

Brief Report

A Video Decision Aid Improves Informed Decision Making in Patients With Advanced Cancer Considering Palliative Radiation Therapy



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Abstract

Context. Advanced cancer patients have unrecognized gaps in their understanding about palliative radiation therapy (PRT).

Objectives. To build a video decision aid for hospitalized patients with advanced cancer referred for PRT and prospectively test its efficacy in reducing decisional uncertainty, improving knowledge, increasing treatment readiness and readiness for palliative care consultation, and its acceptability among patients.

Methods. Forty patients with advanced cancer hospitalized at Memorial Sloan Kettering Cancer Center watched a video decision aid about PRT and palliative care. Patients' conceptual and logistical knowledge of PRT, decisional uncertainty, treatment readiness, and readiness for palliative care consultation were assessed before and after watching the video with a six-item knowledge survey, the decisional uncertainty subscale of the Decisional Conflict Scale, and Likert instruments to assess readiness to accept radiation treatment and/or palliative care consultation, respectively. A postvideo survey assessed the video's acceptability among patients.

Results. After watching the video, decisional uncertainty was reduced (28.3 vs. 21.7; $P = 0.02$), knowledge of PRT improved (60.4 vs. 88.3; $P < 0.001$), and PRT readiness increased (2.0 vs. 1.3; $P = 0.04$). Readiness for palliative care consultation was unchanged ($P = 0.58$). Patients felt very comfortable (70%) watching the video and would highly recommend it (75%) to others.

Conclusion. Among hospitalized patients with advanced cancer, a video decision aid reduced decisional uncertainty, improved knowledge of PRT, increased readiness for PRT, and was well received by patient viewers. *J Pain Symptom Manage* 2019;58:1048–1055. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative radiation therapy, advanced cancer, video tool, decision aid

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Accepted for publication: August 9, 2019.

Introduction

Palliative radiation therapy (PRT) is a cancer-directed therapy delivered by radiation oncologists for patients with advanced or incurable cancer. Its purpose is to ameliorate or prevent pain and other symptoms from tumor masses pressing or invading into organs, nerves, and tissues. PRT can successfully alleviate cancer-related symptoms and improve quality of life. On the other hand, it is often associated with temporary but significant adverse effects that precede clinical benefits. It generally does not extend survival. Moreover, PRT can involve lengthy hospital stays for patients with significant functional impairment or inability to travel to/from a radiation facility.¹ In many cases, benefits and quality of life improvements may not manifest until weeks after treatment completion.² Thus, PRT can result in both benefits and harms, and treatment decision making can be complex for patients weighing risks and trade-offs.

The decision to undergo PRT is often made quickly and sometimes without sufficient information to make a fully informed choice, especially during hospitalization. This is due to the shortened interval between an inpatient radiation oncology consultation and actual treatment. Also, the often abrupt nature by which metastatic lesions are found prompting an urgent palliative radiation referral can leave patients little time to process implications of the results. Hence, patients receiving PRT may hold inaccurate expectations of treatment, believing it to be potentially curative when it is in fact not.³ Clinical decision aids may help, yet few have been created for PRT.

A comprehensive review of patient decision aids in radiation oncology describes tools providing written information (e.g., pamphlets, decision boards, and workbooks), audiotaped consultations, online materials, and videos. However, the studied populations included primarily breast and prostate cancer, and the decisions studied were related to curative treatment options in early stage disease.⁴ A decision board for ambulatory care patients undergoing PRT for bone metastases demonstrated that most patients preferred a longer course of radiation and expressed positive opinions about being involved in the decision-making process.⁵ Ultimately, the choice of decision aid format depends on the decision in question, the type of information being provided, and the patient population being studied.⁶ Video aids can provide visual representations of radiation therapy, often a challenging concept to grasp given its inherent abstractness. Videos allow the possibility of explaining a concept like PRT, which can often be difficult to fully describe using text or static images.

