Quality of Life for Men with Prostate Cancer: Targets for Intervention

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Agenda

- What is “quality of life”?
- How do we measure it?
- Why do we care?
- What do we know?
- What do we still need to know?
- Where do we go from here?

What is Quality of Life?

- **Quality of life** is a descriptive term that refers to people's emotional, social and physical well-being, and their ability to function in the ordinary tasks of living.
- Ex.
  - Functional status
  - Symptom distress

How is it usually measured?

- General health-related quality of life
  - SF-36, SF-12, FACIT, EUROQOL, etc.
- Disease-specific
  - UCLA Prostate Cancer Index,
  - Expanded Prostate Cancer Index

Why do we care about PCa QOL?

- Generally dx is early in disease process
- Survival time is usually good
- Current treatments carry with them a number of side-effects for many men

Prostate Cancer Treatment-Related Symptoms

Depends on Treatment Selected

- **Radical Prostatectomy** may lead to
  - Erectile difficulties
  - Urinary incontinence
- **Radiation Therapy** may lead to
  - Bowel problems (burning/pain, incontinence)
  - Erectile difficulties
- **Hormonal therapy** may lead to
  - Fatigue, cognitive changes, weight gain, bone loss, hot flashes, gynecomastia, loss of libido and erectile functioning

What do we know about PCa QOL?

PCa registries

- Clinical and QOL data
  - Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE™)
  - Prostate Cancer Outcomes Study (PCOS)
- Clinical data only
  - Center for Prostate Disease Research (CPDR)
  - Shared Equal Access Regional Cancer Hospital (SEARCH)

PCa QOL timeline

- 1994 – PCOS begins enrollment
- 1995 – Litwin publishes QOL *JAMA* article
- 1995 - CaPSURE™ begins enrollment
- 2000 – Wei publishes EPIC validation study

- 2007 - > 1,900 studies on PCa QOL since 1995

PCOS

- Drawn from six NCI SEER cancer registries
- Participants diagnosed between October 1, 1994 and October 31, 1995, N = ~3,500
- Survey questionnaire sent to patients at 6, 12, 24, and 60 months after the initial diagnosis.
- ~ 26 publications
- Penson and colleagues recently funded to collect longer term outcome data

