Improving Access to Patient Education: an Audit of Extant Educational Materials

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Abstract

Health information exchange between provider and patient, along with patient participation in their care (self-management), can lead to improved health outcomes. A step towards achieving better outcomes is the systematic provision of education materials to patients and caregivers throughout the cancer trajectory. An audit of patient education (PE) materials was conducted at a cancer center to identify content gaps and determine areas for future development. The PE audit was conducted in all outpatient clinics (13) and clinic-specific PE materials were identified, reviewed, and categorized by cancer type and under the following topics: About Cancer/Disease, Medical Tests and Imaging, Treatment, Symptom Management, Rehabilitation/Survivorship, General Wellbeing, Medical Device Care, Practical and Other. Four hundred forty-seven PE materials were included in the audit. Totals for each topic were summed and analyzed for education development opportunities. Results varied based on clinic and cancer type. Majority of the materials were found in the following clinics: Hematology (75), Genitourinary (74), and Gastrointestinal (57). The most common information topics were treatment (277), about cancer/disease (134), and symptom management (120). When broken down by cancer type, it was clear that while the collection of PE materials is well established for some diagnoses (e.g., 28 prostate cancer materials), there is a significant dearth in materials for others (e.g., 0 penile cancer materials). Audit results will be used to identify opportunities for future education material development. Determining cancer-specific information gaps is important in achieving equal information access for patients and caregivers, regardless of cancer diagnosis.

Keywords Information access · Information exchange · Information gaps · Patient education · Patient education material · Audit · Cancer patient · Cancer · Cancer trajectory · Cancer center

Introduction

Despite the availability of online information, patients and caregivers obtain most of their health information from health care providers [1]. Health care providers give information to patients and caregivers in verbal and/or written forms (hard or soft copy) and can supplement information by providing links to patient education (PE) videos and/or online learning modules. Having access to materials that augment learning gives patients the option to become more knowledgeable about their diagnosis, treatment options, and other pertinent information. Additionally, the provision of PE materials has shown to be effective in medication compliance [2]. Cancer patients who had access to pertinent PE materials report improvements in quality of life, treatment adherence, psychological wellbeing, pain management, daily functioning, and satisfaction with decision-making [3].
Giving patients PE materials that they need during their cancer journey is an important aspect of providing well-rounded care. After a cancer diagnosis and throughout the cancer journey, patients and caregivers can feel mixed emotions. When receiving shocking and unexpected news, such as a cancer diagnosis or a suboptimal response to cancer treatment, a person’s ability to comprehend health information diminishes [4]. Having access to disease-specific PE materials can give patients and caregivers a sense of control during confusing and uncertain times throughout the cancer trajectory [3]. Access to PE is especially relevant within the cancer context; most care is delivered in the outpatient setting, where individuals must become more involved with their care at home as compared to inpatients [5].

Information retention is another challenge, with anywhere from 40 to 80% of health information forgotten almost immediately after a medical appointment [6]. In addition, approximately 50% of information shared by health care providers is incorrectly recalled by patients and caregivers [6, 7]. When asked to recall medical instructions without supplementing patients with PE materials during a simulated medical appointment, patient knowledge significantly decreased fifteen minutes after the simulation ended [8]. Older adults could only correctly recall about half of the information provided to them [8]. Individuals with adequate and low health literacy also had trouble correctly remembering this information [8]. The combination of these factors demonstrates that it is critical that patients are given health information for continuous learning, to augment teaching during clinical appointments and to serve as useful reminders regarding current and future care.

The exchange of health information between provider and patient, along with patient participation in their care (self-management), can lead to improved health outcomes [9, 10]. A step towards achieving better outcomes is the systematic provision of PE materials to patients and caregivers throughout the cancer trajectory and a critical ingredient to making this happen is ensuring that health care providers have access to the PE materials that they need to provide to patients.

