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EDUCATION FOR NEWLY DIAGNOSED SARCOMA PATIENTS: A COMMUNITY SERVICE PROJECT

A MASTER'S PROJECT

SUBMITTED TO THE GRADUATE FACULTY

GRADUATE SCHOOL

BETHEL UNIVERSITY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF

MASTERS OF SCIENCE IN PHYSICIAN ASSISTANT

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Abstract

Sarcoma is a rare neoplasm that may be found in any location in the body's soft tissues or bone (NCCN, 2020). As with all cancer, early diagnosis is important. With sarcoma, there is increased urgency to obtain a proper diagnosis early on because of the common incidence of metastasis of the primary tumor. The increased rate of metastasis in sarcoma is due to the favorable spread of cancer cells through the blood and lymphatic system (Pennacchioli et al., 2012). The treatment protocol after a new diagnosis of sarcoma depends on the type and may include multi-targeted therapies such as chemotherapy, radiation, and/or surgery (Gebhardt, et al., 2022).

There exists a lack of access to sarcoma patient education and an increasing population in the U.S. with decreased health literacy. These factors contribute to a decreased patient understanding of their diagnosis and are found to decrease survival. Literature review and analysis of online sarcoma education shows that existing education is written above what the NIH considers the general U.S. population's reading level (Patel et. al., 2015). This led to a partnership between the authors and Rein in Sarcoma (RIS), a non-profit organization based out of Minnesota. The authors partnered with RIS to enhance remotely accessible and easy to understand sarcoma education through online videos aimed for newly diagnosed sarcoma patients and their families. The five video series describes what sarcoma is, treatment options, experiences from sarcoma survivors, caregiver experience, and education on various topics such as: advanced directives, hospice, and palliative care. The videos were professionally edited and distributed by RIS online to increase accessibility of sarcoma education.

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We would like to say thank you to all of the wonderful people that contribute to and make Rein in Sarcoma possible. This organization that is near to our heart has far reaching impacts that have helped improve the lives of many. A special thanks to the RIS executive director, Janelle Calhoun, education and communications manager, Katy Engelby, and our videographer Alan Christensen. All of whose contributions allowed this project to happen. Alan Christensen graciously volunteered and dedicated many hours and equipment to filming this project.

Lastly, thank you to all of our volunteer video participants, most of whom have been greatly impacted by a diagnosis of sarcoma. We are honored to hear and share your sarcoma experiences, education, and advice to newly diagnosed sarcoma patients and their families. Without these shared experiences and time volunteered to this project, it would not have been possible. Because of the contributions of these volunteers: the authors are better providers, many PA's at Bethel have received sarcoma education, and patients and their families who access these videos will have access to education and hear stories of hope.

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Chapter 1: Introduction

Introduction

Sarcoma is a connective tissue cancer that originates from bone, fat, cartilage, and muscle tissue (Rein in Sarcoma [RIS], 2020). Sarcoma can be found anywhere in the body and is considered a rare cancer (NCCN, 2020). Sarcoma is divided into two main types: soft tissue and bone (NCCN, 2020). However, there are many subtypes of sarcoma within each main type. Generally, both soft tissue and bone sarcoma have rapid rates of lymphatic and hematogenous metastatic spread (Pennacchioli et al., 2012). Researchers are unsure of the precise etiology of sarcoma formation and more research is needed in this area (RIS, 2020). Diagnosis and treatment of sarcoma is determined by tumor location in the body, subsequent removal of tissue through core needle biopsy, and analyzing cellular anatomy when closely viewed under a microscope (NCCN, 2020). Core needle biopsy is the preferred method for obtaining tissue samples. If an incisional biopsy is used, it should be planned and performed by the surgeon who will be performing the final resection. A poorly placed biopsy may promote metastasis, require subsequent surgical repair, or more extensive surgery at the time of resection (Ryan & Meyer, 2022). Healthcare providers require adequate education to appropriately recognize, diagnose, and treat sarcoma (American Cancer Society, 2018d). Due to the rarity of sarcoma, many providers are not experts in diagnosing or treating these tumors. In fact some subtypes of sarcoma are so rare that there are no specific treatment recommendations (NCCN, 2020). It is important after a diagnosis of sarcoma to locate an expert with knowledge and experience in that specific diagnosed subtype of sarcoma (NCCN, 2020).

Rein in Sarcoma (RIS) is an organization based out of Fridley, MN. The organization's mission statement is as follows: "Rein in Sarcoma is dedicated to educating the public and

medical community about sarcomas, supporting sarcoma patients and their loved ones, and funding research directed toward developing new treatments and finding a cure for sarcoma cancers" (RIS, 2020, Our Mission section). Rein in Sarcoma identified a need to expand sarcoma patient education materials aimed toward the newly diagnosed at an appropriate health literacy level. Rein in Sarcoma and the authors determined the best approach during COVID to expand and enhance sarcoma patient education was to create online videos aimed toward newly diagnosed sarcoma patients that would be published through the RIS YouTube and the organizations webpage.

Chapter one begins with a background to the problem, the needs assessment that inspired this community service project, the problem statement, the purpose, significance of this project, limitations encountered, and concludes with definitions of common terminology used throughout this paper.

Background to the Problem

Sarcoma is a rare connective tissue cancer that arises from mesenchymal cells and accounts for less than 1% of adult cancers and 12% of pediatric cancers (Ryan & Meyer, 2022). Sarcoma is divided into two main types: soft tissue sarcoma (STS) or bone sarcoma. Soft tissue sarcoma is a broad category that contains over 100 different histological subtypes (Schöffski et al., 2014). Bone sarcomas are less common than STS and do not have as many subtypes (Fossum et al., 2020). Osteosarcoma is the largest subtype of bone sarcoma and accounts for half of all diagnoses of bone cancers (Hornicek & Agaram, 2020).

Soft tissue sarcoma typically presents as a gradually enlarging painless mass (Ryan & Meyer, 2022). Some patients will experience pain and paresthesias due to compression of the surrounding structures by the tumor, edema of the affected area, and rarely, systemic symptoms

like fever and weight loss (Ryan & Meyer, 2022). The exact etiology of sarcoma is unclear, but literature supports that there are specific genetic contributions. Increased incidence of sarcoma is seen in those with the genetic syndrome Li-Fraumeni, neuroblastoma type I, retinoblastoma, previous radiation exposure, exposure to chemical carcinogens, and lymphedema (Ryan & Meyer, 2022).

The primary tumor sites of osteosarcoma differ depending on the age of the patient. In children, the metaphysis of the long bones is the most common; however, the axial skeleton and craniofacial bones are commonly affected in adults (Wang et al., 2022). Symptoms of osteosarcoma is a localized bone pain at the primary tumor site that may wax and wane, a palpable mass, or a pathological fracture that can decrease ability to move the limb or cause a limp when walking. Systemic symptoms are typically absent (Wang et al., 2022). Predisposing factors for osteosarcoma include previous chemotherapy and radiation exposure, Paget disease, and the same genetic conditions seen with soft tissue sarcomas (Wang et al., 2022).

A favorable prognosis of sarcoma is dependent on early recognition and diagnosis as well as prompt treatment due to the aggressive and metastatic nature of the cancer that often involves lymphatic or hematogenous spread throughout the body. Sarcoma is often diagnosed at an advanced stage due to this lymphatic or hematogenous metastasis, secondary to a delayed diagnosis or misdiagnosis. When sarcoma metastasis occurs, it is preferentially located in the lungs, and is associated with increased mortality rates (George & Grimer, 2012). Through proper education, medical providers may be more readily able to recognize sarcoma, add it to their list of differentials, diagnose at an earlier stage, and initiate treatment sooner (Fossum et al., 2020). The differentials list is broad when a provider encounters a mass and may be more likely to include common and benign conditions. The provider differentials list may exclude rare cancers

such as sarcoma, as a common approach to diagnosis in medicine is to ‘look for horses not zebras’. It is imperative that patients are referred to a specialist for an appropriate biopsy and evaluation of a mass (Fossum et al., 2020).

After an initial diagnosis of sarcoma subtype, careful analysis of the tumor's cells and genetics occurs which helps guide treatment. All factors are looked at in regards to determining treatment of the primary tumor including, what subtype of sarcoma it is, where it is located, and if the tumor is localized or widespread. Treatment of soft tissue sarcoma often includes a combination of radiation, chemotherapy, and surgical excision in contrast to osteosarcoma treatment which is resistant to radiation and involves mostly surgical intervention and chemotherapy (DeLaney et al., 2020; Janeway & Maki, 2020). Research clinical trials are important in treatment of sarcoma. Patients must meet specific eligibility criteria to participate in a clinical trial and must be provided an opportunity for shared decision making with their provider.

After a sarcoma diagnosis, a patient may choose to obtain a second opinion to confirm the diagnosis or explore available academic clinical trials for treatment, however, this is not mandatory and is a patient’s personal preference (Peier-Ruser & von Greyerz, 2018). Patient’s and their families may see getting a second opinion as valuable in providing reassurance and building confidence in an existing diagnosis thus enhancing the trusting relationship with the provider. When discussing and deciding on treatment options with their provider, patients must have a good understanding of who makes up their sarcoma care team, the treatment benefits and risks, and the timeline of treatment course.

Following a sarcoma diagnosis patients experience grief. It is commonly accepted that there are five stages of grief according to Kübler-Ross’ *On Death and Dying*. However, patients

may not encounter all of the five stages: denial, anger, bargaining, depression, and acceptance; and there is no set order (Singer, 2018). Every patient's experience with grief looks different and the length of time spent in each stage may vary (Singer, 2018). Patient support after a new cancer diagnosis is essential and may include resources like cancer support groups, individual or group therapy, or patient advocacy through cancer organizations (Taylor et al., 1986). Patients may find support groups through online resources, medical provider recommendations, or patient advocacy groups. These support services offer a safe space outside of the medical setting to share personal experiences and both receive and provide encouragement to others.

According to Giuliani et al. (2020), patient education is "a critical aspect of quality cancer care". It better equips patients after a new diagnosis to understand and manage their medical care. Effective oncological patient education involves one-on-one teaching from the provider alongside supplemental educational materials. Patients often report they did not initially have a good understanding of their diagnosis, which may be attributed to low health literacy, the quality and quantity of patient education delivered, the patient's comprehension, health, and emotional state during cancer diagnosis (Giuliani et al., 2020). One-on-one delivery of education poses challenges to the unwell patient as they are required to attend additional appointments. This raises concerns of inequity when it comes to patient education at time of diagnosis. Patel et al. (2015) presents that the general population in the United States has an overall low health literacy. Health literacy is a patient's ability to access, gather, understand health information and services while applying this information to make appropriate health decisions. When patients receive educational materials at their respective health literacy level this leads to a greater understanding of their cancer diagnosis and the treatment course (Giuliani et al., 2020). Receiving appropriate educational materials has been shown to reduce anxiety, increase patient

satisfaction with care, and improve self-care (Patel et al., 2015). In contrast, patients report distress, misunderstanding, and treatment non-compliance when they are unable to access information at an appropriate level of health literacy. While evaluating patient understanding of educational resources, Patel et al. (2015) presented data showing across 72 websites and 774 articles that online sarcoma resources are written above an eleventh-grade reading level, which is incompatible with the average reading level of Americans. The National Institute of Health (NIH) recommends that medical education materials be written at a seventh-grade level or below to more closely match the reading level of the general American population. This current disparity reveals a need for improvement of and increased access to online sarcoma patient education material written at an appropriate reading level (Patel et al., 2015).

Needs Assessment

Karen Wycoff founded Rein in Sarcoma (RIS) in 2001 to "raise awareness and fund cures for sarcoma patients" (RIS, 2020, Karen's Story section). Wycoff was a Minnesota native and while attending college at Willamette University in Oregon in 1997, she found a growth in her axilla during a self-exam. She underwent a biopsy of the mass, which was assumed to be benign; however, pathology confirmed her diagnosis was sarcoma. In 2001, Wycoff hosted the first annual RIS fundraising event. Two months later, two weeks before her 26th birthday, she passed away, but her foundation still remains active today (RIS, 2020). Rein in Sarcoma currently has close relationships with various organizations including local medical programs at the University of Minnesota, the Mayo Clinic, and Children's Minnesota, which collaborate on advancing sarcoma research. Rein in Sarcoma is one of the largest sarcoma foundations in the Midwest and primarily serves patients in Minnesota, Iowa, North and South Dakota, and Wisconsin, but is known nationally and globally and continues to build new partnerships (RIS, 2020).

Rein in Sarcoma provides a free patient guidebook to people who have been diagnosed with sarcoma. The purpose of the patient guidebook is to extend support and provide sarcoma education to patients and their families (RIS, 2020). The patient guidebook covers the following topics: an overview of bone and soft tissue sarcomas, sarcoma subtypes, treatment options, navigating medical appointments, resources for patients and their caregivers who are undergoing treatment, resources for finding support, and organizational tools that can be utilized during treatment (RIS, 2020). Rein in Sarcoma identified a need to add accessible online sarcoma patient education material. The authors collaborated with RIS to create videos to supplement their current educational materials, in hopes of enhancing access to and improving understanding in newly diagnosed patients (see Appendix A).

