

Tailoring Education for the Oncology Patient



Since 1985, Clearview Cancer Institute has served hematology and oncology patients in our community of north Alabama. Clearview Cancer Institute is a private, physician-owned community practice with three full-service locations. Two of these locations are in Huntsville, and one is in Decatur. We have three satellite clinics in Athens, Madison, and Scottsboro that are available for patient office visits on select days of the week. Our practice is home to 14 physicians and 17 mid-level providers.

Clearview is fully committed to quality, patient-centered care for *all* patients. The mission statement for Clearview is as follows: “Clearview is committed to providing cutting-edge quality, compassionate, comprehensive care.” It is our belief that education is at the center of providing high-quality patient care. We strive daily to ensure that patients have excellent education so that they can make informed decisions about their care as they travel through the cancer journey.

A Unique Patient Population

Because of our geographic locations, we serve a varied patient population. Huntsville itself is nicknamed “Rocket City,” and many individuals hold advanced degrees and work as rocket scientists for the National Aeronautics and Space Administration or other government agencies. Our home county of Madison is the second most educated county in Alabama.¹ Conversely, the state as a whole has a lower than average high school graduation rate,² and it is currently estimated that between 15 and 25 percent of Alabamians are functionally illiterate.³

Residents of at least 20 counties in Alabama are represented in our patient population. Furthermore, of these 20 counties, 17 were designated in 2015 as primary care physician shortage areas by the Alabama Department of Public Health, and 15 of these counties were considered medically underserved areas. Therefore, poor access to healthcare providers and healthcare facilities is the reality for many of our patients. Additionally, many of our patients travel substantial distances to our facilities and/or satellite locations. Finally, from 2001 to 2010, Alabama has experienced a 145 percent growth in its Hispanic population,⁴ resulting in significant language barriers.

Education plays a vital role in the patient’s cancer journey. It is our role as healthcare professionals to ensure that our patients are well informed about their disease and treatments so that they can make the best possible decisions for themselves and their families.

The Adult Learner

In addition to a differentiated patient population in terms of education, access to care, and cultural differences, Clearview Cancer Institute has multiple avenues with which we communicate and disseminate information to our patients. Education can be delivered through live classes and one-on-one teaching, which includes verbal instruction, visual instruction, and written instruction. Education may also be provided via phone, secure email, and written documents, among other methods.

We know that learning styles are constantly evolving with changes in technology and information delivery. Each generation also brings with its own preferences in effective learning formats. Studies have demonstrated that the use of multiple teaching methods is beneficial to patients. One analysis revealed that almost 67 percent of patients had better outcomes when receiving multiple forms of patient education than those who received routine care only.⁵

At Clearview Cancer Institute, we believe that providing multiple formats for educating our patients is the best practice to ensure that patients receive the education they need in the format that best suits their needs. So how do we help our patients learn? A prevalent adult learning theory of andragogy comes from Malcolm S. Knowles. Knowles et al. proposed that for adult learning to be effective, the following items are essential to recognize⁶:



The infusion suite boasts views of a pond and floral landscaping for patients to enjoy during their treatments.

- Adults want to know why they should learn something.
- Adults need to take responsibility for learning skills.
- Adults bring personal experiences as a resource to learning.
- Adults are ready to learn when there is a real-life situation or need.
- Adults are task-oriented or problem-centered learners.
- Adults are responsive to internal and external motivators.

This further enforces the idea that adult learners are often internally motivated.⁷ It has also been demonstrated that about 70 percent of adult learning is considered to be self-directed, meaning that the individual is taking the initiative to learn without help from someone else. This may include an informal learning process in which patients may seek out external content and/or resources to determine needs, problems, goals, and outcomes.⁸

Additionally, when patients are well informed about their disease and treatment options, patients have been shown to have an increased sense of control. They are more involved with their care and have reduced psychosocial distress. These patients are also more likely to adhere to their treatments.⁹

Education plays a vital role in the patient's cancer journey. It is our role as healthcare professionals to ensure that our patients are well informed about their disease and treatments so that they can make the best possible decisions for themselves and their families. Additionally, as healthcare professionals, we need to be open to altering and/or personalizing teaching styles to keep up with patient needs and preferences.

