



ORIGINALES

“It’s something you don’t talk about”: miscarriage testimonies on youtube

“Es algo que no se cuenta”: relatos sobre pérdidas gestacionales en youtube

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ABSTRACT:

Objective: To analyze the content of testimonial videos about pregnancy loss in Spanish on YouTube, so as to explore whether such narratives are framed in relation to the modern or postmodern biomedical logic of this experience as formulated by Frank and Bauman.

Methods: Systematic search of videos in Spanish from 2011 to May 2019, using the following inclusion criteria: contain the key words miscarriage or pregnancy loss in their title and have had more than 100,000 views on YouTube since their publication. To enable further content analysis, the videos were viewed to detail the characteristics of the publication channel in each case and to catalog their contents in terms of reasons for talking about the experience, the time chosen to tell the story, interaction with followers, the stages in the narrative, and the language used.

Results: We identified nine YouTubers that met the inclusion criteria, comprising a total of ten videos. Only two of the nine channels focused exclusively on motherhood. The stories are inscribed in a postmodern biomedical logic, due to the clear need to explain the traumatic event online, the recognition of the grief phase, and the limited use of survival language.

Conclusions: This study shows that the need to talk about the experience online is motivated by a decision to make the experience visible and offer support to other women. The results of this study may be useful to nursing professionals whose clinical practice involves caring for women who have suffered pregnancy loss.

Keywords: miscarriage, motherhood, grief, personal experiences, content analysis, youtube.

RESUMEN:

Objetivo: Analizar el contenido de los videos testimoniales sobre pérdidas gestacionales en *Youtube* en español para poder concluir si las narrativas se enmarcan en la lógica biomédica moderna o posmoderna de vivir esta situación de acuerdo a los postulados de Frank y Bauman.

Métodos: Búsqueda sistemática de los vídeos en español desde 2011 a mayo de 2019, que contuvieran en su título las palabras clave “aborto” o “perdida gestacional”, y que tuvieran más de 100.000 visualizaciones en Youtube desde su publicación, como criterios de inclusión. Visualización de los vídeos para su posterior análisis de contenido para detallar las características del canal, los motivos para contar la experiencia, el momento en que se cuentan, la interacción existente con las seguidoras, las etapas que se narran sobre el suceso y el lenguaje utilizado para relatarlo.

Resultados: Se encontraron nueve youtubers que cumplieron los criterios de inclusión, y un total de diez vídeos que recogían relatos sobre pérdidas gestacionales. Sólo dos de los nueve canales estaban centrados exclusivamente en la maternidad. Los relatos se inscriben en una lógica biomédica posmoderna, por la necesidad manifiesta de explicar el suceso online, el reconocimiento de la fase del duelo, y la poca presencia del lenguaje de la supervivencia.

Conclusiones: Este estudio muestra que la necesidad de explicar la experiencia online responde a la decisión de visibilizarla y de servir de apoyo a otras mujeres. Los resultados de este estudio pueden ser de utilidad para los/as profesionales de Enfermería que en su práctica clínica tienen contacto directo con las mujeres que han sufrido pérdidas gestacionales.

Palabras clave: aborto, pérdida gestacional, maternidad, duelo, experiencias personales, análisis de contenido, Youtube

INTRODUCTION

At the end of the twentieth century, the emergence of the Internet and digitalization in general enabled ordinary people to publish personal testimonies for mass audiences via user-friendly content creation platforms such as blogs and personal webpages ⁽¹⁾. These contents include health-centered testimonials published or broadcast on webpages, blogs, forums, social networks and audiovisual platforms like YouTube ^(2,3), accessed by general viewers as sources of information ⁽⁴⁾. Personal testimonials relating to motherhood appeared and spread exponentially in the early 2000s; initially known as 'mommy-blogs', they offered first-hand accounts of pregnancy and child-rearing ⁽⁵⁾. Nowadays, women tend to use platforms such as YouTube and Instagram to tell their stories about motherhood, in specific channels about raising children or more general interest streams. Some of these YouTubers and Instagrammers have professionalized their media projects, becoming influencers ⁽⁶⁾ with large numbers of followers. Recent studies show that 46% of mothers turn to YouTube for content relating to motherhood and child-rearing ⁽⁷⁾.

