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The Power of Storytelling: Digital Stories as a Health Promotion Tool in the Yakima Valley

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Abstract

The Power of Storytelling: Digital Stories as a Health Promotion Tool in the Yakima Valley

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Purpose: Digital storytelling is an emergent method in health promotion work for addressing health inequities through combining technology with the voices of members of vulnerable, often underrepresented populations. The Fred Hutchinson Cancer Research Center (FHCRC) has combined efforts with Seattle community organizations to spread the reach of the digital storytelling project to the Yakima Valley. This is an evaluative study of the effectiveness of the digital storytelling process in the Yakima Valley.

Following the creation of a number of digital stories, we collected one-on-one interviews to understand the impact of creating a digital story, and convened focus groups to better comprehend the power of watching a digital story.

Methods: The FHCRC collaborated with Creative Narrations, an organization that specializes in multimedia support for nonprofit organizations. Creative Narrations conducted a “Train-the-Trainer” workshop to train FHCRC community health workers who in turn conducted three community workshops in the Yakima Valley region. A total of eighteen digital stories were created through these workshops, nine of which were created during the Train-the-Trainer workshop and nine others through subsequent community workshops. Recruitment was primarily through the snowball effect of

targeted community outreach with flyers and word-of-mouth. Later we collected one-on-one interviews (n=11) with participants of the digital story training workshops to evaluate the experience of creating a story. We also conducted focus groups (n=4) with groups who watched the digital stories in order to learn about the impact of viewing the digital stories of others. We reviewed and coded transcriptions from one-on-one interviews and focus groups using Atlas.ti.

Results: Overall, participants found the digital story experience to be positive and beneficial for improving health and engaging others within their community. The common themes in the data demonstrate that storytelling is a uniquely valuable tool in health promotion work, and that there are healing benefits inherent to sharing personal stories of overcoming or managing health issues. As a community engagement tool, digital stories also provide a structure for disseminating health education and fostering relationships for further advocacy and health promotion programming.

Conclusions: The findings of this study support other literature that shows the many benefits of digital stories in health promotion work. For storytellers, it provides a healing outlet to critically reflect on a difficult experience and find support and connection within one's own community. For story viewers, digital stories are far more impactful than other forms of health education materials that may not be culturally appropriate or accessible to the members of this population. Furthermore, the engagement process of building capacity and collaborating within a community is an important way for community organizations to foster relationships within the community. Many of our participants indicated that they would be very happy to continue digital storytelling work with Fred Hutchinson Cancer Research Center.

Table of Contents

List of Figures	v
List of Tables	vi
Introduction	1
Background and significance	1
Conceptual Framework: Community-Based Participatory Research	3
Study Goals and Objectives	6
Research Question	6
Methods	7
Setting	7
Intervention	7
Study Design	7
Analysis	9
Results	11
Discussion	15
Conclusion	22
Bibliography	23
Appendices	26
Appendix 1: Interview questionnaire	26
Appendix 2: Focus group questions	31

List of Figures

Figure Number

1. Community-Based Participatory Research Logic Model.....	5
2. Logic Model: Intervention and Research Implementation.....	10

List of Tables

Table Number

1. Demographic makeup of Interview participants.....	12
2. Themes Chart	13

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Introduction

Digital story creation is a developing method to increase community engagement in Community-Based Participatory Research (CBPR). Such stories can be used to empower and inspire community members while learning more about health disparities and promoting education on specific health issues. Digital stories are 3 to 5 minute visual narratives that synthesize images, video, audio recordings of voice and music, and text to create compelling accounts of personal experiences (Gubrium 2009). In particular, this technology can be used to provide an outlet for individuals who often do not have a strong voice in their community because of various factors such as social stratification by race, age, class, and language ability (Bader, Wanono, Hamden, & Skinner 2007, Gubrium 2009, 2013). Most notably, digital stories have been a powerful tool for members of communities of color and/or low socioeconomic status to share their individual stories, which often go unnoticed by mainstream media (Wexler, Gubrium, Griffin & Difflulvio 2013). By concentrating these stories by neighborhood or geographical region, we can learn more about the shared experiences of a community. The goal of this type of participatory community engagement is to use the process of reflection and engagement to build partnerships and empower storytellers to use their difficult experiences to promote health equity in their communities.

Background and Significance

MOVE (Mapping Our Voices for Equity) is a King County initiative that began in 2010 to combine grassroots organizing with new media technology so that communities can produce digital stories and strategically use them to improve health outcomes (Benson, et al 2013). The MOVE project began as a partnership between four Seattle organizations:

Two community health clinics—Sea Mar and International Community Health Services (ICHS)—joined with Entre Hermanos, a nonprofit serving the Latino Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ) community and Creative Narrations, a small multimedia training company.

For this study, Fred Hutchinson Cancer Research Center (FHCRC) received funding from the National Cancer Institute (NCI) to implement a digital storytelling project. FHCRC employed Creative Narrations to provide a train-the-trainer workshop to FHCRC community health promoters (promotores). These FHCRC employees then conducted community workshops in the Lower Yakima Valley of Washington State to create digital stories with members of the community. In this paper, we analyze the effectiveness and impact of these digital story workshops and the resultant digital stories in the Yakima Valley.

As a relatively new tool for community engagement and health promotion, literature on the effectiveness of this approach is lacking. This study seeks to contribute to the growing body of knowledge on the benefits and challenges of utilizing this type of technology to reach community members and their communities that are disproportionately affected by poor health outcomes. By understanding the experiences of individuals who participated in story creation workshops, we can continue to improve participation in these efforts. Further, the focus groups of individuals who viewed the digital stories provide a unique perspective on how stories can impact others. In the field of health promotion, it is often far more powerful to hear the inspiring story of a member of one's own community than receiving information in the form of a brochure or pamphlet.

