



# YouTube videos on lymphedema as an information source for Spanish speaking breast cancer survivors

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## Abstract

**Background** Breast cancer-related lymphedema in the upper limb remains one of the most distressful complications of breast cancer treatment. YouTube is considered a potential digital resource for population health and decision making. However, access to inadequate information or misinformation could have undesirable impacts. This cross-sectional study aimed to evaluate the reliability, quality and content of YouTube videos on lymphedema as an information source for Spanish-speaking breast cancer survivors.

**Methods** A search of YouTube was conducted in January 2023 using the key words “breast cancer lymphedema” and “lymphedema arm breast cancer.” Reliability and quality of the videos were evaluated using the Discern tool, content, source of production, number of likes, comments, views, duration, Video Power Index, likes ratio, view ratio and age on the platform.

**Results** Amongst the 300 Spanish language videos identified on YouTube, 35 were selected for analysis based on the inclusion and exclusion criteria. Of the 35 selected videos, 82.9% ( $n=29$ ) were developed by healthcare or academic professionals and 17.1% ( $n=9$ ) by others. Reliability ( $p < 0.017$ ) and quality ( $p < 0.03$ ) were higher in the videos made by professionals. The Discern total score ( $r=0.476$ ;  $p=0.004$ ), reliability ( $r=0.472$ ;  $p=0.004$ ) and quality ( $r=0.469$ ;  $p=0.004$ ) were positively correlated with the duration of the videos.

**Conclusions** Our findings provide a strong rationale for educating breast cancer survivors seeking lymphedema information to select videos made by healthcare or academic professionals. Standardised evaluation prior to video publication is needed to ensure that the end-users receive accurate and quality information from YouTube.

**Keywords** Lymphedema · Breast cancer · YouTube · Patient education · Internet

## Introduction

At least one in five of more than 7.8 million women treated for breast cancer worldwide are affected by lymphedema [1, 2]. Lymphedema in the upper arm remains one of the most distressful and long-term complications of breast cancer treatment [3] and negatively impacts the quality of life of breast cancer survivors [4, 5]. Lymphedema is characterised by the presence of swelling, pain, aching, soreness, tenderness, heaviness or impaired movement in the affected upper limb [6, 7]. Research evidence demonstrates that lymphedema information is essential for breast cancer survivors to reduce the risk of and manage lymphedema [8]. Several investigations have shown that providing information about lymphedema and self-care has positive effects on the improvement of lymphedema symptoms and the adoption of healthy behaviours [9–12]. Such findings are

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supported by the Behaviour Change Wheel Model [BCW] [13] that emphasises the positive effects of educational strategies on the psychological capacity of individuals and reflective motivation to promote behavioural changes. Despite the positive effects of providing lymphedema information and the long-term adverse impacts of lymphedema on breast cancer survivors, several studies have shown that a considerable percentage of survivors claim not to receive adequate information about lymphedema from health professionals [14–16]. This often leads breast cancer survivors to search for information from other sources, such as the Internet [17] or social networks [18, 19].

YouTube is the second most visited website in the world after Google [20, 21], and is considered to be a digital resource that may have a potential impact on population health behaviours and decision making. As such, YouTube may be a potential digital resource for breast cancer survivors seeking lymphedema information. Given that the information contained on YouTube is not subject to a review process by experts [22, 23], videos may contain inaccurate information or misinformation that affects their effectiveness, scientific quality and reliability [24, 25]. In addition, inaccurate or misleading content may produce harmful or ineffective effects on the promotion of healthy behaviours (e.g., behaviours to prevent or manage lymphedema) [26]. Most importantly, a video with misleading content can mislead viewers into wrong decisions or behaviours (e.g., dietary habits) [27]. For example, women with breast cancer should be educated about and encouraged to follow healthy dietary habits recommended by experts [28], since excess body weight increases the risk of developing lymphedema [29]. Singh et al. [30] and Ayoub et al. [31] identified the most common misleading videos including information about therapies that are scientifically inaccurate, or lack research evidence, and respectively concluded that 30.4% and 42% of the YouTube videos could be classified as misleading. The most common misleading videos include information that is scientifically unproven or inaccurate, for example, unscientific therapies [26, 27]. Several studies have provided evidence that inadequate or misleading content on YouTube can be harmful, after having evaluated the quality of YouTube content regarding various chronic illnesses such as fibromyalgia [32], rheumatoid arthritis [30], endometriosis [33] or breast cancer [31, 34, 35], as well as other chronic diseases [36–38].

