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UNIVERSITY OF CALIFORNIA SAN DIEGO

The Context and Development of a Vaccine Promotion Intervention with a Somali Community

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of
Philosophy

in

Anthropology

by

Samantha Aubrey Streuli

Committee in charge:

Professor Amy Non, Chair
Professor Bonnie Kaiser, Co-Chair
Professor Wael Al-Delaimy
Professor Hanna Garth
Professor Saiba Varma

2021

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University of California San Diego

2021

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CURRICULUM VITAE

EDUCATION:

- 2021 PhD Anthropology
University of California San Diego
Dissertation Title: The Context and Development of a Vaccine Promotion Intervention with a Somali Community
- 2016 MA in Anthropology
University of California San Diego
Thesis Title: Maize, Meat, and Migration: Stable Isotope Analysis at Chalcatzingo, Morelos, Mexico
- 2014 BA in Anthropology
The Ohio State University
- 2012 AS Liberal Arts & Sciences
Sinclair Community College

RESEARCH EXPERIENCE:

- 2016-2021 University of California San Diego
Graduate Student Researcher
Dissertation
- 2014-2016 University of California San Diego
Graduate Student Researcher
Master's Thesis

FELLOWSHIPS AND GRANTS:

- 2020 Fletcher Jones Dissertation Completion Fellowship, \$42,385
F.G. Bailey Fellowship, \$3,200
Gil Kushner Memorial Travel Award, \$500
The Critical Refugee Studies Collective Grants in Critical Refugee Studies, \$4,500
- 2016-2018 UCSD Interdisciplinary Collaboratories Fellowship, \$29,000
- 2014-2018 San Diego Fellowship, \$54,000
- 2014 The Ohio State University Undergraduate Research Office Travel Grant, \$300
- 2013-2015 Critical Difference for Women First Generation Scholarship, \$1,000
- 2011-2012 Sinclair Community College Honors Program Scholarship, \$500

PUBLICATIONS:

Streuli, S.A. and T.L. Lewis. Shifting Priorities and Neoliberal Ideologies in Refugee Health Intervention Design. Submitted for review.

Streuli, S.A., N. Ibrahim, A. Mohamed, M. Sharma, M. Esmailian, I. Sezan, C. Farrell, M. Sawyer, D. Meyer, K. El-Maleh, R. Thamman, A. Marchetti, A. Lincoln, E. Courchesne, A. Sahid, and S.P. Bhavnani. Development of a Cultural and Linguistically Sensitive Virtual Reality Educational Platform to Improve Vaccine Acceptance within a Refugee Population: The SHIFA Community Engagement-Public Health Innovation Program. Submitted for review.

PRESENTATIONS:

Streuli, S.A. and Lewis, T.L. (2021). Epistemological Negotiations and Shifting Priorities in the Design of a Vaccine-Promotion Intervention for Somali Refugees. 81st Annual Meeting of the Society for Applied Anthropology. Virtual.

Ulrich, L., Bhavnani, S., Ibrahim, N., and **Streuli, S.A.** (2020) The Paradox of Corrective Communications: Findings from an MMR Vaccine Awareness Strategy. AMWA Medical Writing & Communication Conference. Virtual.

Streuli, S.A. (2020) “The Mother's Instincts Should be Listened To”: How a Somali refugee population navigates a technology-based vaccine-promotion intervention. 80th Annual Meeting of the Society for Applied Anthropology. Albuquerque, NM. Canceled due to COVID-19.

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Streuli, S.A., Somerville, A.D. and Schoeninger, M.J. (2016) Maize, Meat, and Migration: Stable Isotope Analysis at Chalcatzingo, Morelos, Mexico. Submitted Podium Presentation. 82nd Annual Meeting of the Society for American Archaeology. Orlando, FL.

Streuli, S.A., Ahern, J.S., Kolotarowicz, A., and Vercellotti, G. (2014) Application of FORDISC to an Historic Italian Population for Sex Determination. Poster presentation. Southwestern Association of Biological Anthropologists 2nd Annual Meeting. Tucson, Arizona.

Streuli, S.A., and Hubbe, M. (2014) Trauma and Pathology in Western European Pleistocene Hominins: Implications for Relative Adaptability. Poster presentation. 83rd Annual Meeting of the American Association of Physical Anthropology. Calgary, Canada.

Streuli, S.A., and Hubbe, M. (2014) Trauma and Pathology in Western European Pleistocene Hominins: Implications for Relative Adaptability. Poster presentation. Ohio State University Denman Undergraduate Research Forum. Columbus, Ohio.

TEACHING AND MENTORING EXPERIENCE:

- 08/2020 – 09/2020 **Associate In,** UC San Diego
Course: Immigrant and Refugee Health
- 10/2015-06/2020 **Graduate Teaching Assistant,** UC San Diego
Courses: Debating Multiculturalism, Human Osteology, Human Origins, Evolution of Human Diet, Humans are Cultural Animals, Bioarchaeology, Global Health and Cultural Diversity, #BlackLivesMatter, Biology and Culture of Race, Culture and Mental Health
- 10/2015-06/2021 **Director and Mentor,** UC San Diego Anthropology Mentor-Protégé Program.
- 03/2015-07/2016 **Science Instructor,** TRIO Outreach Program.
Courses: Introduction to Biological Anthropology, Evolution of Human Diet
- SERVICE:**
- 2020-2021 **Executive Board Member,** Medical Anthropology Student Association
- 2015-2016 **Secretary,** UCSD Anthropology Graduate Student Association
- 2015-2016 **Member,** UCSD Diversity Advisory Council

ABSTRACT OF THE DISSERTATION

The context and development of a vaccine promotion intervention with a Somali community

by

Samantha Aubrey Streuli

Doctor of Philosophy in Anthropology

University of California San Diego, 2021

Professor Amy L. Non, Chair

Professor Bonnie Kaiser, Co-Chair

The measles, mumps, and rubella (MMR) vaccination has been the subject of many disinformation campaigns claiming that it is associated with the development of autism. Somali immigrants and refugees have been particularly targeted by such campaigns and, as a result, are hesitant to accept the MMR vaccine. However, these campaigns are not the sole reason for

vaccine hesitancy within this population. This dissertation is concerned with the social and political context of vaccine decision making within a Somali population in Southern California. I also examine an organization attempting to counter disinformation. I consider the context within which vaccine decision making occurs for a marginalized population using a social ecological model, allowing for a multi-level analysis of factors associated with vaccination decisions. This analysis has significant implications for health interventions. Additionally, I explore the development of a vaccine promotion intervention that was co-designed with the Somali community using virtual reality. In my study of this intervention, I explore epistemological negotiations and shifting priorities that shaped intervention design, highlighting how non-profits engage neoliberal ideologies such as “social enterprise” while attempting to simultaneously meet community needs. I also deconstruct how community co-design of the intervention takes place in practice and examine the role it plays in improving the intervention.