Problem Statement

Rein in Sarcoma was looking to expand educational and supplemental videos for newly diagnosed sarcoma patients and family members. When patients receive a new cancer diagnosis, the information presented by the medical professional one-on-one may be misunderstood or overwhelming. The information may be subject to distortment because of the acute trauma of a cancer diagnosis. Patients will often “find that [they] can only take in small amounts of information [and] need to have the same information repeated to [them]” (Cancer Research UK, 2017, Shock and Denial section). There was a need for improved and accessible sarcoma education created at a health literacy level that is easily understood by sarcoma patients, especially during the time of a new diagnosis. The videos are available on the RIS website and their YouTube channel, which allows patients and their families the ability to watch remotely.

Purpose

The purpose of this project was to create educational videos that newly diagnosed sarcoma patients and their families can watch remotely in hopes of addressing initial questions they may have following a diagnosis. The intention was to reinforce medical information that is presented by the provider one-on-one in an accessible format that improves patient understanding of sarcoma. The videos featured sarcoma survivors, caregivers, a discussion of advance care planning, an overview of sarcoma, and standard sarcoma treatment options. This project was given to RIS to be used as a supplemental patient resource that the organization can provide to newly diagnosed sarcoma patients.

Significance of the Project

With the guidance and support of RIS, this project allows newly diagnosed sarcoma patients the opportunity to learn more about sarcoma remotely. The goal was to support patients during a new diagnosis through the experiences of the various video participants who shared their stories while instilling hope. The aim for this project was to enhance education and address patients most commonly asked questions. In addition, this project impacts physicians, physician assistants, nurse practitioners, nurses, and all other healthcare team members by providing more education and stressing the importance of early diagnosis of sarcoma. During time of diagnosis, providers have the opportunity to enhance patient education by providing the RIS guidebook, and this project allows for the opportunity to refer patients to the videos online or through a QR code that will direct patients to the videos.

Limitations of the Project

In acknowledging existing limitations to this project, the first identified limitation to achieving project goals would be viewers with limited resources lacking access to computers or

the internet. In addition, the organization of the videos and how the videos are displayed on the RIS YouTube channel determines if patients will find them accessible. Lastly, if patients or healthcare team members are unaware that the videos exist, they would not benefit from the videos intended purpose.

Definition of Terms

The following definitions are used commonly throughout this paper:

Acceptance: The final stage of grief. The "quality of being able to recognize [something] as true" (Merriam-Webster, n.d., Definition 1.a.).

Anger: A stage of grief. A "strong feeling of displeasure or rage" (Merriam-Webster, n.d., Definition 1.b.).

Advanced care directive (advance directive or AD): "Documents a person completes while still in possession of decisional capacity about how treatment decisions should be made on their behalf in the event they lose the capacity to make such decisions" (Silveira, 2020, Advance Directive section).

Bargaining: A stage of grief in which one "negotiates over terms" (Merriam-Webster, n.d., Definition 1.c.) or makes a promise for an exchange of wellness.

Chemotherapy (chemo): Medicine or drugs that are used to treat cancer that are cytotoxic or have the ability to kill tumor cells (American Cancer Society, 2020b).

Denial: A stage of grief. A "refusal to admit the truth or reality of something (such as a statement or charge)" (Merriam-Webster, n.d., Definition 1.d.).

Depression: A stage of grief "marked by sadness, inactivity, difficulty in thinking and concentration, a significant increase or decrease in appetite, time spent sleeping, feelings of

dejection and helplessness, and sometimes [having] suicidal tendencies" (Merriam-Webster, n.d., Definition 1.e.).

Do not hospitalize (DNH): An "order which [is] created in effort to reduce hospitalizations unlikely to improve patient survival or quality of life" (Conner & Weis, 2020, Definitions section).

Do not intubate (DNI): An "order which seeks to prevent unwanted mechanical ventilation" (Connor & Weis, 2020, Definitions section).

Do not resuscitate (DNR): A prevention of undesired cardiopulmonary resuscitation, including rescue breathing and/or chest compressions, defibrillation, and any type of advanced cardiovascular life support (Connor & Weis, 2020, Definitions section).

Genome: "The genetic material of an organism" (Merriam-Webster, n.d., Definition 1.f.).

Grief: A "strong, sometimes overwhelming emotion for people, regardless of whether their sadness tems from the loss of a loved one or from a terminal diagnosis they or someone they love have received" (Mayo Clinic, 2016, para. 1). Grief can be both "a universal and a personal experience" (Mayo Clinic, 2016, para. 3) and can last anywhere from a few days to months to years. "Pain is tempered as time passes and as the bereaved adapts to the news of a terminal diagnosis" (Mayo Clinic, 2016, para. 5).

Healthcare power of attorney (HCPOA): A person or persons that a patient designates to "make medical decisions on their behalf in [the] event of [their] lost decision-making capacity" (Connor & Weis, 2020, Definitions section).

Malignant: "Cancerous. Malignant cells can invade and destroy nearby tissue and spread to other parts of the body" (National Cancer Institute, n.d., Definition 1.a.).

Margin: “The margin is described as negative or clean when the pathologist finds no cancer cells at the edge of the tissue, suggesting that all of the cancer has been removed” (National Cancer Institute, n.d., Definition 1.b.).

Metastasis: “The spread of a disease-producing agency (such as cancer cells) from the initial or primary site of disease to another part of the body” (Merriam-Webster, n.d., Definition 1.h.).

Neoplasm: “An abnormal new growth of tissue that grows by cellular proliferation more rapidly than normal” (Dictionary.com, 2020, Definition 1).

Osteosarcoma: “A sarcoma derived from bone or containing bone tissue” (Merriam-Webster, n.d., Definition 1.i.).

QR Code: “Short for quick response code, it is a type of barcode that contains a matrix of dots. It can be scanned using a QR scanner or a smartphone with built-in camera. Once scanned, software on the device converts the dots within the code into numbers or a string of characters. For example, scanning a QR code with your phone might open a URL in your phone’s web browser” (TechTerms.com, 2022, paragraph 1).

Radiation therapy: A type of cancer treatment that “uses high-energy particles or saves, such as x-rays, gamma rays, electron beams, or protons, to destroy or damage cancer cells” (American Cancer Society, 2019c, “What is radiation therapy?” section) and is often “used alone or with other treatments, such as surgery, chemotherapy, hormones, or targeted therapy” (American Cancer Society, 2019c, Radiation Therapy Section).

Resection: “Surgical removal of part of an organ or structure” (Merriam-Webster, n.d., Definition 1.j.).

Sarcoma: “A malignant tumor arising in tissue (such as connective tissue, bone, cartilage, or striated muscle) of mesodermal origin” (Merriam-Webster, n.d., Definition 1.k.).

Soft tissue sarcoma: “A rare type of cancer that begins in the tissues that connect, support, and surround other body structures. This includes muscle, fat, blood vessels, nerves, tendons, and the lining of your joints” (Mayo Clinic, 2018, para. 1).

Surveillance: “In medicine, closely watching a patient’s condition but not treating it unless there are changes in test results. Surveillance is also used to find early signs that a disease has come back. It may be used for a person who has an increased risk of a disease, such as cancer. During surveillance, certain exams and tests are done on a regular schedule” (National Cancer Institute, n.d., Definition 1.c.).

TNM Staging: The “most often used by doctors to stage cancer. It is maintained by AJCC (American Joint Committee on Cancer) and UICC (Union for International Cancer Control). In this system, the letters T, N, and M describe a different area of cancer growth.” T= tumor size, N=node status, and M= presence of distant metastasis (National Comprehensive Cancer Network, n.d.,TNM staging system section).

Tumor suppressor gene p53: “A tumor suppressor gene, i.e., its activity stops the formation of tumors. If a person inherits only one functional copy of the p53 gene from their parents, they are predisposed to cancer and usually develop several independent tumors in a variety of tissues in early adulthood” (National Center for Biotechnology Information (US), 1998, para. 1).

Conclusion

Receiving a new cancer diagnosis is overwhelming, and patients often enter an emotional state of shock after hearing the word ‘cancer’ (Cancer Research UK, 2017). Patients can miss essential information or the opportunity to ask questions at the time of diagnosis due to the unexpected and life-changing news. The objective of this community service project was to collaborate with RIS to create educational videos for newly diagnosed sarcoma patients and their

families with the intention to provide support through supplemental sarcoma educational materials, in addition to the RIS guidebook and one-on-one provider education. Chapter two provides a review of both foundational sarcoma literature and up-to-date research. It provides a detailed overview of soft tissue and bone sarcoma, common treatments, important topics of consideration after a new cancer diagnosis, and support information for family members and caregivers.

Chapter 2: Literature Review

Introduction

Sarcomas are a rare and diverse group of malignant neoplasms that arise from connective tissue. Specifically, sarcoma arises from mesenchymal cells that differentiate into a specific type of connective tissue. These connective tissues are found in all areas of the body and include the framework of support tissues that surround all organs, muscle, blood vessels, make up adipose, and bone (Zahm & Fraumeni, 1997). The majority of diagnosed sarcoma cases arise from soft connective tissues and make up roughly 80%, while the other 20% of new cases originate from bone (Ryan & Meyer, 2022). The ability of medical providers to recognize and include sarcoma as a differential diagnosis when a patient initially presents is vital to early diagnosis and is very important due to the highly metastatic nature of sarcoma (Ryan & Meyer, 2022). If sarcoma is suspected, a skillful biopsy containing a cellular sample must be done which is subsequently used to identify the specific subtype of sarcoma and genetic tumor markers. All of this information serves to provide accurate diagnosis, complete staging, and direct course of treatment aimed toward the specific genetics of the developing sarcoma (Skubitz & D'Adamo, 2007).

This literature review includes a general overview of the main categories sarcoma is classified into: soft tissue sarcoma (STS) and bone sarcoma. For this review the authors included foundational sarcoma literature as well as included current literature to provide a broad view into the subject. Next, the literature review includes the current standard in treatment of sarcoma, as well as the importance of proper patient education and support after a new sarcoma diagnosis. Also discussed are important and commonly encountered topics such as the stages of grief, support and patient advocacy, and advanced care planning.

Soft Tissue Sarcoma Formation

The environment of an organism has a large impact on small specialized structures inside the body called cells. Natural cellular protective mechanisms exist inside the cell's nucleus, which are advantageous to preserve the normal structure of the cell's genetic material, thereby maintaining cellular integrity, which encourages survival and inheritance of traits (Laurini et al., 2020). These protective mechanisms include the cell's direct ability within the nucleus to repair its DNA through complex chemical structural changes (Laurini et al., 2020). When genetic mutations occur and cannot be repaired by these protective intra-nucleus repair mechanisms, the genetic makeup of the cell becomes permanently damaged and can lead to genetic changes of subsequent cell lineages via mutations. The mutations may act on specific gene segments of the DNA inside the nucleus or may rearrange the chromosomes, which causes permanent genomic instability of the cell. The overall impact is modification and initiation of abnormal cell cycles, which contribute to cancer formation (Laurini et al., 2020). There is not a clear etiology why sarcomas form but they are thought to arise spontaneously after new mutations occur (Ryan & Meyer, 2022). Past and present research supports a specific genetic germline mutation of the tumor suppressor gene, TP53, that may play a central role in the development of a high proportion of various cancers (Zahm & Fraumeni, 1997). Mutation of the TP53 gene is the most frequently detected molecular alteration in STS (Pollock et al., 1998). Cells in the primary tumor with the TP53 gene point mutation expand and become the dominating cellular metastatic component (Pollock et al., 1998). This mutation can be linked to poor prognosis in STS patients as some studies have frequently found this gene point mutation in metastatic STS. As a result of metastasis, these neoplasms are diagnosed as high-grade sarcomas and correspond with a poor prognosis (Pollock et al., 1998).

Soft Tissue Sarcoma Overview

Soft tissue sarcomas are relatively rare but account for 80% of new sarcoma cases per year (Ryan & Meyer, 2022). There are approximately 11,000 cases per year in the United States; this may be a conservative estimate as these cancers can often go misdiagnosed (Nystrom et al., 2013). Soft tissue sarcomas are characteristically diverse cancers, as they arise from embryonic mesenchymal cells, which differentiate into different types of connective tissue throughout the body (Ryan & Meyer, 2022). A recent estimate is that there are over 100 different histological subtypes of malignant STS (Schöffski et al., 2014). According to Dr. Charles Forscher, co-medical director of the sarcoma program at Cedars-Sinai Medical Center, the most common subtypes of STS are angiosarcoma, clear cell sarcoma, dermatofibrosarcoma protuberans, epithelioid sarcoma, malignant peripheral nerve sheath tumors, myxofibrosarcoma, rhabdomyosarcoma, solitary fibrous tumor, synovial sarcoma, and undifferentiated pleomorphic sarcoma (Forscher, 2020). Although soft tissue sarcoma is rare overall, many researchers believe that the incidence is underestimated (Zahm & Fraumeni, 1997). This underestimation may be attributed to the misdiagnosis of STS as cancer of a particular organ instead of the connective tissues around it (Zahm & Fraumeni, 1997). It remains difficult to determine the frequency of STS due to their rarity and the number of cases that remain undiagnosed, or get misdiagnosed (Forscher, 2020).