The Journey Ahead

Each of the factors discussed thus far heavily impact Clearview Cancer Institute's patient education efforts. Over the years, we have experienced many failures and successes in developing

education that meets our patients' needs. Verbal education through one-on-one interaction with physicians and nurses was the initial primary form of education conducted at Clearview. Handouts were printed for patients and given to them during the one-on-one session. Physicians would give an overview of the disease and treatment options, and patients would get more in-depth education from nurses on the specific medications they would receive.

This verbal education continues at Clearview today, but modifications have been made to cater to the ever-changing needs of the patient population. Materials can now be printed in multiple languages. Spanish interpreters are available on-site. An interpreter phone line is also used to communicate when a patient speaks another language. These improvements ensure that no matter what language patients speak, they will receive the education they need. Language should never be a barrier in preventing high-quality education and care for a patient.

The establishment of Clearview Cancer Institute's survivorship program, *Journey Ahead*, brought about more changes in how education is conducted. The survivorship program is targeted toward all newly diagnosed cancer patients. Each patient is given a binder with information about what to expect before, during, and following treatment. Information in the binder includes side effect management education, financial resources, and support group information, among others. These binders are given to patients at their first treatment appointment. Patients are instructed to bring their binders back during each office visit so that they can add to the binder and take notes. Printed materials that have been tailored specifically for the patient have been shown to improve patient recall better than generalized materials¹⁰; therefore, *Journey Ahead* binders can be tailored to include disease-specific and treatment-specific education for the patient. The binders have

divided sections for patients to add their pathology report, labs, and imaging reports.

The *Journey Ahead* binder is meant to be an educational resource for patients and their caregivers. Patients can easily reference their binder to help them navigate their way through their cancer journey. Because patients will interact with many different healthcare professionals throughout their cancer journey, the binder also serves as a tool for patients to take back to their other providers to keep them in the loop and educated about their care. It is important that communication is seamless and that everyone one is on the same page so that the patient can receive the best possible care.

Using printed materials to educate patients has created many challenges. Finding materials that are informative and written in easy-to-read terms can be difficult. The use of illustrations within written materials has shown to be a useful teaching strategy, especially for those with a low literacy level.¹¹ The education department at Clearview Cancer Institute is constantly striving to ensure that materials are up to date and patient friendly. The goal is to provide consistent education to all patients no matter what member of the cancer care team is providing the education. Standardized education materials are made available to all Clearview staff so that the materials given to patients are consistent.

Education materials are kept in an electronic format and then printed out for patients while they are in the clinic. The education materials can also be sent electronically to patients through email. Having the materials stored electronically for staff helps combat the need for storage space. Though there are many great resources offered in hard copy, Clearview has found that long-term storage is a problem and that materials get pushed in closets never to be seen or used. By having electronic educational materials, staff can access information easily and print as needed. The majority of our educational materials are available at the push of a button.

Live Educational Classes

Clearview Cancer Institute started these educational classes to educate multiple patients at one time. Classes covered broad cancer topics such as side effect management, nutrition, psychosocial needs, and financial issues. Classes were initially offered during the day, but with an increase in the number of people working through treatment or returning to work quickly following treatment, educational classes were added in the evenings to accommodate patients' schedules.

Our "Chemo and You" course is designed specifically for patients who have not yet started treatment or those who are very early in their treatment cycles. The course is meant to complement the education that infusion nurses teach patients during their first chemotherapy infusion and is offered weekly at the same time of day. To increase the number of patients attending the class, it is built into the patient's chemo regimen and is added to the patient's schedule. Though the class is not mandatory, it is highly encouraged.

We have noticed that those patients who attend the "Chemo and You" course prior to the start of chemotherapy report a better understanding of their treatment. The infusion nurses have

also noticed an increase in patient knowledge when doing their chemotherapy teaching prior to the start of the patient's treatment.

Though attendance has continued to be positive for the "Chemo and You" course, this has not been the case for other live, in-person classes. Like many institutions, attendance at live, in-person classes has continued to dwindle. The day of the week or time a class was offered seemed irrelevant; attendance just was not what it had been in previous years.