We have identified three key themes through the analysis of thematic coding in the text of the interviews and focus groups. This paper provides the framework used as well as a discussion of the digital stories' significance. The key themes for discussion in this paper are: 1) Storytelling is a uniquely powerful tool in community engagement and a valuable part of the healing process, 2) The particular community of study, in the Yakima Valley, does not have enough opportunities to tell their stories due to social barriers and structural oppression, and 3) Digital Stories can be helpful in health prevention and education work.

Conceptual Framework: Community-Based Participatory Research

A model for the applied framework for this study is shown in Figure 1. The community-based participatory research (CBPR) approach promotes an equitable exchange between researchers and community members, and can address barriers to engaging with a population that is particularly vulnerable due to social status, language skills, legal concerns, or other factors (Duran & Wallerstein, 2007). By employing bilingual promotores, and collaborating with the MOVE project, it is a clear priority of this study to build on established trust with the community in the Yakima Valley. By engaging the community to tell their stories and participate in the health promotion process, we are hoping to increase understanding of health disparities and further develop community partnerships in this region to improve health inequities. Furthermore, by training our participants in the use of video-making software, we are increasing technical skills and promoting literacy in the use of health technology.

A key tenet of the CBPR approach is to develop lasting relationships with community members in order to build a partnership in reducing health disparities. Over the last

decade, CBPR has gained recognition as an intervention research method where an increase in knowledge through partnerships can lead to improved health outcomes (Duran & Wallerstein, 2007). Through the workshops led by promotores, the FHCRC project further solidified their role as a trusted community health organization in the Yakima Valley. The storytelling process is an exercise in building trust and sharing stories that may be emotional and revealing. Not only did the promotores provide skilled assistance to the community participants but they also created their own stories and shared them in the workshops to promote an equitable exchange of information and vulnerabilities.

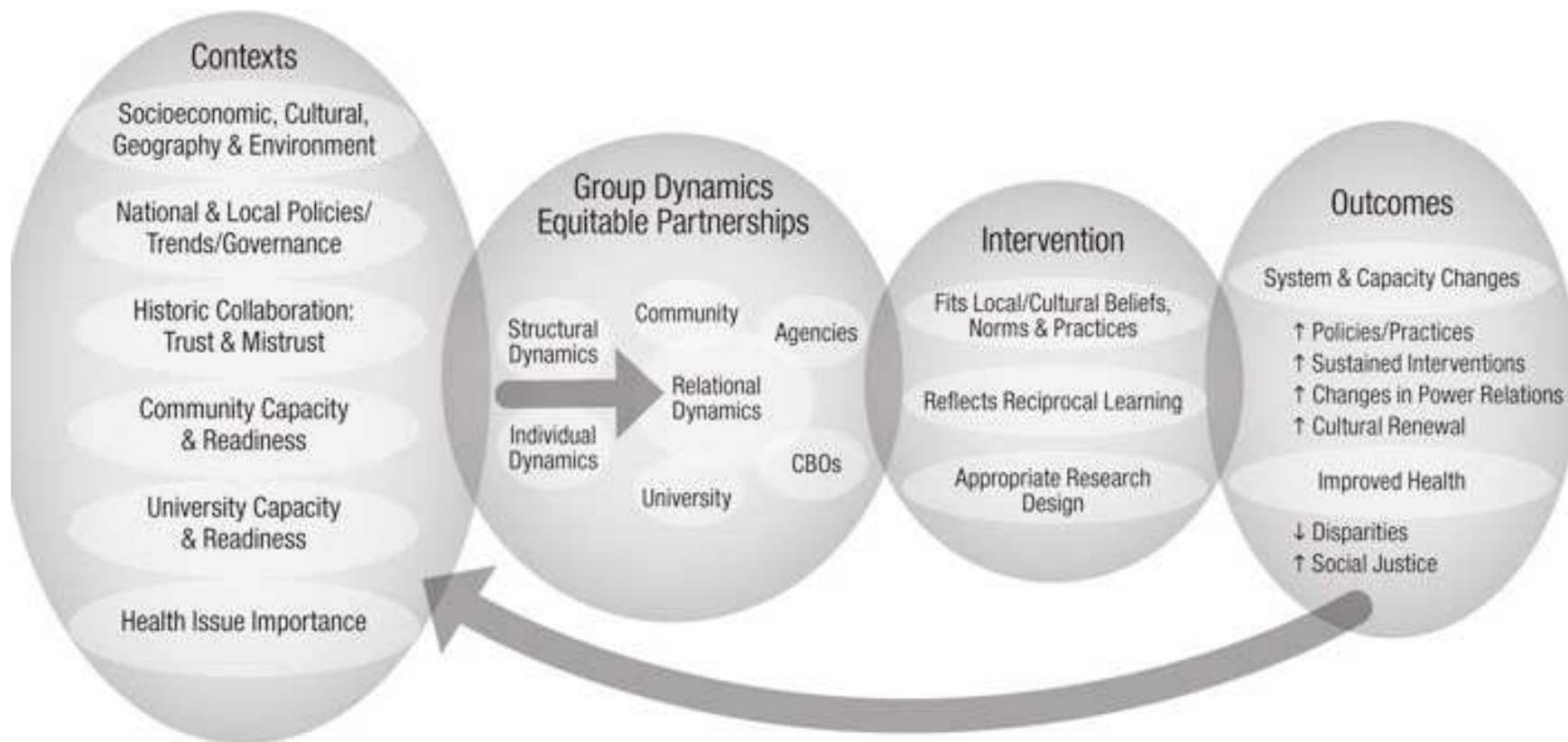


Figure 1: Conceptual Logic Model of Community-Based Participatory Research. Wallerstein, N., Oetzel, J., Duran, B., Tafoya, G., Belone, L., & Rae R., 2007

Study Goals and Objectives

The primary goal of this study is to evaluate the use of digital stories as an effective tool for community engagement and health promotion in the Yakima Valley from two different perspectives:

- The one-on-one semi-structured interviews (n=11) will provide qualitative data on the experience of the individual creating a digital story.
- The semi-structured focus groups (n=4) will demonstrate the community impact of watching the digital stories created by the community members.

