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INTRODUCTION

One of the most challenging interactions between a cancer physician and a newly-diagnosed cancer patient is a discussion about prognosis. Patients want doctors to be realistic when providing generalized survival information, to recognize the patient as an individual, and to provide patient-specific survival information.2 More than ever, patients today are seeking data independently and unsupervised. When information, or misinformation, is more available literally at our fingertips, patients often gather information from a variety of other sources before coming to the office. Not infrequently, this information is inaccurate and may inappropriately influence patient’s decision making.

A substantial barrier to presenting survival statistics is limited health literacy and mathematical numeracy of the general patient population. It has been reported that up to half of the adult United States population are unable to function adequately within the healthcare system due to limited literacy. Limited health literacy may impact a patient’s understanding of screening tests, diagnoses, and treatment, thus impacting his or her decision-making and compliance.

Another important barrier to providing prognostic information to cancer patients is the fundamental lack of comprehensive and accurate survival statistics. While certain common cancers have websites devoted to detailing prognosis according to morphologic cancer stage, they are not individualized to include patient age, sex, race, and comorbidity health problems. Multiple investigators have demonstrated that the presence of comorbidities is an important prognostic factor of survival in cancer patients.

Formative research conducted by our team indicated that most patients and their families routinely used an internet-based resource to procure cancer information. The Prognostigram, a Web-based tool designed to provide individualized cancer survival statistics, was created to bridge the gap between clinicians and cancer patient, and facilitate the understanding of statistical information and prognostic data. The goal of this current study was to assess patient and physician views on providing patient-specific survival information in this format.

METHODS AND MATERIALS

Part 1 – Oncologists (n=5) were asked their views on the importance of survival statistics, sharing prognosis with patients, as well as their thoughts on using a web-based program that created individualized survival curves.

Part 2 – Patients (n=40) were asked to complete the Newest Vital Sign11 to assess baseline literacy.

Patients were given a booklet with a series of graphs, which included graphical representation of temperatures between two cities (City A and City B, Figure 1) and graphical representations of five-year survival of two fictitious cancers – “Cancer A” and “Cancer B” (Figure 2). Participants were also shown and queried about graphs depicting the decrease in survival that occurs when a patient has other comorbid medical conditions in addition to their index cancer (Figure 3). Patients were asked basic questions about the graphs.

Open-ended questions and participant preferences regarding the manner of sharing prognostic information were analyzed using descriptive statistics. A Grounded Theory Approach was utilized to evaluate the data. Line-by-line review of the interview transcripts allowed for concepts to be tagged as they became apparent. A “content comparison” method was utilized to ensure that additional text assigned to the same tag accurately reflects the same concept as other bodies of text assigned the same code. Coding was performed until the point of “theoretical saturation”, or the point at which no new concepts emerged from analysis. This process allowed for the development of common themes.

Usefulness of Survival Statistics - 98% of patient participants (n=39) and 100% of physician participants described survival statistics as “Very Useful” or “Somewhat Useful.”

Prognostic Timelines - More than half (58%) of patients volunteered that they were seeking specific timelines related to their survival. 80% of physicians believed that patients want general trends rather than specific information regarding survival estimates. Four out of five of the physicians interviewed also stated that their decision to share survival estimates was prognosis-specific.

DISCUSSION

Physicians and patients report that survival statistics are useful to cancer patients. Our research has confirmed the previously identified large void in cancer communication, specifically the communication of prognostic information to cancer patients. In general, patients are not necessarily seeking successful prognosis from their physicians, but rather accurate prognosis successfully communicated.

Most of our patient participants reported using the Internet to gain information about their cancer although some were frustrated by the amount of data available – too little in certain areas and too much in other areas.

A recurring theme identified in our research was that patients want individualized cancer information that applies to them. A unique component of Prognostigram is the incorporation of comorbid health problems as well as other demographic information to create individualized survival curves. Despite the varied educational background of our patient participants, the overwhelming majority did well on numeracy assessments and appeared to easily grasp the survival information presented on Prognostigram. Participants’ responses encouraged us that the program content and display were well conceived and designed. The positive responses suggest a strong likelihood that patients would regularly use this tool in the future.

CONCLUSIONS

Computer technology has revolutionized the healthcare industry in many aspects. Simultaneously, improving patient education is seen as an effective and integral part of informed decision making. Many organizations are implementing PC- and Web-based performance measurement tools that allow patients and health-care providers to make more informed treatment decisions. Our results suggest that cancer patients are able and willing to use a web-based computer program, Prognostigram, which generates patient-specific survival information to fill a much-needed void in cancer communication between physicians and patients in the twenty-first century, and that will make the patients an active part in treatment decision making process.

REFERENCES


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