Using Animation as an Information Tool to Advance Health Research Literacy among Minority Participants

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Abstract

Lack of adequate consumer health information about clinical research contributes to health disparities among low health literate minority multicultural populations and requires appropriate methods for making information accessible. Enhancing understanding of health research can enable such minority multicultural consumers to make informed, active decisions about their own health and research participation. This qualitative study examines the effectiveness and acceptability of an animated video to enhance what we call health research literacy among minority multicultural populations. A team analyzed the transcripts of 58 focus groups of African Americans, Latinos, Native Hawaiians, and Filipinos in Los Angeles/Hawaii. Participants were accepting of animation and the video's cultural appropriateness. Communicating information about health research via animation improved participants' ability to identify personal information-gaps, engage in meaningful community-level dialogue, and ask questions about health research.

Introduction

Increasingly, investigators in the field of consumer health informatics have identified limited health literacy as a primary barrier to accessing healthcare resources among medically underserved minority populations.^{1,2} The Institute of Medicine (IOM) defines health literacy as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."¹ Nearly half of American adults struggle to function in the health care system due to low levels of health literacy, ^{3,4} and studies suggest that differences in health literacy levels are related to racial and ethnic health disparities.⁵ While minority populations suffer from significantly lower levels of health literacy than the general population,^{6,7} such populations are also inadequately represented in clinical health research.^{8,9} In this paper, we make use of the concept of "health research literacy" to highlight the increasing evidence that minority underrepresentation in health research is, in part, due to lack of awareness of research opportunities¹⁰ and limited understanding of research processes.¹¹⁻¹³ General health literacy is linked with the ability to gather and use information to make health-related decisions, and clinical trial participation is one such health-related assessment minority enrollment in health research and clinical trials.

Increasing minority participation in clinical health research is important and necessary in addressing equity in health care provision, ensuring the generalizability of research findings and improved health outcomes.¹⁴⁻¹⁶ Paramount to this need are approaches that promote effective dialogue among minority and multicultural health consumers about all stages of research (recruitment, enrollment, and retention) at individual and communal levels through the exchange of information. Inadequate health communication, including limited consumer access to relevant health information and intercultural communication barriers in the healthcare setting, contribute to health disparities among poor, at-risk, vulnerable, and minority populations.¹⁷⁻¹⁹

The challenges of inadequate health communication, combined with low consumer health literacy, are especially visible in the limitations inherent in the current informed consent process – the key manner in which health care consumers gain information about participation in research. In fact, Institutional Review Boards (IRBs) and researchers often fail to provide research subjects with study information that is literacy-level appropriate.⁷ Furthermore, researchers and IRBs have focused on the presentation of risks and benefits, without a concurrent meaningful discussion that ensures participants understand the information disclosed.^{4,20,21} Limited health research

literacy can impede healthcare consumers' comprehension of the consent information, consequently limiting consumers' ability to ask questions and make decisions.^{22,23} At a minimum, health research requires that researchers ensure true comprehension is achieved so participants may make more informed choices about participation.

Medical sociologists have elucidated the complexities of 'choice' and the extent to which decision-making maybe constrained in the healthcare setting.^{24,25} Building on these insights, researchers in the field of consumer health informatics have pointed to the importance of considering the social and cultural context in which individuals seek information and make health decisions,.²⁶ The inclusion of community in a dialogue around research participation matters among minorities because the decision to participate is frequently not independent of community involvement and may support consumers in making informed decisions throughout the trial in an on-going process – a dialogue – rather than a discrete act of choice that takes place in a singular moment. 27,28

Commonly used methods of informing minority and multicultural populations about clinical research have not adequately improved their participation in clinical trials or their ability to comprehend and give informed consent. ^{14,29} The lack of easily accessible information about clinical research for minority populations with limited health research literacy is a key barrier.³⁰⁻³² Institutional Review Board (IRB) requirements have facilitated efforts in the development of informed consent forms that meet readability standards for low literacy groups.³³⁻³⁵ However, there is some indication that IRBs may be inadvertently advancing content that is beyond their own readability guidelines.⁷ In addition, there is a need for informational resources that increase awareness about clinical research and take into account the unique cultural and communal aspects of decision-making among minority populations.