The power of sharing stories and hearing stories is difficult to quantify, but we are interested in the common experiences of the interviewees. Further, we hope to assess how the use of digital stories can advance the growing community partnership that FHCRC has created in the Yakima Valley and thereby improve and further promote health equity.

Research Questions: What are the shared experiences and observations of participants in the creation of the digital stories? What is the impact of the stories on members of the focus groups? How can FHCRC continue to build strong community health partnerships through the digital story process to improve overall health outcomes in the Valley? How can these stories be used to educate community organizations, local leaders, and policy makers to influence change and improve Valley health outcomes?

Methods

Setting

This project was implemented in the Lower Yakima Valley of Washington State, which is a rural, agricultural area in Eastern Washington. Many communities in this area are majority-minority (Hispanic) towns. The Hispanic ethnicity (primarily Mexican) forms about 67% of the population. The population in general is underserved in terms of poverty, educational status, and health insurance status (American FactFinder, 2010 Census).

Intervention

Creative Narrations delivered a three-day train-the-trainer workshop for health promoters at the Northwest Communities Education Center in Granger, WA in January of 2013. Nine health promoters participated, three were partners from community organizations and six were FHCRC staff. This training resulted in nine digital stories. Between April and October of 2013, FHCRC health promoters held three digital storytelling workshop series. Community members were invited to create digital stories through a series of 4-5 weekly meetings of about 2 hours each. Meetings were held at the Center for Community Health Promotion in Sunnyside, WA. Each participant who completed a digital story received a \$50 gift card for their participation. These workshops resulted in 9 digital stories. A logic model describing this process can be seen in **figure 2**.

Study Design and Sampling

An evaluation of the three digital story community workshops was conducted.

Participants of the workshops were members of the Yakima community, many of whom were recruited through targeted snowball sampling, using word-of-mouth and flyers primarily. For this evaluation, we collected data from the following two sources:

- Between September and December of 2013, FHCRC staff conducted semi-structured face-to-face interviews (n=11) with individual participants of the workshops who created digital stories
- In February of 2014, FCHRC staff conducted semi-structured focus groups (n=4) with members of the community who did not participate in the workshops, but viewed the digital stories during the focus group session.

All interviews and focus groups were coded using a thematic codebook developed collaboratively by authors. Using Atlas.ti, the authors were able to compare their use of codes and draw conclusions about common themes throughout the coding process.

Interviews

Between September and December of 2013 interviews were conducted by FHCRC staff with 11 workshop participants in the language of their choice (English or Spanish).

Interviews ranged in length from 10 to 40 minutes, with an average time of about 18 minutes. All interviewees classified themselves as Hispanic. Ten of the participants were female, and one was male. The average age of participants was 51 years old. All interviews were recorded and then later transcribed by FHCRC staff into a Word document for analysis. Five of the interviews were conducted in Spanish, transcribed, and

then translated into English by an FHCRC hired translator.

Focus Groups

Four focus groups were held in February of 2014. There were a total of 34 participants across the four groups. These groups were facilitated by FHCRC staff. They were semi-structured discussions, and varied in length from approximately 60 to 120 minutes. One of the focus groups was conducted in Spanish, while the other three were in English. All focus groups were recorded and then later transcribed by FHCRC staff into a Word document for analysis. The focus group conducted in Spanish was transcribed and translated into English by an FHCRC hired translator.

Analysis

Data was analyzed through a process of collaborative thematic coding. The authors created a codebook for each set of data collected through an inductive multi-step process. First, each author read through all of the data individually and came up with a preliminary list of codes based on frequent themes observed in the data. Later, the authors compared their lists of codes and agreed on a final list by combining similar codes. This codebook was then entered into Atlas.ti software, and the authors each coded the data files using the finalized codebook. Once each author finalized their codes, they merged the files to compile all codes together.

