About CAPE

• The Cancer Advocacy & Patient Education (CAPE) initiative aims to create a web-based library of best-practice information that providers in a specific cancer space can give to their patients and caregivers at each point of interaction.
Mission Statement

OUR MISSION
To improve patient experience from cancer diagnosis, treatment, through survivorship/ end of life care with personalized education

OUR VISION
Engage, inform, and empower newly diagnosed cancer patients utilizing a predetermined quality-of-life model to reduce distress and improve patient experience between diagnosis and first treatment and then through their patient journey
Main Objectives

• To make the time between diagnosis and treatment as productive and meaningful as possible for patients with cancer and their caregivers through interactivity and education to meet patients’ psychosocial needs

• Improve communication and shared decision-making around diagnosis, testing, and treatment between the patient (and caregiver) and their cancer treatment team

• To ensure patient understanding of their diagnostic and treatment journey individualized to their disease state
Benefits of Digital/Social Prescribing

• The concept of digital prescribing in the care of cancer patients is communication, forming relationships, and providing information/resources that support and empower patients through their cancer journey.

• Through communication and assessment, healthcare providers and navigators assist patients and caregivers to identify areas of focus or need, such as taking an active role in decision-making, tips for self-care, and dealing with financial concerns.

• Social prescribing is essential to the clinical toolkit of healthcare providers and navigators to tackle wider social determinants of ill health by focusing on what matters to patients as opposed to what’s the matter with the patients.

• Healthcare providers and navigators would utilize the digital tool to select the relevant modules that may relate to a patient, curate relevant resources, and print/e-mail them to the patient.
Foundational Work

Building the coalition

Quality-of-life framework identified

Literature search

- CLL Example: A total of 5393 articles were screened, 873 full text publications were reviewed, and 59 relevant articles were identified.
- At the request of the advisory board, an additional 236 articles were screened, 64 full text publications were reviewed, and 16 articles were identified.

Identifying the modules

- Developing modules based on the domains that represent the most prominent areas of concern for CLL oncology patients and their caregivers

Narrowing the resources
Quality-of-Life Model Applied to CLL Cancer


Patients with CLL Cancer

- Physical well-being and symptoms
- Psychological well-being
- Social well-being
- Spiritual well-being

Family Caregiver

- Physical well-being and symptoms
- Psychological well-being
- Social well-being
- Spiritual well-being
Identifying Patient Facing Materials

1. Identify evidence-based patient materials
2. Identify validated patient assessment tools
3. Types of Educational materials: Videos, apps, handouts/printed material, websites, resource/support tools
Evidenced Based Practice (EBP):

“EBP is a paradigm and life-long problem-solving approach to clinical decision-making that involves the conscientious use of the best available evidence with one’s own clinical expertise and patient values and preferences to improve outcomes for individuals, groups, communities, and systems” (Staffer et al, 2013)
Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."

https://www.accc-cancer.org/home/learn/Patient-Centered-Care/health-literacy

CLCL CAPE Modules

1. First 90 Days
2. Understanding Your Diagnosis
3. Understanding Your Treatment
4. Living with CLL
5. Understanding the Financial Implications
6. Self-Care & Coping
7. Caregiver & Family
Chronic Lymphocytic Leukemia

First 90 Days
Understanding your Diagnosis
Understanding your Treatment
Living with CLL
Understanding the Financial Implications
Self-Care & Coping
Caregiver & Family

Get Results
Your Selection
Selected health topics will appear here
GET RESULTS
Integration of CAPE into Workflow

Start at intake and build upon education throughout trajectory

Newly diagnosed patient waiting for appointment

Provide digital prescription at each step of cancer journey
Preliminary Insights - CAPE Lung

Implementation needs to be designed locally to adapt to navigation model/workflow

Patient population characteristics (Demographics, Tech-literacy, Health-literacy, Acuity)

Clinical workflows

Patients were more likely to remember going through the CAPE materials when they were introduced to them in clinical space with their Thoracic Nurse Navigator

Patients are sometimes overwhelmed by the robust nature of some of the materials or were overwhelmed with their diagnosis in general and did not want more information. Caregiver voiced need for educational materials.

