Photography in Telemedicine

Improving diagnosis of chronic graft-versus-host disease

Brianna Busby, BSN, RN, Shannon Campbell, BSN, RN, Rachel Cole, BSN, RN, Charisse DeVries, BSN, RN, Kamille Dobbins, BSN, RN, Mary Beth Trimble, BSN, RN, and Mihkaila Wickline, MN, RN, AOCN®, BMTCN®

BACKGROUND: The long-term follow-up (LTFU) team at the Seattle Cancer Care Alliance uses telemedicine to diagnose and treat post-transplantation complications in hematopoietic cell transplantation (HCT) survivors. Photos are often requested via the telemedicine service to aid in diagnosis, but they are typically of poor quality, making them unusable.

OBJECTIVES: This project offered bachelor of science in nursing students, partnered with a comprehensive cancer center, the opportunity to participate in an evidence-based practice project to improve detection and management of chronic graft-versus-host disease (cGVHD) in patients after HCT.

METHODS: Students partnered with RNs to develop instructional tools using multiple evidence sources. A brochure and video were developed.

FINDINGS: Providing these instructional tools to those in the LTFU program improved patient outcomes for managing cGVHD through telemedicine. This partnership provided an opportunity for mutual learning and improved clinical practice.

THE SEATTLE CANCER CARE ALLIANCE (SCCA) is a leading cancer treatment center in Seattle, Washington, that cares for patients with all cancer diagnoses. The long-term follow-up (LTFU) program at SCCA provides lifelong support to patients after they receive hematopoietic cell transplantations (HCTs). In addition to onsite clinical HCT survivorship care, the LTFU program uses telemedicine to continue working with patients after they relocate to their homes in various places around the world (SCCA, n.d.-b). Multiple authors have reported the myriad challenges of caring for HCT survivors as they leave the transplantation center and return to their home communities, as well as the importance of a continued partnership between the transplantation center and local providers to reduce morbidity and mortality in this population (Bhatia, 2014; Majhail & Rizzo, 2013; Tichelli & Rovó, 2015). A study of 441 Australian patients undergoing HCT evaluated, for the first time, HCT survivor preferences in long-term post-transplantation care delivery (Dyer et al., 2016). In this study, many HCT survivors preferred to receive LTFU care from their transplantation physicians (45%), and 74% of survivors preferred follow-up care administered at the transplantation center or through a satellite clinic or telemedicine service offered through the transplantation center (Dyer et al., 2016). Some outcomes of telemedicine in oncology care (teleoncology) are patient and local healthcare provider satisfaction, particularly as it relates to reduction in travel time and less disruption to family or work routines for patients, and the ability to network and receive support from tertiary centers for local providers (Sabesan, 2015). Providers in the LFTU program often rely on patients’ at-home photos of problems to improve diagnosis and propose treatments. One study from Brazil evaluating the effectiveness of teledentistry reported that, in 88% of cases, a correct diagnosis was made for oral cavity diseases using photos sent via email (Torres-Pereira et al., 2008). In a similar study done in Switzerland evaluating teledermatology, skin conditions were diagnosed correctly in 67% of cases, with a narrowing of the differential diagnoses in an additional 17% of cases; therapeutic recommendations could be made 70% of the time from digital images sent by patients (Rimner, Blozik, Fischer-Casagrande, & Von Overbeck, 2010).

With expanding indications for HCT and improvements in supportive care, the use of HCT is increasing. About 600,000 HCTs are performed annually.
worldwide, with a projection of 500,000 HCT survivors in the United States by the year 2030 (Hashmi, Carpenter, Khera, Tichelli, & Savani, 2015). HCT survivors can be medically challenging; more than 90% have at least one chronic health condition. Long-term complications are particularly difficult in those who receive HCT when aged younger than 35 years. As a result, physicians in all specialties, but particularly those in primary care, are confronted with the demands of managing long-term survivors (e.g., unclear symptoms and complications) more frequently than in the past (Hilgendorf et al., 2015).