For centuries, maternity-related information was the prerogative of healthcare professionals and institutions; the testimonies of individual women were not available to wider audiences. Historically, pregnancy loss or miscarriage has been silenced, treated as a taboo because it involves reproduction and female sexuality, and connotes death. Thus, for many years the topic was not spoken of outside small or specialist circles ^(8,9).

Structural changes in Western society over the course of the twentieth century had a profound impact on many aspects of life, leading to a new understanding of pregnancy and, as a consequence, pregnancy loss, stillbirth and neonatal death. Among these changes were the widespread availability of ultrasound scans and pregnancy tests. The possibility of seeing ultrasound images of their unborn children transformed women's attitudes towards pregnancy.

More comprehensive knowledge of the pregnancy experience has also made women more acutely aware of miscarriage than at any other time in history. However, because these developments have not led to greater visibility of such experiences in the traditional media ⁽¹⁰⁾, many women are not familiar with them and feel they have nowhere to turn to should they experience them directly in their own lives. Worden ⁽¹¹⁾ argues that the evolution of loss is a primarily relational process and describes three factors that may complicate the situation: the loss may not be spoken of, the social context acts as though no loss has occurred, and there is not social support network in place.

Miscarriage is defined as pregnancy loss before 22 weeks, usually due to genetic defects in the embryo, although it may be the result of many causes. In the absence of comprehensive evidence in this regard, between 30% and 40% of all pregnancies are estimated to be miscarried ⁽¹⁰⁾.

The modern/postmodern approach to lived, health-related experiences, as outlined by the sociologist Arthur Frank ⁽¹²⁾, is shaped by a distinctive way of framing the problematics of the body. In *The Wounded Storyteller: Body, Illness and Ethics*, Frank sets out three narrative frames in which to interpret the stories people tell about their experience of ill-health: restitution, chaos and quest. In chaos, storytelling as such – description using words – is impossible because the patient is wholly subsumed within the illness. However, in both the restitution and quest frames, the patient is able to tell a story about their situation, which is shaped by the modern or postmodern logic of the contingency of the body. The logic of restitution is modern, a narrative in which the doctor is in control and established as the competent authority, whereas the patient's body is a passive reality returned to its former state through the treatment process. According to Bauman ⁽¹³⁾, the restitution narrative is the prevalent logic in contemporary society because it reflects a denial of mortality and the assumption that all natural phenomena are amenable to rational explanation. People tell restitution stories in medical terms, often using the language of survival, stressing an ongoing concern with health and hygiene, as well as control over one's own body, thus attributing part of the responsibility for loss of health to a lack of proper care.

The logic of the quest is postmodern: the disruption to normal life is seen as a challenge and the individual aims to take control of their own fate. There is an acceptance of vulnerability and loss of control over one's body, and people often look for ways to share their experience with others: the illness is a reason to try to bond with others.

While a number of studies have addressed the sharing of first-person blogs on health-related issues ⁽¹⁴⁻¹⁶⁾, relatively little research has been carried out on how people who have experienced health problems use YouTube ⁽¹⁷⁻¹⁹⁾, and none at all focusing on pregnancy loss, although the latter has been explored in other contexts ⁽²⁰⁻²⁴⁾.

Frank's narrative frames have been applied in the study of patient stories about diabetes ⁽²⁵⁾, breast cancer ^(17,26,27), the menopause ⁽²⁸⁾ and acquired disability ⁽²⁹⁾, centering on qualitative interviews or blog-post analysis.

The purpose of this paper is to describe the content of the most viewed YouTube testimonial videos on pregnancy loss, so as to explore whether such narratives are framed in relation to the modern or postmodern biomedical logic of health-related situations as formulated by Frank and Bauman.

