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Optimising methods for communicating survival data to patients undergoing cancer surgery ☆

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ABSTRACT

Background: Patients undergoing cancer surgery require outcome data to inform decisions, but communication of numerical risk is difficult. This study assessed patient understanding of survival data presented in different formats.

Methods: Semi-structured interviews in which patients interpreted four presentation formats of survival data (three graphical and one narrative) were audio-recorded. The interviewer and a blinded observer (listening to the audio-recordings) scored patients' understanding of each format. Logistic regression examined associations between understanding and clinical and socio-demographic details.

Results: Seventy participants with colorectal cancer were interviewed and 67 [95.7%, 95% confidence intervals (CIs) 90.9–100%] correctly interpreted a simplified Kaplan–Meier survival curve. A high proportion accurately understood data presented as a bar chart or pictograph (94.3%, 95% CIs 88.7–99.9% and 92.9%, 95% CIs 86.7–99.0% respectively). Standard narrative alone was least well understood ($n = 53$, 75.7%, 95% CIs 65.4–86.0%). Multivariable analyses demonstrated that older and female patients had poorer overall understanding (OR 0.93 per year, 95% CIs 0.87–0.98, $p = 0.01$ and OR 0.24, 95% CIs 0.07–0.86, $p = 0.03$).

Conclusion: Patient understanding of survival data was higher when presented with graphs compared to narrative alone. Further work examining understanding in the clinical context and before surgery is recommended before this can be used routinely.

1. Introduction

Informing patients of the potential advantages of cancer surgery primarily includes communication of expected survival benefits synthesised from available evidence. It is necessary to effectively explain operative risks and to describe the longer term consequences of surgery on patient's health. In most healthcare settings this is the responsibility of the operating surgeon. Ensuring that information is understandable and relevant will also meet patients' information needs and the standards required for informed consent for surgery.[1–3]

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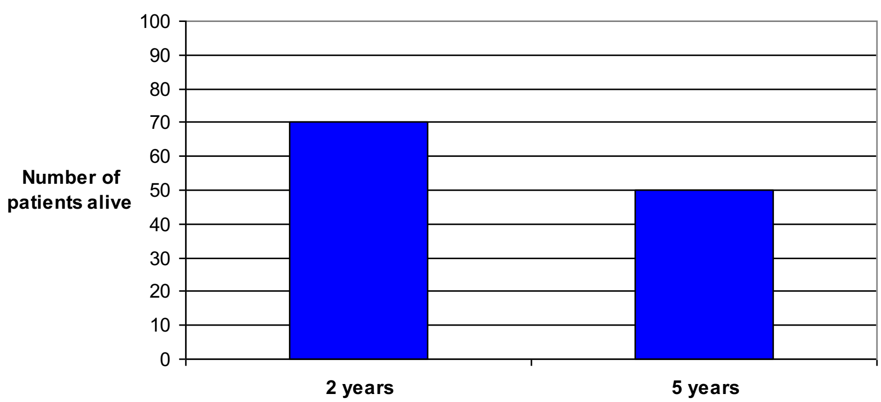
Communicating survival information effectively is complex because of the sensitive nature of the information and the potential problems with misunderstanding numerical concepts. Recent work has shown that after cancer surgery patients prefer surgeons to initiate these discussions and that most patients want to discuss this type of sensitive data.[4–7] Options to improve patient understanding of survival data are to supplement traditional narrative consultations with graphs in a simple clear format or to use pictographs illustrating proportions of alive patients.[5,8] The aim of this study was to examine patient understanding of different graphical presentation types of survival data or information expressed as narrative alone and to investigate whether understanding was influenced by clinical and socio-demographic variables.

2. Materials and methods

Patients were identified from the colorectal multi-disciplinary cancer team records at University Hospitals Bristol NHS Foundation Trust. Eligible for the study were those with carcinoma of the colon, rectum or anus that had completed, were undergoing or awaiting potentially curative treatment, including

Scenario A: A 60 year old man has bowel cancer, and is discussing the operation with the surgeon.