This dissertation is written at the intersection of medical anthropology and public health. I contribute to the literature on vaccine hesitancy by demonstrating that vaccine decision making in the Somali community is a highly complex negotiation of beliefs and values that take place at many different levels of social interaction. In my examination of the intervention, I argue that while social enterprise models are, in theory, supposed to be designed to place the community’s needs at the heart of the enterprise, this project shows that it is not always the case that the community remains at the center of profit driven models. Finally, I demonstrate the value of community co-design in the development of a vaccine promotion intervention that makes use of technological approaches. I argue that community co-design is necessary to ensure that technological public health campaigns avoid inequitable top-down approaches.

Chapter 1

INTRODUCTION

Vaccine hesitancy is a substantial, multifaceted phenomenon that has led to a decrease in vaccination rates for preventable illnesses such as measles. Hesitancy to accept the measles, mumps, and rubella (MMR) vaccine has become widespread largely due to a purported (but now debunked) link between the MMR and the development of autism (Hviid et al., 2019). As a result, the US has seen a resurgence of measles outbreaks despite having previously made significant progress toward the eradication of this highly infectious disease (Gardner et al., 2020). The primary aim of this dissertation is to explore the development of a community-based health intervention in the context of complex issues of vaccine hesitancy in a racialized immigrant and refugee population.

One important driver of vaccine hesitancy has been structural violence. Structural violence is a form of violence that is “embedded in the political and economic organization of our social world” (Farmer et al., 2006). Although for many, the word violence may evoke ideas about physical harm, structural violence is more frequently present within social structures and institutions and is normalized within society (Galtung, 1969; Farmer et al., 2006). One example of structural violence driving vaccine hesitancy is the ubiquitous presence of structural racism in medicine which leads to unequal distribution of medical resources as well as an uneven distribution of health risks (Corbie-Smith, 2021). These inequities have led many marginalized communities to lack faith in a medical system which causes them disproportionate harm and has impacted willingness to vaccinate.

Due to their intersecting identities as Black, Muslim immigrants and refugees, members of the Somali diaspora throughout the United States have been subject to myriad forms of

structural violence which have put them at disproportionate risk for negative health outcomes (Bowleg, 2012; Farmer et al., 2006). Some examples of these violences which impact Somali immigrants and refugees include structural barriers to healthcare access, experiences of racial discrimination, and Islamophobia (Morrison et al., 2012; Ellis et al., 2010; Samari, 2016). There are also language barriers which prevent full access to healthcare as well as discordant beliefs about health between Somalis and biomedical practitioners in the Global North (Pavlish et al., 2010).

Recent measles outbreaks among Somali children resettled in Minnesota serve as a clear example of the impact of structural violence on refugees belonging to racial, ethnic, and religious minority groups (Samudzi, 2017). Upon resettlement in the Global North, many Somalis were faced with the widespread diagnosis of autism – a developmental disability that was not familiar to them prior to migration (Decoteau, 2017). One study found that 1:32 children in Somali communities in Minnesota are diagnosed with autism compared with the state-wide average of 1:48 children (Henneberry, 2013). The search for answers about the high prevalence of autism in their communities led a number of Somali parents to discover anti-vaccination resources via the internet and these parents were subsequently targeted by anti-vaccination activists who suggested that the measles, mumps, and rubella (MMR) vaccine was responsible for causing childhood autism (Dyer, 2017). While there is an abundance of evidence that MMR vaccination does not cause autism, Somali parents remain concerned because no one has been able to tell them what does cause it (Decoteau, 2017; Hviid et al., 2019). Because Somali immigrants and refugees often maintain highly interconnected social networks throughout the world, ideas about MMR vaccination causing autism spread throughout the diaspora and have been expressed in Somali

communities in Sweden, Canada, the UK, and the US (Campeau, 2019; Decoteau, 2017; Barnevik-Olsson et al., 2010; Hussein et al., 2018).

While it is true that anti-vaccination activists were involved in producing vaccine hesitancy in Somali communities, it is not the case that this was the only influence on vaccine decision-making for Somali immigrants and refugees. The story is not as simple as one of influential groups in the Global North targeting “vulnerable” and “powerless” immigrant and refugee communities. Instead, Campeau (2019) suggests that Somali parents exercise considerable agency in their vaccine decision-making and draw upon highly informed and political reasons for vaccine hesitancy and refusal. Vaccine refusal, in this case, may be seen as a way to push up against exclusionary research practices, ideas about Somali communities as a “generalizable” group, and medical systems which seek to discipline and control displaced populations (Campeau, 2019). Indeed, various researchers have shown that vaccine decision making is always a complex practice involving biological, social, and political factors (see: Leach and Fairhead, 2007; Sobo, 2016). In the case of Somali immigrants and refugees, it is also the case that biopolitics plays a role in vaccine decision making. According to Michel Foucault (1976), biopolitics is a method to discipline and control life which includes control exerted by the state over populations as well as individual bodies. Within Foucault’s (1973, pp. 196, 198) conception, medicine has been one of the primary methods of controlling and disciplining human bodies. Aihwa Ong (1995) uses this framework to argue that in the case of Khmer refugees, clinics that practice refugee medicine serve as sites of discipline and socialization of refugees into “governable citizens” (p.1254). Much like the Khmer refugees, Somali refugees also undergo a rigorous process of health screening, vaccination, and medical control (Ong, 1995). Thus, the ability of Somali refugees to make decisions about issues such as vaccination,

including refusing or delaying vaccination, may represent one way to exercise agency in the face of control by state and medical systems.