A common complication of HCT is chronic graft-versus-host disease (cGVHD), which occurs in 40%-60% of patients undergoing allogeneic transplantation, typically within three months to three years after transplantation (SCCA, n.d.-a). Chronic GVHD is an immunoregulatory disorder that is the primary cause of late nonrelapse mortality and morbidity following HCT and is the major determinant of quality of life (QOL) in HCT survivors (Hull at al., 2015). Manifestations of cGVHD are seen in the lungs, liver, genitals, gastrointestinal tract, muscles, joints, fascia, eyes, and skin, with a prevalence in the oral cavity (Margaux-Muñoz, Bagán, Jiménez, Sarrión, & Poveda-Roda, 2015). The signs observed by physicians to diagnose oral cGVHD include lichenoid lesions, hyperkeratotic plaques, xerostomia, mucocoeles, mucosal atrophy, pseudomembranes, and ulcers (Margaux-Muñoz et al., 2015). Patients have reported that the most common symptoms of oral cGVHD are dry mouth; oral sensitivities to temperature, spicy foods, toothpaste, or soda; and restricted oral opening (Treister, Duncan, Cutler, & Lehmann, 2012). Hull et al. (2015) stated that oral cGVHD must be managed with close liaison with patients' transplantation physicians, because cGVHD can be a significant source of pain, limiting nutritional intake and affecting overall QOL. Excellent patient and clinician education resources for oral cGVHD are available through Be the Match, which facilitates transplantations, at http://bit.ly/2iDg08j.

**Assessment of the Population**

SCCA's LTFU program serves about 6,000 HCT survivors from all over the world but primarily from Washington, Idaho, Montana, Alaska, and Hawaii. Forty-five patients are typically served via telemedicine each week. The LTFU program comprises four patient care coordinators (PCCs), four RNs, and six attending physicians. PCCs answer and triage telephone calls to determine the purpose of the call and the acuity level of each patient's request. Incoming phone calls originate half of the time from patients and the other half of the time from their local providers. RNs in the LTFU program then call the patients or their physicians to perform an assessment over the telephone and review patient records to understand the issues at hand. When provider input is needed, the RNs take the patient cases to LTFU telemedicine rounds, held three times a week, where the LTFU attending physician can develop a treatment plan after reviewing the patient's history and relevant photos. The LTFU team collaborates with other providers to ensure that each patient receives comprehensive care.

**Background**

Standardization of photography is often a challenge in telemedicine. Patients in the LTFU program commonly struggle with taking and selecting clear and usable photos that accurately depict the signs of oral cGVHD. When quality photos are taken correctly, the team can determine diagnoses and treatments more conveniently and effectively. The importance of patients taking accurate photos for use in telemedicine has been noted in the literature (Jakovenko, 2009). Patients often do not have awareness of the skills that are necessary to capture, edit, and send their photos. Providers may avoid asking their patients to take photos because of this common problem. Mutalik (2010) listed tips for taking these diagnostic photos, including using natural light and macro mode without using the digital zoom on a digital camera, as well as stabilizing the camera with an assistant or tripod. Picture quality is also enhanced when patients rest their chin on a stabilized surface. If patients can increase the quality of their photos by following these tips, they can send the photos via email to the LTFU providers to be used as a tool for diagnosis and treatment.

A helpful strategy for assessing the problems observed in the current process of procuring photos from patients was asking the expert opinions of various LTFU providers (see Figure 1). In addition to the PCCs, RNs, and attending physicians on the LTFU telemedicine team, the oral medicine department at SCCA has dentists who serve as frequent consultants for patients with oral issues. A two-question survey was emailed to the dentists and attending physicians concerning what aspects of oral photography they would like to see improved to feel more comfortable making diagnoses and treatment recommendations via telemedicine. The RNs and PCCs were also surveyed for this project; they were asked three and four questions, respectively, about the process of obtaining patient photos for the LTFU program; these questions related to the instructions currently provided to patients to take photos, feedback given to patients when substandard photos are received, and barriers encountered when patients are asked to send in photos.

