BRIEF REPORT

Using Survival Curve Comparisons to Inform Patient Decision Making

Can a Practice Exercise Improve Understanding?

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BACKGROUND: Patients often face medical decisions that involve outcomes that occur and change over time. Survival curves are a promising communication tool for patient decision support because they present information about the probability of an outcome over time in a simple graphic format. However, previous studies of survival curves did not measure comprehension, used face-to-face explanations, and focused on a VA population.

METHODS: In this study, 246 individuals awaiting jury duty at the Philadelphia County Courthouse were randomized to receive one of two questionnaires. The control group received a questionnaire describing two hypothetical treatments and a graph with two survival curves showing the outcomes of each treatment. The practice group received the same questionnaire preceded by a practice exercise asking questions about a graph containing a single curve. Subjects' ability to interpret survival from a curve and ability to calculate change in survival over time were measured.

RESULTS: Understanding of survival at a single point in time from a graph containing two survival curves was high overall, and was improved by the use of a single curve practice exercise. With a practice exercise, subjects were over 80% accurate in interpreting survival at a single point in time. Understanding of changes in survival over time was lower overall, and was not improved by the use of a practice exercise. With or without a practice exercise, subjects were only 55% accurate in calculating changes in survival.

CONCLUSION: The majority of the general public can interpret survival at a point in time from self-administered survival curves. This understanding is improved by a single curve practice exercise. However, a significant proportion of the general public cannot calculate change in survival over time. Further research is necessary to determine the effectiveness of survival curves in improving risk communication and patient decision making.

KEY WORDS: decision making; communication; patient education.

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Patients often face medical decisions involving outcomes that occur and change over time. Choosing an aggressive treatment over a less aggressive treatment may trade short-term increase in mortality for long-term increase in survival. In many situations, a patient must understand both the conditional probabilities of an outcome and how those probabilities change over time. Although it is well established that patients want to receive risk information, how best to present this complex information is not clear.¹ Extensive numerical information may overwhelm a patient's ability to process and understand it.^{2,3} However, presenting limited information, for example, survival probabilities at two or three time points, may bias decisions.^{4,5}

Survival curves may overcome these problems by presenting information about the probability of an outcome over time in a simple graphic format without extensive numeric data. Several studies have used survival curves to convey information about treatment choices to patients in face-to-face discussions.⁶⁻⁹ We have chosen to extend this research for several reasons. First, recent literature suggests patients may have difficulty understanding even simple probabilities.¹⁰ Prior studies did not measure subjects' ability to understand survival curve information. Second, because many decision aids being developed are self-administered, it is important to establish whether patients can understand self-administered survival curves.^{11,12} Finally, participants for prior studies came from Veterans' Administration (VA) clinics and may not be generalizable to other patient populations.

Using survival curves to aid decision making involves making comparisons between multiple curves. Although a survival curve is a relatively simple method of presenting complex information, a graph containing multiple survival curves may appear sufficiently complex to be overwhelming. The ability to perform many cognitive tasks is dependent on the development of cognitive rules or heuristics.^{3,13} For survival curve understanding, we hypothesized that these rules would be more easily developed on a relatively more simple graph containing a single curve, and, thus, presenting individuals with a graph containing a single curve prior

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to a graph containing multiple curves would improve understanding of the more complex, multiple curve graph.

The objectives of our study were to determine: 1) if the general public can understand survival curves when presented in a self-administered format; and 2) if understanding of a graph containing a two-curve comparison improves with a single curve practice exercise.

METHODS

Study Design

We randomized study subjects to receive one of two questionnaires. The control group received a questionnaire describing a hypothetical health condition with two possible treatments and a graph with two survival curves showing the outcomes of the treatments. The practice group received the same questionnaire preceded by a practice exercise asking questions about a graph containing a single curve. The study protocol was approved by the Human Subjects Committee of the Institutional Review Board at the University of Pennsylvania.

Study Setting and Participants

Prospective jurors awaiting jury selection at the Philadelphia County Courthouse were offered a candy bar to complete the study questionnaire. The two versions of the questionnaire were randomly ordered and distributed sequentially to volunteers. Based on our prior experience, we estimated that approximately 75% of prospective jurors volunteer to participate and over 90% of individuals who volunteer complete the questionnaires. In Philadelphia, individuals are randomly selected for jury duty from voter registration and drivers license records.

Intervention

Each participant received a self-administered questionnaire that included a brief explanation of survival curves and a graph containing two survival curves illustrating the outcomes of two hypothetical treatments and outcome measurement questions (see below) (Appendix A). The brief explanation read:

We will show you a graph of survival curves. A survival curve is a picture that shows how long people live after being diagnosed with a disease. You will notice there are different curves on the graph. Each curve shows how many people survive using the different treatments for a disease. Survival curves are shown to patients to help them understand their disease and to decide which treatment option is best for them.

A brief explanation of the graph was provided below the two curve graph:

The graph above shows how many people survive after either having surgery or being put on medication for an imaginary disease called Soap-operatitis. At year 0, 100 patients were started on Soap-operatitis medication and 100 patients had Soap-operatitis surgery. The curve

marked by the squares shows the patients who had surgery. The curve marked by the circles shows the patients who are on medication. The curves show how many people are alive every five years after having surgery or being put on medication.

For participants randomized to the practice arm, the questionnaire began with an additional page containing a practice exercise with a single survival curve for a hypothetical condition and several questions about the information contained in the curve (Appendix B). The correct answers to these questions were not provided.