MATERIALS AND METHODS

A systematic search for the most viewed testimonial videos about pregnancy loss posted on YouTube was carried out. The inclusion criteria were that the videos be in Spanish and have had over 100,000 views. The search was performed in May 2019, using YouTube's own search engine and the following terms: *miscarriage*, *pregnancy loss* and *curettage*; as well as viewing the videos suggested by the search engine algorithm that met this study's inclusion criteria. Table 1 presents data relating to the

videos analyzed including upload date, number of views, number of comments, and the features of the channel where they were posted.

Table 1: Features of most-viewed videos about miscarriage on YouTube

| No | Subscribers | Main topic(s) of channel | Video title | Date | Views | Comments |
|----|-------------|---------------------------------------|--|----------|-----------|----------|
| 1 | 4,391,647 | Fashion and make-up | I LOST MY BABY A DIFFERENT #StoryTime | 18/10/17 | 3,264,875 | 13,484 |
| 2 | 193,578 | Beauty and religion | I had an anembryonic pregnancy There was no baby | 5/4/19 | 1,194,716 | 3,106 |
| 3 | 464,606 | Beauty, cooking, motherhood, homecare | Natural abortion or miscarriage (my personal experience) | 18/6/13 | 1,101,508 | Disabled |
| 4 | 1,367,696 | Fitness | The reason for my absence... | 12/10/16 | 1,099,851 | 9,560 |
| 5 | 1,067,846 | Motherhood | MY SECOND MISCARRIAGE MY STORY AND EXPERIENCE!! | 5/5/12 | 797,105 | Disabled |
| | 1,067,846 | Motherhood | My experience of losing my baby. The story of my miscarriage | 17/5/11 | 452,049 | Disabled |
| 7 | 400,834 | Fashion and lifestyle | MY MISCARRIAGE (two years ago). MY EXPERIENCE | 9/9/18 | 339,069 | Disabled |
| 8 | 8,622 | Fashion | We lost our babies. Our experience. | 31/8/17 | 253,965 | 656 |
| 9 | 98,072 | Beauty | I was pregnant and I miscarried | 15/6/16 | 206,679 | 1,064 |
| 10 | 7,520 | Health and beauty | MY ANEMBRYONIC PREGNANCY/BLIGHTED OVUM AND MISCARRIAGE MY EXPERIENCE | 2/2/18 | 120,136 | 672 |

Repeated viewing of the videos and transcription of their voiced elements by the authors of this paper yielded systematic descriptions of each story that could be analyzed in content terms so as to identify their main features, including the main topic(s) of the channel, the reasons for telling the story, the time when the story is told, interaction with followers, the stages in the story, and the language used to talk about the experience. The information was organized in an Excel spreadsheet. The analysis

disclosed similarities and differences in discourse terms across these five broad categories, outlined one by one in the Results section below.

RESULTS

Nine Youtubers who have shared their experiences and whose stories met the inclusion criteria were identified, five from Latin American countries and four from Spain. A total of ten videos were analyzed (one of the YouTubers had two miscarriages, each described in a separate video); key features of the videos are set out in Table 1 above. The videos cover a period of eight years (2011–2019). As regards the channels to which they are posted on YouTube, only two focused exclusively on motherhood. The average running time of the videos is 20 minutes; the shortest runs for 16:08 minutes, and the longest for 34:43 minutes.

The videos are analyzed here in terms of the time chosen to talk about the experience, the reasons for doing so, interaction with followers, the stages in the narrative structure, and the language used to tell the story.

Time to talk

In relation to when the YouTubers chose to share their experiences of miscarriage, five did so weeks after the event. Two (numbers 6 and 8) did so one or two years later; and only one (YouTuber 5) did so having “just got back from the hospital”, in the case of her first miscarriage. The two YouTubers who were slowest to share their experience did so when they had had a child subsequently or were pregnant again.

“I didn’t say anything until I felt ready, now that I have my daughter and am pregnant again” (YouTuber 6).

All those who shared their stories within a shorter time frame were already mothers, except for YouTuber 2, whose video is the most recent testimonial analyzed here.