**Oral Medicine Group Response**

Three dentists from the oral medicine team replied (100% response rate). This allowed the student group to understand the common problems related to picture quality and to the picture features that would improve dentists' ability to make treatment recommendations. Two dentists identified common problems in photos as being poor image focus, inadequate lighting, and inadequate view of the problem area; they also expressed that they would like to see surface detail and color of the oral cavity. Another dentist explained that the main problems regarding patient photos included deficient photo resolution, out-of-focus lesions, poor coloring, insufficient lighting, and poor quality...
What barriers do patients face when asked to provide oral GVHD photos?

What key features do you want to see in oral GVHD photos to feel comfortable making treatment recommendations?

What feedback do you give to patients when the photos are unclear and cannot be used for assessment and/or diagnosis?

What are the most common problems you see in the quality of oral GVHD photos?

**ORAL MEDICINE PROVIDERS AND ATTENDING PHYSICIANS**
- What are the most common problems you see in the quality of oral GVHD photos that are sent to you?
- What key features do you want to see in oral GVHD photos to feel comfortable making treatment recommendations?

**REGISTERED NURSES**
- What instructions are you providing now when you ask patients to send in photos of oral GVHD?
- What feedback do you give to patients when the photos are unclear and cannot be used for assessment and/or diagnosis?
- What barriers do patients face when asked to provide oral GVHD photos?

**PATIENT CARE COordinators**
- What instructions are you providing now when you ask patients to send in photos of oral GVHD?
- What feedback do you give to patients when the photos are unclear and cannot be used for assessment and/or diagnosis?
- What are the most common problems you see in the quality of oral GVHD photos that are sent to you?
- What barriers do patients face when asked to provide oral GVHD photos?

GVHD—graft-versus-host disease; LTFU—long-term follow-up

printouts. Good quality, close-up digital photos or high quality prints on photo paper are preferred. The dentists concurred that blurriness and poor coloring contribute to loss of detail in photos of a patient’s oral abnormalities.

**Attending Physician Response**
Five of six attending physicians responded to the survey. Most of the physicians explained that suboptimal illumination and blurriness were issues in the photos they reviewed. They recommended that, along with providing detailed photos of the lesion(s), photos should also be taken from different views: bilateral buccal mucosa, posterior oropharynx, soft palate, and lips. One provider recommended that patients receive examples of helpful photos and non-helpful photos. Another provider recommended that patients receive instructions to have their photographer hold the camera still and far enough away from the subject of the photo so that the providers are able to orient the location of the problem. Providers would like to see the problem area in relation to the surrounding tissues. Patients should also include captions with the photos that they send. These providers included responses that encouraged improved patient instruction regarding taking oral photos. The providers agreed that patients should have examples of quality photos and instructions for what they should try to include in their photos.

**Long-Term Follow-Up Nurse Response**
Four LTFU nurses were surveyed (100% response rate). One nurse directed patients to use natural light, without flash, and to have someone assist in capturing the photos. Two of the nurses recommended using a flashlight or bright white light to illuminate the oral cavity. All four of the nurses instructed patients to take multiple photos and review the photos prior to sending them to SCCA. The four nurses also reported occasionally asking patients to retake photos when the photos received were blurry or dark. They noted that patient-reported barriers in providing oral cGVHD photos included complaints of not having smartphones or being skilled with technology. One nurse also stated that some patients do not have a friend or family member to help them take photos. All four nurses agreed that offering clear instructions on how to capture quality images would benefit patients in the LTFU program and improve providers’ ability to make an accurate assessment and diagnosis in the absence of an in-person evaluation.

**Patient Care Coordinator Response**
Three out of four PCCs responded to the survey questions. Overall, the PCCs felt that evaluating oral cGVHD photos of LTFU patients is not within their scope of practice. Each PCC expressed that these questions were more appropriate for the triage RN role. They did acknowledge common barriers that patients face when they are asked to take photos of their oral cavity (e.g., lack of caregiver assistance; knowledge deficits regarding camera use; poor photography skills; lack of technology skills, such as uploading photos or using email). Although the PCCs will ask patients to send in photos of their oral cavity in instances of oral issues, the job does not involve assessing the oral cGVHD photos that are sent in to triage.