Nevertheless, YouTube has been recognised as a tool for disseminating health information. According to Norgaard et al. [39], YouTube encompasses system features for digital services that do not require users to have specific or high-level skills to search and access information based on individual needs. These features make YouTube a popular digital service with the potential to impact public health in the digital era.

The accessibility to health-related content on YouTube and women's desire for information suggest that survivors will seek information in web-based contexts, including YouTube. The lack of professional or expert evaluation of YouTube sources concerning lymphedema implies that women have a high chance of finding health information that is inaccurate, false or inadequate. With the sheer number of videos available, it is essential to establish professional criteria to systematically evaluate videos on health issues, such as lymphedema following breast cancer treatment, in order to determine which videos should be recommended to patients. Such systematic evaluation of videos on health issues such as lymphedema in Spanish is critical, as Spanish is the fourth most commonly spoken language in the world, and currently there are 22 Spanish-speaking countries worldwide [40]. In addition, patient education on lymphedema prevention and treatment is usually not considered part of clinical practice, and many patients still have not received any education on lymphedema risk reduction and treatment from health providers [14–16]. This is also true for Spanish-speaking breast cancer survivors, and these patients certainly seek lymphedema information on YouTube [17–19]. To date, no studies have been conducted to evaluate the adequacy of YouTube videos on lymphedema following breast cancer treatment in the Spanish language, and there is an urgent need to assess whether YouTube Spanish language videos on lymphedema are adequate for health professionals to recommend them to patients for the prevention and management of upper-limb lymphedema related to breast cancer. Thus, the purpose of this study was to assess the characteristics, content, quality and reliability of YouTube videos on lymphedema in the Spanish language for breast cancer survivors in preventing and treating lymphedema in the upper limbs.

## Methodology

### Design

The present study comprised a cross-sectional design with a two-step process to (i) identify relevant YouTube videos in the Spanish language focused on the prevention or treatment of breast cancer-related lymphedema in the upper limbs; and (ii) assess the characteristics, content, quality and reliability of the selected videos. No human subjects were involved in the study.

### Step One: Identification and selection of relevant videos

A simulation method was used to imitate the way in which a patient would access YouTube to try to find videos providing information on breast cancer-related lymphedema

prevention or treatment. In January 2023 a search of YouTube was performed to identify Spanish language videos on breast cancer-related lymphedema using the following keywords in Spanish: “linfedema cáncer de mama” (breast cancer lymphedema), “linfedema brazo cáncer de mama” (lymphedema arm breast cancer). The searches resulted in 300 videos that were listed based on the rank of relevance of the YouTube videos [41].

Inclusion criteria for the selection of videos were: i) content focusing on breast cancer-related lymphedema in the upper limbs; ii) free access; and iii) availability in Spanish. Exclusion criteria were: i) advertisement videos; ii) video malfunction; and iii) content focusing on other forms of lymphedema, including leg lymphedema, congenital lymphedema or filariasis. Two researchers conducted the initial assessment of the 300 videos to eliminate 100 duplicated videos and evaluate the eligibility of 200 videos based on the inclusion and exclusion criteria. The initial assessment yielded 35 videos for the systematic evaluation.

## Step Two: Assessment of the characteristics, content, quality and reliability of selected videos

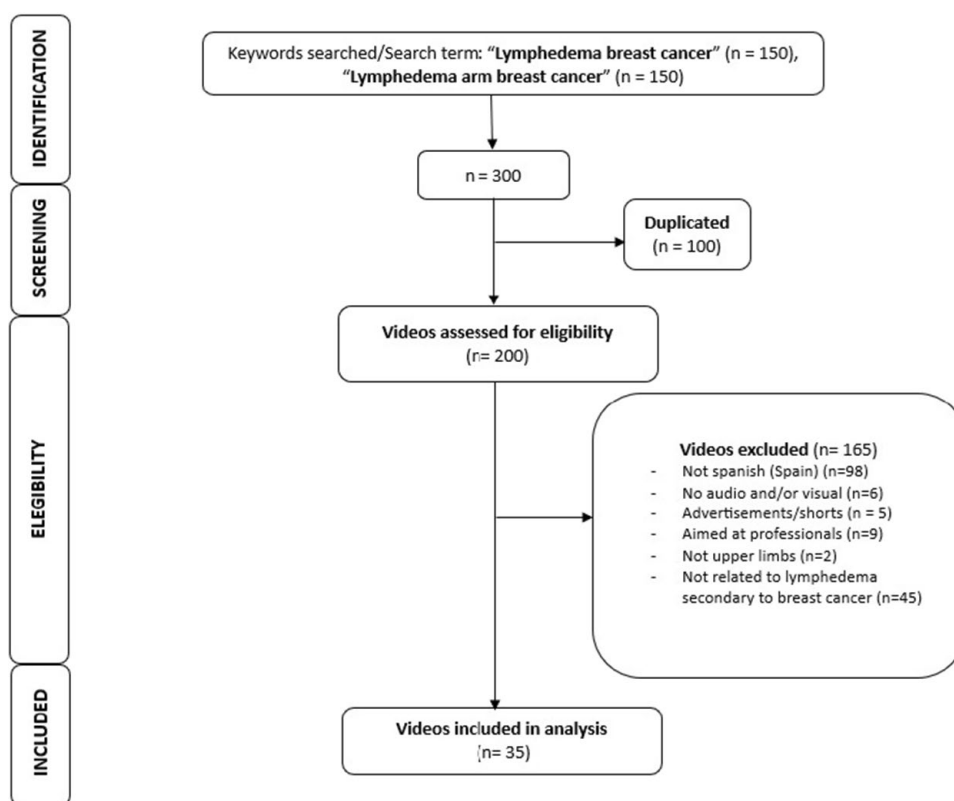
Two researchers independently evaluated the 35 selected videos systematically for characteristics, content, quality and reliability (Fig. 1). Any discrepancies between the evaluators

