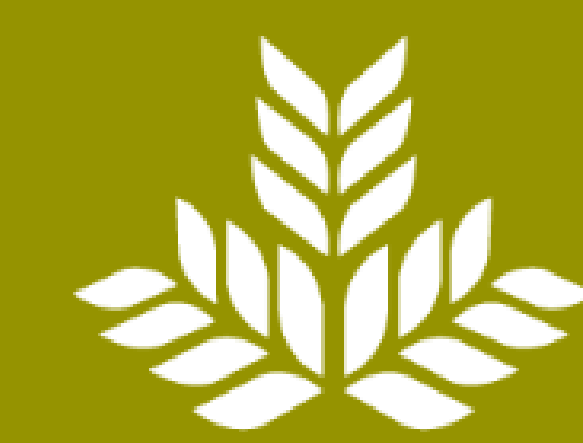




Designing a Referral Process in a Large Adult Health System to Address the Needs of Adolescent and Young Adult (AYA) Patients with Cancer



Northeast Georgia Health System

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Introduction

Patients with cancer have unmet needs that can impede their medical care and treatment uptake. Addressing these needs begins with a measure of a cancer patient's level of distress. Distress is routinely measured by oncology services in two ways: through the use of a visual "distress thermometer" to rate stress from 0-10 and a list of 21 questions on psychosocial distress, physical impairment, speech pathology, functionality and practical concerns. The responses to these questions are entered directly into the electronic medical system (EMR) by staff upon questioning over the phone or in person. Yet these categories do not adequately capture the particular type of concerns that adolescents and young adults (AYA) with cancer have because they are in the early stages of family planning, careers, education, and financial planning. Furthermore, the results of assessment tools currently utilized do not trigger referrals to the appropriate resources. Ideally, an automated approach would ensure that a referral process for self-identified needs occurs consistently. A holistic approach to specific needs of the AYA cancer population and implementing a targeted referral process will lead to improved physical and mental wellbeing, willingness to adhere to the prescribed treatment, increased patient satisfaction, and potentially decreases in cancer morbidity.

Study Purpose

The purpose of the study is to:

- 1) to describe the development of a referral system that uses validated scales for assessing AYA cancer survivor needs and referring them to appropriate resources in palliative care, chaplaincy, and social work within a large health system
- 2) to evaluate the implementation and effectiveness of the screening and referral process from a provider and patient perspective.

Theoretical Model

The Life Span Theory of Control (Heckhausen & Schulz, 1995) theoretical research model was used to guide and plan the work of the researcher team. The Life Span Theory of Control "suggests that threats to or actual losses in the ability to control important outcomes such as performing self-care may activate individuals to use strategies to buffer threats and losses." (DePoy & Giltin, 2016). Specifically, the proactive use of positive strategies, interventions, and resources may help AYAs reduce the current and future negative physical and psychosocial health issues associated with cancer treatment.

Additionally, National Comprehensive Cancer Network (NCCN) Distress Management Guidelines and Adolescent and Young Adult (AYA) Oncology Guidelines were adapted to categorize five domains for AYA survivorship care and help to guide and plan the work of the study (NCCN, 2022).

Research Questions

- 1) What are the most common resource needs that AYA cancer patients have?
- 2) To what extent can a referral system be implemented in a large health system to automate a targeted response?
 - a. What stakeholders are needed to create an automated referral system?
 - b. What are the barriers to implementing an automated referral system?
- 3) To what extent do AYA cancer patients respond to automated questionnaires in the five domains?
- 4) What are the barriers to responding to these automated questionnaires?
- 5) How well do the resources meet the perceived needs of the AYA cancer patients?
- 6) To what extent does a referral system affect their sense of control for the AYA cancer patients to manage their treatment, relationships, and work/life responsibilities?

Study Procedures

Institutional Review Board approval was obtained. Presentation and approval obtained from organizational Professional Nursing Governance Council/Research and Evidence-Based Practice Council.

Recruitment: Patients were identified through Oncology Registry pathology uploads and contacted by the Primary Investigator (PI) through MyChart messaging.