Research shows that populations with low health research literacy are often more open to visual multimedia based information³⁶⁻³⁹ and that practitioners and health educators should make use of a wide range of traditional and novel health information resources, from static informational Webpages to information visualization tools such as online digital content and audio/video programming.²⁶ There is some evidence of the positive impact of video-based educational efforts on potential research participants' improved attitudes about participation in clinical research, increased knowledge and satisfaction and decreased anxiety regarding participation.⁴⁰⁻⁴² Despite extensive video use in education, health promotion and intervention efforts among non-English speaking groups in the United States, video-based research recruitment and consent efforts among these populations has been limited.³²

Animated videos have been found to be effective in providing information, particularly for minority populations with low health literacy.^{36,43,44} Because animation is typically perceived as non-threatening, familiar and accessible across age groups, cultures and literacy levels, it may hold the attention of viewers and enhance recall. In addition, animation has been shown to be more effective than live-action as an educational tool because it gives filmmakers' greater control over presentation, characterization, staging and timing, making it a powerful medium for conveying symbolic theories and concepts.⁴⁵ There is evidence that when compared to written materials alone, cartoon illustrations and pictographs have been more successful in improving patient recall, comprehension of consent materials, satisfaction with care and compliance, particularly among low literacy populations.⁴⁶⁻⁴⁸ A prospective randomized controlled trial comparing the effectiveness of written materials versus animation found the latter to have significantly improved post-intervention levels of knowledge and long term retention of health information among study participants.⁴⁴ This study addresses a gap in the existing literature regarding the acceptability of animation about clinical research more accessible to them in a culturally concordant fashion. The unique health information needs of minority healthcare consumers and research participants, and the urgency of increasing minority representation in clinical research, make these findings both timely and significant.

Methods

This IRB approved project entailed a three-stage methodology for the development of a an animated video promoting health research among minority populations: 1) literature review, 2) development and production of the video and 3) assessment of acceptability of the video. This paper focuses on results from the stage three.

A systematic review of the literature was conducted in order to create a taxonomy⁴⁹ of unique and shared barriers and facilitators to participation in health research among minority populations. The taxonomy informed the development of an educational video script enhanced with entertainment qualities^{50,51} and cultural concordance through strategies such as ethnically appropriate character rendering and accents, color schemes and inclusion of

culturally familiar terms and values in the script.⁵² Cultural concordance was informed and assessed by community members, who were representative of the minority characters created in two stages of the development of the video. First, a draft of the script was circulated among ethnically representative non-academic and academic community members, both in Los Angeles and Hawaii, for initial feedback, which was used to revise the script before the development of the video. Second, a draft version of the video was circulated among a similar group of ethnically representative community members for feedback and revision of the video. The community members' feedback spanned a range of topics from ethnically appropriate character rendering and accents to choice of language used in the script. The video length is seven minutes and features four adults of diverse age, gender, and ethnicity. The story follows the conversation of four work colleagues sharing their curiosity, reservations, and knowledge about health research participation, with two characters sharing their personal experiences. The video does not address the details of participation in any specific research study but instead addresses participation as a research subject generally. (To view video, see http://axis.cdrewu.edu/what_is_health_research).

Focus group techniques⁵³ were used to assess acceptability of the video among minority participants, who were screened and enrolled by multicultural staff. Focus groups included a moderator and a facilitator who took notes during the focus group proceedings. Participants were limited to English-speaking, lower literacy adults who selfidentified as Latino, African American, Filipino, or Native Hawaiian. Participant literacy level was inferred by limiting enrollment to those who had not completed secondary education, a method supported by the National Adult Literacy Survey of 1992, the significant finding of which is that literacy proficiency is strongly related to levels of formal schooling.⁵⁴ Latino and African American participants were recruited from South Los Angeles and Filipino and Native Hawaiian participants were recruited from Oahu, Hawaii through network snowball sampling and convenience sampling methods, such as advertising through public forums. Eight focus groups were conducted, 2 per ethnic group, each comprised of 8-12 individuals (for a total of 58 participants). A script guided interviews with questions arranged by category to facilitate content analysis. After the introduction, participants were asked to discuss their initial impressions of health research. Participants were then asked to watch the animated video entitled "What is Health Research?" After the video was screened, focus group interviews were conducted to evaluate responses to the use of animation and the likelihood of participating in health research after viewing the video. Focus group sessions were recorded and transcribed, demographic information was collected, and participants were remunerated \$25. Using Atlas ti software to help manage and analyze the data, focus group transcripts were coded and indexed by team members to develop analytical categories based on qualitatively informed and modified grounded theory techniques. Initial codes were independently generated by team members, and then sorted into agreed upon categories. Transcripts were then recoded. Constant comparison within and across categories allowed researchers to check codes and establish categories that reflect the nuances of the data and key themes.