No decision aid currently exists for hospitalized patients considering PRT. Yet, PRT is common, which

comprises up to 35%–50% of patients in a radiation oncology practice, and patients may spend significant portions of their remaining lives undergoing PRT.^{7–10} We chose a video format for our decision aid because the information being presented was highly visual in nature and benefited from animated graphics and footage of radiation treatment processes that could not have been equivalently portrayed through other formats.

Our primary objective was to test the ability of a newly created video decision aid for hospitalized patients considering PRT to reduce decisional uncertainty. Our secondary objectives were to assess the video's ability to improve patients' knowledge of PRT and palliative care, increase patients' readiness to accept PRT, readiness to see a palliative care specialist, and to ascertain its acceptability among patients.

Methods

Design and Setting

Patients at the Memorial Sloan Kettering Cancer Center with advanced cancer who were referred for PRT consultation during a hospitalization between August 2012 and April 2013 were eligible for recruitment onto an Institutional Review Board-approved, prospective, single-arm cohort study (Memorial Sloan Kettering Cancer Center Institutional Review Board #12–172; NCT01667965) in which patients were surveyed before and after viewing a video decision aid about PRT.

Intervention

The study intervention was a video tool (accessible at <https://www.mskcc.org/videos/palliative-radiation-therapy>) that explained PRT and introduced key concepts of palliative care using patient actors. The video was built according to International Patient Decision Aids Standards criteria to ensure the information conveyed was balanced, unbiased, provided sufficient detail for patients to make their decisions, and used plain language and visual representations to improve patient understanding.^{11,12} It contained four segments explaining: 1) the process of radiation simulation including making a face mask; 2) what to expect at the time of treatment; 3) commonly encountered treatment PRT side effects; and 4) the purpose of palliative care. Content related to the palliative care specialty included a two-minute segment narrated by a palliative care physician (R. T.) describing palliative care's role in addressing physical and nonphysical symptoms, the possibility of its concurrent delivery with ongoing cancer treatments to add an extra layer of support, and its distinctness from hospice care. The video storyboard was approved by the director

of patient and caregiver engagement (C. B. W.), a cancer communication expert (T. T. L.), a palliative care specialist (R. T.), and two radiation oncologists (K. V. D. and B. M.).

Participants

Patients with metastatic cancer who were candidates for PRT, older than 18 years, English speaking, and had capacity to provide informed consent and answer questions were eligible. Those with malignant spinal cord compression were ineligible because enrollment procedures could have delayed urgent treatment.

Assessments

On enrollment, patients answered baseline paper-based assessments about decisional uncertainty, PRT knowledge, and their readiness to accept PRT and/or a consultation with a palliative care specialist. Patients then watched the video decision aid about PRT in their hospital room on an iPad (Apple, Cupertino, CA) and answered the same questions within 24 hours postviewing, also in their hospital room. We chose the 24-hour period to minimize the possibility that a patient may have been discharged before completing the study. Patients were given one additional assessment postviewing to rate the video's acceptability. The study process is shown in [Fig. 1](#). All assessments were captured with pen and paper. The assessment items, scoring, and time points of administration are further detailed in the [Supplementary Index](#).

The primary outcome, uncertainty regarding the decision to undergo PRT, was assessed by the three-item decisional uncertainty subscale of the validated Decisional Conflict Scale developed at the Ottawa Hospital Research Institute and rated on a five-point scale from zero indicating *strongly agree* meaning feeling certain about decision making to four indicating *strongly disagree* meaning feeling least certain.^{13,14} Basic knowledge of PRT and palliative care was assessed using a six-item questionnaire (one multiple-choice questions and five true/false/unsure questions). Questions were created by the investigators based on a study of video education used in advance care planning, given the absence of a validated tool in radiation.¹⁵ Readiness to accept PRT and to see a palliative care specialist were assessed separately by investigator-created Likert instruments with an ordinal one (most ready) to 10 (not ready at all) scale, with a text box allowing explanation if greater than five. Acceptability of the video aid was rated via a five-item tool with a four-point scale from zero indicating very helpful to four indicating not helpful and included perceptions regarding usefulness, comfort of seeing information in the video-based format, and likelihood of recommending it to

others facing a similar treatment choice. The knowledge, readiness, and impressions scales have not been previously validated and were developed for use in this study because of the lack of available tools relevant to this particular patient population and study question.

