

JOSE RIBAMAR SABINO BEZERRA JUNIOR

"EVALUATION OF AN EDUCATIONAL VIDEO TO IMPROVE THE UNDERSTANDING OF RADIOTHERAPY SIDE EFFECTS IN HEAD AND NECK CANCER PATIENTS"

"AVALIAÇÃO DE VÍDEO EDUCACIONAL PARA MELHORIA DA COMPREENSÃO DOS EFEITOS COLATERAIS ASSOCIADOS À RADIOTERAPIA EM PACIENTES COM CÂNCER DE CABEÇA E PESCOÇO"

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UNIVERSIDADE ESTADUAL DE CAMPINAS FACULDADE DE ODONTOLOGIA DE PIRACICABA

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Orientador: Prof. Dr. Márcio Ajudarte Lopes

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Doctorate thesis presented to the Piracicaba Dental School of the University of Campinas to obtain the Ph.D. grade in Stomatopathology in Pathology area.

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RESUMO

O câncer de cabeça e pescoço representa o sexto tipo mais comum em todo mundo e é uma preocupação crescente das agências de saúde pública. O tratamento é baseado em cirurgia, radioterapia e quimioterapia, isoladas ou em conjunto e, são responsáveis por importantes sequelas que afetam negativamente as atividades diárias dos pacientes, contribuindo para uma diminuição na qualidade de vida. Entretanto, as informações prévias ao tratamento e a compreensão destas complicações pelos pacientes são insuficientes para prepará-los para o tratamento. Na literatura médica a utilização de vídeos educativos é documentada como uma ferramenta importante na transmissão de informações prévias a tratamentos complexos, demonstrando resultados promissores na melhoria da compreensão dos pacientes. No entanto, a utilização de vídeos educacionais esclarecendo as complicações do tratamento direcionadas aos pacientes com câncer de cabeça e pescoço é escassa, não havendo nenhum artigo que se dedique exclusivamente a estes pacientes. Portanto, o objetivo deste estudo foi avaliar o efeito de um vídeo educativo sobre a melhoria da compreensão dos pacientes com câncer de cabeça e pescoço submetidos à radioterapia sobre as complicações do tratamento. Para isto, a equipe de oncologia multidisciplinar, composta por membros do Centro de Oncologia do Hospital dos Fornecedores de Cana (CEON-HFC) e da Faculdade de Odontologia de Piracicaba (FOP-UNICAMP), produziu um vídeo de 6 minutos sobre os efeitos colaterais da radioterapia na região de cabeça e pescoço. Um estudo clínico controlado foi realizado com dois grupos: o grupo controle (n = 19), que recebeu informação verbal, e o grupo de vídeo (n = 19), que recebeu informação verbal e assistiu ao vídeo. Para medir o nível de compreensão, bem como levantar dados socioeconômicos, dois questionários foram dados a ambos os grupos, um antes do início da radioterapia e outro após o término da radioterapia. Trinta e oito pacientes foram incluídos no estudo. Trinta e um pacientes (81,58%) tinham um nível de escolaridade inferior ao ensino médio. Todos os pacientes do grupo de vídeo responderam corretamente por que eles foram submetidos à radioterapia.

Por outro lado, três pacientes (15,79%) do grupo do controle não conhecia o motivo para o tratamento. Apenas um paciente (5,26%) do grupo de vídeo tinha dúvidas sobre o tratamento, em comparação a sete do grupo de controle (36,84%). Como conclusão, o estudo demonstra que a utilização de vídeo educativo pode melhorar a compreensão do paciente com câncer de cabeça e pescoço sobre o tratamento com radioterapia e seus efeitos colaterais, independente de seu nível de escolaridade.

Palavras-chave: Filmes e vídeos educativos, Neoplasias de cabeça e pescoço, Cuidados para prolongar a vida.

ABSTRACT

The head and neck cancer is the sixth most common type worldwide and is an increasing concern for public health agencies around the world. The treatment is based on surgery, radiotherapy and chemotherapy, alone or combined, and are responsible for important consequences that negatively affect patients' daily activities, contributing to a decrease in quality of life. However, the information prior to treatment and understanding of these complications by patients are insufficient to prepare them for treatment. In the medical literature the use of educational videos is well documented as an important tool in transmitting complex information prior to treatment, demonstrating promising results in improving understanding of the patients. However, the use of educational videos explaining the complications of treatment directed to patients with head and neck cancer is scarce, and there is no article devoted exclusively to these patients. Therefore, the aim of this study was to evaluate the effect of an educational video on improving the understanding of patients with head and neck cancer undergoing radiotherapy on complications of treatment. For this, the multidisciplinary oncology team, composed of members of the Oncology Center of the Hospital of Sugarcane Suppliers (CEON-HFC) and Piracicaba Dental School (FOP-UNICAMP), produced a 6 minute video about the side effects of radiotherapy in the head and neck. A controlled clinical study was conducted with two groups: a control group (n = 19) who received verbal information and the video group (n = 19) who received verbal and watched the video. To measure the level of understanding and raise socioeconomic data, two questionnaires were given to both groups, one before the start of radiotherapy and another after the end of radiotherapy. Thirty-eight patients were included in the study. Thirty-one patients (81.58%) had an education level less than high school. All patients in the video group answered correctly why they underwent radiotherapy. Furthermore, three patients (15.79%) in the control group did not know the reason for the treatment. Only one patient (5.26%) in video group had doubts about the treatment, compared to seven in the control group (36.84%). In conclusion, this study demonstrates that the use of educational video can improve

understanding of the patient with head and neck cancer on treatment with radiotherapy and its side effects, regardless of their level of education.