were resolved by discussion with a third researcher to reach a consensus.

**Characteristics** The description of the characteristics of the videos included the number of likes, number of comments, number of views, duration of the video (in minutes), year of upload to the platform, time elapsed from upload to analysis (days), and popularity using the Video Power Index (VPI). This index was calculated using the formula (likes ratio  $\times$  view ratio) / 100 [42]. In previous research [33], dislikes were included for the evaluation; however, due to the recent change in YouTube policy, the videos do not publicly display the number of dislikes and, therefore, dislikes could not be used as an indicator for the characteristics in this study.

**Content** The videos were classified according to content and source of production [20, 32–34, 37]. The videos were categorised into 5 groups based on their content: (1) informative videos, explaining lymphedema, its aetiology, symptoms and/or diagnosis; (2) preventive videos, focusing on the prevention of lymphedema; (3) treatment videos, focusing on different lymphedema treatment options; (4) informative and preventive (I+P) videos; and (5) preventive and treatment (P+T) videos. The videos in turn were classified based on the source of production as videos made by healthcare/academic professionals, or by others, such as patients (e.g.,

**Fig. 1** Flowchart of app search process



personal experiences) or commercial entities (brands of health products).

**Video quality and reliability** The Discern tool was used to assess quality (i.e., content accuracy) and reliability (i.e., content consistency) of the videos [43]. The Discern tool was published in 1998 to facilitate health decision-making [43]. Discern has been widely used to evaluate the reliability and quality of YouTube videos referred to other disease conditions [31, 34, 37, 38], and is the most used method according to Betancourt et al. [44]. Discern consists of 15 items with two parts: reliability (items 1 to 8), and quality of information about treatment options (items 9 to 15). Each item is scored from 1 (low reliability/quality) to 5 points (high reliability/quality), and the average total score ranges from 15 (very poor) to 75 (excellent) [43].

### Statistical analysis

The SPSS version 27.0 statistical package was used to analyse the data. A descriptive statistical analysis was performed to quantify the characteristics of the videos in terms of frequencies and percentages. The Kolmogorov–Smirnov test was used to assess sample distribution; the results indicated non-normal distribution of the data. The Mann–Whitney *U*-test was used to identify differences between the video creation sources, and the Kruskal–Wallis test was used to compare video content between groups. Spearman’s correlation coefficient ( $\rho$ ) was used to analyse correlations between raters and between the characteristics of the videos and the Discern scores.

## Results

### Video characteristics

Of all the videos identified ( $n=300$ ), 35 were included in the analysis, with 28.6% ( $n=10$ ) being categorised as videos focused on combined prevention and treatment, and 82.9% ( $n=29$ ) were made by healthcare or academic professionals. The video characteristics are described in Table 1 and in supplementary material 1.

### Video quality and reliability assessment

The median scores of the two evaluators showed significant and strong correlations in terms of reliability ( $r=0.896$ ;  $p<0.001$ ), quality ( $r=0.911$ ;  $p<0.001$ ) and the total Discern score ( $r=0.872$ ;  $p<0.001$ ).