Follow-Up

Patients were followed for four months after study enrollment. Patient characteristics, occurrence of palliative care consultations, and death were ascertained by chart reviews.

Case Study

One case example of the video's impact on a patient was highlighted and described separately as a case study. The case was included because it provides a more detailed qualitative description of how viewing the video specifically affected a patient's outcome by stimulating discussion of expectations of PRT and trade-offs that the particular patient was willing to make to undergo PRT in light of these expectations.

Statistical Analysis

Assuming a desired power of 80%, Type I error of 5%, and a lowest expected Decisional Conflict Scale effect size of 0.4, we calculated a target sample size of 40 patients. Patient characteristics were examined using descriptive statistics. Paired t-tests and Wilcoxon signed rank tests compared prevideo and postvideo assessments. A planned subgroup analysis was conducted between patients who had prior RT vs. patients who did not. Analyses were performed using SPSS Statistics 20 (IBM, Chicago, IL).

Results

Of 45 patients ($n = 56$ screened) who consented, 40 completed all questionnaires and were included in the analysis. Three patients did not complete timely baseline questionnaires and were excluded. One patient developed delirium, precluding further participation. One patient withdrew from the study after hearing the word palliative and did not wish to hear more. Patient enrollment is described in [Fig. 2](#). Patient and treatment characteristics are described in [Table 1](#). Nineteen patients (48%) had prior radiation therapy. Most patients received a radiation dose of 30 Gy in 10 once-daily treatments, one of the most commonly used palliative radiation regimen by radiation oncologists.

Assessment scores are detailed in [Table 2](#). The mean baseline decisional uncertainty score was 28.3, which declined to 21.7 ($P = 0.02$) in the postvideo setting, meaning patients were more certain about their

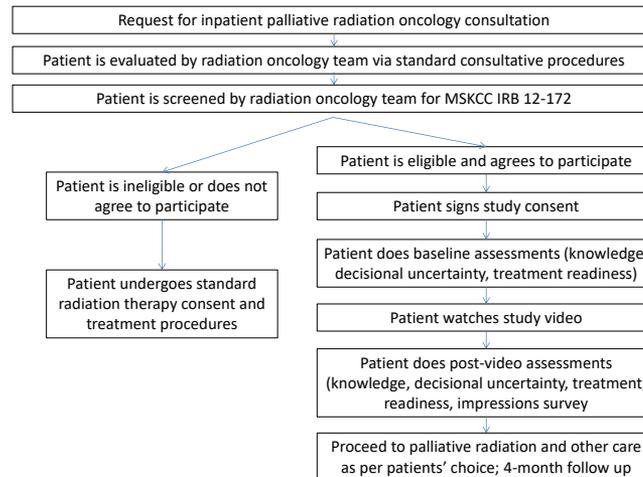


Fig. 1. Study flowchart. MSKCC = Memorial Sloan Kettering Cancer Center; IRB = Institutional Review Board.

decision. The effect was greater among patients with no prior radiation therapy, in whom the mean baseline score of 30.2 declined to 21.4 ($P = 0.02$). No significant change in decisional uncertainty was seen among patients with prior RT ($P = 0.28$).

Patients demonstrated improved knowledge of PRT and palliative care after seeing the video. Mean knowledge increased from 60.4 to 88.3 ($P < 0.001$). In the subgroup analyses of patients with no prior RT and those with prior RT, score increases were also seen after viewing the video. Scores of patients with no prior RT increased from 61.1 to 89.7 ($P < 0.001$) after the video, and those of patients with prior RT increased from 59.6 to 86.8 ($P < 0.001$) after the video. Readiness to accept PRT improved from a mean of 2.0 to 1.3 ($P = 0.04$), meaning patients felt more ready for PRT after the video. Postvideo, no patient chose a