Getting the entire healthcare team involved in promoting patient education has helped to inform patients and family members about our new educational offerings. It truly does take a village to ensure that patients and their families have access to quality cancer education.

Through patient feedback and team discussion, we discovered that patients trying to work through treatment or returning to work immediately following treatment simply did not have the time or resources to attend a live class. Their lives were busy, and they needed to get back to or keep up with their "normal" routine. We know and recognize that time, family reactions, situational obstacles, and special individual obstacles can all be barriers to education.⁷ These findings did not mean that patients did not want or need the information presented in the classes; patients just were not able to effectively fit it into their daily lives.

So, how do we reach patients who no longer have the necessary resources—whether time, money, or another factor—to come to one of our facilities for a class? How else can we disseminate information we feel is important for our patients to have?

A Technological Springboard for Patient Education

Some research supports the idea that web-based instruction and classroom instruction are equally satisfying and beneficial to learners.¹² Additionally, it is estimated that 87 percent of Americans regularly access the Internet.¹³ More than two-thirds of Americans have smartphones with Internet access. Of these, 62 percent of users report using their smartphone to acquire information about a health condition.¹⁴ These findings coupled with the knowledge that individuals will seek out external content and resources for educational purposes helped us identify how our practice could better serve our patients. Specifically, we needed to better leverage online and electronic platforms.

Though this solution appears to be an obvious one, it was no easy task to accomplish. The first step was an overhaul of our practice website to even be able to provide online educational

opportunities. This work required hiring a professional web designer to work with us to restructure our website, making it easier to navigate and able to host multiple videos. We also wanted our website to be more interactive for patients and family members who would be using it. This process took several months to accomplish, and maintenance of the site is ongoing.

In addition to adding virtual classes, we wanted to provide the same e-learning opportunities to patients in our offices. Clearview Cancer Institute works closely with Russel Hill Cancer Foundation on patient assistance and special patient projects. Through a fundraising event supporting Russel Hill Cancer Foundation, we secured the funding necessary to place iPads at each infusion chair in all our facilities. These iPads are loaded with reading content and videos, allowing patients to access educational offerings while having their chemotherapy treatment.

The next step we took was to determine which classes we wanted to offer virtually. At first, we believed that recording the live classes would be the easiest, most efficient, and most cost-effective option, but we soon realized that many live classes did not translate well on screen. There was too much background noise and too many distractions in the videos. We needed to create separate recordings of classes for our patients to view. We settled on creating scripted PowerPoint presentations for the educational classes.

Because there was no direct interaction with class participants, we realized that the audio had to be dynamic in nature so that the speaker holds the interest of the virtual audience. This realization and the production process initially slowed the release of videos for patients, so we chose to focus on two of our most needed and most popular educational offerings: “Chemo and You” and a “Strong Lungs, Strong Life” smoking cessation course.

Both classes are broken down into multiple video sections so that patients can play small sections of the class at a time. Viewers only need 5 to 10 minutes to watch each segment, and it can be done in the infusion room or in the comfort of their own home when it is convenient for them. These classes are available to be referenced multiple times by patients. This repeatability has been helpful for patients when questions arise. They are no longer forced to call the office for common questions. This e-learning also allows family members to be involved in the educational process.

The “Chemo and You” course is broken down into five sections:

1. General Chemotherapy and Side Effect Management
2. Gastrointestinal Side Effect Management
3. Intimacy Issues
4. Interpreting Lab Results
5. Management of Neuropathy.

The information presented in the videos is the same information presented during the live class. The educational material in this course also mirrors the material provided in the *Journey Ahead* survivorship binder. We believe that continually providing consistent, streamlined information to patients gives them the tools they need to manage their cancer diagnosis.

The “Strong Lungs, Strong Life” smoking cessation course is broken down into seven weekly sections. Participants are asked to watch one presentation per week. The course has weekly “homework” assignments that help them prepare for their “quit” date. Participants are not expected to have quit smoking prior to the start of the course but should use the class as a guide to help them quit by the end of the course. Participants can contact staff while they are taking the online course for support and guidance. By offering the online course, participants can quit smoking when the time is right for them instead of having to wait until a live course is offered.

