COPING WITH HARD TIMES THROUGH VIDEO NARRATIVES

Nihan G. IŞIKMAN¹

¹Assoc. Prof., Baskent University, Ankara, Turkey Corresponding aurthor: Nihan G. Işikman; e-mail: ngider@baskent.edu.tr

Abstract

Creative artistic production is a basic tool for selfexpression and sharing of personal struggles. As the accessibility of the equipment used for the creation of audiovisual narratives in the digital age has increased, and the internet has begun to play an important role in the circulation of personal narratives, individuals can be content producers beyond being viewers. At this point, it is important to evaluate the narratives in online platforms as a tool to deal with personal traumas, especially illness narratives that address the difficult times of various individuals. It is much more accepted that creating these narratives can well affect the health status and the quality of life in general. In the study, different vlogs of different characters from Turkey like Esra Dankı, Neslican Tay, Gursel Nur Dag, and Melisa Karagöz on their own personal traumatic events such as cancer are examined. Thus, it became possible to assess online storytelling for all actors of the communication process as a means of therapy, confronting a trauma and building a new life.

Keywords: Online Storytelling, Video Narrative, Therapy, Cancer, Vlog.

1. INTRODUCTION

Focusing on patients with cancer in order to produce video narratives online about their experiences with their illness, the aim of this study is to explicitly characterize and investigate how to use videos as a way of helping people deal with their problems. The videos' content discussing a stressful event, determined through what aspects of the production were helpful to the patients, making them and predicted to be helpful to those watching them, is highly significant.

Creative therapies and both formal and informal social support have been listed as being among the best treatments of the psychosocial impact of cancer on patients. Arts helps to humanise medical treatment. As explored by James Pennebaker, expressive writing paradigms encourage patients to express their feelings and thoughts through prompts. In his initial research, Pennebaker found that participants who were able to engage in the expressive writing paradigm had better mental and physical health outcomes (PENNEBAKER, 1993).

Multiple studies have pointed to the expressive and social components of creative therapy as being vital to aiding in skill building around the coping and processing of emotions in cancer patients, thus leading to a more overall positive mood, in addition to decreasing the impact of the physical side effects of illness and treatments such as pain and nausea (COHEN & WALCO, 1999; KENNELLY, 2001; MADDEN et al., 2010). Ann Jurecic says that illness narratives grow from the need to make the meaning of the experience of illness and suffering and to fill the spiritual and existential vacuum left by the biomedical model (JURECIC, 2012). Other research involving video storytelling used both acting on film and personal narratives to cope with trauma, social and adjustment difficulties, grief, and sexual health in patients (ANDERSON & WALLACE, 2015; GARDANO, 1994; GUSE et al., 2013; JOHNSON & ALDERSON, 2008; MCGURL et al., 2015).

2. HOW DOES ONLINE STORYTELLING WORK AS A THERAPY TOOL?

Over the last two decades, as computers and the internet gained popularity and self-reflective video making became effective, developing appropriate ways for patients to access social life, increase their knowledge and share their feelings about their illness, the new treatment directions for patients with cancer begun utilizing these technologies. Many patients have access to the internet, social media, even in the isolation of a hospital room. Because of the easy access possibilities and the ability to give information and support globally, the internet became an ideal medium for professionals to contact patients and their relatives.

Besides, as the accessibility of the equipment used for the creation of audiovisual narratives in the digital age increased, and the internet begun to play an important role in the circulation of personal narratives, individuals became content producers beyond being viewers. Just as written illness memoirs have multiplied partly due to technologies of self-printing and internet blogging, the production of filmic representations of cancer has been aided by the advances in video and digital technologies, funding, markets, distribution (KARPINSKI, 2013). First person videos, such as those found on YouTube and creative videos have become another means by which vloggers choose to share their stories about a variety of topics in a creative manner, including cancer (ANDERSON & WALLACE, 2015; TOSONE et al., 2005; YOUNG & BURROWS, 2013). Johnson's research supports therapeutic film-making as a viable creative therapy and that patients who enjoy telling stories would particularly benefit from this kind of outlet (JOHNSON, 2015).

With the rise of YouTube and of other forms of video hosting services online, vlogs and video testimonials are also gaining attraction, as a viable method of communication and selfexpression. Researchers pointed to the value of self-created videos in helping patients process health issues and cope with other trauma experiences (TOSONE, et al., 2005; YOUNG, & BURROWS, 2013). Suzuki and Beale suggest that online interventions that prompt the sharing of personal experiences for patients with cancer represent an ideal treatment option as they offer three key benefits patients often cite as being particularly important to them: access to true peers despite forced isolation during and after treatment; the ability for patients to give support to their fellow patients and in doing so, be experts of their own medical experiences; and immediate access to

information about their illness and treatments (SUZUKI & BEALE, 2006).