Keywords: Instructional Films and Videos, Head and Neck Neoplasms, Life Support Care.

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INTRODUÇÃO

O câncer é uma doença que desperta uma crescente preocupação por parte das agências de saúde públicas mundiais e, apresenta uma indiscutível relevância social. A tomada de consciência é importante, uma vez que, representa a principal causa de morte nos países desenvolvidos e a segunda principal causa de morte em países em desenvolvimento (Jemal *et al.*, 2011). A despeito dos avanços tecnológicos aplicados na área da saúde e do aprimoramento das técnicas diagnósticas e terapêuticas para o câncer, sua incidência mundial continua aumentando.

Os cânceres que acometem a região de cabeça e pescoço (cavidade bucal, faringe – constituída por nasofaringe, orofaringe e hipofaringe - e da laringe), representam uma importante parcela na estatística mundial de câncer, representando o sexto tipo mais comum (Warnakulasuriya, 2009). O carcinoma espinocelular é a neoplasia maligna mais frequente em boca, representando mais de 90% dos casos (Scully & Bagan, 2009). Os fatores mais comumente associados à etiologia do carcinoma espinocelular são idade, gênero, hábitos, influências genéticas, estado de saúde e exposição a um ou mais agentes carcinogênicos principalmente devido ao uso indiscriminado de tabaco e álcool.

Cirurgia, radioterapia (RT) e quimioterapia, isoladas ou em conjunto, constituem as principais modalidades de tratamento para o câncer de cabeça e pescoço. A escolha entre as modalidades de tratamento depende da localização do tumor, extensão da doença, a preferência do paciente, co-morbidades, experiência da equipe multidisciplinar e equipamentos disponíveis (Licitra & Felip, 2009). Entretanto, de maneira geral, uma única modalidade de tratamento , seja através de cirurgia ou radioterapia, é geralmente recomendada para pacientes que se apresentam com estágios I ou II da doença, com controle regional similar entre as duas estrátegias (Licitra & Felip, 2009). Em contrapartida, em câncer de orofaringe (base da língua), hipofaringe e laringe, a radioterapia é geralmente o tratamento de escolha, pois, a cirurgia nesses pacientes é frequentemente

associada a uma maior morbidade pós-operatória mesmo em estágios precoces da doença. Para os pacientes que apresentam doença localmente avançada, estágios III e IV, a combinação de terapias é geralmente recomendada. Como técnica padrão, cirurgia associada à radioterapia pós-operatória. Já para os pacientes que durante a cirurgia apresentem algumas características como margens cirúrgicas comprometidas, extensão extracapsular e infiltração neural, há indicação de radioterapia associada ou não a quimioterapia no pós-operatório. Para pacientes não operáveis, a combinação de radioterapia e quimioterapia concomitante é o tratamento padrão (Licitra & Felip, 2009; Bhide & Nutting, 2010).

A radiação ionizante produz energia que prejudica ou destrói células ao danificar o DNA nuclear ou alterar as características moleculares das células individuais (Bose et al., 2013). Historicamente, para radioterapia convencional de raios externos (2D), o tratamento baseia-se no fracionamento de 60-70 Gy. Essas doses são tipicamente fracionadas por um período de 5 a 7 semanas, uma vez ao dia, cinco dias por semana, com uma dose diária de 2 Gy (Corvo, 2007). Usualmente, o tratamento diário dura em torno de 10 a 15 minutos (Zackrisson et al., 2003). Entretanto, outros métodos mais modernos de tratamento também podem ser utilizados, como a radioterapia conformacional em três dimensões (sigla em inglês, 3DCRT) e a radioterapia externa com intensidade modulada (sigla em inglês, IMRT), objetivando principalmente, poupar os tecidos normais (Corvo, 2007). Além do mais, alterações no processo de fracionamento da dose podem também ser utilizadas, como o fracionamento acelerado, com ou sem uma redução da dose total, ou um aumento de dose total por hiperfracionamento de pequenas doses de radiação diárias (Antognoni et al., 2005). Esta estratégia de tratamento com radiação fracionada permite que os tecidos normais se recuperem melhor dos danos subletais de DNA do que os tecidos do tumor, especialmente, na faixa de baixas doses (Bourhis et al., 2006; Corvo, 2007).

O tratamento com radioterapia causa complicações significativas tanto de caráter agudo (*i.e.*, ocorrem durante o tratamento e até três meses pós-radiação) quanto crônicas. Estes efeitos colaterais são causados, principalmente, devido às

altas doses de radiação necessárias para o controle da doença e por muitas estruturas críticas estarem envolvidas no campo de radiação. (Bhide & Nutting, 2010). As complicações de caráter agudos da RT incluem a mucosite, candidose, disfagia, hipossalivação, radiodermite e dor. Em especial, a mucosite induzida por radiação do trato aero-digestivo superior resulta em significativa morbidade e alteração da qualidade de vida (QV) durante radioterapia (Kelly *et al.*, 2007). As complicações tardias são compostas pela hipossalivação, disfagia, osteorradionecrose dos ossos gnáticos, perda auditiva, fibrose da pele e a necrose da cartilagem da laringe (Bhide & Nutting, 2010).

