Advanced Prostate Cancer Decision Support through C PREFS (CANCER PREFERENCE REFLECTION AND ELICITATION FOR FAMILY SUPPORT)

Thayer W[1], Mohandoss G[2], Lewis J[1], Chepkorir J[1], Aziz A[2], Jones R[3], Winch P[2], Wenzel J[1]

[1]Johns Hopkins University School of Nursing, Baltimore, MD, USA [2]Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA [3]University of Virginia School of Nursing, Charlottesville, VA 22903

RWD32

Introduction

Advanced prostate cancer, defined as disease that originated in the prostate and spread outside the primary organ and regional lymph nodes, is not curable with currently available therapies. Patients have available a variety of therapies for advanced prostate cancer. The purpose of this research is to collect qualitative data about advanced prostate cancer decisions and develop a discrete choice experiment (DCE) to measure patient preferences for advanced prostate cancer treatments. This Cancer Preference Elicitation for Family Support (C PREFS) study is nested with the Cancer Health Aid to Manage Preferences and Improve Outcomes through Patient Navigation (CHAMPION) intervention, which pairs patient navigation with a modular decision support intervention targeted to cancer patient dyads.

Preliminary Results

We have screened 419 medical records, 391 unique, from which 161 eligible participants were identified. 32 metastatic prostate cancer patients have been approached and 26 have consented. 18 patients and 11 supporters have been interviewed.

We identified decision points along the advanced prostate cancer treatment trajectory that are preference sensitive from a patient perspective. Major decision points include the choice of clinic, testosterone management decisions, decisions about adjuvant therapy, is an area of primary concern to patients.

Patients and their supporters described difficult physical and emotional effects of androgen deprivation therapy (ADT). These include frequent mood swings, irritability, hot flashes, lack of libido, inability to have or maintain an erection, and cognitive decline. Participants relayed the tradeoffs they face between the desire to treat the cancer aggressively to live as long as possible and trying to maintain a high quality of life.

Some patients in this sample described early negative experiences that led them to seek cancer care at Johns Hopkins University. These experiences commonly included perceived poor-quality care or inadequate available treatments.

Patients discussed the tradeoffs they consider when joining clinical trials, including the desire to help others in the future, a desire for the most advanced treatment, and hope to live long enough for a cure.

Methods

Candidates were identified at the Johns Hopkins University Sidney Kimmel Comprehensive Cancer Center, Baltimore, MD, USA, through attendance at weekly GU clinical trial conferences and medical record screening. African American patients were intentionally oversampled to ensure representation of a group negatively impacted by cancer disparities. Eligible patients were invited to participate in a 30- to 60-minute semi-structured interview, with a supporter if available. Formative qualitative research was undertaken following qualitative research guidelines for health preference research (Hollin et al., 2020). We employed a qualitative descriptive approach to data analysis using f4analyse software. Thematic analyses were conducted with a team of researchers, at least two members coded each transcript.
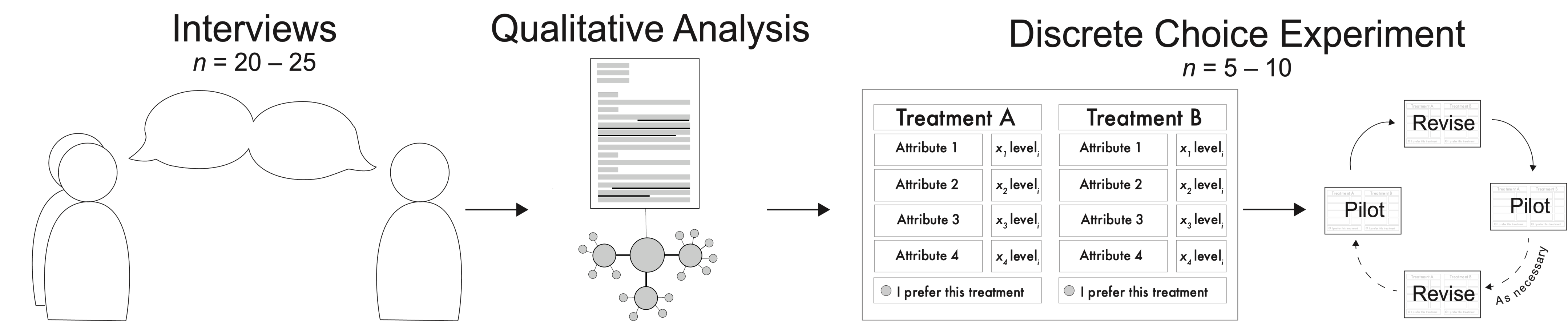
Study Flow