Previous research has explored the low rates of MMR vaccination among Somali refugees in Minnesota. This research has determined that friends and family make significant contributions to Somali parents' decisions regarding vaccination, that parents are concerned about childhood autism and widely accept that there is a causal link between the MMR vaccination and the development of autism, and that clinicians have an important role to play in vaccination education and advocacy among this population (Bahta et al., 2015). Research on vaccination has historically focused on the personal responsibility of minoritized populations to become less "vaccine hesitant" rather than focusing on the trustworthiness (or lack of trustworthiness) of medical institutions (Khan et al., 2021). Within this dissertation, I seek to examine the complex factors that contribute to vaccine hesitancy and to acknowledge personal agency in vaccine decision making without assigning blame to individual parents who choose not to vaccinate or framing vaccine hesitant parents as a "problem."

THE SOMALI REFUGEE CONTEXT

Somalia is located in the Horn of Africa and is bordered by Kenya, Ethiopia, and Djibouti. Historically, British, French, and Italian colonial powers competed for control of Somalia, partitioning the country into five territories (Ibrahim, 2017, p. 4). Eventually during the colonial period, Somalia was partitioned into a northern British territory and a southern Italian territory. By 1960, both the British and Italian territories achieved independence (Gardner and El Bushra, 2004, p. 2). In 1969, Siad Barre became president of Somalia via a successful coup, and initially allied himself with the Soviet Union. As Barre mounted an attack on Ethiopia, the Soviet Union chose to back Ethiopia over Somalia, and Barre turned to support from the United States.

Barre offered the United States military access to Somalia – which the U.S. saw as a strategically valuable location during the Cold War – and received large amounts of military and economic aid from the US in exchange (Besteman, 2016, p. 42-43). Thus, the United States played an important role in the support of Barre’s military regime.

The 1991 overthrow of Siad Barre has been cited as the cause of a civil war in Somalia which has led to the mass displacement of millions of people. However, as noted by Mohamed Abumaye (2017), the U.S. military invasion of Somalia in 1993 is directly implicated in the creation of Somali refugees. Abumaye (2017) shows that the U.S. began to accept refugees from Somalia shortly after their failed war in Somalia in order to improve their own international image. Yen Le Espiritu (2014) discusses Vietnamese refugees as “militarized refugees” whose refugee identities are created through U.S. militarism. This challenges the U.S. narrative of providing humanitarian “refuge” by highlighting the imperial violence enacted by the U.S. that produces refugees to begin with. Similarly, Abumaye (2017) emphasizes that U.S. involvement in Somalia has produced a “militarized” Somali refugee.

Southern California has been a major resettlement site for Somali refugees. While resettled in the U.S., refugees are exposed to a new set of structural and interpersonal challenges. For instance, Somali refugees in the U.S. face discrimination due to their religion, skin color, refugee status, and socioeconomic status (SES) (Pittaway and Bartolomei, 2001; Zine, 2006). Somali refugees also face significant difficulties in terms of the necessity to learn a new language, adjust to shifting gender roles, and find stable employment (Yakushko et al., 2008; Hadley and Patil, 2009; Nilsson et al., 2008). Additionally, anti-Black racism and Islamophobia play a significant role in the over-policing of Somali refugee populations in Southern California (Abumaye, 2017).

The policing and surveillance of Somali communities in the United States can be seen as an extension of U.S. militarism and imperialism in Somalia (Abumaye, 2017). One example of this surveillance is Countering Violent Extremism (CVE) programs, which disproportionately target Somali youth and posit the Somali community as “inherently criminogenic and violent as both Black and Muslim” (Sheikh, 2019). In the post-9/11 United States, fears about terrorism and the imagined figure of the “extremist Muslim” have enabled police to target Muslim institutions and to profile Black Muslims in the name of “counter-terrorism” (Abdi, 2015a). This history of colonialism, disproportionate policing and surveillance, anti-Black racism, and Islamophobia has significant implications for the experiences of Somalis in the United States. These forms of racism and discrimination are used to justify violence against Somalis in the United States and also to justify the need to enforce programs to “civilize” these communities (Abumaye, 2017, p. 147).

Somali populations were exposed to widespread violence due to U.S. military intervention and the collapse of the Somali state, including “widespread killings, rape, and looting” (Abdi, 2015b, p. 32). These experiences before and during forced migration have led to significant trauma in Somali refugees, impacting physical and mental health outcomes (Bhui, 2002). Somali immigrants and refugees also experience substantial amounts of discrimination in medical settings post-migration. For instance, one study found that Somali refugees experienced less thorough communication from doctors at medical appointments due to provider assumptions about their ability to understand medical information (Pavlish et al., 2010). Additionally, Somali mothers experience poor treatment from medical providers during pregnancy and childbirth due to their perceived English proficiency and their racialized identities (Herrel et al., 2014). These

negative experiences with medical systems may greatly impact trust in healthcare providers and in procedures such as vaccination.

A COMMUNITY-BASED INTERVENTION

In response to a 2017 outbreak of measles in the Minnesota Somali community, a number of educational interventions were developed to combat disinformation and to improve Somali comfort with the MMR vaccine (Shastri, 2019). One such intervention was developed in southern California by a Somali-run nonprofit organization I will call Somali Community Group (SCG). This dissertation explores the development of this particular intervention.