Devido à localização anatômica e as complicações associadas à RT os pacientes com câncer de cabeça e pescoço experimentam considerável sofrimento durante e após o tratamento, prejudicando atividades funcionais diárias como comer, deglutir, falar e respirar. Secundariamente, os pacientes experimentam problemas psicológicos e sociais, como redução das atividades sociais, estresse emocional, dificuldade de relações interpessoais, dificuldade nas tarefas do dia a dia e falta de autoconfiança. Isso em conjunto afeta negativamente a qualidade de vida (Hammerlid & Taft, 2001; Vissink *et al.*, 2003; Bornbaum *et al.*, 2012; Chen *et al.*, 2012).

Além disso, entre o diagnóstico do câncer, o início do tratamento e a recuperação pós-operatória existe um tempo extremamente curto, o que pode resultar na falta de informações necessárias que esclareçam o tratamento para os pacientes. Este tempo merece especial atenção por ser exatamente quando o paciente se sente mais temeroso pelo diagnóstico, pelo tratamento e sua chance cura, experimentando, nestas circunstâncias, alto grau de ansiedade e incerteza (Chen *et al.*, 2009).

Tendo em conta que os pacientes vivenciem mudanças drásticas em suas vidas após o diagnóstico de câncer, é importante oferecer aos pacientes informações necessárias para prepará-los para este período. Estudos anteriores relatam a correlação entre a necessidade de informação dos pacientes e seu nível de estresse psicológico (Chen *et al.*, 2009). Dessa forma, sugerem que os

profissionais de saúde devem avaliar as necessidades de informações referentes aos cuidados e fornecer orientações adequadas no momento do diagnóstico sobre os diversos tipos de tratamentos, sejam eles cirúrgicos ou outros tratamentos disponíveis (Ziegler *et al.*, 2004; Chen *et al.*, 2009).

A forma pela qual o paciente deve ser abordado é um desafio em muitas áreas da saúde, pois se sabe que é crucial que os pacientes devam possuir no mínimo o conhecimento básico sobre a doença que irá tratar, para que possa participar ativamente nas decisões sobre seu tratamento. Para isto, vários métodos são utilizados com o objetivo de melhorar as informações sobre o tratamento e efeitos colaterais, com o propósito, principalmente, de padronizar as informações mais relevantes e melhorar a compreensão. Um dos principais meios utilizados é através de material impresso, porém sua eficácia é reduzida pela baixa compreensão (Cooley *et al.*, 1995; Butow *et al.*, 1998).

Baseando-se no fato de que métodos de informações verbais e escritas podem ser de difícil compreensão por parte dos pacientes, os clínicos podem lançar mão de ferramentas visuais para educar seus pacientes sobre assuntos complicados e, a utilização de vídeo oferece muitas características favoráveis (Bouton *et al.*, 2012). Na literatura médica, a ideia de utilizar vídeos como auxilio não é recente e apresenta numerosos estudos. Estes estudos têm demostrado uma melhora na classificação de conhecimento, sensação de melhora na informação e altos níveis de satisfação entre os pacientes (Gagliano, 1988; Luck *et al.*, 1999; Phelan *et al.*, 2001; Dunn *et al.*, 2004; Hahn *et al.*, 2005) .

No entanto, poucos artigos na literatura são dedicados à formulação de vídeo educacional no intuito de instruir pacientes com câncer de cabeça e pescoço (Dunn et al., 2004; Hahn et al., 2005) e, sozinhos não são capazes de comprovar a eficácia deste método. Neste sentido, existe a necessidade de estudos com o objetivo de avaliar a eficácia de recursos audiovisuais educativos prévios a radioterapia de pacientes submetidos a tratamento para câncer de cabeça e pescoço, bem como analisar a compreensão do paciente, a ansiedade, o medo, a

predisposição para cuidados de suporte, e satisfação com a informação recebida, antes e após a terapia.

CAPÍTULO 1

Evaluation of an educational video to improve the understanding of radiotherapy side effects in head and neck cancer patients

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ABSTRACT

Purpose: Side effects of head and neck radiotherapy are common and can interfere with treatment. However, scientific information on a patient's understanding of these complications is scarce and confusing. Therefore, the aim of this study was to assess the effect of an educational video on improving the understanding of head and neck cancer patients undergoing radiotherapy about treatment complications. Methods: A 6-min video about head and neck radiotherapy side effects was produced by a multidisciplinary oncology team. A controlled clinical study was performed with two groups: the control group (N=19), which received verbal information, and the video group (N=19), which received verbal information and watched the video. Two questionnaires were given to both groups, one before the beginning of radiotherapy and the other after finishing radiotherapy. Results: Thirty-eight patients were included in the study (mean age of 59.7 years in the video group and 57.9 in the control group). Thirty-one patients had an education level less than high school education. All patients of the video group answered correctly why they were undergoing radiotherapy. On the other hand, three patients of the control group did not know the reason for the treatment. More patients of the video group demonstrated better knowledge about radiotherapy side effects than patients of the control group. Only one patient of the video group had doubts about the treatment, compared to seven of the control group. Conclusions: The present study showed that an educational video may improve patient understanding of head and neck radiotherapy and its side effects despite their education level.