At the cancer center, systems have been established to facilitate health care provider access to PE materials. These materials are available to health care providers through the Digital Education Station (DES), an electronic order system and inventory of educational materials used to distribute to patients, or through the Digital Education Prescription (DEP), a software application that is used by health care providers to access and email educational materials to patients and caregivers. Over the course of several years, the center’s Cancer Education program worked alongside health care providers and clinics to compile inventories of PE materials. These materials were organized into a centralized database for easy access and sharing between health care providers and patients. Hard copies of PE materials are available through the Education Stations, located within clinics and soft copies are available for distribution through the DEP. Materials within these systems are categorized into disease-specific and treatment inventories to make it easy for health care providers to find the information they wish to provide to patients in the context of busy clinical environments.

Through the process of establishing these inventories, the Cancer Education program and health care providers noted major gaps in the availability of materials for some cancer diagnoses, while others seemed to have more comprehensive collections. We sought to explore this disparity in depth to develop plans to remediate it. The aim of this work was to conduct an audit of PE materials at an urban, academic cancer center, to establish priorities for material development toward achieving comprehensive availability of materials across cancer diagnoses.

Methods

Establishing the Inventory

The audit was conducted from May to August 2021. Inventories of existing electronic and paper-based PE materials were compiled into an Excel spreadsheet. All outpatient clinics (13) were included and consisted of the following: Brain Metastases, Breast, Endocrine, Gastrointestinal, Genitourinary, Gynecology, Head and Neck, Hematology, Lung, Ocular, Primary Brain Cancer, Sarcoma, and Skin and Melanoma clinics. Materials included brochures, videos, eLearning modules/online classes, and Web sites. Materials that were included were both internally developed and curated from reputable external organizations (e.g., Canadian Cancer Society). Of note, all PE materials distributed at the cancer center must meet health literacy best practices and are subjected to a quality review prior to being integrated into the PE collection.

Materials were retrieved from the DES, DEP, Resource Centre inventories (paper-based materials located at each outpatient clinic that patients and caregivers can access independently), and the Patient and Family Library (library at the cancer center that contains paper-based and digital educational materials for patients to browse and take home).

Inclusion and Exclusion Criteria

PE materials that were clinic-specific were included in the audit. Materials that were applicable to multiple cancer
types (general materials) were excluded. This was because the purpose of the project was to capture materials that were tailored specifically towards each cancer type. Ideally, this would allow for gaps in PE material numbers to become apparent upon comparing them between different cancer types. General materials included drug fact sheets, smoking cessation information, and COVID-19-related materials. Materials were parsed out by a research assistant and a separate, smaller list of cancer-specific education materials was compiled for analysis. Each material within outpatient clinics was further sorted by cancer type. Material counts were then summed for each outpatient clinic and cancer type. Table 1 presents the breakdown of outpatient clinics and cancer types for each clinic.

Data Analysis

Librarians across the organization reached a consensus regarding the taxonomy of health information categories of all PE materials available at the cancer center (see Table 1). The health information categories were used to determine the content count categories for the audit. However, the medical device care, practical, and other categories were additionally selected because some materials did not fit into the pre-existing health information categories. Determining whether materials exist that cover each stage of this journey was another outcome of this audit.

Results

A total of 447 PE material titles were found to be distributed across the 13 outpatient clinics. The average number of PE materials available ranged between 0 and 77 across outpatient clinics with an average of 34 PE materials per clinic. Depending on the clinic, several cancer types are treated, while others treat a specific type of cancer. PE materials that could not be categorized under one specific category were sorted into a separate category, “Applicable to Several Cancer Types” (ASCT). For example, if the PE material applied to more than one cancer within the clinic or were considered useful materials for all cancer

| Patient education content category | Categorization criteria |
|------------------------------------|-------------------------|
| About Cancer/Disease               | • Describes cancer and non-cancer-related illnesses |
| Medical Tests and Imaging          | • Describes medical tests/procedures |
|                                    | • Describes imaging tests/procedures |
| Treatment                          | • Describes any cancer treatments |
|                                    | • Describes any non-cancer treatments |
| Symptom Management                 | • Managing side effects throughout the cancer journey (before, during, and after treatment) |
| Rehabilitation/Survivorship        | • Life after cancer |
|                                    | • Physiotherapy and exercise |
| General Wellbeing                  | • Psychological, social, spiritual, and emotional wellbeing support |
|                                    | • Links to support materials not included—material must discuss support information directly |
| Medical Device Care                | • Disassembling and reassembling devices |
|                                    | • Cleaning devices |
| Practical                          | • Diet and exercise |
|                                    | • Directions and accessibility |
|                                    | • Patient logs/notebook entries |
|                                    | • Managing everyday life before, during, and after treatments |
|                                    | • Personal care |
|                                    | • Prosthesis, hair accessories, personal products |
|                                    | • Disease prevention |
| Other                              | • Materials containing links to other resources such as Web sites or videos |
|                                    | • Materials about physicians at the cancer center |