SCG has been serving the Somali community for nearly 20 years and they have learned that due to great variations in degree of literacy (in both English and Somali) among community members, image-based learning has the most significant impact on community education (Quinzon, 2017). While they explored ways to develop an image-based educational intervention for the Somali community, SCG became aware of an innovation grant which could fund the development of a new solution to vaccination education in the Somali community. Because SCG was already interested in research and the use of new methodologies to reach the community, and because they were applying for an innovation grant, they determined that they would use virtual reality (VR) to design their image-based educational intervention. To design and strategically develop this intervention, SCG put together an interdisciplinary leadership team to lead what I will call the Somali Tallaal Project (Tallaal is Somali for vaccination).

As a community-based organization, SCG was interested in keeping the interests of the community at the heart of the Somali Tallaal Project team's intervention development. However, as they negotiated the contract for the innovation grant that they received to develop the intervention, they realized that they were required by the funding foundation to develop a social

enterprise model. Social enterprises “adopt a business model typical of commercial enterprises and a social mission typical of non-profits” (Di Lorenzo and Scarlata, 2018). In other words, social enterprises focus on the acquisition of profit while attempting to alleviate social problems such as poverty and inequality. Social enterprises are becoming increasingly popular in the non-profit sector and have been frequently associated with neoliberalism because they represent the privatization of services for the “public good” and also the “marketization” of such services (Eikenberry and Kluver, 2004; Gerrard, 2017). While the intervention team was open to the development of a social enterprise model, there were some initial concerns that this would detract from centering the needs of the community.

Marcus Cueto (2013) discusses the use of contemporary technologies in global health campaigns, suggesting that these technologies are often viewed as “magic bullets” in vertical campaigns and rely upon a certain faith that technology is the best solution to intractable health problems. While the use of VR in the Somali Tallaal Project intervention may be seen as a technological solution to a health problem, the team attempted to avoid a vertical technology campaign by engaging the Somali community in co-design of the VR experience. Community Co-Design uses the principles of design thinking combined with community-based research approaches to enable underserved communities who are not trained in design to be directly involved in the design and creation of content and products that are developed to benefit them (Sanders and Stappers, 2008). Community Co-Design approaches have previously been used in refugee communities to identify the unique needs and concerns of these populations and to inform interventions using technology (Fisher et al., 2016).

AIMS AND KEY RESEARCH QUESTIONS

I hope to understand how organization, ethical, and sociopolitical factors interact to shape the design and delivery of a vaccine-promotion intervention designed by and for Somali immigrants and refugees. To accomplish this, I aim to answer three primary research questions with the three articles that comprise this dissertation.

- 1) What social and structural factors contribute to vaccine decision-making in a Somali population in Southern California, and how can we understand these factors through a social ecological model?
- 2) How does an immigrant and refugee-run nonprofit organization approach the development of a community-based, virtual reality vaccine promotion intervention that aims to be in the best interests of the community they serve, while simultaneously dealing with shifting priorities and neoliberal ideologies of funding foundations?
- 3) How does community co-design of a public health intervention happen in practice, and how does this impact community perceptions of the intervention?

METHODS OVERVIEW

The fieldwork for this dissertation took place between 2017-2021 and consisted of participant observation, semi-structured interviews, focus groups, and surveys. I engaged both with the intervention team and with the Somali community. I attended regular meetings with the intervention team, facilitated design workshops with the Somali community, facilitated focus group discussions with the Somali community, and interviewed the Somali community and the intervention team. While I originally intended to follow the vaccine promotion intervention from conception to testing within the Somali community, the last phase – in-person testing with VR headsets at in-person community events – became impossible due to the constraints of the

COVID-19 pandemic. Additionally, although I had planned to spend more time in-person with Somali community members to make more connections and more deeply engage with them, I instead had to opt for telephone interviews to protect the health and safety of the community during the COVID-19 pandemic. I further describe my data collection and analysis methods in each chapter of the dissertation.

POSITIONALITY STATEMENT

It is important to address the fact that I am a white anthropologist who was born in the U.S. who is working with a racialized and othered immigrant and refugee community. Within the discipline of anthropology, there is a long history of the white anthropologist studying the “other” and through ethnographic methods, claiming expertise on the topic of “the other” (Trouillot, 2003). This othering has especially been applied to Black and Muslim immigrants and refugees in Western countries who have been positioned as either “problems” or “victims” (Silverstein, 2005). This is a history and a context of which it was necessary for me to be mindful during all stages of my research. At the beginning of my research, I felt confident that my work would be useful for Somali immigrant and refugee communities insofar as it would provide them with an opportunity to speak out about issues impacting them and their families and would enable me and the intervention team to design something with the community which could benefit them. As I learned more from the community, I began to understand that as an outsider, I would never be able to fully comprehend the answers to the research questions I hoped to ask. Nor was I necessarily in the best position to be the one asking those questions in the first place.

As a white woman who was born in the United States, my status as an outsider was frequently felt when performing this research. For instance, after introducing myself at one of the focus groups and explaining what we would be discussing, some of the women still expressed

confusion and skepticism as to why I was there and why I wanted to speak with them. However, because I was a PhD student and was affiliated with the university, I received a certain degree of trust and respect from community members. This privileged status also impacted the power dynamics of my discussions with Somali community members and at times limited the depth of my interactions. Due to my lack of Somali language capabilities, it was also necessary for me to employ a translator for many interviews and focus groups, which undoubtedly made communication slightly more challenging. This is not to say that communication was impossible or that no Somali community members wished to speak with me. In fact, I was often welcomed to focus groups by the community with a large spread of homemade Somali food and was told that participants were eager to be involved in research and to have their voices heard. My status as a woman meant that Somali women were more comfortable speaking with me than men were, and aside from one focus group and one interview, all of my interactions with the Somali community were with women. This undoubtedly gave me a unique and gendered view of the Somali community's experiences.

