



Usability Testing of an Online Self-Management Program for Adolescents with Cancer

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Outline

1. Review need for novel interventions for young people with cancer

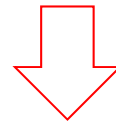
2. Opportunities for eHealth and mHealth in the adolescent sphere

3. *“Teens Taking Charge: Managing Cancer Online”* Program

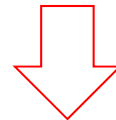
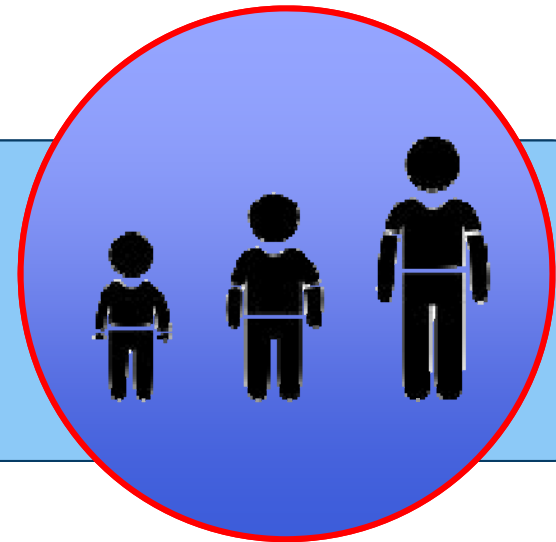
4. Opportunities and challenges related to eHealth and mHealth

Background to the problem

Cancer can negatively impact quality of life



Adolescents expected to assume greater responsibility for managing their illness and its symptoms



Adherence to self-management activities is less than optimal

Background to the problem

- Greater self-management might:
 1. Diminish illness exacerbations and adverse health outcomes
 2. Promote successful transition

Adolescents with cancer face an accessibility to care dilemma
Lack of high-quality self-management programs, geographic/social isolation etc.

eHealth, mHealth and Young People

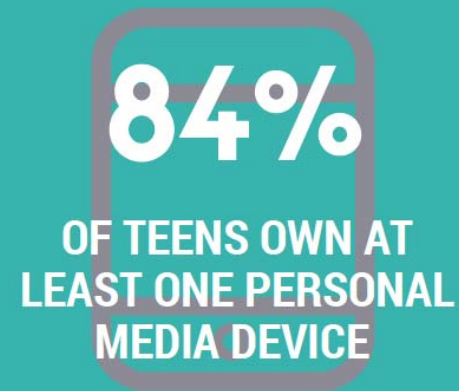
Teen Internet & Smartphone Use



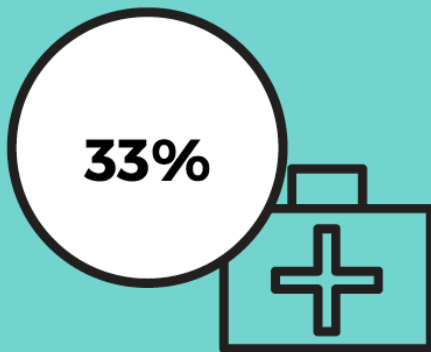
9/10 TEENS ARE WIRED



USE THE INTERNET DAILY

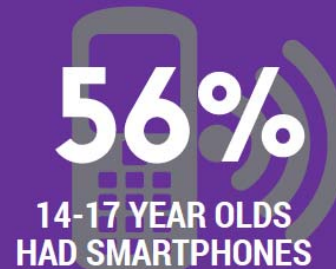


84%
OF TEENS OWN AT
LEAST ONE PERSONAL
MEDIA DEVICE



33%
USE INTERNET TO
ACCESS HEALTH-
RELATED
INFORMATION

IN 2012...



56%
14-17 YEAR OLDS
HAD SMARTPHONES



72%
18-24 YEAR OLDS
HAD SMARTPHONES

(Pew Foundation 2010; e-Marketer Digital Intelligence, 2012)

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“Why don’t you put all that stuff away, and go watch some good old-fashioned TV?”