Each of the 9 PE content categories with corresponding criteria used by the research assistant for categorization.
Table 2  Results table for outpatient clinics and cancer types that are treated within each clinic

| Clinic                  | Material count | About Cancer/Disease | Medical Tests and Imaging | Treatment | Symptom Management | Rehabilitation/Survivorship | General Wellbeing | Medical Device Care | Practical | Other |
|-------------------------|----------------|----------------------|--------------------------|-----------|--------------------|-----------------------------|-------------------|---------------------|-----------|-------|
| Brain metastases        |                |                      |                          |           |                    |                             |                   |                      |           |       |
| Total                   | 18             | 8                    | 2                        | 13        | 12                 | 1                           | 3                 | 0                   | 2         | 0     |
| Breast                  |                |                      |                          |           |                    |                             |                   |                      |           |       |
| Ductal carcinoma in situ (DCIS) | 1            | 1                    | 0                        | 1         | 0                  | 0                           | 0                 | 0                   | 0         | 0     |
| Invasive breast cancer (no metastasis) | 0            | 0                    | 0                        | 0         | 0                  | 0                           | 0                 | 0                   | 0         | 0     |
| Invasive breast cancer (metastasis) | 1            | 1                    | 1                        | 1         | 1                  | 1                           | 1                 | 0                   | 0         | 0     |
| ASCT (general breast)   | 50             | 12                   | 11                       | 28        | 10                 | 12                          | 13                | 2                   | 8         | 0     |
| Total                   | 52             | 14                   | 12                       | 30        | 11                 | 13                          | 14                | 2                   | 8         | 0     |
| Endocrine               |                |                      |                          |           |                    |                             |                   |                      |           |       |
| Adrenal                 | 1              | 0                    | 0                        | 1         | 1                  | 0                           | 0                 | 0                   | 0         | 0     |
| Parathyroid             | 0              | 0                    | 0                        | 0         | 0                  | 0                           | 0                 | 0                   | 0         | 0     |
| Pituitary               | 2              | 0                    | 0                        | 2         | 1                  | 0                           | 0                 | 0                   | 0         | 0     |
| Thyroid                 | 10             | 2                    | 6                        | 5         | 1                  | 1                           | 1                 | 2                   | 0         | 1     |
| ASCT (general endocrine) | 1              | 0                    | 1                        | 0         | 0                  | 0                           | 0                 | 0                   | 0         | 0     |
| Total                   | 14             | 2                    | 7                        | 8         | 3                  | 1                           | 2                 | 0                   | 1         | 0     |
| Gastrointestinal        |                |                      |                          |           |                    |                             |                   |                      |           |       |
| Ampullary               | 1              | 1                    | 0                        | 1         | 0                  | 0                           | 1                 | 0                   | 0         | 0     |
| Anal                    | 4              | 0                    | 0                        | 2         | 3                  | 0                           | 0                 | 0                   | 0         | 0     |
| Appendix                | 0              | 0                    | 0                        | 0         | 0                  | 0                           | 0                 | 0                   | 0         | 0     |
| Carcinoid               | 4              | 4                    | 1                        | 3         | 2                  | 1                           | 2                 | 0                   | 4         | 0     |
| Colorectal              | 13             | 2                    | 1                        | 5         | 0                  | 1                           | 2                 | 0                   | 3         | 3     |
| Esophageal              | 4              | 1                    | 1                        | 2         | 0                  | 1                           | 1                 | 0                   | 0         | 0     |
| Gall bladder            | 6              | 2                    | 0                        | 6         | 1                  | 0                           | 2                 | 1                   | 0         | 0     |
| Liver                   | 3              | 1                    | 1                        | 3         | 0                  | 1                           | 1                 | 0                   | 0         | 0     |
| Pancreatic              | 7              | 3                    | 2                        | 6         | 2                  | 1                           | 1                 | 0                   | 2         | 0     |
| Stomach                 | 5              | 1                    | 1                        | 2         | 0                  | 1                           | 1                 | 1                   | 0         | 1     |
| ASCT (general gastrointestinal) | 10            | 0                    | 0                        | 7         | 1                  | 0                           | 0                 | 3                   | 3         | 0     |
| Total                   | 57             | 15                   | 7                        | 37        | 9                  | 6                           | 11                | 5                   | 12        | 4     |
| Genitourinary           |                |                      |                          |           |                    |                             |                   |                      |           |       |
| Bladder                 | 16             | 1                    | 2                        | 9         | 1                  | 0                           | 1                 | 6                   | 3         | 0     |
| Kidney                  | 7              | 3                    | 2                        | 5         | 0                  | 0                           | 1                 | 1                   | 2         | 0     |
| Penile                  | 0              | 0                    | 0                        | 0         | 0                  | 0                           | 0                 | 0                   | 0         | 0     |
| Prostate                | 28             | 7                    | 7                        | 22        | 7                  | 1                           | 6                 | 1                   | 11        | 0     |
| Testicular              | 12             | 3                    | 2                        | 2         | 0                  | 2                           | 3                 | 0                   | 3         | 6     |
| ASCT (general genitourinary) | 11            | 0                    | 0                        | 3         | 1                  | 0                           | 0                 | 0                   | 2         | 6     |
| Total                   | 74             | 14                   | 13                       | 41        | 9                  | 3                           | 11                | 8                   | 21        | 12    |
Table 2 (continued)

