Closing the Gap, Bridging the Divide: How to Effectively Teach Patients and Families

POGO Nursing Education Symposium, November 1, 2018

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Stephanie Cox, MN, NP–Peds
Objectives

- Review the trajectory of research in pediatric oncology patient/family education

- Review the theories of clear communication and health literacy and how it affects healthcare and our patients

- Explore how to implement the clear communication techniques and how to use these recommendations in our current practice
Cancer Diagnosis Treatment plan Clinical trials

Line care Home care Follow up appointments

when/why to call Who/how to call Medication management

Fevers Prevent infection Neutropenia Bleeding Anemia Side effects

Nutrition Blood counts Fertility Pain Safety G-CSF Local control Post op care
Children’s Oncology Group (COG) Nursing Discipline

Patient/Family Education in COG

- Informational Needs of Newly Diagnosed Patients (Expert Panel + Delphi)
- Systematic Review
- Comprehensive Survey
- Parent/Caregiver Perspective of Education at Diagnosis (Expert Panel + Qualitative)

State of the Science Summit

Expert Consensus

Develop / Disseminate Best Practice Recommendations

Evaluate

Develop / Disseminate Interventions to Improve Uptake of Best Practices

2014

2015

2016-18

2019

RNAO Fellowship
RNAO fellowship

- Self-directed learning
- Mentoring
- Topic of interest
- Builds
capacity/professional
growth
Educational strategies to improve content and delivery of education by pediatric oncology nurses to families of pediatric patients that are newly diagnosed with cancer

A diagnosis of cancer is emotionally distressing news to process for a newly diagnosed pediatric oncology patient and their family. There is an enormous amount of information that these families require to learn about their child’s diagnosis, side effects and treatment. In order for parents to properly care for their child and manage potential emergency situations at home, nurses need to effectively educate families about their child’s condition and treatment. On McMaster Children’s Hospital’s Pediatric Oncology Unit, 40% of nurses have less than five years’ experience. In a survey of the nurses, 93% of nurses expressed the need for formal

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Author: Angela Flice, BA, BSN, RN, CPCH
Organization: McMaster Children’s Hospital
Year: 2016

A Standardized Education Checklist for Parents of Children Newly Diagnosed With Cancer: A Report From the Children’s Oncology Group

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Nancy Tena, MSN, RN, CNS-BC, CPON
BMTCN
Cindi Winkle, BSN, RN, Joan Darling, PhD
Abigail Slaven, RN, CPHON
Jeneane Sullivan, MSN, RN, CPON
Kathryn M Tomkinson, BSN, RN
Kate Windt, BSN, RN, CPHON
Marilyn Hockenberry, PhD, RN, PPCNP-BC, FAAN
and Wendy Landier, PhD, RN, CPNP, CPON, FAAN

Abstract
Parents of children newly diagnosed with cancer must acquire new knowledge and skills in order to safely care for their child at home. Institutional variation exists in the methods and content used by nurses in providing the initial education. The goal of this project was to develop a checklist, standardized across institutions, to guide nursing education provided to parents of children newly diagnosed with cancer. A team of 21 members (19 nurses and 2 parent advocates) used current hospital educational checklists, expert consensus recommendations, and a series of
Children’s Oncology Group (COG) Nursing Discipline

New COG Discharge Checklist
Benefits of Standardized Education Checklists

- Checklists promote process improvement and foster consistent practice

- Provide a method to ensure that information delivery is accurate and complete

- Helps to ensure that essential information is delivered consistently without overwhelming parents with information that could be delivered after the initial hospital discharge

- Enhances communication between interdisciplinary health care team members and can be employed across various settings and potentially institutions