Social support is accepted as one of the most important aspects of aiding a patient with cancer in coping with the diagnosis, treatment, and other difficulties experienced. While faceto-face interactions may be preferred, because of the medical necessity or of the physiological symptoms, it may not be possible for patients to socialize with the members of their support system. Online support groups accessible through social media become a medium for patients to express their feelings about numerous sensitive topics and receive support from others with similar experiences. Research supports that these methods have been frequently used and are beneficial to patients because of a combination between the social support received and the ability to express and process negative emotions (SUZUKI & BEALE, 2006).

Over the last decade online diaries, blogs and vlogs have become an increasingly popular form of expression. This may in part be due to the psycho-social protection they offer writers, vloggers from the stigma they might face from being their true selves. Studies show that narrators who receive more visits and have high feedback rates are more motivated to tell, write and film because they think that they can reach people and are supported by being read, watched and commented on. Just like an online channel which offers its owner time to reflect on his or her emotions. Many people who keep personal vlogs do so for introspective purposes. Having more subscribers, receiving feedback from audience, about their growth stimulates writers even further, thus creating a cycle of expression of emotions, feedback and feelings. Research also supports that when vloggers upload videos regarding the specific difficulties they face, they show additional personal and interpersonal gains in the areas with which they struggle (PEREIRA, 2017). While extensive research on the overall benefits of blogs, vlogs and other forms of internet expression in cancer patients has not yet been completed in Turkey, the initial research suggests promising positive outcomes, including improvements in the overall quality of life.

3. FROM THE PERSPECTIVE OF ONLINE VIDEO MAKERS AND THE AUDIENCE

The movies are a great way of turning a social event into a self-healing experience because the healing stories can help the patient reach out to others who could not or would not otherwise get involved in recovery. And so much of making that first move toward recovery is the process of coming out of denial. Online videos allow us to suspend our disbelief long enough to get the message. Suspense of disbelief is like coming out of denial. By suspending the disbelief about ourselves or about what's going on in our lives, we have a chance of seeing things as they really are rather than the illusion we have created in our lives. The videos would help the patient and/or supporting family members and friends along their own healing path. Besides that, videos may teach the patient that he/she is not. If there were people out there who told stories about something that patients could relate to, there must also be other people who suffered from the same things. Each developmental stage has its own set of challenges during the course of cancer treatment, so patients must find a way to emotionally cope when confronted with their own mortality and illness. After receiving a cancer diagnosis, more sophisticated coping techniques would need to be in place in order to cope with the existential dilemmas often faced by any patient with cancer, such as concerns about future happiness or death.

Peer relationships are an integral part of the patient's psycho-social development; however, patients who are usually physically isolated also find themselves socially isolated as well. At times, the medical necessity requires hospitalization treatment and/or for complications of cancer and patients may also be sequestered to prevent infection and illness. These hospitalizations often cause frequent and/ or lengthy absences from social life. Also, patients report frustrations with being treated as "the sick one," feelings of guilt over the stress their family's experiences, the desire to protect close the ones who may not be able to handle stress, and worries about the cultural acceptance of their illness (DREW, 2003; HILTON et al., 2009).

Cancer narratives including online videos also respond to the need to overcome the social domination that imposes invisibility on the marginalized subject and rejects public existence. Therefore, these online narratives should be considered not only as sharing the cancer story, but also as a more general response and a positive perceptual construction effort. Whether there's an article in a magazine or a newspaper, a blog or a vlog, cancer memories paradoxically build a social network. For the subject, it creates a sense of intimacy with distant strangers. There are "virtual" friends, followers and supporters for online video makers. In this context, videos that draw on the authenticity of the image and its power to transcend the boundaries of time and space become a great way of starting a dialogue.

It's important to understand why people decide to make their stories public. It seems that the experience of cancer stimulates the need to share, to be with witnessed, as if one can truly understand it only if one experiences it closely and intensely under the gaze of others. Another possibility is to read it as the trauma causing the awakening, the heightening of the senses, a feeling of vitality, that is both intense and vulnerable, as well as encouraging the desire to live each day to the fullest. There is a need to understand that the desire to make an impact emerges in such narratives and encourages them to act as an activist, to articulate oppositional identities, and to try to unblock what is perceived as unsayable. This can be considered as a decision to go public in response to silence and denial in the media and social life (KARPINSKI, 2010).

