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Co-Creation of a Hematopoietic Stem Cell Transplant e-Learning Patient Education Module on
Fertility Preservation and Family Planning

DNP Project
Submitted in Partial Fulfillment
Of the Requirements for the Degree of
Doctor of Nursing Practice

St. Catherine University
St. Paul, MN

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May 2018

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This is to certify that I have examined this
Doctor of Nursing Practice DNP project manuscript
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and have found that it is complete and satisfactory in all respects,
and that any and all revisions required by
the final examining committee have been made.

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DEPARTMENT OF NURSING

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FERTILITY AND FUTURE FAMILY PLANNING

Abstract

Doctoral Project Title: Co-Creation of a Hematopoietic Stem Cell Transplant e-Learning Patient Education Module on Fertility Preservation and Family Planning.

Problem: Hematopoietic Stem Cell Transplant (HCT) is associated with high rates of infertility in both men and women of childbearing age. There are barriers to providing fertility preservation and future family planning education despite the national guidelines that all patient should be informed about these options. HCT patients undergo treatment regimens that result in life changing consequences affecting the patient's future quality of life (QOL). Barriers can be multifaceted as it relates to the urgency of treatment, risk of mortality, acuity of disease, financial implications communication with health professionals and social, emotional or cultural considerations. Patients and caregivers would like to receive as much information as possible, which is a challenge for patients and families during times of acute distress. The topic of fertility, fertility preservation and future family planning options requires a personal and emotionally driven conversation. It can be challenging for a patient to advocate for themselves to promote the discussion of fertility preservation with a physician or caregiver. Additionally, physicians need education and skills to discuss fertility preservation with their patients.

Purpose: The purpose of this doctoral quality improvement project is to develop a self-directed e-learning educational tool for patients and caregivers on fertility preservation and future family planning options.

Projected Outcomes: Research is limited on HCT patients' self-assessed knowledge of fertility risk, fertility preservation, and options for their future family planning before and after HCT. After dissemination of this educational resource, an evaluation of patient-related outcomes will be completed to determine the effectiveness of a patient-centered web-based education on communication, self-advocacy, and shared decision-making for this population. In addition, the

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information gained from the development and a quality assurance process will help direct future e-learning education.

Keywords: hematopoietic stem cell transplantation, e-learning, patient education, computer, patient outcomes, interactive and shared decision making.

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Co-Design of a Hematopoietic Stem Cell Transplant e-Learning Patient Education
Module on Fertility Preservation and Family Planning

Because of the advances in diagnosis and treatment, the number of hematopoietic stem cell transplant (HCT) survivors has grown over the past decade. Studies have demonstrated that transplant patients (ages 18-40) lack knowledge about fertility risks and fertility preservation options, which may have a significant influence on the quality of life (QOL) after transplantation. The evidence reveals that HCT survivors continue to have concerns about their fertility even ten years after treatment (Hammond, Abrams, & Syrjala, 2007). Research is limited on patient self-assessed knowledge of fertility risk, fertility preservation, and future family options before or after HCT and educational tools to reduce those disparities. Together these variables can potentiate the educational barriers for transplant patients regarding fertility.

To achieve this goal, this DNP quality improvement project includes a description of how to develop, complete quality assessment and disseminate an interactive web-based educational tool on fertility preservation and future family planning options for HCT patient at Be The Match. To achieve this goal, this project includes a description of the improvements in the organization's current patient education development process to incorporate stakeholder engagement along with a formal vetting process. This is a change in the operational process to integrate interactive education to improve the patient and caregiver's experience of care.

This paper will also outline Be The Match organizational structure, professional culture, and how the system promotes patient safety and interdisciplinary team collaboration to describe the creation of a patient centered, self-paced e-learning educational program for adult HCT patients on fertility risks and future family planning. Strategic decision making in the healthcare environment is guided by an organization's professional culture and interdisciplinary collaboration. Determining the culture of a clinical system helps to determine how agile the

organization is and whether they can nurture the implementation of a clinical project through team leadership that requires a change and safeguards patients. A successful organization considers the paradigm between its mission and vision to integrate improvements in health care delivery to address specific public health concerns.

Background and Significance

In the United States (US) 23,000 transplants were performed in 2017 to treat blood cancers (e.g. leukemias and lymphomas), and blood and immune system disorders (e.g. sickle cell disease and severe-combined immunodeficiency) and the number of survivors will double by 2020 (Center for International Blood and Marrow Transplant Research (CIBMTR), 2016). HCT is the transplantation of hematopoietic stem cells derived from the bone marrow (sibling or unrelated donor) or syngeneic (from an identical twin), peripheral blood or umbilical cord blood (Be The Match, 2017).

Patients with diseases treatable with HCT are at considerable risk for infertility due to the acuity of their disease and urgency of treatment. For some patients, particularly those with hematologic malignancies, the primary treatment given to control disease can result in the initial injury to reproductive organs. Then patients may go onto additional treatment because HCT is an important curative component of the treatment trajectory. Transplantation consists of increasing doses of alkylating agents and total body irradiation resulting in the permanent gonadal damage and infertility (Carter et al., 2006).

Widespread use of transplant is attributed to improvements in preparative regimens, supportive care, and donor sources, all resulting in a growing number of long-term survivors (Carter et al., 2006). A quality of life issue for adults is fertility preservation and future family options after cancer treatment. The evidence reveals that HCT survivors have continued concerns about their fertility even ten years after treatment (Hammond, Abrams, & Syrjala, 2007). Studies

demonstrated that transplant patients, ages 18-40, lack knowledge about fertility risks and fertility preservation options which can have a significant influence on their QOL after transplantation (Loren et al., 2013a).

Research is limited on patient self-assessed knowledge of fertility risk, fertility preservation, and future family options before HCT (Loren et al., 2013a). There are limited resources that provide tailored patient education to men and women of childbearing age at high risk of infertility related to HCT (Loren et al., 2013a). There is a vast amount of printed educational materials that can prompt the discussion, in addition to several websites that focus on reproductive options for patients with cancer such as (myoncofertility.org), (fertilehope.org), and (savemyfertility.org). Furthermore, a new iPhone app, iSaveFertility, allows providers and patients instant access to fertility preservation information. These electronic resources improve education (although not specific to the HCT population) and help patients navigate the complexity of their treatment trajectory.

In the past two decades, several patient education programs have attempted to incorporate computer-based tools. Today, with the evolution of the Internet as a readily accessible source of health care information, computer-based educational programs take advantage of a patient's comfort with technology (Eysenbach, 2003; Lee, Gray & Lewis, 2010).

Problem Statement

There are still barriers to communication despite the guidelines from the American Society of Clinical Oncology that patients should be informed about fertility preservation options (Lee et al., 2006, Loren et al., 2013b). Fertility preservation options are not routinely explored early in the treatment timeline of patients diagnosed with hematologic malignancies (Loren et al., 2013b). The problem this quality improvement project will address is the fertility and future family planning education gap experienced by HCT patients.

Needs Assessment

Be The Match is a nonprofit organization established in 1986, operated by the National Marrow Donor Program® (NMDP). It is the world's largest donor registry providing unrelated bone marrow and umbilical cord blood transplants to patients in need. Be The Match operates the Office of Patient Advocacy, Single Point of Access for the C.W. Bill Young Transplantation Program. The mission of Be The Match states, "We save lives through cellular therapy" (Be The Match, 2017). The organization's culture is based on a walk the talk philosophy and the employees are dedicated to promoting self-advocacy and shared decision-making for the HCT patient population. Be The Match strives to develop services for health care professionals and patients nationally and internationally.

Be The Match Patient and Health Professional Services (PHPS) department provides tailored information to support patients, families, caregivers and health professionals to promote informed decision making from time of diagnosis through survivorship. PHPS provides free services and guidance before, during and after transplant, focusing on the emotional, medical and financial needs of patients and healthcare professionals, and conducts health services research (Be The Match, 2017).

Be The Match is a dynamic system embracing change to adapt and stay current in the ever-changing healthcare environment. It has historically provided educational resources in the written medium or in voice over PowerPoints to HCT patients and health professionals, yet has never incorporated an interactive web-based tool. Be The Match's interest in collaborating with the author to develop the web-based educational tool was due to the organization's cultural dedication to their mission and vision.

In 2016, Be The Match established a working group with the Patient-Centered Outcomes Research Institute (PCORI) to identify important focus areas related to sexual health and

relationships for HCT patients (Clauser, Gayer, Murphy, Majhail, & Baker, 2015). The framework for this working group included:

- An extensive literature search to identify gaps in knowledge;
- Discussions with patients about their experiences to identify focus areas; and
- Identification of interventions that have been tested for comparative effectiveness research (CER).

The five areas that were identified as important focus areas related to sexual health include:

1. Sexual activity
2. Sexual health
3. Communication
4. Body image
5. Fertility

The problem statements or recommendations of the working group regarding educational gaps and fertility resources include:

- fertility preservation options are not initiated early enough in the cancer therapy trajectory;
- preservation options for pre-pubertal males and females are limited;
- form a better understanding of the patient and caregiver's barriers to fertility preservation options;
- develop longitudinal studies to explore the emotional response to infertility and its impact of infertility on self-esteem and relationships;
- focus future clinical effectiveness research (CER) on interventions to facilitate healthy adaptations.

Currently, Be The Match has written fertility fact sheets for women and for men. The fact sheets are available to patients through the online materials catalog and may be ordered by HCT health care professionals to hand out to patients. The fact sheets provide a very basic overview of the issues, but do not explore in detail any communication strategies with providers, insurers, shared decision-making or the emotional impact of loss of fertility.

Patients, families and health care professionals, need easy to access material they can reference in the moment. Their schedules are varied and busy, and they often do not have a lot of time to dedicate to researching or participating in long educational sessions. The assumption is an easily accessible web-based educational tool will be most appropriate for the target audience.

Project Purpose and PICO

It is imperative to determine the effectiveness of patient-centered education on communication, self-advocacy, shared decision making and health outcomes in the HCT population. The purpose of this project was to develop a self-directed e-learning education resource with a menu of topics on fertility preservation and future family planning. The PICO question developed for the problem of limited educational resources directed at HCT patients ages 18 to 40 years old prior to HCT. What is the effect of a web-based education program focused on fertility risks, fertility preservation and future family planning on program satisfaction, usability of the information, level of knowledge, and behavior change pre and post participation?

The DNP evidence-based project intervention was to develop a web-based educational tool that will be available to HCT patients. The project plan included a new process for developing and vetting an online educational product with stakeholder involvement.