Results

Table 1 shows participant characteristics. Participants were similarly distributed across ethnic groups, with slightly more representation among Latinos (33%) and slightly less representation among Native Hawaiians (21%) than among the other groups. Ninety-two percent of participants across ethnic groups had never participated in health research. Fifty percent (50%) of participants reported a secondary education or less, although it is likely this number is higher since it was unclear how participants interpreted "college". The majority of participants earned a monthly income of \$2000 or less (74%), with 36% earning below the 2012 poverty level of \$ 11,170 per year.⁵⁵

Characteristics	Race/Ethnicity n(%)				Total n(%)
	African American	1 Latino	Hawaiian	Filipino	
	13(22)	9(33)	12(21)	14(24)	58(100)
<u>Age</u> y, mean	40	34	48	32	39
<u>Gender,</u>					
Male	7 (37.0)	7 (37.0)	1 (5.0)	4 (21.0)	19(100.0)
Female	6(15.0)	12(31.0)	11(28.0)	10(26.0)	39(100.0)
Education,					
Secondary or Less	5(17.0)	13(44.0)	6(21.0)	5(17)	29(100.0)
Some College	8(28.0)	6(21.0)	6(21.0)	9(31.0)	29(100.0)
Income (US \$)					
0-500	3(14.0)	7(33.0)	4(19.0)	7(33.0)	21(100.0)

Table 1. Participant Characteristics

501-1500	6(33.0)	5(28.0)	2(11.0)	5(28.0)	18(100.0)
1501-2000	1(25.0)	2(50.0)	0(0.0)	1(25.0)	4(100.0)
2001-5000	3(23.0)	3(23.0)	6(46.0)	1(8.0)	13(100.0)
NR	0(0.0)	1(50.0)	1(50.0)	0(0.0)	2(100.0)
NR Health Research					
Yes	1(50.0)	0(0.0)	1(50.0)	0(0.0)	2(100.0)
No	9(18.0)	17(35.0)	11(22.0)	12(24.0)	49((100.0)
NR	3(43.0)	2(29.0)	0(0.0)	2(29.0)	7(100.0)

Participant responses to video production and animation – acceptability

There was an overall preference for animation among participants (Table 2). Participants reported a preference for animation because they perceived it as more engaging, "lively", and easier to relate to. They felt that real actors may be inauthentic or "just acting". Participants generally felt that the video's dialogue was accessible and clear, familiar sounding, understandable, and the coloring, accent, and ethnicities of the characters were well-done. Constructive responses to the video's animation varied across ethnic groups, and tended to focus on pacing and tone, as well as certain aspects of character rendering. Filipino viewers generally reported feeling overwhelmed by the amount of information provided in the short video. The majority of Native Hawaiians felt that the video had a tone of recruitment, somewhat like begging, while a minority of African American participants felt that the video was not long enough to give adequate attention to some of the serious material that it addresses, such as the abuse of research subjects uncovered in the Tuskegee syphilis experiment. While there was a range of responses to character rendering across ethnic diversity of the characters represented in the video.