Teens Taking Charge—Cancer: Managing Cancer Online

Development and Testing of an Online Cancer Self-
management Intervention

Internet-based self-management programs

- Based on effective face-to-face interventions (cognitive-behavioral therapies)
- Highly structured
- Self-guided or partially self-guided (coach)
- Personalized and tailored to user
- Interactive (quizzes, goal setting, discussion boards etc.)
- Makes extensive use of graphics, animations, audio or video clips (peer role modeling)
- Provides follow-up and feedback (e.g., decision-making support through emails)

Ritterband et al., 2003

Potential benefits

- ✓ Reduce inconvenience of scheduling appointments, missing work/school, travel
- ✓ Reduce barrier of distance/proximity to skilled professionals/multidisciplinary treatment programs
- ✓ May increase patient willingness to seek help
- ✓ Quickly disseminate educational and treatment information
- ✓ Reduce time and costs of treatment
- ✓ May improve patient compliance

Review of cancer websites

Objective

- To assess the quality and content of Internet information about cancer from the perspectives of AWC, their parents and HCPs.

Methods

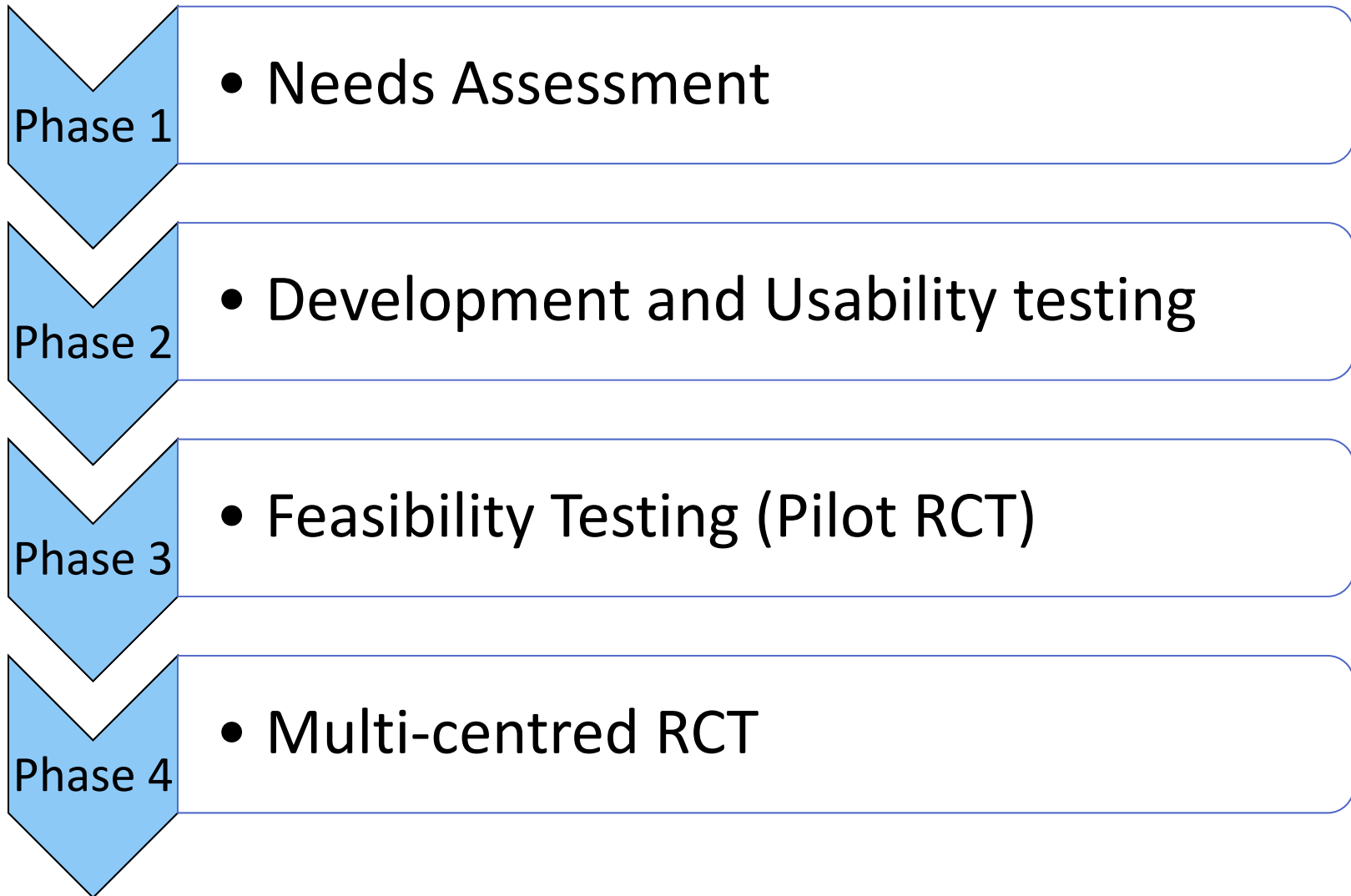
- Searched 6 search engines using key words in pediatric cancer
- Assessed content on: Quality of information, completeness, accuracy, readability, cultural sensitivity and desirability

