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For the LOvE of Reproductive Health Communication: Assessment of the LGBT Oncofertility Education (LOvE) Module

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Purpose: The lesbian, gay, bisexual, transgender, and queer (LGBTQ) Oncofertility Education (LOvE) module aims to improve knowledge on providing inclusive and affirming care for LGBTQ adolescents and young adults (AYAs) with cancer. The objective of this study is to evaluate the role of the module in improving reproductive health communication for the care of LGBTQ AYAs with cancer.

Methods: A 10-item multiple-choice pre-test and post-test assessed learner knowledge, with total knowledge scores ranging from 0 (no correct responses) to 10 (all correct responses). A post-module survey and open-ended questions assessed relevance of the module, quality, and appropriateness to professional practice. Paired *t*-tests analyzed changes in knowledge before and after the module. Content analysis was applied to qualitative responses.

Results: Thirty-seven learners completed both the pre-test and post-test. Around 8.1% correctly answered all pre-test questions; 59.5% correctly answered all posttest questions. The average pre-test score was 8.3, versus posttest score of 9.5 ($p < 0.0001$). Eighty-nine percent of learners strongly agreed that LOvE Enriching Communication Skills for Health Professionals in Oncofertility was relevant to their work; 95% strongly agreed that it was easy to understand and navigate. Open-ended responses highlighted how the module helped learners strengthen the provider-patient relationship in the context of oncofertility, create a safe space for patients, and understand the relevance of educational materials about fertility to LGBTQ patients.

Conclusions: We found significant improvement in knowledge of reproductive health care for LGBTQ AYAs with cancer after completing the module. Improving provider knowledge may improve confidence in providing inclusive and affirming care for LGBTQ AYAs with cancer, resulting in improved whole-person care.

Keywords: oncofertility, reproductive health, sexual health, education, fertility

Introduction

ADOLESCENTS AND YOUNG ADULTS (AYAs) WITH cancer have unique psychosocial needs, with reproductive health being a primary concern. In the United States, AYA is defined as individuals between 15 and 39 years of age.¹ Fertility information and sexual health are two of the most cited unmet needs among AYAs with cancer and this lack of information has been associated with both reduced mental

health and overall quality of life for patients.²⁻⁴ Studies have shown that AYAs with cancer report uncertainty and self-doubt after cancer treatment when discussing issues such as starting a family, sexual health, and dating.^{5,6} The majority of practice guidelines on cancer in the AYA population focuses on treatment and survivorship, but do not address sexual health, sexual functioning and satisfaction, or fertility-related issues.⁷⁻⁹

Health disparities exist among lesbian, gay, bisexual, transgender, and queer (LGBTQ) AYAs with cancer.^{10,11} AYA

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cancer survivors are at increased risk of experiencing challenges in psychosexual development in terms of sexual functioning, body and self-image, sexuality, dating, relationships, and fertility.^{5,12,13} These psychosocial and psychosexual developmental risks may be exacerbated among LGBTQ AYAs with cancer due to minority stress and lack of structurally competent care. Compared to non-LGBTQ patients, LGBTQ patient populations report lower satisfaction with cancer care treatment, higher rates of psychological distress in survivorship, and LGBTQ-based discrimination.¹⁴ A systematic review of barriers to cancer screening in LGBTQ populations revealed the top barriers to screening were fear of discrimination from health care providers and lack of cancer screening guidelines specific to LGBTQ populations.¹⁵

In general, LGBTQ AYAs are also more likely to delay seeking medical care due to negative past interactions with the health care system and health care professionals.^{14,16,17} A qualitative study on the cancer care experience among LGBTQ patients highlighted providers' lack of LGBTQ-specific knowledge, especially misgendering patients. The study also notes patients felt they had to self-advocate throughout most of their treatment; however, this becomes difficult when severely ill.¹⁸ Other studies have stressed the need for health care professionals to be aware of and address potential patient vulnerabilities as it relates to cancer care for LGBTQ patients, including lack of social support and discrimination within the health care system.^{19,20}