number greater than five. Among patients with no prior radiation, a trend was observed in the direction of feeling more ready for PRT (baseline mean score 2.0 vs. postvideo mean score 1.3; $P = 0.06$). No difference was seen among those with prior RT. In terms of readiness to see a palliative care specialist, the mean score was 3.5 (baseline) and 3.1 (postvideo) ($P = 0.58$). No significant differences were seen in the subgroups of patients who had or did not have prior radiation. Several free-texted reasons cited by patients for their lack of readiness to see a palliative care specialist included needing approval from their primary oncologist beforehand; being satisfied with their current level of care; feeling the video supplied enough information to decide that seeing a palliative care specialist was not necessary at that time; and being potentially interested in a consultation in the

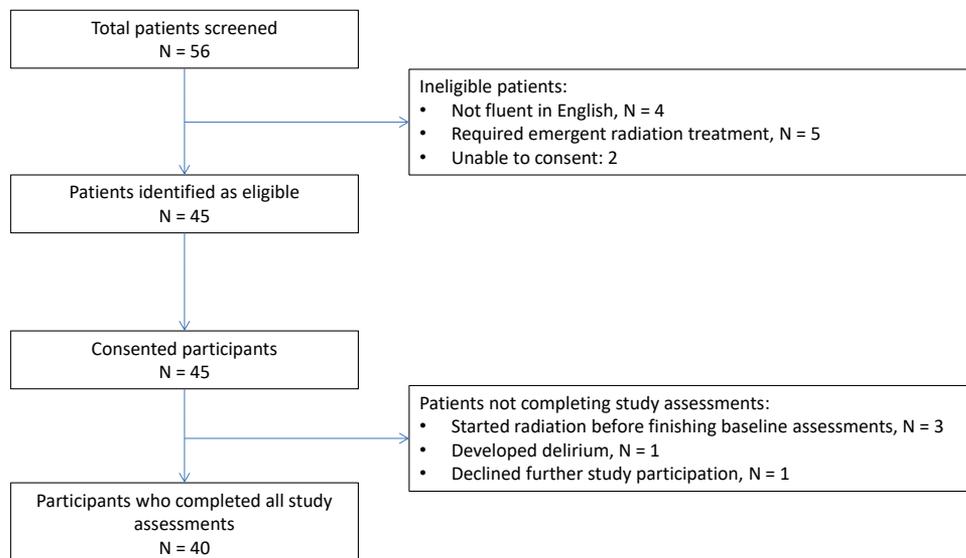


Fig. 2. Recruitment and enrollment.

Table 1
Baseline Patient Characteristics

Variable	N	Proportion (%)
Median age (yrs)	59 (range 31–76)	
Male sex	17	43
Race		
White	30	75
Black	6	15
Hispanic	3	8
Asian	1	2
Primary cancer diagnosis		
Prostate	9	23
Lung	7	18
Ovarian	6	15
Breast	5	13
Gastrointestinal/ hepatobiliary	3	8
Renal/adrenal	2	5
Lymphoma	2	5
Central nervous system	1	2
Uterine	1	2
Thyroid	1	2
Bladder	1	2
Melanoma	1	2
Sarcoma	1	2
Extent of prior cancer treatment		
Patients with at least one prior course of radiation	19	48
Average number of prior lines of chemotherapy per patient	2 (range 0–7)	
Prior palliative care		
Patients with prior palliative care consultations	2	5
Reasons for radiation oncology consultation		
Pain	24	60
Neurologic symptoms (e.g. weakness, numbness)	11	28
Bleeding (e.g., vaginal, gastrointestinal)	4	10
Obstruction (e.g., of blood/lymph flow by mass compression)	1	2
Treatment site		
Spine	15	38
Bone	12	30
Soft tissue	10	25
Brain	3	8

future. Overall, patients indicated relatively less readiness to see a palliative care specialist in comparison to readiness to undergo PRT.