The topic of survival is discussed. To help explain this, the doctor shows the patient this diagram.

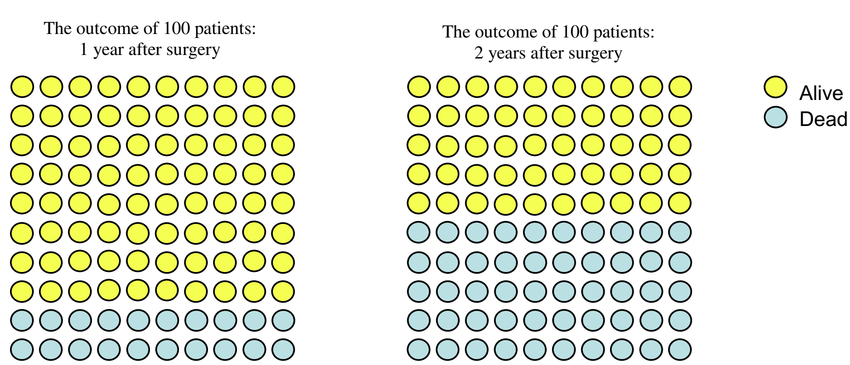


Question 1. How many patients are alive after 2 years? (answer 70)

Question 2. How many patients are alive after 5 years? (answer 50)

Scenario B: A 50 year old man has cancer of the gullet and is discussing the operation with the surgeon.

The topic of survival is discussed. To help explain this, the doctor shows the patient a diagram.



Question 1. How many patients are alive after 1 year? (answer 80)

Question 2. How many patients are dead after 2 years? (answer 50)

Fig. 1 – Scenarios A and B and survival data presented as a bar chart (A) or a pictograph (B) with the questions asked of participants to assess understanding.

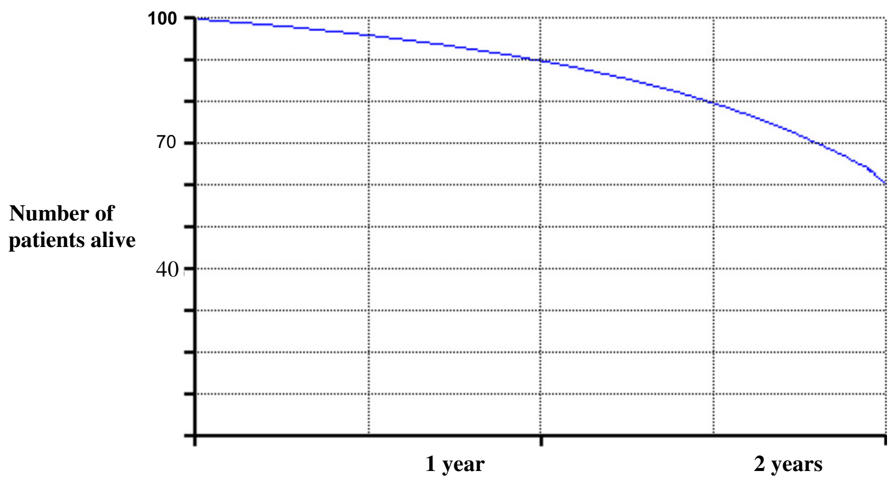
surgery, surgery and adjuvant chemotherapy or pre-operative radiotherapy. Patients were excluded if there was evidence of concurrent malignancy or if they could not speak and understand English. Ethical approval was granted by the North Somerset and South Bristol Research Ethics Committee (Project 07/H0106/185). Written informed consent was obtained from each participant.

Patients were visited at home or in hospital and underwent audio-recorded semi-structured interviews (performed by CRD). Four hypothetical surgical scenarios (A–D), involving treatments with differing survival outcomes, were described sequentially (Figs. 1 and 2). Each scenario presented data in a different format. Scenarios A–C used graphical methods (A, Bar chart; B, Pictograph; C, Simplified Kaplan–Meier survival curve). Scenario D consisted of a textual description of the survival data. Each presented survival information at two time points.