Key words: Education, Video, Radiotherapy, Patient, Head and neck cancer, Understanding

INTRODUCTION

Head and neck cancer represents almost 3 % of all malignancies in humans and is frequently diagnosed at advanced stages [1]. The treatment is mainly surgery associated with radiotherapy and/or chemotherapy [2, 3]. Conventional head and neck radiotherapy generally involves high doses of about 60 Gy or higher in fractionated daily doses. The radiation field is limited by the proximity of radiosensitive tissues such as the spinal cord, brain, and parotid gland [4]. All the tissues in this area may suffer alterations, causing acute and chronic side effects [2, 5–9]. These alterations particularly depend on the volume of irradiated tissue, radiation dose, and individual patient factors such as poor oral hygiene, smoking, alcoholism, immune system, and dental follow-ups [2, 6, 7]. Xerostomia, mucositis, ageusia, dermatitis, and candidiasis are described as acute reactions that occur during treatment. Although they are often reversible, they can interfere with the therapy. Xerostomia is often a permanent complication, and is associated with other side effects such as radiation-related caries and osteoradionecrosis [2, 4-11]. All these complications can be controlled if the patient is evaluated by a dentist before treatment and maintains follow-up during and after therapy [6, 12, 13].

Patients undergoing head and neck radiotherapy often arrive at the first consultation after surgical treatment with physical and psychological sequelae, uncertainty, anxiety, depression, stress, shame, guilt, changes in facial appearance, and self-esteem [14, 15]. Surgical treatment may also cause disorders in speech, feeding, taste, and smell. Consequently, diagnosis, treatment, and rehabilitation are stressful for patients and their relatives [16]. For these reasons, most of the cancer patients want as much information as possible about their disease and treatment, and to be included in the decision-making process [14, 15, 17, 18]. Radiotherapy is technically complex and often unfamiliar to the patients; thus, providing them with proper information is very important [19]. The pre-radiotherapy visit to medical and dental teams aims to solve doubts about the therapy and allows for the explanation of the treatment, as well as making

recommendations. Unfortunately, many patients have difficulty in understanding the treatment, the language, and the content of the provided information [16, 17, 19–21]. Some patients do not remember the information given and many of them are not satisfied with the information received prior to treatment [22]. Although the understanding of cancer and treatment has been associated with the level of education and employment status, it has been shown that the use of an educational video could improve the understanding of these patients [23, 24].

Several methods have been suggested to improve the medical information delivered to patients. The most common way of informational support are written materials; however, their effectiveness is reduced [25]. The use of audiovisual methods is associated with an improvement in the retention of information, without undesirable psychological detriments [14, 17]. Videos have been shown to yield better results in patient satisfaction of the information given and is generally well accepted, being a cost-effective way of educating patients [14, 16, 19, 26, 27]. Educational videos about collateral effects in medical treatments have been used in different areas of medicine to improve patient adherence to treatment and prevent its complications [19], but there are only very few reports on head and neck radiotherapy patient [16]. Moreover, these studies have not shown significant differences in the measured knowledge, stress or reduction of physical symptoms [16]. Publications on the use of videos in cancer patients are still insufficient to support the evidence that it is a useful tool for treatment [16, 19, 28, 29]. The present study included only patients with head and neck cancer, and the aims were to evaluate an educational video about the collateral effects associated with head and neck radiotherapy, as well as to analyze patient understanding, anxiety, fear, predisposition to supportive care, and satisfaction with the received information before and after therapy.

MATERIALS AND METHODS

This study was approved by the Ethics Committee for Human Studies, Piracicaba Dental School, State University of Campinas (protocol number 021/2010). A longitudinal controlled clinical study was performed with two groups (n=38), a control group (N=19) that received verbal information and an interventional (video) group (N=19) that received verbal information and watched the video. The participants were diagnosed with head and neck cancer during the years 2011 and 2012, and were prescribed radiotherapy in the Oncology Center (CEON) of Fornecedores de Cana Hospital of Piracicaba, Brazil.

The patients were selected in two sequential samples in different periods. Each group was evaluated over a period of approximately 6 months. The first 19 patients were included in the control group and the following 19 patients were placed in the interventional group to avoid transmission of information between the two groups. No patients declined to participate in the study. The inclusion criteria were head and neck cancer patients aged between 40 and 85 years. The exclusion criteria were patients with mental confusion or other disabilities that hampered their ability to answer the questionnaires.

Video

A 6-min video about radiotherapy side effects was produced by the multidisciplinary oncology team of Fornecedores de Cana Hospital of Piracicaba, Brazil, emphasizing the cooperation of patients to prevent these complications. The video was shown on a laptop screen (14 in.), with speakers, in the dental room of the Hospital.

Questionnaire

A pre-radiotherapy questionnaire with 14 items was given to both groups 1 week after receiving the information. The answers of the questionnaire were "yes" or "no". The understanding of the patients was determined by the first ten questions, and the results were classified as: high understanding (nine to ten right answers), intermediate understanding (six to eight right answers), and low

understanding (zero to five right answers). The following questions were applied to determine doubts before the therapy and anxiety level. A post-radiotherapy questionnaire with 11 items was used in both groups 1 week after finishing the radiotherapy. The answers of the questionnaire were "yes" or "no". The questions were formulated according to those of the pre- radiotherapy questionnaire. The first six questions were related to the understanding of the therapy. The remaining questions were applied to determine the satisfaction of the received information after the therapy and fear. There was one correct answer for each question to determine the understanding. Finally, the results were correlated with age, educational level, localization of the tumor, presence of teeth, doubts about the treatment, fear, and if they knew someone who had received radiotherapy. A comparison of the groups was performed with regard to the answers of the questionnaires.