A New Direction for Patient Education

The success of our videos and patient education courses has been exciting, and feedback from patients and staff has been positive. We continually monitor our website to find out how many hits we have on each educational video. Because of the positive responses, we are working diligently to expand our e-learning opportunities. We also know that informing patients and spreading the word about our online educational offerings can be challenging. We continually strive to promote our e-learning opportunities, working closely with the marketing director. Getting the entire healthcare team involved in promoting patient education has helped to inform patients and family members about our new educational offerings. It truly does take a village to ensure that patients and their families have access to quality cancer education.

Clearview Cancer Institute is also looking to improve our patients’ fitness. Through the YMCA, we offer a 12-week exercise program to our patients free of charge. This activity gets patients moving and combats some of the symptoms they may be experiencing. Though we are proud to be able to offer it to our patients, we have noticed that many people were not taking advantage of the program. Some of the reasons people cited for not using the program included embarrassment and intimidation, the gym’s inconvenient location, and a lack of time in the day to get to the gym. In light of this information, we decided to offer an online exercise video. This short, 10-minute video features chair exercises that can be performed in the home. By offering an e-exercise activity, we were able to alleviate some of the barriers our patients faced in becoming healthier and physically fit. This exercise video is now one of the more popular online videos offered.

As a growing practice, we also noted that some of our new patients were confused about practice locations, what to expect at an appointment, and other general concerns. Because we had success with the “Chemo and You” and smoking cessation classes, we determined that online education may be beneficial for our new patients as well. We contracted with an external company to create videos for each service location that would be promoted at the time of referral. Once a patient is referred to Clearview Cancer Institute, he or she is contacted via telephone by the scheduling department. Patients with Internet access are directed our website to complete new patient paperwork and view the video for their referral location. This e-learning opportunity has helped immensely with completion of new patient paperwork in

Our physicians and advance practice providers take the time to address patient needs at the chair side.



a timely manner, as well as alleviation of first-day jitters for our new patients.

Our newest venture into the virtual education world has been Facebook Live. With Facebook Live, Clearview Cancer Institute has held live speaker programs while a virtual audience joins us in real time. This option has helped expand the number of people we can reach at one time. It has also allowed our virtual audience to ask questions to the speaker—something that was lacking in our previous online courses. Though we are still in the early stages of using this technology to broadcast educational events, we believe that it has been quite successful. We have had great feedback from the audience, both in person and from virtual participants. Those individuals who could not make it to the clinic due to conflict, including work schedules, transportation issues, and illness, can now participate just as easily as those in the live audience. It is our goal that all live educational presentations held at Clearview will also be offered via Facebook Live.

Planning for the Future

To continue meeting the needs of our unique patient population, we have enlisted the help of some of our patients and their family members to create an advisory committee. This new committee, the Patient Family Advocacy Committee, will provide insight into the resources and educational programs that patients and families want to see. This valuable information will help us tailor our educational programs accordingly. Patients and their families are our top priority, and we want to make sure that we are meeting their needs.

As we look to the future, we have several goals that we would like to achieve in expanding our educational offerings and improving our educational programs:

- **Translated education materials.** Due to the increase in patients speaking languages other than English, we are making it a priority to continue translating currently used education tools,


whether print or electronic media, into other prominent languages in our area. As discussed, we already have some information available, but this is an area for growth that would make a significant impact on our patients and their families.

- **Additional educational videos.** Because of the success with educational videos online, at chairside, and on Facebook Live, we are working to expand course offerings. Classes that we would like to add to our education library include a nutrition class, an oral chemotherapy class, and a class on financial management during the cancer journey.
- **Continued dissemination of printed and written educational materials.** Many of our patients still enjoy and benefit from receiving a paper copy of home care instructions and lab or imaging results, among others. We will continue the use of our *Journey Ahead* binders in addition to paper copies of information to patients as needed and requested.
- **Continued offering of live, in-person classes.** Because the “Chemo and You” class is built into treatment regimens in our electronic health record and scheduled for each patient, we have had higher attendance rates. This class will continue to be offered as a live educational opportunity at regular intervals. In addition, if the need presents itself through the Patient Family Advocacy Council or other patient feedback avenues, we will hold additional live education events on a regular or as-needed basis.
- **Special interest education events.** As we continue to expand our support groups and support services, we have come to realize that there are special and specific education needs. Through partnering with specialized groups and service lines, as well as our marketing team, we want to continue offering programs that meet these patients’ specific needs such as support groups and targeted education for growing patient populations like young adult and head and neck cancer patients and survivors.



