

Integrative Oncology Patient Education: Creating Resources For Supportive Care

Powered by *KNOWoncology.org*, *BCCT.ngo*, and *OICC.ca*

Jen Green, ND, FABNO; Heather Wright, ND, FABNO; Dugald Seely ND, FABNO
Casey Martell, ND, MBA, FABNO; Laura Pole, RN, MSN, OCNS
Ellen McDonnell ND; Nancy Hepp, MS

Introduction

Studies report that 40-60% of people with cancer have unmet needs during their treatment.¹ These needs fall into 5 categories: practical, familial, emotional, spiritual and physical.² Need for information is a practical need that may also touch on other categories. Most conventional oncology centers do not include comprehensive integrative oncology information. Often, patients looking to support their wellbeing will gather information from online sources, many with questionable credibility. In cancer treatment settings, physicians, out of concern for safety or lack of awareness of the evidence base of integrative oncology, may advise patients not to use complementary therapies.

To address the resulting information needs, a group of integrative oncology providers and researchers are collaborating to develop patient education handouts. These handouts can be shared during point of care by providers and advocates, and accessed online. Using *KNOWoncology.org* in addition to *PubMed.gov*, the group synthesized data on initial topics relevant to cancer survivors. The example titled "Wellness During Tamoxifen Treatment" is presented in this poster.

Background

Beyond Conventional Cancer Therapies or BCCT (<https://bcct.ngo>) is a website dedicated to patient and clinician education providing expert level synthesis of up-to-date and evidence-informed online information along with integrative cancer care resources.

Knowledge in Naturopathic Oncology (<https://www.knowoncology.org/>) is a research database that contains searchable summaries of human studies relevant to integrative oncology published between 2010 and 2018. *KNOW* provides clinicians with efficient access to data and facilitates collaboration between providers, researchers and organizations.

The Ottawa Integrative Cancer Centre (<http://www.oicc.ca>) provides multidisciplinary supportive cancer care and is active in the conduct of research in the field of integrative oncology. The OICC is committed to serving as a community resource via education, delivery of clinical care, and research regarding the evidence and benefits achievable through evidence-informed integrative cancer care.

KNOW, in collaboration with BCCT and OICC, invited multidisciplinary providers to create evidence-informed patient educational materials. The group consists of naturopathic doctors, medical doctors, researchers, nurses, nutritionists, and patient advocates. This group reviewed the literature and developed synthesis information in language directed to the patient culminating in brief, easy to read, and referenced educational brochures. Work thus far has focused on several topics related to breast cancer as well as broader topics related to nutrition, stress reduction, social isolation, promising natural therapies and the management of side effects of cancer treatments.

Bibliography

¹ Capelan M, Battisti NML, McLoughlin A, Maidens V, Snuggs N, Slyk P, Peckitt C, Ring A. The prevalence of unmet needs in 625 women living beyond a diagnosis of early breast cancer. *Br J Cancer*. 2017 Oct 10;117(8):1113-1120.

² Okediji PT, Salako O, Fatiregun OO. Pattern and Predictors of Unmet Supportive Care Needs in Cancer Patients. *Cureus*. 2017; 9(5): e1234.

³ Online Utility. Readability Calculator. Available at http://www.online-utility.org/english/readability_test_and_improve.jsp. Accessed on Sep 27 2019.

Methodology

KNOW search methodology used the PubMed® dietary supplement subset as its initial search criterion and customized this to include additional natural therapy terms identified by naturopathic doctors. Using the Ovid® platform, *KNOW* searched Ovid MEDLINE®, Ovid MEDLINE In-Process & Other Non-Indexed Citations and Embase Classic+Embase from inception to December 2018. Relevant studies (English language, human level, all cancer types) were parallel screened for inclusion criteria, and data were extracted, tagged, peer-reviewed and uploaded to *KNOW*. In addition to the use of the *KNOW* database, a scoping review on natural interventions in combination with tamoxifen for breast cancer survivors was conducted as well as ad hoc literature review for developing patient educational materials.