| Clinic                        | Material count | About Cancer/Disease | Medical Tests and Imaging | Treatment | Symptom Management | Rehabilitation/Survivorship | General Wellbeing | Medical Device Care | Practical | Other |
|-------------------------------|----------------|----------------------|---------------------------|-----------|--------------------|----------------------------|-------------------|---------------------|-----------|-------|
| **Gynecology**                |                |                      |                           |           |                    |                            |                   |                     |           |       |
| Cervical                      | 5              | 3                    | 4                         | 1         | 1                  | 1                          | 1                 | 0                   | 1         | 0     |
| Uterine                       | 7              | 1                    | 1                         | 6         | 1                  | 1                          | 1                 | 0                   | 0         | 0     |
| Vulvar                        | 2              | 1                    | 1                         | 2         | 0                  | 0                          | 0                 | 0                   | 0         | 0     |
| Vaginal                       | 3              | 0                    | 0                         | 1         | 2                  | 0                          | 0                 | 0                   | 1         | 0     |
| Ovarian                       | 7              | 4                    | 1                         | 3         | 1                  | 3                          | 5                 | 0                   | 3         | 0     |
| Gestational trophoblastic     | 0              | 0                    | 0                         | 0         | 0                  | 0                          | 0                 | 0                   | 0         | 0     |
| ASCT (general gynecology)     | 26             | 2                    | 2                         | 16        | 16                 | 16                         | 0                 | 2                   | 0         | 8     |
| Total                         | 50             | 11                   | 9                         | 29        | 21                 | 5                          | 9                 | 0                   | 13        | 0     |
| **Head and neck**             |                |                      |                           |           |                    |                            |                   |                     |           |       |
| Esophageal/tracheal           | 5              | 1                    | 1                         | 1         | 1                  | 1                          | 1                 | 3                   | 0         | 0     |
| Laryngeal                     | 3              | 2                    | 1                         | 2         | 0                  | 1                          | 1                 | 1                   | 1         | 0     |
| Oropharynx                    | 0              | 0                    | 0                         | 0         | 0                  | 0                          | 0                 | 0                   | 0         | 0     |
| Hypopharynx                   | 0              | 0                    | 0                         | 0         | 0                  | 0                          | 0                 | 0                   | 0         | 0     |
| Oral                          | 9              | 6                    | 1                         | 5         | 2                  | 1                          | 1                 | 0                   | 4         | 0     |
| Thyroid                       | 7              | 0                    | 5                         | 1         | 0                  | 0                          | 0                 | 0                   | 2         | 0     |
| ASCT (general head and neck)  | 14             | 1                    | 0                         | 6         | 5                  | 2                          | 2                 | 0                   | 6         | 0     |
| Total                         | 38             | 10                   | 8                         | 17        | 8                  | 5                          | 5                 | 4                   | 13        | 0     |
| **Hematology**                |                |                      |                           |           |                    |                            |                   |                     |           |       |
| Leukemia                      | 14             | 10                   | 9                         | 11        | 1                  | 1                          | 5                 | 0                   | 3         | 0     |
| Lymphoma                      | 8              | 6                    | 4                         | 6         | 1                  | 1                          | 3                 | 0                   | 4         | 0     |
| Multiple myeloma              | 21             | 16                   | 10                        | 20        | 8                  | 1                          | 6                 | 0                   | 2         | 0     |
| ASCT (general hematology)     | 32             | 6                    | 4                         | 22        | 11                 | 1                          | 7                 | 0                   | 13        | 0     |
| Total                         | 75             | 38                   | 27                        | 59        | 21                 | 5                          | 21                | 0                   | 22        | 0     |
| **Lung**                      |                |                      |                           |           |                    |                            |                   |                     |           |       |
| Non-small cell                | 0              | 0                    | 0                         | 0         | 0                  | 0                          | 0                 | 0                   | 0         | 0     |
| Small cell                    | 0              | 0                    | 0                         | 0         | 0                  | 0                          | 0                 | 0                   | 0         | 0     |
| Thymoma                       | 1              | 0                    | 0                         | 1         | 1                  | 1                          | 0                 | 0                   | 0         | 0     |
| Mesothelioma                  | 2              | 1                    | 1                         | 1         | 0                  | 0                          | 0                 | 0                   | 0         | 1     |
| ASCT (general lung)           | 26             | 9                    | 8                         | 16        | 10                 | 3                          | 3                 | 4                   | 2         | 1     |
| Total                         | 29             | 10                   | 9                         | 18        | 11                 | 4                          | 3                 | 4                   | 2         | 2     |
| **Ocular**                    |                |                      |                           |           |                    |                            |                   |                     |           |       |
| Total                         | 5              | 0                    | 0                         | 3         | 1                  | 0                          | 0                 | 0                   | 2         | 0     |
| **Primary brain cancer**      |                |                      |                           |           |                    |                            |                   |                     |           |       |
| Glioblastoma                  | 0              | 0                    | 0                         | 0         | 0                  | 0                          | 0                 | 0                   | 0         | 0     |
Each outpatient clinic with cancer types are listed, along with corresponding material counts and content counts. Totals for each clinic are listed, along with a final running total for all cancer types treated at the cancer center. A total of 447 PE material titles were found to be distributed across the 13 outpatient clinics. The average number of PE materials available ranged between 0 and 77 across outpatient clinics with an average of 34 PE materials per clinic.

