patient navigation may include but is not limited to oncology social worker(s) and nurse(s) who may:
   - Act as a coordinator to ensure the patient, their family members, and caregivers move through
the complexities of the system in a timely fashion
• Provide psychosocial services to patients, families, and caregivers or refer to oncology social worker for psychosocial care
• Link patients, families, and caregivers with appropriate community resources (i.e., financial, transportation, translation services, and hospice)
• Provide education to the patient, families, and caregivers throughout the continuum of care
• Link patients, families, and caregivers with appropriate post-treatment follow-up care.

2. Trained volunteers and non-clinical paid staff may provide some of the navigator activities and functions under defined conditions and with professional oversight.
• Cancer programs may choose to select, train, and oversee their own volunteers or nonclinical paid staff. Cancer programs may choose to partner with an organization that employs patient navigators or uses volunteers.
  – The cancer program will help determine who will oversee these navigators.
  – The cancer program will develop a contract between the navigator(s) and the program that clearly outlines the role the navigator(s) will have with patients and families.
  – The cancer program will develop an orientation and training program that the navigators must attend.
  – The cancer program will provide an ongoing in-service education program for the navigators.

3. The program should provide adequate space for confidential interviews and counseling.

4. Navigators should receive training in ethnic, cultural, and religious diversity as well as ethics.

5. Mechanisms exist, when necessary, to review the plans and coordinate among team members.

6. Navigators should facilitate communication between patient and providers.

7. Navigators should educate the oncology staff about the navigator program and how it will be integrated into the oncology program.

For more information, visit:

**Association of Community Cancer Centers**
http://accc-cancer.org/education/patientnavigation-questionsandanswers.asp

**Patient/Provider Communication**

**Questions to Ask Your Doctor When You Find Out You Have Cancer**
Learning that you have cancer can be a shock, and you may feel overwhelmed at first. When you meet with your doctor, you will hear a lot of information. These questions may help you to find out more about your cancer and what to expect going forward. For more information, visit:
http://www.cancer.gov/cancertopics/cancerlibrary/questions

**Questions about the cancer**
• What type of cancer do I have?
• Can you explain my test results to me? Will I need more tests before treatment begins?
• What is the stage of my cancer? Has my cancer spread to other areas of my body?
• What is my chance of recovery?
• How will cancer and its treatment affect my body?
Questions about finding a specialist and getting a second opinion
• How do I decide where to go for treatment?
• Will I need a specialist(s) for my cancer treatment?
• Will you help me find a doctor to give me another opinion on the best treatment plan for me?

Questions about clinical trials
• Would a clinical trial (research study) be right for me?
• How do I find out about studies for my type and stage of cancer?

Questions about lifestyle, finances, and resources
• How will my daily activities, such as work or school, change?
• How can I get help if I feel anxious or upset about having cancer? If I need help coping with family responsibilities?
• What costs will my insurance cover? Who can answer my questions about how to pay for treatment?
• How can I get help with financial and legal issues (for example, getting financial assistance, preparing a will or an advance directive)?
• How can I get help with my spiritual needs?
• Can you suggest a support group that might help me?

For more information, visit:

CANCERcare®
“Doctor, Can We Talk?” Tips for Communicating with Your Health Care Team
http://www.cancercare.org/publications/53-doctor_can_we_talk_tips_for_communicating_with_your_health_care_team

MD Anderson Cancer Center
Interpersonal Communication and Relationship Enhancement: I*CARE
http://www.mdanderson.org/education-and-research/resources-for-professional-professionals/educational-resources/i-care/index.html

National Coalition of Cancer Survivorship
Talking With Your Doctor

Patient Safety

Patient and family education is integral to advancing the safety of care. Education enables patients and families to acquire the knowledge and skills required to take an active role in care and care decisions. Patients who are actively involved in their care are more likely to experience better care outcomes and safer care.

“The single most important way you can help to prevent errors is to be an active member of your health care team. That means taking part in every decision about your health care. Research shows
that patients who are more involved in their care tend to get better results.” ~ Agency for Healthcare Research and Quality, 20 Tips to Prevent Medical Errors, p. 1, July 13, 2011.