During my research, I learned the importance of community collaboration as opposed to approaching a community with pre-formulated ideas about their wants and needs. For instance, when I initially decided to work with the Somali community, I was personally interested in issues of stress and shifting gender roles. However, upon consulting with the community, I learned that this was not something of great interest to them. Instead, many people were concerned about having their basic needs met and being good parents to their children. Additionally, many parents were concerned about autism and vaccination. As such, I decided to examine autism and vaccination concerns within the community. I also recognize the importance of working with a trusted community-based organization such as SCG, whose work always

centered on their deep understanding of community needs. I also found it important to work with a Somali research assistant who I collaborated with and shared authorship with. Collaborating in research and sharing authorship are two ways to potentially disrupt the usual unequal power structures of academic research. Another valuable practice was talking through my research with community members who provided feedback on interview questions and research trajectory. Ultimately, academia and academic research are sites of extreme inequity that require significant intervention in order to be able to sincerely improve power dynamics between researchers and the communities with which they work. Until these large-scale changes are made, it is important for us as researchers to do all we can to act as accomplices in the community and to advocate for more community involvement in the development of research agendas.

Additionally, in working with the Somali Tallaal Project team, I was a consultant on this project as well as an employee of SCG at the time of the research. While this granted me access to the project team and to the community, it was also necessary to navigate between my duties as a consultant and employee, and my duties as a researcher with a critical perspective. However, I was able to use this critical perspective at times to impact project methodologies. For instance, I was able to advocate for community engagement at every stage of the project and to make the case for the importance of community engaged methods to the funder. While I write about the imperfections of neoliberal frameworks as a researcher, as a member of the project leadership team I also recognize that the project team and the funder both cared deeply about the project. It is with this deep respect for the project and the team that I engage in critical analysis that can hopefully lead to future improvements on such interventions.

OUTLINE OF THE DISSERTATION

This dissertation examines the context of vaccine hesitancy in a Somali immigrant and refugee population in Southern California as well as the design and development of a vaccine promotion educational intervention to address this issue using virtual reality (VR). This dissertation is comprised of three manuscripts, each of which is a stand-alone publication. The dissertation is organized to tell the story of the intervention. First, I examine the complexities of vaccine decision making for Somali parents living in Southern California. Next, I explore the initial intervention design and outline some of the challenges of creating such an intervention including shifting priorities and neoliberal ideologies of project funders. Finally, I expound upon the community engaged creation of the intervention with special attention to the iterative co-design process. *The final dissertation is the first to examine a community co-designed VR intervention within a Somali community and the first to systematically explore issues of vaccine decision making among Somali immigrants and refugees in Southern California.*

Chapter 2 focuses on vaccine decision making in Somali refugee parents in Southern California with an emphasis on MMR vaccination. I use a social ecological model to examine the complex personal, interpersonal, community, and institutional factors that go into MMR vaccine decisions among these parents. The social ecological model reveals the many layers of complexity that influence vaccine decision making, and this chapter provides examples of the different levels at which to intervene in the design of future interventions.

Chapter 3 reports on ethnography of an interdisciplinary intervention team designing the VR vaccine education intervention. I examine the tensions associated with intervention development including tensions within the intervention team as well as between the intervention

team and the funding foundation. Specific attention is paid to the neoliberal ideologies of the funder with regard to how these ideologies impact intervention design.

Chapter 4 details the community-engaged development and testing of the VR educational intervention. I examine the ways that the Somali Tallaal Project team involved the community in every step of the process of VR development, and argue that community engagement is necessary when designing interventions for marginalized communities, especially when interventions concern complex issues such as vaccine hesitancy.

Chapter 5 is the discussion and conclusion for the dissertation including a summary of key takeaways and future directions for research.

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Chapter 2

“THE MOTHER’S INSTINCTS SHOULD BE LISTENED TO”: A SOCIAL ECOLOGICAL EXPLORATION OF VACCINE DECISION MAKING IN A SOMALI COMMUNITY IN SOUTHERN CALIFORNIA

ABSTRACT

The measles, mumps, and rubella (MMR) vaccination has been the subject of many disinformation campaigns which claim that it is associated with the development of autism in children. Somali immigrants and refugees have been particularly targeted by such campaigns and, as a result, are hesitant to accept the MMR vaccine. However, these campaigns are not the sole reason for hesitancy within this particular population. This study aims to understand how the spread of vaccine messaging throughout the Somali diaspora impacts vaccine decision making by investigating vaccine decision making among Somali parents in Southern California. I use a social ecological model to demonstrate that parents are highly informed and do their own research when making vaccination decisions while also being influenced by family support and information that is spread throughout the wider diaspora. Additionally, parental experiences with the medical system impact their decisions regarding vaccination. Finally, I discuss the implications for vaccine hesitancy during a pandemic.

INTRODUCTION

Recent outbreaks of vaccine-preventable diseases such as measles in the United States have been attributed partly to vaccine refusal and hesitancy (Phadke et al., 2020). Unlike vaccine refusal, wherein individuals outright reject vaccination, vaccine hesitancy represents uncertainty as to whether vaccination will be accepted: it is a complex phenomenon wherein parents are hesitant about certain vaccines but readily accept others (McDonald et al., 2019). Vaccine hesitancy has thus been described as a continuum from refusal to acceptance, rather than an all-or-nothing phenomenon (McClure et al., 2017).

Vaccine hesitancy has been cited as a major reason for under-vaccination in marginalized populations, especially within low-income and Black communities (Quinn et al., 2016; Gowda and Dempsey, 2013; Smith et al., 2004). Purported drivers of hesitancy in these communities include lack of trustworthy healthcare providers and systems, disinformation campaigns, and concerns about the cost of vaccines (Mesch and Schwirian, 2014; Reiss and Diamond, 2019; McMorrow and Thomas, 2021). The practice of labeling Black communities as “vaccine hesitant” has been critiqued for its tendency to place blame for under-vaccination on marginalized communities, who supposedly do not make the “right choices” with regard to individual and community health (Bass et al., 2021). However, there is evidence that resource availability, not just hesitancy, is driving much of this under-vaccination (Webb Hooper et al., 2021). For example, marginalized communities may be less likely to have access to health insurance, transportation to access vaccination, and appropriate health resource navigation. Many of these issues are exacerbated for immigrant and refugee communities, who often lack access to culturally and linguistically appropriate resources and who may also experience specific forms of structural vulnerability due to their immigrant or refugee status (Quesada et al., 2011).