Results



- Majority of websites targeted parents; **only 4 targeted AWC**
- **Completeness:** moderate completeness
- **Accuracy:** high accuracy
- **Readability:** very difficult to read (SMOG = 11.87; Flesch = 57.44)
- **Cultural sensitivity:** adequately culturally sensitive
- **Desirability:** low desirability

Steps in development and evaluation



Phase 1: Self-management needs assessment

Theme	Subthemes
Disease knowledge & Cancer-care skills	<ul style="list-style-type: none">• Knowledge of the disease• Knowledge of treatments, therapies and procedures• Practical skills to manage cancer
Knowledge and skills to support effective transition to adult care	<ul style="list-style-type: none">• Knowledge of adult care and transition process• Skills supporting self-advocacy and communication with health care team• Knowledge of late effects to support survivorship
Delivery of AWC-accessible healthcare services	<ul style="list-style-type: none">• Developmentally appropriate services and resources• Up-to-date, trustworthy information, easily accessible
Supports for AWC	<ul style="list-style-type: none">• Body image and lifestyle information• Connection with other AWC• Information about available resources and financial support

Phase 2A: Development of Program

“Teens Taking Charge: Managing Cancer Online” Program

- Multi-
pro



TAKE CHARGE CANCER

Français Parents Ask an Expert

SESSIONS

- Introduction
- 1. About cancer
- 2. Understanding diagnosis
- 3. Cancer medications
- 4. Cancer treatments and support therapies
- 5. The health care team
- 6. Communication
- 7. Managing your symptoms
- 8. Managing stress and emotions
- 9. Relaxation and distraction
- 10. Self-monitoring and supports
- 11. Your lifestyle
- 12. After cancer