# Standardized Education Checklist

## Primary topics Checklist.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Learner</th>
<th>Pref</th>
<th>Method</th>
<th>Eval</th>
<th>Date/ Initials</th>
<th>Final Checkoff</th>
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<td>Meeting with physician for diagnosis and treatment plan</td>
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<td>Meeting with social worker to screen for immediate psychosocial needs</td>
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<td>Diagnosis (parents know how to convey this in an emergency)</td>
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<td>When to call for help</td>
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<td>Who to call for help</td>
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<td>Temperature-taking</td>
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<td>Handwashing</td>
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<td>Preventing infection</td>
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<td>Treatment side effects to know before next appointment</td>
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<td>Home medication: Names and purpose</td>
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<td>Home medication: Dose and frequency</td>
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<td>Home medication: Administration</td>
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<td>Home medication: Storage</td>
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<td>Home medication: Prescriptions filled</td>
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<td>Home care company (contact information and supplies)</td>
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<td>Chemotherapy safe-handling/item disposal</td>
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<td>Follow-up appointments</td>
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<td>For patients with external central line</td>
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<td>Emergency care of central line</td>
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<td>For CNS tumor patients</td>
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<td>Symptoms of increased intracranial pressure, shunt malfunction, headache</td>
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<td>Seizures</td>
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<td>Postop/wound care</td>
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<td>Pain/pain management</td>
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<td>Topical anesthesia for port</td>
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</table>

Rodgers et al., A standardized education checklist for parents of children newly diagnosed with cancer, 2018
## Standardized Education Checklist

### Secondary Topics Checklist.

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<thead>
<tr>
<th>Topic</th>
<th>Learner</th>
<th>Prefs</th>
<th>Method</th>
<th>Eval</th>
<th>Date/Initials</th>
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<tr>
<td>What is cancer?</td>
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<td>Chemotherapy overview</td>
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<td>Introduction to emergency department</td>
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<td>Introduction to outpatient nurse and/or clinic tour</td>
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<td>Effects of cancer treatment on the bone marrow</td>
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<td>Effects of cancer treatment on the digestive system</td>
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<td>Other side effects</td>
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<td>Varicella exposure</td>
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<td>Nutrition</td>
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<td>Bathing and swimming precautions</td>
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<td>Environmental precautions</td>
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<td>Activity restrictions</td>
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<td>No rectal medications or exams</td>
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<td>Home medication: Side effects</td>
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<td>For patients with external central line</td>
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<td>Care of central line dressing</td>
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<td>Demonstration of cap change</td>
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</table>

Rodgers et al., A standardized education checklist for parents of children newly diagnosed with cancer, 2018
### Tertiary Topics Checklist