The Institute of Medicine, The Joint Commission, the Agency for Healthcare Research and Quality (AHRQ) and other organizations at the forefront of healthcare quality and safety have emphasized patient and family partnership in care as an essential patient safety strategy. In its patient fact sheet,”20 Tips to Help Prevent Medical Errors,” AHRQ underscores the benefits of patients’ participation in care.

Patent and family education fuels such care partnerships. The Joint Commission’s Speak Up initiative urges patients to take an active role in preventing medical errors by asking questions and becoming well-informed participants in care. AHRQ’s Questions Are the Answer campaign likewise encourages consumers to “...enhance the quality, safety, and effectiveness of your health care by asking questions about your care, your diagnosis, your treatment, and any medications prescribed to you.” ~ AHRQ, Questions Are the Answer home page, July 13, 2011.

It is important to respect the fact that patients vary in their preferences and abilities to take an active role in their care. Cultural values and beliefs may discourage “speaking up” and questioning physicians and other respected authority figures. Patients may be too physically ill or emotionally stressed to assume greater responsibility for care and decision-making.

Multiple Joint Commission standards and National Patient Safety Goals include elements of performance focused on patient and family education. The Joint Commission requires, for example, that education and training provided to the patient include safe and effective use of medications, information on the safe and effective use of medical equipment or supplies, fall reduction strategies, hand and respiratory hygiene practices and how the patient/family can communicate concerns about patient safety issues before, during and after care is received.

Educating cancer patients about potential chemotherapy side effects and how to manage them is critical to patient safety. Patients must understand which side effects require an immediate trip to the nearest emergency room, which necessitate a call to their physician right away and which can wait for their next physician visit.

Patient and family educators are uniquely positioned to address a key threat to patient safety: low health literacy. The Joint Commission’s publication, “What did the doctor say? Improving health literacy to protect patient safety” underscores the importance of low health literacy as a leading cause of adverse care outcomes.

Patient and family education forges partnerships that advance the safety of care.

“Ensuring patient safety also requires that patients be informed and participate as fully as they wish and are able...The committee believes that an informed patient is a safe patient.” ~ The Institute of Medicine, Committee on Quality of Health Care in America, Crossing the quality chasm: A new health care system for the 21st Century, 2001, p. 45.
For more information, visit:

**Joint Commission**
www.jointcommission.org

**Psychosocial Oncology**

For patients and their families, the physical challenges of cancer are difficult enough, but what are often overlooked are the accompanying psychosocial concerns. Cancer patients can experience a myriad of emotions such as fear, anxiety, sadness and anger, as well as thoughts about self-image, sexuality, and personal relationships. To help address these issues, the following resources have been recommended.13

**American Cancer Society**

**American Psychosocial Oncology Society**
http://www.apos-society.org/

**Canadian Partnership Against Cancer**
http://www.partnershipagainstcancer.ca/wp-content/uploads/2.4.0.1.4.5-Guide_CJAG.pdf

**Cancer Care Ontario**
https://www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=8736

**NCCN Distress Management Guidelines**
http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#supportive

**Sexuality and Cancer**

Many people do not talk to their health care team about sexual issues. They may feel embarrassed, ashamed or afraid. To help address patient and family concerns regarding the effects of cancer and its treatment on sexuality, go to:

**The American Cancer Society**
http://www.cancer.org/treatment/understandingyourdiagnosis/afterdiagnosis/after-diagnosis-how-will-cancer-affect-my-sex-life

**American Society for Reproductive Medicine**
www.asrm.org

**American Association of Sexuality Educators, Counselors and Therapists**
www.aasect.org
Social Media

Social media has invaded health care from at least three fronts: innovative startups, patient communities and medical centers. The Health 2.0 movement has nurtured dozens of startups with creative concepts to revolutionize health care: tools from vertical search and social networks to health content aggregators and wellness tools.

Patient communities are flourishing in an environment rich with social networks, both through mainline social communities and condition-specific communities. Meanwhile, hospitals and academic medical centers are diving into the social media mix with more than 300 YouTube channels and 500 Twitter accounts. Hospitals are moving from experimentation (Twittering from the OR to Flipcam videos) to strategic use of social media to enhance brand loyalty and recruit new patients. They are taking on monitoring and monetization of social media.