Taking Charge: Cancer

00:00 / 02:37

Hear stories and get advice from youth cancer patients

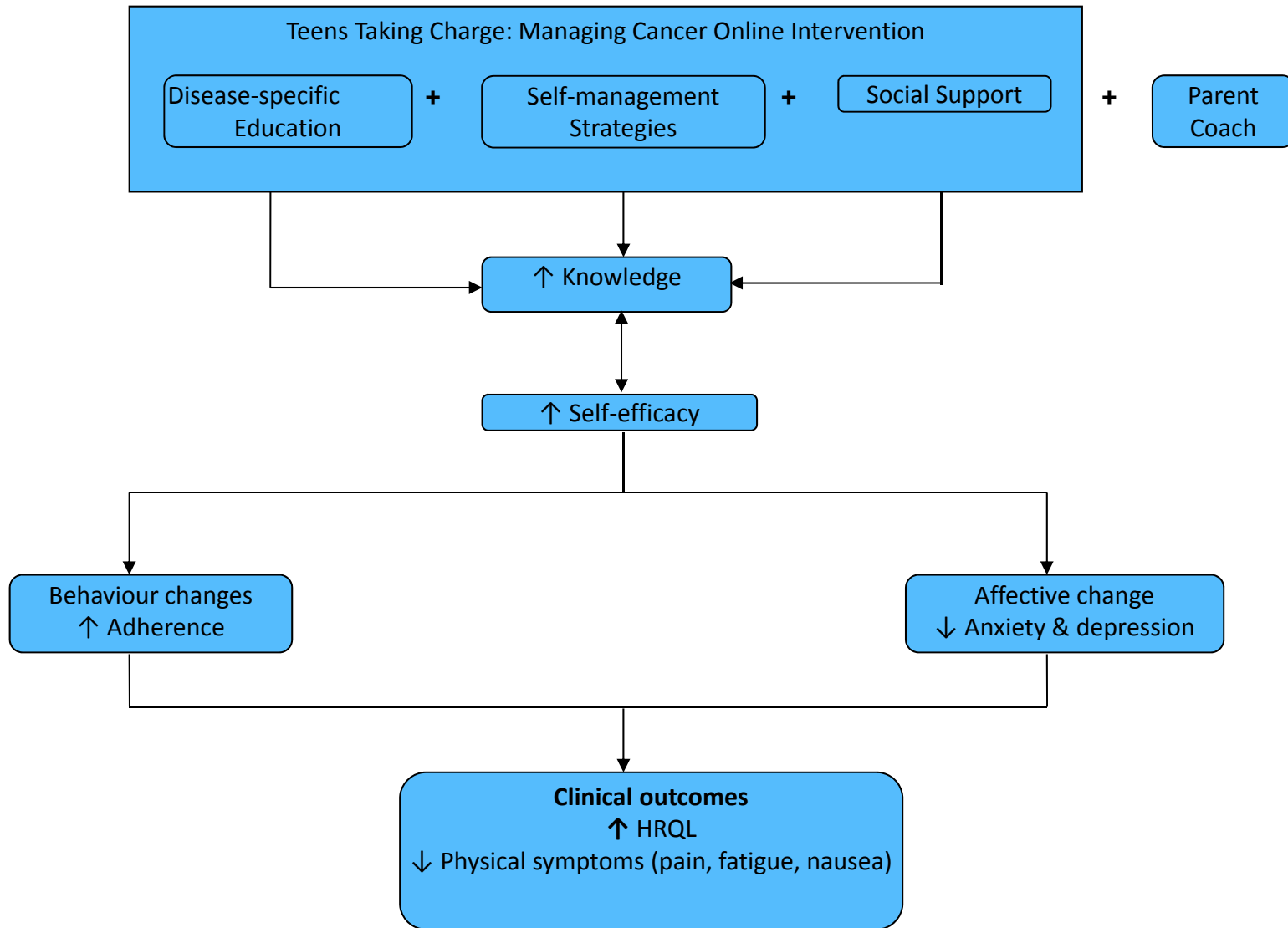
Learn how chemo works

"Going on my own to my appointments, I was taking charge of my life"

- Bethany

- 12 i
- 2 m
- Hea
- Eng

Proposed mechanism of action



Disease-specific education

SESSIONS

- Introduction
- 1. About cancer
 - What causes cancer?
 - Types of cancer in young people
 - How will my cancer affect me now?
 - Do all cancers need treatment?
 - What you have learned
 - What is cancer?**
- 2. Understanding diagnosis
- 3. Cancer medications
- 4. Cancer treatments and support therapies
- 5. The health care team
- 6. Communication
- 7. Managing your symptoms
- 8. Managing stress and emotions
- 9. Relaxation and distraction
- 10. Self-monitoring and supports
- 11. Your lifestyle

What is cancer?

Cancer is not just one disease. There are over 100 different types of cancer, each with different names, effects, and treatments. Even though each type of cancer is different, there are some basic things that are similar to most cancers.

To understand more about cancer, you first need to understand a bit about cells.

What are cells?

Cells are the building blocks of the body. They are very small and can only be seen under a microscope. There are billions of cells in an adult human body, but not every cell is the same. There are hundreds of different kinds of cells in the body and each has a different job. For example, bone cells are different from skin cells, which are different again from muscle cells. The cells work together to form organs such as the heart, brain, or intestines.

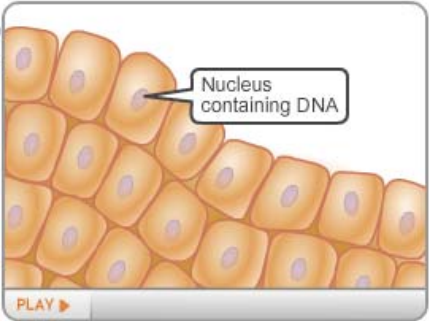
Even though cells do different jobs in our body, they still have some things in common. Each cell has something called a nucleus. This contains DNA. The DNA contains genes, which are like instructions for our cells. Genes tell cells what to do and how and when to do it. Genes tell the cells when to reproduce (make copies of themselves) and when to die. If a cell is damaged, instructions in the genes tell the cell how to repair itself or, if it is too damaged, that it is time for the cell to die.

How do cells reproduce?

Cells reproduce through a process called cell division. In cell division, the cell copies all its DNA and then divides into two identical cells. Normally, cells only reproduce to replace cells that have died or to make more cells when your body is growing. This way, your body carefully regulates how many cells are in your body.