**Plan**
A review of the literature and results from the multidisciplinary survey have shown that the LTFU patient population needs more instruction on the process of taking photos of the oral cavity. A nursing diagnosis that the students felt to be appropriate for the LTFU patient population was as follows: deficient knowledge related to the lack of provision of standardized photography instructions. Evidence for this diagnosis was a reported lack of quality photos taken by patients; in addition, uniform instructions for nurses to provide to patients to assist in increasing picture quality were lacking (Ackley & Ladwig, 2011). Specific education and tools were needed to aid this population because of the common problems that were arising from current practice. These tools needed to be adaptive and comprehensive for each patient participating in the LTFU program.
because of geographic and technologic barriers. After assessing the population and the problem, the goal for the project was further defined: to create and disseminate instructions for oral photography among the LTFU patients and their local providers to improve picture-taking of signs and symptoms of potential cGVHD. The specific tools for instruction were a brochure and video that are informative, sustainable, and readily available for LTFU patients and their local providers on the LTFU website. These two modalities were selected with support from the literature. Partin et al. (2004) conducted a randomized trial with 893 patients that compared the effectiveness of a brochure, a video, and usual care for delivery of prostate cancer screening education; the authors concluded that the video and brochure were comparable in effectiveness and that each resulted in better knowledge retention than usual care. Delgado, Ginde, Pallin, and Camargo (2010) studied patient education modality preferences among 1,010 patients receiving care in four Boston emergency departments, finding that reading a brochure was the most preferred method of instruction (34%), followed by watching a video (25%), speaking with an expert (24%), using a computer (14%) and attending a class or taking part in another format (3%). Similarly, Chan et al. (2015) compared four methods for delivery of stroke education to patients (video, brochure, one-on-one teaching, or a combination of these methods) in an emergency department and found that, although all 231 patients improved their knowledge in the immediate postintervention period, those in the combination group retained the most knowledge one month later. Frentsos (2015) explored the benefit of using videos as supplemental education tools for patients with cancer, citing multiple benefits of adding this modality to patient education.

Methods
This project was undertaken by six bachelor of science in nursing (BSN) students with a 10-week deadline. These undergraduate students from Seattle Pacific University in Washington had never had a clinical practicum at the SCCA, so establishing the partnership with an agreement signed by both parties was done within one month of the start of the quarter, and appropriate onboarding activities were done within the first week of the quarter. The estimated project cost, assuming a new graduate RN wage of $28 per hour and 480 person-hours, would have cost the institution more than $13,000 in salaries. This partnership was beneficial to both parties: the students, who learned how to implement an evidence-based practice (EBP) project in a clinical setting, and the institution, which gained quality EBP tools in a short time frame in addition to the opportunity to mentor BSN students interested in cancer care. Careful planning and intentional organizational strategies were discussed at the outset of the project. Attention to group process and commitment to the outcome was a critical component of the team’s success. The foundational planning work allowed the group to establish how to effectively collaborate, communicate, and problem-solve. The team learned how to use new technology for sharing files, writing a brochure, and creating a video.

To organize the project efficiently, the team members developed a project timeline at the beginning of the project (see Table 1). Each week, the team used the project timeline to gauge what tasks needed to be completed. The group stayed on task by creating a daily agenda for each weekly meeting (involving the students and the LTFU program nursing supervisor/adjunct clinical faculty member at Seattle Pacific University) and completing weekly minutes to document progress. The brochure and instructional video were then completed and uploaded to SCCA’s website (http://bit.ly/2iywyr).