CaPSURE

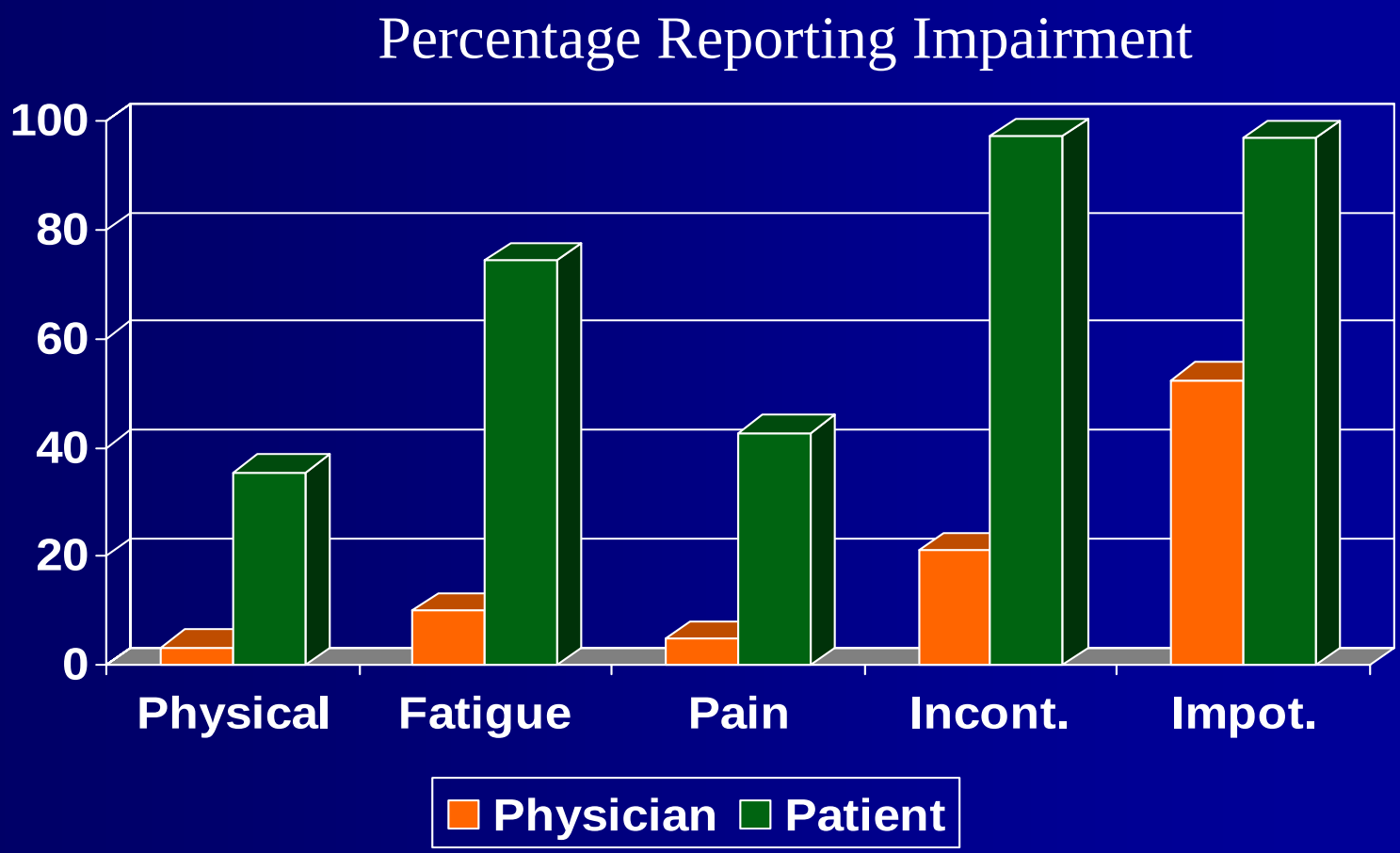
- 31 sites, primarily community-based urology practices around the US
- ~ 13,000 men ever enrolled, ~ 7,500 men currently being followed
- Approximately 100 published papers, 25 in QOL
- Patient-reported outcomes collected at enrollment and in biennial mail survey

Major Categories of Data

- ~ 1,000 data variables
- Clinical Data
  - Physician reported
  - At diagnosis and each subsequent visit
  - Hospitalizations, death data
- Patient-Reported Outcomes
  - QOL, resource use
  - Enrollment Qx
  - 2 follow-up Qx mailings each year, 75-80% response rate

