Impact of the COVID-19 Pandemic on Cancer Patient Educators

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Abstract
Patient education (PE) is vital in reducing anxiety, increasing satisfaction with treatment, helping with self-management, and creating a sense of control for cancer patients. Patients access much of their material from health care providers through in-person visits, patient libraries, and in-person classes. Due to reductions in in-person visits throughout the pandemic, we sought to understand how PE programs responded under varying levels of COVID-19 restrictions to meet the information needs of patients and families. A cross-sectional survey was distributed to members of the Cancer Patient Education Network (CPEN) and the Health Care Education Association (HCEA) via the respective listservs. The survey consisted of five sections that included closed and opened questions. Participants were asked questions to describe their PE programs and how their duties were affected during the pandemic. Forty-two CPEN members completed the survey (N = 42, 66%) with a 35% response rate and a 55% completion rate, and 19 HCEA members completed the survey (N = 19, 30%) with a 5% response rate and 16% completion rate. The majority of staff surveyed were not furloughed (N = 57/64, 89%). Just under half reported a change in daily PE program activities (N = 23/52, 44%) and most reported a change in developing PE materials (e.g., pamphlets) (N = 10/26, 63%), finding information for patients/families (N = 11/19, 58%), and delivering classes (N = 12/21, 57%). COVID-19 has ushered in a new era in the delivery of PE with the rapid deployment of digital cancer patient education. Results can inform future directions for the delivery of PE post-pandemic.

Keywords Patient education · Pandemic · COVID-19 · Coronavirus · Patient educators

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Introduction

When a person receives a cancer diagnosis, education is vital in reducing anxiety [1], increasing satisfaction with treatment [2], helping with self-management [3], and creating a sense of control [4]. When the COVID-19 pandemic became a reality in the spring of 2020, many patient education programs in Canada and the USA suddenly found themselves closing their physical spaces; moving their staff to remote work; and, in some cases, redeploying their staff to COVID-19-related roles [5]. However, COVID-19 did not stop the education needs of people with cancer. In fact, the pandemic increased patient information needs on how the virus would affect cancer patients and their treatments, and more recently, the vaccine recommendations for cancer patients [6]. Patient educators were faced with the challenge of delivering education in a much greater capacity, despite global COVID-19 restrictions and lockdowns [7].

Patient education has traditionally been provided through one-on-one teaching with health care providers, through
in-group classes, or through written materials that are typically distributed by health care providers during clinical encounters, through resource centers or patient libraries [8, 9]. With these avenues of distribution and teaching stopped or restricted, many patient education programs found themselves with the challenge of providing education through different means [10].

This practice paper reports on the results of a cross-sectional survey circulated to members of the Cancer Patient Education Network (CPEN) and the Health Care Education Association (HCEA) to determine how the work of patient educators has been affected by the COVID-19 pandemic. Findings from this paper provide insight on how patient educators adapted during the pandemic and lessons learned for the delivery of patient education for future pandemics and other disruptions.

Methods

Survey Development

Study team members from the Cancer Education Program at the Princess Margaret Cancer Centre developed a list of core activities/responsibilities of patient educators to be included in the survey. Members of the Cancer Patient Education Network (CPEN) Executive Board were then invited to review and refine the list of activities. Consensus was reached for survey content and was tested for face validity with four patient educators. The survey questions were found to be consistently understandable by each participant and were finalized.

The survey included 34 questions and was divided into five major sections. Each section included closed-ended questions, and when appropriate, open-ended questions for participants to provide detail. The sections were as follows:

(I). Participant characteristics: This section reported on membership, organization, and time spent on cancer patient education activities.

(II). Impact on work status: Participants were asked to report whether patient education staff were furloughed, transitioned to working remotely, or deployed to other roles. If staff were furloughed, additional information was gathered on the number of staff furloughed, the reason for the furlough, and duration of the furlough.

(III). Changes in duties and daily activities due to COVID-19: This section included 13 items to assess changes in daily patient education activities during the COVID-19 pandemic. Participants were required to report whether the “activity has stopped,” “activity has changed,” or if the item was “not applicable.” Participants were also asked to describe how the activity changed.