Soft tissue sarcoma can affect males and females of all age groups, although the largest population affected is adults 45-90 years of age (Schöffski et al., 2014). Risk factors for STS are family history, genetic mutations, and prior radiation exposure (Ryan & Meyer, 2022). Radiation increases the risk for secondary STS, as evidenced in patients who have received radiation treatment for breast and other cancers (Meyer et al., 2009).

Soft tissue sarcoma can develop anywhere in the body, with the arms and legs being the most common location (Ryan & Meyer, 2022). Other common locations and the percentage of occurrence are: thigh/buttocks/groin (46%), torso (18%), retroperitoneum (13%), and head/neck (9%) (Ryan & Meyer, 2022). Soft tissue sarcomas typically present as a slow-growing painless mass. These tumors can eventually become large enough to cause pain and compression symptoms such as paresthesias, or cause edema when located in an extremity (Ryan & Meyer, 2022). Less commonly, STS patients present with fever, weight loss, or regional lymph node involvement (Ryan & Meyer, 2022).

Often there is a delay in a STS diagnosis, which may be attributed to the relatively small number of cases seen and a suspicion that the growth is benign or does not require an extensive workup (Ryan & Meyer, 2022). A soft tissue mass is 100 times more likely to be benign than malignant. Due to this fact, roughly 10% of sarcoma patients have detectable metastases at the time of diagnosis (Fossum et al., 2020; Pennacchioli et al., 2012). The United Kingdom Department of Health has created criteria for soft tissue masses that may help medical providers determine if a patient needs an urgent referral to an oncologist for appropriate biopsy and initiation of treatment. This criteria includes a soft tissue mass greater than 5 cm (golf ball size or larger), a lump that is painful or has increased in size, any lump deep to the muscle fascia, and any recurrence of a lump after excision (Ryan & Meyer, 2022). There are proper biopsy techniques utilized when making a STS diagnosis and care should be given, even if sarcoma is unsuspected at the time of diagnosis (Ryan & Meyer, 2022). After biopsy and diagnosis, experts recommend that all newly diagnosed STS patients have a chest computed tomography (CT) to evaluate for the possibility of lung metastasis (Ryan & Meyer, 2022). The prognosis of STS

greatly depends on the size of the mass, evidence of metastasis, and the histological subtype of the STS.

Genetics of Osteosarcoma Formation

It is challenging to diagnose and treat osteosarcoma due to its rarity (Franceschini et al., 2019). As seen in STS, the exact pathogenesis is not well established, but for osteosarcoma, it is believed to be a sporadic occurrence including both genetic and environmental factors (Gorlick, 2019). The cells from which osteosarcoma originates are mesenchymal cells that differentiate into osteoblasts (Gorlick, 2019). Osteoblasts are cells within bone that are responsible for new bone formation. Changes in specific genes within these cells contribute to the development of osteosarcoma (Gorlick, 2019).

There have been recent molecular breakthroughs in determining how bone tumors generally arise. Bone tumors are divided into neoplasms that have either a simple or complex karyotype (Franceschini et al., 2019). Osteosarcoma has a complex karyotype that shows multiple genetic abnormalities (Franceschini et al., 2019). The genetic abnormalities include an irregular increase in copies of a gene segment, deletions of a gene segment, and random translocations. All of these genetic mutations affect the genes involved in maintaining the genomic stability of the osteoblast (Franceschini et al., 2019). There are hidden driver genes or mutant forms of genes that encourage cancer growth, which lead to further genomic instability (Franceschini et al., 2019). Chromothripsis, a mutational process in which chromosomes are ‘shattered’ into thousands of segments that are irregularly put back together, is another factor that contributes to the genomic instability of osteosarcoma formation (Franceschini et al., 2019). Chromothripsis is a mechanism observed in only 3% of other cancers, but is found in over 30% of osteosarcoma cases (Franceschini et al., 2019).

The most commonly altered genes observed in osteosarcoma are genes TP53 and RB1, which ordinarily function to regulate and maintain genome stability (Franceschini et al., 2019). These genetic variations occur more frequently in association with osteosarcoma than in other types of cancer (Gorlick, 2019). Certain germlines are predisposed to develop osteosarcoma and are commonly found in hereditary syndromes such as Li-Fraumeni, retinoblastoma, and Rothmund-Thomson (Franceschini et al., 2019). The gene RB1 is the retinoblastoma gene that is associated with a rare childhood cancer that forms in the eye.

Bone Sarcoma Overview

Bone sarcoma is the second largest sarcoma group and includes osteosarcoma, Ewing's sarcoma, and chondrosarcoma (Casali et al., 2018). Mavrogenis and Ruggieri (2015) point out in the article "Therapeutic Approaches for Bone Sarcomas" that bone sarcomas can be osteolytic, produce calcified matrixes (osteosarcomas), form from a cartilaginous matrix (chondrosarcomas), or may include both an osteolytic and osteoblastic mechanism. This review will specify when referring to a specific subtype of bone sarcoma or population affected.

When considering all bone forming tumors of the skeleton, osteosarcoma is the most common malignant neoplasm that forms in bone (Franceschini et al., 2019). These tumors are non-epithelial malignant neoplasms that originate from either the precursors of bone cells or from the bone cells themselves (Mavrogenis & Ruggieri, 2015). This review will focus on osteosarcoma as it is the most common primary malignant tumor of bone sarcomas (Franceschini et al., 2019). The five-year survival rate for osteosarcoma patients has maintained a steady 71% (Franceschini et al., 2019).

The affected population of osteosarcoma is bimodal, occurring in both children and adults (Mavrogenis & Ruggieri, 2015). Primary high-grade osteosarcomas have a pattern that occurs in

adolescents aged 10-19 years, with a second peak in adulthood, usually over the age of 60, and sometimes form secondarily to radiation (Franceschini et al., 2019; Gorlick, 2019). Osteosarcoma affects both males and females, with a slightly higher occurrence in males (Franceschini et al., 2019). Osteosarcoma also has a higher prevalence in African American and Latino populations (Gorlick, 2019). In adults, the osteosarcoma neoplasm, also known as an osteoid, is most commonly seen in the femur, tibia, pelvis, upper long bones of the humerus, radius, ulna, facial bones, and the skull (DynaMed, 2018a). In children, the most affected bones are the pelvic bones and upper and lower long bones (humerus, distal femur, and proximal tibia) (DynaMed, 2018b). The formation of osteosarcoma commonly occurs at the metaphysis, or growth plate, of the long bones in children (DynaMed, 2018a). Osteosarcoma can also invade the medulla of long bones or may form near the bone surface (Franceschini et al., 2019).

The common presentation of osteosarcoma is a swelling and enlarging mass that is described as a dull, aching, and persistent localized pain (Mavrogenis & Ruggieri, 2015). Patients report a feeling of ‘deep pain’ that is more noticeable with rest at night and gradually develops over weeks to months (Franceschini et al., 2019). Patients may present with decreased or limited mobility and localized palpable heat (Franceschini et al., 2019). The enlarging growth may feel tender upon palpation during physical exam (Franceschini et al., 2019). If the osteosarcoma has progressed to a later stage and the provider is seeing the patient for the first time it may present as a pathologic fracture (DynaMed, 2018a).

Osteosarcomas are classified as high-grade, intermediate-grade, or low-grade cancers (Gorlick, 2019). The grade classification is determined by looking at the cancer cells microscopically and deciphering the extent of cell growth and metastasis (Gorlick, 2019). High-grade osteosarcomas are the most common type in children and are the fastest-growing

metastatic form (Gorlick, 2019). Ten percent of patients who present with high-grade tumors present with metastatic disease, and 70% of patients with high-grade sarcoma will eventually develop metastatic disease (Pennacchioli et al., 2012).

Metastatic Component of Sarcoma

Metastasis of all sarcoma subtypes happens when cancer cells spread to secondary locations via blood vessels or the lymphatic system from where the neoplastic cells first arose in the body (Pennacchioli et al., 2012). Understanding sarcoma's metastatic potential is extremely important to help predict outcome and mortality (Pennacchioli et al., 2012). There are multiple processes involved in metastasis, but initially it involves a molecular change that disrupts the connection between the primary tumor site and the surrounding cells (Pennacchioli et al., 2012). The molecular changes that impact the cancer cells may come from cell adhesion molecule (CAM) signals, or tissue remodeling by proteinases, chemokines, or growth factors (Pennacchioli et al., 2012). The tissue remodeling molecules ordinarily regulate cellular processes such as proliferation, apoptosis, migration, and invasion (Pennacchioli et al., 2012). The metastatic sarcoma cascade is still a largely unknown mechanism. After cellular disruption, the tumor cells can metastasize via lymphatic drainage from the primary site to the lymph nodes, or spread through the vasculature into distant organs (Pennacchioli et al., 2012). In sarcoma, the main metastasis sites are the lungs and bone, which predominantly spreads hematogenously through the blood vasculature (Pennacchioli et al., 2012).

Specific types of sarcoma spread differently, either lymphatically or hematogenously as previously stated. For example, epithelioid sarcoma, clear cell sarcoma, angiosarcoma, and rhabdomyosarcoma metastasize in the body via the lymphatic system, specifically into neighboring lymph nodes, but most other sarcoma types spread through the vascular system

(Pennacchioli et al., 2012). The cancer cells get into the bloodstream where they can become lodged in the capillaries because of their small size or they may adhere to the endothelial lining in the capillary lumen (Pennacchioli et al., 2012). The preference for vascular spread by sarcoma can be catastrophic because of its potential to cause metastatic foci in the lungs (Pennacchioli et al., 2012). Lung metastasis is known to worsen the prognosis and is an indication of widespread cancer within the body. In this instance, a patient's outcome is usually limited to no more than five years (UCLA Health, n.d.).

Common Types of Treatment for Sarcoma

Surgery

Surgery is a common component in sarcoma treatment plans unless the sarcoma has metastasized extensively or is in a region in which wide excision of the tumor would be difficult to obtain clear margins (American Cancer Society, 2018c). Areas of the body that are challenging for surgical removal include the spine, pelvis, skull base, jaw, and STS in the thoracic or abdominal cavity (American Cancer Society, 2020d). These areas are complex because removing sarcoma requires a wide excision to remove the tumor entirely, along with one or more centimeters of healthy tissue margins around the tumor (DeLaney et al., 2020). After the tumor removal, the pathologist inspects the tissue margin under a microscope looking for cancer cells. If cancer cells are present in the resected tissue margin, it is labeled as having positive margins which suggests that there may still be cancer cells left behind at the resection site (American Cancer Society, 2018c). When this occurs, there is an increased risk for cancer regrowth and metastasis. When no cancer cells are present microscopically from the resection, the tumor is labeled as having negative margins and the chance of sarcoma regrowth is diminished (American Cancer Society, 2018c).

A surgical resection of osteosarcoma can pose a difficult challenge due to the need of a wide excision to remove the tumor and its surrounding tissue, which can result in limb amputation. Limb salvaging procedures are becoming more popular, but there is no clear data exhibiting a survival rate difference between an amputation and a limb salvaging procedure (Hornicek & Agaram, 2020). The surgeon may use several different techniques to remove the tumor, which is dependent on the size, location, and whether the surgeon feels an amputation or limb salvaging procedure would be the best option. If the surgeon is going to attempt a limb salvaging approach, the patient may receive bone grafts or an internal prosthesis to replace the removed bone (American Cancer Society, 2020d). Limb salvaging procedures often require additional follow-up surgeries later to replace the prosthesis, especially when placed in children that are still growing (American Cancer Society, 2020d). Rehabilitation after limb amputation or limb salvage procedure is often difficult and may take months to fully recover (American Cancer Society, 2020d).

Chemotherapy

Chemotherapy is a combination of medications given in cycles through intravenous administration that help kill cancer cells throughout the body (American Cancer Society, 2020b). Chemotherapy not only targets cancer cells, but also healthy cells. Killing healthy cells causes a wide range of side effects that are commonly associated with chemotherapy such as nausea, vomiting, hair loss, fatigue, mouth sores, increased infection risk, loss of appetite, and bruising (American Cancer Society, 2018a).

Chemotherapy is prescribed more often in osteosarcoma patients than in STS patients because of its proven efficacy. Adjuvant chemotherapy in osteosarcoma patients has shown to significantly increase survival when combined with surgical resection (Janeway & Maki, 2020).

Research has not shown an optimal chemotherapy regimen for osteosarcoma; however, three-drug regimens are better than two-drug regimens (Janeway & Maki, 2020). The commonly used three-drug regimen chemotherapy for osteosarcoma includes methotrexate, doxorubicin, and cisplatin (Janeway & Maki, 2020). The standard chemotherapy approach for osteosarcoma has not been agreed upon worldwide and the development of adjuvant chemotherapy has been largely empiric (Janeway & Maki, 2020). Oncologists usually prescribe chemotherapy adjuvantly for 29 weeks post surgery, but will also use chemotherapy neoadjuvantly for ten weeks prior to surgery to shrink the tumor and control metastasis (Janeway & Maki, 2020).