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<tr>
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<th>Date/Initials</th>
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<tr>
<td>Vaccinations</td>
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<td>Websites for cancer related information</td>
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<td>Sexual activity including precautions for pregnancy and sexual</td>
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<td>transmitted infections</td>
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<td>Risky behaviors (i.e., smoking, alcohol consumption, tattoos, piercing)</td>
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<td>Introduction to child life specialist</td>
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<td>Talking with child and siblings about cancer</td>
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<td>Coping skills</td>
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<td>Work and school absences</td>
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<td>Insurance issues</td>
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<td>Financial resources, including cancer organization referrals</td>
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<td>Overall Mandatory Topics</td>
<td>MRP</td>
<td>Timing of Education</td>
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<td>Health Care Team</td>
<td>Inpatient Nurse</td>
<td>First 48 hours of admit</td>
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<td>Hospital Daily Routine</td>
<td>Inpatient Nurse</td>
<td>First 48 hours of admit</td>
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<td>Diagnosis</td>
<td>Physician</td>
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<td>Prognosis</td>
<td>Physician</td>
<td>At diagnosis</td>
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<td>Provide COG Handbook</td>
<td>Inpatient RN</td>
<td>At diagnosis</td>
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<td>Clinical Trials</td>
<td>Physician/CRA</td>
<td>Following diagnosis</td>
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<td>Treatment Plan</td>
<td>Physician/Clinic RN</td>
<td>Following diagnosis</td>
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<tr>
<td>Procedures</td>
<td>Physician/Inpt RN</td>
<td>Following diagnosis</td>
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<td>Lumbar Puncture</td>
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<td>Blood Counts</td>
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<td>Anemia</td>
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<td>Neutropenia</td>
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<td>Inpatient RN/NP/Clinic Nurse</td>
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<td>What constitutes a fever</td>
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<td>Proper way to take temp</td>
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<td>Family has thermometer</td>
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<td>Signs of Infection</td>
<td>Inpatient Nurse/ NP/Clinic Nurse</td>
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<td>Inpatient Nurse/ NP/Clinic Nurse</td>
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<td>Avoidance of crowds</td>
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<td>**need MD consensus</td>
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<td>Sick contact/exposures</td>
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<td>**need MD consensus</td>
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<td>Inpatient Nurse</td>
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<td>Activity/site care</td>
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<td>Medication Management</td>
<td>Pharmacy/Inpatient Nurse/Child Life</td>
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<tr>
<td>Practice drawing up meds G-CSF*</td>
<td>Pharmacy/Inpatient Nurse/Child Life</td>
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<td>Medication Adherence</td>
<td>Pharmacist/Inpatient Nurse/Child Life</td>
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<td>Medication Side Effects</td>
<td>Pharmacist/Inpatient Nurse</td>
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<td>Steroids*</td>
<td>Inpatient Nurse/Clinic Nurse</td>
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<td>Chemotherapy Safe Handling</td>
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<td>Rectal tems/supps</td>
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<td>Signs of Increased ICP</td>
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<td>Bleeding Precautions*</td>
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<td>Post Op Care*</td>
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<td>NG teaching *</td>
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<td>Mouth care/Clean Routine</td>
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<td>Constipation</td>
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<td>Anti-emetics</td>
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<td>Pain management</td>
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<td>Psychosocial</td>
<td>SW/Child Life</td>
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<td>Home Care</td>
<td>NP/Interlink Nurse</td>
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<td>Activity</td>
<td>Clinic RN/NP</td>
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<td>Fatigue</td>
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<td>Physical Limitation</td>
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<td>School</td>
<td>Interlink Nurse</td>
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<td>Finger Poke Tour</td>
<td>Child Life</td>
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<td>3F Clinic</td>
<td>Child Life/Clinic Nurse</td>
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<td>Tour</td>
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<td>How to prepare for appointment/ametop</td>
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<td>Clinic Routine</td>
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<td>When/Why to Call</td>
<td>Inpatient Nurse/Clinic Nurse</td>
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<td>Within 72 hours pre DC</td>
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<tr>
<td>Who/How to Call</td>
<td>Inpatient RN/Clinic Nurse</td>
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<tr>
<td>3F Nurse/Inpatient Nurse</td>
<td>Within 72 hours of discharge</td>
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<tr>
<td>Chemo Admission</td>
<td>How to prepare for admission/What to expect</td>
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</table>
McMaster Experience– New Patient Discharge Checklist

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<table>
<thead>
<tr>
<th>Moment 1</th>
<th>Moment 2</th>
<th>Moment 3</th>
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<tr>
<td>_____</td>
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```

- **Chemotherapy side effects to know before next appointment**
- **Supportive Care/ Applyable**
- **Consilization**
- **Nasogastric tube**
- **(uri) may management**
- **Post operative care**
- **Accessing care**
- **Where to call for help**
- **Who to call for help**
- **Follow up appointments**

- **Medication management**
- **Drugs and purdue**
- **Uses and degradation**
- **Administration care**
- **Storage**
- **Medication schedule**
- **Prescription filled and reviewed**

**Note:**
- Use ACP family handbook as reference with each learning block.
- Provide ACS family handbook as soon as diagnosis is confirmed.
- Use various reference pages in ACS family handbook.

**Signature:**

<table>
<thead>
<tr>
<th>Signature</th>
<th>Date</th>
<th>Initials</th>
</tr>
</thead>
</table>
As we start a new school year, Mr. Smith, I just want you to know that I'm an Abstract-Sequential learner and trust that you'll conduct yourself accordingly!
Understanding Effective Delivery – Recommendations

- Written material, short verbal discussions, audio recordings
- Families need time to process the diagnosis before teaching about essential care can begin
- For families to receive medical information such as prognosis, etiology, procedures, treatment and side effects, and for AYA sexuality and fertility information
Understanding Effective Delivery – Recommendations

- Psychosocial information related to learning how to adjust, how to interact with friends/family, return to school, job/career plans

- Use of anticipatory educative content (families usually unaware of what to ask)
Understanding Effective Delivery – Recommendations

- Educational and developmental level should be considered when delivering information.