Theoretical Framework

Theoretical underpinnings provide a foundation to improve patient and healthcare outcomes. This project is designed around several conceptual and theoretical frameworks. The primary theoretical frameworks for this project are on Neuman's Systems Model and Lewin's Theory of Planned Change.

The proposed theories consider the culture and values of an organization to incorporate successfully a change by developing a self-directed patient education resource focusing on how to effectively participate and manage patient transitions through continuum of care. Neuman's Systems Model addresses the challenge of information use to effectively manage patient transitions with standardized procedures, carried out by dedicated personnel along a continuum of care. Nurses play a distinct role in navigating health care and helping patients through transitions of care. Nurses support a patient's existential experience during an illness or health care deficit through the nurse-patient relationship (Neuman, 2002).

Neuman's Systems Model is a wellness model in which the client system is exposed to stressors from both within and outside the system. The focus is the relationship of the stressors on a client system. The client system is a composite of interacting variables, including the physiologic, psychological, sociocultural developmental, and the spiritual (Neuman, 2002). The stressors are classified as intrapersonal, interpersonal, or extrapersonal depending on their relationship to the client system (Neuman, 2002). The Neuman Systems Model is health orientated, with an emphasis on prevention as an intervention, along with a focus on assessment of all potential stressors and client system perceptions. Neuman's model provides a framework for health professionals to design targeted interventions and timing. Neuman (1989) describes a three- stage prevention plan; primary, secondary, and tertiary prevention. Each of these stages can operate independently.

The change theory informing the DNP project was Lewin's Force Field Analysis, which encompasses three-phases of change (Lewin, 1951). Lewin's model for change management involves unfreezing the present level, moving towards change and then re-freezing the improvements at the new level (Bozak, 2003). As the project leader, it was essential to oversee each phase of change management.

The overall goal of this project was to incorporate components of the two theoretical frameworks to deliver a final e-learning tool that can influence health outcomes by increasing patient and caregiver knowledge before the reproductive consultation and promote shared decision- making.

Critical Review and Appraisal of Evidence in the Literature

Literature Search Strategy

A literature review was conducted to achieve a comprehensive understanding of the effectiveness of published interactive computerized patient education programs and the data to support the evidence-based project's intervention.

The first step of the literature search was to consider the elements of the PICO question. A three-step search strategy was utilized in this review. The initial search of MEDLINE and CINAHL included and analysis of the text words contained in article titles and abstracts to create a list of keywords used to describe the articles. A second search was conducted across all the databases using all identified key words. A reference list of all identified reports and articles was searched for additional studies. Articles were obtained and abstracts were reviewed to determine content, type of study, inclusion and exclusion criteria. If an article met the criteria to support the quality improvement projects intervention, then the article was appraised for the level of evidence to support the EBP project and to provide a guideline for the use of a computer-based fertility education program.

The following databases were utilized: Cumulative Index to Nursing and Allied Health (CINAHL), Medline via EBSCO, Cochrane Library, PubMed, Google Scholar and Hand searching was also employed. The inclusion criteria were as follows: 1) articles in English, 2) published in peer-reviewed journal, 3) patient education, 4) adults. Exclusion criteria: 1) age under 18 years of age, 2) health care provider education. The Medline, CINAHL and Google Scholar databases were searched for articles published from 2000 through 2016, and the start date was chosen because it coincided with rapidly growing technology and access to computers. Search terms included “e-learning,” “patient outcomes,” “learning systems,” “knowledge transfer,” “patient education,” “interactive,” “shared decision making,” “in-service training,” “computer,” and “cancer.”

The Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) rating scale was used to rate the evidence and is shown in the Appendix (Johns Hopkins Medicine, n. d.). The JHNEBP appraisal tools for research and non-research articles assisted the in the appraisal process (Johns Hopkins Medicine, n. d.).

Literature Review

Nine articles were selected (Appendix A). The reviewed studies focus on Internet usability, computer-based education, the feasibility of computer-based education, empowerment or communication and outcomes related to preparatory education.

Internet Usability

Two articles were appraised using the John Hopkins Evidence-Based Practice Appraisal tool and were evidence level I quality A/B (Johns Hopkins Nursing Evidence-Based Practice, n.d.). Technology and the increase of web-based information have affected the way patients interact with the healthcare system. There is a strong relationship between computer use and self-efficacy.

Eysenbach (2003) conducted a systematic review and meta-analysis of all studies containing data on the portion of patients with cancer who are using the internet. Twenty-four studies were reviewed resulted in 8,697 cancer patients surveyed, resulted in an average 39% patients using the internet, which translates to approximately 2.3 million patients with cancer online. Internet use has also been accompanied by the acceptability of computer technology in both older individuals and health care professionals to maximize the benefit of computer-based approaches.

A limitation of the meta-analysis is its inability to explain fully the effect that the Internet has on cancer outcomes because it is hard to complete a randomized trial utilizing the Internet. Determining Internet use is difficult due to the direct or indirect real-world usage of the web by the patient or family and the level of computer literacy.

Lee, Gray, & Lewis (2010) conducted a correlative study to examine whether cancer patients use the Internet to be more active in their health care decisions. The study utilized a random sample from a Cancer Registry comprised of breast, prostate and colorectal cancer patients. The number of respondents was 1,239 for the baseline survey and (76%) completed the follow-up survey at one year about their experiences with cancer. The study found that Internet use was positively associated with active participation in medical decision making although higher education was not a determinate of Internet use.

The authors indicated that the survey elicited preferences but the actual decision-making was not measured. The lack of measurement of decision-making was identified as a limitation of the research. The effect of patient use of the Internet on their medical preference is difficult to determine and it is unclear if the results of this study are generalizable to patients with other cancer diagnoses.

Preparatory Education

The cancer treatment trajectory is complicated especially when coupled with anxiety resulting from the fear of the unknown, side effects, pain, or loss of self. Several studies evaluated the effectiveness of preparatory education on shared decision making aiming to provide coping strategies to reduce anxiety and decisional conflict. The research evaluated examined the effects of providing preparatory education and contrasted it to standard education. Two articles were appraised using the John Hopkins Evidence-Based Practice Appraisal tool and were evidence level I quality A (Johns Hopkins Nursing Evidence-Based Practice, n.d.).

Poroch (1995) conducted a quasi-experimental study to compare the degree of anxiety and satisfaction among patients receiving preparatory education with those receiving a standard education. Fifty patients receiving radiation therapy were randomly assigned and the preparatory education provided to the experimental group. Preparatory education was offered twice. The first session introduced the treatment and was conducted before the patient underwent any treatments or procedures. The second provided education specific to treatment, side effects and self-care. The mean age of patients in the sample was 62 years with a range of 27-88 years. Sixty-two percent were women, and 80% had completed some secondary education. Both groups were evaluated for baseline trait anxiety scores. Data supported that the experimental group had significantly less anxiety than the control group and this was maintained following a second educational session. Both groups were satisfied, and the author correlated this to regular contact with the investigator. The author associated the experimental group's satisfaction with the nursing care. The findings suggest that preparatory education can reduce anxiety and improve patient satisfaction.

There is limited evidence regarding a patient's knowledge following a particular educational intervention. A randomized controlled trial evaluated the impact that providing an e-

feedback intervention (e-Re-Know) to assess a patient's knowledge of radiation therapy before treatment will have on women with breast cancer (Siekkinen, Kesänen, Vahlberg, Pyrhönen & Leino-Kilpi, 2015). The 128 women were randomly assigned to either the e-Re-Know intervention or standard education. The e-Re-Know was designed to provide feedback on a patient's radiation therapy knowledge to empower them to improve it. Patients receiving the e-feedback knowledge intervention had a higher level of knowledge related to self-care and side effects (Siekkinen et al., 2015).

Empowerment and Decision Making

The diagnosis of cancer is complex and generally causes an intense emotional response, lending complexity to informed decision making difficult for patients. Patients need to feel comfortable with their communication skills to participate fully in health care discussions. Incorporating patient preferences and beliefs is an important aspect of shared decision-making. Two articles were appraised using the John Hopkins Evidence-Based Practice Appraisal tool; one was evidence level I quality A and the other was evidence level III quality A (Johns Hopkins Nursing Evidence-Based Practice, n.d.).

When fertility is a concern, interventions need to be addressed before the initiation of chemotherapy, although many patients do not receive timely information. Peate and colleagues, in a descriptive correlational study, explored the knowledge level of fertility and fertility-related options, with decisional conflict and decision making a preference of younger patients with breast cancer (Peate et al., 2011). A study of 111 patients with a mean age of 33 years was completed to understand how to manage fertility in younger patients with breast cancer. Many of the patients were not aware of the effect that breast cancer treatment would have on their fertility. The patients who had higher levels of fertility knowledge experienced less fertility related decisional conflict. All subjects wanted information regarding fertility preservation

options. Lastly, most of the women wanted as much information as possible at the time of diagnosis.

A randomized controlled trial conducted by Ryhänen et al. (2013) studied the effect of an Internet-based patient education program on breast cancer patient empowerment. As part of the patient's process, the level of empowerment was measured, along with QOL, anxiety, and side effects management. A total of 90 patients were randomized to the control group with standard education, or to the intervention group with Internet-based patient education. The groups were well balanced demographically. The intervention was an Internet-based educational pathway providing detailed information about surgery, chemotherapy, and radiotherapy that could be assessed at any time during their course of treatment. There were no statistical improvements in QOL or anxiety for Internet-based breast cancer patient pathway program compared to the control group (Ryhänen et al. 2013). The results did show a correlation between QOL, anxiety, and treatment-related side effects. A significant difference was not found. Because the data collection time was nine months, on average, patients may have received other educational materials during that time period.

Computer-Based Education

Patient education is time-consuming and involves repetition for patients to comprehend fully the content. Numerous research studies demonstrate the use of computer-based education and can provide a cost effective, efficient mode of delivery. It can be self-paced and allow the patient to return to content repeatedly for deeper understanding. Three articles were appraised using the John Hopkins Evidence-Based Practice Appraisal tool; two were evidence level I quality A and one was evidence level IIIA (Johns Hopkins Nursing Evidence-Based Practice, n.d.).