A standardised description of each graphical format was delivered by a single researcher (CRD) and the direction of the axes in Scenarios A and C were explained (i.e. a high score on the vertical axis represents more patients alive, whilst the horizontal axis shows time in months since surgery). For Scenario B, a standardised description of the pictograph was given (i.e. a yellow circle represents a patient that is alive, a blue circle a patient that has died). If patients asked for this information to be repeated or clarified, the standardised

Scenario C: An 80 year old man has colorectal cancer, and is discussing the operation with the surgeon.

The topic of survival is discussed. To help explain this, the doctor shows the patient this diagram



Question 1. After 1 year how many patients are alive? (answer 90)

Question 2. After 2 years how many patients are alive? (answer 60)

D: Narrative alone: An 80 year old man has bowel cancer, and is discussing the operation with the surgeon. The surgeon tells the man that after having the operation:

"He has a 60% chance of being alive in 2 years"

Question 1. If 100 patients had the same condition as him, 60 patients will be alive in two years time, is this True or False? (answer True)

Question 2. This man has a 40% chance of dying during the next 2 years, True or false (answer True).

Fig. 2 – Scenarios C and D and survival data presented as a simplified Kaplan–Meier chart (C) or narrative alone (D) with the questions asked of participants to assess understanding.

description was delivered a second time. No further explanation was provided.

Two questions were asked individually to each patient after each scenario was described to assess understanding of the survival data (Figs. 1 and 2). Accurate understanding was defined if participants correctly answered both questions in a given scenario. If participants' responses were uncertain or unclear, the interviewer asked for further explanation and the final correct or incorrect assessment of patient understanding of the graphs was interpreted within this context. To examine observer reliability, a subset of interviews ($n = 39$, 56%) were selected from an anonymous database by a blinded researcher (A.G.K.M.). These interviews were independently scored by a blinded second assessor (A.B.) who had no knowledge of the background to the research or the results of the initial interpretations.

Clinical and socio-demographic patient variables including age, sex, educational level, social class, American Society of Anesthesiologists (ASA) grade,[9] tumor site and cancer stage[10] were recorded. Educational level was defined as up to basic education (to the age of 16 or completion of the UK General Certificate of Secondary Education or equivalent) or further education (all subsequent education or qualifications). Social class was defined according to the UK Registrar-Generals social class,[11] and classified into manual and non-manual.

Table 1 – Socio-demographic and clinical data of study participants.

	Number ($n = 70$)
Male (%)	42 (60)
Mean age in years (SD; range)	66 (13.6; 29–88)
Educational level[a] (%)	
Up to basic education	41 (60.3)
Further education	27 (39.7)
Social class[b] (%)	
Non-manual	44 (62.9)
Manual	26 (37.1)
ASA grade (%)	
1	43 (61.4)
2	21 (30.0)
3	6 (8.6)
Tumor site (%)	
Colon	43 (61.4)
Rectum	25 (35.7)
Anus	2 (2.9)
Cancer stage[c] (%)	
I	12 (17.1)
II	22 (31.4)
III	36 (51.4)
Treatment (%)	
Surgery alone	41 (58.6)
Surgery and adjuvant chemotherapy	22 (31.4)
Neoadjuvant radiotherapy and surgery	5 (7.1)
Primary chemoradiotherapy	2 (2.9)
Current treatment phase (%)	
Pre-treatment	24 (34.3)
Undergoing treatment	7 (10.0)
Post-treatment	39 (55.7)

SD, standard deviation and ASA, American Society of Anesthesiologists grade.
[a] Basic education is up to the age of 16 or completing a General Certificate of Secondary Education (GCSE) or equivalent. Further education is all other qualifications.
[b] UK Registrar-General's Social Class.[11] (Non-manual = I to IIIN; manual = IIIM to IV).
[c] American Joint Committee on Cancer Staging system grouping.[10]

Table 2 – Patients' understanding of survival data according to presentation type used in the four scenarios ($n = 70$).