At the same time, health care organizations find challenges in adopting social media. Hospitals and medical practices are risk averse and generally cautious about new technology trends without clear value. There are questions about whether social media use by hospital employees is a waste of time, or even worse, presents risks of violating HIPAA or leaking proprietary information. Hospital IT departments are concerned about security risks, such as the use of tinyurl.com, which can mask malicious Web sites. Privacy concerns, particularly the vulnerability of social media accounts, are also cited as a reason to avoid social media.

Current Trends in Social Media

Current trends to watch in social media in health care include:
• Managing a conversation;
• Engaging e-patients;
• Convergence with personal health records; and
• Social media for providers.

An important distinction in this two-way conversation is between medical advice and medical...
information. Hospitals and providers need to walk a fine line between giving specific medical advice in the relatively public forums of social media and providing more generalized medical information.

At the same time, there are ways to create a conversation with health care consumers. Sites like Medhelp.org have provided this kind of information using medical experts to answer patient-submitted questions in general terms. For instance, promoting wellness is a win-win; medical information relevant to many is provided without specific medical advice for a patient’s medical condition.

The rise of e-Patients creates many opportunities for engagement. E-Patients are defined as those “who are equipped, enabled, empowered and engaged in their health and health care decisions.” E-patients can provide feedback not only on improving hospital Web sites but also as participants in quality improvement within the health system.

**PHRs and Online Communities**

As the similarities between online patient communities (e.g., http://www.patientslikeme.com and http://curetogether.com) and PHRs begins to blur, will PHR information from providers be shared with online communities with the appropriate privacy settings so that the user can decide what to share?

Recording one’s medical condition online and abandoning privacy are part of the “Quantified Self” movement. The Robert Wood Johnson Foundation’s Project Health Design uses the concept of “Observations of Daily Living,” which extends the quantified self to behavioral self-observations. The next step in quantified self is self-monitoring, also known as home monitoring and telemedicine. Being quantified in terms of one’s weight, blood pressure or blood glucose provides another way of self-monitoring and participatory medicine.

Some are predicting that in the near future, multiple monitoring devices will be phased out to give way to connections with smart phones that will record and transmit medical monitoring data directly to a PHR. Innovators, such as Google Health and Microsoft Health Vault, as well as edgy startups, will provide the conduit from smart phones to the cloud.

**Social Media for Providers**

Finally, a relatively untapped resource is the use of social media among medical professionals. If anything, there have been negative stories about abuses and misuses of social media by health professionals and questions about the ethics of connecting with patients online.

Currently, few health care professionals see the value in social networking with other physicians, or they are not convinced that the benefits are worth the time. Although well over 90% of physicians use the Internet for continuing education, medical reference and e-mail with colleagues and a majority of doctors have a smart phone, taking the leap into online communities is less common.

Perhaps current business models dependent on financial incentives and industry sponsorship in exchange for private data have not engaged physicians. Could a different model that provides privacy and collaboration in the context of a community of similar interests demonstrate value and promote adoption?
Future Evolution of Social Media
Social media is here to stay in health care, but it will evolve quickly. Patient engagement will continue to characterize this change. Organizations will use social media tactically within their overall marketing and communications efforts -- videos and mobile technology will likely dominate these approaches.

Online patient communities will expand and will become a rich source of information for others. Physicians and other health care providers will discover social media, which will have the potential of progressing medical research.

There may be regular news reports of privacy violations, dangerous misinformation and fraud promoted via social media, but these reports are not likely to stop a wave of innovation and conversation.

For more information, visit:

iHealthBeat

Special Populations

According to the University of Illinois at Chicago, special populations are defined as follows:

Children
• ChildStats.gov
• America’s Children: Key National Indicators of Well-being
• Reports for each year back to 1997.
• PeriStats
• (March of Dimes) # Developed by the March of Dimes (in collaboration with NLM, NIH & NY Academy of Medicine) PeriStats provides free access to US, state, city, and county maternal & infant health data with over 60,000 graphs, maps and tables available! Create customized charts or maps based upon indicators you select.
• National Maternal and Infant Health Survey
• The National Maternal and Infant Health Survey (NMIHS) vital records are linked with data from mothers’ questionnaires. The 1988 NMIHS is the successor to earlier NCHS National Natality and Mortality Follow-back Surveys.
• Youth Risk Behavior Surveillance System
• A special CDC project through Adolescent & School Health. Much of the results reported in MMWR, and special files available at this site.