The video was well received by patients (Table 3). Overall, 55% of patients felt that it was very helpful, 75% felt very comfortable watching it, and 70% would highly recommend it to others considering similar treatment decisions. In addition, patients liked the video’s step-by-step structure, felt that information was clearly and noncondescendingly presented, it could be viewed in a private setting, and the description of palliative treatment was not overwhelming. Two patients did not like the emphasis on palliative treatment citing that it took away hope. No difference

Table 2
Mean Baseline and Postvideo Scores of Decisional Uncertainty, Knowledge, and Treatment Readiness Assessments

Item	Entire Cohort (n = 40)			Subgroup With No Prior Radiation (n = 21)			Subgroup With Prior Radiation (n = 19)		
	Baseline (Range)	Postvideo (Range)	P	Baseline (Range)	Postvideo (Range)	P	Baseline (Range)	Postvideo (Range)	P
Decisional uncertainty	28.3 (0–66.67)	21.7 (0–66.67)	0.02	30.2 (0–66.67)	21.4 (0–58.33)	0.02	26.3 (0–66.67)	21.9 (0–66.67)	0.28
Knowledge	60.4 (16.67–100)	88.3 (33.33–100)	<0.001	61.1 (16.67–100)	89.7 (66.67–100)	<0.001	59.6 (16.67–100)	86.8 (33.33–100)	<0.001
Readiness to consent for palliative radiation	2.0 (1–10)	1.3 (1–5)	0.04	2.0 (1–7)	1.3 (1–3)	0.06	2.0 (1–10)	1.4 (1–5)	0.31
Readiness to consult with palliative care specialist	3.5 (1–10)	3.1 (1–10)	0.58	3.8 (1–10)	3.6 (1–10)	0.82	3.2 (1–10)	2.5 (1–10)	0.35

Table 3
Impressions Survey of Acceptability

Item	Entire Cohort	Subgroup With No Prior RT	Subgroup With Prior RT	P
Impression—total score Mean (range)	11.67 (0–44.44)	8.99 (0–33.33)	14.61 (0–44.44)	0.093
Impression—tally (frequency) by question item	Yes, very, n (%)	Yes, somewhat, n (%)	A little, n (%)	Not at all, n (%)
Was the video helpful?	22 (55)	17 (43)	1 (2)	0
Did you feel comfortable watching the video?	30 (75)	10 (25)	0	0
Would you recommend the video to others?	28 (70)	11 (28)	1 (2)	0

was observed between the subgroup of patients who had prior RT vs. that of those who did not.

Patients were followed for 3.9 (median) months (range 0.1–7.0). Five patients (13%) did not complete their prescribed radiation course because of clinical deterioration or a change in their choice. The remainder of patients underwent the prescribed course of PRT. Ten patients (25%) ultimately underwent consultation with a palliative care specialist within one month of study enrollment. Of these, nine patients indicated the highest level of readiness, a score of 1, on their postvideo assessment. At study completion, 25 (62.5%) patients had died.

In one notable case of a patient with leptomeningeal carcinomatosis for whom whole brain radiation therapy was being considered, the video prompted a discussion of the bigger picture and is presented in [Table 4](#) to illustrate the video's impact on decision making and end-of-life planning.

Discussion

The primary goal of the study was to determine whether a video intervention could improve hospitalized advanced-stage cancer patients' understanding of the process and implications of PRT and alleviate uncertainty around decision making. Our study is the first to use an educational video decision aid that serves as an adjunct to standard radiation oncology consultation for a treatment that may improve quality of life but will likely not extend

survival, may be burdensome, and may harbor potential adverse side effects. A video format was chosen based on previous research demonstrating that video is superior to standard verbal and text-based methods in improving understanding of complex health information.^{16–19}

We saw an improvement in patients' decisional uncertainty after watching the video. The magnitude of the effect was greater in patients who had no prior experiences with radiation therapy. One potential explanation for this finding is that patients who were wholly unfamiliar with radiation treatment were less certain about how a course of PRT might impact their lives. For patients with prior RT, adding more detailed information about the specific differences between curative radiation and PRT may further help in reducing decisional uncertainty and should be studied in future trials.