Participant	Video Production and Animation			
responses				
Positive	Preference for animation. "Animated was way better. I don't know why, just because -It was			
responses	more lively." - Latino. "I think if it would have been live people, I would have been going, oh,			
	boring. Because if it would have been live, [I would have thought this] dude is full of BS. So I			
	thought it was better, the animation." – Latino. "I think they drew the characters well. They looked			
	like what they were supposed, and I think the colors were attractive." – Native Hawaiian			
	Accessibility of content. "If anything, like how they was having the conversation and stuff like that			
	was very open, you know, for everybody to understand." - Native Hawaiian. "It explained the			
	benefits of what participating in the research would do. It was short, to the point. It was a good			
	representation of the different ethnic groups, at least for this country. It was just very clear,			
	simple, and easy to understand and follow." – African American			
	Character rendering. General rendering of the characters across groups, especially the coloring,			
	accent, and the ethnicity. "I thought it was characterized right because just with different entities			
	and you could tell which one had an accent and all that, so that was cool." - Latina			
	Ethnic representation was relatable. "I liked it because There wasn't just one nationality at the			
	table talking. There was a variety. I liked that" - Native Hawaiian			
Responses	Pacing. "One of the things I thought they could do to improve the video was they covered a lot of			
indicating	information, a lot of different points that were all important, but it was covered really fast. I mean,			
needs	you really had to pay attention or you missed things, so possibly it could be slowed down. It felt a			
improvement	little bit like we were in a race." - Native Hawaiian			
	Tone. (a) Recruitment; (b) Trivialization. (a) <i>"It seemed like it was just trying to get you to join"</i>			
	something." – Filipina (b) "That was way deeper than a commercial - I was like, really? Really, in			
	the 7 minute commercial you're going to go Tuskegee on me?" - African American			
	Preference for live actors. "But I think real people would have delivered a more sobering			
	message Because when we see animation we're not really in reality." - African American.			
	Character rendering. (a) Ethic representation; (b) Speech. (a) "They looked almost the same			
	ethnicity until you heard the accents. Ethnicity wise, they looked similar." –Latino. (b) "I think the			
	Hawaiian part was too fast. Nobody speaks Hawaiian like that" - Native Hawaiian "I didn't like			
	the older gentleman's voice at all 'Cause we all don't speak with a southern Louisiana slash,			
	drawl. Not all black folks are from the south." – African American			

Table 2. Summary of Results: Participant Responses to Video Production and Animation

Pre-video perceptions of health research

Participants indicated a broad understanding of the health problems that afflict their ethnic community and, consequently, a desire to participate in health research to find new medical discoveries that would improve the lives of the people they know, and their communities at large (Table 3). They also made a strong association between health research and scientific discovery, including improvements in a range of health aspects, from lifestyle and education to the often-cited "cure for cancer." Participants believed that health research can promote disease prevention through the development of new health techniques, information about one's own health, and access to the latest medications, not only for the individual, but also for friends, family, and other community members. African American participants expressed reservations about certain aspects of health research (and clinical trials of all kinds), as well as a greater general distrust of the medical establishment. Participants across ethnicities were concerned that corporations, medical providers, and/or pharmaceutical companies might benefit financially from health research at the expense of their ethnic minority research subjects. They were also concerned about the corporatization of healthcare and the rising cost of care and worried that the personal physical risks of health research could outweigh the benefits. This latter concern was particularly pronounced among women.

Post-video perceptions of health research – effectiveness

Participants demonstrated a marked improvement in their ability to identify their own knowledge-gaps, to ask questions, and to seek information after viewing the video. They appreciated learning about the subject both in terms of potential indirect benefits to be gained by participating as well as about the process of research. In terms of personal benefits, the majority of participants felt that health research may result in indirect benefits to their health through health education or a supportive and structured healthcare environment. After viewing the video, participants across ethnic groups remained wary of the benefits of clinical drug trials, but expressed a willingness and desire to learn more about specific studies. With regards to process, the involvement of family members was exceptionally reassuring for participants in all groups. Family involvement entailed family members helping participants by asking questions on their behalf, providing advocacy, and offering support throughout the research.

Ultimately, participants reported a better understanding of the process of health research after viewing the video. For example, some of the participants were reassured by learning about the IRB. For some this was new information, while for others, the video improved their understanding of the process and reasoning behind IRB oversight of clinical studies. Several participants were interested in learning more about how participants expressed a general desire to help their communities; however, this desire became more concrete after viewing the video. For example, some participants told personal stories about people they knew who were ill, while others where moved to plead for greater community involvement in health research. For these individuals, the video provoked both a desire to participate on behalf of the community, as well as a desire to promote health research in their own communities.