(IV). About your library/learning center: Participants were asked to report whether their patient education program had a library or resource center, the status of the library/resource center during the pandemic, and the number of patients/family members served prior to and during the pandemic.

(V). Provision of patient education resources: The last section of the survey asked participants if they distribute print patient education resources at their organization, whether any special precautions were taken during the COVID-19 pandemic, and if the way patient education resources were delivered has changed. Participants were also asked to report on whether patient education classes are offered, how they are delivered, if they were still being offered during the pandemic, and whether the mode of delivery changed.

Sampling Methods

This study employed purposive sampling and participants were invited to complete the survey. The survey was emailed to 120 CPEN members via the CPEN listserv and 400 HCEA members via the HCEA listserv. Two reminders were sent over 5 months before the survey was closed. Data collection took place at the end of the first and the start of the second wave of the pandemic (June 2020 to October 2020).

Statistical and Thematic Analysis

Descriptive statistics are reported. All analyses were done using RStudio Version 1.2.5033 [11]. Open-ended responses were coded independently by two reviewers using an iterative approach. A third reviewer corroborated the coding schema and resolved any discrepancies that arose. Codes were sorted into general thematic categories pertaining to cancer patient education activities, distribution of cancer patient education resources, and implementation of special precautionary measures.

Results

Participant Characteristics

Forty-two CPEN members completed the survey (N = 42, 66%), totaling a 35% response rate and a 55% completion rate, and only 19 HCEA members completed the survey (N = 19, 30%), totaling a 5% response rate and 16% completion rate. One respondent reported that they were a member of both CPEN and HCEA (N = 1, 2%).
Just over half of participants worked at a cancer center ($N = 33, 52\%$) and spent more than half of their time working on cancer patient education ($N = 35, 55\%$). Most respondents indicated that there were between two to five staff members working in the patient education program. Participant characteristics are further described in Table 1.

**Impact on Work Status**

The vast majority of patient education staff surveyed were not furloughed ($N = 57/64, 89\%$). However, of those that were furloughed ($N = 7/64, 11\%$), five reported that the furlough was due to budgetary reasons and the duration of the furlough ranged from 1 week to several months. One respondent reported a permanent furlough. The majority of respondents reported working remotely ($N = 41/53, 77\%$) and most were not deployed to other roles ($N = 29/45, 64\%$). Of staff that were deployed into other roles ($N = 16/45, 36\%$), ten respondents reported being redeployed to COVID-19 screening of patients or staff at hospital or cancer center entrances. Three respondents had been redeployed to contact tracing, other priority areas in the hospital, and telephone check-ins on patients. Only two saw their overall hours being reduced due to the pandemic.

**Changes in Duties and Activities Due to COVID-19**

Just under half of the respondents reported a change in the daily activities of their patient education program ($N = 23/52, 44\%$). Most reported a change in committee work ($N = 15/19, 79\%$), developing patient education materials (e.g., pamphlets, videos) ($N = 10/26, 63\%$), finding information for patients/families ($N = 11/19, 58\%$), and delivering patient education classes ($N = 12/21, 57\%$). Over half reported a complete stop in library or resource center collection management ($N = 11/20, 55\%$) and training and supervising volunteers ($N = 12/22, 55\%$). A breakdown of patient education activities is shown in Fig. 1. When asked to elaborate on changes to duties or activities, six respondents reported that the focus of patient education material development was to develop COVID-related communications for patients and health care providers. Three respondents reported that there was an increase in the development of patient materials generally.

Respondents wrote about the shift to providing patient classes, staff education, and committee work in a virtual manner. For 16 respondents, shifting to a virtual environment involved moving existing patient education materials to a digital format. Three participants noted that volunteers were no longer being utilized and as one participant wrote, “responsibility for organizing the distribution of patient education materials has been transferred from volunteers to the Patient Education Coordinator.” In some instances, routine library or resource center work like collection development or cataloguing stopped. As one participant wrote, “we have stopped developing the library for the most part.”

