VALUE IN HEALTH 19 (2016) 218–225

Available online at www.sciencedirect.com

ScienceDirect

journal homepage: www.elsevier.com/locate/jval

Preferences for Prostate Cancer Outcomes: A Comparison of the Patient Perspective, the General Population Perspective, and a Population at Risk for Prostate Cancer

Katharine S. Gries, PharmD, PhD[1,*], *Dean A. Regier, PhD*[2,3], *Scott D. Ramsey, PhD, MD*[4], *Donald L. Patrick, PhD, MSPH*[5]

[1]*Evidera, Seattle, WA, USA;* [2]*Canadian Centre for Applied Research in Cancer Control, BC Cancer Agency Research Centre, Vancouver, BC, Canada;* [3]*School of Population and Public Health, University of British Columbia, Vancouver, BC, Canada;* [4]*Fred Hutchinson Cancer Research Center, Seattle, WA, USA;* [5]*Department of Health Services, University of Washington, Seattle, WA, USA*

ABSTRACT

Objective: To collect disease-specific and generic preference values for three populations. **Methods:** Prostate cancer-specific health states were developed with attributes that varied across five health domains: sexual function, urinary function, bowel function, pain, and fear of the future. Men with prostate cancer, men at risk for prostate cancer, and a sample of the general population assigned value to 18 disease-specific health states using standard gamble (SG) methodology. Study participants also completed the Health Utilities Index (HUI) to obtain generic, community-based preference values to capture their current health rating. **Results:** A total of 136 participants were enrolled (n = 43 prostate cancer; n = 40 at risk for prostate cancer; n = 49 general population). Mean HUI mark 3 current health ratings: men with prostate cancer 0.75 ± 0.260; men at risk for prostate cancer 0.77 ± 0.238; general population 0.84 ± 0.178. Mean SG preference values ranged from 0.46 to 0.85 among men with prostate cancer, 0.37 to 0.75 among men at risk for prostate cancer, and 0.32 to 0.81 among the general population group. **Conclusions:** In general, preference values for disease-specific health states using the patient perspective were higher than those for the general population. Generic preference values calculated from the HUI were higher than disease-specific preference values calculated from the SG. The higher values calculated from the HUI, from all three perspectives, indicate that a generic measure may not be sensitive enough to capture the disutility of prostate cancer symptoms, specifically sexual dysfunction, urinary dysfunction, and bowel dysfunction, which are being directly measured in the disease-specific health states.

Keywords: outcomes, perspective, preference values, prostate cancer.

Introduction

Health-related quality of life (HRQOL) can influence treatment options and decision making for both the clinician and the patient. For use in a preference-based study, a given combination of HRQOL attributes represents a health state. A health state reflects presence, frequency, intensity of symptoms, functional status, and feelings and is assigned a value to measure an individual's well-being or satisfaction in that state [1]. The value assigned to a health state, referred to as a *preference weight* or *utility value*, has application in health economics research, cost-effectiveness modeling, and evidence-based medicine. Utility values can also be captured using generic measures, such as the Health Utilities Index (HUI), or disease-specific preference-based measures or valuation of disease-specific health states. Although a generic measure allows for comparison and benchmarking across conditions, it may not be sensitive enough to capture the disutility of disease-specific attributes.

HRQOL plays an important role in prostate cancer given the long duration of life after diagnosis, occurrence of symptoms, and potential serious adverse effects from treatment. A review of preference values for prostate cancer outcomes found variations depending on the method used for eliciting preferences, study population, various context effects, and mode of presentation [2]. This finding emphasizes the inability to compare results across studies without understanding the study context, population, and data collection methods. Studies in a range of therapeutic areas examined differences in preferences based on the perspective, with most of the studies reporting higher preference values being reported by patients than by people without experience in the disease state [3–16].

Health states can be evaluated from the patient (postillness) perspective, the societal perspective, or a third-party perspective. There is no clear consensus on the preferred perspective. Welfare economic theory posits the perspective of the health state of the affected person as the preferred source of preference valuation,

* *Address correspondence to:* Katharine S. Gries, 1417 4th Ave, Suite 510, Seattle, WA 98121.
E-mail: Katharine.gries@evidera.com.

1098-3015$36.00 – see front matter

http://dx.doi.org/10.1016/j.jval.2015.11.012

whereas extra-welfarism supports a generic, community-based preference to allow for comparison of preferences across disease categories and for use in allocating limited recourses [17]. The extra-welfarist believes that the postillness preferences would too often result in the provision of marginally beneficial care and are subject to change and adaption [18]. Given the strengths, limitations, and biases of both the patient and societal preferences, understanding the difference and the consequence of selection on decision making warrants further investigation [19].