ASCT Applicable to Several Cancer Types

| Clinic                        | Material count | About Cancer/Disease | Medical Tests and Imaging | Treatment | Symptom Management | Rehabilitation/ Survivorship | General Wellbeing | Medical Device Care | Practical | Other |
|-------------------------------|----------------|----------------------|---------------------------|-----------|--------------------|-------------------------------|--------------------|---------------------|-----------|-------|
| Meningioma                    | 0              | 0                    | 0                         | 0         | 0                  | 0                            | 0                  | 0                   | 0         | 0     |
| Pituitary                     | 0              | 0                    | 0                         | 0         | 0                  | 0                            | 0                  | 0                   | 0         | 0     |
| ASCT (general primary brain cancer) | 21             | 3                    | 7                         | 12        | 9                  | 2                            | 5                  | 0                   | 7         | 0     |
| Total                         | 21             | 3                    | 7                         | 12        | 9                  | 2                            | 5                  | 0                   | 7         | 0     |
| Sarcoma                       |                |                      |                           |           |                    |                               |                    |                     |           |       |
| Total                         | 0              | 0                    | 0                         | 0         | 0                  | 0                            | 0                  | 0                   | 0         | 0     |
| Skin and melanoma             |                |                      |                           |           |                    |                               |                    |                     |           |       |
| Melanoma                      | 8              | 6                    | 4                         | 6         | 3                  | 1                            | 2                  | 2                   | 2         | 1     |
| Non-melanoma                  | 2              | 2                    | 2                         | 2         | 0                  | 1                            | 1                  | 0                   | 0         | 0     |
| ASCT (general skin and melanoma) | 4              | 1                    | 0                         | 2         | 2                  | 0                            | 0                  | 0                   | 2         | 0     |
| Total                         | 14             | 9                    | 6                         | 10        | 5                  | 2                            | 3                  | 0                   | 4         | 1     |
| Grand total                   | 447            | 134                  | 107                        | 277       | 120                | 47                           | 87                 | 23                  | 107       | 19    |
types being treated within that clinic, they were assigned to ASCT category. See Table 2 for a summary table of material counts and content counts that are organized by cancer type and clinic.