Built in 2006, CCI was designed to meet all patient needs by offering comprehensive cancer care under one roof.

Closing Thoughts

There is no one-size-fits-all approach to patient education. Different approaches are successful in different circumstances. By using multiple teaching and education methods, we can provide our patients and their families the best chance for success. Clearview Cancer Institute is committed to allowing our educational offerings to grow and change to meet patient needs. Feedback from patients and families will be key to building and producing successful educational events and resources moving forward. Every member of the cancer care team will also be needed to help improve the education provided to our patients. There is no doubt that advances in technology and social media will also play an increasingly larger role in how we educate patients in the future. Change is a part of life, and we continue to evolve. 

Kristin Shea Donahue, MSN, RN, OCN, is director of Educational Services and Anne Marie Fraley Rainey, MSN, RN, CHC, is compliance and quality control officer at Clearview Cancer Institute, Huntsville, Ala.

References

1. Bonvillian C. Huntsville best-educated of Alabama's metro areas, with 20,000 residents holding engineering degrees. Available online at: blog.al.com/breaking/2012/03/huntsville_best-educated_of_al.html. Last accessed October 17, 2017.
2. Chapman C, Laird J, Ifill N, et al. Trends in high school dropout and completion rates in the United States: 1972–2009. Available online at: nces.ed.gov/pubs2012/2012006.pdf. Last accessed October 17, 2017.
3. Womack TW. Redefining literacy for Alabama families. Available online at: uab.edu/news/service/item/6245-redefining-literacy-for-alabama-families. Last accessed October 17, 2017.
4. Passel JS, Cohn D, Lopez MH. Hispanics account for more than half of nation's growth in past decade. Available online at:

pewhispanic.org/2011/03/24/hispanics-account-for-more-than-half-of-nations-growth-in-past-decade/. Last accessed October 17, 2017.

5. Theis SL, Johnson JH. Strategies for teaching patients: a meta-analysis. *Clin Nurse Spec*. 1995;9(2):100–105, 120.
6. Knowles MS, Elwood EF III, Swanson RA. *The Adult Learner: The Definitive Classic in Adult Education and Human Resource Development*. 8th ed. London, UK: Routledge; 2015.
7. Marquis BL, Huston CJ. *Leadership Roles and Management Functions in Nursing: Theory and Application*. 7th ed. Philadelphia, PA: Wolters Kluwer Health; 2012.
8. Teaching Excellence in Adult Literacy. Adult learning theories. Available online at: lincs.ed.gov/sites/default/files/11_%20TEAL_Adult_Learning_Theory.pdf. Last accessed October 25, 2017.
9. McPherson CJ, Higginson IJ, Hearn J. Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *J Public Health Med*. 2001;23(3):227–234.
- Friedman AJ, Cosby R, Boyko S, et al. Effective teaching strategies and methods of delivery for patient education: a systematic review and practice guideline recommendations. *J Cancer Educ*. 2011;26:12–21.
10. Houts PS, Doak CC, Doak LG, et al. The role of pictures in improving health communications: a review of research on attention, comprehension, recall and adherence. *Patient Educ Couns*. 2006;61(2):173–190.
11. Sitzmann T, Kraiger K, Stewart D, et al. The comparative effectiveness of web-based and classroom instructions: a meta-analysis. *Pers Psychol*. 2006;59:623–664.
12. Anderson M, Perrin, A. 13% of Americans don't use the Internet. Who are they? Available online at: pewresearch.org/fact-tank/2016/09/07/some-americans-dont-use-the-Internet-who-are-they/. Last accessed October 25, 2017.
13. Smith A. U.S. smartphone use in 2015. Available online at: pewInternet.org/2015/04/01/us-smartphone-use-in-2015/. Last accessed October 25, 2017.