Videos made by healthcare or academic professionals had a significantly higher reliability score ( $p<0.017$ ) and Discern total score ( $p<0.03$ ) than those made by others. No

**Table 1** Video characteristics

	Median (RI)
Likes	71 (555)
Comments	3 (15)
Views	7276 (25,875)
Length (minutes)	9.52 (12.52)
Likes ratio	100 (0)
View ratio	4.38 (28.22)
VPI	3.43 (28.85)
Days online	1072 (1514)
Video content	% (n)
Informative	25.7 (9)
Preventive	25.7 (9)
Treatment	14.3 (5)
Informative and preventive	5.7 (2)
Preventive and treatment	28.6 (10)
Video source	
Healthcare or academic professionals	82.9 (29)
Others	17.1 (6)

significant differences were observed in other video characteristics based on the source of production between videos made by healthcare or academic professionals and by others (Table 2).

There were no significant differences in reliability and quality and total Discern score based on the content of the videos between videos made by healthcare or academic professionals and by others (Table 3).

### Correlation between VPI and Discern scores

An important and significant correlation was observed between the comments assessed with the VPI ( $r=0.472$ ;  $p=0.004$ ) and the number of likes ( $r=0.407$ ;  $p=0.015$ ). Likewise, a significant and large effect was observed between the duration of the videos and reliability ( $r=0.472$ ;  $p=0.004$ ), quality ( $r=0.469$ ;  $p=0.004$ ) and the total Discern score ( $r=0.476$ ;  $p=0.004$ ) (Table 4).

## Discussion

The findings of this study demonstrated that videos made by healthcare and academic professionals had higher reliability, quality and overall Discern score than those made by individuals (e.g., personal experience). YouTube is a platform widely used by the general population to access health-related information [19]. However, the results of this study suggest that there is clear heterogeneity in terms of quality and reliability depending on the source of content. Such heterogeneity could be due to the lack of a standardised method

**Table 2** Comparison of video characteristics according to source of production

	Median (RI)			<i>P</i>
	Total ( <i>n</i> = 35)	Healthcare or academic professionals ( <i>n</i> = 29)	Other sources ( <i>n</i> = 6)	
Discern				
Reliability (1–8)	2.6 (0.44)	2.6 (0.35)	2.1 (0.50)	0.017
Quality (9–15)	1.4 (0.5)	1.5 (0.39)	1.2 (0.52)	0.145
Discern score	30.5 (7.00)	31.0 (6.25)	25.5 (4.88)	0.03
Likes	71 (555)	86 (646.51)	34 (90.25)	0.076
Video length	9.5 (12.52)	9.5 (12.98)	9.4 (20.46)	0.569
Views	7276 (25,875)	10,762 (51,224)	1087.5 (7883.75)	0.066
Comments	3 (15)	3 (20.50)	4 (8.25)	0.623
VPI	3.4 (28.85)	5.7 (44.29)	1.8 (3.30)	0.088

**Table 3** Comparison of quality, reliability and total Discern score of the videos based on content

	Median (RI)					<i>p</i>
	Informative ( <i>n</i> = 9)	Preventive ( <i>n</i> = 9)	Treatment ( <i>n</i> = 5)	Informative and preventive ( <i>n</i> = 2)	Preventive and treatment ( <i>n</i> = 10)	
Discern	30.5 (13.50)	29 (3.75)	30.5 (5)	31.75 (-)	31.3 (9.25)	0.856
Reliability	2.4 (1.06)	2.5 (0.09)	2.5 (0.44)	2.7 (-)	2.7 (0.58)	0.795
Quality	1.6 (1.04)	1.3 (0.39)	1.4 (0.25)	1.5 (-)	1.6 (0.75)	0.496

**Table 4** Correlation between the video characteristics and Discern scores

		Discern	Reliability	Quality	Comments	Length
VPI	<i>r</i>	0.124	0.213	0.002	0.472	-0.150
	<i>p</i>	0.477	0.219	0.989	0.004	0.390
Likes	<i>r</i>	0.054	0.143	-0.056	0.407	-0.196
	<i>p</i>	0.758	0.413	0.750	0.015	0.259
Comments	<i>r</i>	0.084	0.172	0.094	-	
	<i>p</i>	0.631	0.322	0.591		
Views	<i>r</i>	0.079	0.167	-0.035		
	<i>p</i>	0.653	0.3383	0.843		
Length	<i>r</i>	0.485	0.400	0.497		-
	<i>p</i>	0.003	0.017	0.002		

for content evaluation prior to video release [24]. The lack of standardised evaluation for videos related to disease prevention and treatment (e.g., lymphedema) on YouTube raises concern about the potential harmful impact of low-quality videos and misleading contents on patients seeking information from YouTube [22]. Whilst accurate and adequate information can contribute to improve the capacity of individuals to change or form healthy behaviours [9], given that zero risk does not exist, the access to inadequate information or misinformation could result in undesirable or even harmful effects. For example, the adoption of inappropriate health-related decisions based on erroneous or inaccurate information [27] causes delays in the provision of care or in seeking medical attention, as well as misallocation of health

resources [45]. Therefore, as suggested by O'Rourke et al. [46] and Madathil et al. [22], it is essential to carry out an adequate assessment of digital resources, focusing on the content of YouTube videos that provide information regarding disease information and related health behaviours.