Analysis

The results were tabulated and analyzed with the software Origin Pro 8.0 (OriginLab Corporation, Northampton, MA,179 USA). The variables were evaluated based on a Fisher's exact test. Standard deviation was also determined in some variables. All significance levels were set at 5 %.

RESULTS

Clinicopathological and demographic findings

Thirty-eight patients agreed to be included in the study. All of them answered the pre-radiotherapy questionnaire (19 video patients and 19 control patients), and 24 patients answered the post-radiotherapy quationnaire (12 video patients and 12 control patients). No statistical differences were observed between the groups regarding the demographics and clinicopathological data (Table 1). The drop in the number of participants answering the questionnaire before and after treatment was due to the complications of the cancer that impeded the start of

radiotherapy, comorbidities of the patient, mental confusion after treatment, loss of contact with the patient, and death before finishing the treatment.

All patients were over 40 years old and were mainly in the sixth and seventh decades of life (mean age of 59.7 years in the video group and 57.9 in the control group), with male patients predominating. The majority of the patients had an educational level less than a high school education. The most common diagnosis was squamous cell carcinoma, and the most common tumor location was the oral cavity. The patients received radiotherapy exclusively or associated with surgery and/or chemotherapy. The total dose received by the patients ranged from 3,060 to 7,200 cGy, fractioned in daily doses of 180 or 200 cGy. The majority of the patients went to a hospital accompanied by relatives or friends (15 in the video group and 12 in the control group). Nine patients included in the video group and six patients in the control group were edentulous (Table 1).

Table 1. Patient demographics and clinicopathological data.

		. (11 00)		.	(3.1	0.4)
		otherapy (N=38)		Post-radio	24)	
	Video	Control		Video	Control	
	group	group	<i>P</i> -value	group	group	<i>P</i> -value
	(N=19)	(N=19)		(N=12)	(N=12)	
Age at first consultation	59.7	57.9		56.7 (9.9	58.4 (11)	
(SD)	(10.2)	(10.6)				
<40	0	0	0.4869*	0	0	0.7111*
40-49	2	5		2	3	
50-59	8	6		6	4	
60-69	5	6		2	4	
>70	4	2		2	11	
Gender						
M	16	15	1.0000*	11	8	0.5903*
F	3	4		1	3	
Educational level**						
0	2	1	0.0945*	1	0	0.1353*
1	16	12		10	6	
2	1	6		1	4	
3	0	1		0	0	
Diagnosis						
Squamous cell	40	40	0.0000#			4 0000#
carcinoma	18	16	0.6039*	11	11	1.0000*
Other diagnosis	1	3		1	1	
Location	<u> </u>			-	<u>-</u>	
Oral cavity	11	9	0.8675*	9	6	0.2256*
Larynx	5	5	0.00.0	2	2	00
Unknown primary	1	1		0	1	
Other location	2	3		1	3	
Treatment						
RxT	5	4	0.4803*	3	3	0.3015*
RxT + Surg	3	4	0.4000	3	2	0.0010
RXT + CT	9	5		3	3	
RxT + Surg +CT	2	5		3	4	
not yet scheduled	0	1		0	0	
Total dose of radiation	U	ı		U	U	
<6000	2	3	0.2404*	1	3	0.6002*
6000-7000	2 15	3 10	0.2404	9		0.000∠
					6	
>7000	2	3		2	3	
not yet scheduled	0	3		0	0	
Companion	4.5	40	0.4750*	0	0	0.0450*
Yes	15	12	0.4756*	8	9	0.8156*
No	4	7		4	3	
Edentulous	_					
Yes	9	6	0.5077*	6	3	0.2002*
No	10	13		6	9	
N=number of pati	ents:	SD=standard	devia	ition: M	1=male:	F=female:

N=number of patients; SD=standard deviation; M=male; F=female; RxT=radiotherapy; Surg=surgery; CT=chemotherapy. *Fisher's exact test (P-value \leq 0.05); ** Educational level, 0 = non educated; 1 = fundamental education; 2 = high school; 3 = college.

Pre-radiotherapy questionnaire findings

The understanding of radiotherapy and its side effects was evaluated by the first ten questions, and for most of them, the patients of the video group showed a better understanding than those of the control group. However, the difference between the groups was significant only for question #8 (P=0.0318), which was about loss of food taste. Osteoradionecrosis, which corresponded to question #10 and was displayed to the patients as a bone healing problem after tooth extraction, was the most unknown collateral effect. Radiation-related caries, answered in question #4, was also a little known complication associated with radiotherapy (Table 2).

Regarding the questions verifying doubts before treatment and anxiety level, the vast majority of the patients of the video group (18 out of 19) did not have doubts. On the other hand, seven patients of the control group had doubts about the treatment (P=0.0422). In addition, more patients of the control group were afraid or scared about treatment (P<0.0001). However, the anxiety level was similar between the two groups (P=0.6967; Table 2).