Reasons to talk

Seven of the videos start with an account of the reasons for telling the story. Four of the women say they were unaware of how common an experience miscarriage is until they experienced it themselves, a realization that prompted them to record their own testimony: “I didn’t know anyone who’d had a miscarriage” (YouTuber 3).

Another reason to tell their stories was the hope of helping other women who had had the same experience or might do so in the future: “Losing a baby is so common and happens to so many women, and it’s a taboo, and it shouldn’t be like that because talking about it makes it easier to get over” (YouTuber 4). “I hope my experience may be of some help to you” (YouTuber 9), although she also makes it clear that the video is the story of her personal experience and “not about setting an example”. Similarly, “This is our story. Your experience might be nothing like ours, or it might be, but what we want to do is help, give support, or simply let you know about other situations” (YouTuber 7).

Also noteworthy is that the expression “my experience” is included in the titles of six of the ten videos discussed here.

YouTuber 6 also pointed out that she wanted to tell things about her life that “are not good at all, it’s not a perfect or idyllic life”, thus framing her video in sharp contrast to most contents shared on social media. YouTuber 8 noted that “I feel a bit strange talking about this”, highlighting the difficulty of projecting a less than ideal image of motherhood. YouTuber 4 explained why she chose YouTube rather than other platforms: “I didn’t want to use Snapchat because its contents are erased, or Instagram because messages can be misinterpreted. I wanted to sit down and talk about it here”. In a video recorded in 2012, YouTuber 5 was the only one to give a content warning: “If you’re pregnant, I think it’d be better not to watch this video”, believing that the worry it might cause would outweigh the benefits of raising awareness of the experience.

Interaction

Four of the YouTubers encouraged other women to share their experiences in the comments section; three of them also went on to reply to some of the many comments posted there. YouTuber 7 said: “I’ve also looked at all kinds of social networks (...) and I know what many of you are in the same situation as me (...). I’ve always thought that social media were for sharing good news, but my husband and I thought it’d be good to tell our story here, to help other people going through the same thing as us”.

Comments are disabled on three of the videos, in one case (YouTuber 3) because the contributor had first shared her story or posted the video on other, preferred platforms. As regards references to and/or interaction with followers, three of the women mention the many messages of support they had received when they spoke about their experience on other social media, primarily Instagram in more recent times.

Stages in the story

All the stories start with the woman finding out she is pregnant, followed by the news that something is not quite right (because of bleeding or during an ultrasound check-up), the treatment of the miscarriage (by curettage or medication), rest and recovery, grief and, finally, the decision to try to get pregnant again soon (if they had not already done so). All of the women describe the grieving process, with some more than others focusing on the sadness they felt. YouTuber 3 presents it as a stage that is finished and, in some sense, overcome: “The best approach is to see it as something that didn’t work out, we didn’t want to think we’d lost a baby. (...) Thinking of every pregnancy loss as a lost child is too sad”. YouTuber 6 said, “everything looked dark. But it passes, you get over it”. YouTuber 7: “I had an awful time, I cried a lot. And hormones are the worst. You feel guilty”. Most of the women, therefore, saw grief as lasting for a fixed time period.

Language used

YouTuber 3’s video (posted in 2013) shows a lack of knowledge of what miscarriage is and the medical vocabulary associated with it: “They did a curettage on me, I didn’t even know the word existed”. YouTuber 7 (2017): “It was all Greek to me at the time”. More recent videos reflect a more empowered use of medical vocabulary and sense of the time chosen to share the story. Both YouTubers 2 and 9 give a detailed description of what an anembryonic pregnancy is, and YouTuber 3 discusses the percentage probability of experiencing miscarriage in relation to numbered weeks of pregnancy.

Only YouTuber 6 uses the language of survival; she talks about how she felt guilty when she found out that there was no heartbeat and “although the gynecologist said no, that it simply hadn’t worked out, I sometimes think I shouldn’t have lifted such heavy weights. (...) And I think I had a hot bath once or twice, and then I read somewhere that that wasn’t a good idea either”.

While two YouTubers (1,4) refer to other sources of stress that might have led to their miscarriage, the others say that women should not blame themselves, “the body is wise”; two of the women, both from Latin America (2,9) even cite the will of God.