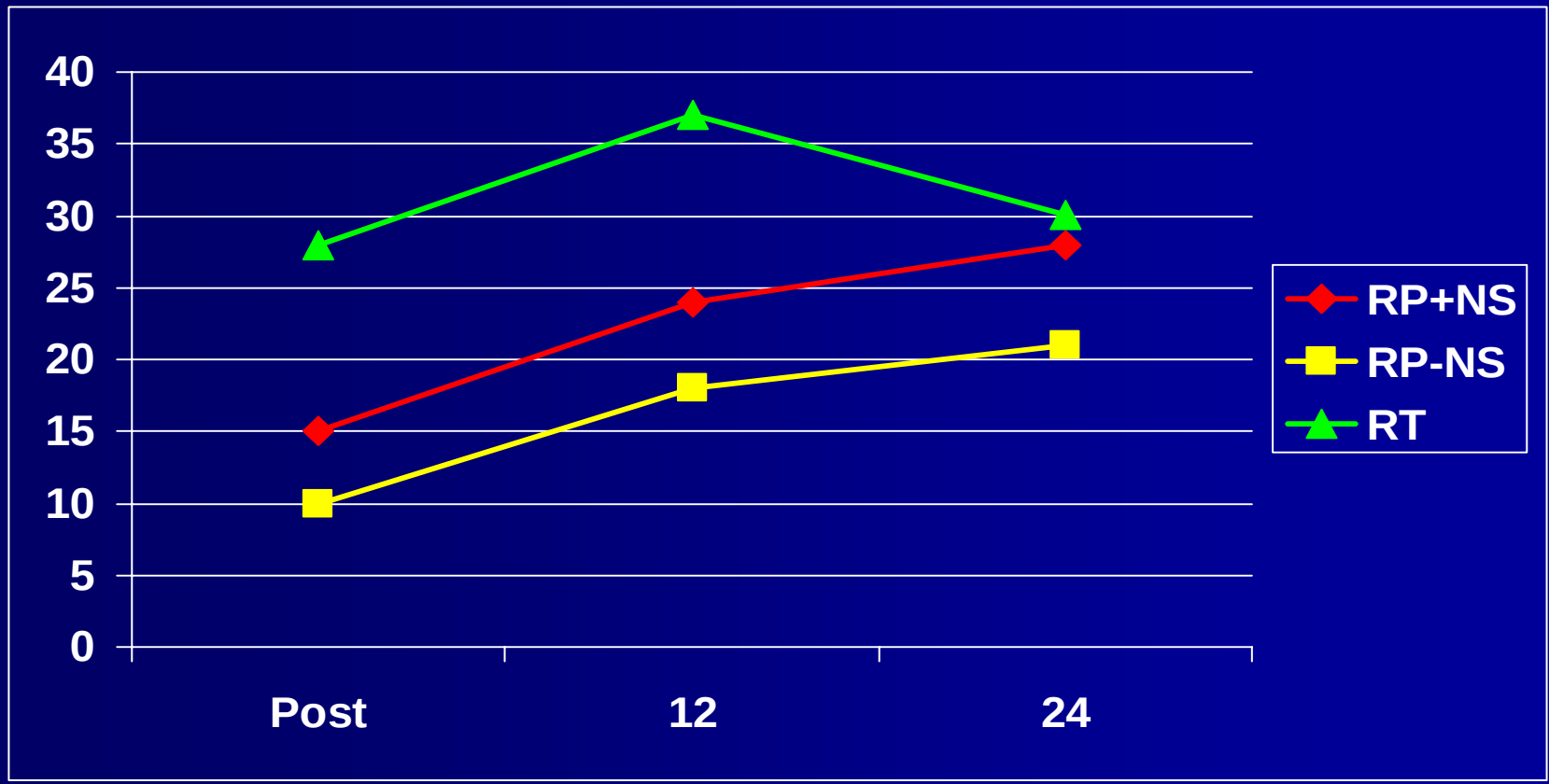
Early CaPSURE QOL Studies

Patient/Physician Reporting HRQOL