Key Findings and Evaluation
Evaluation is important to determine the effectiveness of the intervention and the fulfillment of the project’s outcomes and goals. Formative evaluation was most pertinent to this project because it is a means of continually assessing materials through the development phase (Stetler et al., 2006). Internal and external

<table>
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<tr>
<th>TABLE 1.</th>
<th>ORAL PHOTOGRAPHY EVIDENCE-BASED PRACTICE PROJECT TIMELINE</th>
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<tbody>
<tr>
<td><strong>WEEK(S)</strong></td>
<td><strong>TASKS</strong></td>
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<tr>
<td>1</td>
<td>Review timeline, assign tasks, and establish group communication and collaboration norms.</td>
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<tr>
<td>1-2</td>
<td>Participate in on-site learning to understand LTFU program, learn about the population served, and identify possible interventions for site-identified problem.</td>
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<tr>
<td>1-5</td>
<td>Review literature, identify additional data needed, and analyze all data sources for applicability to project; for each of these five weeks, the six students each evaluated and shared with the group one article that was then discussed among all the students, resulting in the compiling of a total of 30 applicable articles.</td>
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<tr>
<td>3-5</td>
<td>Create expert opinion survey, solicit participation, and evaluate results; this was done in teams of two by provider type.</td>
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<td>4-6</td>
<td>Use evidence to develop brochure and video; three students each worked on the brochure and the video.</td>
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<tr>
<td>7</td>
<td>Gather and evaluate feedback on the brochure and video from nurses, providers, patients, and volunteer child reviewers.</td>
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<tr>
<td>8-10</td>
<td>Revise and finalize brochure and video; again, three students each worked on the brochure and the video.</td>
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<tr>
<td>9</td>
<td>Develop evaluation and sustainability plan to assess and adjust tools, as needed.</td>
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<tr>
<td>10</td>
<td>Present project to LTFU team, with rationale behind the tools created, and teach the LTFU team how to implement the new process.</td>
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<td>LTFU—long-term follow-up</td>
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evaluators gave feedback on the video and brochure to ensure project goals were met.

Designing materials for patients, such as brochures and videos, must take into consideration the health literacy of the targeted patient population. Health literacy is the capacity of a patient to obtain, interpret, and understand health education and is the single most important predictor of a patient’s health status (Badarudeen & Sabharwal, 2010). Health literacy in patients undergoing HCT has been found to be not only a simple function of age, ethnicity, race, or education, but also a more complex and dynamic factor that demands careful assessment, clear educational tools, and improved communication strategies to help HCT patients better understand vital health information (Cohen, Jenkins, Holsten, & Carlson, 2013). Readability of written materials is a key component of health literacy that must be considered to ensure that patients can easily comprehend them. Patient education publications are recommended to have no greater than an eighth-grade reading level so that patients of varying literacy levels are able to read and understand the content (Badarudeen & Sabharwal, 2010). The Flesch-Kincaid Grade Level scale is commonly used to determine readability because of the ease of its use within the Microsoft Word® program (Ridpath, Greene, & Wiese, 2007); the scale provides a grade-level score based on the U.S. school grade-level system (i.e., reading level of 8 being equivalent to an eighth-grade reading level). The overall readability of the first draft of the brochure had a reading level of 9.6 on the Flesch-Kincaid Grade Level scale, with each paragraph ranging from 3.7–12 on the same scale. The LTFU nurses reviewed the brochure draft for readability, with all four providing feedback, which was used to update the brochure. The second draft of the brochure had an overall Flesch-Kincaid Grade Level reading level of 6.8, with sections ranging from 4.3–10.5 on the same scale. The second draft of the brochure was then reviewed by the LTFU nurses, attending physicians, oral medicine providers, and three LTFU patient reviewers; these reviewers were asked if the brochure was easy to understand and if they were able to follow the steps to take pictures of their mouths, as well as to provide any additional comments. The LTFU patient reviewer comments were particularly helpful because these individuals are the target population for the materials. In addition, two volunteers, an 8-year-old and a 9-year-old, verified readability by reviewing the second draft of the brochure. Both children had difficulty with some wording, such as the word neutral, which was changed; they also had difficulty with disease-specific terminology, such as lichenoid, bone marrow transplant, and graft-versus-host disease, which could not be changed. Fourteen of 18 potential reviewers (patients, healthcare providers, and volunteer child reviewers) provided feedback, which was reviewed and incorporated into the final draft of the brochure. The final draft had an overall Flesch-Kincaid Grade Level reading level of 6.5, with sections ranging from 3.7–12 on the same scale.