Personal concerns about participating in health research expressed after viewing the video were primarily characterized by participants' lingering fears about the risks, particularly the possible long-term side effects and the role of the placebo. Filipino and Hawaiian participants also raised new questions about the amount of time it takes to participate in health research. This concern was framed as a practical concern about the financial costs of participating in health research, including loss of hourly wage and work scheduling issues. After viewing the video, African Americans, Latinos, and Hawaiians also reported a continuing concern about the ethics of health research for ethnic communities. This concern was framed by extensive discussion about contemporary and historical racial inequality in health care and human testing (e.g., the Tuskegee syphilis experiment).

Participants Responses	Pre-video Perceptions	Post-video Perceptions
Positive	Community Participation. "I think it's a	Community participation. "I was going to say that I
responses	chance to look at problems and to try to	like the whole approach and the dynamic of the video.
	collect information about the truth and be	But I think my humble opinion is that they should
	as objective as possible. And you try to find	make more emphasis in showing the community how
	knowledge so that we can maximize	important it is for us to volunteer and help you, the

Table 3. Summary of Results: Participant Perceptions of Health Research, Pre- and Post-Video Viewing

	everybody's health and [help us] that way." – Native Hawaiian Scientific Discovery. "New discoveries about how to improve our health or our lifestyle, education, anything. New findings." -Latino Prevention. "Absolutely positive, research. New discoveries about how to improve our health or our lifestyle, education, anything. New findings." -Latino	scientists. We want solutions. We want our family members to be healthy, to live longer, even ourselves. So how is that going to happen? They can't experiment everything on animals. We got to participate. We got to get involved." – Latino Desire to help friends and family. "I have a friend, a close friend- she's battling breast cancer. And within a year, both of her breasts got removed. So, I would like to get more information on that. I tell you, I would be willing to take medication or studies or whatever to get information." - Latina Reassuring. (a) Family support, (b) IRB, (c) a better understanding of the process of health research. (a) "Yeah, and it didn't exclude the family member if they wanted to be there, instead of saying oh, no, it just has to be this person." – Latina. (b) "That IRB, that's the first time I've ever heard it where it was utilized to make sure that the thing is a committee talk first before it's utilized. I dig that because it's like making sure that something that is trial doesn't harm a person." – Native Hawaiian. (c) "[I] like how thorough they are about telling you how the health research goes. They go into details, so you kind of know before you do it, the process." - Filipino Personal health benefits . "Because I have high blood pressure and it's sort of related to his heart disease. And it's - they always tell you the same thing, watch your diet and exercise. If you're in a
		[research] program, I think it would be better for you." - African American
Responses indicating needs improveme nt	Health research not easily understood. "I just think numbers whenever the news come on and they give me numbers, like data, stats and stuff like that. Yeah, when they dump – sometimes I don't know what it means but it takes you awhile to figure out, oh, it's pretty bad." – African American Corporate ethics of health research. "I think of medical providers. Is it about health or is it about money? "– African American Risks of health research. (a) side-effects (b) role of the placebo. (a) "Because [the treatments are] not FDA approved, they're investigational, that's why. So you're taking risks, you knowThe person's life could be changed forever." – Latino . (b) "For me, both positive and negative. Sometimes it's good medicine and sometimes it doesn't work. Yeah, because you get a placebo sometimes." – Latino	Amount of time it takes to participate. "Because see I have a part-time job and then I babysit and I don't think that I have enough time to, you know, come and participate." - Filipina Politics of Race /ethics of health research. (a) "a lot of times the benefits [of a new medication] aren't that great but its' more so a financial issue for pharmaceutical companies [who benefits-] Is it the patient or is it the pharmaceutical company" African American. (b) "I'm just concerned that why would you only test a certain group. If you're going to have okay for diabetes, then it doesn't matter what ethnicity you areThat's what concerns me." - Latino.(c)"[Why do you] only want to use these drugs on people of color?" - Latino Lingering concerns about risks. (a) the side effects, (b) and the role of the placebo. (a) "with an experimental drug, am I going to grow another head? Am I going to grow a tail? I mean, and I've got little ones to think of, what I may not have now with all the side effects, are all those side effect actually going to go away, are they gonna stay?" - Latina. (b) "I would not [participate]Because they make it clear that some people's going to get the real thing and some neople's not and they're not going to tall you:

	which." - African American

Discussion

This study developed and evaluated the acceptability of the use of a culturally concordant animated video as a tool for promoting health research literacy in clinical research among multicultural populations. The results indicate that participants generally responded positively to video animation and ethnic representation of characters. Specifically, many participants found the animation aesthetically pleasing, engaging, and trustworthy. While some participants preferred live-action, the majority of respondents felt that the animated characters were more relatable than live actors. This finding suggests that video animation may be an appropriate tool and method for educating low health literacy populations about health research. Animation may be utilized as an education tool at multiple stages of health research, including recruitment, informed consent, and retention. Participants' varying range of responses about video pacing, tone, character rendering, and preference for animation vs. live-actors highlights the particular communication needs of distinct minority communities. Researchers can ensure the appropriateness of these aspects by incorporating feedback from community members during the development, production, and testing of the video.

Having the capacity to obtain, critically evaluate, communicate and use health information are characteristics of proficiency in health literacy.^{1,2,17} After viewing the video, participants appeared to be able to identify gaps in their own knowledge about health research and to express an increased desire to seek information to address these gaps. For example, before viewing the video, participants expressed general concerns about the risks of participating in health research. After viewing the video, participants were able to ask more precise questions, such as about the role of the placebo in drug trials, IRB process, and overall procedures of health research. These outcomes have been linked with better-informed and more engaged research participants who are capable of informed consent.^{17,18,24}

Similarly, after viewing the video, participants demonstrated an increased ability to critically assess and inquire about the benefits and burdens of health research participation. For example, after viewing the video, Filipino participants raised questions about how trial participation might economically impact their families if they were required to miss work or find childcare to participate- significant deterrents to participation for these individuals. This may be a particular problem in immigrant communities, where individuals often have family members living abroad who depend on the income that working-migrants provide.^{56,57} Female participants worried more about the personal physical risks than did male participants. Such concerns may stem from the women's greater need to take into consideration the needs and opinions of their families when making such decisions.. Participants may need more information about time commitments and health risks to assess the acceptability of these participation burdens.

This study further emphasizes the importance of the role of family in individual health decisions of minorities. After viewing the video, participants across ethnic groups reported feeling positive about being able to give or receive family support throughout the research process. This finding supports studies that show the importance of family in the individual health decision-making of minorities.^{35,58} Researchers may be able to promote minority participation and understanding at all stages of health research by educating participants' family members about health research and by allowing family to accompany participants throughout the research process.

During the focus groups, participants demonstrated a desire to dialogue with one another and process information related to health research. Participants discussed the questionable ethics of health research historically conducted in minority communities, shared personal stories about the illness of their friends and family, expressed a desire for greater community involvement in health research, and exchanged information with each other about community health resources and health education. These findings suggest that community context and dialogue are important to these minority participants when processing information and making health-related decisions.⁵⁹ These findings also suggest that animated videos may be augmented when accompanied by a community facilitator.

There are several limitations to our data and study findings. We had a relatively small convenience sample, and consequently our participants are not necessarily representative of the larger ethnic populations. Thus, we are unable to make definitive assertions about significant differences in participant responses to the video. Furthermore, while differences in age and stage of life may have affected their perspectives about health research even more than ethnicity, we were not able to discern such differences in a systematic manner, given our small samples. However, the data represent information-rich cases, homogenously stratified across these ethnic groups to allow in-depth understanding of their perceptions about health research and the use of an animated video. Future research may

include comparatively testing the impact of the educational video when rendered in other formats (such as liveaction), testing a video tailored to a specific clinical trial, and developing alternate animations based on focus group feedback.

Conclusions

Consumers' need for health information continues to be a barrier for minority populations experiencing health disparities and requires appropriate methods and tools for making information accessible to such consumers. An animated video may be an effective educational tool that enhances the health research literacy of minority populations. Specifically, an animated video can address knowledge gaps regarding research participation among minority populations, thereby enhancing informed consent and empowering research participants as decision-makers. Further, such an educational video may initiate meaningful dialogue around health research participation at the individual and communal level. The social and cultural contexts in which individuals make health-related decisions may be even more important among minority populations in which the centrality of community and family members has been noted. Health research literacy and improve comprehension about research and informed consent for minority populations. Improving literacy about the research process may also reduce the risk of undue inducement among these vulnerable populations and may contribute to better-informed participants in the recruitment, enrollment and retention of low health-literate minority populations in health research.

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