Somali immigrants’ and refugees’ hesitancy to accept the measles, mumps, and rubella (MMR) vaccine represents one case of vaccine hesitancy that has received much attention (Bahta and Ashkir, 2015; Jama et al., 2018). Many Somali immigrant and refugee parents are reluctant to vaccinate their children with MMR specifically because they fear that it will cause their children to develop autism (Bahta and Ashkir, 2015; Jama et al., 2018). It is not yet clear how common vaccine hesitancy is toward other vaccines such as the COVID-19 vaccines, which became available during the course of this study. In this article, I report on work examining vaccine decision-making in a Somali immigrant and refugee community in Southern California.

Research on vaccine hesitancy in Somali communities in the United States has focused on the largest Somali population in Minneapolis, which is often targeted by anti-vaccination messaging. This article explores how other parts of the diaspora experience and grapple with vaccine hesitancy, in part influenced by messaging coming from Minneapolis.

Background

Vaccination has never been entirely uncontested. Anti-vaccination movements have existed since the early 19th century and were initially largely formed due to objections to compulsory vaccination laws imposed by the state (Grignolio, 2018). Present-day anti-vaccination activists have cited a number of reasons they are hesitant toward vaccination, including concerns over the number and contents of vaccines, as well as distrust of government and pharmaceutical companies (Kata, 2012). The MMR vaccination has been specifically singled out by anti-vaccination activists because of a now-debunked link to autism in children (Olpinski, 2012). The supposed autism-vaccination link arose from a 1998 paper by former physician Andrew Wakefield, in which he claims that MMR vaccines directly caused autism in a number of children (Wakefield, 1998). Despite the fact that the paper was retracted and Wakefield lost his license to practice medicine, the belief that MMR causes autism persists today in many communities.

Somali refugees have been resettled in various parts of the world since the early 1990's when they were displaced by civil war. Post-migration, this community has experienced high rates of childhood autism (Henneberry, 2013). This high prevalence of autism has been shown in the United States, the UK, Canada, and Sweden (Henneberry, 2013; Decoteau, 2017; Barnevik-Olsson et al., 2010; Fox et al., 2017). While it is currently unknown why this trend persists in Somali refugee communities, there are large-scale studies which show no association between MMR and autism (Hviid et al., 2019).

In their search for answers about autism, Somali parents found resources from anti-vaccination activists, who began targeting this population with vaccine disinformation in 2010 (Dyer, 2017). Following these interactions, MMR vaccine rates dropped dramatically in a Somali refugee community in Minneapolis, Minnesota over the span of a decade (from 92% to 42%), resulting in a measles outbreak in 2017 (Dyer, 2017). Due to the highly interconnected nature of the Somali diaspora and their strong oral tradition, the disinformation that anti-vaccination activists directed toward Somalis in Minnesota has spread throughout the diaspora, causing significant hesitancy with regard to the MMR vaccination. However, as shown by Campeau (2019), targeting by anti-vaccination activists and lack of “correct information” is not the sole reason for vaccine hesitancy in Somali populations. Instead, these communities make agentic vaccination decisions based on complex beliefs about vaccination that are the product of their personal experiences, political beliefs, and experiences of structural violence (Campeau, 2019).

In this article, I aim to illustrate the ways in which a Somali immigrant and refugee population in Southern California makes vaccine-related decisions incorporating input from the individual, interpersonal, community, and institutional levels. Rather than paint these communities with the broad brush of “vaccine hesitancy,” I aim to show the myriad factors that go into the complex process of deciding whether or not to vaccinate a child.

METHODS

This study draws on interviews and focus group discussions within the Somali community in Southern California between 2017-2021. Most relevant to this article, I conducted seven focus group discussions (FGDs) and 13 in-depth interviews. While the majority of participants were women, there was also a small number of men who participated. Data collection took place at the offices of a local nonprofit organization that is run by and serves the

Somali community, and later via telephone due to the Covid pandemic. Data were collected in a mix of Somali and English, and a Somali translator was present when needed. All participants provided verbal consent as approved by [blinded]. Interviews and FGDs were recorded and transcribed, or extensive notes were taken in the event that participants declined to be recorded.

I first engaged in open coding of all transcripts and notes, with a subset double-coded by a research assistant. I then cross-referenced initial inductive codes with the results of earlier literature reviews on vaccination in Somali immigrant and refugee communities to develop a refined codebook including both deductive and inductive codes. I then coded all transcripts and notes, while a subset of these were double-coded by a research assistant. I grouped codes into thematic areas and developed descriptions of each theme. Finally, I mapped the themes onto a social-ecological model to better illustrate the various levels of vaccine decision-making (Stokols, 1992; Fleury and Lee, 2006).

Social-ecological models have been used in studies of health promotion in order to remove the emphasis from individual behavioral change and to instead situate the individual within a broader context in which they make health-related decisions (Stokols, 1992). These models allow for the examination of health behaviors according to facilitators and constraints that impact health decision-making (Fleury and Lee, 2006). Because decisions surrounding vaccination are dependent on a number of interrelated factors, I examine vaccine decision-making here through a social-ecological model in which I emphasize the individual, interpersonal, community, and social levels of context in which vaccine decision-making takes place (Figure 2.1).

RESULTS

Individual Level: Personal Research and Personal Experiences

When making medical decisions, many of the Somali parents I interviewed exercise agency by engaging in their own online research. This research consists not only of cursory Google searches, but parents were also very familiar with the scientific literature surrounding their particular medical concerns. One father named Letif¹ stated:

Up to today, I've read many articles, as I said, [including] many different people, including parents, including advocates, including just a lot of people...and it's weird I don't have a clear picture where I can say, "Yes, vaccination is safe. Go ahead and vaccinate your child. That's it. MMR is safe."

As with Letif, many parents are quite well-versed in the scientific literature, yet some doubt still remains as to whether MMR vaccination is a safe choice. Letif has one child with autism who has not been immunized and four additional children who have been immunized but who did not develop autism. He often tells his story to other Somali community members to illustrate that vaccination is not what caused autism in his child. Nonetheless, he is still not completely certain that MMR is safe.