For STS, radiation and surgery are usually the preferred treatment. Chemotherapy is not a widely accepted treatment standard for STS except for in clinical trials and specific sarcoma subtypes such as Ewing sarcoma or rhabdomyosarcoma (Gebhardt et al., 2022). There is currently limited data on the optimal chemotherapy agent and regimen for STS, however research is being carried out in this area.

Radiation

Radiation uses high-energy particles to target malignant cells at the specific location of the tumor (Mitin, 2020). Radiation is an outpatient procedure where the patient visits a cancer treatment center or hospital multiple days a week for several weeks to receive radiation treatment (American Cancer Society, 2019b). Side effects of radiation are highly dependent on the location of the tumor. Radiation may cause swelling, erythema, blistering, or skin peeling at the targeted area (Mitin, 2020). A precise technique is used when delivering radiation to prevent damage to the surrounding organs. Several radiation techniques are used with sarcoma and include external beam radiation, brachytherapy, and intraoperative therapy (Mitin, 2020). The most frequently used type of radiation for sarcoma is external beam radiation (American Cancer Society, 2018b).

Soft tissue sarcoma patients frequently receive radiation, but radiation is not the primary treatment option used for osteosarcoma patients. Osteosarcoma is typically resistant to radiation (Janeway & Maki, 2020). The standard osteosarcoma treatment plan includes using chemotherapy and surgical excision. Adjuvant radiation in osteosarcoma patients has not proven to increase survival or prevent secondary tumor recurrence (Janeway & Maki, 2020). In contrast, radiation is very effective in STS and is the main treatment used in conjunction with surgery. Radiation and surgical treatment plans for STS in the extremities has reduced the need to perform limb amputations (DeLaney et al., 2020). There is limited available research on whether neoadjuvant or adjuvant radiation is more effective in STS (DeLaney et al., 2020).

Clinical Trials

Clinical trials are another option to consider when deciding on a cancer treatment plan. A cancer clinical trial is real-time research involving volunteer cancer patients, in which the goal is to discover better cancer detection methods, treatment strategies, and prevention (National Cancer Institute, 2020). The initiation process of a clinical trial is rigorous and starts years before it can be offered in the treatment of cancer. Researchers perform experimentation on animals first, proving safety and efficacy, and must be approved by regulatory bodies before making the trial widely available to patients (National Cancer Institute, 2020).

There are numerous clinical trials available for both STS and osteosarcoma patients in the United States. The NIH has a ‘find a study’ search engine that finds clinical trials worldwide (National Institute of Health, n.d.). At time of this publication, there are currently 614 osteosarcoma and 2,214 STS clinical trials worldwide (National Institute of Health, n.d.). A patient can also find clinical trials on the National Cancer Institute's website or through many major cancer centers. An oncologist may recommend a clinical trial to a patient, but due to the

large number of clinical trials available, oncologists may be unaware of specific details for every available clinical trial, unless they are personally involved in carrying out the trial. Patients that are interested in participating in a clinical trial can do their own research online to determine the eligibility requirements (American Cancer Society, 2020c). If a patient finds a clinical trial they are interested in and meets the eligibility requirements, they would contact the clinical trial coordinator and use shared decision making with their oncologist to determine if it is appropriate for their treatment plan (American Cancer Society, 2020c).

Sarcoma Prognosis/Prognostic Variables

There are three important variables that need to be considered when determining the prognosis with the primary neoplasm: tumor location, tumor size, and evidence of metastasis (DynaMed, 2018c). Prognosis will vary depending on the type of sarcoma, the histological subtype, the resection margins, and tumor characteristics. Poor prognostic factors for sarcoma are an increased size of the primary tumor, presence of positive margins post-surgery, evidence of metastasis, a poor response to treatment, and an increased patient age (DynaMed, 2018c). The five-year survival rate for osteosarcoma patients is 71% and has not seen improvement in the last decade. This indicates a compelling need for the development of novel therapeutic strategies (Franceschini et al., 2019).

Stages of Grief After Diagnosis

When a patient initially learns about a new cancer diagnosis, many report entering an emotional state of shock (Cancer Research, UK, 2017). Some have reported that the moment they learned about their diagnosis was like a scene from a movie, where time stops around them. Patients are in disbelief and can feel numb, emotionless, or may need information repeated back to them (Cancer Research, UK, 2017). Psychology Today defines an emotional or psychological

shock as “when you experience a surge of strong emotions and a corresponding physical reaction, in response to a (typically unexpected) stressful event (Boyes, 2018). This reaction to a new diagnosis can last minutes, hours, or days and can be a way that patient’s temporarily avoid their new reality. Experts recommend that patients continue with their usual day-to-day activities during this period (Westburg, 1971). Grief is a natural response to loss, and although a newly diagnosed patient is not grieving for the loss of life, there are other losses associated with a cancer diagnosis that bring grief (McKee & Kelley, 2020). Losses a patient may be concerned about include their physical abilities, cognitive functioning, how they will fit in socially, and new financial burdens that are associated with a cancer diagnosis. Patients may also experience a loss of “control”, certainty, hope, and expectations for the future” (McKee & Kelley, 2020, p. 504). According to McKee and Kelley (2020), grief is unique to each individual and symptoms can vary from person-to-person.

Elisabeth Kübler-Ross (1969), author of several books on the subject of death and dying, states there are five stages of grief that patients go through at the end of life, especially if they have been diagnosed with a terminal illness. These original stages were written about those who are dying or have a terminal illness, but the five stages of grief are widely accepted today as applicable to newly diagnosed cancer patients. The five stages of grief include denial, anger, bargaining, depression, and acceptance. Often patients will experience each of the stages in the order listed above, but there are no set rules stating that a patient has to complete a specific stage before moving on to another. Patients have reported that grief is cyclical and each of the individual stages can be experienced differently from person-to-person (Singer, 2018). The length of each grief stage is dependent on the patient and their coping abilities (Singer, 2018). At

one time or another in their cancer journey, patients will typically come to accept the reality of their diagnosis.

Denial

Denial is a coping mechanism and "adaptive strategy to detect against overwhelming events and feelings" (Vos & de Haes, 2007, p. 12). Psychoanalyst Anna Freud described denial as "an unconscious defense against painful and overwhelming aspects of external reality" (Vos & de Haes, 2007, p. 12). During a new cancer diagnosis, a patient and their family should be given the opportunity to ask questions and process this new reality with a medical provider. Patient denial can act as a barrier to initiating treatment. If a patient feels pressured to start treatment before coming to terms with their diagnosis this may lead to delayed course of treatment, anger, and aggravation (Singer, 2018). When addressing the denial a patient may be experiencing, providers should "strengthen [their] psychosocial resources and avoid denial in one's own perspective" (Singer, 2018, p. 2). The provider is recommended to take a neutral stance and acknowledge the patient's denial, but not join them with their own denial. Providers should allow for extra time and support services to ensure a patient has time to ask questions, with the aim of assisting them in overcoming this stage of grief (Singer, 2018).

Anger

Anger and aggression are innate reactions that many patients experience after a cancer diagnosis. Patients will often fight or argue with their loved ones, members of the healthcare team, and question their faith beliefs (Singer, 2018). Patients may think that they will be able to overcome their diagnosis by arguing, and when they realize this is not the case, they can become depressed and have feelings of guilt and helplessness (Singer, 2018).

According to Heussner (2016), anger is a coping strategy explained by the unfairness of the fate that a person faces when they have a threatening illness. Heussner claims that it is more difficult to blame fate than to hold the physicians accountable for a diagnosis. Patients will often react with 'why me?' and become angry at the thought of having their future taken away from them (Heussner, 2016). These ruminations often lead to a sense of panic where patients think that there is not enough time to get their affairs in order or carry out certain desires, which usually casts a temporary anxiety (Kübler-Ross, 1974).

Bargaining

In the bargaining stage, patients often aim their pleading towards God or their faith, while others choose to involve their family or friends. Patients will bargain with God and plead to extend their life, make promises of good behavior, or make a religious dedication in order to be spared from their suffering (Kübler-Ross, 1974). Patients report feeling they know there is a slim chance of God answering their pleas but hope to be rewarded for their good behavior and religious dedication. Prayers may not always involve extending life or miraculous healing, but can be as simple as getting through a day without pain or difficulties (Kübler-Ross, 1969). Commonly, patients will bargain for more time in order to attend a big event, such as a child's wedding or a specific holiday. Patients presume their reward for good behavior should be surviving long enough to attend that particular event (Kübler-Ross, 1969).

Depression

The depression stage may begin with patients mourning past losses before losing interest in everything happening around them. Often in this phase, the patient will not want to socialize with people and will lose interest in objects or activities they once cared about (Kübler-Ross, 1974). Depression symptoms are common among patients with a new diagnosis of cancer and

can affect a patient's quality of life. Depression can amplify some of the physical characteristics that are involved with having cancer like pain, fatigue, loss of appetite, and quality of sleep (McKee & Kelley, 2020). According to one article, depression can cause a person to feel hopeless and experience a lack of joy (Berry, 2018). Sleep may be interrupted and food either acts as a comfort or is unappetizing (Berry, 2018). Lastly, self-esteem is often absent and concentration may be hard to achieve during this phase (Berry, 2018).

Acceptance

When a patient is given enough time to go through the denial, anger, bargaining, and depression stages, they hopefully reach the acceptance stage of their diagnosis. Most become comfortable with sharing their diagnosis with people they know and love, and they are able to talk about cancer without associating the aforementioned feelings (Kübler-Ross, 1969). Acceptance should not be confused with happiness (Kübler-Ross, 1969). A patient who has accepted their diagnosis is not necessarily happy about it, but eventually comes to realize that cancer is a part of their life forever, whether they go into remission or not (Kübler-Ross, 1969).

One thing that tends to be present through all stages of grief is hope. Hope is to "want something to happen or be true" (Merriam-Webster, n.d., Definition 1.g). When hope is present, the thought of a challenging situation, like a cancer diagnosis, can help sustain a patient through a period of suffering (Kübler-Ross, 1969). Hope is a sense of "rationalization for [certain patient's] suffering, and for others, it remains a form of temporary but needed denial" (Kübler-Ross, 1969, p. 134). Once a patient stops showing signs of hope, it could be an indication that they have given up on any thought of a possible cure, recovery, or survival (Kübler-Ross, 1969). The ultimate goal of the five stages of grief is for patients to come to the

realization that cancer does not define them; it is merely something that is happening to them (Kübler-Ross, 1969).

Steps After Getting Diagnosed

Getting a Second Opinion

Getting a second opinion may be a desired option for some patients, while others may find it unnecessary. Second opinions can be affirming to a patient who has a new cancer diagnosis and may be an option that some feel they need to explore before beginning treatment (American Cancer Society, 2019a). One reason to get a second opinion includes verifying the pathology of the biopsy to confirm the cell type of the neoplasm. Confirming the pathology will help the medical team tailor the most precise treatment plan for the cell type. A second opinion may also be worth obtaining to give "reassurance for diagnosis [and] confirm treatment and prognosis" (Peier-Ruser & von Greyerz, 2018, para. 2). However, others may feel this is not necessary as they have established an agreed upon treatment plan and have built a relationship with their care team.

According to one study, there are some common factors that have been identified as obstacles that keep patients from seeking another opinion (Peier-Ruser & von Greyerz, 2018). First is the state of emotional shock someone goes through when first diagnosed with cancer. Once the word 'cancer' is heard, patients may tune out information that is given at the time of diagnosis. In addition, patients can have immediate fears and concerns about the state of their future, which contributes to their emotional state at time of diagnosis (Peier-Ruser & von Greyerz, 2018). The recommendations for urgent treatment initiation by the care team and caregivers may cause the patient to feel pressured to start a regimen and forgo a desired second opinion (Peier-Ruser & von Greyerz, 2018). Another factor is the difficulty of getting an

appointment with a specialist on short notice, as appointments may not be available for weeks or months, which could delay treatment. During this process of diagnosis, patients can be overwhelmed with the amount of information they receive, making them hesitant to see another specialist (Peier-Ruser & von Greyerz, 2018). Lastly, patients have noted a fear of compromising the patient-physician relationship (Peier-Ruser & von Greyerz, 2018). Patients do not want to offend their physician by getting a second opinion and jeopardize the established relationship with the diagnosing medical provider (Peier-Ruser & von Greyerz, 2018).

Advanced Care Planning and Directives

Advanced care planning is a decision-making process that often occurs after a diagnosis, learning of an ill-fated prognosis, or near end-of-life, and defines a patient's wishes and medical preferences in the event they are no longer able to make their own decisions (Conner, 2020). The Institute of Medicine's report *Dying in America* defines advanced care planning as "a process for setting goals and plans with respect to medical treatment and other clinical considerations. It brings together patients, families, and clinicians to develop a coherent care plan that meets the patients' goals, values, and preferences. It can begin at any point in a person's life, regardless of his or her current health state; is revisited periodically; and becomes more specific as changing health status warrants" (Sudore et al., 2017, Delphi Methods section). The advanced care plan should be initiated early in a diagnosis and completed while the patient still has cognitive function in order for the documents to be legally recognized (Conner, 2020). Advanced care planning is important to put into place early, so that in the event the patient is no longer able to express their wishes or speak for themselves, a document is already in place stating those wishes. If there is no such document at the time a patient can no longer speak for themselves, family is often left to make medical decisions, which may or may not align with the patient's wishes. The

document should state the overall goals of the patient in regards to their medical care and assign someone to speak for them in the event they cannot do so. There are several legal documents involved when establishing advanced care directives, and patients should obtain these documents from their provider or care coordinator (Sudore et al., 2017).