Patients had improved knowledge of PRT after watching the video. At baseline, we discovered that patients had an incomplete understanding of the risks, benefits, and expected outcomes of radiation treatment even after speaking with a radiation oncologist. This knowledge gap may hinder patients' abilities to align decisions about therapy with overall treatment goals. A similar magnitude of improvement was also seen in the subgroup of patients who had prior RT, suggesting that gaps in knowledge about the palliative nature of treatment are present despite patients' familiarity with RT. Our results are in line with a Cochrane review of decision aids, which found they facilitated informed decision making by improving patients' knowledge of options, conferring more

Table 4
Case Presentation

A patient was diagnosed with leptomeningeal carcinomatosis from ovarian cancer and was contemplating palliative whole brain radiation therapy. On viewing the video, the patient wished to understand differences between palliative and curative treatments and prognosis. After this discussion, the patient opted to try radiation but had significant difficulty tolerating the face mask because of claustrophobia and pain. The patient decided to forego further attempts at whole brain radiation citing that the hassle, discomfort, and life-altering side effects were not worth the potential benefit of slightly increased longevity but no chance of cure. The patient accepted the referral to palliative care and was seen five days after hospital discharge. At that time, the patient told the palliative care specialist she had decided to stop all cancer-directed therapies. Goals of care were discussed; do-not-resuscitate orders were signed, a health care proxy was chosen (previously none was listed), and the patient initiated home hospice. The patient noted a wish for more openness about the goals of treatment from the beginning of the diagnosis. The patient died six weeks later without any subsequent emergency room visits or hospitalizations.

accurate expectations regarding side effects and benefits, and helping them reach choices that were more consistent with their informed values.¹⁶ van Oorschot et al.²⁰ in fact posited that certain conditions are important to take into account when considering PRT aside from the simple probability of treatment success, for example, the practical requirements and impact of unwanted side effects.

Patients had a small improvement in readiness to accept PRT but not in their readiness to see a palliative care physician. All study patients had a high symptom burden at the time of study enrollment, which would have warranted a palliative care referral according to National Comprehensive Cancer Network guidelines.²¹ However, despite the information presented on the supportive role of palliative care, individuals remained relatively hesitant to accept this initial consultation perhaps because of misperceptions that accepting palliative care means giving up hope, a fear that two patients expressed in this study. Previous interventions have also struggled to break down the stigma toward palliative care among cancer patients.^{22,23} Several studies have shown that a name change to supportive oncology led to a higher number of earlier referrals.^{24,25} Further work is needed to better clarify whether patients' reluctance stems from persistent misconceptions of palliative care's role or from other causes. Nonetheless, we found the video became a useful conversation starter about palliative care, prompting many questions about the scope and breadth of services offered within palliative and supportive oncology and also about goals of care, as illustrated by the case presentation, and as such deserves further study. Caution is warranted in interpreting the outcome of the singular case presentation as it may not, nor should it, be representative of the expected outcome from all hospitalized PRT cases.

Our results should be interpreted in the context of several limitations. First, the study was conducted using a prepost design rather than a randomization. Postvideo responses may thus be biased by patients' familiarity with question sets or an inclination to provide positive answers to not offend. Nonetheless, we found significant knowledge gains by asking objective data-driven questions in the knowledge portion of our assessment (rather than eliciting subjective responses in this area). Second, there was no significant improvement in readiness for a palliative care specialist. These points argue that respondents tended toward more socially neutral responses. Third, our study used nonvalidated measurement tools for assessing secondary outcomes of knowledge, readiness, and acceptability because of the lack of availability of validated tools relevant to our study population and question. Fourth, our study was limited to hospitalized patients with high symptom burden and may not be

generalizable to ambulatory patients considering PRT. Finally, the video was approved by the Director of Patient and Caregiver Engagement (C. B. W.), who had years of experience developing tools for engagement and education for patients and caregivers. However, we did not explicitly seek approval from a single patient or caregiver advocate before administration of the video. Rather, we intended to incorporate the qualitative feedback solicited from all patients enrolled in the study when filming subsequent versions of the video in the future.