Table 2. Pre-radiotherapy questionnaire results in control and interventional group.

rable 2. Pre-radiotherapy questionnaire results i			iai group.
	Video group	Control group	P-value*
4 Daniel Institution will de madiethere au	(N=19)	(N=19)	
Do you know why you will do radiotherapy? You	10	10	0.0007
Yes No	19 0	16 3	0.2297
2. Do you know if there are complications (mouth, teeth, bone,	U	<u> </u>	
skin) associated with radiotherapy?			
Yes	16	12	0.2691
No	3	7	0.2031
3. Do you think that dental evaluation (examination of the mouth		•	
and teeth) before radiotherapy is needed only in patients who			
have teeth?			
Yes	8	2	0.2513
No	11	17	
4. Do you think that the patient who will undergo radiotherapy is			
more likely to get caries?			
Yes	15	13	0.7140
No	4	6	
5. Do you think that radiotherapy can burn the skin?			
Yes	16	14	0.6928
No	3	5	
6. Do you think that you can get ulcers in the mouth because of the radiation?			
Yes	18	15	0.3398
No	10	4	0.3330
7. Do you think that thrush can appear during radiotherapy?		-	
Yes	16	14	0.4570
No	3	5	0.1070
8. Do you think that you can lose the taste of food due to radiotherapy?			
Yes	18	13	0.0318
No	1	6	0.00.0
9. Do you think yhat you can stay with dry mouth or without saliva because of the radiotherapy?			
Yes	18	17	1.0000
No	1	2	1.0000
10. Radiotherapy can impair bone healing if you need to	·	_	
remove the teeth?			
Yes	11	11	1.0000
No	8	8	
11. Still have doubts about the radiotherapy treatment?			
Yes	1	7	0.0422
No	18	12	
12. Do you feel afraid or scared to do radiotherapy treatment?			
Yes	3	10	<0.0001
No No	16	9	
13. How would you define the level of anxiety you have before			
radiotherapy?	,	-	0.0007
a) Very anxious	4	7	0.6967
b) Anxious	3 7	4	
c) A little anxious	· · ·	4 4	
d) Not anxious	5	4	
14. Do you know someone (friend or relative) who had radiotherapy treatment?			
Yes	9	10	1.0000
No	10	9	1.0000

N=number of patients. *Fisher's exact test (*P*-value≤0.05).

Educational level and understanding grade

Most of the patients presented a high level of understanding (n=18), and there was a statistical difference between the groups (P=0.0095), with the majority (n=11) of patients in the video group showing more understanding, particularly in the educational level 1 (n=10). The remaining 7 and 13 patients showed low and intermedium levels of understanding, respectively, and no statistical differences were observed between the video and control groups (Table 3).

Table 3. Educational level and understanding level in both groups.

	Understanding level								
	Low (N=7)			Intermedium (N=13)			High (N=18)		
Educational	Video	Control	<i>P</i> -value*	Vidoo	Control	<i>P</i> -value*	Vidoo	Control	<i>P</i> -value*
level	Viueo	Control	r-value	video	Control	r-value	video	Control	r-value
0	1	0	1.0000	1	1	1.0000	0	0	0.0095
1	3	3		3	6		10	2	
2	0	0		0	2		1	4	
3	0	0		0	0		0	1	
Total	4	3		4	9		11	7	

N=number of patients. *Fisher's exact test (*P*-value≤0.05).

Post-radiotherapy questionnaire findings

There was no statistical significance in all the 11 questions between the video and control groups. However, some interesting information was collected. One patient in the control group answered that he did not know why he had received the treatment. Nine patients in the control group and six in the video group reported that they did not have any complication caused by radiotherapy, although all the patients did have side effects. Only one patient answered that he had some complications associated with radiotherapy that were not informed previously, and another patient affirmed that dental evaluation before radiotherapy was not necessary (Table 4).

All patients thought that the information received before treatment was enough to be prepared for it. It is important to emphasize that about half of the patients in both groups were afraid before therapy, with a few contemplating about quitting the treatment. Finally, although it was not statistically significant, more patients in the video group reported to be more worried about taking care of their oral health during radiotherapy (Table 4).

Table 4. Post-radiotherapy questionnaire results in control and video group.

		-	•
	Video group (N=12)	Control group (N=12)	<i>P</i> -value*
Do you know why you did the radiotherapy?	, ,	, ,	
Yes	12	11	1.0000
No	0	1	
2. Did you have any complications caused by radiotherapy?			
Yes	6	3	0.4003
No	6	9	
3. There was some complication during radiotherapy that you were not informed?			
Yes	1	0	1.0000
No	11	12	
4. Do you think that dental evaluation before radiotherapy was necessary?			
Yes	12	11	1.0000
No	0	1	
5. Do you think that the patient who underwent radiotherapy is more likely to get caries?			
Yes	8	7	1.0000
No	4	5	
6. Do you know if extractions should be avoided in the future in patients who were treated with radiotherapy?			
Yes	7	9	0.2138
No	5	3	
7. Do you think that the information received prior radiotherapy were enough to prepare you for treatment?			
Yes	12	12	1.0000
No	0	0	
8. Did you feel afraid or scared before radiotherapy?			
Yes	5	6	1.0000
No	7	6	
9. Did you think about quitting radiotherapy?			
Yes	3	2	1.0000
No	9	10	
10. Did you feel more worry about taking care of your oral health during the radiotherapy?			
Yes	10	8	0.6404
No	2	4	
11. Would you include some other information before the radiotherapy?			
Yes	1	0	1.0000
No	11	12	

N=number of patients. *Fisher's exact test (*P*-value≤0.05).