Patient handouts are designed with these criteria:

- Write for patients as the primary target audience.
- Focus on healthful behaviors and natural therapies having evidence to support benefits for overall wellness, side effect management, or other factors relevant to cancer and complementary medicine.
- Choose natural therapies by consensus based on review of evidence for safety and efficacy, prioritizing those that have a high interest for public use, and those that may be controversial.
- Use language that is supportive, encouraging, honest, and accurate.
- Target a manageable length of one to two pages in trifold format.
- Include references for primary, secondary and tertiary literature in the form of hyperlinks.
- Compose at a 10th grade or lower reading level whenever possible. Flesch Kincaid, SMOG (Simple Measure of Gobbledygook) and ARI (Automated Readability Index) were used.³

KNOW

Knowledge in Naturopathic Oncology Website



Beyond Conventional Cancer Therapies

OncANP

KNOWoncology.org created by OncANP



OICC

OTTAWA INTEGRATIVE
CANCER CENTRE
FOUNDATION

Results

Shown below is the tri-fold patient handout "Wellness During Tamoxifen Treatment."

The report from three validated measures of readability³:

| | |
|-----------------------------------|-------|
| Flesch Kincaid Grade level | 10.90 |
| ARI (Automated Readability Index) | 10.44 |
| SMOG | 12.30 |

Conclusion

Patient education handouts can be developed collaboratively by multidisciplinary providers who seek a meaningful way to inform patients about integrative options in cancer care. To facilitate best patient education, the *KNOW*, BCCT, and OICC teams along with a group of oncology providers collaborated to create evidence-informed patient information handouts. The intent of these handouts is that they be made available to patients and clinicians wherever care is delivered.

Discussion

An initial collaboration for creating patient education handouts sought a replicable approach.

The primary purpose was to create free patient education materials that promote patient engagement in wellness and self-care using evidence-informed natural therapies. Available in electronic format, and as tri-fold hard copy, brochures may fill information gaps in the area of integrative oncology. The handouts also direct patients to more in depth resources for guidance on the BCCT.ngo, OICC.ca, and OncANP.org websites. It is our hope that providers will review these brochures one-on-one with patients. The brochures will also be available online for viewing and printing. The authors intend to collect further input from patients, incorporate additional information relevant to integrative oncology, and continue to improve readability through peer review. Patient education materials introduce healthful concepts for families affected by cancer as well as help reduce or eliminate focus on non-credible approaches. These resources are intended to synthesize patient empowering information and reduce some of the uncertainty or anxiety provoked by the sheer volume of available information. Additionally, this project may bridge gaps for patients who do not have ready access to integrative providers.

Download this and other patient education brochures from <https://bcct.ngo/patient-brochures>



The brochure is a tri-fold document. The top section is titled "TIPS TO BE PROACTIVE" and lists "FOLLOW THE 7 HEALING PRACTICES" with icons for: Exploring What Matters Now, Sharing Love & Support, Creating a Healthy Environment, Moving More, Managing Stress, Seeing Well, and Exploring What Matters Now. The middle section is titled "WELLNESS DURING TAMOXIFEN TREATMENT" and "INTEGRATIVE ONCOLOGY APPROACHES", featuring an image of a bowl of green soup. The bottom section is titled "REFERENCES" and lists authors/editors: Jen Green, ND, FABNO; Gwen Stritter, MD; Heather Wright, ND, FABNO; Casey Martell, ND, MBA, FABNO; Dugald Seely ND, MSc; Ellen McDonnell, ND; Laura Pole, RN, MSN, OCNS. It also includes logos for OncANP, KNOW, and OICC, and a version number of 9/24/19.

The brochure is a tri-fold document. The top section is titled "TAMOXIFEN AND INTEGRATIVE CARE" and discusses the importance of tamoxifen and how integrative approaches can help manage side effects. The middle section is titled "NATURAL THERAPIES" and lists several natural approaches for hot flashes, including acupuncture, melatonin, CoQ10, vitamin C, and black cohosh. The bottom section is titled "NATURAL APPROACHES FOR HOT FLASHES" and lists several natural approaches for hot flashes, including acupuncture, melatonin, CoQ10, vitamin C, and black cohosh. It also includes a "PRECAUTIONS" section and a version number of 9/24/19.