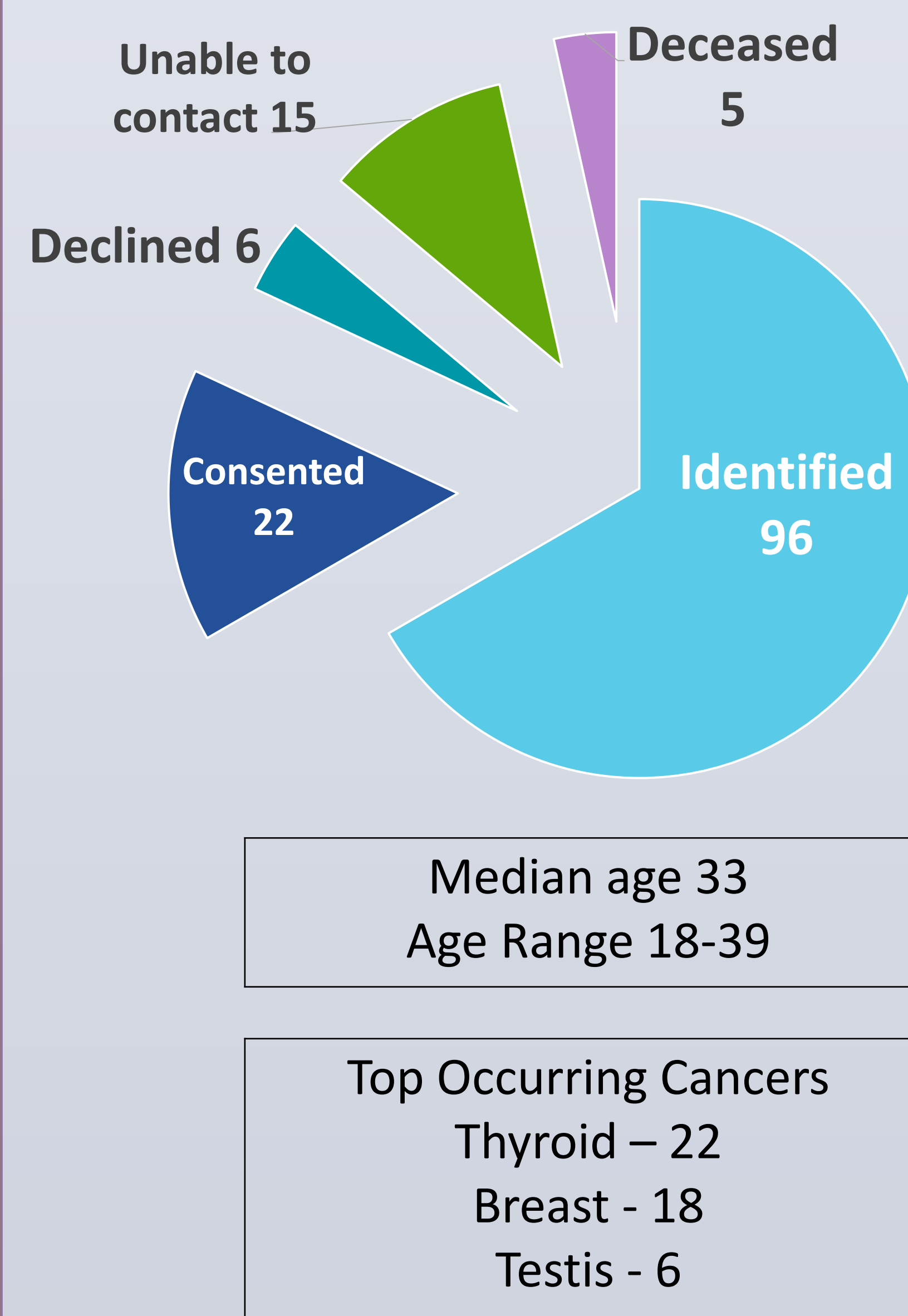
Consenting: PI consented patients in person at an agreed upon office or clinic appointment.

Notifying the team members: After consent obtained, PI send MyChart message with Distress Scale Screening to study participant, message to the team members, updated Teams site, identified study participant in the EMR, and informed the Care Team of enrollment into the study through MyChart messaging.

Interviews with study participants: Study participants were contacted by preferred method of communication to conduct the interview questions. Interviews were recorded when given permission. Study participants were asked about their experience, satisfaction and sense of control when using the referral system

Interviews with clinical and hospital staff: Research team members conducted the interviews of chaplains, social worker, and nurse navigators every 6 months. Interviews were recorded when given permission. Clinical and hospital staff involved in the referral process were interviewed about experiences that positively influenced or acted as barriers to the implementation of the referral system

9 Month Preliminary Study Findings



Methodologies

Study design

The study has an observational design to describe the creation and implementation process of a patient referral system, and quantitative and qualitative measures of the extent and effectiveness in serving the AYA cancer patient population identified within the health system.

Study Population

Inclusion/exclusion criteria: Included in the study were patients ages 16-39 with a diagnosis of cancer of any kind from December 1, 2022–December 1, 2023. Excluded in the study were patients that did not have MyChart accounts.

Sample size: The sample size was determined by the number of patients deemed eligible for the study, and who consented to take part.