In an interview with two mothers, Dalia and Sanura, they echoed the sentiment that they do their own online research, including reading publications on the topics they are concerned about:

Interviewer: Where do you usually get medical information- any kind of medical information?

Dalia: Well lately, it's just been googling [laughs]. A lot lately, yeah [laughs] just reading publications on Google, and you know, stuff like that. A lot.

Sanura: And with me it depends. Usually from the doctors. I ask them. If they don't know, if I want more – I mean if I want more information on it then we Google it [laughs]

Interviewer: So, you say...you do a fair amount of research on your own it sounds like.

Sanura: Mmhm, we try to, yeah. And then - you know - but always get the doctor's point of view also.

¹ Pseudonym, as are all names herein

Exchanges like these were common in my interviews with Somali parents, who often said that they looked for medical information online. Like Sanura, many parents also emphasized that they valued input from their doctors but ultimately would still do an online search before making medical decisions. For instance, Maryam told me: “If I have a question about a medication I use, or medication like I used for a disease my doctor told me about, or for the kids or anything, I do research.” These examples show that while parents are often caught up in complex medical systems, they also arm themselves with scientific and medical knowledge to be able to interface with doctors and medical systems so that they can be advocates for their own health and the health of their children.

Parents also discussed their roles as medical decision-makers and emphasized that while they received input from their communities and doctors, they ultimately felt in control of the medical choices they made for themselves and their families. When asked who was responsible for her children’s health, Inira noted: “Number one, definitely for me, I think it comes from me. And then second, I would say community and clinics and doctors.” Thus, while parents use many resources available to them to make health-related decisions, they ultimately consider themselves to be what one participant called the “main character” in medical decision making.

Noor is another mother who relayed to us a story about taking her child to the emergency room for stomach pains. Noor was told by the doctor that her child needed immediate surgery to remove his appendix, but she did not feel satisfied with the explanation the doctor gave her or the lack of appropriate tests to determine that surgery was warranted. Her child remained in the ER for observation overnight, and in the morning, he felt much better. Surgery was not needed after all. According to Noor:

The doctor came and said, “He doesn't have the illness that I thought he had. If you weren't his mother, I would've performed surgery on a child that was healthy.” He said, “The mother's instincts should be listened to!”

Noor's experience illustrates the fact that parents often feel in control of their children's health and advocate for them in the context of medical encounters. Not only are parents armed with scientific and academic research when interacting with doctors, but they also trust their own parenting instincts to tell them what the right decision is for their children. Based on Noor's account, the doctor deferred to her parental expertise and avoided an unnecessarily risky and expensive surgery.

When Somali parents make medical decisions, such as those about vaccination, they exercise individual agency and draw from a number of resources, including personal research and their own parental instincts. Far from being powerless and uncritically accepting any information given to them, parents act as highly discerning decision-makers who feel in control of their own health and the health of their children. As such, they negotiate with doctors and seek out resources to empower themselves to better navigate the complex healthcare system.

Interpersonal Level: Family Support

In addition to their personal experiences, Somali parents draw from their relationships with family and friends when making medical decisions. In the case of vaccination, parents engage in a distinct cost-benefit analysis that – among other things – accounts for their anticipated ability to support a child who they believe may become disabled by vaccination. Parents also may *delay* vaccination if they have family nearby, because they believe that their family can support them if the child does become ill with measles or a similar illness. This is shown in the following conversation with Sanura and Dalia:

Sanura: Like if you're an individual who has a lot of family nearby then they don't - they're not quick to give them the medication...

Dalia: Give them the shots, yeah.

Sanura: Because somebody can take care of them while they run errands or do something. And we're like those type of community that - we always help each other. Families - they are to help each other. So...and if that other person doesn't have like as much family around, they're forced to [vaccinate] because they need time for the kid to go to school.

Dalia: They have to take the kid to daycare!

Sanura: Or daycare, you know.

Dalia: even in daycare they always want the immunization, so you have to get the kid the shots.

Sanura and Dalia emphasize the importance of being able to take your child to school or daycare if you do not have family nearby who can help to care for your child. In this case, it is necessary to vaccinate on schedule due to the requirements of most childcare and educational facilities.

The presence or absence of family support had an impact on parents' decisions whether or not to vaccinate their children with MMR. One concern among parents upon considering MMR vaccines was that if their child developed autism, they wouldn't be able to care for a disabled child on their own while simultaneously attempting to work to provide for their often-large families. Many parents stated that they had a lot of social support from family and friends who lived nearby in Somalia, but that this social network was lost when migrating to the United States. The decreased social network combined with shifting gender roles and the necessity to work full time to provide for their families made parents feel that there were significantly more challenges to raising a disabled child in the U.S. At the same time, parents felt more empowered to delay vaccination if they had family nearby to help them care for their children if they did become sick with measles or if the children were unable to attend daycare or school due to not being vaccinated on schedule. However, having family nearby to help care for a potentially disabled child did not necessarily result in more parents taking the risk of vaccinating their child.

Community Level: Spread of Information Throughout the Diaspora

In addition to doing their own research, trusting their instincts, and making vaccination decisions according to their available social support, parents also made decisions based on what they learned from the broader Somali community. Many parents reported learning about autism from members of the Somali community, including those who live outside of Southern California. When asked where she learned about the supposed link between autism and vaccination, Maryam told me:

I have [learned] from community. I had a lot of community - even in London, I have cousins. I have a lot of family who has autism. I know a lot of people claim that it's not only in Somali communities. A lot of people - a lot of communities - they complain it's vaccination, but I don't think [so].

Maryam's comments emphasize the fact that members of the Somali diaspora from all over the world are considered part of her community, and she learns about autism and vaccination from family members who live in London. She states that many individuals who are members of the Somali community believe that vaccination leads to autism, but she herself does not believe in this association.

In a conversation with Damsa, a 45-year-old mother of 5, she echoed the fact that she learned that vaccination can lead to autism from her community:

Interviewer: Where did you learn what you know about autism?