An original Adobe Photoshop® version of the brochure was given to the LTFU nurses so that changes and adjustments can be made in the future when technology changes or as the LTFU program has the opportunity to evaluate for possible improvements. Sustainable programs must be continually evaluated over time for quality improvement to maintain relevancy (Akin et al., 2013). As part of this continual evaluation process, this project included a face-to-face presentation to the LTFU team to teach members how to use the instructional tools created. Providing the LTFU team with an educational session on the brochure and video was consistent with the Iowa Model of Evidence-Based Practice to Promote Quality Care (Keel, 2011) for implementing a change in practice. During the presentation, the nursing students offered additional tips for patients that were not included in the video or brochure so that nurses could troubleshoot poor quality pictures; the LTFU nurses were told to relay these tips to patients if they continued to struggle with taking clear pictures of their oral cavity. The nursing students also recommended that the LTFU nurses follow up with patients who received and used the instructional tools to continually assess the effectiveness of these interventions, ensuring that the project remains sustainable over time.

Limitations
Some limitations that exist for this patient population include wide variations in health literacy; poor vision because of cGVHD, which makes reading difficult; poor overall health and functional status related to HCT and/or non-HCT morbidity, which makes accessing information challenging; and the lack of proper resources necessary for better photography (e.g., smartphones, camera, Internet access, caregiver to serve as photographer). In addition, the brochure and video were developed in English, but patients may not speak or read English. The team accounted for some of these limitations by making instructional tools in an audiovisual format in addition to a written format, as well as by using a large font, symbols, and simple language. Another limitation that was encountered in this project was the inability of the students to see the project through to the evaluation phase because they were limited to a 10-week academic session.

Implications for Practice and Conclusion
Telemedicine is growing in quality and popularity, and technological advances will continue to support its development. The

“Standardization of photography is often a challenge in telemedicine.”
goal of this project was to develop a sustainable intervention that patients and LTFU staff could use to increase picture quality of possible oral cGVHD, with the intention of improving diagnosis and treatment. The brochure and video that were created provided audio and visual instructions for patients that are supported by research and LTFU staff recommendations.

This partnership between a BSN program and an outpatient specialty department of a comprehensive cancer center was a successful one. Although completing regulatory requirements and working with a school of nursing to sign partnership agreements and onboard students into the center can be daunting, the benefits to the students as learners and to the institution as partners in teaching outweigh the burden. An outpatient telemedicine program is not an obvious choice for a clinical placement, but the learning objectives for this course lent themselves beautifully to the setting. Creative alliances between academia and clinical practice should be explored for mutual benefit.

This project was an excellent example of how to make a practice change when applicable, high-level evidence is not readily available. When the students were unable to find traditional EBP resources for answering the question of how to improve home oral photography for the benefit of telemedicine diagnosis and management of oral cGVHD, they had to expand their search criteria and find evidence to support the project. They discovered evidence to support improved clinical photography in related disciplines and learned to incorporate multidisciplinary expert opinions. The students also integrated evidence about how to create patient instructions in written and audiovisual formats for health concerns other than cGVHD and translated the evidence to work for this problem. Finally, they also incorporated patient (end user) opinion into the project, which is always a critical component of an EBP project.

In addition, the students created tools using a patient- and family-centered approach by providing the content in an easy-to-read written format, as well as a video format. The tools were created to be uploaded to the LTFU website and can be accessed by patients and local healthcare providers. The brochure is printable and the video is viewable from the website. Multiple modalities are important for nurses to consider when evaluating barriers to accessing health information, as well as patient preferences, when learning about health-related topics.

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