People are repeatedly made aware of the importance of visual representation in the imagesaturated culture. Using the accessible media of video, online narrations bring forth to the public gaze images that are often unbearable to watch, thus moving cancer discussions beyond the clinic or academic circles, to the intimacy of people's everyday life. It is possible to say that they create potential sites for public debate, dialogue, and engagement with diverse audiences, but they also reveal the constraints placed on the possibility of emerging counter-publics (KARPINSKI, 2013).

This common knowledge can be empowering to ones with cancer by granting them the possibility of taking responsibility for their own life choices in the face of uncertainty and risk. Beyond that, cancer narratives enable the public to see the dangers of privatizing responsibility for care by not asking the right questions about cancer policy, the internal links between the cancer patient and the political, economic, environmental, social and medical situation. In fact, the pink ribbon campaign is a good example of such depoliticized "intimate publics," as an attempt to remove the stigma of shame and secrecy that has kept the breast cancer experience locked in the private sphere. Increasingly, commercial organizations seeking to increase their profits and political authorities have had to cooperate in order to raise funds for cancer research (KARPINSKI, 2010).

4. VLOGS AS A MEANS OF THERAPY, CONFRONTING A TRAUMA

Through the restriction of the study exemplifying vlogs have been chosen through the video platform YouTube with the keywords "cancer" and "vlog" in Turkish. Through the search it has been seen that the vloggers sharing their cancer treatment process are mostly women aged 20-30.

Neslican Tay,ⁱ as one of the pioneers of cancer diagnosed in public sphere, was diagnosed with cancer for four times since she was 19 and has lost her life by September, 20, 2019. She has lost one of her legs and had gone through hard times and treatment process but she never gave up, she never left life as an "Iron Woman," as she called herself. She joined YouTube by December 6, 2018 and shared 12 videos. The last one she uploaded was on September 7, 2019, during the days she started chemotherapy for her fourth diagnosis. Her videos have been viewed for 17.224.516 times and she had 400 thousand subscribers. After the widely effect of her vlog, she was invited to a TEDx Talkⁱⁱ by April 2018. As she rarely shared videos, her subscribers gathered information about her health situation from the comments made to her other social media accounts. This is a good example of how visual forms such as vlogs reality, credibility, elimination of distances with preliminary acceptance of proofness, build warm relations with the illusion of face-to-face communication, reveal new relationships networks. Individuals are paradoxically creating intimate networks, moving away from their subjectivity and contacting strangers. These narratives can transform an individual process into a social activity, a collective recovery experience.

Esra Dankıⁱⁱⁱ describes herself through her YouTube channel as "Hi, I'm Esra. How I met cancer, what was my first reaction, how my treatment process went, what I felt like when I lost my hair, I will share with you many things. I hope everything will be great." Her YouTube channel has 18,9 thousand subscribers. She joined on September 24, 2018 after her 3 year long war with cancer. Her videos got 2.416.026 views till today. Her 31 videos are all telling her treatment process. The shortest is 2'31" and the longest is 28'59". She receives many comments wishing her good luck and health from her audience, some of them being direct cancer patients or relatives of cancer patients. She describes the aim of her vlog in the beginning video, as she wishes to share emotions and knowledge with everybody interested, with the aim of touching even one person's life with a positive effect. As the audience follow her entire treatment process, haircut, high and low terms also see and learn about her family, the decisions they make together, mostly with her daughter and both Dankı and the audience begin to understand that cancer is not just her disease; it affects the entire family. The last video was uploaded on December 14, 2020.

Esra Dankı and Neslican Tay are the ones having the most subscribers and the largest video collection. The other vloggers like Gürsel Nur Dağ^{iv}, Esra Uslu^v, Melisa Karagöz^{vi}, Berfin Bolat^{vii}, Gülşah Demir^{viii}, Gülbahar Baykal^{ix}, Sevil Türker^x, Veli Kaan^{xi} are also trying the same thing, sharing their cancer treatment process for positive mode and effect. In an interview, Karagöz explains the aim of her vlog as "I have two options: either surrender to fatigue and spend my time doing nothing, or get over the fatigue and do something that can be useful to people. Of course, I chose the second option. Anyway, whatever I choose, this treatment will be done. Then why wouldn't I do the best I could? And it's fun to shoot something for YouTube... Cancer is strong, but we are stronger! And I think it's amazing. There is no need to hide, be ashamed, and be shy, to pity ourselves. We will not give up; we will continue to live from treatment as we left off.^{xii''}

All these vlogs represent a journey of selfdiscovery and also a display of the otherwise "invisible" bald head on YouTube. This may be seen as a temporary venturing into the territory of the glamorized white heterosexual healthy 'other.' through a self-reflexive portrait, as they are filming directly themselves, promoting empathy. This testimonial gesture of displaying themself as evidence is equivalent to proudly claiming space for the indigenous body so as to expand the content of the culturally available imagery of cancer patients.