Lymphedema prevention, independently or in conjunction with treatment options, was addressed by approximately 50% of the videos analysed. This result differs from the data found in previous studies, where informative content about lymphedema diagnosis, symptoms or treatment predominated over other contents [32, 33, 37]. Nevertheless, the results of our study, from a salutogenic point of view, are essential for healthcare providers and patients, as lymphedema is currently incurable



and produces a long-term and debilitating effect upon the functional [47] and psychological [48] well-being of breast cancer survivors, as well as on the quality of their social relationships [49]. Thus, videos that provide accurate information regarding lymphedema prevention may help patients, but misleading information may bring more harm to patients.

Our study found that most of the videos on breast cancer-related lymphedema were made by healthcare or academic professionals, which is common for YouTube videos related to other health issues [32, 34, 37, 42]. Similarly to videos on other health issues [23, 33, 36, 43], our study also found that videos on breast cancer-related lymphedema made by healthcare or academic professionals yielded significantly higher scores in terms of quality and reliability. It is worth highlighting the study carried out by Küçükakkaş et al. [37], who evaluated English language videos on lymphedema rehabilitation after breast cancer. This study also found higher reliability scores for educational videos made by health professionals. High quality and reliability videos made by healthcare or academic professionals reflect expert knowledge and clinical experience needed for creating educational videos regarding health issues, such as lymphedema prevention and treatment. Clinical practice should include patient education as part of routine care; in this regard, emphasis should be placed on the importance of the source of production of the videos, prioritising the selection of those made by healthcare or academic professionals.

An important finding in this study was the significant correlation between VPI and the number of comments and non-correlation with the Discern scores—these being results previously observed by other researchers [38]. This finding raises concerns regarding the value of VPI as an indicator of quality. Perhaps it is important to limit its use and the elements that constitute it, such as likes and views on videos regarding disease and health.

Another finding consistent with the existing literature was the positive correlation between the quality and reliability of the videos and their duration [33, 37, 39]. Shorter videos may include less detailed information than longer videos. However, it is important to highlight that we live in a culture of immediacy, which translates into the need to obtain a quick response amongst people between 25 and 54 years of age, who are the main users of YouTube [20]. This culture of immediacy presents important and difficult challenges for future video productions. Therefore, future videos on lymphedema should be critically evaluated before being hosted on the platform, and/or the people who make the videos should consult experts and pay special attention to the quality and reliability of the videos [43, 46].

## Limitations

Firstly, the YouTube platform changes over time, and new videos are uploaded every day without evaluation. However, our study provided fundamental criteria for patients and healthcare professionals to identify quality videos on lymphedema based on their personalised needs. The dynamic nature of YouTube reinforces the importance of the continuous evaluation of YouTube videos related to health issues (e.g., lymphedema), and other digital resources. Secondly, YouTube policy sorts videos according to its rating system and displays personalised results based on the search history and views; thus, the results could differ depending on how people perform the searches. However, the consistency of the results of our study with those found in previous publications highlights the need to ensure the rigour, quality and reliability of the health-related videos hosted on this platform.

## Conclusions

Higher reliability and quality scores were found in Spanish language YouTube videos on breast cancer-related lymphedema made by healthcare or academic professionals. This finding provides a strong rationale for educating breast cancer survivors searching for lymphedema information to select videos made by healthcare or academic professionals. Given the heterogeneity of content, quality and reliability regarding the breast cancer-related lymphedema videos hosted on YouTube, it is essential to perform a standardised evaluation prior to video publication in order to ensure that the breast cancer survivors, as end-users, receive accurate and quality information from YouTube.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s00520-024-08746-2>.

**Author contribution** All authors designed the study; JCR and PSF conducted the study; RMP supervised statistical analyses; all authors interpreted the data, drafted, revised and approved the manuscript.

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**Data availability** No datasets were generated or analysed during the current study.

## Declarations

**Ethics approval** No ethical approval is required due to the study design.

**Conflict of interest** The authors declare no competing interests.

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