Many hospitalized cancer patients with advanced stage disease face complex treatment choices with regard to PRT as they approach the end of life. Standard consultative procedures are not sufficient for patients to optimally comprehend necessary information about the risks and benefits of treatment. These knowledge gaps are associated with decisional uncertainty and less readiness to undergo PRT. We have shown that a clear and simple video tool can lead to reduced decisional uncertainty, improved knowledge, and increased readiness to receive PRT in these seriously ill individuals. This approach could stimulate patient-provider discussions around PRT and palliative treatments in general and may help clinicians better align treatment goals with patients' informed values and priorities.

Disclosures and Acknowledgments

This work was supported by the American Medical Association Foundation (K. V. D.), the Memorial Sloan Kettering Patient & Caregiver Education Program (K. V. D., C. B. W.), and the National Palliative Care Research Center (K. V. D.). The authors declare no conflicts of interest.

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Supplementary Index

A. Decisional Uncertainty Subscale of the Decisional Conflict Scale

Would you agree or disagree with the following statements?

I am clear about the best choice for me.	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I feel sure about what to choose.	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
This decision is easy for me to make	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree

Each item is rated on a five-point scale from zero indicating strongly agree to four indicating strongly disagree. The three items are summed, divided by three, and then multiplied by 25. Score range is 0–100. Higher scores indicated increased uncertainty about the best choice. Two scores are issued for each patient: a baseline score and a postvideo score obtained within 24 hours after watching the video.

B. Knowledge Instrument

If I decide to undergo palliative radiation treatment, there is a chance I will be cured of my cancer.	True	False	Unsure
Palliative radiation treatment must be started and completed while I remain hospitalized.	True	False	Unsure
I can begin my radiation treatment here and continue it at my local community hospital outside MSKCC after I am discharged.	True	False	Unsure
Once I begin seeing a specialist in palliative care, I will not be able to continue receiving treatment for my cancer from my other doctors (e.g., medical, surgical, or radiation oncologist).	True	False	Unsure
Palliative care means the same thing as hospice care.	True	False	Unsure
How long is a course of palliative radiation therapy, most commonly?	<10 days	Two to three weeks	More than three weeks

MSKCC = Memorial Sloan Kettering Cancer Center.

Each correct response is worth one point. The total score for each patient is calculated by summing the number of correctly answered questions, dividing by six, and then multiplying by 100. Score range is 0–100. Higher scores indicated higher knowledge levels. Two scores are issued for each patient: a baseline score and a postvideo score obtained within 24 hours after watching the video.

C. Treatment Readiness (1 = Most Ready; 10 = Not Ready at All)

With the information you know now, how ready do you feel to consent to palliative radiation therapy?	1	2	3	4	5	6	7	8	9	10
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If you chose a number between 5 and 10, please state your reasons here.

With the information you know now, would you be interested in scheduling a visit with a specialist in palliative care?	1	2	3	4	5	6	7	8	9	10
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If you chose a number between 5 and 10, please state your reasons here.

Two scores are generated for each patient: a baseline score and a postvideo score obtained within 24 hours after watching the video.

D. Impression of Video Intervention

How helpful was the information on palliative radiation in making a decision about your medical care?	Very helpful	Somewhat helpful	A little helpful	Not helpful
Did you feel comfortable receiving information about palliative care services in a video format?	Very comfortable	Somewhat comfortable	Not comfortable	Do not know
Would you recommend the video on palliative treatment to others facing a similar decision?	Definitely recommend it	Probably recommend it	Probably not recommend it	Definitely not recommend it
Is there any information about palliative radiation you felt was missing from the video that should be added?				
What did you like/not like about the video?				

Responses to each four-point question are treated as categorical variables and grouped. The number of responses in each category is tallied. Patients filled out the impressions survey within 24 hours after watching the video. To obtain a score (range 0–100), the scores of the three quantitatively assessed items were summed, dividing by three and multiplied by 33.333.