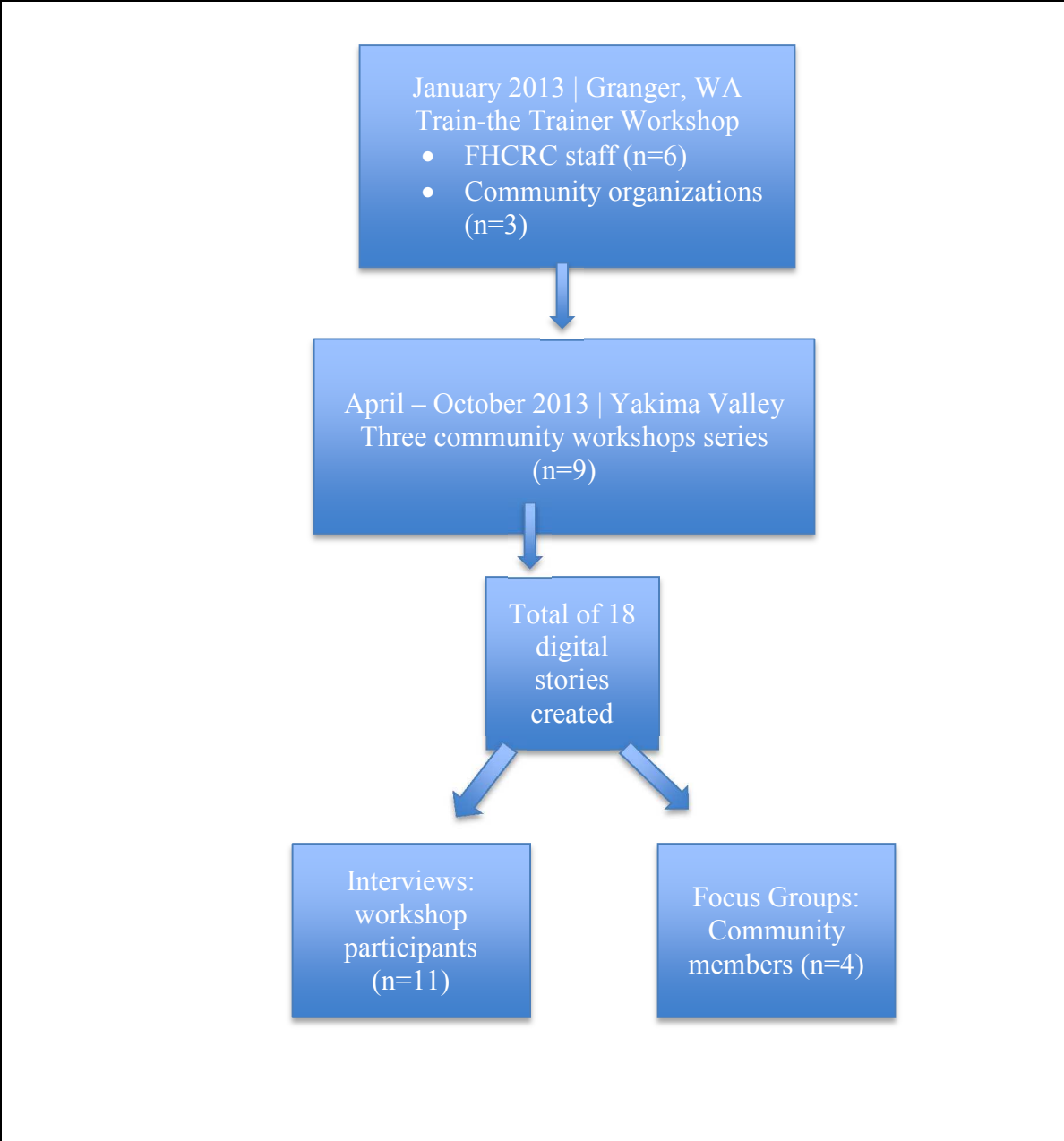


Figure 2: Logic Model – Intervention and Research Implementation

Results

As a community-based participatory research (CBPR) process, results were based upon insights gathered from members of the Yakima Valley community through interviews and focus groups. The questions were designed to invite critical thinking and reflection on broad concepts about the application of digital stories and health promotion. The authors also included “agree/disagree” statements in order to confirm or deny researchers’ assumptions about the participants’ prior knowledge of digital stories. Since one of the goals of this study is to reinforce community ties and further engage the community in health promotion programming, some of the questions were designed to explore how stories and health information are shared among each other. We were also interested in the role of technology in the daily life of our participants, and what kinds of benefits or challenges were presented by the digital aspect of this storytelling process.

As CBPR theorists point out, it is useful to carefully consider the demographics of study participants and the social implications of such participation (Duran & Wallerstein 2006). **Table 1** provides a demographic breakdown of interview participants. Demographic data was not collected in the focus groups. The participants of this study are mostly female and Latino. We had a fairly wide range of participants in terms of age and education level. The absence of male participants may represent a more general lack of male participation in community engagement programming. It also may indicate that our interviews could have been timed more appropriately to meet the differing work schedules of community members.

Table 1: Participant Demographic Characteristics for Digital Story Interviews

CHARACTERISTIC	*TOTAL (11)	
	n	%
Preferred Language		
English	3	27.27
Spanish	8	72.72
Gender		
Female	10	90.90
Male	1	9.10
Age		
30 – 39	2	18.18
40 – 49	2	18.18
50 – 59	6	54.54
60 – 69	1	9.10
Education Level		
8 th grade or less	3	27.27
9 th – 12 th grade (no diploma)	1	9.10
HS Diploma or GED	3	27.27
Some College, no degree	2	18.18
College degree	2	18.18

*All respondents self-identified as “Hispanic or Latino”

framework for deeper analysis (Corbin & Strauss 2008).

As **Table 2** displays, the authors were able to delineate three overarching concepts that were significant in the participant narratives. These concepts and themes can inform further implementation of storytelling practices. The discussion section of this paper will further explore the relevance of these themes in the context of other literature on the use of storytelling methods to engage communities and promote health equity.

Table 2 displays key concepts found within the data with associated emergent themes and representative quotes. These results are based on the authors’ impressions of the most significant themes that the participants described through interviews and focus groups. The use of concepts and themes helps group together common experiences and provides a

Table 2: Themes chart

Overarching category & Key Concepts	Emergent Themes	Representative Quotes
Storytelling is uniquely powerful	Storytellers & listeners feel less alone	<p>FG: ...it could be shared with people that hasn't been sick with those types of diseases and also with those that already have the disease so they know what to do and don't feel so alone.</p> <p>I: ...I feel that people who see my story will gain something out of it...you're not alone out there. We're also here with the same disease that anybody can go through.</p>
	Therapeutic to tell one's story	<p>FG: I feel like it confirmed a lot of things that I know. This one specifically about diabetes in a culture and in a family, and so it felt like it confirmed it.</p> <p>I: ...it's a very challenging illness and having done the digital video helped me remember and instead of feeling sadness or shedding tears it felt good being able to talk about the topic.</p> <p>I: ...There were tears in my heart and in my eyes...because I finally learned what it meant to to live with a chronic disease and how difficult it was...it helped me so much to create a digital story.</p>
	Allows survivors to connect with other survivors and share with friends/family in a way they never have before	<p>I: For me, the most interesting was participating in this thing where I can help not just one person but an infinite number of people and through one's story one can share the experiences.</p>
		<p>I: I have a [Facebook] friend from Italy...She saw it in Italy and contacted me if I wanted to be her friend and she has a sister with the same illness.</p>
		<p>FG: If I can share this digital story with anybody, I'd probably share it on my Facebook. They can...just take a moment to see this because it can affect you and it can affect your family and it can save a life.</p>
	This particular community does not have enough opportunity to tell their stories	Storytellers are surprised that anyone is interested
<p>I: [Fred] Hutchinson surprised me because I don't, I never imagined that someone would be interested in finding us to make a digital video, so it's something that, I don't know, well, is welcome</p>		
<p>I: When they sent the invitation, I said, "Can I really make a digital story? No. No,I don't qualify."</p>		
Many are not literate and do not have many channels to tell a story or read a story	<p>I: The most difficult part was learning to read the card. I am a very slow reader, for lack of education</p>	