An advanced care directive is a document that defines a patient's desires and specific treatment wishes, which are kept on hand by their medical team and referred to when needed during the course of treatment. This document may be changed at any point during the patient's treatment course and addresses resuscitation and life support wishes, pain management, and specific treatment goals (Silveira, 2020). A healthcare power of attorney (HCPOA), also known as a healthcare proxy, or a durable medical power of attorney (DPOA) is designated by the patient to make medical decisions on their behalf in the event they are unable to make their own decisions (Conner, 2020). Refusal of treatment orders include a do-not-resuscitate (DNR), a do-not-hospitalize (DNH), and a do-not-intubate (DNI) order. A DNR is a statement preventing unwanted cardiopulmonary resuscitation (CPR) in the event a patient's heart stops beating and/or they stop breathing. This document protects the patient from unwanted lifesaving measures such as chest compressions, rescue breathing, defibrillation, and advanced cardiovascular life support in order to allow for a natural death (Conner, 2020). A DNH expresses a patient's wish to avoid hospitalization under specified circumstances in an effort to limit the number of hospital admissions in hopes of increased quality of life (Conner, 2020). A DNI states that if a patient stops breathing, they do not wish to be intubated or put onto a mechanical ventilator. In this instance, other measures like CPR or defibrillation can be utilized to get the heart pumping again, but no form of assisted respiratory effort can be attempted (Conner, 2020).

Coping Strategies

Receiving a new cancer diagnosis is an emotionally overwhelming experience in the life of a patient (Taylor et al., 1986). Due to the nature of a cancer diagnosis, it is a continuous physical and psychological stressor in a patient's life. Having social support from others who are also experiencing cancer, outside of family and friends, can be reassuring (Taylor et al., 1986). One way to achieve this sense of community is through support groups or patient advocacy groups. A support group involves people undergoing a similar situation that may interact through organized therapy, social events, virtual meetings, etc. There is an emphasis on providing support through participation and discussion of shared feelings, emotions, or any other topic. Attendance is voluntary and the purpose of the group meetings are to provide social support and help patients cope with their illness (Taylor et al., 1986). This social support includes emotional support provided by other patients experiencing similar situations (Taylor et al., 1986). Rein in Sarcoma is an organization that provides patient advocacy through events that are offered to sarcoma patients, survivors, caregivers, family members, and friends. Activities include regularly scheduled small group meetings for survivors, patients, and caregivers, the annual Party in the Park fundraiser, and numerous other fundraising and silent auction events held yearly to support sarcoma patients, education, and research (RIS, 2020).

Support of a Newly Diagnosed Cancer Patient

A new cancer diagnosis has been described as an overwhelming, scary, and emotional event for the patient and their family members. In one study, family members reported feeling unsupported and had several concerns during their loved one's cancer journey (Dionne-Odom et al., 2019). The most significant concerns reported were managing stress, dealing with fatigue, worrying about the future, talking about emotions, and finding financial help (Dionne-Odom et

al., 2019). Cancer is sometimes referred to as a ‘family disease’ because it can cause significant strain and bring about new and unexpected lifestyle changes for family members (Coyne et al., 2020). The journey after a cancer diagnosis can be long, depending on the type of cancer, prognosis, or treatment plan. The average active treatment phase is 14-24 months, and even when treatment is successful, there is often a need for family and caregiver support for months and/or years after (Coyne et al., 2020). Family members and caregivers often help their loved ones get to various appointments, prepare meals, provide housekeeping tasks, and provide physical and emotional support (Nipp et al., 2016).

Caring for someone with cancer is not an easy task, especially with the uncertainty that comes with cancer. Nipp et al. (2016) found that family members and caregivers who offer a great deal of support for their loved ones have been known to suffer significant adverse health consequences themselves. Family members, caregivers, and the patient can equally suffer from depression, anxiety, physical changes, reduced socializing, and a diminished quality of life (Coyne et al., 2020). Family members and caregivers need to remember to address their own physical and mental health needs. The American Cancer Society (2020a) has several recommendations for self-care, such as eating healthy, reducing alcohol and tobacco use, exercise, finding time to focus on oneself, and reaching out to medical professionals or therapists if needed. When caregivers have social support, it has been shown that their own stress and burden are decreased (American Cancer Society (2020a). Taking a short break throughout the day or utilizing respite care to provide temporary relief of duties can also be used as caregiver self-care. Caregivers need short periods of rest and relief to stay emotionally and physically capable of their caregiving duties (American Cancer Society (2020a).

Family members and caregivers of newly diagnosed patients may not know what to expect or be prepared in regards to physical and mental changes their loved ones may experience. Cancer patients can experience hair loss, weight loss, nausea, vomiting, pale skin, and fatigue (American Cancer Society, 2016). A patient may experience a wide range of emotions, including sadness, anger, fear, uncertainty, and mood swings (American Cancer Society, 2016). Family and caregivers need to understand that it is normal for their loved one's emotions to fluctuate and it is part of the grieving process while going through cancer (American Cancer Society, 2016).

How to Talk With a Cancer Patient

After a patient's new cancer diagnosis, it is not uncommon for family and caregivers to feel uncomfortable around the patient or not know how to talk to them. A loved one's cancer diagnosis "often reminds us of our own mortality" (American Cancer Society, 2016, "How Do I Get Over Feeling" section). If a family member or caregiver feels uncomfortable or guilty because they are healthy, it is important to realize that this response is normal. To help overcome these feelings or fears, the American Cancer Society (2020a) recommends frequent communication. Specifically, family members and caregivers should talk about what makes them frightened or uncomfortable with the person who has cancer. Despite this, it is reported to be difficult to talk to a loved-one with cancer because they are afraid to say the wrong thing. In addition, one of the most important aspects of communication is listening. Caregivers and family members should hear what their loved one is saying, try to understand what they are saying, and put their own feelings and fears aside (American Cancer Society, 2020a).

When speaking with cancer patients, family and friends should try to avoid common phrases like 'I know how you feel' or phrases about their appearance like 'You are looking pale'

(American Cancer Society, 2020a). Unless a family member or caregiver has experienced the exact situation, they cannot truly understand what their loved one is experiencing. Instead, family and caregivers should take their cues from their loved one and let the patient guide the conversation, respect treatment decisions they have made, and keep their relationship as normal and balanced as possible (American Cancer Society, 2020a). During this time, patience and compassion may be called upon more frequently.

Conclusion

An early sarcoma diagnosis is imperative as this cancer is highly metastatic and is associated with a high mortality rate. Proper patient education at an appropriate health literacy level may improve quality of life, adherence to treatment plans, and improve outcomes. Also, it is helpful to educate patients on the stages of grief and associated emotions that come with a sarcoma diagnosis. Teaching healthy coping techniques and providing support services may improve outcomes and can be utilized during treatment courses. In addition, family and caregiver support is an important factor that plays into the emotional well-being of the patient. It is necessary that caregivers and family members also utilize support services and take care of themselves during a cancer diagnosis.

Chapter three will discuss the methodology utilized in creating the five educational videos aimed toward newly diagnosed sarcoma patients and their families, which are available on Rein in Sarcoma's website and YouTube channel.

Chapter 3: Methodology

Introduction

Chapter three describes the methodology that the authors used in this community service project to create five videos for the RIS YouTube channel. This chapter discusses the rationale for the project, the intended audience that the videos impact, along with the project details, tools, and a discussion of project barriers.

The intention of this project was to partner with RIS to create videos that are informative, supportive, and provide hope for newly diagnosed sarcoma patients and families at a health literacy level that is appropriate for the general public. A sarcoma diagnosis can often be unexpected and overwhelming for patients and families. These videos provided RIS with an additional patient education tool that the organization can provide to newly diagnosed sarcoma patients in conjunction with the materials they currently provide to patients.

Rationale for Project

Rein in Sarcoma was founded by Karen Wycoff in 2001 and is now the largest sarcoma foundation in the Midwest with recent national and global outreach. Rein in Sarcoma provides support to any sarcoma patient, survivor, and family member who accesses their organization; however, their primary target audience are residents of Minnesota, Iowa, North and South Dakota, and Wisconsin (RIS, 2020). They also provide information to improve sarcoma education among the general public and healthcare providers using their website, YouTube channel, and social media. Rein in Sarcoma's mission is "dedicated to educating the public and medical community about sarcomas, supporting sarcoma patients and their loved ones, and funding research directed toward developing new treatments and finding a cure for sarcoma cancers" (RIS, 2020, Our Mission section). Rein in Sarcoma raises and provides funding and

maintains partnerships with the University of Minnesota, the Mayo Clinic, and Children's Minnesota to support and enhance sarcoma research.

Rein in Sarcoma was looking to expand their education materials to include informational and supplemental videos for newly diagnosed sarcoma patients and family members, which can be used in conjunction with the RIS patient guidebook that is given to patients at time of a new sarcoma diagnosis. Patient education is essential after receiving a new cancer diagnosis. Proper patient education increases both the patient's and family's quality of life (Giuliani et al., 2020). It is commonly reported that cancer patients do not understand the information given by medical providers after a new cancer diagnosis. Two main factors contribute to this misunderstanding: low health literacy and the emotional process that may leave patients feeling overwhelmed and stressed after a cancer diagnosis (Giuliani et al., 2020).

The authors volunteered their services in this community service project by providing research, medical knowledge, and devoted time in the creation and production of the five educational videos. The intended goal of the five videos was to improve access and patient education for newly diagnosed patients and families at an appropriate health literacy level, with the hope of reducing negative emotional aspects that accompany a new diagnosis.

Population

The intended target population for this community service project is broad and consists of current sarcoma patients, previously diagnosed patients, individuals in remission, family members, caregivers, and acquaintances of sarcoma patients. Although this project is aimed towards newly diagnosed sarcoma patients, caregivers, and family members, anyone who accesses the RIS YouTube channel can utilize these five videos. For this project, the authors worked with RIS executive director, Janelle Calhoun, and education and communication

manager, Katy Engelby. Alan Christensen, a volunteer videographer and sarcoma caregiver emeritus, recorded the videos. The RIS board members approved a budget to assist in professional video editing before they were given to RIS to post.

Project Plan and Implementation

To fulfill the need of expanding and improving access to quality sarcoma education, RIS and the authors collaborated with volunteers, which included educators, sarcoma specific medical and treatment providers, sarcoma survivors, and caregivers. Rein in Sarcoma and the authors approached the volunteers to ensure their desire to participate in this community service project and obtained consent via a volunteer waiver through RIS. The volunteers in return provided personal testimony and public education through participation in the five videos that were subsequently uploaded to the RIS YouTube channel and premiered at the 2022 annual American Society of Clinical Oncology (ASCO) conference. Through collaboration and discussion between the authors and RIS, the five video topics were selected. The aim of the selected topics were to cover frequently addressed questions or concerns of newly diagnosed sarcoma patients. The videos were then presented in such a way that were designed to inform, educate, and encourage patients and caregivers.

During the early stages of planning, the authors met virtually with each volunteer video participant where talking points and topics for each video were discussed and decided upon collaboratively. The authors acknowledged that the volunteers contributed and incorporated their own ideas or topics into the talking points. Janelle Calhoun and Katy Engelby of RIS provided final approval of the talking points and topics prior to initiating filming of the videos. The volunteers were provided the option of filming in person or remotely due to the immunocompromised status of a few of our volunteers combined with the fact that this

community service project was initiated in 2020 during the COVID-19 pandemic. The authors maintained adherence to all state laws and COVID-19 regulations during video production, which included reducing participant numbers, wearing masks, and enforcing social distancing guidelines.

Video number one provides an overview of sarcoma that features an orthopedic surgeon who specializes in surgical treatment of sarcoma. The aim of this video was to educate viewers after a new sarcoma diagnosis in hopes of demystifying the concept of sarcoma and elaborating on its definition. Specifically, the aim was to break down major subtypes and address common questions patients often ask about the formation of sarcoma. The second video gives an overview of sarcoma treatment and features a hematology/oncology physician assistant who discusses chemotherapy treatment of sarcoma. He also addresses side effects, symptom management, and self-care through the process of chemotherapy. Next, a radiation oncologist demystifies the concept of sarcoma treatment via radiation. Radiation is not generally well understood by the public, so the education provided by the radiation oncologist addressed topics such as delivery of radiation, side effects, and timeline of treatment. Lastly, a sarcoma surgeon discussed the surgical treatment of sarcoma, which is the mainstay treatment course for both STS and osteosarcoma. The surgeon discussed risks and benefits of surgical excision, amputation, and limb-salvage along with the average timeline and follow up.