Keulers, Welters, Spauwen & Houpt (2006) conducted a Randomized Controlled Trial (RCT) to determine if computer-based patient education was just as effective as face-to-face education. Patients were randomized to carpal tunnel disease education via a physician or by using a computer. Due to sample size, stratification for computer use and previous disease education prevented the rate of differences between the groups. Findings demonstrated that the intervention group receiving the computer-based intervention demonstrated significantly greater knowledge than the group receiving education from a physician (Keulers, Welters, Spauwen, Houpt, 2006). Patient satisfaction appeared to be equal in both educational methods, but this was not validated in this study.

Patient education has become a directive of several organizations to improve health outcomes. The Joint Commission on Accreditation of Health Care Organizations (JCAHO) mandates patient education requirements as a condition of accreditation (Fox, 2009). Fox (2009) conducted a systematic review of the literature and identified 25 studies of current research to determine the impact interactive, computer-based education (ICBE) has on patient education. Many of the studies that supported ICBE programs to promote knowledge gains were as effective than education provided by a health care provider. Use of these programs also led to payroll savings. One limitation was that there is no standardization across the studies, and some of the studies did not consistently demonstrate improved clinical outcomes or economic savings.

Fox (2009) states the research reviewed provides a foundation for the development of best practices for ICBE program, protocols, and implementation procedures. An important aspect of patient education development and utilization is health literacy and language skills (Fox, 2009). The use of ICBE may incorporate features that could address health literacy because it can be viewed multiple times by a patient.

Lewis (1991) completed a systematic review of studies examining computer-based approaches to patient education in the management of chronic diseases. The reviewed literature supported health care information technology in patient education. Many of the studies reported that patients were able to use ICBE without difficulty and that the knowledge presented resulted in improved clinical outcomes in computer-based and traditional education. It was found to be effective in persons across different age groups. Patients with low literacy skills appear to benefit because it is individually paced and a non-threatening learning environment. In some studies, reviewed by Lewis (1991), use of computer-based education had a positive impact on clinical outcomes, knowledge acquisition, self-care management, and skill development.

This systematic review further substantiates the results of these studies, confirming that computer-based education is an excellent resource for patients to increase knowledge levels related to complicated health information. The author identified the potential for selection bias because this was a single author review. The limits of computer-based educational tools could include: the impact of long-term health care, age, learning styles, mode of knowledge acquisition, and cost-benefit analysis.

Literature Synthesis

The literature supports that patient education is attributed to an improvement in patient health outcomes; however several patients may need additional instruction with repeated viewing or supplementary material to support knowledge retention. The JHNEBP rating scale was used to rate the evidence (John Hopkins Medicine, n.d.). The remaining nine articles were appraised for the level of evidence to support the quality improvement project and are outlined in Appendix B. Given the results of the synthesis and strength of the evidence, it can be concluded that a web-based education tool may significantly improve understanding of fertility risks, fertility preservation and future family options in a high-risk population.

Internet Usability

After the health care provider, some studies cite the Internet as an important source of information for cancer patients (Eysenbach, 2003). The two studies confirm that patients are comfortable utilizing the Internet to find educational information, although the actual number of individuals accessing the Internet is difficult to quantify (Eysenbach, 2003; Lee, Gray, & Lewis, 2010). The relevant findings suggest that there may be a correlation between the internet and improved outcomes along with patients wanting to be more involved in medical decision-making. The review by Eysenbach (2003) provides insight on how to identify potential harms that can occur related to low-quality information, confusion, stress, anxiety, or depression. While the articles have similarities, it is crucial to understand how they differed in the evaluation of Internet use. Eysenbach (2003) distinguishes Internet use by patients diagnosed with cancer in four distinct areas, including communication, support, health information, and e-commerce, while Lee, Gray & Lewis (2010) surveyed the effect of internet use on patient's preferences for active participation in decision making.

The Internet has evolved into a rapidly growing resource for health-related information. Substantial, compelling evidence supports this evidenced-based project's use of the Internet to improve variables such self-efficacy, empowerment, and coping to decrease decisional conflict. Based on the evidence, it is important to consider the audience's level of Internet access, computer literacy, and if a web-based educational tool is the right medium.

Preparatory Education

In the context of oncology treatment, patients facing life-altering treatment regimens, experience increased anxiety due to knowledge deficits accentuated by the fear of the unknown. A patient can receive information, but an individual expects to receive as much knowledge as possible (Poroch, 1995; Siekkinen et al., 2015). Studies done by Poroch (1995) and Siekkinen

(2015) randomized patients before radiation therapy to either a control group with standard education or an intervention group utilizing tailored preparatory education.

Poroch's (1995) method contained sensory and procedural preparatory education delivered by a health professional. The educational intervention was offered at three different time points and the effect that the education had on anxiety and patient satisfaction was measured. Variables examined by Siekkinen et al. (2015), were knowledge level and the influence a computer based preparatory education approach had on side effect self-care. Although Poroch's (1995) method conveyed patient sensitivity associated to information overload and anxiety related to providing the education at basic time points, it is unclear how much effect the education had on the patient's understanding. Siekkinen et al. (2015) took the time to adequately evaluate the patient's knowledge base before the educational intervention, but it is unclear on how much this decreased the patient's emotional distress.

Interventions differed in the frequency, delivery, population of interest, and the outcomes evaluated but the literature demonstrated that preparatory education provides an improvement in knowledge, well-being, and sense of control. Furthermore, it would be valuable to combine aspects from each of these studies.

Empowerment and Decision Making

The articles acknowledge the importance of decision making, education, and empowerment based interventions (Peate et al., 2011; Ryhänen et al., 2013). Before empowerment or education can occur, it is imperative to inquire about a patient's current level of knowledge and understanding of the risks they will be facing. Peate et al. (2011) noted that despite the apparent stress of a new diagnosis and informational overload, a patient still wanted as much information about infertility as possible. This ties into education about the empowerment process, patient self-efficacy and sense of autonomy. Although, if the patient

education was not reinforced it was not as successful. The randomized controlled trial by Ryhänen et al. (2013) is an example of an Internet-based tool that did not improve QOL and decrease anxiety in breast cancer patients. A limitation in the study design was lack of reinforcement of the educational intervention to encourage the patients to maximize the tool available to them. An empowerment-based approach seeks to reinforce some general abilities in people as well as their capacity to identify needs and psychosocial problems and determine personal goals.

Computer-Based Education

The articles used in this synthesis agree that computer-based patient education is effective and can promote knowledge gains in patients, although there are inconsistencies related to economic benefit and clinical outcomes (Lewis, 1991; Keulers, Welters, Spauwen, Houp, 2006; Fox, 2009). Systematic reviews identified several different computer-based learning interventions: simple tutorials, interactive applications, videos, or CD-ROM programs. However, the literature did not evaluate the differences between the interventions (Lewis, 1991; Fox, 2009). Keulers, Welters, Spauwen & Houp (2006) noted the benefits of an interactive computer-based education utilizing instructional animations with voice over on a touch screen laptop for carpal tunnel disease state education.

The growing funding limitations and demands on health professionals to provide patient education promote the use of technology in interactive ways (Fox, 2009). Evidence supports that computer-based yields an improvement in knowledge over education by a health care provider (Lewis, 1991; Keulers, Welters, Spauwen, Houp, 2006; Fox, 2009). While the articles used in this synthesis support computer-based education, it is not clear which intervention application (i.e. simple tutorials, interactive, videos or CD-ROM) is most effective or how often it should be

updated. It is imperative to consider the design and implementation of a computer-based program because this directly affects the patient's experience (Fox, 2009).

The literature establishes computer-based education has a positive effect on knowledge improvement and self-efficacy, although there can be a potential adverse effect such as anxiety and decision conflict. The patient care experience is enhanced when education improves knowledge or intentions as a consequence of the educational intervention. All of the appraised articles supported the use of a computer-based educational format.

Ethical Considerations and Social Justice

The initiation of the oncofertility process should occur at the time of diagnosis. However, this can be affected by the urgency to start treatment, failure of health professional to start the conversation and financial barriers. The urgency of the diagnosis and treatment requirements limit referrals to specialist and reduces the health care providers' ability to provide appropriately informed consent regarding fertility risks related to treatment (Hammond, Abrams & Syrjala, 2007; Patrizio & Caplan, 2010).

The right to reproduce is protected under the U.S. and international law and has been reaffirmed by the U.S. Supreme Court. An alternate factor is the pressure patients face if they feel they must use the technology to preserve their fertility or meet the expectation to have children. Ethical and legal barriers relate to informed consent and autonomous decision making. Patients have the right to refuse counseling, treatment, fertility preservation and future family planning counseling needs to be free of coercion (Quinn et al., 2011). Other ethical concerns relate to health literacy, along with understanding cultural and religious beliefs. Health professional barriers to discussion include lack of knowledge regarding fertility preservation options, financial barriers and a patient's life expectancy (Basco, Campo-Engelstein, & Rodriguez, 2010).

According to U.S. law, gametes and embryos are considered property and this creates social justice implications related to disputes over frozen material, sometimes needing to be resolved in court (Rodriguez, Campo-Engelstein, Emanuel, 2013). The effect of personal or social allocation of resources to preserve ovarian tissue, gametes or embryos for someone whose cancer treatment causes iatrogenic infertility is unknown (Basco, Campo-Engelstein, & Rodriguez, 2010).

The financial implications creating social justice concern is that health insurers do not currently think of fertility preservation as a cancer benefit. This lack of coverage reinforces socioeconomic inequalities. Most patients undergoing fertility preservation are white, educated, middle and upper class because they are most likely to be able to afford the high cost of out-of-pocket expenses. The lack of insurance coverage for oncofertility disadvantages those of lower socioeconomic status. There is a history of sterility without consent among the black communities. It is important to recognize how health policy decisions affect people from diverse backgrounds in different ways (Basco, Campo-Engelstein, & Rodriguez, 2010).

Fertility and future family planning e-learning education addresses social disparities by supporting shared decision-making between patients and providers. The educational tools and resources will be available to a larger population. Increasing knowledge about the social support networks around oncofertility through delivery of accurate, accessible and actionable health information targeted to the HCT patient population. This resource will increase health literacy about oncofertility while connecting directly with culturally diverse and hard-to reach populations. A web based educational tool facilitates the use of health information technology to provide health information among health care and public health professionals. Providing new educational resources supporting autonomous decision making can help to promote proactive oncofertility counseling.