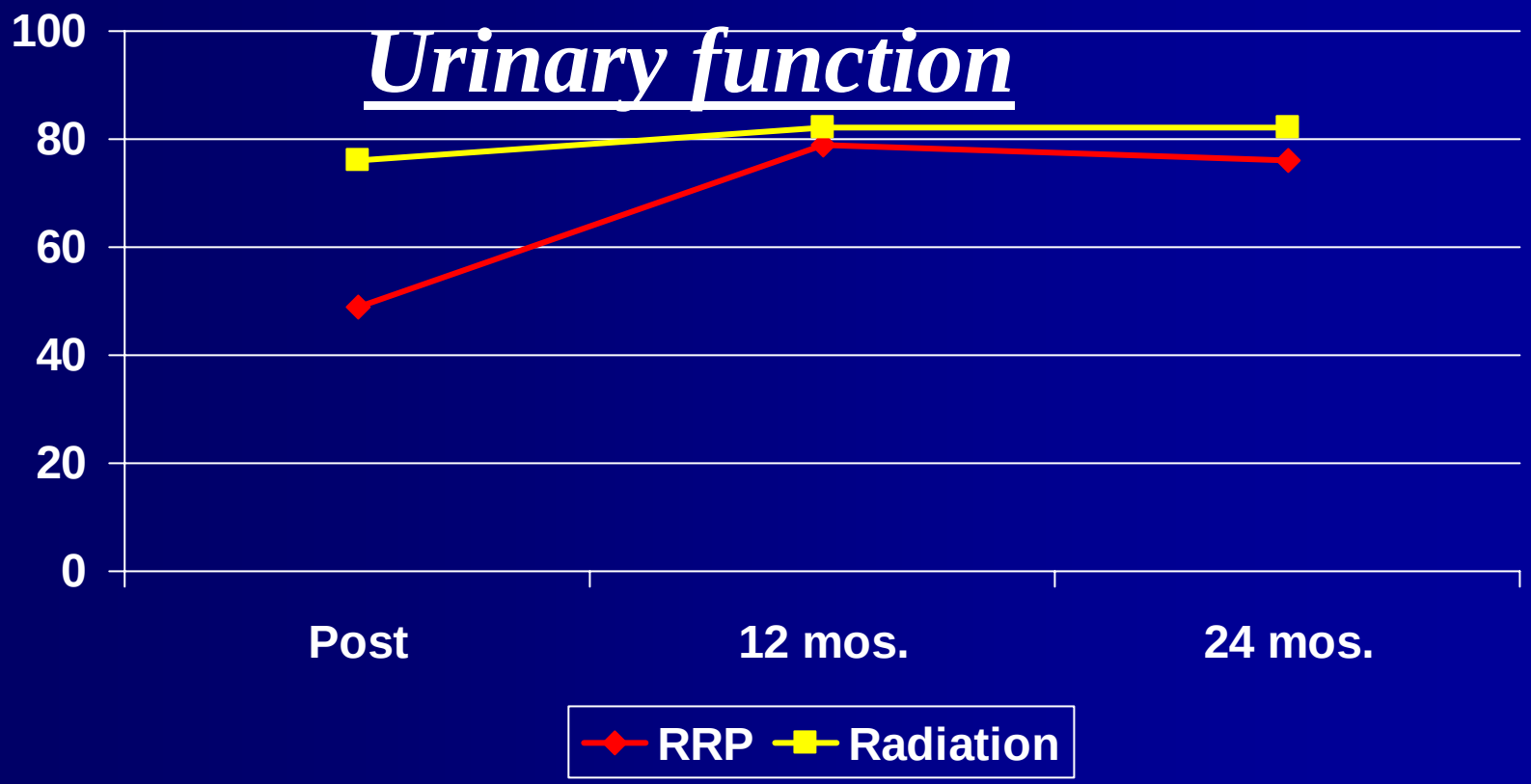
J Urol, 1998. 159: 1988 - 1992

Nerve-sparing surgery



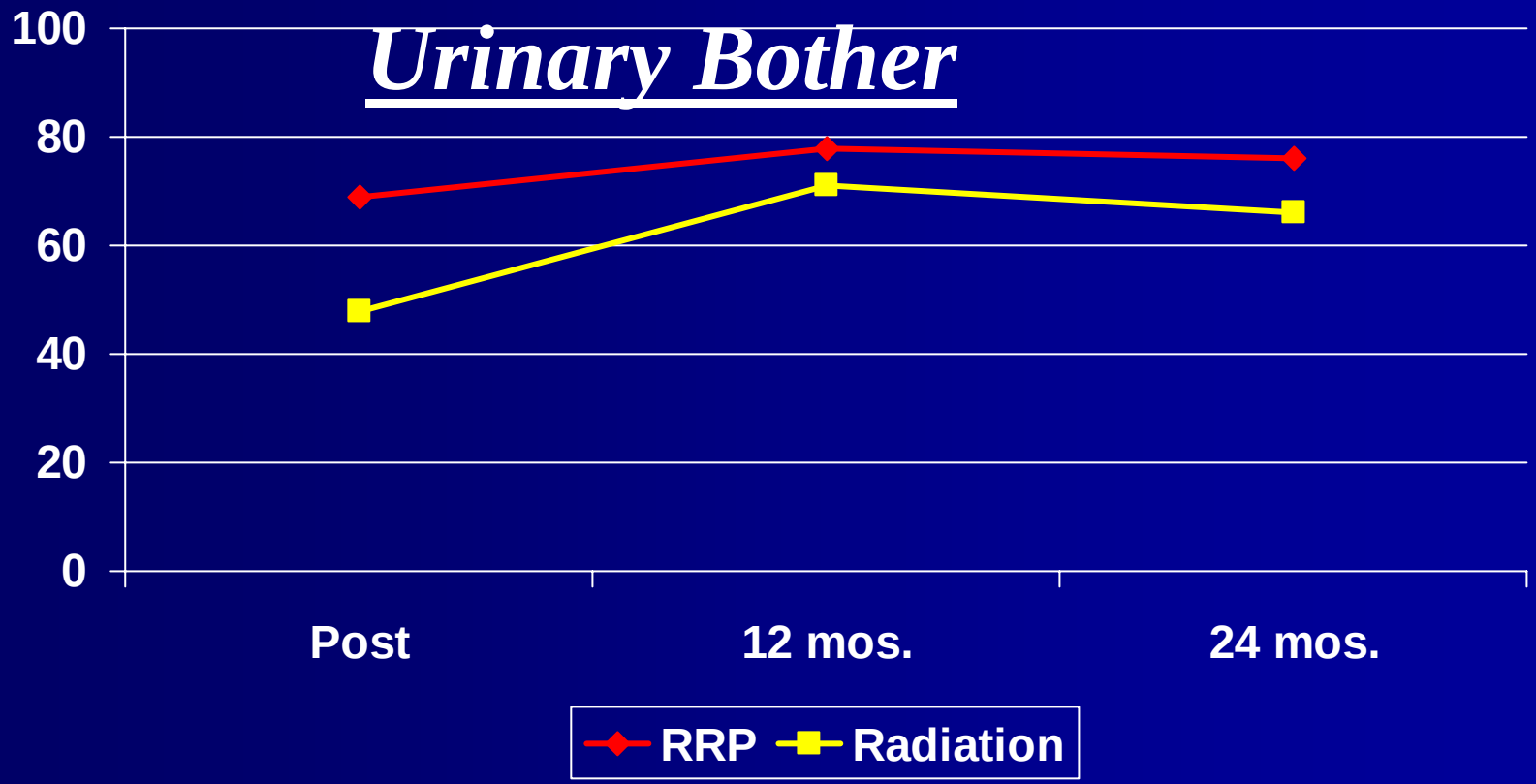
Urology, 1999. 54: 503 - 508

RP vs. Ext Beam Rad.



J Urol 164: 1973, 2000

RP vs. Ext Beam Rad.