The third video featured sarcoma survivor testimony from three RIS volunteers whose experiences include differing stages of treatment and remission. The goal of this video was to provide hope and support to patients and caregivers through survivor experiences that are relatable and provide insight into the process when receiving a new sarcoma diagnosis. The first participant featured is a fifteen year fibrosarcoma survivor who discussed her story starting with

recognition of her lump via her hairdresser, her initial diagnosis and journey, as well as self-care and what life looks like post-diagnosis and surviving sarcoma. The second participant featured in this video is a myxoid sarcoma survivor who, at the time of this publication, was still undergoing surgical reconstruction to improve functionality of her hand. She addressed what life was like during her treatment and gave advice to those who may be going through a similar journey. The third participant is a rhabdomyosarcoma survivor who is five years out and still has no evidence of disease. He discusses his journey through initially feeling unwell, to sarcoma diagnosis, and through his treatment experience. He also gave his perspective of the five stages of grief and provided advice on the importance of self-care.

The fourth video addressed the experience and importance of the caregiver's journey after a sarcoma diagnosis. This was achieved through personal testimony of volunteers that provided perspectives from a mother/caregiver whose daughter is currently disease-free from sarcoma and two other perspectives from a male and female spouse/caregiver who's loved ones have since passed away from sarcoma. The goal of this video was to provide education and support for caregivers with the aim of normalizing what often feels like an isolating experience.

Video five is an educational tool that aimed to address advanced care directives and featured a physician assistant educator and an end-of-life doula/sarcoma caregiver. The aim of this video was to explain terminology and elaborate on topics that may not be well understood by patients, such as advance care planning, durable power of attorney, palliative care, and hospice. Other relevant topics addressed were obtaining a second opinion, the five stages of grief, and alternative support services for patients and caregivers who are experiencing a sarcoma diagnosis.

The videos were filmed by a volunteer videographer from RIS, Alan Christensen, who provided his personal filming equipment, which included but not limited to iPhones staged from differing angles, stands, personal microphones, and lighting equipment. Filming for all five videos were done at the Bethel University Anderson Center common areas and at the University of Minnesota. During filming, the authors observed and directed off view of the camera and conversed with each volunteer participant through an interview style where the author proposed a topic or question and the participant responded. The aim was for responses to flow with an appearance of ease as one would see during a conversation. Filming was completed over a course of eight months from October 2021 to May 2022.

Upon the completion of filming, the raw video footage was sent to be formally edited by Northern Lights Video, Inc., a local Minnesota-based editing company. Rein in Sarcoma has utilized the services of Northern Lights Video for prior projects and it was the preference of the organization to use their services for this project. Funding for the editing of this project was generously donated by RIS. The editing process took approximately four months and required frequent virtual collaboration between the authors and the editor. The video footage was condensed, organized, and music, graphics, and photos were added to produce the final project. The authors then approved the final edits of the videos. The videos were sent from the editor to RIS where they were then uploaded onto the RIS YouTube channel and webpage. The videos were assigned to a QR code, which was printed on cardstock and detailed the project videos. The QR codes were handed out and presented at the 2022 ASCO conference in Chicago to a global audience of medical providers.

When starting a community service project it is important to consider the ethical implications associated with the project, which includes consideration of the sarcoma patient and

their healthcare team. An ethical implication of this community service project that was acknowledged was that the information presented in the five videos may not be representative of the viewer's precise healthcare team opinions or current treatment regimen. To address this issue, a statement was displayed at the beginning of each of the five videos that stated "Every individual's medical situation, sarcoma experience, and recovery is unique. Always consult with your own medical team or personal physician about your situation. The information presented in this video is not intended to replace and should not replace a physician's medical judgment or advice". The author's goal during the creation and implementation of this project was to protect the integrity of shared medical decision making and the members of the sarcoma healthcare team. This was achieved through careful consideration of the narrative of this paper, specifically avoiding word usage or ideas that may be offensive or controversial. This reinforced our project goal by encouraging healthy communication and trust in the relationship between the sarcoma patient and their healthcare team.

Project Tool

The project tool created for this project consisted of five videos aimed to enhance sarcoma education by providing an educational resource at an appropriate health literacy level, enhancing access to education via the remote delivery of the videos online, and provide support and hope to newly diagnosed sarcoma patients and caregivers. The tool consists of five videos, which remain under 60 minutes in length to avoid loss of interest, but may be paused and resumed at the viewer's convenience. This hopefully allows for increased information comprehension and by delivering the videos through YouTube, subtitles may be added to enhance learning. The videos covered important topics in sarcoma including: a sarcoma overview, overview of sarcoma treatment options, survivor stories, caregiver experiences, and

education on advanced care planning, coping, support services, and the five stages of grief. The video participants discussed their personal sarcoma experiences and gave advice to newly diagnosed sarcoma patients. The original talking points for each of the five videos are located in Appendix B of this paper. Upon completion of the project, the project tool consists of five videos that were sent directly to RIS from the editor. The videos were reviewed, approved, and uploaded by RIS to their YouTube channel and website, and attached to a QR code that was distributed to oncology professionals at the 2022 ASCO conference.

Barriers to the Project

During this community service project, there were barriers that the authors had to overcome. This project was initiated during the COVID-19 pandemic in 2020, which created a barrier to the filming of the project. Throughout the majority of the project, the COVID-19 case rate in the Twin Cities and morbidity and mortality burden was high. The video participants consisted of a few immunocompromised volunteers, which required careful consideration and planning. Throughout the filming of this project, there were several filming delays due to COVID-19 illness from either volunteer participants or authors. Despite this barrier, the video participants were able to be filmed in person for all five videos. A second barrier to the completion of this project was the difficulty in coordinating schedules of the many contributors to this project. The authors were creating this project during their physician assistant master's program, which consisted of full-time classroom based learning and traveling out-of-state to complete clinical rotations. The project relied on the availability of the videographer's equipment and utilization of his expertise during the filming. Also, coordination of filming the videos was dependent on the availability of the videographer, participant, and authors.

Conclusion

Through literature review by the authors and collaboration through RIS, a need was identified to provide support and hope, expand access, and enhance health literacy through creating educational information for newly diagnosed sarcoma patients and their caregiver. In addressing existing barriers during the start of the project, such as the COVID-19 pandemic, the project tool was established as a series of five videos that would accompany patient advocacy materials that RIS currently use such as the patient guidebook. The five videos may provide viewers with access to sarcoma education and support through the experiences of medical providers, educators, survivors, and caregivers. Overall, this may enhance patient health literacy and allow for improved engagement in treatment and medical decision making while increasing quality of life through reduction of emotional trauma after a new sarcoma diagnosis. Chapter four will discuss the project outcome, the project's limitations, and discussion on how this project may be expanded in the future by RIS or through further volunteer contributions.

Chapter 4: Discussion

Introduction

With the support and guidance from RIS, this community service project was created to expand access to sarcoma education and enhance health literacy by adding to existing RIS educational materials such as the sarcoma patient guidebook. This chapter discusses all aspects of this community service project, including author review of the foundational and new literature from chapter two, project creation and implementation, and lastly will summarize the outcome of the project. Also discussed are the limitations that were encountered during the project and concludes with a discussion of possible enhancements to how this project can be expanded in the future.

Summary of Results

Rein in Sarcoma was looking to expand educational videos aimed towards newly diagnosed sarcoma patients and their family members. During the literature review, a need was identified that patients may not have access to educational material with an appropriate health literacy level after a diagnosis of sarcoma. Education given at the time of diagnosis is imperative for patients as this enhances their cooperation in the treatment process, quality of life, and overall patient outcomes. An emotional burden and associated trauma exists after a diagnosis of sarcoma, and information presented at this time is subject to distortion and misunderstanding. Patients “find that [they] can only take in small amounts of information [and] need to have the same information repeated to [them]” (Cancer Research UK, 2017, Shock and Denial section). One specific study found when looking at online sources of sarcoma education, that the overwhelming majority is written at or above an eleventh-grade reading level (Patel et al., 2015). The project goals were to expand patient sarcoma education that is accessible remotely. With

careful consideration, the videos were created to more closely match the general population's average health literacy at a reading level of seventh grade and below. Upon filming completion, the five videos were provided to RIS. Rein in Sarcoma posted each individual video to their YouTube channel, website, and produced QR code handouts that were distributed at the 2022 ASCO conference providing easy access to the online videos.

The topics for the five videos produced attempted to address commonly raised questions and concerns of newly diagnosed sarcoma patients, families, and caregivers. The topics for each video were decided upon during review of sarcoma literature and by collaboration of the authors, RIS, and video participants. Rein in Sarcoma provided volunteers who shared experiences and expertise of their sarcoma journey.

In addition, a videographer/sarcoma caregiver volunteered to film this project, which was successfully produced using the videographer's personal filming equipment. The five videos were filmed at two separate locations: Bethel University Anderson Center and the University of Minnesota. Upon completion of filming, the footage was sent electronically to Northern Lights Video, Inc., for professional editing.

The final edits were approved by the authors before the videos were sent directly to RIS for final approval. Rein in Sarcoma subsequently uploaded the videos to their website and YouTube channel where viewers can utilize the closed captioning option if language barriers exist. Viewers can also pause the videos as needed if they are unable to complete the video in its entirety or need breaks for comprehension. This delivery improves the accessibility of the material for non-English speaking patients and families, which was a common question professionals asked the author at ASCO. The videos were also assigned to a QR code and printed on handouts that will accompany the patient guidebook when given to patients with a new

sarcoma diagnosis. The QR code handouts, which provide direct access to all five videos, were distributed to a global audience of oncology professionals at the 2022 ASCO conference in Chicago.

A major barrier to the completion of this project was the COVID-19 pandemic. To minimize disturbances in the project, the authors followed all COVID-19 precautions as suggested by the state of Minnesota, such as limiting the number of participants allowed in the filming space, wearing facemasks, and remaining socially distanced. In addition, film scheduling was made difficult due to unforeseen illnesses, cancellations, and scheduling conflicts between the authors, videographer, and video participants.

It is difficult to assess the outcome and effectiveness of the five videos at this time of publication. This is largely due to time constraints, which include a short timeline from when the videos were debuted online in June 2022 to the authors completion of this community service project in July 2022. This does not allow for the opportunity of the authors to receive direct feedback or distribute surveys that may analyze the effectiveness of the project tool. In the future, RIS may choose to collect feedback via the participants, online viewers, track the number of views of each video, or read viewer comments, which may indicate viewer reception to this project and its effectiveness. In the future, RIS can use this project and materials to further expand or update the video series. There is also a plethora of unused video footage, which allows for future opportunities to repurpose the video into creation of educational videos.

Limitations

Limitations of this project were identified and acknowledged after its completion. After filming, the authors discovered that the video participants were composed of a population of primarily females, Caucasians, those with higher educational achievements, and middle to upper

class privileges. The authors acknowledge that a sarcoma diagnosis impacts people of all ages, races, genders, education levels, and socioeconomic backgrounds. In the future, the limitations to this project may be overcome by expanding and incorporating a population of sarcoma patients and caregivers more inclusive of different identities, races, ethnicities, educational backgrounds, and income levels into the video series.

Another limitation to this video series is that the videos are presented in an English option only, which limits the targeted audience by decreasing accessibility to non-English speakers. To circumvent this, authors recommend watching the videos on YouTube and utilizing closed captioning options, which may allow for reading and comprehension in one's native language.

There is a resource limitation to this project as the videos are only accessible virtually and require viewers to have personal or public access to the internet, computer, cell phone, or other viewing device, and be able to access the RIS website or YouTube. Additionally, to benefit from the five videos, viewers must know the videos exist, and this may happen by direct word of mouth, association with RIS, or through the Bethel University Physician Assistant program.

Further Projects

After the completion of the five videos for newly diagnosed sarcoma patients, the authors released all materials including videos, talking points, and all raw footage to RIS. In the future, if RIS desires to expand or update this community service project, they have access to and may use all resources above. This may be done through RIS directly or possibly through future Bethel physician assistant student volunteers for RIS. The authors identified a limitation to the current series as a lack of inclusivity, and suggested as a possible future project expansion, a video that addresses cultural elements of racial and ethnic diversity that may contribute to sarcoma

diagnosis and care. Additionally, it would be recommended to create a video with equal representation and identification of the sarcoma journey from different perspectives of gender and identity.

Lastly, a future project expansion may want to collect feedback from viewers or a cohort of sarcoma patients and caregivers after watching the five videos. The video series could then be expanded based on specific feedback received by the participants.

Conclusion

Sarcoma is a connective tissue neoplasm that, due to its intrinsic characteristics of formation, is a cancer that is often accompanied with delayed diagnosis, misdiagnosis, and requiring specific biopsy technique to prevent metastasis. Early detection and diagnosis is vital for all cancer types, but particularly in cancers like sarcoma, which have a heavy metastatic disease burden due to the ease of lymphatic and vascular metastasis.

During the literature review of this community service project, the authors discovered a need to expand sarcoma education through improvement of remote access and by matching viewer health literacy, with the goal to improve patient cooperation, engagement in care, quality of life, and patient outcomes. A retrospective study by Patel et al. (2015) that the authors discuss in chapter two shows that the majority of online sarcoma education utilized by patients and caregivers is written above an eleventh grade reading level, which is far above what the NIH has established as the reading level of the general US population. After the literature review and subsequent identification of this disparity in the sarcoma population, there was a responsibility by the authors during the creation of this project to decrease this health literacy gap. The authors believe this was accomplished by the successful completion of the five videos that improve

health literacy through education presented via experiences of participants and educators that is easily accessible in an online format.