Patient Safety

Patient safety is a priority for Be The Match. The goal of fertility education is to reduce adverse outcomes, not cause additional psychological distress. The Institute of Medicine (IOM) defines patient safety as preventing harm to patients (Aspden, Corrigan, Wolcott, 2004). Organizations are obligated to prevent harm and negative outcomes by adhering to patient safety practices. Some of the indirect concerns for patient safety were the potential social justice barriers related to cultural sensitivity and financial or insurance barriers. To address these concerns, the team incorporated additional resources to counsel patients about ethical, social and financial matters. Patients can also be connected to experts through stakeholder involvement. An additional safeguard was to send the final draft of the module through a vetting process with coordinated reviews by health care professionals, HCT patients, and caregivers to evaluate any gaps or patient safety concerns related to the web-based education before implementing it to a broader audience. Be The Match is driving change by encompassing strong team leadership with patient safety as a priority to ensure a successful fertility and future family planning web based education program.

Methodology

Preparatory

Prioritizing patient-centered outcomes in HCT is an important aspect of Be The Match's mission and vision. Program evaluation plays a vital role in PHPS program planning, improvement, and dissemination plans. The PHPS program planning worksheet encourages program planners to engage stakeholders and incorporate evaluation into program planning and implementation for quality improvement (Moore, Preussler, Denzen, Payton, Thao, Murphy, & Harwood, 2014). The program planning worksheet was adapted from the evidence-based Centers for Disease Control and Prevention's (CDC's) Framework for Program Evaluation in

Public Health (CDC, 2005). Be The Match's planning and workflow processes are aligned with the major steps of evaluation (Appendix A).

The DNP quality improvement project development was conducted in collaboration with the Patient and Health Professional Services department. Be The Match internal team members included DNP student, senior patient education specialist, health policy analyst, program analyst, senior evaluation specialist, supervisor of counseling services serving as the DNP site mentor, and a supervisor of the health economics and policy team.

The internal team incorporated feedback throughout the quality improvement project from the patient education advisory group (PEAG). PEAG members are volunteers they are committed to providing input and feedback on Be The Match patient education materials at minimum two review assignments per year. Any educational resources that are developed for patient, caregivers or health professional are evaluated by the following groups:

- Volunteer Education Resource Reviewers: patients and caregivers who are post-transplant;
- PEAG (Patient Education Advisory Group): HCT health care professionals; and
- PEAG – Diverse Populations: HCT health care professionals focused on the needs of diverse populations;

An important preparatory step was to gather insight on the current written fertility fact sheets. The goal of the needs assessment was to identify strengths and gaps of current written materials and patient preferences regarding fertility preservation and future family planning topics. The Volunteer Education Resource Reviewers, a group that consists of patient and caregivers post-transplant provided a review of the fertility fact sheets. The educational reviewers were informed that Be The Match would use their feedback to justify the feasibility of creating a new educational resource for HCT patients and caregivers. The patient education department in June

2017 collected the following information as part of a needs assessment. Surveys were used to gather patient and caregivers feedback regarding current educational material and what information was missing in the current educational resources. A paper survey was administered to a patient volunteer group via email and 28 reviewers; seven surveys were completed (Appendix D) for a 25 percent response rate. Some of the patient underwent their transplant at an older age and fertility was not a concern for them.

Key findings in the responses can be summarized as:

- Fertility preservation process was the most important topic.
- Cost and financial aid were the second-most important concerns followed by where to go for fertility preservation.
- Responders had neutral feelings or concerns regarding the importance of learning about legal and ethical issues.
- One responder out of seven indicated they were not considering fertility preservation and family planning before or after transplant.
- Another responder wanted to understand the fertility preservation and treatment process.

Patient's and Caregivers listed the key topics for future education:

1. Embryo vs. Egg: Legal implications
2. Alternatives for Having Kids: Adoption, Surrogacy, etc.
3. Financial Assistance for Fertility Treatments
4. National Resources for Fertility
5. Insurance Coverage and Claims
6. Fertility Treatment Process

The information from the PCORI working group and the needs assessment confirmed that there is a need for self-directed, easy to access educational material. Their schedules are varied and

busy, and they often do not have a lot of time to dedicate to researching or participating in long educational sessions. The easily accessible web-based educational tool will be most appropriate for the target audience, so that patients can read the information when they are ready to do so.

The fertility project team applied the problem identification, PCORI working group conclusions, and needs assessment analysis to prepare the program planning worksheet. The results assisted with identifying the types of resources and information that are lacking in patient and caregiver education materials. The needs analysis was used to develop goals and objectives to address the gap between both the current resources and learners' perceptions of the current educational tool. The objectives focused the design of the web-based education, including the evaluation.

The second part of the program preparatory plan was to determine the technical resource requirements and details of the web design. The fertility project team identified an information technology specialist to assess the capabilities of the network and if e-learning management software was available.

Financial Considerations:

The C.W. Bill Young Cell Transplantation Program (CWBYCTP) is funded through the federal government for some of the services provided by Be The Match (Be The Match, 2017). The Office of Patient Advocacy (known internally as PHPS) focuses on providing education and support to family members, physicians, or other individuals acting on the patient's behalf and can engage in public and professional activities related to treatment options and supportive services to patients from the time of diagnosis through all stages during and after transplant. At a minimum, the Office of Patient Advocacy must provide patients with patient advocacy and case management services with resources available through the CWBYCTP. Provides a comparison

of transplant centers about searches and other costs that before transplantation along with post-transplant outcomes for individual transplant centers.

Be The Match's leadership did not require a formal budget to support the project. Salaries of the internal project team members made up the majority of the cost related to this project. The quality improvement project fulfills the requirements outlined by the Office of Patient Advocacy. PHPS satisfies the requirements by identifying and reducing non-HLA barriers to facilitate informed decision-making and increasing access to HCT. Fertility education for patients supports this work along with the mission of Be The Match.

An essential aspect of the web-based education is to include education on financial barriers to care, available resources, and information on how to navigate insurance related concerns on the fertility preservation process. The Public and Payer Policy team at Be The Match has a parallel project focusing on the financial barriers related to fertility preservation for the HCT patient population. The research will include a cross-sectional analysis of longitudinal administrative claims data to understand utilization of fertility preservation in patients needing HCT across several possible predictors including age, sex, and disease state. In addition, the policy work will engage payer stakeholders to discuss the cost-benefits of including fertility preservation coverage within HCT benefits and help to identify specific patient populations that would benefit most from fertility preservation education.

Be The Match plans to utilize the web-based fertility and future family planning education to educate insurance providers to educate health plans on why fertility preservation methods should be covered. If there is not a coverage mechanism, patients will struggle to find the financial means to pay for fertility preservation medical services. Patients might feel that they have to choose between medical services (fertility versus treatment) resulting in them forgoing or delaying medical services.

Program Implementation

The project team completed a program planning worksheet using the data from an extensive literature search, PCORI working group conclusions, and the findings of the needs assessment. The planning worksheet outlined the focus of the project, along with mechanisms to improve upon the Be The Match's current process for content development and vetting of educational material for final dissemination. After completion, the program planning worksheet was submitted to the leadership team for final approval. An additional evaluation of the tool will be completed during the dissemination phase.

The leadership team at Be The Match approved the project. A Human Subjects Research Determination form outlining the Fertility Education and Future Family Planning Options project (content and feasibility review with volunteer groups) was submitted to the National Marrow Donor Program (NMDP) Institutional Review Board (IRB). The NMDP IRB concluded that the project did not require review and determined that the project falls into a program evaluation and improvement category and is not human subjects research as defined by the regulations. In addition, St. Catherine University IRB deemed the project as exempt from formal review.

Program Description

There are no effective strategies to provide education to HCT men and women of childbearing age who are at high risk of infertility related to treatment (Loren et al., 2013a). A patient's decision to pursue fertility preservation is related to the effectiveness of the health care professionals' communication and patient-centered education. If the health care professional does not address fertility risks then the patient or caregiver may seek out information independently.

The proposed change was to develop a self-paced computer-based educational tool. The goal of the educational tool is to aid patients or clinicians in their decision-making process to

maximize self-efficacy. The web-based education can also be designated as a clinical decision support system (CDS) in the clinic, to be used by the health care provider or by the patient if the clinical conversation did not occur and education was not provided, or additional information is desired. The project team compiled a comprehensive program description to identify the needs, activities and resources.

A new process for developing and vetting an online educational product was incorporated into the project. The final educational product will be provided to adult patient's pre-transplant who may or may not have had fertility education along with their cancer or disease trajectory. The course content was developed by clinical experts, Be The Match staff, and a DNP student. Once the project is complete, Be The Match plans to evaluate the course content using a pre-post knowledge assessment of fertility risk, preservation and future family options, navigation of insurance system, shared decision making and self-advocacy skills, and perception of individual fertility risk. The assessment will be conducted with caregivers and patients.

Target Audience

The target audience for the educational content is HCT adults ages 18 to 40. The pediatric population was not included in the educational content due to the complexity of legal and ethical concerns related to children and fertility preservation. This population will be considered in further iterations of the e-learning tool.

Everyone in the target audience, regardless of education level or socioeconomic status, benefits from information in plain language. The target audience differs in a variety of ways including race and ethnic background, age, relationship or marital status, sexual orientation, geographic location, socioeconomic status, and educational levels. For this audience, learning happens while they are coping with the psychosocial distress of transplant and potential impaired fertility. For some people in the target audience HCT is treatment for a blood cancer. These

people may already have some familiarity with fertility risks if they received education prior to chemotherapy. For patients with blood disorders, such as sickle cell disease or aplastic anemia, the risk of infertility may be new to them and there may be socio-cultural fears or anxiety surrounding this topic. An easily accessible web-based educational tool is appropriate for this target audience.

Stakeholder Identification and Engagement

The project team identified stakeholders to promote advocacy, provide credibility, and to assist with content development. The DNP student provided initial engagement with the stakeholders and organizations participating in content development. Expectation of the selected stakeholders included regular participation at key milestones of developing the program content, evaluation questions, and future patient related outcomes research opportunities.

Stakeholder engagement was important to obtain recommendations regarding content development, program activities and program development. A multidisciplinary team of patient educators established learning objectives for a self-paced e-learning module.

Partnerships with experts in the field of fertility preservation provided a mechanism for exchange of subject matter expertise and resources in accordance with an official memorandum of understanding. The legal department developed a memorandum of understanding (MOU) to outline the details related to content development, responsibilities of the stakeholders and final product rights. The MOU was provided to each stakeholder to share with the legal department. Be The Match's cross utilization of the stakeholders' intellectual knowledge and resources was outlined in each MOU. Relationships with the stakeholders are vital for the future of the e-learning educational resource. Ongoing stakeholder engagement is valuable for their insights or preferences on patient related outcome research interests.