DISCUSSION

The present paper reports a controlled clinical study about an educational video intervention in head and neck cancer patients undertaken before radiotherapy. The English-language literature has studies showing the use of interventional videos before radiotherapy and other treatments [19, 24]. Before our study, only one research about video intervention was performed in head and neck cancer patients, and it was together with breast cancer patients [16]. For this reason, to the best of our knowledge, this is the first study of an interventional video only in head and neck radiotherapy patients. The clinicopathological and demographic findings of our study groups were consistent with those of most of the studies on head and neck cancer, where patients are usually over 40 years old, most are men and the main histological diagnosis is squamous cell carcinoma [1, 30]. Our sample showed a low educational level of the patients, which was associated with the diagnosis of the cancer at advanced stages, as already reported in the literature [31, 32].

Communication between the oncology team and the patient at time of diagnosis and during the whole treatment process is of vital importance in helping to achieve proper results, obtain patient cooperation and allow a high level of quality of life post-therapy [21]. The video has been reported as a simple and cost-effective way of educating patients [27], with previous studies showing that an informative video can improve patient understanding [16, 19, 23, 24]. The current study was performed exclusively with head and neck radiotherapy patients and demonstrated that the video is helpful in communicating important information before treatment. These results were more evident in patients with a low level of education. Hahn et al., studying patients undergoing radiotherapy for treatment of diverse tumors, reported that most of the subjects achieved a better understanding of radiotherapy after watching the video. Additionally, the patients reported that they felt safer and better informed [19]. These authors suggested performing studies with videos adapted to different diagnoses and assessing patient anxiety

[19]. Dunn et al., in a similar study with breast and head and neck cancer patients, found similar results, concluding that educational methods are important and can be used in a complementary way to verbal information [16].

In the control group, three patients stated that they did not know why they would be receiving radiotherapy, while in the interventional group, all the patients knew why. These data are extremely important because there are people who begin a difficult treatment without knowing the reason. For the questions regarding side effects, most of the patients in the video group had a better understanding than those in the control group. Osteoradionecrosis and radiation-related caries were the most unknown side effects associated with radiotherapy in the pre- and post-treatment questionnaire, probably because the patients were not so interested in the late effects during this phase of the treatment and also because there was a high proportion of patients without teeth.

The presence of a relative or friend during medical treatment can influence the psychological status of the patient, but in the present study, a high proportion of the patients came to treatment by themselves. No statistical difference was observed between the video and control groups regarding this point. Anxiety is considered a common finding that may influence radiotherapy treatment [15]. However, the current study did not find statistical differences between the video and control groups when the pre-treatment anxiety was evaluated. Moreover, patients in the video group had less doubts and were less afraid before the radiotherapy than those in the control group. These results show that a preradiotherapy educational video could be an important tool in head and neck cancer patients because they feel more comfortable when they are better informed about the treatment. In the present study, only anxiety was considered being associated with radiation therapy in the pre-treatment questionnaire. In future research, the level of anxiety in the post-treatment questionnaire may be considered since it can be associated with different aspects such as side effects developed during treatment and expectations of recovery after radiotherapy. In the post-treatment questionnaire of the video group, a few patients changed their answers when consulted about fear. The data that more patients felt afraid after radiotherapy could be in part explained by negative experiences during treatment. The literature highlighted the importance of giving information to patients because improving the understanding about cancer and its therapy can help to make decisions and obtain better results with medical treatments [23, 33]. We believe that the use of images with verbal communication is the best way of giving pre-treatment information and obtaining better results.

Less educated patients are also less knowledgeable about their treatment, and these factors correlated with lower scores of quality of life following treatment [24, 34]. It is important to note that a high proportion of head and neck cancer patients have a low educational level and that many of them are not able to read, making communication difficult. Therefore, video as a complementary educational tool could be helpful and better than booklets [25]. It has been reported that a video is a useful educational tool for the undereducated population [23, 24]. Indeed, in the current study, we observed that a high level of understanding was particularly seen in patients with a low educational level in the video group.

In addition, it has also been reported that the information given by videos is more relevant for older patients than young ones [19]. In the present study, this was difficult to determine since all the patients were older than 40 years, and no association with age was observed.

In the post-radiotherapy questionnaire, no statistical diferences were observed between the video and control groups. The similarity between the groups after radiotherapy could have been because many of the patients suffered side effects or that more information could have been given during treatment. Interestingly, 15 patients answered that they did not have collateral effects associated with radiotherapy, although all of them had some collateral effect during treatment. This could be due to several reasons such as the state of confusion of the patient after therapy, difficulties of understanding the therapy, low educational level, and the question not being well or clearly formulated. It has been reported that head and neck cancer patients are unsatisfied with the information given to

them, showing high levels of fear and depression, as well as low quality of life [35, 36]. Patient dissatisfaction has been associated with emotional distress, and this can be improved with a better patient knowledge about treatment [24, 37]. In the current study, all the patients in both groups answered that they were satisfied with the information given before therapy. Other authors have also observed high satisfaction in patients after watching an educational video [19]. Our control group felt that the information received prior to radiotherapy was enough to prepare them for treatment and that they would not include other information before treatment, despite showing less understanding of the therapy. This could have been due to several factors. We believe that the low educational level of the head and neck cancer patients and probably a desire not to receive further bad news could be some of them.