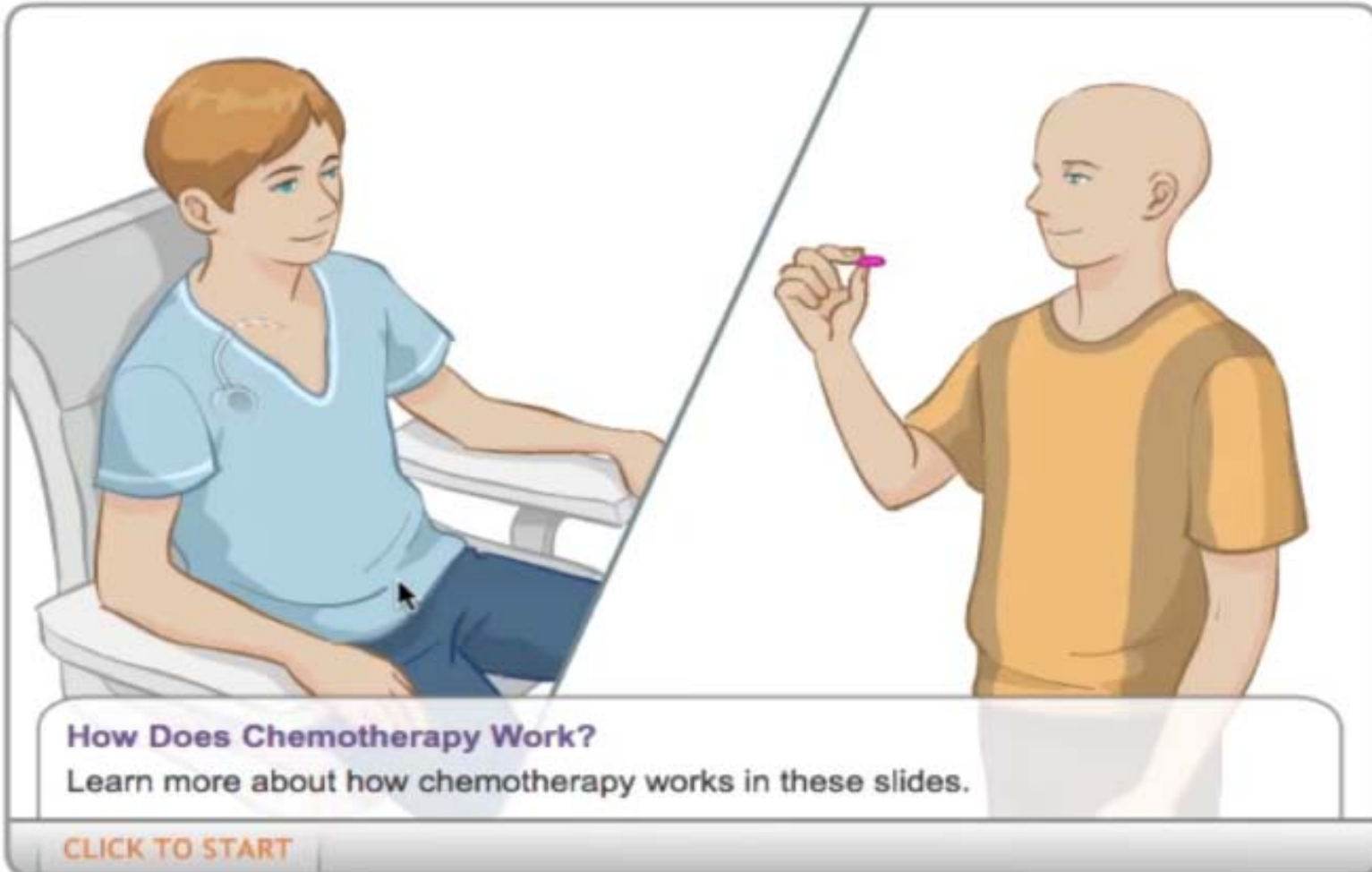
Different types of cells reproduce at different rates. For example, cells in your mouth and the lining of your stomach and intestines live a short time and reproduce very often. Cells in your brain and spinal cord, called neurons, live a long time. In adults they almost never reproduce.