There were times where patients did not understand everything in the materials and needed to consult their clinical team

Opportunity for various stakeholders to use CAPE - Social work, health educators, lay navigators, etc.
Cancer Advocacy & Patient Education (CAPE)
Perspectives from Patients & Providers

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BACKGROUND
The Cancer Advocacy & Patient Education (CAPE) Lung Cancer Initiative is a web-based patient education platform that warehouses best-practice resources and educational materials. Created by the Academy of Oncology Nurse and Patient Navigators (AONN+), CAPE is designed to improve patient education and enhance patient care. CAPE permits navigators and other cancer care team members to send patients “e-prescriptions” that contain personalized education, customized for each patient’s circumstances and treatment status. AONN+, in collaboration with Fox Chase Cancer Center (FCCC), conducted a pilot study to evaluate patient and healthcare provider feedback regarding the CAPE resources and to assess CAPE implementation at 4 cancer centers (2 urban medical centers and 2 rural medical facilities).

OBJECTIVES
The pilot study was commissioned with 2 objectives:
● Could the participants identify at least 2 benefits of CAPE?
● Could the participants identify at least 2 possible barriers to CAPE implementation?

METHODS
Fifty-three English-speaking patients with non-small cell lung cancer were enrolled in the CAPE program within 12 weeks of their diagnosis. Participants completed a baseline survey, received personalized e-prescriptions (printed or via e-mail), and completed a 1-month follow-up survey over the phone with the FCCC research team about their experience with CAPE. Implementation strategies were site-specific and tailored to meet the needs of each site’s clinical workflows. The FCCC research team conducted an analysis of the perceived usefulness and educational value of CAPE across the diverse sites, and conducted interviews with staff members using the Consolidated Framework for Implementation Research to better understand the differences between sites and guide future dissemination.

RESULTS
Of the 53 patients enrolled, 16 patients reported viewing the CAPE materials, and the majority of those patients felt that CAPE helped them understand their diagnosis and treatment options. The patients who recalled receiving CAPE materials felt that the resources equipped them to talk with their doctor. Notably, the patients were more likely to remember receiving the materials when enrollment was in-person with their navigator, which was how the study was implemented at the urban sites. As with many technology-based patient resources, several factors influenced effective CAPE implementation: overwhelmed patients, short-staffing, low technology literacy, and provider handoffs, which varied between the rural and urban sites. Overall, providers felt that CAPE is a great resource for patients, that it fit within their patient workflow practices, and matched patient educational needs.

CONCLUSIONS
The majority of the patients who used the CAPE resources viewed it positively. However, some patients felt overwhelmed by the diagnosis or other external factors, so their ability to use or absorb the information provided through CAPE was diminished. Based on these findings, AONN+ believes there are strategic points in the patient care process at which CAPE could be introduced into the treatment trajectory. A one-size-fits-all approach to implementation timing may not be optimal. The insights from these preliminary findings will guide future implementation and dissemination of CAPE.
NOW AVAILABLE!

CLL CAPE
Cancer Advocacy & Patient Education

to
ENGAGE, INFORM, AND EMPOWER PATIENTS
"Because every hero needs a CAPE"

A comprehensive online library of information for oncology professionals to disseminate to patients at each point of interaction.

The CAPE Resource Center for Chronic Lymphocytic Leukemia is now available. Register today!
Coming Soon
Access CAPE

https://aonnonline.org

Overview of CAPE

The objective of the Cancer Advocacy & Patient Education (CAPE) initiative is to create a web-based library of best practice information that providers in the cancer space can give to their patients and caregivers at each point of interaction. The objectives are:

- To make the time between diagnosis and treatment as productive and meaningful as possible through interactivity and education to meet patients’ psychosocial needs
- To improve communication and shared decision-making around diagnosis, testing, and treatment between the patient, caregiver, and the cancer treatment team
- To ensure patient understanding of their diagnostic and treatment journey, individualized to their disease state

The CAPE program’s web-based platform will allow navigators and healthcare providers to deliver a personalized digital prescription to cancer patients and caregivers of clinician-recommended best practices based on their physical, psychological, social, and spiritual well-being needs to make the time between diagnosis and treatment as productive and meaningful as possible. By providing education, improving communication, shared decision-making, and ensuring patient understanding through interactivity, and personal tailoring of the CAPE program, navigators and healthcare providers can engage, inform, and empower newly diagnosed cancer patients, resulting in reduced distress and an improved patient experience. The education platform will assist the identification of interventions or tools to improve quality of life throughout the disease process.

Please use the icons below to access each platform.
Thank you