**About Your Library/Learning Center**

Most participants reported having a library or resource center ($N = 31/47, 66\%$). Of those that had a library or resource center, some respondents reported complete closing of the library/resource center ($N = 11/31, 36\%$) or closing to everyone except essential staff ($N = 4/31, 13\%$). For a small number of participants, the library/resource center remained open to staff and to the public ($N = 5/31, 16\%$). Five respondents described restrictions that were implemented in their library/resource centers. This included reduced hours of operation and staff control over the handling of material as opposed to allowing patients and staff to “self-serve.” Prior to the pandemic, most respondents reported serving over ten patients/family members per day in their library/resource centers ($N = 26/31, 84\%$). During the pandemic, most respondents ($N = 20/31, 65\%$) reported serving fewer than ten patients/families per day.
Provision of Patient Education Materials

**PE Resource Distribution of Print Materials**

Over half of the respondents were responsible for distributing patient education materials at their respective organization (N = 26/44, 59%) and continued to distribute print resources during the pandemic (N = 17/26, 65%). The vast majority implemented safety precautions (N = 20/26, 77%) in order to distribute various print materials in libraries/resource centers. Eight respondents reported providing print copies upon request, asking patients to discard material they have used, sanitizing material, and providing material in plastic sleeves. In addition, three respondents wrote about other measures such as limiting handling and retrieving of resources to staff only, limiting print copies to select areas, and quarantining material that had been borrowed. Six respondents wrote about the extra safety measures instituted such as staff wearing personal protective equipment, increasing hand hygiene, and the enhanced cleaning of high-touch surfaces. Additionally, most respondents noted a change in the method of delivery (N = 19/26, 73%), such as through virtual classes and workshops or via the patient portal. Of the organizations that continued to distribute print copies, nine respondents wrote that distribution of these materials was being done by clinical staff during clinical visits.

**Patient Education Classes**

Just under half of the respondents reported that prior to the pandemic, their department offered patient education classes (N = 22/46, 48%). Most reported that classes were delivered in person (N = 15/22, 68%); however, a small number offered virtual classes (N = 3/22, 14%) or provided a combination of both (N = 4/22, 18%). When asked if patient education classes were still being offered during the pandemic, most respondents reported that classes were offered (N = 12/22, 55%) but that the method of delivery had changed (N = 18/19, 95%). When asked to elaborate on how the method of delivery had changed, all respondents indicated that patient education classes were being delivered virtually via platforms such as Zoom and WebEx.

**Discussion**

This work endeavored to provide a snapshot of cancer patient education in the midst of the unprecedented COVID-19 pandemic. Findings from this work indicate that COVID-19 changed the delivery of patient education early in the pandemic with a transition to increased cancer and COVID-19 communications, a widespread shift to virtual education and digital platforms, and changes to in-person practices within clinics, libraries, and resource centers.

The results from this survey reveal several important findings. First, they indicate that most patient educators were not furloughed or deployed to other roles, even with the complete or partial closure of libraries and resource centers. Our finding is not wholly surprising considering the immensely transferrable skills that many patient educators possess, such as plain language communication, that can be leveraged for COVID-related communications. However, in comparing our findings with the literature, recent studies have shown that rates of furloughs increased for many
other health care workers during the pandemic, including clinicians [12], with approximately 50% of these staff being furloughed and many being relocated to different areas due to widespread restrictions, decreased case numbers, and changes in workflow [13–15]. One plausible reason for the low number of furloughs seen among patient educators may be their unique role in being able to deliver and implement effective COVID-19 communication and education for patients at a critical time [16]. Patient educators play a vital role in creating accessible, relevant, understandable, and shareable resources for patients and families [17], and indeed, many survey respondents described changes in daily activities, such as creating more COVID-19-specific materials and promoting credible sources for patients. With the “misinfodemic” of COVID-19 information, countering misinformation with up-to-date, accurate information became an important function for patient educators during the pandemic [17]. With the COVID-19 pandemic exposing long-standing systemic inequities, educators help mitigate some of the health disparities by providing COVID-19 information in a manner to address limited health literacy.