Stakeholders include:

- Allison Loren, MD, MS. Hematology/Oncology in Department of Medicine, Perelman School of Medicine at University of Pennsylvania, Vice Chair, Faculty Development and Associate Professor of Medicine, Co-Chair Regimen Related Toxicity Working Committee CIBMTR and the Co-Chair of Expert Panel ASCO Fertility Preservation Clinical Practice Guideline. Served as Transplant Basics content development.
- Meghan Bowman-Curi, MPH. Research Coordinator at Moffitt Cancer Center Enriching Communication Skills for Health Professionals in Oncofertility (ECHO) training program. Served as content reviewer.
- Gwendolyn Quinn, PhD Multiple principal investigator of training program for health professionals in communication about reproductive health (ECHO) New York University. Served as content reviewer.
- Susan Vadaparampil, PhD, MPH. Multiple principal investigator of training program for health professionals in communication about reproductive health (ECHO), Moffitt Cancer Center. Served as content reviewer.
- Katarina Lee, MA, JD. Clinical Ethics Fellow at Baylor College of Medicine Center for Medical Ethics and Health Policy, Adjunct Professor of Law at South Texas College of Law. Content developer of Ethical and Legal considerations.
- Teresa K Woodruff, PhD. Dean and Associate Provost for Graduate Education in the Graduate School Northwestern University, Director of the Center of Reproductive Science, Founder and Director of the Women's Health Research Institute, Director of the Oncofertility Consortium. Served as a content reviewer.
- Kristin Smith, RN. Northwestern University Oncofertility Consortium Patient Navigator for Fertility Preservation. Served as content developer and reviewer of Navigation and Self Advocacy.

- Brigid Martz Smith, CCRP. Clinical Director, Oncofertility Consortium, Northwestern University. Served as a content reviewer

Content Development

An iterative process was used to write, design and review the educational content and adapt the material into structured sections for the target patient audience. The pre-implementation phase of content development included stakeholder involvement, finalization of the content and the creation of a voice over script.

The initial plan was to incorporate all the content into a one-hour long module. Following stakeholder discussions, the team determined due to the complexity of the content and the fact that patients could access the resource at any time along their treatment trajectory an interactive format would be more conducive to learning. The web resource can enhance learning by giving users the ability to navigate and tailor education to their personal preferences. The educational content was formatted into structured sections and incorporates multimedia and hyperlinks.

Eight e-learning modules were planned based off the needs assessment and PCORI conclusion. The topics include the basics of fertility, transplant, fertility for men and women, family planning, financial considerations, legal and ethical considerations and strategies for communicating with your health care team (Appendix C).

The content of the eight e-learning modules was developed in collaboration with the stakeholders and finalized into a power point template. Once the topic specific content was completed, a detailed script was written to be incorporated into the interactive, web based format. The content and script development process took four months to complete. Once the script was completed, the project team reviewed the content for readability and flow. The education and training department converted the educational content into an interactive web based format. The process took six weeks to complete. Once the interactive web based

educational resource was finalized, the project team evaluated the content to ensure plain language principles and adult learning principles were applied throughout the course content.

Date Collection

Data collection incorporated a formal vetting process by submitting the educational content to stakeholders, patient and health professional content reviewers for formal review. A link to the web based education was sent via email and all evaluation team members or volunteers were blind copied to the message so that the feedback was only sent back to Be The Match patient education specialists. The reviewers were given three weeks to provide feedback. The feedback was kept confidential and compiled before being shared with the project team.

The open-ended qualitative questions provided to the reviewers were measured for the perceived usefulness and appropriateness of the resource for patients and caregivers (Appendix F). In addition, the project team worked with stakeholders to provide insight on the clarity, accuracy, and completeness of the educational material presented in the eight e-learning modules. The open-ended answers were analyzed using an Excel spreadsheet to input all the responses; all the responses were counted to determine the key takeaways. Responses that were easily quantifiable (yes or no answers), were counted to provide percentages of agreement versus dissent. The project team reviewed the data as described in the evaluation section to finalize the content for dissemination.

Evaluation

The overarching goal of the vetting process was to pilot the website before full implementation. It was important to understand the coordination and efficiency of the technology before launching it to a broader audience. Vetting the online educational content provided a way to gather feedback on the completeness of the educational material, and on the feasibility and usability related to using the technology.

The patient education advisory group (PEAG) members are responsible for reviewing the patient education developed by Be The Match and are committed to complete at minimum two review assignments each year. A link to the web-based education was sent via email to the content reviewers (32 PEAG members and five HCT navigators). There were two emails sent to the PEAG groups, one initial email and one reminder. Fourteen content reviewers provided feedback. Twelve of the reviewers were from the PEAG groups and two patient navigators with the Patient Education Services team responded.

The evaluation teams included: PEAG (HCT health care professionals); PEAG - diverse populations (HCT health care professionals focused on the needs of diverse populations); and the patient and health professional services patient navigators. The project team reviewed the data from qualitative surveys and educational outcomes to make corrections or additions to the web based education. The details of the feedback (Appendix F) and specific e-learning modules were not assigned to the content reviewers out of respect for the reviewers' time. The reviewers decided what chapters they felt comfortable reviewing. There was a balanced representation of the eight e-learn chapters reviewed and all the reviewers were in concurrence that the educational content was easy to navigate.

Negative critique from the content reviewers included the lack of education directed towards adolescent and young adults, caregivers, health care professionals and a lack of multiple languages. Computer-based glitches and inconsistencies with content language were also mentioned. The reviewers requested more information on a variety of content. All reviewers responded that they would feel comfortable sharing the e-learning education with patients. Reviewers were asked what patient education resources they currently use when teaching patients and families about fertility preservation or family planning. The most common

responses were to refer patients to fertility clinics. Additional suggestions included adding mobile app accessibility, option to print text, and to create a Spanish language version.

The e-learning site will be maintained and monitored to resolve any technical issues. In addition, the future data collection plan is to monitor traffic related to e-learning time spent utilizing the educational resource, how well the learning objectives are met and overall user satisfaction. Maintaining the educational content requires faculty time to monitor any technical problems that might arise, implement changes related to course evaluations and update educational content as clinical advancements occur. An advantage of the e-learning content is that it can be easily modified.

The dissemination strategies will encourage use of the e-learning educational resource by patients and caregivers, transplant centers, and health professionals and to make the website accessible and user-friendly.

Discussion

Be The Match is a dynamic organization that embraces change and stays current in the ever-changing healthcare environment. It has historically provided educational resources to HCT patients and health professionals in written format or voice over PowerPoints but has never incorporated an interactive web-based tool. The change theory informing the DNP project was Lewin's Force Field Analysis. This model encompasses three phases of change (Lewin, 1951): unfreezing the present level, moving towards change, and re-freezing the improvements at the new level (Bozak, 2003). It was essential for the DNP project leader to oversee all phases of the change management process.

A major component of the unfreezing stage for this project was to connect with national stakeholders to motivate the staff, managers, and administration to adopt a new method for delivering patient education. Encouraging change allowed the organization to envision how

dynamic and emotionally driven the topic of fertility preservation and future family planning education is and how it could be optimized by an interactive medium. This new perspective shaped ownership for the change leading to the successful implementation of the project.

In the moving stage, it was essential to determine the project's development and implementation timelines. An important aspect of this stage was to promote participation and open communication among team members, stakeholders and leadership to encourage successful change management (Lewin, 1951). Another part of the overall project plan is to develop a counseling resource tool and training for the Be The Match patient navigators to assist patient and healthcare professional with communication related to the web-based tool. The counseling resource will also enhance staff engagement and increase references to and promotion of the new educational resource.

Refreezing occurred during the vetting process of the interactive web-based education and at the time of implementation. The vetting process resulted in minor changes and positive feedback. A future aspect of this stage is to evaluate how patients, caregivers and health professionals use the tool, accomplished through knowledge assessments pre and post completion of the learning module. Satisfaction use patterns will also be examined. User feedback will allow Be The Match strengthen marketing strategies to expand use of the educational tool.

Strengths and Limitations:

The vetting process identified the strengths and limitations of the e-learning resource and ways to improve the resource. The strengths identified by the content reviewers were that the modules were easy to navigate and links to external content provides a Self-directed feature for patients who are seeking additional information. Reviewers noted that the resources (e.g., list of

question to ask your doctor) were extremely valuable. The language was appropriate for the sensitive subjects related to sexuality, gender, culture and religion.

Some of the limitations identified included the lack of feedback from the patient volunteer group and technological issues associated with links to some of the resources. The content reviewers also pointed out that the patient audience should include adolescents, young adults and patients without cancer. A specific request for future iterations was that the e-learning modules be translated into different languages and Spanish was specifically requested.

The evaluation plan following dissemination of the module is to evaluate patient impact through self-assessments, reflection, self-directed learning, problem-based learning, learner interaction, and feedback.

Significance and Contribution to the Literature:

Findings related to the feasibility and outcomes of the web-based educational tool will be published in an academic journal. The results of the project development, feasibility, outcomes, and process were presented at the 2018 American Society for Blood and Marrow Transplantation (ASBMT) meeting.

Significance to the Nursing Profession:

The web-based educational resource can enhance patients' ability to navigate the health care system in addition to identifying where knowledge gaps exist. In regard to nursing, this tool can enhance and complement the treatment consent process in addition to preparing the patient for specialty referral consultation. Future practice implications include adding this educational resource as a clinical decision support system to guide communication and understanding of what patients need to make time-sensitive decisions.

Significance for Interprofessional Collaboration

The DNP project interprofessional collaboration was exemplar. There was no conflict among the team members although there was some uncertainty with the quality improvement project timeline. Questions surrounding the project related to legal approval of the stakeholder's memorandums of understanding and addressing whether the DNP intern owned any of the final content. The team immediately identified the challenges and worked hard to address them. The project team considered the anticipated barriers related to the stakeholder's involvement and the time it took to complete content development. One stakeholder's content development was delayed slightly altering the timeline to convert the content into its interactive formal. The DNP student worked closely with that stakeholder to assist with content development by arranging multiple conferences calls to review and help development. Throughout the project's development and implementation, Be The Match leadership skills consistently demonstrated the organization's capabilities to execute successful patient support programs through its expertise and experience. The staff and stakeholders of Be The Match actively participated in decision-making and took ownership in the process of problem-solving.