**Brain Metastases**

The Brain Metastases clinic was not further separated into other cancer types, as it only treats brain metastases. This clinic had 18 PE materials within it.

**Breast**

The Breast clinic is split into three cancer types. These include ductal carcinoma in situ (DCIS), invasive breast cancer (no metastasis), and invasive breast cancer (metastasis). Fifty-two PE materials were identified within this clinic. DCIS and invasive breast cancer (metastasis) had one material, whereas invasive breast cancer (no metastasis) had zero materials. Most materials were placed into the ASCT category (50). These remaining materials discussed breast cancer information, although did not break down this information by specific breast cancer types.

**Endocrine**

This clinic treats four cancer types and had 14 PE materials. Cancer types include adrenal (1), parathyroid (0), pituitary (2), and thyroid (10). One remaining material was placed into the ASCT category.

**Gastrointestinal**

Fifty-seven PE materials were identified within this clinic, making it the clinic with the third highest number of PE materials. At the cancer center, this clinic treats the largest number of cancer types (10). These cancer types include ampullary (1), anal (4), appendix (0), carcinoid (4), colorectal (13), esophageal (4), gall bladder (6), liver (3), pancreatic (7), and stomach (5). The remaining PE materials were placed in the ASCT category (10).

**Genitourinary**

Seventy-four PE materials were identified within this clinic, which treats five cancer types: bladder (16), kidney (7), penile (0), prostate (28), and testicular (12). The remaining PE materials were placed in the ASCT category (11). This clinic had the second highest number of PE materials compared to other clinics, in which prostate cancer materials account for approximately 38% of these counts.

**Gynecology**

Fifty PE materials were identified within this clinic, which treats the following cancers: cervical (5), uterine (7), vaginal (3), ovarian (7), and gestational trophoblastic (0). The remaining PE materials (approximately half of all materials) were placed in the ASCT category (26).

**Head and Neck**

Thirty-eight PE materials were identified within this clinic, in which the following cancers are treated: esophageal/tracheal (5), laryngeal (3), oropharynx (0), hypopharynx (0), oral (9), and thyroid (7). The remaining PE materials were placed in the ASCT category (14).

**Hematology**

Seventy-five PE materials were present within the Hematology clinic, which treats the following cancers: leukemia (14), lymphoma (8), and multiple myeloma (21). The remaining PE materials were placed in the ASCT category (32).

**Lung**

Twenty-nine PE materials were present within the Lung clinic, which treats the following cancers: non-small cell (0), small cell (0), thymoma (1), and mesothelioma (2). The remaining PE materials were placed in the ASCT category (26).

**Ocular**

This clinic was not further separated into other cancer types. This clinic had five PE materials within it.

**Primary Brain Cancer**

This clinic treats three cancer types: glioblastoma (0), meningioma (0), and pituitary (0). This clinic had 21 PE materials, all of which were sorted into the ASCT category.

**Sarcoma**

This clinic did not have any sarcoma-related PE materials.

