Objectives In this study we will develop a detailed characterization of the life transitions that men perceive as related to prostate cancer. We will do this through a comparative, qualitative analysis of men’s narratives of their experiences with prostate cancer, which we will collect through in-depth interviews with participants in two, well-defined cohorts constructed in our ongoing studies, and one new cohort of newly diagnosed patients. Research Plan The study is proceeding in three phases. First, we have interviewed participants in our quality of life survey of previously treated patients, stratified by quality of life defined by scales previously developed in this cohort (development cohort). Second, we have interviewed members of our prospective cohort who have completed 36-month follow-up, stratified by quality of life states (as defined by the same quality of life scales) and observed changes in urinary, bowel, and sexual function from pre-treatment baseline (verification cohort). Third, we are prospectively interview patients with new diagnoses of early prostate cancer twice—prior to treatment and then at 12 months following the initiation of treatment—in order to describe qualitative changes.

Methods All data collection has been completed. Interviews are being analyzed using qualitative analysis procedures informed by grounded theory methodology. Survey data are being analyzed using descriptive and inferential statistics.

Findings The survey of the Talcott-Clark prospective cohort, which was used to define groups for in-depth interviews, also provided data for an analysis of perceived cancer control and the quality of treatment decisions among long-term survivors of prostate cancer. 235 respondents had survived 4 to 6 (median = 5) years. Most reported good cancer control (65%), good confidence in treatment decisions (57%) or both (44%); the 2 outcomes were only modestly correlated (r=.32). Poor cancer control was associated with higher pre-treatment Gleason scores, elevated or rising post-treatment PSA, and bowel dysfunction. Difference in decisions was greater among older, unmarried men who had survived more than five years after external beam radiation rather than surgery or brachytherapy, and those with bowel and sexual dysfunction. Poor outcomes in both domains were associated with lower quality of life, especially diminished confidence in sexual capability. These data suggest that perception of cancer control does not entail confidence in one’s treatment decisions among long term survivors of early prostate cancer. The former may be a function of clinical indicators of severity and biochemical control, while the latter relates to social support and the preservation of sexual function and well-being.

Findings highlight complex psychosocial outcomes of treatment and suggest points where we can supportively intervene.

On-going qualitative analysis of the in-depth interviews has identified the following major domains of men’s narratives of the long term consequences of prostate cancer: Disease, including talk about cancer, cancer control, and mortality as it relates to cancer; Disease Acts, including actions taking with regards to the cancer itself, such as discovery, decision account, and account of treatment; Physical Dysfunction: Social Context, such as their intimate partner, family, friends, different members of the medical world and doctors; identity issues, including masculinity, and work and family roles.