Dissemination of Findings

To date, the fertility and future family planning web based educational tool has been finalized and is live on Be The Match's Web site. In February of this year, the DNP author presented the project at the American Society Blood and Marrow Transplantation (ASBMT) Tandem Nursing Conference, Salt Lake City Utah. The tool has been in high demand since its introduction. The finalized educational tool will be promoted through Be The Match network announcements, volunteer ambassadors, transplant site visits, social media channels, directly to patients and stakeholder organizations.

Suggestions for Future Study and Direction

The e-learning module format is mobile-friendly and will be applied to other HCT patient education topics. The future enhancements will include an additional chapter for parents of children and adolescents undergoing HCT, and addition of a version in Spanish.

After dissemination, the plan is to evaluate patients' knowledge and satisfaction to understand further the patient population educational needs. The educational outcomes will be evaluated through participant feedback survey (face validity); validated instruments administered pre and post; perceived knowledge of risk; self-efficacy for advocacy via participant feedback survey (face validity). The data will be collected and analyzed using Snap Survey, Microsoft Excel, and SPSS version 10. To determine statistically significant associations among pre and post outcomes, a Fisher's Exact analysis will be conducted. Descriptive analysis will be conducted to determine satisfaction outcomes.

The public and payer policy team is working on a parallel project to address the barriers related to financial or insurance limitations to fertility preservation or future family planning. This project will inform future work to improve access to fertility or future family planning for HCT patients.

Conclusions

Multiple resources are available to cancer patients via the Internet although those current educational modalities are not tailored to HCT patients. The educational resources can be improved and enhanced to help transplant patients and families learn to navigate the complexity of fertility preservation driven during an emotionally and time sensitive situation. Fertility and future family planning web based educational tool will assist patients to make informed and timely decisions regarding fertility preservation and future family planning. It will also enable providers to provide evidence-based interventions to improve communication and to address

emotions around a patient's loss of fertility after HCT.

Be The Match will further evaluate the effect the education has on patients with a knowledge-based assessment via pre and post test. The evaluation will assess the patient's personal preferences, baseline knowledge and perceptions on how the additional education will impact their decision making. Further evaluation is an important part of the iterative process to determine the impact that the web-based educational resource has on the patient's knowledge of fertility risks, preservation options, and future family options.

Education empowers patients to gain the courage and confidence to advocate for their life after treatment. The web-based educational program *Fertility Education and Future Family Planning* is an innovative approach to assisting patients and caregivers to improve their understanding of their fertility risks and communication with their health care team as they undergo HCT. This program provides a safe place for patients to find accurate information about the effects HCT has on fertility, fertility preservation, and coping strategies, along with resources from Be The Match to connect them with peers who have completed transplant for advice and encouragement. The ongoing development and refinement of this program will ensure a trusted web-based resource designed to improve the quality of life for HCT patients.

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Appendix A

Studies with internet usability, preparatory education, shared decision making, computer based education.

Internet Usability

Study	Population	N*	Design	Intervention	Results	JHNEBP Rating
Eysenbach (2003)	Surveys from RTC evaluated on the impact internet has on cancer outcomes	24	Systematic Review with Meta-Analysis		Est four areas of internet use with cancer patients	1B
Lee, Gray & Lewis (2010)		2013 (baseline) 1293 (1yr)	Correlational	Survey Baseline & 1 yr	p<0.05 internet use positively associated with shared decision-making p>0/05 no interactive effect Internet use of active participation preference	3A

Preparatory Education

Study	Population	N*	Design	Intervention	Results	JHNEBP Rating
Siekkinen, Kesänen, Vahlberg, Pyrhönen, Leino-Kilpi (2015)	Breast cancer patient	128	RCT 65 control 63 intervention	Control group routine education/Intervention group e-feedback	Baseline knowledge: between group p=0.0003 Stat sig change in Intervention group P<0.0001	1A
Poroch (1995)	Patient receiving radiation therapy	50	Quasi-experimental	Preparatory patient education prior to radiation therapy	Anxiety: experimental group was normal/high in control Patient satisfaction: sig difference TX week 1/TX completion no sig different	2A

Shared Decision Making

Study	Population	N*	Design	Intervention	Results	JHNEBP Rating
Ryhänen, Rankinen, Siekkinen, Saarinen, Korvenranta, & Leino-Kilpi, H. (2013)	Breast cancer patients	90	RCT 43 control 47 interventional	Internet-based breast cancer pathway (intervention)	No significant difference between groups	1A
Peate et al. (2011)		111	Descriptive Correlational	Aim to explore knowledge, decision conflict, decision making preferences	No limitations noted	3A

Computer Based Education

Study	Population	N*	Design	Intervention	Results	JHNEBP Rating
Fox (2009)		25	Systematic Review with Meta-Analysis			1A
Keulers, Welters, Spauwen, Houpt (2007)		113	RCT	Education by MD vs interactive computer program	Total satisfaction was no stat sig between groups, knowledge level with computer group p=0.001	1A
Lewis (1999)	Computer-based approaches to pt education	66	Systematic Review		Supports the use of information technology	3A

N-number of participants; stat sig-significance; RCT-random controlled trial; Pt-patient; TX-treatment; ICBE-computer based education

Appendix B

Synthesis of Evidence

Internet Usability			
Category (level type)	Number of sources per level	Overall quality rating	Synthesis of findings- Evidence that answers the EBP question
Level 1-	1	B (1)	Four areas of internet use in persons with cancer: communication (electronic email, virtual support groups), content (health information) and e-commerce.
Level 3-	1	A (1)	Established that internet use was positively associated with preferences for active participation in medical decision making.
Recommendations: There is good and consistent evidence to show that internet usability is not a barrier to communication and medical decision making. The DNP author recommends web based educational tool be implemented in the quality improvement (QI) project because it is not a restrict the patient's ability to communicate with health care providers.			
Preparatory Education			
Category (level type)	Number of sources per level	Overall quality rating	Synthesis of findings- Evidence that answers the EBP question
Level 1-	1	A (1)	Statistically significant findings support electronic that feedback in cancer patients improved level of knowledge related to treatment course.
Level 2-	1	A (1)	Electronic preparatory education prior radiation therapy to did not increase anxiety and patient demonstrated an increased level of satisfaction with both the information and did not change the patient's perception of nursing.
Recommendations: The review of preparatory education provided electronically improved patients knowledge base related to treatment course without diminishing the satisfaction with health care provider relationships. There is suggestive evidence to support the use of electronically delivered preparatory education to increase patient level of understanding. The DNP student further recommends the development of an interactive web based educational tool.			
Level 1: Experimental, RCT, Systematic review of RCT with or without meta-analysis Level 2: Quasi-experimental study, Systematic review or RCTs with quasi-experimental studies with or without meta-analysis Level 5: Evidence obtained from literature reviews, quality improvement, program evaluation, financial evaluation, case reports, opinion of nationally recognized expert(s) based on experimental evidence			

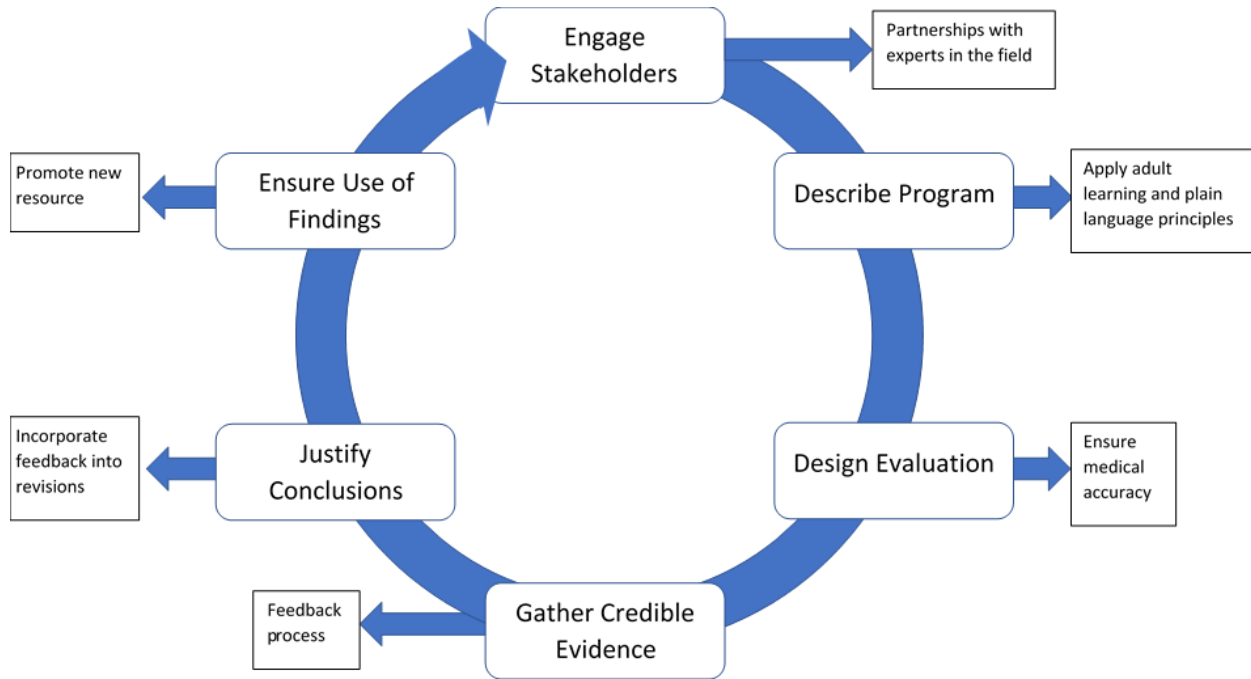
Synthesis of Evidence

Shared Decision Making			
Category (level type)	Number of sources per level	Overall quality rating	Synthesis of findings- Evidence that answers the EBP question
Level 1-	1	A (1)	The anxiety level and QOL of breast cancer did not worsen because of internet based pathway. Although the study did not reveal statistically significant results it suggested that there were other sources to support the patient’s knowledge base.
Level 3-	1	A (1)	Decisional conflict is associated with decreased knowledge to pursue fertility preservation. patients.
Computer Based Education			
Level 1-	2	A (2)	Computer based education supports knowledge gain.
Level 3-	1	A (1)	Computer based education had a positive impact on clinical outcomes, knowledge acquisition, self-care management and skill development. The advantage computer based education provides just in time availability and private learning.
Recommendations: The review of computer based education supports self- care management, improves knowledge and provide real time availability. The DNP author recommends computer based education to be implemented in the QI project.			