Ethnicity
• African American Health
• (MedlinePlus) The statistics sections have pulled together resources for information on specific diseases in regards to African Americans.
• Asian-American Health
• (MedlinePlus) The statistics sections have pulled together resources for information on specific diseases in regards to Asian Americans.
• Hispanic-American Health
• (MedlinePlus) The statistics sections have pulled together resources for information on specific diseases in regards to Hispanic-Americans.
• Native American Health
• (MedlinePlus) The statistics sections have pulled together resources for information on specific diseases in regards to Native Americans.

Note: Health Information Translations provides education resources in multiple languages for health care professionals and others to use in their communities. Resources are easy to read and culturally appropriate. For more information, go to: https://www.healthinfotranslations.org/

Underserved
• State Health Departments
• A directory of state health departments from the CDC.
• Health Professional Shortage Areas
• From the Health Resources and Services Administration
• Medically Underserved Areas/Medically Underserved Populations MUA/MUP
• Maintained by HRSA’s Bureau of Primary Health Care, search by state or by state & county.

Selected Group Data
• Cancer Statistics from the NCI

For more information visit:

University of Illinois at Chicago
http://researchguides.uic.edu/content.php?pid=90523&sid=674090

Survivorship

In the United States, half of all men and one-third of all women will develop cancer in their lifetimes. Advances in the detection and treatment of cancer, combined with an aging population, mean greater numbers of cancer survivors in the near future.

Despite the increase in survivors, however, primary care physicians and other health care providers often are not extremely familiar with the consequences of cancer, and seldom receive explicit guidance from oncologists. Furthermore, the lack of clear evidence for what constitutes best practices in caring for patients with a history of cancer contributes to wide variation in care.

Citing shortfalls in the care currently provided to the country’s 12 million plus cancer survivors, From Cancer Patient to Cancer Survivor: Lost in Transition recommends that each cancer patient receive a “survivorship care plan.” Such plans should summarize information critical to the individual’s long-term care, such as the cancer diagnosis, treatment, and potential consequences; the timing and content of follow-up visits; tips on maintaining a healthy lifestyle and preventing recurrent or new cancers; legal
rights affecting employment and insurance; and the availability of psychological and support services.

To ensure the best possible outcomes for cancer survivors, the committee aims in this report to:
2. Define quality health care for cancer survivors and identify strategies to achieve it.
3. Improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices, and health insurance.

The committee’s findings and recommendations in this report are directed to cancer patients and their advocates, health care providers and their leadership, health insurers and plans, employers, research sponsors, and the public and their elected representatives.

For more information, visit:

**The Institute of Medicine**

Other helpful resources include:

**American Cancer Society – Cancer Survivor Network**
http://www.acscsn.org

**American Society of Clinical Oncology**
http://www.asco.org/portal/site/ascov2/gsasearch?q=survivorship

**Cancer.Net**
http://www.cancer.net/patient/Survivorship

**Cancer Survival Toolbox Living Beyond Cancer**
http://www.canceradvocacy.org/toolbox/

**Centers for Disease Control and Prevention**
http://www.cdc.gov/cancer/survivorship/what_cdc_is_doing/action_plan.htm

**Lance Armstrong Foundation**
http://www.livestrong.org

**National Cancer Institute – Office of Cancer Survivorship**
http://dccps.nci.nih.gov/ocs/

**National Coalition for Cancer Survivorship**
http://canceradvocacy.org/
Treatment Side Effects

Fear about side effects from cancer treatment adds to the stress of a cancer diagnosis. This fear comes from a belief that the discomfort of side effects cannot be relieved. That is not true. Many advances have been made in preventing or managing the most common treatment-related side effects.

Side Effects Differ in Many Ways
Managing side effects is important because if you feel better, you are more likely to complete your treatment as planned by your oncologist, and treatment is most effective when it is carried out as planned. Learning the facts about side effects can help people with cancer cope better with them.