J Urol 164: 1973, 2000

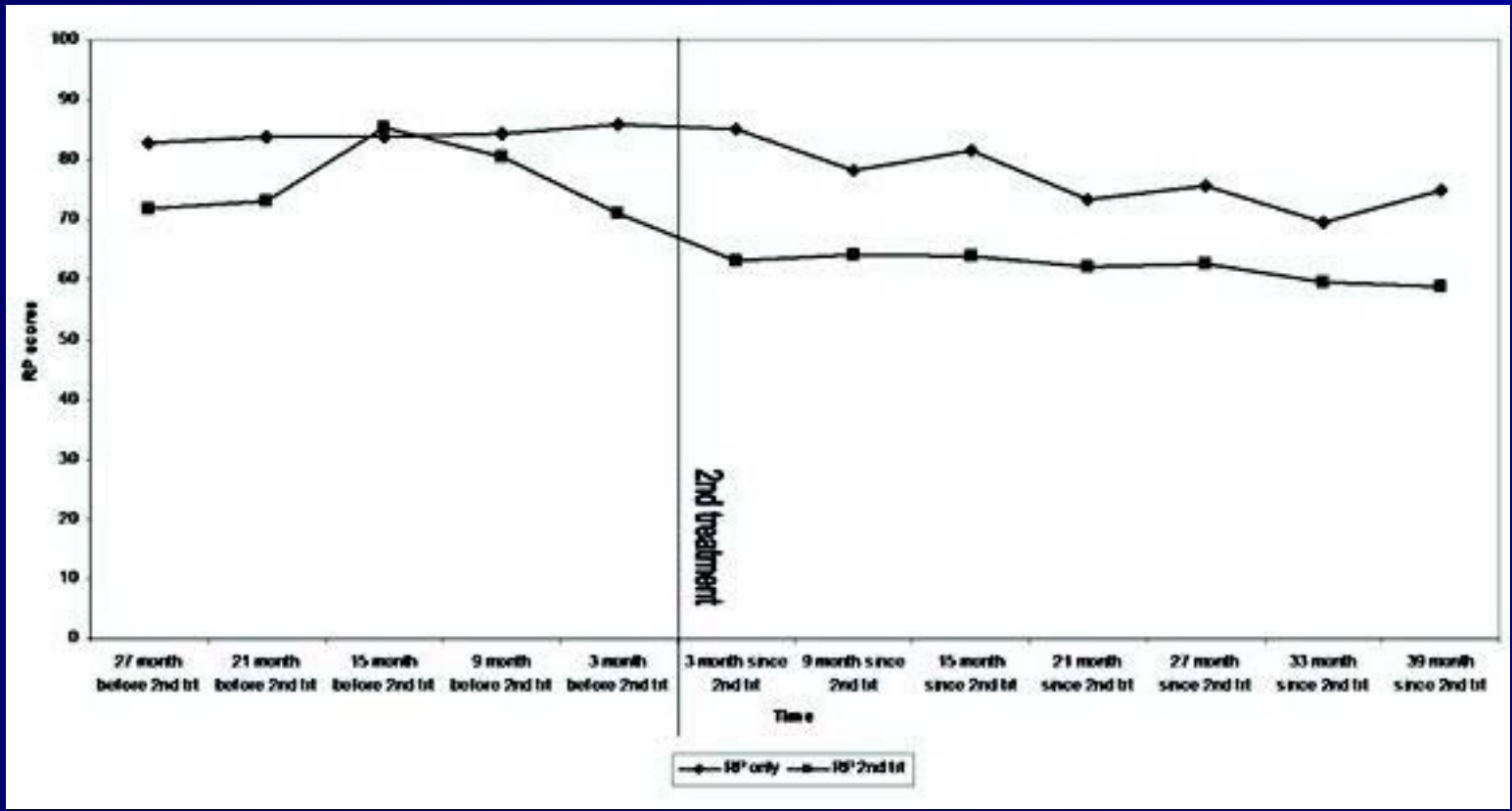
Recent CaPSURE QOL Studies

QOL after 2nd tx post-rp

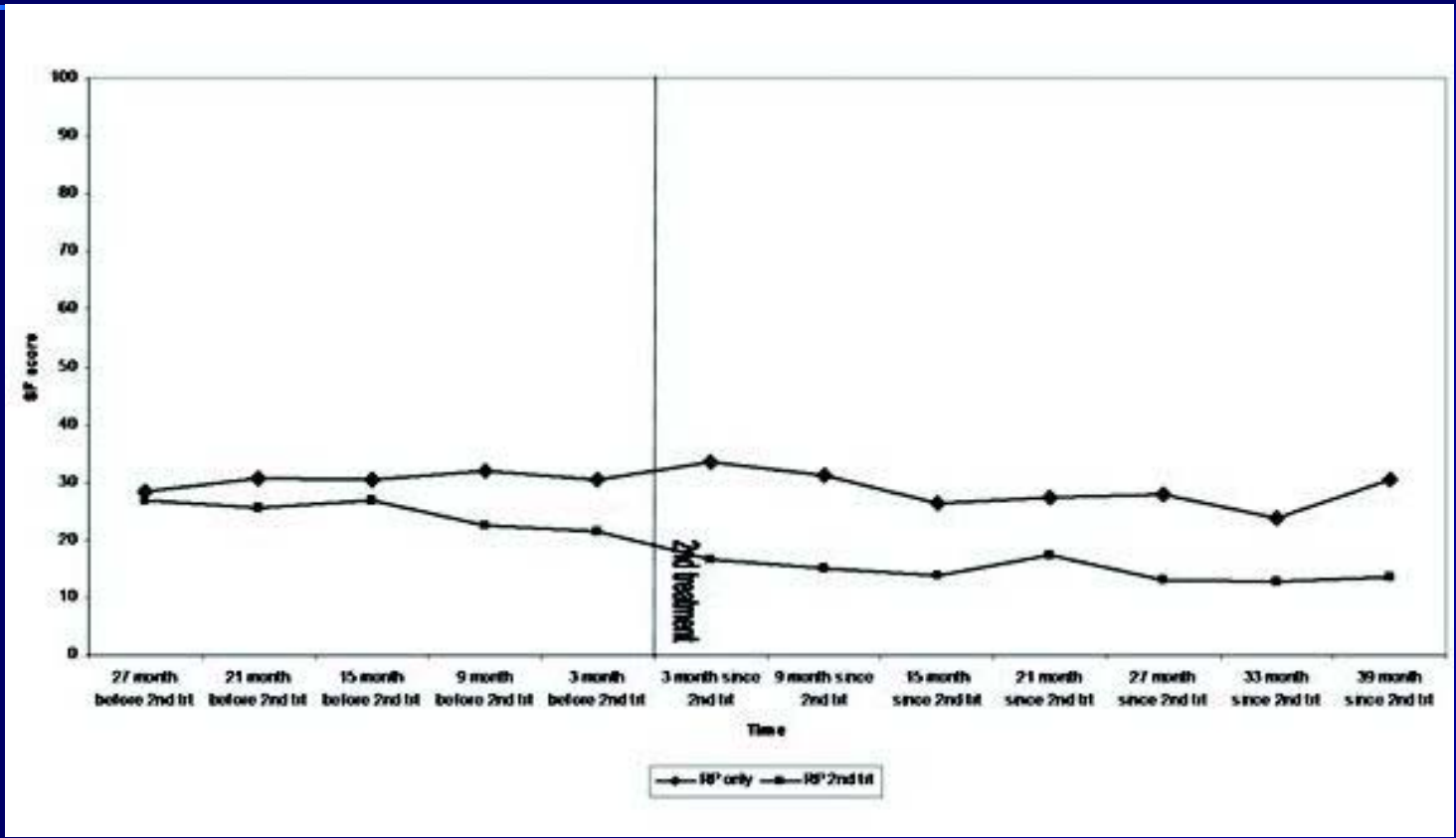
- 2 groups – surgery and no 2nd tx vs. surgery plus 2nd tx
- 897 men – 722 had surgery only and 175 had 2nd tx
- Compared QOL over time for the 2 groups
- 2nd tx men presented with worse disease at enrollment and had worse general QOL

Arredondo, S. A., Latini, D. M., Sadetsky, N., Pasta, D. J., DuChane, J., Carroll, P. R., CaPSURE Investigators (2007) Quality of life after second treatment for prostate cancer: Data from CaPSURE, *Journal of Urology*, 177 (1), 273-279

SF-36 – Role Physical – 2nd tx after RP



SF-36 – Sexual Fx – 2nd tx after RP



Education and QOL in the VA

- VA is an equal-access system
- 248 CaPSURE participants treated by 3 VA sites
- Controlling for age, ethnicity, income, year of diagnosis, and site, men with less formal education, compared with those with more, had worse QOL at 24M in
  - Physical Functioning ($p < .05$),
  - Role Physical ($p < .01$),
  - Role Emotional ($p < .01$),
  - Vitality ($p < .01$),
  - Mental Health ($p < .01$),
  - Social Function ($p < .01$),
  - General Health ($p < .001$)
  - Urinary ($p < .01$)
  - Sexual ($p < .05$) functioning.