		<p>FG: The digital story helps many people because there are many people that don't know how to read and [when they see] the digital stories, they only listen and see and that helps them understand more about diseases</p> <p>FG: Pamphlets or brochures that you sometimes take go straight to the trashcan [because] there are words you don't understand, while the [video] grabs more of your attention and it gives me more information</p>
	Lack of access to computers/software	<p>I: It so happens that I didn't grow up with a computer so when they put a computer like that in front of me, I momentarily freeze and I say, "God, now this program, what do I do here?"</p> <p>I: In our community I still see a lot of barriers in the use of the computer and technology, it even happens to me...I say, "Oh, what do I do? What do I press here?"</p>
Digital stories can be a helpful in prevention work	Digital stories are educational and can teach community about important health issues	<p>I: I think my digital story can influence people that are going through cancer or any chronic illness or difficult problem. I think they can see my experience, and there could be an end, maybe not a happy one but a good end.</p> <p>FG: I think [the video] opens up doors. I would definitely use it if I'm trying to educate my husband and I want it to be an open discussion because it's affecting him but I want all my family to know, including my grandkids.</p>
	Hearing the story from a survivor is better than reading about a disease in a pamphlet	<p>FG: I also liked the story because that person, from a young age lived with cancer and lived it in herself and also because she is brave enough to record and tell her story</p> <p>FG: It just seemed much more familiar and sensitive to exactly what touches our family, what affects our family.</p> <p>I: I think it can help because one learns from listening to other people and telling a little bit of our story as one that has lived the illness.... I think that it helps other people if they are going through the same evil to trust a little of that to see if it works for them too.</p>
	Study participants are eager to continue Digital Story work	<p>I: I uploaded my video and I have had responses, so it could be continued. There are many people in the community with better stories than mine that have gone through the same problem</p> <p>FG: I would like to participate with you because just like the other stories that you have just put on for us—they helped me to get another point of view about diseases, I would like to contribute in that way</p> <p>I: Don't Stop. Continue letting people be aware of what other people have gone through. The stories are very helpful, I think, for other people that need help and don't know where to go.</p>

Discussion

Throughout history, storytelling has been a valuable tool for reflection and healing in a variety of cultural outlets (Gazarian 2010). In songwriting, religious practice, academics, poetry, and many other forms, we use stories to teach each other and to remember our struggles so that others may struggle less. Furthermore, the act of telling one's story can in itself be a healing process. Digital stories provide a technological format to synthesize this longstanding human tradition so that it may reach across generational, geographical and cultural and social class divides into an easily accessible video that can be shared and distributed easily.

The results of this study support the theoretical framework of CBPR, which asserts that intervention programs are strengthened by the insight of community members and that participation in community-based research can lead to improved health practice and better health overall (Wallerstein & Duran 2006). Digital stories are potent and effective because storytelling is an emboldening and therapeutic process that has the added benefit of engaging and inspiring peers. Through this discussion section, the authors will elaborate on the significant concepts and themes that are displayed in **Table 2** above.

THEME 1: Why is storytelling so uniquely effective?

Storytelling is globally ubiquitous in part because it requires minimal literacy. As long as we speak a language that others can understand, we can teach about our experience and try to extrapolate lessons that will improve future practices. Its omnipresence also speaks to an innate human desire to connect with others. Digital story programs are particularly

useful in underserved populations where literacy and economic resources may be low but cultural tradition is rich. It is an intervention program that draws from the expertise and wisdom of the at-risk population it seeks to serve.

Storytellers and listeners feel less alone

The act of storytelling can be a vulnerable process that stimulates empathy and understanding from listeners (Christiansen 2010). Our participants frequently discussed the feeling that the digital story experience contributed to a sense of belonging. In the interviews and focus groups, the participants described the ways they could relate to each other through the videos. In the workshops, the participants discussed their stories with each other and found new connections with their peers. In our viewing group, focus group members would process the story through relating it to their own personal experience. Whether or not they enjoyed the video, they were able to identify with the storyteller and find a connection with their own life.

This feeling that one is not alone, is not only valuable as a means for community engagement and relationship-building, but can also lead to improved health behavior. In a web-based study of women who viewed digital stories about common symptoms of menopause, 73% of respondents said that they subsequently discussed issues with their doctor that they had previously been too embarrassed to disclose (Cumming et al 2010). Similarly, some of our group participants describe a new motivation to go to preventive checkups with their doctors and be more proactive about their healthcare.

For the storytellers, there was a strong desire to help others who might be struggling with a similar health issue. When asked about the community impact of their story, several respondents indicated they hoped to show others that they were not alone. Some of our focus group members expressed that the digital story was inspiring and put their own health issues into perspective: “*When I think I have it hard, I can remember [this story]. Her struggles make my struggles seem easier.*” This is a feeling that a doctor or a nurse cannot provide patients in an exam room. Digital stories impart more than information about the symptoms of an illness; they provide hope, strength, and encouragement.