Study Procedures

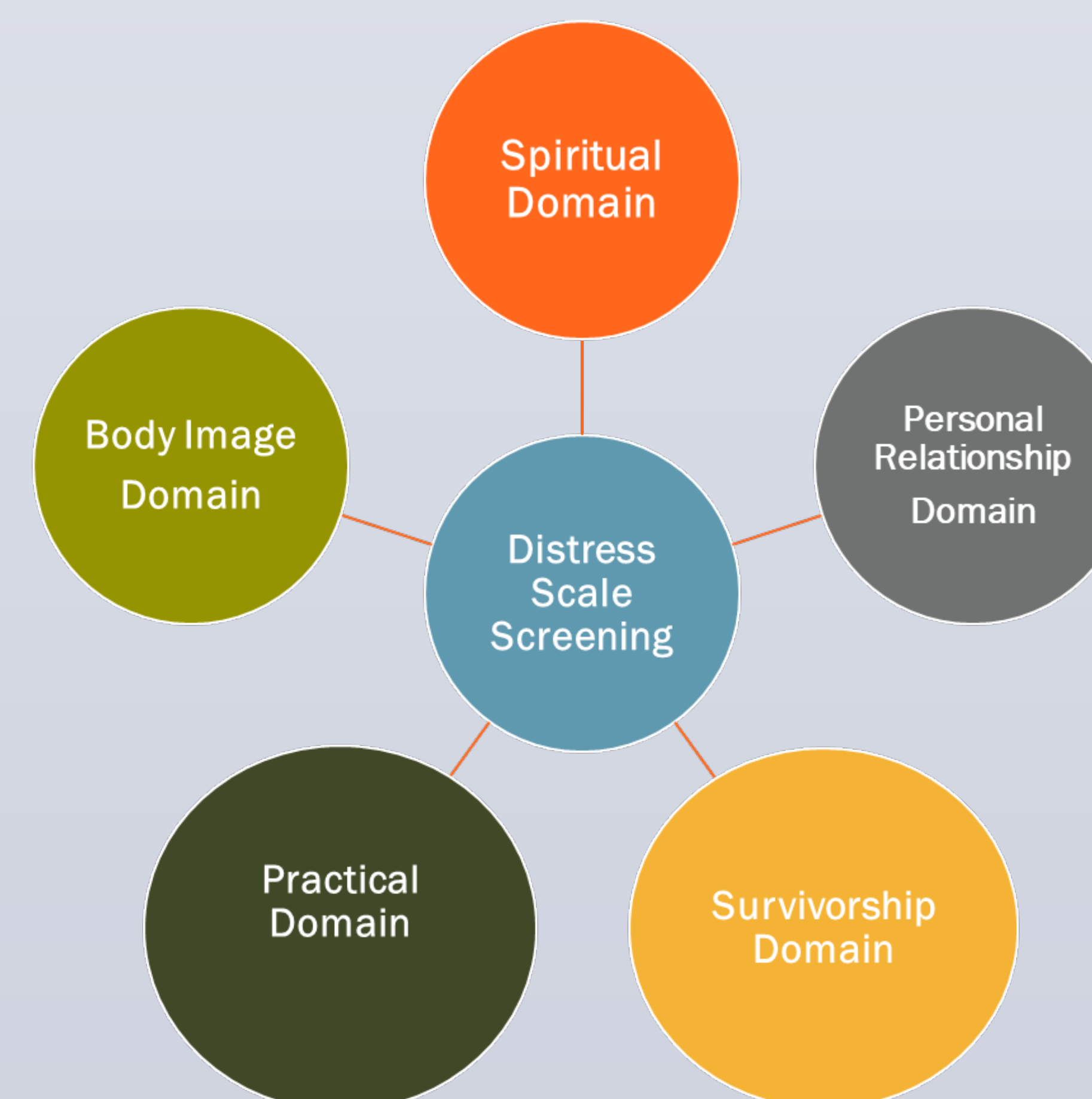
Recruitment: Patients were identified through uptake as analytic cases by the Oncology Registry at NGHS and recruited when contacted by the health system's Oncology Navigators.

Consenting: Patients were consented by primary investigator in person once identified through analytic cases.

Outcome measures

Young adult needs were first assessed using the Epic distress scale, then based on self-identified concerns, additional scales were used to assess the young adult and automatically send referrals to team members through the EMR.

- 1) Spiritual distress – Functional Assessment of Chronic Illness Therapy, FACIT-SP
- 2) Personal relationships – Cancer Behavior Inventory-Social Relationship Efficacy Scale, SRCE
- 3) Survivorship concerns – Supportive Care Needs Survey, SCNS; European Organization for Research and Treatment of Cancer, EORTC, Quality-of-Life questionnaire Cervical Cancer and Testicular Cancer
- 4) Practical concerns – Visual Analog Scale for Pain, VAS; Falls Risks Assessment; Nutritional Screening
- 5) Body Image concerns – Sexual adjustment and body image scale, SABIS



Barriers/Limitations

1. Coordination of appointments for consenting: no shows, appointments and/or locations changed at the last minute
2. Potential AYA participants not responding to multiple MyChart messaging
3. Unexpected number of Spanish speaking only AYAs.
4. Inability to consent six limited English proficiency AYAs due to lack of consents in Spanish and referral questionnaires not in Spanish

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