- Educational information should be provided to parents by consistent HCPs, using vocabulary that the recipient understands, in a consistent manner, allowing time to answer questions.
Understanding Effective Delivery – Recommendations

- Parents emotional state, language barriers, cultural issues, and condition of child be considered

- Structured teaching tool(s) be used to guide the provision of general education and d/c instructions to parents

- Siblings should receive age appropriate interactive education

Wizowski, Lindsay Connect for success slides May 2014;
Why is it this important?

- Providing education is a foundational competency of all nurses
  - RNAO Best Practice Guidelines
  - APHON Scope and Standards

- Unique position to provide daily education to promote, maintain, restore, and improve the health and comfort of the child with cancer

- Necessary to use strategies to educate families about maintaining health and provide a safe environment of care
As a nurse, how much of your time do you spend helping patients learn?

a) 25% or less
b) 25 to 50%
c) 50 to 75%
d) 75% or more
How confident are you in your ability to teach patients/families?

a) Not confident at all
b) Somewhat confident
b) Confident
c) Very confident
<table>
<thead>
<tr>
<th>Educational Theories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Traditional Expert Model</strong></td>
</tr>
<tr>
<td>Provider-centred</td>
</tr>
<tr>
<td>Nurse provides information and outlines goals for the patient</td>
</tr>
<tr>
<td>Focused on physical and biomedical aspects of patient’s condition</td>
</tr>
</tbody>
</table>

Wizowski, Lindsay Connect for success slides May 2014
What is literacy?

“The ability to identify, understand, interpret, create, communicate, and compute using written materials”. – UNESCO
What percent of Canadian adults have below-proficiency reading skills?

a) 12%

b) 25%

c) 37%

d) 48%
What is health literacy?
Health literacy is the ability to obtain, process and understand basic health information and services, and to make appropriate health care decisions or act on health information.

- Ability to navigate healthcare system
- Ability to understand basic health information and services
- Ability to make appropriate health care decisions and act on health information
Low Health Literacy

What percentage of Canadian adults have difficulty understanding health information?

a) 18%  
b) 36%  
c) 47%  
d) 60%
Some people are at a higher risk ...

Cultural or Language Barrier
Almost 25% of Hamilton residents were born outside Canada

Poverty
Close to 1 in 5 Hamiltonians live in poverty.

Level of Education
38% Hamilton residents over age 20 have high school education or less

Wizowski, Lindsay Connect for success slides May 2014;
What are some other warning signs that may indicate low health literacy?
Low health literacy warning signs

- Frequently missing appointments/ lack of follow through on tests or referrals
- Incomplete registration forms
- Noncompliance with medication therapy or inability to name medications or explain the purpose or dosing of the medications
- Identifying the pill by looking at them and not by reading the label
- Asking few questions
Low health literacy is associated with:

- Less knowledge about health
- Poor self-management skills
- Medication errors
- Less preventative, more emergency care
Low health literacy is associated with:

- Increased risk of hospitalization
- Chronic disease
- Higher mortality (seniors)
- Higher healthcare costs

Wizowski, Lindsay Connect for success slides May 2014;
I totally forgot what you told me when I got home...

I’m worried about my child

I wasn’t expecting this

I’m so tired and not sleeping well

How can I support my family

How will we get to all the appointments?
Have you or someone you know had trouble navigating the health care system?
What is it like?

Your naicisyhp has dednemmocer that you have a ypocsonoloc. Ypocsonoloc is a test for noloc recnac. It sevlovni gnitresni a elbixelf gniweiv epocs into your mutcer. You must drink a laiceps diuqil the thgin erofeb the noitianimaxe to naelc out your noloc.

