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Platinum Priority – Editorial

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Patient Decision-making: Where Are We Going?

Peter C. Albertsen *

Department of Surgery (Urology), University of Connecticut, Farmington, CT, USA

Providing good medical care requires mastery of the art of evaluating incomplete data and making decisions without adequate information. An experienced clinician learns to identify and weigh important predictive variables when counselling patients regarding treatment of newly diagnosed disease. Two factors dominate the decision-making process: (1) what is the natural history of the disease in question; and (2) how will various treatments alter the outcome? Each of these unknowns requires its own analysis and discussion. To address the threat posed by newly diagnosed prostate cancer, urologists usually focus on patient-specific variables such as age and medical comorbidities and disease-specific variables such as biopsy Gleason score and an estimate of tumor volume, often expressed as the prostate-specific antigen (PSA) level or the number of positive biopsy cores. Once an experienced urologist has estimated the likely natural history of disease, he or she then draws on his or her understanding of the efficacy of different treatment strategies and the potential for complications. When this complex decision-making process is finally presented to the patient, there should be no surprise that patients will hear different recommendations from different physicians. How can we do better?

Clinicians obtain data from several sources, including personal experience, case series data, population-based registries, and randomized trials. Each of these sources is associated with potential biases, but most clinicians recognize that data validity and generalizability improve as study design becomes more rigorous and sample size increases. What is lacking is a standardized methodology to transform this qualitative process of data evaluation into a more quantitative formal decision analysis. One of my first prostate cancer research projects was to develop a Markov model evaluating survival outcomes associated with patient age and treatment choices [1]. Probability estimates were drawn from relatively limited data available in the literature at the time. The model was not accepted by the urological community, but the effort encouraged me to capture data from the Connecticut tumor registry to quantify the competing risks associated with the progression of prostate cancer and other medical conditions [2]. With time the original model was validated by three randomized trials [3–5].

In this issue of *European Urology*, Auffenberg et al. [6] describe their efforts to quantify qualitative concepts using data from the Michigan Urological Surgery Improvement Collaborative (MUSIC). They employ a standard analytic methodology, but offer a novel contemporary twist that reflects our digital age of mobile apps. Auffenberg et al help new patients to identify their potential treatment options by quantifying the choices made by men similar to them. What is particularly compelling is the potential for patients to access this information on their iPhones at some future date.

While a promising beginning, this effort is just one step along a much longer journey. Their model relies on relatively few well-validated variables: patient age, a limited comorbidity estimate, Gleason grade, and PSA scores. These variables were used by Michigan urologists to estimate the threat posed by a patient's prostate cancer. Urologists then made treatment recommendations based on their own estimates of treatment efficacy and potential treatment outcomes. It is unclear how patients participated in this decision-making process and what estimates were used to weigh the risk/benefit decision. The authors felt the need to censor data before 2015 to avoid the urologists' biases concerning the role of active surveillance in the management of newly diagnosed disease.

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* Department of Surgery (Urology), University of Connecticut, 263 Farmington Avenue, Farmington, CT 06030-3955, USA. Tel. +1 860 6793676; Fax: +1 860 6791318.
E-mail address: albertsen@uchc.edu.

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What do patients really need? To make an informed choice, patients require information on the natural history of their disease and on the impact of treatment on their future longevity and quality of life. Specifically, will treatments cure or will disease recur and require more therapy? What is the potential for impotence and incontinence on the basis of their age and medical history? How do rates of complications compare by treatment received, by the delivery site providing treatment, and by the skill of the surgeon or radiation oncologist? Each of these factors requires independent data capture and synthesis. Amazon can predict our purchasing preferences and Facebook can predict our likes and dislikes, but the quantity of data they collect is multiple orders of magnitude greater than those used in the MUSIC collaborative. The true power of artificial intelligence comes from the quantity and diversity of the data used to model potential outcomes.

A future in which *askMUSIC* can provide detailed probability estimates of treatment outcomes is not fantasy. Several key milestones along this journey have already been passed during my career. Three randomized trials have provided a much better understanding of the natural history of this disease and the efficacy of treatment [3–5], Tools such as the Expanded Prostate Cancer Index Composite [7], International Index of Erectile Function [8], and the Charlson comorbidity index [9] have been developed to provide quantitative estimates of important factors associated with quality of life and overall life expectancy. The electronic medical record has been widely adopted and offers the potential to aggregate and analyze data much faster and cheaper than can be done on paper. Researchers have begun proposing standardized core outcome data sets that identify criteria critical to patients and how they should be measured [10]. Finally, advances in information transmission, processing, and storage allow us to analyze and manipulate data on a global network. The MUSIC collaborative represents the next logical step in data acquisition beyond the traditional academic health center. Similar steps are being taken at the national level in many European countries, especially the UK and Sweden. Version 1.0 of *askMUSIC* is a good start, but we have much farther to travel. With each advance, however, patients and physicians have more quantitative information to make informed decisions. Some day we will have a global network repository of standardized data elements documenting the personal characteristics, disease stage, and clinical outcomes for millions of men. Some day, when we consult *askMUSIC* we will be able to get a response that accurately predicts tailored outcomes for men with newly diagnosed disease. Artificial intelligence will drive this process much sooner than we think, but until then a second opinion is probably a good idea.

Conflicts of interest: The author has nothing to disclose.

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