



an interview with

Prof. Stephen Lepore

by Nihal Mohamed, Co-editor

Stephen Lepore is Professor of Public Health and PhD Director in the Department of Public Health, Temple University. Previously, he has held faculty posts at Columbia University, Brooklyn College, and Carnegie Mellon University. Prof. Lepore is one of the most outstanding researchers in the field of quality of life research (QOL) in the US. He completed his undergraduate training in psychology at Clark University, received his Ed.M degree from Harvard University, and his Ph.D. in Social Ecology from the University of California, Irvine. Professor Lepore's work addresses social disparities in health, particularly through the development and application of evidence-based behavioral and social interventions, among others. Professor Lepore is a Fellow of the Society of Behavioral Medicine and has received numerous awards in recognition of his research accomplishments, including an Award for Outstanding Contributions to Health Psychology from Division 38 of APA, and the Young Investigator Award for Outstanding Contributions to Behavioral Medicine from the Society of Behavioral Medicine, and a Fulbright Award. His current projects include several National Institutes of Health-funded randomized controlled trials that are designed to test the efficacy of educational and behavioral interventions for resolving diverse health problems, including increasing informed decision making about prostate cancer testing in men of African descent and promoting quality of life in colorectal cancer patients using expressive writing therapy.*

On the Front Lines: Improving Prostate Cancer Decision Making and Quality of Life**Prostate Cancer**

Prostate cancer (Pr Ca) is the most prevalent solid tumor malignancy and the second leading cause of cancer-related death in the United States (US). Early medical interventions of Pr Ca can cure a potentially disabling and deadly disease, however, evidence suggests that the commonly recommended Pr Ca treatments may not improve survival and may result in adverse effects.

The *European Health Psychologist* interviews Prof. Stephen Lepore about some of the conflicting issues in Pr Ca screening and the psychosocial care needs of patients and their families.

**Stephen J. Lepore**

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NM: Prof. Lepore, can you talk about prostate cancer screening and early detection?

SJL: The incidence of prostate cancer is quite high throughout the world and the only chance of curing the disease is to catch it and treat it in the early stages. However, there is much controversy related to prostate cancer screening. Although the incidence and number of deaths from prostate cancer is quite high, the vast majority of men diagnosed with prostate cancer die from other causes. Because of this, identifying and treating all men with prostate cancer may result in many men receiving unnecessary treatments—treatments that can have serious untoward side-effects, such as urinary and sexual dysfunction. In addition, the prostate cancer tumour is often slow-growing and the majority of men get it at a late stage in life when they may be susceptible to more lethal illnesses. Finally, due to a lack of clinical trials showing that screening actually saves lives, current national guidelines do not recommend prostate cancer screening. Instead, various medical societies, including the American Cancer Society, recommend that men over the age of 50, or over 40 for high-risk men, participate in decisions about whether prostate cancer tests are right for them after learning about the disease and the potential benefits and limitations of testing. Increasingly, men are getting tested for prostate cancer, but it is not clear whether they are making fully informed decisions ►

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about testing. Many primary care physicians do not have the time to educate their older male patients about prostate cancer testing or they may not know the best way to present the possible risks and benefits of testing in a balanced and effective manner. Thus, men may get tested with little more than a simple recommendation from their physician. There is even evidence of so-called "opportunistic testing," in which physicians order a PSA tests as part of a panel of other blood tests during a routine physical exam without discussing the test with the patient. Thus, there is a major need for more public education and awareness about all aspects of prostate cancer testing and for men to talk with health care providers about whether testing is right for them. This need is especially great among those segments of our population who are at especially high risk for prostate cancer morbidity and mortality. Health psychologists are uniquely qualified for designing programs that facilitate decision making under uncertainty and doing so with cultural sensitivity.