Figure 1. Linear diagram of major study components

Demographics

Figure 2. Barplot of participants by relationship to the patient and race/ethnicity

Figure 3. Barplot of participants by income and race/ethnicity

Figure 4. Histogram of participants' years of schooling since first grade

Preference Sensitive Decision Points

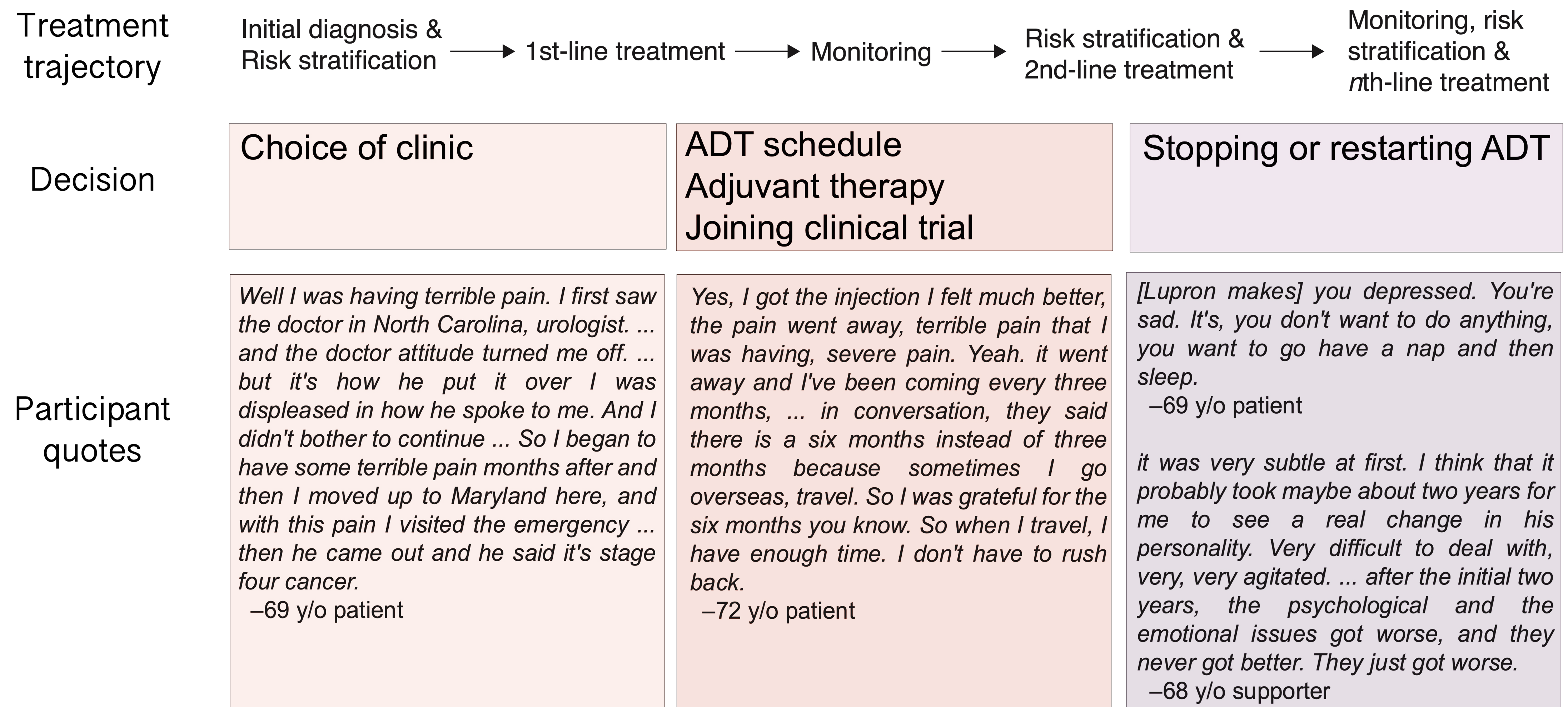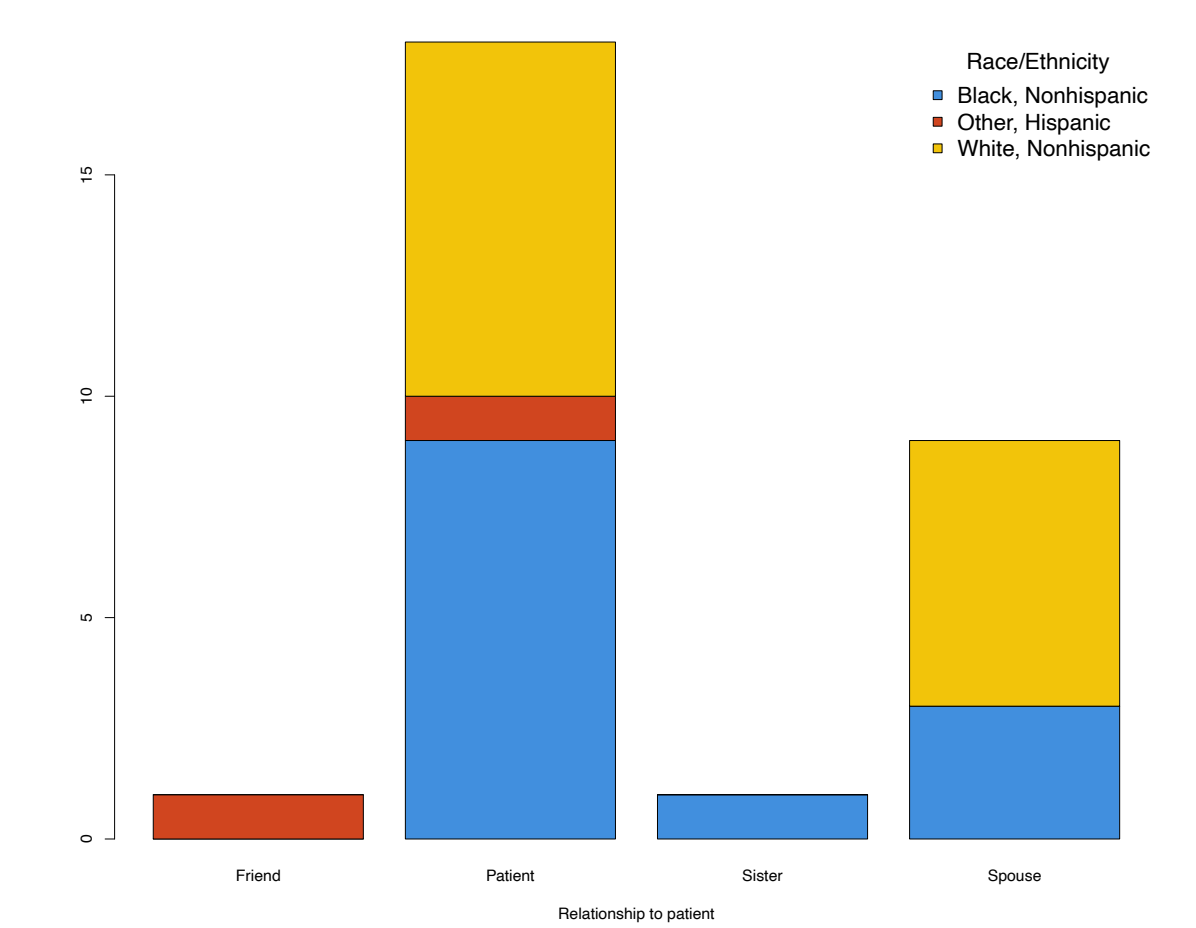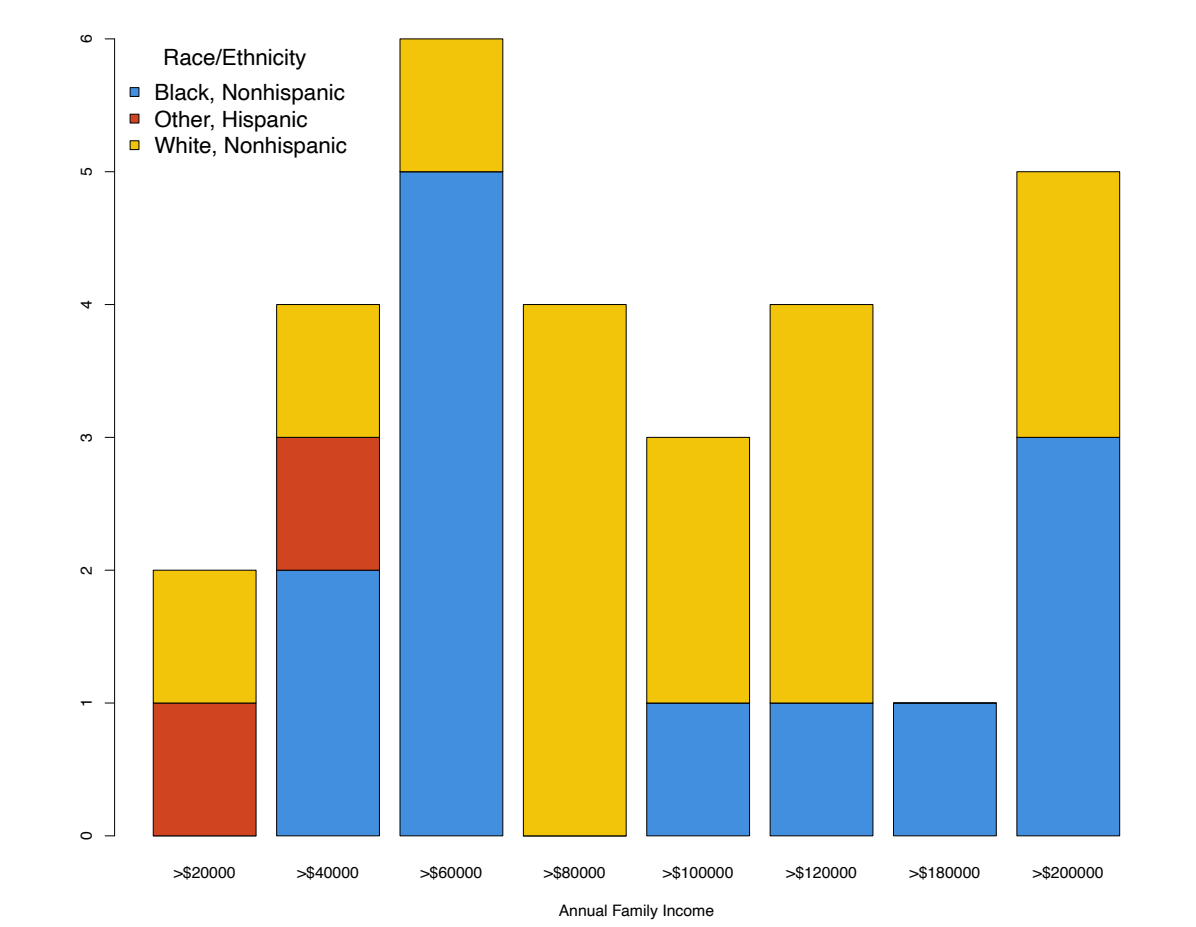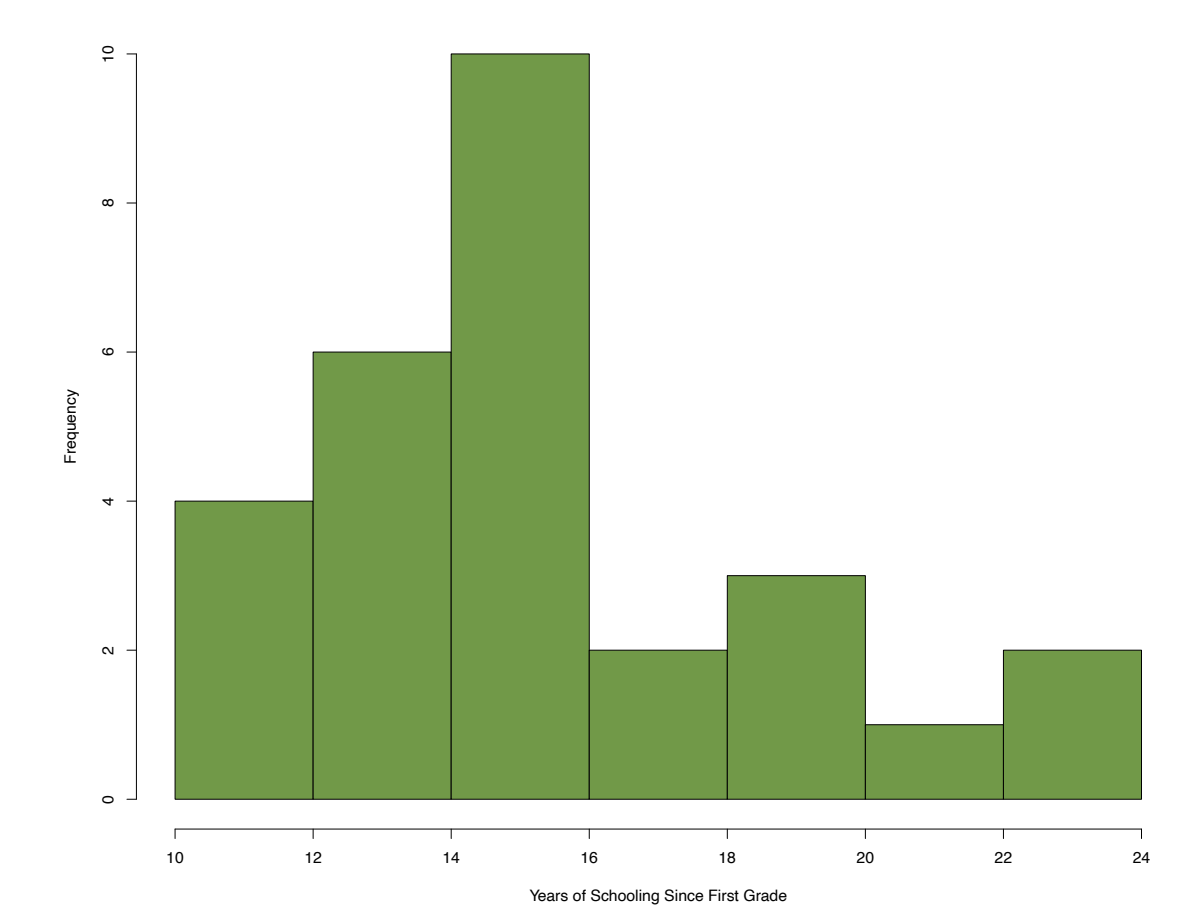|			
Treatment trajectory	Initial diagnosis & Risk stratification → 1st-line treatment → Monitoring → Risk