In collaboration with RIS, the authors produced five videos that gave an overview of sarcoma, standard treatment options, sarcoma survivor testimonies, the impact of sarcoma through personal testimonies of caregivers, and an overview of advance care planning. At the time of publication, all five videos are currently available for viewing on the RIS website and YouTube channel. Despite being unable to directly assess the effectiveness of the videos due to the constraint of limited time availability that the videos have been online, the authors are hopeful that the overall takeaway from the videos will provide support and hope, all while helping to relieve patient and caregivers fears and anxiety that accompany unknowns with a new sarcoma diagnosis.

Throughout this community service project, the authors expanded their skill set, knowledge of oncology concepts, sarcoma specific literature, and patient care through an extensive literature review, composition of this thesis paper, designing and creating the five videos, and the collaboration with survivors, caregivers, medical professionals, and educators. The importance of early sarcoma diagnosis and patient accessibility to appropriate literacy level education materials that accompany one-on-one provider teaching cannot be emphasized enough. Newly diagnosed sarcoma patients encounter a heavy emotional burden due to the inherent nature of sarcomas and associated prognoses. The authors' hope that this video series will be utilized by sarcoma patients and caregivers as an educational tool that may assist in providing hope and support. Secondly, the authors hope that healthcare professionals with access to this community service project will recommend the five videos to newly diagnosed sarcoma patients, family, and caregivers as a supplement to the one-on-one education they provide alongside the

RIS patient guidebook, which may assist in comprehension, participation of diagnosis and treatment plans, improve patient outcomes, and quality of life.

References

American Cancer Society. (2016). *When someone you know has cancer.* Retrieved October 31, 2020, from https://www.cancer.org/treatment/caregivers/whensomeoneyouknowhascancer.html

American Cancer Society. (2018a). *Chemotherapy for soft tissue sarcomas.* Retrieved November 3, 2020, from https://www.cancer.org/cancer/softtissuesarcoma/treating/chemotherapy.html

American Cancer Society. (2018b). *Radiation therapy for soft tissue sarcomas*. Retrieved July 5, 2022, from https://www.cancer.org/cancer/soft-tissue-sarcoma/treating/radiation-therapy.html

American Cancer Society. (2018c). *Surgery for soft tissue sarcomas*. Retrieved November 3, 2020, from https://www.cancer.org/cancer/soft-tissue-sarcoma/treating/surgery.html

American Cancer Society. (2018d). *Test for soft tissue sarcoma*. Retrieved November 20, 2020, from https://www.cancer.org/cancer/soft-tissue-sarcoma/detection-diagnosis-staging/how-diagnosed.html

American Cancer Society. (2019a). *After Diagnosis: A guide for patients and families.* Retrieved November 5, 2020, from https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/after-diagnosis-a-guide-for-patients-and-families.pdf

American Cancer Society. (2019b). *Getting external beam radiation therapy.* Retrieved November 4, 2020, from https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/radiation/external-beam-radiation-therapy.html

American Cancer Society. (2019c). *Radiation therapy.* Retrieved November 20, 2020, from https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/radiation.html

American Cancer Society (2020a). *Caregiver resource guide*. Retrieved November 1, 2020, from https://www.cancer.org/treatment/caregivers/caregiver-resource-guide.html

American Cancer Society. (2020b). *Chemotherapy.* Retrieved November 20, 2020, from https://www.cancer.org/treatment/treatments-and-side-effects/treatment-types/chemotherapy.html

American Cancer Society. (2020c). *Finding a clinical trial.* Retrieved November 6, 2020, from https://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials/what-you-need-to-know/picking-a-clinical-trial.html

American Cancer Society. (2020d). *Surgery for osteosarcoma.* Retrieved November 3, 2020, from https://www.cancer.org/cancer/osteosarcoma/treating/surgery.html

Berry, J. (2018). How do I know I am feeling depressed? *MedicalNewsToday.* Retrieved December 6, 2020, from https://www.medicalnewstoday.com/articles/314071

Boyes, A. (2018). What is psychological shock? and 5 tips for coping. *Psychology Today.* Retrieved July 4, 2022, from https://www.psychologytoday.com/us/blog/in-practice/201803/what-is-psychological-shock-and-5-tips-coping

Cancer Research UK. (2017). Coping with cancer. *Cancer Research UK.* Retrieved November 18, 2020, from https://www.cancerresearchuk.org/about-cancer/coping/emotionally/cancer-and-your-emotions/shock-denial

Casali, P. G., Bielack, S., Abecassis, N., Aro, H. T., Bauer, S., Biagini, R., Bonvalot, S., Boukovinas, I., Bovee, J V M G, Brennan, B., Brodowicz, T., Broto, J. M., Brugières, L., Buonadonna, A., De Álava, E., Dei Tos, A. P., Del Muro, X. G., Dileo, P., Dhooge, C., Eriksson, M., . . . Blay, J. Y. (2018). Bone sarcomas: ESMO–PaedCan–EURACAN clinical practice guidelines for diagnosis, treatment and follow-up. *Annals of Oncology, 29*(Supplement 4). https://doi.org/10.1093/annonc/mdy310

Conner, K. M., & Weis, O.G. (2020). Advance care planning and directives. *DynaMed.* Retrieved November 1, 2020, from https://www.dynamed.com/management/advance-care-planning-and-directives/

Coyne, E., Heynsbergh, N., & Dieperink, K. B. (2020). Acknowledging cancer as a family disease: A systematic review of family care in the cancer setting. *European Journal of Oncology Nursing, 49*, Article 101841. https://doi.org/10.1016/j.ejon.2020.101841

DeLaney, T. F., Gebhardt, M. C., & Ryan, C. W. (2020). Overview of multimodality treatment for primary soft tissue sarcoma of the extremities and chest wall. *UpToDate*. Retrieved November 13, 2020, from https://www.uptodate.com/contents/overview-of-multimodality-treatment-for-primary-soft-tissue-sarcoma-of-the-extremities-and-chest-wall?search=soft%20tissue%20sarcoma&source=search_result&selectedTitle=2~150&usage_type=default&display_rank=2#H3

Dictionary.com (2020). *Neoplasm.* Retrieved November 20, 2020, from https://www.dictionary.com/browse/neoplasm

Dionne-Odom, J. N., Currie, E. R., Johnston, E. E., & Rosenberg, A. R. (2019). Supporting family caregivers of adult and pediatric persons with leukemia. *Seminars in Oncology Nursing, 35*(6), Article 150954. https://doi.org/10.1016/j.soncn.2019.150954

DynaMed. (2018a, December 04). Osteosarcoma in adults. Ipswich, MA: EBSCO Information Services. Retrieved November 1, 2020, from https://www.dynamed.com/condition/osteosarcoma-in-adults

DynaMed. (2018b, December 04). Osteosarcoma in children. Ipswich, MA: EBSCO Information Services. Retrieved November 1, 2020, from https://www.dynamed.com/condition/osteosarcoma-in-children

DynaMed. (2018c). Soft tissue sarcomas. Ipswich, MA: EBSCO Information Services. Retrieved November 1, 2020, from https://www.dynamed.com/condition/soft-tissue-sarcomas

Forscher, C. (2020, June 15). *Soft tissue sarcoma*. National Organization for Rare Disorders. https://rarediseases.org/rare-diseases/soft-tissue-sarcoma/

Fossum, C. C., Breen, W. G., Sun, P. Y., Retzlaff, A. A., & Okuno, S. H. (2020, March 18). Assessment of familiarity with work-up guidelines for bone and soft tissue sarcoma among primary care practitioners in Minnesota. *Mayo Clinic Proceedings: Innovations, Quality & Outcomes, 4*(2), 143-149. https://doi.org/10.1016/j.mayocpiqo.2019.12.002

Franceschini, N., Lam, S. W., Cleton-Jansen, A., & Bovée, J. (2019). What's new in bone forming tumors of the skeleton? *Virchows Archiv: An International Journal of Pathology, 476*(1), 147-157. https://doi.org/10.1007/s00428-019-02683-w

Gebhardt, M. C., Baldini, E. H., & Ryan, C. W. (2022, January 20). Overview of multimodality treatment for primary soft tissue sarcoma of the extremities and superficial trunk. *UpToDate.* Retrieved July 5, 2022, from https://www.uptodate.com/contents/overview-of-multimodality-treatment-for-primary-soft-tissue-sarcoma-of-the-extremities-and-superficial-trunk#H12

George, A., & Grimer, R. (2012, May). Early symptoms of bone and soft tissue sarcomas: Could they be diagnosed earlier? *Royal College of Surgeons of England, 94*(4), 261-266. https://doi.org/10.1308/003588412X13171221590016

Giuliani, M., Papadakos, T., & Papadakos, J. (2020, October 1). Propelling a new era of patient education into practice-cancer care post-COVID-19. *International Journal of Radiation Oncology, Biology, Physics, 108*(2), 404-406. https://doi.org/10.1016/j.ijrobp.2020.05.036

Gorlick, R. (2019, September 13). *Osteosarcoma.* National Organization for Rare Disorders. https://rarediseases.org/rare-diseases/osteosarcoma/

Heussner, P. (2016). Coping strategies in oncology. *Oncology, 22*(11)*,* 860-863. https://doi.org/10.1007/s00761-016-0121-6

Hornicek, F. J., & Agaram, N. (2020). Bone sarcomas: Preoperative evaluation, histologic classifications, and principles of surgical management*. UpToDate*. Retrieved November 13, 2020, from https://www.uptodate.com/contents/bone-sarcomas-preoperative-evaluation-histologic-classification-and-principles-of-surgical-management?search=osteosarcoma%20treatment&topicRef=7723&source=see_link#H8

Janeway, K. A., & Maki, R. (2020). Chemotherapy and radiation therapy in the management of osteosarcoma. *UpToDate.* Retrieved November 13, 2020, from https://www.uptodate.com/contents/chemotherapy-and-radiation-therapy-in-the-management-of-osteosarcoma?search=osteosarcoma%20treatment&source=search_result&selectedTitle=1~118&usage_type=default&display_rank=1#H495376984

Kübler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy & their own families.* Scribner.

Kübler-Ross, E. (1974). *Questions and answers on death and dying.* Macmillan Publishing Co., Inc.

Laurini, E., Marson, D., Fermeglia, A., Aulic, S., Fermeglia, M., & Pricl, S. (2020). Role of Rad51 and DNA repair in cancer: A molecular perspective. *Pharmacology & Therapeutics, 208,* Article 107492. https://doi.org/10.1016/j.pharmthera.2020.107492

Mavrogenis, A. F., & Ruggieri, P. (2015). Therapeutic approaches for bone sarcomas. In D. Heymann (Ed.), *Bone cancer: Primary bone cancers and bone metastases* (2nd ed., pp. 407-414). Academic Press. https://doi.org/10.1016/B978-0-12-416721-6.00034-0

Mayo Clinic. (2018). *Soft tissue sarcoma.* Retrieved November 20, 2020, from https://www.mayoclinic.org/diseases-conditions/soft-tissue-sarcoma/symptoms-causes/syc-20377725

Mayo Clinic. (2016). *What is grief?* Retrieved November 18, 2020, from https://www.mayoclinic.org/patient-visitor-guide/support-groups/what-is-grief

McKee, K. Y., & Kelley, A. (2020). Management of grief, depression, and suicidal thoughts in serious illness. *The Medical Clinics of North America, 104*(3)*,* 502-524. https://doi.org/10.1016/j.mcna.2020.01.003

Merriam-Webster. (n.d.-a). Acceptance. In *Merriam-Webster.com dictionary.* Retrieved November 15, 2020, from https://www.merriam-webster.com/dictionary/acceptance

Merriam-Webster. (n.d.-b). Anger. In *Merriam-Webster.com dictionary.* Retrieved November 15, 2020, from https://www.merriam-webster.com/dictionary/anger

Merriam-Webster. (n.d.-c). Bargain. In *Merriam-Webster.com dictionary.* Retrieved November 15, 2020, from https://www.merriam-webster.com/dictionary/bargain

Merriam-Webster. (n.d.-d). Denial. In *Merriam-Webster.com dictionary.* Retrieved November 15, 2020, from https://www.merriam-webster.com/dictionary/denial

Merriam-Webster. (n.d.-e). Depression. In *Merriam-Webster.com dictionary.* Retrieved November 15, 2020, from https://www.merriam-webster.com/dictionary/depression

Merriam-Webster. (n.d.-f). Genome. In *Merriam-Webster.com dictionary.* Retrieved November 20, 2020, from https://www.merriam-webster.com/dictionary/genome

Merriam-Webster. (n.d.-g). Hope. In *Merriam-Webster.com dictionary.* Retrieved April 27, 2021, from https://www.merriam-webster.com/dictionary/hope

Merriam-Webster. (n.d.-h). Metastasis. In *Merriam-Webster.com dictionary.* Retrieved November 20, 2020, from https://www.merriam-webster.com/dictionary/metastasis