Vloggers, holding the camera, are restored to their professional role, refusing to be positioned as victims. When they bring the camera to the medical appointments, they enhance their role from patient to that of researcher and deflect the medical gaze, recasting themselves to the position of active looking and seeing from the position of being looked at. Working like a reporter on some breaking news gives them a sense of mastery at managing information.

These vlogs rely on cinema vérité techniques and on a subjective point of view. In cinema verité, there is a promise of openness, of following an unscripted, evolving story as it occurs; there is a charismatic character unfolding through monologues, and filmed interactions. As they employ improvised monologues, the convention of the auto-portrait, privileging the aesthetics of realism in order to promote a closer identification with the subject through naturalized proximity and erasure of mediation. Viewers are supposed to forget that the camera is present, it works as an eye-to-eye everyday dialogue. These practices seeks neither to shock nor to seriously challenge the viewer, but to reconfirm certain norms. These give the feeling of looking through, rather than looking at. The audiences' gaze starts to empower them, honour their courage, and offer them a chance to leave a permanent trace.

5. CONCLUSIONS

This study evaluates the social and psychological effects of video narratives and focuses on their potential benefits for people in challenging processes such as cancer treatment. In addition to medical treatment, it should also be considered that the patients' ability to express themselves, socialize, establish a social network, and externalize the process through the narratives they create may facilitate adaptation to the process and the way in which this may affect the treatment. Under the conditions of sharing videos online without strict privacy settings, it will be important to closely monitor the patient's online presence, with this curative effect as essential to ensure that the patient's social media is protected from potential negative consequences. The interdisciplinary field is complex and requires a significant number of progressive researches. Research is needed not only to document and evaluate the benefits of arts and health practices, but also to provide an "evidencebased" basis for future planning and scaling of artistic interventions in a safer way.

References

ANDERSON, K. & WALLACE, B. (2015) *Digital Storytelling as a Trauma Narrative intervention for Children Exposed To Domestic Violence*. In: J. L. Cohen, L. J. Johnson, & P. Orr (Eds.), *Video and Filmmaking as Psychotherapy: Research and Practice*. New York, NY, US: Routledge, pp. 95–107.

DREW, S. (2003) Self-reconstruction and biographical revisioning: survival following cancer in childhood or adolescence. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine*, 7(2), 181.

GARDANO, A. C. (1994) Creative Video Therapy with Early Adolescent Girls In short-Term Treatment. *Journal* of Child & Adolescent Group Therapy, 4(2), 99–116.

GUSE, K., SPAGAT, A., HILL, A., LIRA, A., HEATHCOCK, S., & GILLIAM, M. (2013) Digital storytelling: A Novel Methodology for Sexual Health Promotion. *American Journal of Sexuality Education*, 8(4), 213–227.

HILTON, S., EMSLIE, C., HUNT, K., CHAPPLE, A. & ZIEBLAND, S. (2009) Disclosing a Cancer Diagnosis to Friends and Family: A Gendered Analysis of Young

COHEN, S. & WALCO, G. (1999) Dance/Movement Therapy for Children and Adolescents with Cancer. *Cancer Practice*, 7(1), 34-42.

Nihan G. IŞIKMAN

Men's and Women's Experiences. *Qualitative Health Research*, 19(6), 744-754.

JOHNSON, J. & ALDERSON, K. (2008) Therapeutic Filmmaking: An Exploratory Pilot Study. *The Arts in Psychotherapy*, 35(1), 11–19.

JOHNSON, J. L. (2015) Vision, Story, Medicine: Therapeutic Filmmaking and First nations Communities. In: J. L. Cohen, & J. L. Johnson (Eds.), Video and Filmmaking as Psychotherapy: Research and Practice. New York, NY, US: Routledge/Taylor & Francis Group, pp. 55–65.

JURECIC, A. (2012) *Illness as Narrative*. Pittsburgh: University of Pittsburgh Press.