NM: *What are the biggest concerns that men have when they consider the different treatments options for early stage Pr Ca? And how can the medical care providers help patients during the decision processes?*

SJL: Despite recent trends suggesting declines in the incidence and rates of death from prostate cancer, it is still the big "C". First and foremost, patients, their families and physicians are concerned with curing early stage prostate cancer to prolong life. However, there is no strong evidence that one form of treatment is better at prolonging life than any other form of treatment. Indeed, in many cases, treatment may be no better than observation, or so-called "watchful waiting". A patient's age and overall health status often influence treatment decisions. For example, a 70-year-old man with heart disease is not a good candidate for surgical removal of the prostate. Another consideration is the potential short- and long-term effects of different kinds of treatments on a patient's quality of life. Research with my colleagues suggests that men treated by radical prostatectomy, or surgical removal of the prostate gland, tend to report more post-treatment urinary and sexual problems and more general physical dysfunction than men treated by radiation therapy. Patients and their families should be fully educated about the treatment options and the potential consequences of their choices. Patients can become more knowledgeable by seeking second (or third) opinions about treatments from an oncologist or other cancer specialists, trying to talk with men who have been treated for prostate cancer, possibly in a local support group or through an Internet-

based group, and reading books on the subject. There also are decision aids which can be found on websites, but these are not yet widely available or recommended by physicians. These aids typically educate patients about different treatment options, explain the potential risks and benefits that can be expected, and include exercises that help patients to weigh the relative importance of different risks and benefits so they can make a decision that is concordant with their values. Greater integration of patient decision aids in physicians' practice, or simply greater availability of these aids through public sources, such as the Internet and libraries, would be extremely valuable to patients and their family members who are facing very tough decisions.

NM: *How do you define quality of life and why have you focused on quality of life after prostate cancer treatment?*

SJL: In the context of prostate cancer, health-related quality of life would be those aspects of a man's normal life that have been affected by the disease or its treatment. Because we are talking about "quality" of life, there is necessarily a subjective element: the patient has to interpret the impact of the disease and treatments in relation to prior functioning or his personal expectations and goals. For example, one patient may experience urinary incontinence as a highly bothersome and distressing outcome of treatment, whereas another may view it as a nuisance. There are many areas of an individual's life that may be affected by prostate cancer, including physical, emotional, cognitive, and social functioning and well-being. There has not been much research on the topic, but it is also possible that men can experience positive changes in some areas of their life – for example, after the scare of prostate cancer, a man may decide to retire early and spend more time travelling with his wife and enjoying life.

My work has focused on quality of life outcomes in men treated for prostate cancer for several reasons. First, different treatment protocols – surgery, hormones, radiation, watchful waiting – have very different effects on quality of life, but none has an obvious survival advantage. Thus, understanding the effects of different treatments on quality of life may be critical to men considering treatments. Second, when my colleagues and I started our research in this area, there was relatively little known about the wide-range of effects of prostate cancer on quality of life in men and their families. Third, the majority of ►



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studies that have attempted to improve quality of life outcomes in people who have had cancer have focused on women, specifically women with breast cancer. Until we began our intervention studies, there had been no large-scale, controlled studies comparing different methods for improving quality of life outcomes in men who had been treated for prostate cancer. At least a half-dozen intervention studies have now been conducted with men treated for prostate cancer and we are learning that a variety of approaches may be effective at improving quality of life, particularly for men with high need and relatively low coping resources. There is still much to do, however, to find ways to disseminate promising interventions. In addition, there has been little research addressing the psychosocial needs of men and their families who are coping with advanced prostate cancer. This is an important direction for future research.

NM: *You have conducted controlled trials that are designed to test the efficacy of educational and behavioural interventions for resolving diverse health problems among minority and underprivileged patients, including Pr Ca patients. Were these interventions successful in achieving their goals? Are there any factors that moderated their efficiency?*

SJL: In the context of prostate cancer, we have conducted studies on the effects of educational and support group on quality of life in men treated for localized prostate cancer. In addition to survivorship studies, we have conducted an education intervention designed to enhance informed decision making about early detection (e.g., prostate specific antigen tests and digital rectal exams) and dietary practices in black and African American men, who have an exceptionally high risk for prostate cancer incidence and mortality.

Our research on the efficacy of education and support groups showed overall beneficial effects on employment status and psychological adjustment to sexual dysfunction. However, men with high needs (e.g., high psychological distress) and low coping resources (e.g., low levels of education) showed a broader range of benefits, including improvements in physical functioning and psychological symptomatology, relative to their counterparts with relatively low needs and high coping resources. This makes a lot of sense and suggests that psychological interventions can help to reduce social disparities in quality of life outcomes in cancer patients. In our

research on informed decision making related to prostate cancer testing, we are finding very strong positive effects of tailored telephone education and counselling on knowledge about testing, participation in prostate cancer decision making, as well as reductions in decision conflict. In addition, we are finding that brief telephone counselling is also effective at improving fruit and vegetable intake in men of African descent who have very low fruit and vegetable intake. Preliminary results suggest that these effects are quite strong and do not appear to be moderated by other factors.