**Skin and Melanoma**

Fourteen PE materials were present within this clinic, which treats two cancers: melanoma (8) and non-melanoma (2). The remaining PE materials were sorted into the ASCT category (4).
Discussion

Material Counts

Some clinics had significantly less cancer-specific materials than others. While some clinics had extensive PE collections broadly, when broken down into cancer type, some had a significant dearth in materials. For example, the Hematology clinic, which treats lymphoma, leukemia, and multiple myeloma, had at least eight materials for each cancer type. In contrast, the Gastrointestinal clinic had 57 materials and treats 10 different cancer types. Within these cancer types, appendiceal cancer had no materials and six other cancer types had only five materials or less. A majority of materials that were available in the Hematology clinic were from non-profit organizations. Over half of available leukemia materials were adopted from the Leukemia and Lymphoma Society (LLS), while most of the remaining materials were internally developed. Multiple myeloma also adopted all education materials from LLS and Myeloma Canada. Lastly, lymphoma had adopted all materials from LLS and Myeloma Canada. Due to these non-profit organizations having reliable and readily available materials, these were able to be easily used at the cancer center. With respect to the Gastrointestinal clinic, 68% of PE materials were internally developed, while 32% of PE materials were adopted from Canadian Cancer Society, Pancreatic Cancer Canada, Pancreatic Cancer Action Network, the Canadian Neuroendocrine Tumour Society, Ostomy Canada, and Nourish Magazine. Colorectal cancer had the highest number of materials within the clinic, in which four PE materials were adopted from the aforementioned organizations. Aside from pancreatic cancer, no other cancer types within this clinic had PE materials that were adopted from non-profit organizations. This is not meant to suggest that these organizations do not exist, rather, the materials were not found to be used at the cancer center.

As of 2021, the most common cancers that will be diagnosed in Canadian males include prostate (20.3%), lung and bronchus (12.5%), and colorectal (11.6%) [11]. In contrast, Canadian females will be most commonly diagnosed with breast (25%), lung and bronchus (13.3%), and colorectal cancer (10%) [11]. With respect to cancer rates and educational material availability at the cancer center, 52 breast cancer materials were available (across 3 breast cancer types). Forty-four of these materials were internally developed, which when compared to the Hematology clinic, is quite significant, as out of 75 materials, only 19 materials were internally developed. With respect to lung and bronchus cancer, along with colorectal cancer, these are commonly diagnosed in both males and females. PE materials available at the cancer center in these categories are limited, as 29 lung materials were available (across 4 lung cancer types) and 13 colorectal materials were available. With respect to prostate cancer, 28 materials were available, which is the highest number of materials when compared across all individual cancer types. It is difficult to determine exactly why such variability in material availability exists, considering that breast cancer is a more commonly diagnosed cancer compared to hematological cancers. However, it may be possible that different support organizations have more or less educational materials available compared to others. Organizations may focus their efforts in another direction, for example advocacy, rather than on the development of PE materials.

Notably, the Sarcoma clinic had no PE materials available. Due to the number of sarcoma cancer types (20) and disease complexity (can occur anywhere in the body, in several different types of tissue), deciding which types of sarcomas to focus on for material development presents a challenge [12, 13]. The cancer is also very rare, accounting for less than 1% of newly diagnosed cancer cases in Canada [13]. These reasons may in part explain why there are limited national and/ or international organizations dedicated to sarcoma awareness and education. However, in the case of sarcoma, the Sarcoma Cancer Foundation of Canada provides PE materials, but only on its Web site and the content is not available in print [13]. Other cancer types, such as breast, have multiple organizations dedicated to the provision of public education and awareness materials for patients and caregivers. Notably, breast cancer has 1468 non-profit organizations located in the USA alone, as of 2011 [14]. In contrast, prostate cancer has 229 organizations and lung cancer has 154 organizations across the USA [14]. This is not to imply that no online health information exists with respect to sarcoma, rather, adopting reputable information and gaining copyright permissions when adapting health information presents more of a challenge compared to cancers that have numerous associated awareness organizations. Working with existing sarcoma organizations to create educational materials may benefit patients, who may have limited access to reputable health information. Those with low health literacy may also encounter issues when navigating the Internet to find this information [15]. Accessing links and scrolling for information on the Internet are skills that this population struggles with, which may also impede information access [15]. Moreover, working together with outpatient leads within the cancer center’s Sarcoma clinic alongside determining patient informational needs may be beneficial in addressing these gaps moving forward.