Level 1: Experimental, RCT, Systematic review of RCT with or without meta-analysis
 Level 2: Quasi-experimental study, Systematic review or RCTs with quasi-experimental studies with or without meta-analysis
 Level 5: Evidence obtained from literature reviews, quality improvement, program evaluation, financial evaluation, case reports, opinion of nationally recognized expert(s) based on experimental evidence

Appendix C

Evaluation Framework



Adapted by H. Moore and E. Denzen, November 2012, from U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Office of the Director, Office of Strategy and Innovation. (2005). *Introduction to program evaluation for public health programs: A self-study guide*. Atlanta, GA: Centers for Disease Control and Prevention.

Appendix D

Web-Based Module

Choose a chapter by clicking the title.



Access: BeTheMatch.org/Fertility

Appendix E

Needs Assessment

Needs Assessment	
# Reviewers	7
Reviewers	Patients and caregivers
Topic	Fertility and Family Planning Education

Key Takeaways:

- Overall, the fertility preservation process stood out as the most important topic.
- Cost & financial aid was the second-most important concern followed by where to go for fertility preservation.
- Responders had neutral feelings or concerns regarding the importance of learning about legal and ethical issues.
- One responder out of seven indicated they were not considering fertility preservation and family planning before or after transplant, while another responder expressed a high desire to better understand the fertility preservation and treatment process.

Key Topics for Future Education:

- Embryo vs. Egg: Legal implications
- Alternatives for Having Kids: Adoption, Surrogacy, etc.
- Financial Assistance for Fertility Treatments
- National Resources for Fertility
- Insurance Coverage and Claims
- Fertility Treatment Process

When you think of fertility (ability to have a baby) and family planning after transplant, what are 3-5 questions that come to mind?

Question Topic	% of Responders
How do cancer treatments (BMT, chemo, radiation, medications, etc.) affect fertility? Conception Rates?	71%
How to reduce reproductive damage prior to BMT	14%
Pregnancy and birth defect rates/risks following cancer treatments (BMT, chemo, radiation, medications, etc.)	57%
Fertility Treatment Logistics/Timing	57%
Treatment costs	57%
Other options for family-building	14%

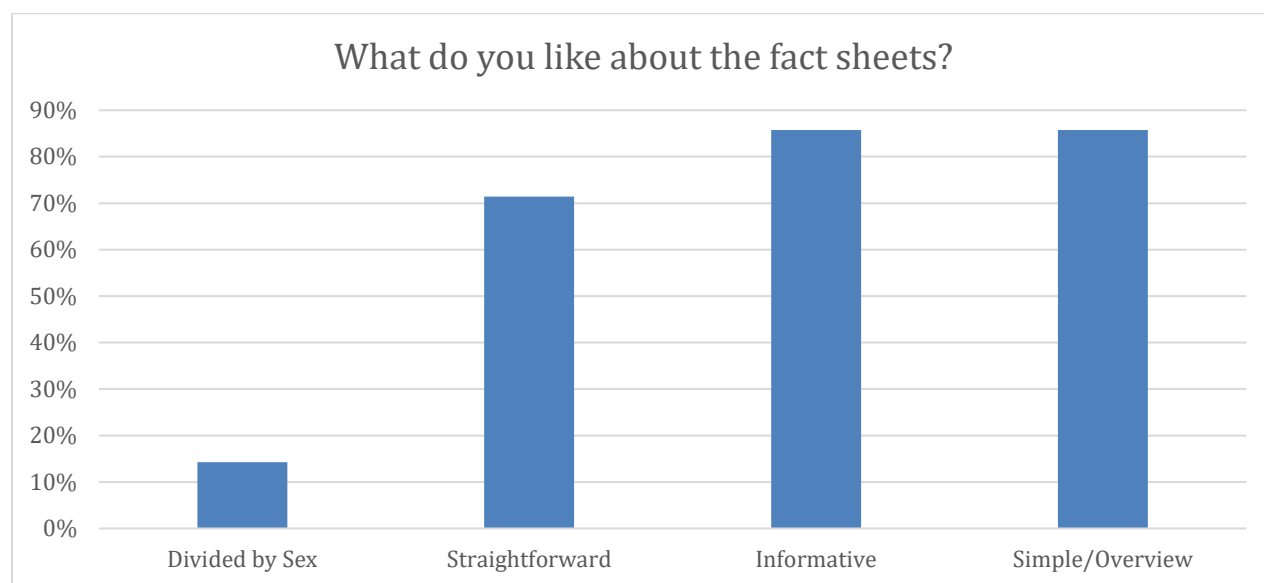
Needs Assessment

Are the (fact sheets) easy to understand? Why or why not?

Metric	% of Responders
# Easy to understand:	100%
# Indicating Simplicity of Content as Positive Attribute:	50%

What do you like about the fact sheets?

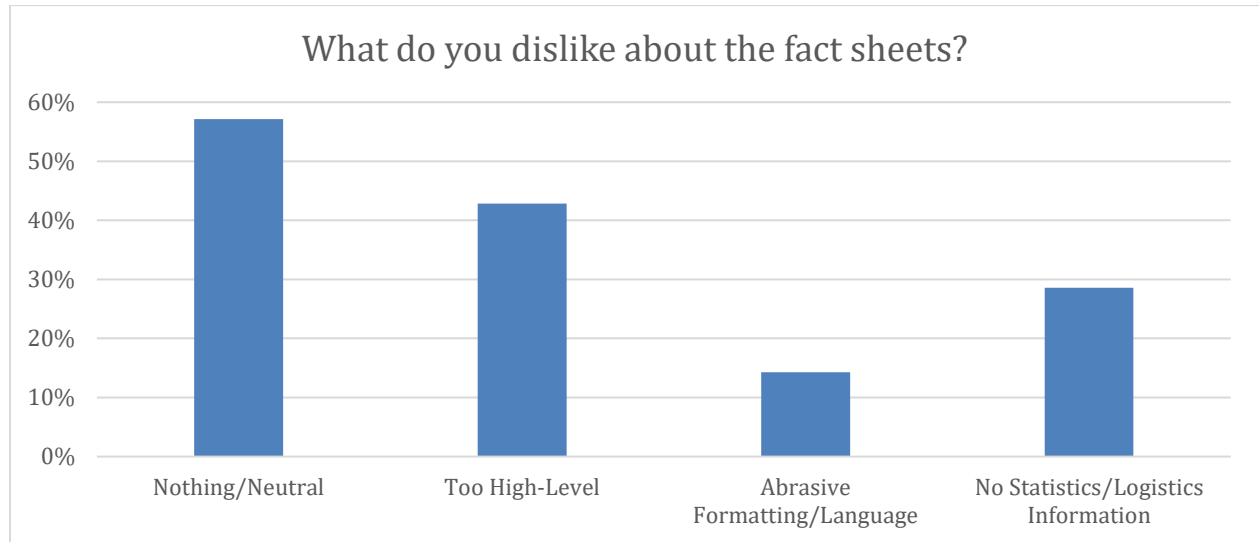
Attribute	% of Responders
Divided by Sex	14%
Straightforward	71%
Informative	86%
Simple/Overview	86%



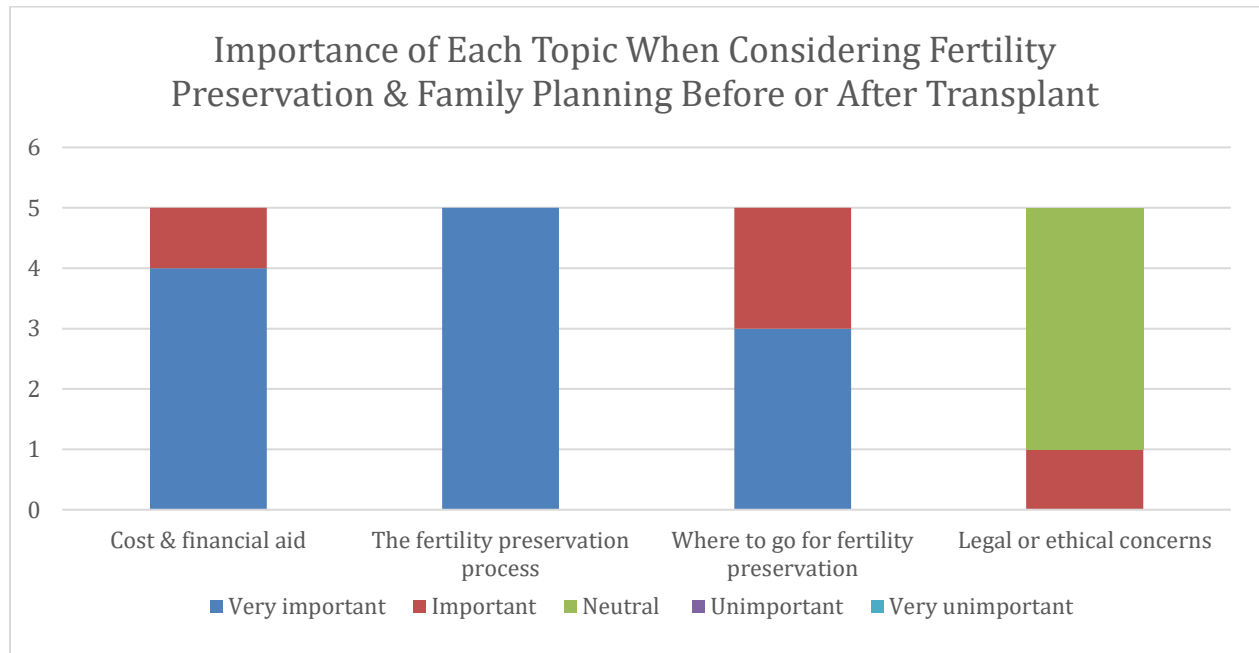
What do you dislike about the fact sheets?

Attribute	% of Responders
Nothing/Neutral	57%
Too High-Level	43%
Abrasive Formatting/Language	14%
No Statistics/Logistics Information	29%

Needs Assessment



Please tell us how important it is for you to learn about each topic if you were considering fertility preservation and family planning before or after transplant:



Appendix F

Vetting Education Module Review

Education Module Review	
# Reviewers	14
Reviewers	PEAG Members and BMT Patient Navigators
# PEAG Members	12
# BMT Patient Navigators	2
Topic	Fertility and Family Planning Education Module

What chapters did you review? Select all that apply.