Scenario and graphical format	Number understanding (%)	95% CI (%)
A: Bar chart	66 (94.3)	88.7–99.9
B: Pictograph	65 (92.9)	86.7–99.0
C: Simplified Kaplan–Meier survival curve	67 (95.7)	90.9–100
D: Standard narrative alone	53 (75.7)	65.4–86.0
All four scenarios	49 (70.0)	59.0–81.0

95% CI, 95% Confidence intervals.

2.1. *Sample size calculation and statistical analyses*

Previous evidence of patient understanding[12–19] suggested that around 80% of patients would be able to understand any single graphical format. A sample size of 80 participants would provide a margin of error of 8% around an estimate of 80%, producing a 95% confidence interval of 72–88%. Logistic regression was performed to examine associations between clinical and socio-demographic data and patient understanding, undertaking univariable and then multivariable analyses (adjusting for all listed variables). Data were analysed using STATA statistical software version 10.1 (StataCorp, College Station, TX).[20]

3. Results

Seventy patients participated (42 male, 60%) of which the majority ($n = 66$, 94%) were interviewed in their homes. Socio-demographic and clinical data are presented (Table 1). Most participants correctly interpreted each presentation style, with understanding ranging from 96% ($n = 67$) for the simplified Kaplan–Meier curve to 76% ($n = 53$) for the narrative alone (Table 2). Indeed, examination of the 95% confidence intervals suggests that understanding of the narrative alone was dramatically poorer than the other graphically supplemented formats. All four scenarios were correctly understood by 49 patients (70%). This percentage is primarily a reflection of poor understanding of the narrative format. The blinded observer categorised 32 (86%) of the interviews in the same way as the initial interviewer.

Univariable analyses demonstrated a consistent reduction in the odds of understanding with increasing age, for each graphical or non-graphical format. However, the 95% confidence intervals could not rule out no effect for any of the formats (Table 3). When all formats were considered together, that is, patients correctly interpreted all four formats, there was much stronger evidence of an association with age. For

Table 3 – Univariable analyses examining associations between clinical and socio-demographic variables and patient understanding of survival data.

Variables	Bar chart		Pictograph		Simplified Kaplan–Meier		Text alone		All formats	
	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*
Further education[a]	1.95 (0.19–19.7)	0.57	0.94 (0.15–6.0)	0.94	1.26 (0.1–14.7)	0.84	2.49 (0.71–8.65)	0.15	1.87 (0.62–5.65)	0.26
Increasing age	0.95 (0.88–1.04)	0.34	0.96 (0.88–1.04)	0.34	0.99 (0.91–1.0)	0.95	0.96 (0.92–1.0)	0.11	0.94 (0.89–0.98)	<0.01
Manual social class[b]	1.83 (0.18–18.56)	0.61	2.5 (0.26–23.7)	0.24	0.28 (0.24–3.23)	0.31	1.58 (0.48–5.12)	0.45	1.72 (0.57–5.21)	0.33
Female sex	2.07 (0.20–21.04)	0.53	1 (0.16–6.40)	1.0	1.35 (0.12–15.6)	0.81	0.26 (0.08–0.81)	0.02	0.27 (0.93–0.79)	0.02
ASA grade > 1	0.60 (0.08–4.60)	0.63	2.66 (0.28–25.2)	0.39	1.2 (0.11–14.70)	0.85	0.33 (0.10–1.0)	0.05	0.44 (0.16–1.25)	0.12
Cancer stage[c]										
I	1	0.9	1	0.85	1	0.73	1	0.78	1	
II	1.90 (0.11–33.5)		1.91 (0.11–33.54)		1.91 (0.11–33.54)		0.53 (0.09–3.18)		0.43 (0.74–2.5)	0.55
III	1.55 (0.13–18.7)		1 (0.09–10.63)		3.18 (0.18–55.19)		0.60 (0.11–3.27)		0.4 (0.75–2.12)	
Cancer site										
Colon	N/A		1	0.39	1	0.85	1	0.41	1	0.96
Rectum			2.67 (0.28–25.2)		1.27 (0.11–14.7)		0.63 (0.21–1.9)		1.02 (0.36–2.95)	