KARPINSKI, E. C. (2010) Cancer Publics: The Private/ Public Split in Breast Cancer Memoir. *Canadian Woman Studies*, 28(2), 110-115.

KARPINSKI, E. C. (2013) Onco-Filmographics: The Politics and Affects of the Canadian Breast Cancer Documentary. *Tulsa Studies in Women's Literature*, 33(1), 163-187.

KENNELLY, J. (2001) Music Therapy in the Bone Marrow Transplant Unit: Providing Emotional Support During Adolescence. *Music Therapy Perspectives*, 19(2), 104-108.

MADDEN, J., MOWRY, P., GAO, D., CULLEN, P., & FOREMAN, N. (2010) Creative Arts Therapy Improves Quality of Life For Pediatric Brain Tumor Patients Receiving Outpatient Chemotherapy. *Journal of Pediatric Oncology Nursing*, 27(3), 133-145.

MCGURL, C., SEEGOBIN, W., HAMILTON, E., & MCMINN, M. (2015) *The Benefits of a Grief and Loss Program with a Unique Technological Intervention*. In: J. L. Cohen, & J. L. Johnson (Eds.), *Video and Filmmaking as Psychotherapy: Research and Practice*. New York, NY, US: Routledge/Taylor & Francis Group, pp. 81–94.

PENNEBAKER, J. W. (1993) Putting stress into words: Health, linguistic, and therapeutic implications. *Behaviour Research and Therapy*, 31(6), 539–548.

PEREIRA, L. (2017) *Can Making Video Narratives Benefit Adolescents with Cancer* (Doctoral dissertation). Palo Alto: Palo Alto University.

SUZUKI, L. K., & BEALE, I. L. (2006) Personal web home pages of adolescents with cancer: Self-presentation, information dissemination, and interpersonal connection. *Journal of Pediatric Oncology Nursing*, 23(3), 152–161.

TOSONE, C., GELMAN, C., & MCVEIGH, L. (2005) Through Their Own Eyes: A Media-Based Group Approach to Adolescent Trauma. *International Journal of Group Psychotherapy*, 55(3), 415-432.

YOUNG, J. & BURROWS, L. (2013) Finding the 'self' after weight loss surgery: Two women's experiences. *Feminism & Psychology*, 23(4), 498-516.

Endnotes

- i For Neslican Tay's YouTube channel see https:// www.youtube.com/channel/UCkb9pFtkQ-3j876gG75ntlA/featured (Date of access 03.08.2021)
- For Neslican Tay's TEDx Talk see https://www. youtube.com/watch?v=Spmn5G00Lng (Date of access 03.08.2021)
- iii For Esra Dankı's YouTube channel see https:// www.youtube.com/channel/UCqUbfFeJO5XW QpKjUCPjKhg (Date of access 03.08.2021)
- iv For Gürsel Nur Dağ's YouTube channel see https:// www.youtube.com/channel/UCVzbzGx9n 3E70Wn2OAX4FUQ (Date of access 03.08.2021)
- v For Esra Uslu's YouTube channel see https:// www.youtube.com/channel/UCb0A0Aks YAhtJ8Rv SXRdDog (Date of access 03.08.2021)
- vi For Melisa Karagöz's YouTube channel see https:// www.youtube.com/channel/UCzKhGpiTYvky NL6iRlcy0pw/videos (Date of access 03.08.2021)
- vii For Berfin Bolat's YouTube channel see https:// www.youtube.com/channel/UCmlBe65yZQpQ_ PMVOQ4fSrQ/featured (Date of access 03.08.2021)
- viii For Gülşah Demir's YouTube channel see https:// www.youtube.com/channel/UCKOPC7Ql74lm U1fkq7ETZIQ/videos (Date of access 03.08.2021)
- ix For Gülbahar Baykal's YouTube channel see https://www.youtube.com/c/GulbaharBaykal/ videos (Date of access 03.08.2021)
- x For Sevil Türker's YouTube channel see https:// www.youtube.com/channel/UCdmLIRT6bk jTUDsyhimftrw/featured (Date of access 03.08.2021)
- xi For Veli Kaan's YouTube channel see https:// www.youtube.com/channel/UCz4v5b2cuJ_ xHJ8Wd0 kmtLQ (Date of access 03.08.2021)
- xii For the interview with Melisa Karagöz see http:// www.hurriyet.com.tr/yazarlar/ayse-arman/ kanser-guclu-ama-biz-daha-gucluyuz-41017244 (Date of access 03.08.2021)