While clinicians are often aware of infertility risks associated with cancer treatment, many report that they lack the skills to discuss this topic with their patients, regardless of identity, leading to a decreased likelihood of fertility conversations.^{21–25} When clinicians were surveyed on their knowledge and attitudes toward providing care to LGBTQ people with cancer, the results showed high levels of comfort in providing medical care, but low knowledge regarding psychosocial needs, particularly regarding fertility and sexual health.²⁶ Clinicians' discomfort discussing fertility in general and the lack of research addressing LGBTQ psychosocial needs during and after cancer treatment likely exacerbate informational needs and communication barriers for LGBTQ AYAs and their clinicians.²⁷

Gaps in clinician knowledge may directly impact the quality of care for LGBTQ AYAs with cancer. Environments that foster inclusivity and provide affirming care can improve the patient-clinician relationship as well as patient comfort. To address this issue, the LGBTQ Oncofertility Education (LOvE) module was created within the Enriching Communication Skills for Health Professionals in Oncofertility (ECHO) program.

The NCI-funded R25 ECHO program provides reproductive health communication training to individuals who provide care for AYAs with cancer.²⁸ The ECHO curriculum was then expanded to include the LOvE module. The module aims to improve knowledge on providing inclusive and affirming care, including collecting information about sexual orientation and gender identity, discussing reproductive health, and minimizing personal bias. The objective of this project is to evaluate the role of the LOvE module in improving reproductive health communication for the care of AYAs with cancer.

Materials and Methods

Module creation

ECHO is an 8-week online training program offered annually since 2011.²⁸ The LOvE ECHO module was created within the ECHO program in the Fall of 2020. The module content was designed by input from interdisciplinary experts, including those in oncology, reproductive endocrinology, sexual and reproductive health, LGBTQ health, and online and adult learning. In addition, 12 LGBTQ AYA cancer survivors reviewed each interactive case within the module and provided feedback through both individual and small group feedback sessions. This feedback was then integrated into the cases.²⁹

Module content

The learning objectives for the module are to identify disparities in health for LGBTQ AYAs, to understand barriers to affirming care and reproductive health for LGBTQ AYA cancer survivors, and to address systems-level barriers to quality reproductive health care for LGBTQ cancer survivors. The module takes about 15 minutes to complete and consists of an interactive glossary as well as lectures on LGBTQ AYA health disparities and outcomes with regard to reproductive health as well as barriers to affirming care. There are also three interactive cases on care for LGBTQ AYA cancer survivors and a final section where learners may create a plan for how to implement what they learned into their day-to-day practice. To assess changes in knowledge, a pre- and post-test assessment was done immediately before starting and immediately after completing the module content.

Study

Learners were selected from a cohort of previous ECHO program participants. Eligibility criteria included being an allied health professional (AHP) from one of the following professions: nurses, psychologists, physician's assistants, or social workers. Learners who participated in the study were from institutions nationwide. Learners completed a 10-item multiple-choice pre-test and post-test assessing knowledge of providing affirming reproductive health care to LGBTQ AYAs with cancer. Pre-test and post-test questions were the same. Total knowledge scores ranged from 0 (no correct responses) to 10 (all correct responses).

A post-module survey assessed relevance of the module, quality, and appropriateness to professional practice on a 5-point scale of strongly agree to strongly disagree. An open-ended item invited learners to describe integrating this knowledge into their practice, barriers for implementation, and suggestions for improving training in LGBTQ AYA cancer care. Paired *t*-tests were used to analyze changes in knowledge before and after the module using a $p < 0.05$ level of significance.

Content analysis was applied to qualitative responses. Responses were analyzed using inductive content analysis guided by COREQ quality standards for qualitative research. Open coding was applied to identify themes within each question (*a priori* theme).³⁰ Emergent themes were considered if they represented a meaningful pattern. Using an Excel file created from all responses, and divided by the question to

which it pertained, all open-ended responses were reviewed, and a list of codes was generated, noting the strength of the pattern in the data (e.g., the majority, a few). A numbered list of all comments for each question was created and the number of times the comment was labeled as belonging with one of the finalized codes was identified. Open comments were anonymous; therefore, demographics of those who provided comments are not available.