OR, odds ratio; 95% CI, 95% confidence intervals; ASA, American Society of Anesthesiologists grade; N/A, not applicable.
Patients with anal cancer ($n = 2$) were excluded from this analysis.
[a] Basic education is up to the age of 16 or completing a General Certificate of Secondary Education (GCSE) or equivalent. Further education is all other qualifications.
[b] UK Registrar-General's Social Class.[11] (Non-manual = I to IIIN; manual = IIIM to IV)
[c] American Joint Committee on Cancer Staging system grouping.[10]

Table 4 – Multi-variable analyses examining associations between clinical and socio-demographic variables and patient understanding of survival data.

Variables	Bar chart		Pictograph		Simplified Kaplan–Meier		Narrative alone		All formats	
	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*
Further education[a]	3.85 (0.27–55.75)	0.32	3.03 (0.29–31.66)	0.36	0.50 (0.01–18.11)	0.70	1.90 (0.39–9.27)	0.43	1.78 (0.39–8.20)	0.46
Increasing age	0.97 (0.88–1.01)	0.49	0.97 (0.89–1.05)	0.49	0.99 (0.89–1.10)	0.86	0.96 (0.91–1.02)	0.18	0.93 (0.87–0.98)	0.01
Manual social class[b]	4.16 (0.20–85.56)	0.36	2.16 (0.13–37.16)	0.60	0.10 (0–5.88)	0.27	1.64 (0.31–8.54)	0.56	1.11 (0.22–5.56)	0.90
Female sex	3.30 (0.24–45.82)	0.34	1.14 (0.15–8.85)	0.90	0.58 (0.03–10.19)	0.71	0.24 (0.06–0.94)	0.04	0.24 (0.07–0.86)	0.03
ASA grade > 1	0.77 (0.09–6.57)	0.81	4.94 (0.40–60.90)	0.21	1.87 (0.10–33.27)	0.67	0.31 (0.08–1.20)	0.09	0.56 (0.16–1.96)	0.37
Cancer stage[c]										
I	1	0.81	1	0.53	1	0.74	1	0.58	1	0.64
II	2.56 (0.13–50.74)		5.74 (0.21–159)		3.8 (0.09–156)		0.36 (0.04–2.95)		0.44 (0.06–3.46)	
III	2.08 (0.13–34.15)		1.54 (0.11–21.09)		2.9 (0.12–73.75)		0.75 (0.11–4.91)		0.42 (0.07–2.65)	
Cancer site										
Colon	N/A[d]		1	0.30	1	0.48	1	0.11	1	0.51
Rectum			4.25 (0.27–66.62)		3.66 (0.10–134)		0.28 (0.06–1.35)		0.60 (0.14–2.68)	

OR, odds ratio; 95% CIs, 95% confidence intervals; ASA, American Society of Anesthesiologists grade; N/A, Not Applicable

Patients with anal cancer ($n = 2$) were excluded from this analysis.

[a] Basic education is up to the age of 16 or completing a General Certificate of Secondary Education (GCSE) or equivalent. Further education is all other qualifications.

[b] UK Registrar-General's Social Class.[11] (Non-manual = I to IIIN; manual = IIIM to IV.)

[c] American Joint Committee on Cancer Staging system grouping.[10]

[d] Not included in analysis because all patients with colon cancer correctly interpreted the bar chart.

each unit increase in age the odds of understanding was reduced by 6%. This association was maintained after adjusting for the other clinical and socio-demographic variables (7% reduction in odds for each unit increase in age, 95% confidence interval 2–13% reduction, $p = 0.01$) (Table 4). There was also evidence to suggest that being female may reduce the odds of understanding narrative alone, reducing the odds by 74% ($p = 0.02$). Evidence of this effect remained after adjusting for the other clinical and socio-demographic variables ($p = 0.04$, Table 4). A similar effect was seen for correctly interpreting all four formats; however this is likely simply to reflect the poorer understanding of the narrative, since there was no evidence of an effect of gender for the other three formats. The magnitude and direction of associations with understanding for the other clinical and socio-demographic variables were inconsistent across the different graphical formats and demonstrated no evidence of any real associations in either the univariable or multivariable analyses.