Another notable finding was the reported shift to digital platforms and virtual patient education. The shift to online platforms included synchronous and asynchronous patient classes and eLearning, creating or expanding the functionality of patient portals, updating external websites, and increasing the amount of content or shifting print content to the web. Digital multimedia has several benefits including widespread coverage, accessibility, and flexibility to adapt content [18, 19]. Digital education also allows patients to control the amount of content reviewed at a time and the format (for example, pamphlets, eLearning, or video), and allows patients to review information more than once [20]. A recent study evaluating the implementation of a digital education platform found that patient videos were viewed over 1000 times in 6 months, with “COVID-19 and oncology” being the most watched video [18]. Virtual patient education and digital media can serve as important tools to help improve patient self-management and understanding of treatments, as well as reach populations with low health literacy—which has become even more critical during the pandemic [18, 21].

Interestingly, over half of survey respondents reported that they continued to distribute print materials, despite early hypotheses that COVID-19 was primarily transmitted via large respiratory droplets and fomites (surfaces or objects) [22]. However, three-quarters of survey respondents reported taking special precautions when distributing print materials, including providing print copies only as requested. Perhaps, the continued use of print materials reflects the recognition by educators that not everyone has internet access or digital literacy, and the literature has shown that generally, patients typically prefer print material than online information—a fact not lost on most patient educators [23]. Additionally, having clinicians distribute educational materials to patients who continued to be seen in clinic was an effective way to ensure patients were given the information they needed in a controlled and safe manner.

Findings from our survey suggest further areas worth exploring. For example, with the rapid deployment to online cancer information, evaluating the positive and negative impacts on patients requires careful consideration. Online content can create more equitable access for those who may not be able to attend in-person education sessions, while being a potential barrier for others who have limited digital literacy or may not have access to web-based platforms [24]. The type of impact these shifts in activities have had on patient educators over the course of the pandemic is also of interest. Currently, it is unknown how many educators will continue to work remotely after it is considered safe to go back to work. And if many do continue to work remotely, consideration may be given as to whether something will be lost without in-person engagement with patients [24, 25]. Face-to-face reference interviews are one way patient educators build rapport with patients in order to best serve their needs and “can be some of the most enriching and rewarding parts of this work” [26].

There are some limitations to this study. The first is it is possible that some CPEN members were on furlough and thus did not complete this survey. In addition, the response rate from HCEA members was extremely low. We surmise this may be attributed to a lack of cancer focus among HCEA members; however, this low response rate remains a significant limitation. Second, the survey was distributed early in the pandemic. One year later and with increased knowledge of the virus, the development of vaccines, and the appearance of new variants, COVID-19 continues to have an impact on activities and roles. How patient education practice has changed since the beginning of the pandemic until now, if at all, is outside the scope of this work. Third, although the survey captured the types of changing roles, duties, and activities experienced by patient educators, it did not capture whether they had the skills or the institutional support to successfully manage these changes. Fourth, our survey also did not capture any information about the personal or mental health effects of COVID-19 on patient educators, especially during the rapid transition to remote work where some may have felt isolated and unable to interact with colleagues, friends, and family or were required to take on the additional role of overseeing online school for children [27]. A previous study examining the effects of the COVID-19 pandemic on health educators reported that in addition to increased job responsibilities, health educators took on a greater role in caring for family members and helping children with online school [5]. These conditions are likely to lead to burnout and elevated stress over time, if
they have not already [28]. Lastly, as a result of the anonymity of the survey, our survey did not capture whether there were multiple respondents from the same institutions, and thus, it is difficult to conclude how broadly these findings can be applied.

Conclusion

“COVD-19 has ushered in a new era for the delivery of patient education” [10] and most of these changes are likely to remain in place, such as the continued delivery of online classes and digital materials, alongside in-person classes and print materials. From an equity perspective, this will have important implications for patients who are unable to travel to the health care organization and take time off work and for those who are caring for someone at home. Currently, there are very few published studies that explore the changes to patient education due to the COVID-19 pandemic. Further studies are warranted as the field of patient education navigates and adapts during these unprecedented times.

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Data Availability Data is available upon request.

Declarations

Ethics Approval This study was granted exemption by the University Health Network Research Ethics Board.

Informed Consent Consent to participate in this survey was implied by virtue of survey completion.

Competing Interests The authors declare no competing interests.

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