The side effects of cancer treatment differ in many ways. First, not all patients will have the same side effects. A friend or relative may have had a certain side effect after treatment, but that does not mean you will experience the same side effect. Whether or not you experience a side effect depends on many factors including your age, your overall health, your specific cancer, and your specific treatment plan.

Side effects vary in how serious they are. Some cause minor inconvenience or discomfort, and others may cause more discomfort, pain, and/or emotional distress. Occasionally, a serious side effect may require immediate medical attention. It is important to know that there are ways to relieve the discomfort of most treatment-related side effects and to prevent them from becoming severe. It is also important to know when you should call your doctor about symptoms related to side effects.

Side effects also differ according to when they occur. Those that occur during treatment are called short term (or acute) side effects. Short term effects usually disappear once treatment ends. In contrast, long-term side effects may not completely disappear until months or years after treatment has ended. The last category of side effects is late effects, which occur less frequently than short term or long term effects. Late effects do not occur during treatment; rather, they occur at least 6 months after treatment has been completed. The most important way in which side effects differ is according to the type of cancer treatment; that is, surgery, radiation therapy, chemotherapy, hormone therapy, or targeted therapy. Many people with cancer receive a combination of treatments, which may increase the possibility of side effects.

For more information, visit:

The Patient Resource™ Cancer Guide
http://www.patientresource.com/Treatment_Side_Effects.aspx?gclid=CIHX8oD7vq8CFYRgTAodO1OftQ

In addition, the Oncology Nursing Society has developed its ONS PEP (Putting Evidence into Practice) Resources by side effect that provides detailed evidence-based information for current nurse-sensitive patient outcomes. Each outcome, or topic area, provides the levels of evidence for all of the interventions identified. Information is organized according to the categories of levels of evidence outlined in the next section.
• Anorexia
• Anxiety
• Caregiver Strain and Burden
• Constipation
• Depression
• Diarrhea
• Dyspnea
• Fatigue
• Lymphedema
• Mucositis
• Nausea and Vomiting
• Pain
• Peripheral Neuropathy
• Prevention of Bleeding
• Prevention of Infection
• Sleep/Wake Disturbances

**Canadian Partnership Against Cancer**

http://www.cancerpatienteducation.org/pdf/Manage_cancer_related_fatigue_Final_EnglishJun152012.pdf

Click the links below to view articles published in the Clinical Journal of Oncology Nursing describing the ONS PEP (Putting Evidence into Practice) Resources:
• Nursing-Sensitive Patient Outcomes: The Development of the Putting Evidence Into Practice® Resources for Nursing Practice
  http://ons.metapress.com/content/b251810n2r130405/fulltext.pdf
• Oncology Nursing Society Putting Evidence Into Practice® Resources: Where Are We Now and What Is Next?
  http://ons.metapress.com/content/t3223p223601qnm1/
• Updated Oncology Nursing Society Putting Evidence Into Practice Resources
  http://ons.metapress.com/content/037248216wm2k054/
Part V: Appendixes

Appendix A – Standards Check List

____ Value Proposition

____ Mission and Vision

Organizational Structure and Culture Standards

____ Institute policies and procedures, approved by the organization’s administrative, medical and education staff, that state the patient education program staff has the authority, responsibility and accountability for the development, implementation, administration, coordination and evaluation of the patient education program.

____ Document the roles and functions of the program as an interdisciplinary entity and emphasize the structural and collaborative relationships between the PEP and other departments/units within the organization. This documentation could be in the form of a PEP Welcome packet that highlights the various components of the program and supporting information (e.g., organizational charts, policies and procedures, staff resources, patient resources, etc.).

____ Write competency-based position descriptions delineating the minimum qualifications, authority, accountability and responsibility of the patient education program staff.

____ Hire qualified program staff and a sufficient number of staff to meet the needs of the organization’s patients, families and caregivers.

____ Provide relevant documents in either print format, electronic format or both.

Strategic Plan Standards

____ The strategic plan gives the program focus and is directly tied to the organization’s mission and vision. The plan should be reviewed and revised annually, based on feedback from program staff and appropriate interdisciplinary team members.

Essential Functions Standards

____ Identify and define the various positions/roles within the PEP, their importance and priority for building the PEP.

____ PEP staff clearly defines scope of services, including its customers, functions and activities.

____ PEP staff provides patient education in an interdisciplinary and collaborative manner and provides training to all disciplines involved in the patient’s care, treatment, and services.