It is therapeutic to tell one’s story

In addition to the capacity-building aspect of acquiring new skills with the video software, the act of creating a digital story has several emotional benefits to the storyteller. One study of a storytelling project implemented in a low-income African-American in a large urban city found that the act of putting photos to words was a highly impactful method for emotional engagement – the visualization of experience allowed participants to reflect on their story in a new way (Carlson et al 2006). The digital story workshops similarly provide a format for this level of personal contemplation, as the participants design and creatively depict their experience through voice and photos. One of our interviewees described this realization: “*It did surprise me [to see] the story once I finished it. It was something different for me, seeing it from living it.*”

The notion that one learns more about the experience through critical remembering and reflection is supported in several other studies of digital story intervention (Gazarian 2010, Carlson 2006, Yu 2011). In one study of young people’s views on digital stories

the authors found that the young participants believed the therapeutic benefits to be one of the most important strengths of the intervention (Yu et al 2011). The healing that occurs through weaving together a narrative about overcoming a difficult time and sharing that narrative with others is unique to the digital storytelling process.

Survivors connect with each other in new ways

The use of digital media for storytelling provides a format for sharing one's story with friends, family members, and even strangers whom they've never met. One of our participants described an experience in which someone reached out to her from Italy, because she'd seen her video on the Internet and was having a similar health experience. All of our workshop participants indicated that they'd utilized a multitude of formats for storing and sharing their video: on DVD, YouTube, Facebook, and email. One interviewee described the positive feedback she'd received from her family who had watched the video: *"They tell me that I am a warrior."*

In addition to the many possibilities for sharing and networking, digital stories also allow participants to connect with each other in new ways because the story itself can shed light into an experience that was previously not completely understood by those who had never gone through it. One creative storytelling project with persons affected by dementia found that personal stories led to improved attitudes and increased comfort level with patients of dementia for care providers (Georgia et al 2012). This study was conducted with fourth-year medical students who were assisting in a dementia care program. Pre and posttests for the storytelling intervention found that the students demonstrated quantifiably improved empathy for the residents of the program. Similarly, in one of the

focus groups, the viewers had a particularly strong reaction to a story about a person living with diabetes: “*Everything [in the story] was so common to us...the way it affected the family. It was real.*” These findings indicate that storytelling is not just a valuable method for promoting health and education within a community, but that it also can improve medical and nursing student education and lead to improved care practices (Georgia et al 2012).

THEME 2: Vulnerable populations do not have enough opportunities to tell their stories

Given what is known about the benefits of storytelling, and its longstanding use in many traditions, it is surprising that there is not more of an emphasis placed on this practice throughout the healthcare field (Gazarian 2010). Vulnerable populations that are subject to social stratification due to class, race, socioeconomic status, and language ability, have less opportunity than others to tell their story and be heard. The community of this study in the Yakima Valley falls into this category. Our participants are Latinos, and the majority of them speak Spanish as a primary language. Some of them did not finish high school and do not use computers regularly. One of the goals of the digital storytelling workshops implemented by FHCRC is to increase capacity for technology use.

Storytellers were surprised that anyone was interested in their story

Mainstream culture mostly portrays the experience of White upper-middle English speaking citizens in advertisements, television, and magazines. The voices of the more “ordinary” community members often go unheard in media and TV culture (Burgess 2006). Members of these socially underappreciated and underrepresented groups subsequently may adopt the belief system that their stories are less important. Several of

our study participants indicated that it was surprising to them when FHCRC reached out to them to create a story: “*We didn’t think that we would be suitable for many people to see us on the Internet.*” The more we can contribute to diversifying the faces of those whose stories are told on the Internet, the more we can create a more accurate representation of society.

Low literacy levels limit effectiveness of other education methods

Many focus group participants described the usefulness of the video for health education purposes. In doctors’ offices, health education materials are often disseminated in the form of literature: pamphlets and brochures that can be quickly handed out in a short doctor’s visit. For patients who do not read well or cannot read in English, these brochures are quickly tossed aside. One participant said: “*It’s like they go straight to the trashcan.*” Video digital stories are useful because they can provide a great deal of information in a short time frame. Some participants suggested having them play on monitors in doctors’ waiting rooms. Many of the digital stories created in our workshops are in Spanish, with English subtitles so they can be understood by members beyond the Spanish-speaking community.

The digital divide inhibits technology use

People with low socioeconomic status have less access to computers and internet. Furthermore, older generations may not be familiar with some of the basic skills involved in computer use. Some interview participants described how the digital story created an opportunity to share their story with their elders. In the focus groups, participants described how digital media is a valuable way for their children to connect with

grandparents. Since the elder generation might not know how to navigate computers, it provides an opportunity for children to show them their own knowledge.

THEME 3: Digital stories are useful in health prevention work

Digital stories provide education about community-specific health issues

The digital stories created by our workshop participants covered topics such as diabetes, pesticide-exposure, breast cancer, second-hand smoking, and food security. Participants were able to choose any topic that was important to them. Focus group interviews revealed that many of their community members could relate to these health issues.

Rather than a health education initiative that might determine the topics of importance, storytellers have the opportunity to speak from their own experience. In navigating the MOVE website where the digital stories are hosted, a viewer might choose a story based on a topic they need to learn about. This structure provides the space for self-determined learning approaches to health topics.

Hearing from a survivor is more impactful than other health education methods

Many other studies of digital story intervention projects are designed to assess the use of digital stories in medical education. The use of stories in the training of medical professionals is found to invoke empathy for patients and contribute to a patient-centered practice (Dickerson 2005, Christiansen 2010, Gidman 2012, Levett-Jones 2013). In one article, titled “Regaining our humanity through story,” the authors describe how the use of digital stories in medical education contributes to the ongoing paradigm shift in biomedical disease perspective toward a more comprehensive outlook on disease through the social determinants of health (Sierpina et al 2007).