What is involved in this test?

a) Mucous removal  
b) Drinking water  
c) Flexible scope  
d) Blood work
Your physician has recommended that you have a colonoscopy. Colonoscopy is a test for colon cancer. It involves inserting a flexible viewing scope into your rectum. You must drink a special liquid the night before the examination to clean out your colon.
Health literacy depends on:

- **Patient**
  - Literacy and cognitive skills
  - Knowledge, beliefs and experience
  - Physical and emotional state
  - Motivation and confidence

- **Providers**
  - Listen to patient’s story to learn their needs and preferences
  - Caring and respectful approach
  - Pace information
  - Clear language without jargon

- **Patient Education Materials**
  - Easy to read and understand
  - Tailored information
  - Choice of formats

- **Places**
  - System easy to access and navigate
  - Welcoming settings
  - Realistic expectations of patients and families

Wizowski, Lindsay, Health literacy and research communications slides, April 2016
Personal skills and abilities

System demands and expectations

Patient

Providers

Places

Patient Education Materials

Low health literacy
A patient’s perspective
The challenge

Evidence shows that patients often:

- do not understand
- misinterpret
- do not remember

information given to them by health professionals

Wizowski, Lindsay Connect for success slides May 2014
"TAKE WITH MEALS? NO PROBLEM!
I EAT ALL THE TIME!"
Memory

Patients forget up to ____% of the information provided by healthcare practitioners.

A) 80%
B) 50%
C) 25%
D) 10%
About ___% of the information they remember is recalled incorrectly.

A) 75 %
B) 50 %
C) 37 %
D) 18 %
Let’s take a few minutes to assess your own communication skills.

1. Take a “Communication Self-Assessment” questionnaire from the package on your table

2. Take a few minutes to read and complete

What can you improve on?

What strategies can you use to improve?
Effective Delivery

Your effectiveness in delivering information depends on your skills as an educator
Best Practice Guidelines

Patient partnership model
Health literacy
L.E.A.R.N.S Model
Universal Precautions
Plain Language
Teach–back Method

RNAO best practice guidelines, Facilitating client centered learning, 2012
Listen to the patient’s story

- Gather information so you can tailor treatment and education to their needs and preferences
- Ask open-ended questions
- Meet the patient/family “where they are”
L.E.A.R.N.S Model

Establish a relationship

Use interpersonal skills to:
- Show empathy and respect
- Build rapport and trust
- Create a therapeutic partnership

Use body language to invite questions:
- Sit, don’t stand (same level)
- Look and listen
- Show that you have time
L.E.A.R.N.S Model

Adopt an intentional approach

Teaching is an intervention that requires planning.

- Structured
- Tailored
- Negotiated
- multimodal
- Planned

Wizowski, Lindsay Connect for success slides May 2014; RNAO Clinical best practice guidelines, facilitating client centered learning, 2012
A combination of methods makes teaching more effective

- Multimodal approach recommended (RNAO best practice)
- Should be tailored to the learning needs of the individual

- printed material
- websites
- videos
- models
- pictures, posters

RNAO best practice guidelines, Facilitating client centered learning, 2012
Effective Material

• Written materials, when used alone, will not adequately inform
• Patients prefer receiving *key messages* from their clinician with accompanying pamphlets
• Effective material should be:
  • 1. Accurate
  • 2. Accessible
  • 3. Actionable

©1996 by J. Wood
L.E.A.R.N.S Model

Reinforce Health Literacy

Use universal precautions

1. Create a welcoming environment
2. Focus on 2 or 3 main points
3. Use plain language
4. Using resources
5. Check for understanding

Wizowski, Lindsay Connect for success slides May 2014; Ballard, D. & Hill, J. The nurses role in health literacy of patients with cancer CJON, 2016 RNAO best practice guidelines, Facilitating client centered learning, 2012
Start by assuming that anyone can have difficulty understanding health information.

- Simplify forms and provide help
- Convey caring and respect
- Welcome a support person
- Encourage questions
- Easy to follow signage

Create a welcoming environment

Shame-free

Wizowski, Lindsay Connect for success slides May 2014
Speak in plain language

Tissue

Stool

Your test is positive

Wizowski, Lindsay Connect for success slides May 2014
Plain language

Use words that are familiar to the intended audience

Avoid jargon (medical, technical, academic and scientific)

Explain unfamiliar words and acronyms that participants need to know

“arms of a trial”

“placebo”
It’s not dumbing it down! It’s clearing it up!

Plain language makes information accessible.
Can you say it simpler?