____ PEP staff provides patient education and training, based on patient’s assessed needs and abilities regarding cultural and religious beliefs, emotional barriers, desire and motivation to learn, physical or cognitive limitations and barriers to communication.

____ PEP staff serves as a resource to all members of the organization with regard to program development, implementation and evaluation (e.g., patient’s understanding of the education and training it provides).

____ PEP staff provides leadership to ensure the organization’s compliance with patient education standards from Joint Commission and other accrediting bodies.
Facilities and Equipment Standards

- An organizational environment, conducive to learning, is assessed and program plans are made accordingly.
- Appropriate space, suitable for teaching patients and families, is identified and maintained.
- Appropriate technical support, as well as print, graphic and audiovisual support, is established.
- A research library and/or reference center is made available for PEP development.
- A consumer health library/resource center is made available for patients, family members and caregivers.

Financial Management Standards

- The PEP staff develops a budget to support the program’s mission and vision.
- The PEP budget includes resources for staffing, operational expenses and materials/resources, as well as projected revenue.
- Supplemental budgets items will require written proposals, grants and special funding, to cover special requests or additional program costs.

Policies and Procedures Standards

- Policies and procedures are clearly written and easily accessible in print or electronic format to the organization’s staff. They encompass interdisciplinary tasks and responsibilities, as well as outline the development and provision of patient and family education.
  - Policies and procedures can include:
    - The purpose of the policy
    - A policy statement(s) that outline the intentions of the policy
    - The type of information to be provided, by whom and when
    - How patient teaching will be documented
    - Mechanisms for review and approval of resources
    - Approaches used for quality improvement
    - Administrative/operational responsibilities
    - Education and competency verification of staff
    - Training volunteers involved in program activities
    - The scope for whom the policy applies
    - The target audience of the policy
    - The strategic goal(s) the policy relates to
    - Any applicable definitions to help clarify the policy
    - Any general instructions or procedures that clarify how the policy will be carried out
- Policies and procedures are reviewed annually and revised as necessary.

Quality/Performance Improvement/Evaluation and Research Guidelines

- The PEP staff utilizes the organization’s quality/performance improvement structure to modify program content or change how a program is delivered.
- The PEP staff applies various methodologies (e.g., evidence-based practice process, research process) to address patient satisfaction, effectiveness of services and expected outcomes (e.g. pre-testing, post-testing, feedback questionnaires, focus groups, etc.). Based on results, practice changes are implemented and evaluated.
- The PEP staff has mechanisms in place for obtaining feedback from patients, families and staff.
When appropriate, patient follow-up is done to determine change in patient skill, knowledge and/or attitude.

The PEP staff utilizes the organization’s research structure to design research studies, prepare proposals or grants to fund a study and/or use standard research protocols to determine the effectiveness of patient education interventions.

**Documentation Standards**

- Records retained for accreditation/regulatory purposes include:
  - Organization documentation
    - Short and long-term strategic plans
    - Budget meeting minutes
    - Policy and procedure reports to committees or governing body (e.g., quality improvement documentation, annual reports)
    - Staff development documentation (e.g., may be maintained in another department, such as Human Resources)
    - Staff competency verification (e.g., may be maintained in another department, such as Human Resources)
  - Patient education material archives
  - Patient teaching documentation
  - Patient documentation and patient teaching records (e.g., the medical record)

**Professional Development Standards**

- The PEP staff has a minimum of a bachelor’s degree in education, nursing, health care administration, health education or related field.
- New PEP staff receives an orientation of sufficient duration and content in preparation for their respective role.
- The PEP staff demonstrates competency in the education process and related activities according to professional standards.
- The PEP staff regularly participates in continuing education and in-service programs based on current education needs in health care and in patient education specifically.
- The PEP staff participates in an annual performance evaluation and identifies professional development goals, in collaboration with their supervisor.
- The PEP staff is encouraged to demonstrate professional role responsibility by membership and active participation in professional organizations and by voluntary service in professional groups or community agencies.
- The PEP staff has relevant texts and journals available to them and a mechanism in place to offer input into the purchase of applicable reference materials.
Part VI: References