	PEAG Member	BMT Pt Navigators	Total
Fertility Basics	11	2	13
Fertility and Transplant	12	2	14
Fertility Preservation for Women	11	2	13
Fertility Preservation for Men	10	2	12
Family Planning	10	2	12
Money Matters	9	1	10
Legal and Ethical Considerations	8	1	9
Talking with your Doctor	10	1	11

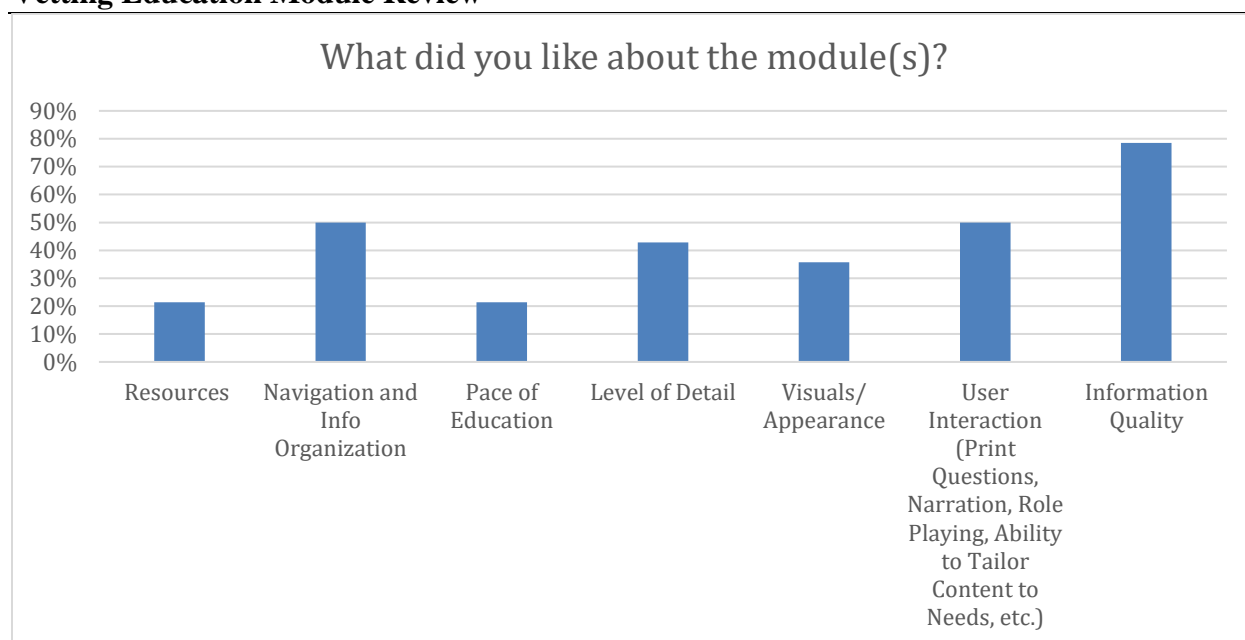
Is the Module easy to navigate and use?

- 100% indicated “Yes”

What do you like about the module(s)?

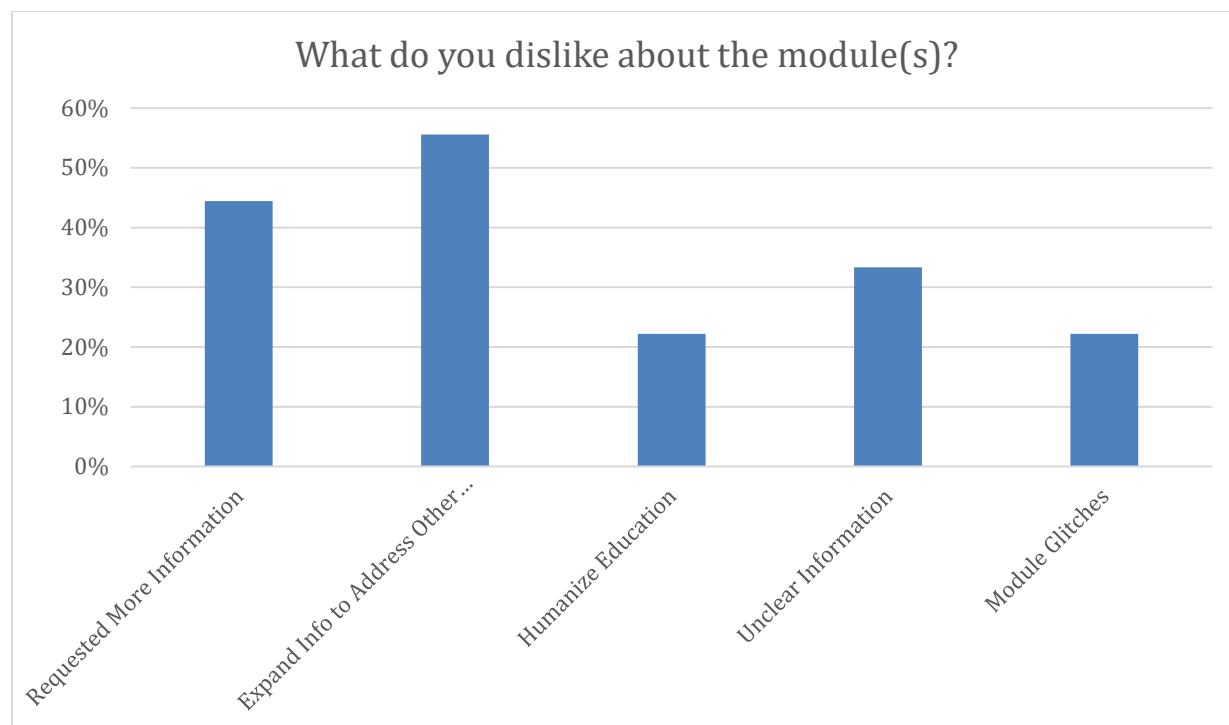
Attribute	# Positive Responses about Attribute
Resources	3
Navigation and Info Organization	7
Pace of Education	3
Level of Detail	6
Visuals/ Appearance	5
User Interaction (Print Questions, Narration, Role Playing, Ability to Tailor Content to Needs, etc.)	7
Information Quality	11

Vetting Education Module Review



What do you dislike about the module(s)?

Issue	# Responses mentioning issue
Requested More Information	4
Expand Info to Address Other Groups (AYA Population, Teens, Caregivers, Providers, Multiple Languages)	5
Humanize Education	2
Unclear Information	3
Module Glitches	2

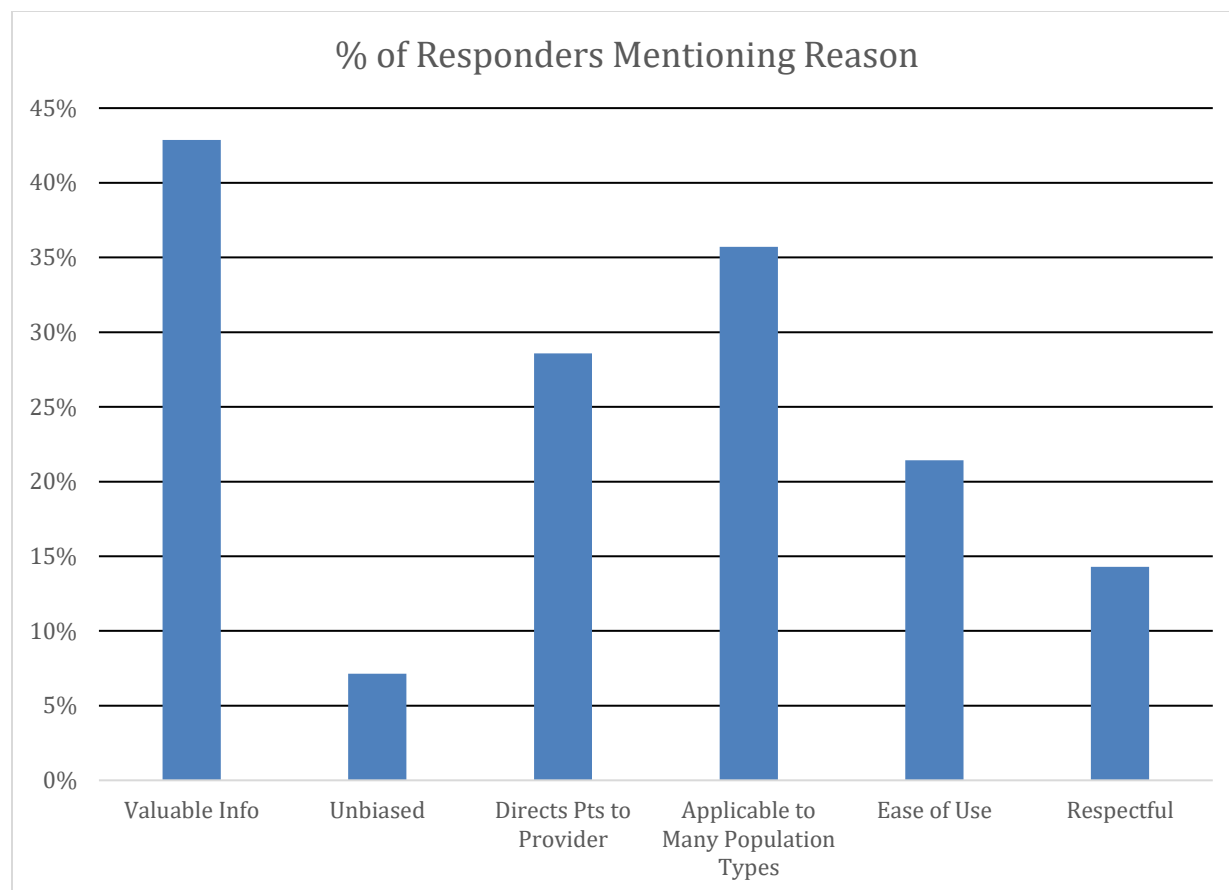


Vetting Education Module Review

Is this something you'd feel comfortable sharing with your patients?

- 100% indicated "Yes"
- Key Takeaways as to responders would feel comfortable sharing the module(s) with their patients:

Reasons the Modules would be Shared	# Responders Mentioning Reason
Valuable Info	6
Unbiased	1
Directs Pts to Provider	4
Applicable to Many Population Types	5
Ease of Use	3
Respectful	2



Vetting Education Module Review

What patient education resources does your center currently use when teaching patients and families about fertility preservation or family planning?

Resource	# References to Resource
Specialists	2
Referral to Fertility clinic	7
Handouts	2
Verbal Discussion	3
Non-Profit Resources	2
Be The Match Handouts	1
Internet Resources	1