DISCUSSION

Our research shows that the type of narrative articulated in the stories analyzed here follows a postmodern biomedical logic – what Arthur Frank defines as the quest narrative. This logic is reflected in the felt need to share one’s story online, the way all the women acknowledge the process of grieving, and the relatively infrequent use of the language of survival. Pregnancy loss is not experienced as a private matter to be kept hidden from others; rather, stories of pregnancy loss are told so that others may have information to draw on, and that – if they so wish – others can talk about their situations in the same digital space as the YouTubers discussed here use to demystify their lived experiences. Personal testimonial videos enable others to watch other people as they go through situations similar to their own, to look for reassurance, a sense of normality and for support, while those who post and share the videos are validated in their experiences ⁽²⁰⁾. At the same time, videos that mention a second, happier pregnancy may give some viewers hope ⁽²⁰⁾.

The number of views the videos had, as well as the volume of comments they prompted, shows that public response to these personal testimonies was high. In five of the ten cases discussed here, the videos had been viewed more times than the channel they were posted in had subscribers, which attests to an audience need to consume such stories and their power to create a sense of community through the comments published under the posts. As Isika, Mendoza & Bosua ⁽¹⁸⁾ have pointed out, users access media to share ideas and exchange opinions in a non-synchronous way. Although YouTube does not have a user-group function, this need was met through the many comments posted under each video. In the cases studied here, however, interaction on each YouTuber’s part with such communities was quite limited; the YouTuber role as producer of a narrative experience took precedence over the role of the viewer (to listen to the experiences of others).

At the same time, although their general features articulate a postmodern narrative logic, these stories are couched in medical terminology which is related to a modern logic – what Frank refers to as the restitution narrative. Therefore, the results of our research may be read in relation to other studies of the logics voiced in first-person online storytelling – that is, a blend of the modern and postmodern, because the current sociocultural context prevents the strict classification of stories in a single category ⁽¹⁶⁾.

The high viewership numbers show that pregnancy loss is a subject that sparks significant general interest, and suggests why some influencers (not only those whose primary focus relates to motherhood) are inspired to post their testimonies so as to raise awareness and demystify this experience.

The fact that earlier YouTubers admit to a lack of knowledge of the subject, while more recently posted contents do not, is evidence of the gradual erosion of the perceived taboo surrounding pregnancy loss and of the key role played in this regard by personal sharing with many viewers on social media.

At the same time, one of the women said that she wanted to tell her story to make the experience she had been through feel real; left untold, it is as though what is narrated in the story never happened, a feeling shared by many women who set up memorials to honor children lost before birth ⁽¹⁹⁾. As one of the YouTubers suggests, women who suffer pregnancy loss ought to be offered psychological support services because they are more prone to negative psychological outcomes, including episodes of depression that may last for up to a year ^(30,31). Thus, the results of this study may be useful to nursing professionals whose clinical practice involves caring for women who have experienced pregnancy loss, enabling them to see which moments or events their patients find most difficult to deal with, as well as when they may need more help. Viewing and sharing these videos may have a therapeutic effect for women in this situation; there is a marked difference in attitude towards pregnancy loss in the cases analyzed here as compared with Linderman's observation ⁽²³⁾ that many women felt there was no space open to them in which they could share their experiences.

Nowadays, many women access information about this issue on YouTube ⁽²⁰⁾. Future research could usefully explore how this trend develops over time, as well as examine how such shared testimonies play out across other social networks and analyze the information posted on profiles linked to healthcare organizations. It would likewise be interesting to see whether awareness is raised through personal testimonies about other 'invisible' experiences relating to motherhood such as stillbirth, the postpartum experience, including postpartum depression, as well as the controversial topic of abortion.

CONCLUSIONS

The sharing of stories of pregnancy loss online responds to a need to raise public awareness and offer support to other women in similar situations. Awareness-raising and sharing their experiences of trauma enabled the women in the testimonial videos posted on YouTube to normalize their experiences, relieve their suffering, and feel part of a community.

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