Merriam-Webster. (n.d.-i). Osteosarcoma. In *Merriam-Webster.com dictionary.* Retrieved November 20, 2020, from https://www.merriam-webster.com/dictionary/osteosarcoma

Merriam-Webster. (n.d.-j). Resection. In *Merriam-Webster.com dictionary.* Retrieved November 20, 2020, from https://www.merriam-webster.com/dictionary/resection

Merriam-Webster. (n.d.-k). Sarcoma. In *Merriam-Webster.com dictionary.* Retrieved November 20, 2020, from https://www.merriam-webster.com/dictionary/sarcoma

Meyer, C. M., George, S., Bertagnolli, M. M., & Raut, C. P. (2009). Secondary sarcomas after radiotherapy for breast cancer: Sustained risk and poor survival. *Cancer, 115*(18), 4055-4063. https://doi.org/10.1002/cncr.24462

Mitin, T. (2020). Radiation therapy techniques in cancer treatment. *UpToDate.* Retrieved November 13, 2020, from

https://www.uptodate.com/contents/radiation-therapy-techniques-in-cancer-treatment?search=osteosarcoma&topicRef=7723&source=related_link#H655093

National Cancer Institute. (2020). *What are cancer clinical trials?* https://www.cancer.gov/about-cancer/treatment/clinical-trials/what-are-trials

National Cancer Institute. (n.d.-a). *Malignant.* National Institutes of Health. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/malignant

National Cancer Institute. (n.d.-b). *Margin.* National Institutes of Health. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/margin

National Cancer Institute. (n.d.-c). *Surveillance.* National Institutes of Health. https://www.cancer.gov/publications/dictionaries/cancer-terms/def/surveillance

National Center for Biotechnology Information (US). (1998, January 01). The p53 tumor suppressor protein. Retrieved November 21, 2020, from https://www.ncbi.nlm.nih.gov/books/NBK22268/

National Comprehensive Cancer Network. (n.d.). *Cancer staging guide*. https://www.nccn.org/patients/resources/diagnosis/staging.aspx

National Institute of Health. (n.d.). *Find a study.* https://www.clinicaltrials.gov/ct2/home

NCCN. (2020). Guidelines for Patients. Soft Tissue Sarcoma. Retrieved July 11, 2022, from https://www.nccn.org/patientresources/patient-resources/soft-tissue-sarcoma

Nipp, R. D., El-Jawahri, A., Fishbein, J. N., Gallagher, E. R., Stagl, J. M., Park, E. R., Jackson, V. A., Pirl, W. F., Greer, J. A., & Temel, J. S. (2016, August). Factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer. *Annals of Oncology, 27*(8), 1607-1612. https://doi.org/10.1093/annonc/mdw205

Nystrom, L. M., Reimer, N. B., Reith, J. D., Dang, L., Zlotecki, R. A., Scarborough, M. T., & Gibbs, C. P. (2013). Multidisciplinary management of soft tissue sarcoma.

The Scientific World Journal, 2013, Article 852462. https://doi.org/10.1155/2013/852462

Patel, S. S., Sheppard, E. D., Siegel, H. J., & Ponce, B. A. (2015). Assessing the reading level of online sarcoma patient education materials. *American Journal of Orthopedics, 44*(1), 1-10.

Peier-Ruser, K. S., & von Greyerz, S. (2018). Why do cancer patients have difficulties evaluating the need for a second opinion and why is needed to lower the barrier? A quantitative study. *Oncology Research and Treatment, 41(1),* 769-773. https://doi.org/10.1159/000492390

Pennacchioli, E., Tosti, G., Barberis, M., De Pas, T. M., Verrecchia, F., Menicanti, C., Testori, A., & Mazzarol, G. (2012). Sarcoma spreads primarily through the vascular system: Are there biomarkers associated with vascular spread? *Clinical and Experimental Metastasis, 29*, 757-773. https://doi.org/10.1007/s10585-012-9502-4

Pollock, R., Lang, A., Ge, T., Sun, D., Tan, M., & Yu, D. (1998). Wild-type p53 and a p53 temperature-sensitive mutant suppress human soft tissue sarcoma by enhancing cell cycle control. *Clinical Cancer Research, 4*(8), 1985-1994. https://clincancerres.aacrjournals.org/content/4/8/1985.full-text.pdf

Rein In Sarcoma. (2020). Retrieved October 24, 2020, from https://www.reininsarcoma.org/

Ryan, C. W., & Meyer, J. (2022). Clinical presentation, histopathology, diagnostic evaluation, and staging of soft tissue sarcoma. *UpToDate*. Retrieved July 1, 2022, from https://www.uptodate.com/contents/clinical-presentation-histopathology-diagnostic-evaluation-and-staging-of-soft-tissue-sarcoma?search=sarcoma%20diagnosis&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1#H2315440511

Schöffski, P., Cornillie, J., Wozniak, A., Li, H., & Hompes, D. (2014). Soft tissue sarcoma: An update on systemic treatment options for patients with advanced disease. *Oncology Research and Treatment, 37*(6), 355-362. https://doi.org/10.1159/000362631

Silveira, M. J. (2020). Advance care planning and advance directives. *UpToDate.* Retrieved November 18, 2020, from https://www.uptodate.com/contents/advance-care-planning-and-advance-directives?source=autocomplete&index=0~1&search=advance%20care

Singer, S. (2018). *Psychosocial impact of cancer* (2nd ed.). Psycho-oncology. https://doi.org/10.1007/978-3-319-64310-6

Skubitz, K. M., & D'Adamo, D. R. (2007). Sarcoma. *Mayo Clinic Proceedings, 82*(11), 1409-1432. https://doi.org/10.4065/82.11.1409

Sudore, R.L., Lum, H.D., You, J.J., Hanson, L.C., Meier, D.E., Pantilat, S.Z., Matlock, D.D., Rietjens, J., Korfage, I.J., Ritchie, C.S., Kutner, J.S., Teno, J.M., Thomas, J., McMahan, R.D., & Heyland, D.K. (2017). Defining advance care planning for adults: a consensus definition from a multidisciplinary delphi panel. *Journal of pain and symptom management,* 53 (5), 821-832.e1. https://doi.org/10.1016/j.jpainsymman.2016.12.331

Taylor, S. E., Falke, R. L., Shoptaw, S. J., & Lichtman, R. R. (1986). Social support, social groups, and the cancer patient. *Journal of Consulting and Clinical Psychology, 54(5),* 608-615. https://doi.org/10.1037//0022-006x.54.5.608

TechTerms.com. (2022). QR Code. In *TechTerms.com.* Retrieved July 4, 2022, from https://techterms.com/definition/qr_code

UCLA Health. (n.d.). *Lung metastases (Metastatic cancer)*. UCLA Lung Cancer. https://www.uclahealth.org/lungcancer/lung-metastases

Vos, M. S., & de Haes, J. C. (2007). Denial in cancer patients, an explorative review. *Psycho-oncology, 16*(1)*,* 12-25. https://doi.org/10.1002/pon.1051

Wang, L.L., Gebhardt, M.C., & Rainusso, N. (2022). Osteosarcoma: epidemiology, pathology, clinical presentation, and diagnosis. *UpToDate.* Retrieved July 10, 2022 from https://www.uptodate.com/contents/osteosarcoma-epidemiology-pathology-clinical-presentation-and-diagnosis?search=osteosarcoma%20presentation&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1

Westberg, G.E. (1971). *Good grief: A constructive approach to the problem of loss.* Fortress Press.

Zahm, S. H., & Fraumeni, J., Jr. (1997). The epidemiology of soft tissue sarcoma. *Seminars in Oncology, 24*(5), 504-514.

APPENDIX A

Rein in Sarcoma Permission Document

1/6/2020

Dear Bethel Physician Assistant Program,

On behalf of the 501c3, Rein in Sarcoma we, Executive Director, Janelle Calhoun and Manager of Sarcoma Education and Communications, Katy Engelby, give permission for students Jennifer Gribble, Jaclyn Robles and Taylor Schreier to work on behalf of our community through their sarcoma education project. We will support them with connections to sarcoma experts at the University of Minnesota, Mayo Clinic and HealthPartners in addition to connecting them with sarcoma patients or other helpful resources. We are thankful for the opportunity to work with these students and increase sarcoma education. Please contact either Katy Engelby, or me with any needs or concerns around the students and their work.

In mission,

Janelle

Janelle Calhoun
Executive Director

Rein In Sarcoma
7401 Central Avenue NE
Fridley, MN 55432
Office: 763-205-1467
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APPENDIX B

Video Scripts

Video one will focus on an overview of sarcoma and will be fifteen to twenty minutes in length. It will highlight one physician who works primarily in the sarcoma field. The beginning of the video will be an introduction of the provider, followed by an overview of sarcoma etiology, clinical presentation, diagnosis, and brief treatment overview.

The following questions will be included in the script:

- How do you come up with a treatment plan?
- How does someone get sarcoma?
- How is someone diagnosed? What is involved with getting a biopsy, what imaging should the patient expect?
- What is sarcoma? What are some of the signs and symptoms that people have when they come to see you?
- What is the remission process?
- What is your advice to newly diagnosed patients or what do you feel is the most important thing for them to know?
- Who gets sarcoma? Age group, ethnicities, genetics?
- Who makes up the medical team?

Video two will be a thirty to forty-minute montage of three different sarcoma experts, which will include an oncological surgeon, a radiation oncologist, and a hematologist/oncologist physician assistant. The purpose of this video will be to highlight their expertise, talk about common pathways for sarcoma treatment, and highlight any new treatment options.

The script will include the following questions:

- Do you see a difference in patient outcome when patients have a close support system?

- How do you build a trusting relationship with the patient?
- How is sarcoma staged (general/basic overview) and how does that guide you when coming up with a treatment plan?
- If chemotherapy is needed, who gets it and why, how do patients prepare for chemotherapy, and what are the risks, benefits, side effects that go along with chemotherapy?
- If radiation is needed, who gets it and why, how do patients prepare for radiation and what are the risks, benefits, side effects, and cost?
- If surgery is indicated, what is done to prepare for the procedure, how do you choose limb salvage or amputation, and what are other considerations you tell patients about?
- What are common imaging options used? (ex: PET scan, MRI, CT)
- What are your thoughts on sarcoma clinical trials?
- What do you want patients to know about radiation, chemotherapy, surgical, etc. before they start treatment and what is involved with each? How long, what is the recovery like, side effects, etc.?
- What is your message to newly diagnosed patients and do you have anything you want patients to know?

Video three will focus on sarcoma survivors and the experience they had when they were first diagnosed with their specific type of sarcoma. This video will be twenty to thirty minutes in length and will feature up to three different people who have been diagnosed with sarcoma. The beginning of the video will be an introduction by the survivor where they will tell their story and personal experiences with sarcoma. The end of the video will be the sarcoma survivor's thoughts and suggestions for newly diagnosed sarcoma patients.

The script will include the following questions:

- Did you get diagnosed quickly or was there some time before it was decided that you had sarcoma?
- Did you go through the stages of grief?
- Did you have a good support system around you who helped you get through this?
- Have you ever heard of this kind of cancer or did you know what it was?
- What advice would you give to a newly diagnosed sarcoma patient?
- What was the treatment like for you?
- What was your first thought when you were told you have cancer?

Video four will highlight family members/caregivers of someone that has had sarcoma. The video will be twenty-thirty minutes in length and feature up to three people who have had a loved one go through sarcoma highlighting various viewpoints of a spouse, parent, and child. The beginning of the video will be an introduction by the caregiver, they will tell the story of their loved one and may include a discussion of the stages of grief they went through or will include a social worker who discusses the stages of grief and what that looks like in both patient and caregiver.

The following questions will be included in the script:

- Did you get involved with any organizations or outside support groups?
- Did you utilize other support groups?
- How did you find support while helping your loved one through cancer?
- How did you offer support during their sarcoma journey?
- How did you yourself get support or what helped you get through this difficult time?
- Social worker: What are the stages of grief? Is this normal? Any suggestions for getting

through these stages? How can family members help get their loved ones through these stages?

- What advice would you give to other families who are going through this difficult time?
- What went through your mind or how did you feel when you first learned they had sarcoma?

Video five will focus on advanced planning that many patients may have to face once they have been diagnosed with cancer. The video will be twenty minutes in length and feature a physician assistant in regards to how to set up a DNR, DPOA, and resources that may include how to get a second opinion. The video will also feature an end of life doula.

The following questions will be included in the script:

- How do patients find alternative support groups?
- How do patients set up a DPOA?
- How do you set up home healthcare and what does that look like?
- How does a DNR get set up?
- How to set up hospice or end of life considerations: wills, etc. When do you suggest starting to make this plan?
- Tell us how to set up a DPOA, what does that mean, and how to choose the appropriate person to make your healthcare decisions.
- Tell us when or how to set up a DNR and what that means.
- What is a second opinion, and should patients consider getting one?
- What other services do you help out with? Getting equipment, helping people to appointments?
- When is home healthcare needed and how do you set it up?

- When should patients consider hospice and how do they set it up?