stratification & 2nd-line treatment → Monitoring, risk stratification & nth-line treatment		
Decision	Choice of clinic	ADT schedule Adjuvant therapy Joining clinical trial	Stopping or restarting ADT
Participant quotes	*Well I was having terrible pain. I first saw the doctor in North Carolina, urologist. ... and the doctor attitude turned me off. ... but it's how he put it over I was displeased in how he spoke to me. And I didn't bother to continue ... So I began to have some terrible pain months after and then I moved up to Maryland here, and with this pain I visited the emergency ... then he came out and he said it's stage four cancer.* —69 y/o patient	*Yes, I got the injection I felt much better, the pain went away, terrible pain that I was having, severe pain. Yeah. it went away and I've been coming every three months, ... in conversation, they said there is a six months instead of three months because sometimes I go overseas, travel. So I was grateful for the six months you know. So when I travel, I have enough time. I don't have to rush back.* —72 y/o patient	*[Lupron makes] you depressed. You're sad. It's, you don't want to do anything, you want to go have a nap and then sleep.* —69 y/o patient *it was very subtle at first. I think that it probably took maybe about two years for me to see a real change in his personality. Very difficult to deal with, very, very agitated. ... after the initial two years, the psychological and the emotional issues got worse, and they never got better. They just got worse.* —68 y/o supporter

Figure 5. Preference sensitive decision points. Adjuvant therapy may include but is not limited to radiation, chemotherapy, and androgen-receptor blockers. ADT: leuprolide-based androgen deprivation therapy.

Funding and Acknowledgements