NM: *How can spouses/partners of patients enhance their adaptation to Pr Ca treatment side effects?*

SJL: This is an excellent question. I would add that cancer affects many people in the patient's social network, including children, friends, co-workers, other family members, and that this is seldom considered in psychological interventions targeting people with cancer. For example, many men in our prostate cancer support groups mentioned that they had not discussed their disease with their adult male children. This is obviously not in the best interest of those male children, because prostate cancer is partly hereditary. Of course, after the patient the spouse is often the one person most directly affected by the disease and its implications. Our research on support groups included spouses of men treated for prostate cancer. However, we have not yet specifically focused attention on helping spouses to cope with their partner's cancer. We did collect data from spouses in our support group studies and found some evidence that they tend to have more cancer-specific distress (e.g., intrusive thoughts) than the patients. Thus, there is some indication that couples-based interventions may be warranted. We are currently developing such interventions for men with advanced prostate cancer because the caregiving demands escalate significantly in this population. ■

Recommended readings:

- Lepore, S. J., & Roberts, K. J. (2007). Cancer: prostate. In S. Ayers et al. (Eds.), *The Cambridge handbook of psychology, health, & medicine* (2nd Edition), 607-609. London: Cambridge University Press.
- Helgeson, V. S., Lepore, S. J., & Eton, D. T. (2006). Moderators of the benefits of psychoeducational interventions for men with prostate cancer. *Health Psychology*, 25, 348-354. ►

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- Roberts, K. J., Lepore, S. J., & Helgeson, V. (2006). Social-cognitive correlates of adjustment to prostate cancer. *Psycho-Oncology*, 14, 1-10.
- Eton, D. T., Lepore, S. J., & Helgeson, V. S. (2005). Psychological distress in spouses of men treated for early-stage prostate carcinoma. *Cancer*, 103(11), 2412-2418.
- Lepore, S. J., Helgeson, V. S., Eton, D., & Schulz, R. (2003). Improving quality of life in men with prostate cancer: A randomized controlled trial of group education interventions. *Health Psychology*, 22, 443-452.
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- Lepore, S. J. (2001). A social-cognitive processing model of emotional adjustment to cancer. In A. Baum & B. Andersen (Eds.), *Psychosocial interventions for cancer* (pp. 99-118). Washington, DC: APA.
- Lepore, S. J. & Eton, D. T. (2000). Response shifts in prostate cancer patients: An evaluation of suppressor and buffer models. In C. Schwartz & M. Sprangers (Eds.), *Adaptations to changing health: Response shift in quality-of-life research* (pp. 37-51). Washington, DC: APA.

For more information on Stephen Lepore's lab and reprints, see:
<http://www.temple.edu/chp/research/SBHI.htm>

Call for contributions

The European Health Psychologist (EHP), the official bulletin of the European Health Psychology Society, would like to issue a general call for contributions to members of the EHPS. The quarterly online publication of the bulletin reaches all members of the EHPS and as such is a vehicle for transmitting timely and thought-provoking ideas and research. Past issues have featured wide ranging scientific topics written by contributors based both within and outside of Europe and the EHP aims to continue this trend into the future. Over the past year, you may have noticed a movement towards publication of empirical results, with an eye on filling a niche which does not fall within the remit of *Psychology & Health* or *Health Psychology Review*. Nevertheless, a diversity of contributions may include, but are not restricted to:

- **Position papers (think pieces)**
- **Overview papers**
- **Research letters**
- **Interviews**
- **Controversy**
- **Reports about conferences and workshops**
- **Country/research group profiles of EHPS conference host countries**
- **Other important information relevant to EHPS members**

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We look forward to discussing your ideas for potential pieces in upcoming issues of the EHP.

Cordially yours,
 Falko F. Sniehotta & Vera Araujo-Soares, Editors
 On behalf of the European Health Psychologist Editorial Team