Although the current study found that the video was helpful, certain limitations should be considered. The first is the small sample of head and neck radiotherapy patients. This was because the study was performed with one radiotherapist to avoid inconsistent information. Furthermore, not all the patients could answer the questionnaires due to deteriorations in their medical conditions. The inclusion of illiterate patients meant that it was necessary for one of the research team to read the questions to the patients. Another limitation was that some patients were at advanced clinical stages. Consequently, some of them died before the conclusion of therapy or could no longer participate in the study due to mental confusion because of the disease. The inclusion of different stages, types of tumors, tumor sites, and treatment modality combinations generated a heterogeneous sample that could have been more restricted with stricter inclusion and exclusion criteria. The present study did not include an evaluation of anxiety and fear during treatment. A questionnaire applied halfway through treatment could have been useful in measuring these factors when the patients were suffering the side effects of radiotherapy. These could have also been compared to the pre- and post-treatment questionnaires. In conclusion, the present study demonstrated that an educational video may improve patient understanding of head and neck radiotherapy and its side effects, and is also important in reducing doubts and fear before therapy, being particularly useful in patients with a low educational level.

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CONFLICT OF INTEREST

We, the authors of this manuscript, declare that there is no financial relationship with any other organization. We also state that we have full control of all primary data and we agree to allow the journal to review the data if requested.

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CONCLUSÃO

O presente estudo demostrou que um vídeo educativo pode melhorar a compreensão do paciente com câncer de cabeça e pescoço tanto quanto ao tratamento de radioterapia quanto seus efeitos colaterais, independente do nível de escolaridade.

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ANEXO 1 - Certificado do Comitê de Ética em Pesquisa

18/02/13

Comité de Ética em Pesquisa - Certificado



COMITÊ DE ÉTICA EM PESQUISA FACULDADE DE ODONTOLOGIA DE PIRACICABA UNIVERSIDADE ESTADUAL DE CAMPINAS



CERTIFICADO

O Comitê de Ética em Pesquisa da FOP-UNICAMP certifica que o projeto de pesquisa **"Avaliação de vídeo como ferramenta educativa prévia à radioterapia em pacientes com câncer em cabeça e pescoço"**, protocolo nº 021/2010, dos pesquisadores Wilfredo Alejandro González Arriagada e Marcio Ajudarte Lopes, satisfaz as exigências do Conselho Nacional de Saúde - Ministério da Saúde para as pesquisas em seres humanos e foi aprovado por este comitê em 31/05/2010.

The Ethics Committee in Research of the School of Dentistry of Piracicaba - State University of Campinas, certify that the project "Evaluation of video as education tool before the radiotherapy in head and neck cancer patients", register number 021/2010, of Wilfredo Alejandro González Arriagada and Marcio Ajudarte Lopes, comply with the recommendations of the National Health Council - Ministry of Health of Brazil for research in human subjects and therefore was approved by this committee at 05/31/2010.

Prof. Dr. Pablo Agustin Vargas Secretário CEP/FOP/UNICAMP Prof. Dr. Jacks Jorge Junior Coordenador CEP/FOP/UNICAMP

Nota: O titulo do protocolo aparece como fomecido pelos pesquisadores, sem qualquer edição Notice: The title of the project appears as provided by the authors, without editing.

ANEXO 2 – Comprovante de Publicação do Artigo

Support Care Cancer DOI 10.1007/s00520-013-1730-x

ORIGINAL ARTICLE

Evaluation of an educational video to improve the understanding of radiotherapy side effects in head and neck cancer patients

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Abstract

Purpose Side effects of head and neck radiotherapy are common and can interfere with treatment. However, scientific information on a patient's understanding of these complications is scarce and confusing. Therefore, the aim of this study was to assess the effect of an educational video on improving the understanding of head and neck cancer patients undergoing radiotherapy about treatment complications.

Methods A 6-min video about head and neck radiotherapy side effects was produced by a multidisciplinary oncology team. A controlled clinical study was performed with two groups: the control group (N=19), which received verbal

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information, and the video group (N=19), which received verbal information and watched the video. Two questionnaires were given to both groups, one before the beginning of radiotherapy and the other after finishing radiotherapy. Results Thirty-eight patients were included in the study (mean age of 59.7 years in the video group and 57.9 in the control group). Thirty-one patients had an education level less than high school education. All patients of the video group answered correctly why they were undergoing radiotherapy. On the other hand, three patients of the control group did not know the reason for the treatment. More patients of the video group demonstrated better knowledge about radiotherapy side effects than patients of the control group. Only one patient of the video group had doubts about the treatment, compared to seven of the control group. Conclusions The present study showed that an educational video may improve patient understanding of head and neck radiotherapy and its side effects despite their education

 $\label{eq:Keywords} \textbf{Keywords} \ \, \textbf{Education} \cdot \textbf{Video} \cdot \textbf{Radiotherapy} \cdot \textbf{Patient} \cdot \\ \textbf{Head and neck cancer} \cdot \textbf{Understanding}$

Introduction

Head and neck cancer represents almost 3 % of all malignancies in humans and is frequently diagnosed at advanced stages [1]. The treatment is mainly surgery associated with radiotherapy and/or chemotherapy [2, 3]. Conventional head and neck radiotherapy generally involves high doses of about 60 Gy or higher in fractionated daily doses. The