To explore the difference in preference values by perspective, three study populations (men diagnosed with prostate cancer, general population, and men at risk for prostate cancer because of elevated levels of prostate-specific antigen [PSA]) were recruited for studying the patient perspective, the societal or general population perspective, and the perspective of men at risk for prostate cancer. Although the perspective of those at risk for the disease is not a traditional perspective used in the application of cost-effective modeling, it is unclear whether this population identifies more with the patient population or more with the general population. Men with elevated risk of prostate cancer may anticipate or imagine the health state more clearly than the general population because of their clinical status, additional education on the disease, and heightened awareness of the disease. Given the lack of prostate cancer diagnosis, these men would traditionally be considered part of the general population, but it is unclear what effect their increased knowledge by being actively monitored and routine clinical care has on their health state valuation. The objective of this study was to collect preference values from the perspective of the patient, the society, and a population at risk for prostate cancer using disease-specific health states and a generic preference-based measure.

Methods

This cross-sectional study recruited participants from three populations from the western Washington region to complete one in-person study visit. Disease-specific health states with prostate cancer outcomes were developed on the basis of a review of the patient-reported outcome literature specific to prostate cancer: currently published prostate cancer patient-reported outcome HRQOL measures and qualitative data collected in men with prostate cancer. The study population assigned value to the health states using standard gamble (SG) methodology. Participants also completed the HUI to obtain generic, community-based preference values to capture their current health rating. The HUI was selected over the EuroQol five-dimensional questionnaire (EQ-5D) because the community-based preference weights were collected using SG methodology.

Development of the Prostate Cancer-Specific Health States

Attributes for prostate cancer health states were identified from a review of prostate cancer patient-reported outcome concepts identified in the literature. For purposes of this study, the study investigators decided to create the health states with five attributes, each with three levels of severity, to obtain 243 possible health state options. Table 1 describes the attributes (sexual function, urinary function, bowel function, pain, and fear of the future), levels, and numeric code. Each health state was assigned a five-digit numeric code with one digit for each attribute. The order in the numeric code represents the order of attribute as written in the health state, and the numeric value represents the level of the attribute, with level 1 being the least severe state (no/none) and level 3 being the most severe state (always/considerable).

Table 1 – Health state dimensions and levels.

Dimension	Level	Numeric code
Sexual function	Never experience problems with achieving and maintaining an erection	1
	Sometimes experience problems with achieving and maintaining an erection	2
	Always experience problems with achieving and maintaining an erection	3
Urinary function	Never experience problems with urination	1
	Sometimes experience problems with urination	2
	Always experience problems with urination	3
Bowel function	Never experience problems with diarrhea and/or constipation	1
	Sometimes experience problems with diarrhea and/or constipation	2
	Always experience problems with diarrhea and/or constipation	3
Pain	No pain that limits your activities	1
	Moderate pain that limits your activities	2
	Severe pain that limits your activities	3
Fear of the future	No fear of the future	1
	Minimal fear of the future	2
	Considerable fear of the future	3

Valuation Sample

Participants from four counties in the western Washington region (King, Kitsap, Pierce, and Snohomish) were invited to participate in the study. To be eligible for the study, participants had to meet the inclusion criteria for one of the three study groups: men with prostate cancer, men at risk for prostate cancer, or a representative sample of the general population. Each study group had a different sampling frame. The study protocol and consent form were submitted and approved by the Fred Hutchinson Cancer Research Center and the University of Washington institutional review boards.

Men with prostate cancer were recruited from the Cancer Surveillance System at the Fred Hutchinson Cancer Research Center. The Cancer Surveillance System is part of the Surveillance, Epidemiology, and End Results program and provides data to the Washington State Cancer Registry. Eligible participants were aged between 45 and 70 years, had a histological confirmed diagnosis of prostate cancer within the past 3 years, and self-reported experience with prostate cancer symptoms at the time of screening. Men at risk for prostate cancer were recruited from the University of Washington Medical Center Urology Clinic and the Prostate Oncology Center. Eligible participants were aged 45 to 70 years, had elevated PSA level ($\geq$2.6 ng/ml), and no prostate cancer-specific symptoms at the time of screening. The general population was recruited from the Washington State Department of Licensing Database. Eligible participants were aged 18 to 70 years and had no self-report diagnosis of prostate cancer.

In addition, eligibility for all three groups required that the participant was able to speak/read English, able and willing to give written informed consent, able to attend an interview