Results

A total of 51 learners completed the module, including the pre-test. Thirty-seven learners completed both the pre-test and post-test (73% of pre-test group). The majority of learners (94%) scored higher on the posttest than on the pre-test. The percentage of learners who correctly answered all pre-test questions was 8.1%, compared to 59.5% of learners who correctly answered all posttest questions. The mean pre-test to post-test total score increased from 83% to 95% ($p < 0.0001$; $t(86) = 7.41$).

There was a significant improvement in posttest compared to pre-test scores on questions focused on fertility risks to LGBTQ AYAs with cancer, including the relevance of fertility educational materials to LGBTQ patients ($t(86) = 14.82$, $p < 0.001$), difference in fertility counseling between LGBTQ and cisgender, heterosexual peers ($t(86) = 12.68$, $p < 0.001$), and sharing information that may reveal gender identity of a patient in the context of fertility ($t(86) = 8.97$, $p < 0.001$). There was a significant improvement in posttest scores for the question on discussing sexual attraction or involvement with LGBTQ AYA patients ($t(86) = 2.69$, $p = 0.0086$) and an improvement in post-test scores on the question on contraception education for LGBTQ AYAs, although not statistically significant ($t(86) = 1.68$, $p = 0.0928$).

Finally, two questions related to patient social support showed significant improvement in posttest answers, including questions on physical and emotional challenges for LGBTQ AYAs ($t(86) = 10.40$, $p < 0.001$) and discussing how patients identify themselves ($t(86) = 3.36$, $p = 0.0014$). The remaining questions showed improvement in posttest answers, although not statistically significant. These questions included differences in referral support for AYA cancer survivors ($t(86) = 1.90$, $p = 0.0629$), the importance of pronoun use for patients ($t(86) = 1.78$, $p = 0.0794$), and how to know what pronouns to use for patients ($t(86) = 1.70$, $p = 0.0912$) (Table 1).

Within the post-module survey, 89% of learners strongly agreed that the LOvE ECHO module was relevant to their work, 95% strongly agreed that it was easy to understand and navigate, and 98% strongly agreed that the module was appropriate for the scope of their professional practice (Fig. 1). A total of 22 open-ended responses were recorded by learners. Open-ended responses revealed three main common themes. The first theme was learners reporting that the module helped with strengthening of the provider-patient relationship in the context of oncofertility, seen in 68% of responses.

The second theme was that the module assisted in creating a safe space for patients. This was noted both in terms of the learners feeling as though they were given the tools to create a safe space for this patient population and based on feedback learners had received from patients. The third theme was the module improving learner understanding of the relevance of fertility to LGBTQ patients. Multiple learners reported feeling confident in the relevance of fertility to cancer before completing the module, but now feeling confident in fertility within the LGBTQ patient population after participating in the module. Representative quotes are included in Table 2.

TABLE 1. PRE- AND POST-TEST QUESTIONS AND RESULTS

<i>Item content</i>	<i>Correct (pre-test)</i>	<i>Correct (post-test)</i>	<i>p</i>
Overall knowledge (% of total items correct)	83% (51)	95% (37)	<0.0001
Fertility risks			
Relevance of fertility educational materials to LGBTQ patients	74% (51)	98% (37)	<0.0001
Differences in fertility counseling between LGBTQ and cisgender, heterosexual peers	67% (51)	92% (37)	<0.0001
Sharing information that may reveal gender identity of a patient in the context of fertility	69% (51)	89% (37)	<0.0001
Sexual health			
Important focus for contraception education with LGBTQ patients	89% (51)	93% (37)	0.0928
Discussing sexual attraction or involvement with LGBTQ AYAs	87% (51)	96% (37)	0.0086
Social support			
Differences in referrals of support for AYA cancer survivors	91% (51)	95% (37)	0.0629
Physical and emotional challenges of LGBTQ AYAs	73% (51)	93% (37)	<0.0001
Importance of pronoun use for patients	95% (51)	99% (37)	0.0794
How to know what pronouns to use for patients	93% (51)	96% (37)	0.0912
Discussing how patients identify	88% (51)	94% (37)	0.0014

AYAs, adolescents and young adults; LGBTQ, lesbian, gay, bisexual, transgender, and queer.