Outcome Measures

The primary outcome measure was comprehension of the information contained in the figure containing two survival curves. Subjects both interpreted survival rates at a single time point (e.g., How many people having surgery are alive at year 20?) and change in survival over a specific time period (e.g., How many people having surgery died between year 20 and year 40?). Answers were considered correct only if they exactly matched the correct answer. Answers left blank were considered missing data, rather than incorrect answers.

Statistical Analysis

Baseline characteristics of the two groups were compared using χ^2 tests for categorical variables and t tests for continuous variables. For each subject, separate accuracy scores were generated for the ability to interpret the number alive at a given point (five questions) and the ability to calculate change in survival (two questions), by dividing the number of questions answered correctly by the total number of questions. Because these scores were not normally distributed, they were compared between groups using the Mann-Whitney U test. For the practice group, accuracy scores were generated for the single curve graph and compared within subject to their accuracy scores for the double curve graph using the Wilcoxon signed rank test.

RESULTS

Of the 246 subjects who completed the questionnaire, 120 received the practice intervention and 126 did not. The two groups were similar in age, gender, education, and ethnicity (Table 1).

Table 1. Subject Characteristics

	Practice Exercise	Control	P Value
Mean age ($\pm$ SD)	39.7(12.4)	39.9(12.7)	.88
Women, %	68	66	.82
Caucasian, %	55	47	.24
African American, %	40	44	.12
Mean years of education (range $\pm$ SD)	13.8(2.2)	14.0(2.2)	.78

Table 2. Comprehension of Double Curve Presentation

	Practice Exercise	Control	P Value
% Correctly identifying number of survivors at a single point	83	74	.03
% Correctly identifying change in number of survivors between two time points	55	55	.89

Understanding of survival at a single point in time from a graph containing two survival curves was high overall and improved with a single curve practice exercise (Table 2). With a practice exercise, subjects were over eighty percent accurate in interpreting survival at a single point in time. Furthermore, two thirds of subjects (66%) answered all of these questions correctly and an additional 14% answered all but one question correctly. Understanding of changes in survival over time was lower overall, and was not improved by the use of a practice exercise (Table 2). With or without a practice exercise, subjects were only 55% accurate in calculating change in survival. Furthermore, only 54% of subjects answered over half of these questions correctly, and 33% were unable to answer any question correctly. Mean accuracy scores did not differ significantly by gender, educational level, or ethnicity (all $P > .10$).

Among individuals receiving a single curve practice exercise, understanding of the graph containing a single curve was greater than understanding of the graph containing two curves. The great majority of errors in interpreting survival or calculating change in survival were large in magnitude. For example, accuracy in interpreting the number of people alive at a point in time declined from 92% in the single curve graph to 83% in the double curve graph ($P = .006$), and accuracy in calculating change in survival over time declined from 67% to 55% ($P = .04$).

DISCUSSION

Our results suggest that the majority of the general public can understand survival at a point in time from a graph comparing two survival curves and that this understanding is improved by a single curve practice exercise. However, almost half of our subjects could not calculate a change in survival over time from a survival curve—a task that requires subjects to correctly estimate the number of people surviving at two time points and to accurately subtract those two numbers.

Prior studies have used survival curves to demonstrate that patients focus on different portions of survival curves than physicians, that order of presentation affects treatment preferences, that length of the explanation affects treatment preferences and that patients are willing to trade a short term increase in mortality for long term increase in survival.⁵⁻⁸ To our knowledge, our study is the first to demonstrate that the general public can calculate survival from a survival curve

even without a face-to-face explanation. Importantly, however, our study raises significant concerns about the ability of the general public to calculate differences in survival from a survival curve. Such comparisons may be an important component of the cognitive tasks necessary for patients to use survival curve information to aid their decision making.

Our study has several limitations. Although the juror pool is highly representative of the Philadelphia population, it is less representative of other segments of the U.S. population. Second, we compared only two formats of our questionnaire. The format of each part of the questionnaire may affect the results. Our results are not necessarily generalizable to other formats. Third, because the instructions on the questionnaire were written at a ninth-grade reading level and in relatively small font, it is possible that they were not understood by some participants.

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APPENDIX A

Double Curve Graph

The graph above shows how many people survive after either having surgery or being put on medication for an imaginary disease called Soap-operatitis. At year 0, 100 patients were started on Soap-operatitis medication and 100 patients had Soap-operatitis surgery. The curve marked by the squares shows the patients who had surgery. The curve marked by the circles shows the patients who are on medication. The graphs show how many people are alive every five years after having surgery or being put on medication.

1. How many people are alive at year 0 who are on medication? _____
2. How many people are alive at year 0 who have surgery? _____
3. How many people are alive at year 15 after receiving medication? _____
4. How many people are alive at year 20 after having surgery? _____
5. How many people are alive at year 25 after having surgery? _____
6. How many people on medication died between years 5 and 15? _____
7. How many people died after having surgery between years 20 and 25? _____
8. Which treatment would you choose? _____

APPENDIX B

Single Curve Practice Exercise

The above graph shows the number of people who survive after having surgery for a disease called Chocalitis. It begins with 100 patients having surgery at year 0. The graph shows how many people are alive every five years after having surgery. For example, twenty years after surgery, 54 people are still alive. Please answer the following questions using the above graph.

1. How many people are alive at year 0? _____
2. How many people are alive at year 25? _____
3. How many people died between year 0 and year 30? _____
4. How many people are alive at year 50? _____
5. Did more people die between years 0 and 5 or between years 10 and 15? _____