4. Discussion

This study has demonstrated that most patients correctly understand prognostic data when presented graphically. The traditional narrative alone was least well understood, especially by women, although 61% of women and 86% of men accurately interpreted the written text. Multivariable analyses adjusting for potential confounding factors suggested that increasing age was associated with poorer understanding of all formats. It is recommended, based on these data, that graphical information is used to supplement conversations between surgeons and patients when communicating survival outcomes in surgery for cancer. It is also recommended that older patients may need additional help and time.

Previous studies have investigated patient understanding of several graphical formats, including bar charts,[14,15] line charts[12,13,19] and pictographs[15,17,18,21] within different populations and clinical settings. They have demonstrated similarly high levels of understanding.[15,16] Recommendations from this evidence were adopted into this study. For example, mortality curves were positively framed to present data in terms of survival rather than mortality.[13] Pictographs displaying data using different colours using on a horizontal format are better understood than vertically presented information[18] and percentages rather than fractions are easier to comprehend.[17] Understanding of pictographs is increased when two sets of data are shown rather than four.[21] As a result, the pictographs used in the study represented data at two points in time. These concepts were incorporated into this study to maximise patient understanding.

There were several limitations of this study. Interviews were performed in patients' homes at their convenience. This familiar environment may have increased the likelihood of patients' understanding compared to a hospital setting. However, it is possible that patients had less incentive to focus on understanding the graphs because scenarios were hypothetical. Patients may have previously engaged in discussions in clinic about their individual survival chances, and therefore be more comfortable discussing this topic. Whether this influenced the results of this study is unknown, although it uncommon in clinical practice to use graphs displaying graphical data. A further limitation of this study may arise from the standardised order that patients were shown the graphical formats. Patients' answers may improve through the task because they have learnt how to answer correctly from the proceeding questions, rather than having a greater understanding of the presentation methods.[12] Results from this study are in contrast to this view, as the least successfully interpreted method was presented last. A final limitation is the possibility that less literate or numerate patients may not have agreed to participate. However, the study sample is representative of patients with colorectal cancer in the UK population, due to the method of sequential recruitment from multi-disciplinary cancer team records. Furthermore, data on patient social class and education status were further dichotomised to allow investigation as a potential confounding factor.

It should also be noted that the sample size for this study was not calculated for regression analyses but to ensure a precise estimate of the percentage understanding each format. Therefore, there may be insufficient power to demonstrate some real associations. At the same time a large number of tests have been performed and so attention should be drawn to the confidence intervals presented rather than the p values alone.

In this study, patients accurately grasped the meaning of graphical information, suggesting that this format may be applicable to use in a surgical clinic. Patients could be shown graphs or pictographs to assist an explanation of the survival benefits of surgery.[16] This may be particularly helpful for less educated patients of lower socioeconomic standing, who have been shown to be less satisfied with current oncological consultations.[22] In addition to survival data, graphical formats could also be used to improve patient understanding of health-related quality of life data.[23] The use of visually representative survival data may therefore assist in the process of pre-operative consent, shared decision-making scenarios and entry into surgical randomised controlled trials. Further work might include trialling graphical formats in real time clinical settings and assessing patient understanding and recall after such consultations. These formats could then be compared with those using traditional narrative resources. Future studies may also allow individualised survival data to be viewed by patients, according to a range of treatment options and clinical information, using software that allows tailor-made data to be entered and viewed using a dynamic and evolving format. Given the importance of effective communication between clinicians and patients with cancer[24] and the support of communication skills training within the literature[25–27] perhaps evidence-based graphical formats such as these may be incorporated into training, research and clinical situations in the future.

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Conflict of interest statement

None declared.

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