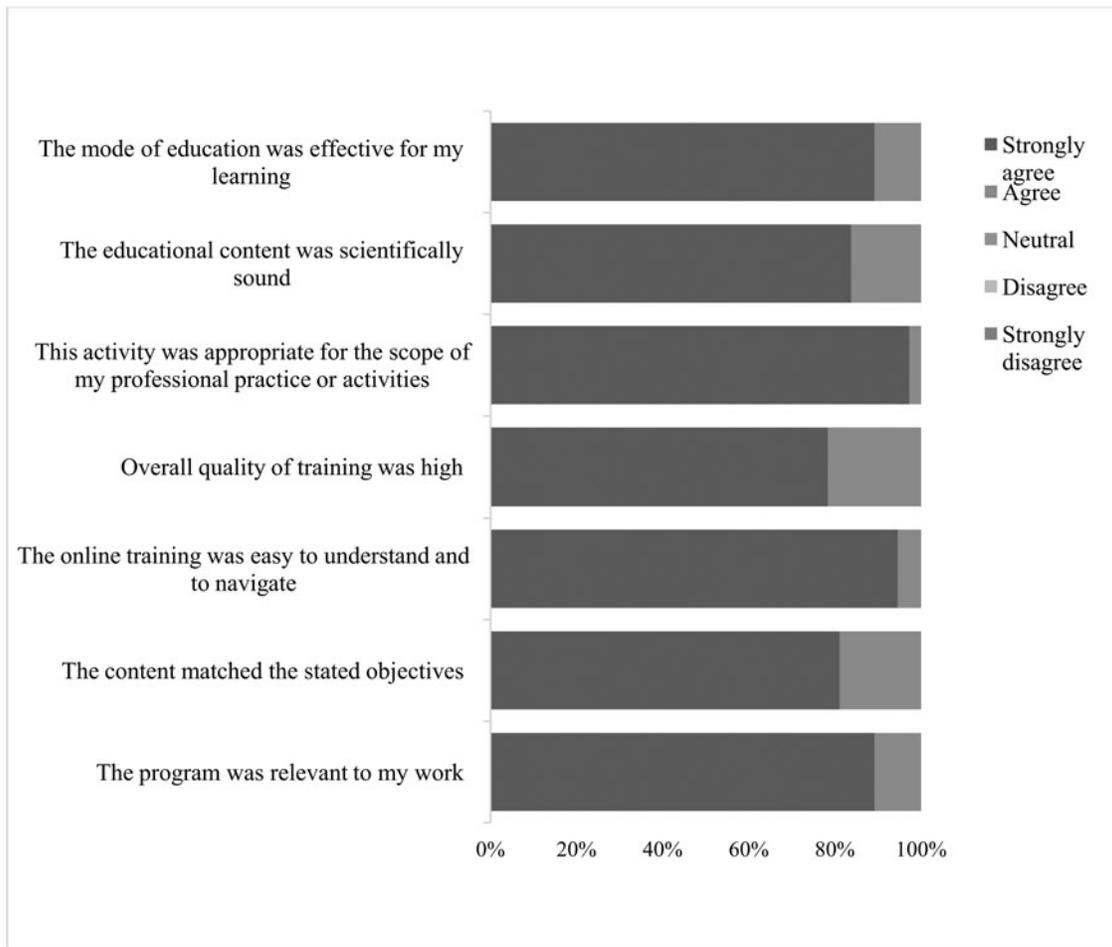


FIG. 1. Post-module survey.