Normal Cells Dividing



The diagram shows a cluster of orange, rounded cells. One cell in the center has a purple nucleus. A callout box points to the nucleus with the text "Nucleus containing DNA". At the bottom left of the diagram, there is a "PLAY" button with a right-pointing arrow.

Click-through educational animations



Managing negative emotions

SESSIONS

Introduction

1. About cancer

2. Understanding diagnosis

3. Cancer medications

4. Cancer treatments and support therapies

5. The health care team

6. Communication

7. Managing your symptoms

8. Managing stress and emotions

Cancer and emotions

Stress and anxiety

What causes stress and anxiety?

Recognizing stress and anxiety

Dealing with stress and anxiety

Stress and thinking

Changing negative thoughts

Feeling good about yourself

Coping with a life-limiting illness

Stress and anxiety

Many things in life can cause stress and anxiety. Cancer is one of them. The first step in managing stress and anxiety is to understand what they are.

What is stress?

Stress is a normal part of life and happens to everyone. It is your body's physical and emotional reaction to something that bothers you. Stress is what you feel when you react to pressure. When you feel overwhelmed, like you have lost control or are unsure of how to cope with the demands placed on you, that's also stress.

- A little stress can be a good thing! It can motivate you to do your best. It can help you stay focused and alert. Stress can motivate you to study for your test when you would rather watch TV or hang out with your friends or it can help you perform in a sports game. Some people think of this as good stress.
- When the going gets too tough and the situation is more than you can handle, stress can affect both your physical (body) and emotional (mind) well-being. This is known as bad stress.

What is anxiety?

Anxiety (say ang-ZY-uh-tee) is a specific kind of reaction to stress and is common in teens with cancer. It is a feeling of fear, dread, worry, uneasiness, or nervousness. It can also show itself in physical ways such as nausea (feeling queasy) or tummy ache. Sometimes anxiety can make it hard to sleep.



Managing symptoms



Belly Breathing



BELLY BREATHING
A step-by-step guide.

[CLICK TO START](#)

Physical modalities—therapeutic yoga



Savasana pose



Nose-to-knee pose

Phase 2B: Usability Testing

Objective

- Assess: (1) ease of use, (2) efficiency, (3) errors, and (4) participants' satisfaction with web-based program

Methods

- A qualitative usability testing approach with semi-structured, audio taped interviews and observation by a trained observer

Results

- Usability testing uncovered issues that led to refinements in the online program.
- Overall, participants found information presented on the website to be appropriate, credible, and relevant to their experiences.
 - *Design*: enjoyed style and colors; easy to navigate
 - *Content*: clear and easy to understand; trustworthy
 - *Relevance*: very relevant to experience; social support
- Participants reported the program would have been extremely helpful when they were first diagnosed with cancer.

Phase 3: Feasibility Testing (pilot-RCT design)

Investigators: Jennifer Stinson (PI), Abha Gupta, Amy Lee Chong, Vicky Breakey, Bruce Dick, France Dupuis, Donna Johnston, Caroline Laverdiere, Sylvie LeMay, Carol Portwine, Charles Victor; **Funding:** CIHR

A Pilot Randomized Controlled Trial of an Online Self-Management and Transitional Care Program for Youth with Cancer

Objective

- To evaluate feasibility of implementing the “*Teens Taking Charge: Managing Cancer Online*” Internet intervention and establish preliminary effect estimates for impact on knowledge, readiness to transition to adult health care, symptom burden, and HRQL

Methods

- Feasibility Pilot RCT
- 120 participants (60 English-speaking and 60 French-speaking) between the ages of 12 and 18 with a cancer diagnosis
- Study period: 12 weeks

Sites

Hospital for Sick Children

McMaster Children’s Hospital

Children’s Hospital of Eastern Ontario

St. Justine

Opportunities for eHealth and mHealth

- Internet interventions show great promise as a mode of delivering tailored self-management interventions to improve health outcomes
- Young people are early adopters of this technology and it is an integral part of their lives
- Dramatically increases the reach (accessibility)
- Scalability (common components)
- First step in “stepped” care approach

Challenges to development and implementation

- Cost to develop
- Lack of guidelines for development and evaluation
- Sustainability
- Essential components (dismantling studies)
- Self-guided or minimal therapist guidance (funding model for this)
- Intra-operability
- Protection of PHI
- Integration within HER
- Sustaining engagement of adolescents overtime

Acknowledgements

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Thank you. Questions?