Our focus group meetings reflect this evidence that survivor stories can provide a much more powerful medium for learning about diseases than the materials that are often provided in doctor's offices. Additionally, our focus groups revealed that some community members distrust their medical providers and do not feel that doctors have their best interests in mind: *“Do doctors really give [us] the care we need or is there some type of...overlook because of the language barrier and where we come from?”* There have been several health promotion initiatives using digital stories in Alaska Native populations as a culturally appropriate tool to relay complicated health information (Cueva et al 2013, Gubrium, 2009, Gubrium et al 2014, Lal et al 2014). Our interviews also demonstrate the necessity of culturally appropriate methods for providing health education.

Conclusion

The findings of this study support other literature that shows the many benefits of digital stories in health promotion work. For storytellers, it provides a healing outlet to critically reflect on a difficult experience and find support and connection within one's own community. For story viewers, digital stories are far more impactful than other forms of health education materials that may not be culturally appropriate or accessible to the members of this population. Furthermore, the engagement process of building capacity and collaborating within a community is an important way for community organizations to foster relationships within the community. Many of our participants indicated that they would be very happy to continue digital storytelling work with Fred Hutchinson Cancer Research Center.

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Appendices

Appendix 1: Interview questionnaire

Participant Name: _____

Interviewer Script:

Hello, may I please speak with [participant name]?

Hello [participant name]. My name is [interviewer name] and I am calling to ask you a few questions to follow-up on the digital storytelling workshops. You participated in the workshops in [month] at the Center for Community Health Promotion in Sunnyside. Is this a good time to complete the questionnaire?

NO: Okay, would you like to reschedule?

YES: When would be a good day and time to call you back?

Thank you, I'll call you then. Good-bye. **END CALL.**

NO: Okay, thank you. **END CALL.**

YES: Okay. Thank you for sharing a little bit of time from your day. Before we get started, I wanted to remind you that during the informed consent process, we let you know that after you completed your digital story, we would like to interview you to learn about your experience with this activity.

Before we begin, can I answer any questions or concerns about the information contained in the consent form?

Do you voluntarily agree to participate in this telephone interview?

NO: Okay, thank you for your time. **END CALL.**

YES: Okay, let's begin. **PROCEED TO #1.**

➤ ***These first few questions are about your thoughts and feelings PRIOR to participating in the digital storytelling workshops.***

- 1) Before you participated in this project, what did you think a digital story was?

- 2) What was your initial reaction to the idea of creating a digital story?

- 3) What did you think you would gain by participating in this project?

- 4) What kinds of worries or concerns did you have about creating a digital story?
(Probes: Had you ever used a computer before the digital storytelling workshops? Had you ever shared your feelings about the topic of your digital story?)

➤ ***These next few questions are about your thoughts and feelings now that you have completed the digital storytelling workshops.***

- 5) What was the most interesting about participating in the workshops to create a digital story?

- 6) What was the most challenging part of creating a digital story?

- 7) What surprised you about the process of creating a digital story?

8) Was the process of creating a digital story helpful in facing with feelings associated with the topic you chose? In what way?

9) How comfortable did you feel with the process overall?

	Disagree	Neutral	Agree
10) It was helpful to have a promotor(a) assist me in the process of creating my digital story.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
11) The promotor(a) made the process of creating a digital story easy to understand.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
12) Working on a computer to create a digital story was frustrating.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
13) Five meetings (of two hours each) was enough time to create and finalize my digital story.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
14) I found the digital storytelling project to be therapeutic.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
15) Creating a digital story brought up too many bad memories.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
16) Creating a digital story helped me talk to my family and friends (about the topic of my digital story).	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³

➤ ***These next few questions are about your opinions about your digital story.***

17) How do you think your digital story can educate/inform other people?

18) Have you shared your digital stories with other people?

¹ Yes → How have you shared it (Vimeo or MOVE link)? What comments have you received?

² No → Why not? Do you plans to share it in the future?

19) Who do you think your digital story may influence?

20) Do you think your digital story says something about your community?

(Probes: What do you think it says? Why does this situation/concern/strength exist? What can we do about it? How can your digital story provide opportunities to improve this in the community?)

	Disagree	Neutral	Agree
21) Storytelling plays an important role in adult education.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
22) Technology plays an important role in adult education.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
23) Watching digital stories improves a person's ability to learn about a topic.	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³

24) Is there anything else you would like to share about this digital story project?

➤ ***In closing, we would like to ask you a few demographic questions to help us with our analysis:***

25) What language do you prefer to speak?

¹ English

² Spanish

³ Other → Specify: _____

26) How many years of school have you completed?

¹ 4th grade or less

² 5th through 8th grade

³ 9th grade through 12th grade, no diploma

⁴ High School graduate or GED

⁵ Some college, but no degree

⁶ College degree

⁷ Advanced degree (MD, PhD, JD Master degree)

27) What is your occupation? _____

28) What is your race? [CHECK ALL THAT APPLY]

¹ White

² Hispanic

³ Black or African-American

⁴ American Indian or Alaska Native

⁵ Asian or Pacific Islander

⁶ Other → Specify: _____

29) What is your gender?

¹ Male

² Female

30) What year were you born in? _____

Appendix 2: Focus Group questions

FOCUS GROUP QUESTIONS FOR THE COMMUNITY DIGITAL STORYTELLING PROJECT

WELCOME

WELCOME PARTICIPANTS AND PROVIDE A COPY OF THE CONSENT FORM TO ALL PARTICIPANTS AS THEY ENTER THE ROOM.