Discussion

The LOvE ECHO module is a promising tool for improving reproductive health communication for AHPs working with LGBTQ AYAs with cancer. Our findings demonstrate that this module meets an essential need in training health professionals. In multiple studies, physicians and AHPs have reported feeling poorly prepared to educate AYA cancer patients on topics such as fertility, sexual health, and contraception and reported a desire for further training in this area.³¹ Surveys of clinicians suggest that discussions about fertility are not routinely occurring, despite existing guidelines on this topic, with a lack of knowledge often cited as the top barrier to providing education to patients.³² In another study, AHPs were surveyed and described the need for additional education focused on reproductive health of LGBTQ patients with cancer.²⁴

This study found that completion of the LOvE module significantly improved knowledge across a variety of reproductive health domains, including fertility risks, sexual health, and overall social support for LGBTQ AYAs with cancer, thus addressing an important need in the care for LGBTQ AYAs with cancer. In addition to an increase in knowledge observed in pre-test to post-test scores, learners perceived an increase in confidence in counseling LGBTQ AYA cancer

patients on reproductive health and this was seen both for learners with a strong background in working with this population as well as for learners with less of a background.

These findings indicate that as knowledge and confidence are improved after completion of the module, frequency of discussions and therefore quality of patient care may increase as well. This is a need that is essential for the holistic care of this patient population, including strengthening the provider-patient relationship and improving health outcomes and patient experience with the health care system.

A limitation of the study was that the number of learners who completed both the pre-test and post-test was only 37. It should also be noted that this module cohort was ongoing during the start of the COVID-19 pandemic. As many learners are AHPs on the front lines, this may have impacted their ability to successfully participate in the program. An additional limitation of the study was a lack of demographic information on the learners, including learner profession and gender identity, as the study did not have an Institutional Review Board to collect identifying data on learners. Finally, all learners who participated in the LOvE ECHO module had previously participated in the ECHO training program. As the ECHO training program provides a framework for the LOvE ECHO module, it is important to note that this is a limitation in evaluating the effectiveness of the module on its own.

TABLE 2. OPEN-ENDED RESPONSES

What specifically did you learn during this activity that you intend to integrate into your practice?

- “This course helped me deepen my ongoing reflective practice and be accountable for how I may have perpetuated systemic cis-heteronormative biases within my own work and institution.”
- “Working with the LGBTQ population is an area of interest and expertise of mine already, but I appreciated thinking of this population within the context of cancer care and oncofertility, and what improvements could be made in my workplace.”
- “How to approach a patient with correct pronouns.”
- “In the LOVE course I gained knowledge in how to adjust my clinical practice in a way that addresses some of the health disparities members of the LBGTQIA-AYA community may face within the continuum of their cancer care.”
- “...learned to be a better advocate and address barriers within the system to support and honor patients and survivors.”

LGBTQIA, lesbian, gay, bisexual, transgender, queer, intersex, asexual; LOvE, LGBT Oncofertility Education.

A strength of the study is that pre-test and post-test questions were the same, allowing for accurate comparison of answers. Another strength of this study is that, to our knowledge, it is the first educational intervention to demonstrate success in enhancing provider knowledge in fertility and sexual health education for this patient population.

The LOvE ECHO module is only offered in an online format, which offers an opportunity to provide training that can be completed in any location and at the chosen pace of the learner. In the future, the module will be continued to be offered online to expand learner access and provide greater learner flexibility. LOvE ECHO will now be a required module in the upcoming ECHO curriculum for new learners and previous learners will also have access to it. Continued assessment of results and learner feedback will also inform changes that may need to be made to further improve the module.

At this point in time, any AHP may apply to acceptance into the ECHO training program, and once accepted, will subsequently have access to the LOvE ECHO module. Integrating the module into existing training for all AHPs working with AYA oncology patients is another future goal. This work may contribute to changes in care at both the individual and the institutional level, as AHPs improve communication and holistic reproductive care for patients.

Conclusion

Our findings demonstrate significant improvement in knowledge of reproductive health care for LGBTQ AYAs with cancer after completing the LOvE ECHO module. Improving provider knowledge may subsequently improve confidence in being advocates and in providing inclusive and affirming care for LGBTQ AYA patients with cancer, resulting in improved whole person care.

Authors' Contributions

J.P. collected, analyzed, and interpreted the data and wrote the article. A.S., R.B., M.E.S., and S.T.V. interpreted the data

and reviewed the article. G.P.Q. reviewed the article and supervised the entire research process. All authors read and approved the final article.

Author Disclosure Statement

No competing financial interests exist.

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