The Ocular clinic was also found to have a limited number of PE materials (5). Similar to sarcoma, ocular cancer is considered relatively rare [16]. Because of this, there is limited data available in Canada regarding annual incidence.
of ocular cancer. However, as of 2016, 290 Canadian’s were diagnosed with ocular cancers [17]. Among these diagnoses, intraocular melanoma was the most common type of eye cancer in Canadian adults [17]. Limited organizations exist for this cancer as well; however, the Eye Tumor Research Foundation does exist in the USA. Although, this organization does not develop PE materials and the content on the Web site appears to be tailored specifically to the patients they serve within their community. Additionally, since a majority of ocular cancers begin in other areas of the body as melanomas and then spread to the eye (known as a secondary cancer), ocular cancer may be grouped into melanoma non-profit organizations [18]. Relevant existing materials from these organizations may be adopted for this clinic, if found to be useful.

At the cancer center, creating PE materials can be a lengthy process. This involves numerous editing iterations, with materials moving back and forth between subject matter experts (health care providers) and plain language specialists over the course of several months. Creating PE materials requires time, skill, and at times funding and the combination of these three factors may not always be available. Due to these reasons, along with ongoing competing priorities, there may be a lack of PE materials in certain clinics. To help create a foundation for the development of these materials, environmental scans of existing online PE materials are conducted across clinics by a consumer health librarian to determine what is currently available to be adopted as information at the cancer centre. These scans can aid to supplement the existing library collection and PE collection at the cancer centre. Moving forward, performing these scans on a more regular basis may be beneficial in addressing educational gaps.

Content Counts

Across the nine content categories and 13 outpatient clinics, Treatment-related materials were most abundant (277), followed by About Cancer/Disease (134) and Symptom Management (120). The Practical and Medical Tests and Imaging categories also amounted to 107 counts each. General Wellbeing (87), Rehabilitation/Survivorship (47), Medical Device Care (23), and Other (19) categories were the least discussed. However, the Rehabilitation/Survivorship and General Wellbeing categories can apply to all cancer types; therefore, general PE materials could fall under these categories. PE materials that can be applied to multiple cancer types were excluded from the audit. This may account for the lack of counts in these categories. Only clinic-specific materials related to Rehabilitation/Survivorship and General Wellbeing were included. Regarding Medical Device Care, this category does not always apply to some cancers and can apply to some more than others.

For instance, Lung, Breast, Gastrointestinal, Genitourinary, and Head and Neck were the only clinics that contained Medical Device Care related materials.

This project did not assess the information needs of patients and caregivers. The Cancer Education program, in collaboration with clinicians, have conducted several informational needs assessments over the years to inform the development of PE materials to meet patient and caregiver needs and to fill gaps in the collection. Needs assessments for certain cancers are still ongoing and are continuously being performed.

Limitations

A limitation of this work was that the depth of the audit was limited in scope because there are no existing guidelines that delineate what should be included in an essential patient education pathway for each cancer diagnosis and treatment protocol. While guidelines like these would be very useful and comprehensive, the process of assembling them would require significant time investments that was outside the scope of this work.

Conclusion

Regarding next steps, results will be presented to outpatient clinic leads to determine which areas to focus on in relation to material development. With outpatient clinics containing some cancer types that have little to no information available for patients, these areas will be prioritized. There is no specific number of materials that is considered appropriate to meet the needs of patients and caregivers. Needs assessments should be conducted on a case-by-case basis with clinical subject matter experts and patients/caregivers to get a fulsome view of the specific gaps in clinic patient education collections. Differences in access to PE materials across cancer types is a familiar challenge across cancer centers, and we hope this audit provides a useful approach to identify disparities and facilitate planning for remediation. Other cancer centre Patient Education programs may perform a similar audit to identify material gaps, as to determine whether equal access to education materials exists among patients and caregivers, regardless of cancer type.

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Data Availability Data is available upon request.
Declarations

Conflict of Interest The authors declare no competing interests.

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