“Hello, my name is _____, and I’m a member of the research team for the Community Digital Storytelling Project at the Center for Community Health Promotion and the Fred Hutchinson Cancer Research Center. We are here today because we are interested in learning if digital stories are a useful way of sharing information with community members. First, we need to review the consent form.”

REVIEW CONSENT FORM AND GET WRITTEN CONSENT. THANK ANYONE WHO DECIDES NOT TO PARTICIPATE FOR CONSIDERING PARTICIPATION. CONSENT FORM WILL PROVIDE SPECIFIC INFORMATION ABOUT RESEARCH, PURPOSE OF THIS GROUP, PROCEDURE, PARTICIPANTS’ RIGHTS, AND COMPENSATION FOR TIME.

“You’ll see from the consent form that the group’s purpose is to learn about people’s opinions of the digital stories.”

BRIEF INTRODUCTIONS

“To begin with, let’s go around the (table, room) and have each of you come up with a nick name and something about yourself. I’ll start...”

Now that we know each other, I wanted to say a few things before we move onto the discussion. Anything we say here today is confidential. We will not be asking any personal questions, only questions related to the digital stories. None of your responses will be reported outside of this study in such a way as to identify you. Only a summary of the evaluations of each message will be used. To maintain full confidentiality of the group responses we ask that you do not share with others anyone’s individual answers from the group today.

Please feel free to share your ideas and opinions even if they are different from others. All views and ideas are important, and there are no right or wrong answers. We would like to get as many different points of view as we can. Since this is a group discussion you do not have to wait for me to call on you to speak, but please try to speak one at a time. If everyone starts talking at once I may ask you to stop so that we can hear everyone.

We would like to record the discussion today to make sure we don't miss any of your comments. We take notes but often they are not as complete as when we record the discussion. If you want to make a comment that you don't want recorded, just tell us that and we'll turn off the recorder and re-start it when you finish making your comment. Is that OK?"

START THE DIGITAL RECORDER

BEFORE SHOWING THE DIGITAL STORY:

"Before we get started, I would like to ask you a couple of questions about how you acquire information, especially information about health."

1. How does your family share health knowledge, wisdom, and experiences? (Is it by showing how to do something, have someone follow an elder around, sharing through stories, etc.)
2. In what ways do you like to learn about health topics? (Prompts: Printed materials like magazines and books, Television – prompt for what kind of shows or news, Library, Doctor, etc.)
3. Have you ever heard of a digital story? What do you think it is?

"Now I am going to show you a digital story and afterwards will ask you some questions about digital stories. This is only one of a number of digital stories that community members have created."

AFTER SHOWING THE DIGITAL STORIES:

1. As you watched the digital story, what did you think about? (Prompts: Did it make you uncomfortable? Did you have difficulty paying attention to it? Did you like it? If so, why? Did you not like it? If not, why? Is there anything in particular that was worth remembering about the digital story?)

2. What is the main message this digital story is trying to get across? What do you think is happening in the digital story?
3. What new information did you learn from the digital story?
4. Did the digital story have any influence on your health plans; that is, are you now motivated to take some action? (Prompts: If so, what does it motivate you to do?)
5. Do you think the digital story can educate and inform people about a topic? (Prompts: How? In what ways?)
6. How does learning from the digital story compare to learning about [topic] from written information (like pamphlets or brochures or booklets?) (Prompts: Better than, same as, worse than. What is better, same or worse?)
7. Does the digital story focus on anything but [topic]? That is, does it emphasize differences in your community about people who are uninsured, poor, ethnically different, and so on?
8. What do you think about sharing this digital story with other people in your community? (How will it be received?) Who should it be shared with?
9. How do you think digital stories can best be shared? (Prompts: Should family members share it with other family members? Should it be shared on a website? Via television? Via social media? Be available in libraries? Other? Is one outlet better than another?)
10. Are there other types of digital stories you believe should be created for other people in your community? What topics, and for what audiences?
11. Is there anything else you would like to share about the digital story?
12. Are you interested in working with us to make a digital story? (Prompts: If anyone says yes, explain what is involved.)

CHECK FOR OTHER IDEAS AND SUGGESTIONS OVERALL: *“Now that you had time to hear each other’s ideas, do you have additional suggestions for us?”*

CLOSING STATEMENT

“That completes the discussion. Does anyone have any other questions, comments, or final thoughts they would like to share?”

Thank you again for your participation.

If anyone thinks of other questions or concerns, you can call our office at 1-866-809-6846. Before we end the session, I have a few administrative/business details to share with you.”

8. ADMINISTRATIVE DETAILS:

“_____ has your \$20 gift card for your participation today.”

[HAVE PARTICIPANTS SIGN THE RECEIPT FORM FOR THE GIFT CARD.]

“Thanks again for your comments – these will really help us.”

DIGITAL RECORDER PROTOCOL

- **PUT DIGITAL RECORDER ON FLAT SURFACE APPROXIMATELY HALFWAY BETWEEN YOU AND PARTICIPANTS**
- **SET UP BACK UP RECORDER**
- **TEST DIGITAL RECORDER AND START RECORDING**

NOTE TAKER PROTOCOL

- **CREATE A DIAGRAM OF THE TABLE WITH AN IDENTIFIER FOR EACH PERSON**
(e.g., 1, 2, 3)
- **AS EACH PERSON SPEAKS, NOTE THEIR IDENTIFIER PROVIDED BY THEIR FIRST FEW WORDS**
- **PROVIDE A COPY OF THE DIAGRAM AND INITIAL WORDS TO THE TRANSCRIPTIONIST TO HELP IN FOLLOWING THREADS OF CONVERSATION IN THE RECORDING.**
- **NOTE ANY OTHER PARTICULAR COMMENTS THAT STAND OUT TO DISCUSS IN THE DE-BRIEFING AFTER THE GROUP**