Knight, S. J., Latini, D. M., Hart, S. L., Sadetsky, N., Kane, C. J., DuChane, J., Carroll, P. R. (2007) Education predicts quality of life among men with prostate cancer cared for in the Department of Veterans Affairs: a longitudinal quality of life analysis from CaPSURE., *Cancer*, 109 (9), 1769-1776

Anxiety and time to treatment for men on surveillance

- 105 men choosing surveillance rather than active treatment
- Observed for 3 years, 36 men treated, 69 remained on surveillance
- After controlling for baseline disease status, ethnicity, education, age, and PSA velocity, the change in cancer anxiety was a significant predictor receiving treatment.
- Some men on surveillance make treatment decisions based on anxiety, rather than on disease status alone.

Latini, D. M., Hart, S. L., Knight, S. J., Cowan, J. E., Ross, P. L., DuChane, J., Carroll, P. R., and the CaPSURE Investigators (2007) The Relationship Between Anxiety and Time to Treatment for Patients With Prostate Cancer on Surveillance, *Journal of Urology*, 178, 821-827

Fear of recurrence, treatment satisfaction, and quality of life after RP

- 333 men treated with surgery
- Treatment satisfaction at 6M, fear of recurrence at 12M, QOL at 18M
- Controlled for age, education, number of comorbid medical conditions, and cancer severity
- Better MH related to lower FOR ($p<0.0001$), higher TS ($p<0.001$), and the interaction of TS×FOR ($p<0.05$) significantly predicted higher mental health QOL scores.
- Better PH related to lower FOR ($p<0.01$), and the interaction of TS×FOR ($p<0.01$)
- Men reporting lower TS and greater FOR endorsed significantly lower levels of QOL compared to other patients in the sample.

Hart, S. L., Latini, D. M., Cowan, J. E., & Carroll, P. R. (2007). Fear of recurrence, treatment satisfaction, and quality of life after radical prostatectomy for prostate cancer. *Supportive Care in Cancer*. Preprint available online.

Where do we need more research?

- Men with low health literacy
  - Bennett et al – low educ. vs. low literacy
- Gay men
  - Blank et al and Latini et al
- Longer term outcomes – 10+ years
  - Penson et al
- Intervention studies

IOM report, 2006

- "Intervention for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors, and their caregivers."

  – *From Cancer Patient to Survivor: Lost in Transition*

Prostate cancer interventions

- Based on effective programs from BrCa, HIV
- Focused mostly on psychological distress
- Main studies to date
  - Bailey et al – Uncertainty mgt for men on AS
  - Canada et al – Couples intervention for ED
  - Carmack Taylor et al – exercise for ADT patients
  - Giesler et al – Computer-based sx mgt
  - Lepore et al – 6 session psychoeducation groups
  - Maliski et al – description of individualized nursing process, not a standardized intervention
  - Mishel et al – telephone, CBT for uncertainty reduction plus physical symptom mgt
  - Penedo et al – CBT/stress management

Unmet needs for PCa information

- Boberg et al, 2003
  - Greatest need – education programs related to treatment-related symptoms and cancer recurrence.
- Templeton et al, 2003
  - Among men on HT, treatment symptoms and how to manage them were the two most commonly reported areas of unmet informational needs
- Ullrich et al, 2003
  - Distress highest in men with recurrence and physical symptoms.

Psychoeducational groups

- Compared 2 interventions (group education with group education plus discussion) and a control group.
- Both intervention groups increased prostate cancer knowledge.
- Less educated men benefited more from the intervention than men with more education.

Lepore et al, Improving quality of life in men with prostate cancer: a randomized controlled trial of group education interventions, Health Psychol. 2003 Sep;22(5):443-52.

The bottom line

- Few intervention studies.
- Most based on what we know from research in breast cancer.
- Most focus on distress, when men are more interested in sx mgt.
- Distress is reduced as sx are better managed.
- Targeted descriptive studies are needed.
- Intervention studies that build on our 10+ years of descriptive studies are needed!

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