1. Divide into groups of pairs
2. Find the stack of cards “Find a simpler way to say it!” on your table
3. Each group takes 5–6 cards each. One person to hold up the cards, the other to translate.
4. The goal is to try to translate as many words as you can into plain language
5. Each person has two minutes per turn
How do you check for understanding?

A) Look for smiling and nodding?

B) Ask “Do you understand?”

C) Ask “Do you have any questions?”

D) Use the Teach-back method!
A provider taught the patient, but did the patient learn?
What is “Teach-Back”?

- Asking patients to repeat in their own words what they need to know or do, in a non-shaming way.

- NOT a test of the patient, but of how well you explained a concept.

- A chance to check for understanding and, if necessary, re-teach the information.

AHRQ, 2001 Report, Making Health Care Safer Wizowski, L., Connect for success slides May 2014
How to use teach back

Teach ‘chunk’ to client

Ask client to teach back

Assess client’s response

Confirm understanding

Clarify or re-teach

Rephrase question

Give feedback

Schillinger et al., 2003 “Closing the loop”
Find what works best for you

- Determine the **critical messages** along the way and especially at discharge

- Give patient a reflective task. How will they apply information to their situation?

- Think of **open-ended** questions

- Put patient at ease. This is not a test. Patient should not feel ashamed if unable to teach-back.

Wizowski, Lindsay Connect for success slides May 2014
How do you confirm understanding?
# Teach-back – Confirming Understanding

<table>
<thead>
<tr>
<th>Ineffective</th>
<th>Ambiguous</th>
<th>OK?</th>
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<tr>
<td></td>
<td></td>
<td>All right?</td>
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<tr>
<td>Less effective</td>
<td>Closed ended</td>
<td>Do you understand?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Do you have any questions?</td>
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<tr>
<td></td>
<td></td>
<td>Does this make sense?</td>
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<tr>
<td></td>
<td></td>
<td><em>Are you using your inhaler?</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Are you sure you’re using it right?</em></td>
</tr>
<tr>
<td>Effective</td>
<td>Open ended</td>
<td>What questions do you have?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What parts of this are hard to understand?</td>
</tr>
<tr>
<td>Most effective</td>
<td>Teach back</td>
<td>To be sure I explained this clearly, could you tell me what you are going to do at home?</td>
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<td></td>
<td></td>
<td><em>Why don’t you show me how you use your inhaler?</em></td>
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</table>

(Kemp et al, 2008)Preferred by patients

- Teach back
- Confirming Understanding
Follow teach-back with:

• How confident are you that you will be able to do this at home?

1  2  3  4  5  6  7  8  9  10
Not confident at all  Very confident

• What questions do you have?
Let’s give it a try!

Check for Understanding

Client recalls and comprehends

Nurse assesses client recall, comprehension and/or skill

Nurse clarifies and tailors explanation and/or demonstration

Nurse reassesses client recall, comprehension and/or skill

Nurse explains or demonstrates new concept and/or skill

“This is what I heard.”

“This is what I meant.”
Role Play Activity

1. Each person take one scenario/topic from the teach-back scenarios.
2. Partner with a person who has a different scenario.
3. Each person has five minutes to review their scenario and to teach the content from scenario to their partner.
4. Confirm understanding using the teach-back method!
L.E.A.R.N.S Model

Strengthen self-management

Patient/family’s skills and abilities

Plain language

Easy to read materials

Welcoming environment

Realistic expectations

Health Literacy

Wizowski, Lindsay Connect for success slides May 2014
Key Communication Strategies

- Warm Greeting
- Eye Contact
- Listen
- Use Plain, Non–medical Language
- Slow Down
- Limit Content
Key Communication Strategies

- Show How It’s Done
- Use Teach–Back
- Repeat Key Points
- Use Graphics
- Invite Patient Participation
- Encourage Questions
Take home messages

- Meet the patient *where they are*

- Don’t judge a book by its cover/assume they know – use *universal precautions*

- *Partner* with your patient/families/caregivers

- *Your* effectiveness as an educator depends on *your* skills/tools used to educate

- Success – *defined* by the patient
Thank You!

What key points will you take away?

What questions do you have for us?
References


References


Wizowski, L PPT Slides: Health literacy and research communication, April 2016.