Damsa: The community. Somali, we are our own media - something happens to somebody we tell each other. Not even in [Southern California], in other states, they say this thing is getting a lot I don't know what's causing them. People say the shots - this is what I hear in the news - affects the boys more than the girls. That's the time I wake up and say "I'm not giving my boys all the shot at the same time. I'm going to try to avoid it." What could cause it is the fever after the shot. The doctor says give Motrin before the time to avoid it, and that's the news coming from the community.

Like Maryam, Damsa feels that Somalis from other states are a part of her community. She refers to the Somalis as their "own media," reflecting the way that news and information

spreads throughout the diaspora. Damsa has chosen to delay vaccination for her own children, especially the boys, due to information she has received through her community.

Saada was another parent who stated that she would delay vaccination due to what she heard from her community. She also emphasized that she would recommend that other members of her community delay vaccination as well, saying: “Yeah some of my friends - they are new friends - they are on second baby I tell them, I say, ‘wait until five years, after five years it's ok [to vaccinate].’”

Saada believes that her community should delay vaccinating their children until they are five years old, when they have already started speaking. This way, Saada says, they will not have to suspect the vaccine of causing speech problems. Concerns about the MMR vaccine leading to speech problems were common among the Somali parents I spoke with. For instance, Alia, a mother of seven told me: “every child who don't get that...MMR they never have problem to speak. But wherever they get that MMR they - most children - they don't speak. That's the reason the parent is scared.” While other behavioral issues were also invoked in discussions of autism (e.g. lack of eye contact, stimming), speech seemed to be the central concern for most parents.

Institutional Level: Trust and Navigating the Medical System

Many parents addressed the challenges that come with making their own medical decisions in what they identified as a difficult-to-navigate healthcare system. Maryam told me: “Nobody's going to knock the door, and tell you, ‘okay, come on, this...’ - nobody's going to tell you. But you'll have to fight and look for what you - what kind of help you need.” Maryam’s account emphasizes the importance of self-advocacy for Somali parents, who are often not well-served by a medical system that often lacks cultural humility or linguistic competency. Maryam

is the mother of an autistic child, and when asked about her experiences in the medical system as she seeks services for her child, she said:

It makes me feel to fight a lot more than I'm supposed to for the system to make the doctors understand me. Because sometimes when they see you have the accent, they feel like you cannot understand them, and they can shut you up. So, I have to fight to make them see 'I am understanding you.' And I'm able to understand, even though sometimes they are going to go by a level of technical language that they use or something like that. I understand. But I have also, my young son which is autistic, he also has seizures. Now I hire someone - an advocate for him - to run to the doctor and the school. Sometimes they fight with you and you're going to be by yourself, and you have all these things to do. It's so hard with the system.

While she has been in the United States for 22 years, speaks English, and has access to resources such as a professional advocate who can help her to navigate the health system, Maryam still struggles to interact with doctors who make assumptions about her due to her appearance and her accent. Maryam feels that doctors do not listen to her despite the fact that she has previously worked as a community health worker and is highly knowledgeable about the health of her community and her family.

In terms of trust in the medical system, some Somali parents expressed distrust due to previous negative experiences, especially with regard to childbirth and childcare. When asked if she trusted doctors, Layan told me:

Before I did; now I don't. This baby made me realize that you really can't trust 'em. You know your infant and you know how you're feeling. They tell you one thing, and another thing happens. You put your trust in God. When I was a pregnant, they said "you're gonna bleed to death. You're gonna die." I didn't have what they said I had.

80% of them, yeah, I trust them but not all the way, you know? They talking about I was gonna die. My baby had to come one month early. They wanted me to sign this paper where they're gonna take my uterus out, and I refused everything. I followed my instincts and I put my trust in God. They were trying to really take my uterus out at the c-section, and I wouldn't sign the paper. All they care about is money. They don't care about your health to be honest.

As discussed by Layan, an emphasis on placing trust in God when it comes to health was also common among the Somali parents that I interviewed. Inira told me:

Because...how do I say this? I don't trust doctors to give me help because there are so many doctors in the world that want to help out. They're doing a great job to help out. They're doing their best to help out. But it comes...if you're sick, if you're really sick or whatever it looks at first, they have to come from you. You have to try your best to take care of yourself first and ask God to cure you. And then if you think you can't do anything much and then second choice is to go doctor and to see if they can help you.

In Inira's case, she places her trust in God first when it comes to her health and the health of her family, with doctors as her second choice.

While some parents felt they could not trust medical providers, others stated that they trusted doctors either completely or partially. For instance, when I asked Damsa if she trusted doctors, she told me:

We do trust doctors - not 100% but sometimes we trust the doctors. Whatever the doctors say... "this is what's good for kids, good for you." Later on, I Google it and make sure to decide it. Every medication has own side effects. I have to ask the doctor. And we do trust the doctor.

As previously discussed, Damsa does place trust in doctors but also takes it upon herself to do her own research when it comes to recommendations for herself and her children, especially when she is prescribed a medication. Thus, in the Somali community – as in every other community – trust in the medical system is complex. Trust does not operate as a binary category wherein patients place complete trust in doctors or do not trust them at all. Instead, it is a constant negotiation with providers and depends on many factors including the relationship with the particular doctor, whether the Somali patient is racialized or othered, and provider language competencies, among others. This negotiation relies upon Somali parents to use their skills as agentive, research empowered, medical decision-makers.

Decisions about MMR vaccination were also complicated by conflicting information from medical providers. While many parents stated that they learned about the safety and efficacy of MMR from their doctors, some parents noted that their doctors showed some skepticism toward the vaccine. During a focus group discussion, a mother named Uba told us:

There was one doctor in Wisconsin that I say, “give me choice.” He says, “This MMR vaccination is a controversy. Do you wanna do for your kids or you wanna wait?” I said “I have no idea what it is [or] what [my child] has.” So I ask him, “If it was your daughter what would you do?” He said, “If [it] was my daughter, I would wait until she’s two or three years old.” And I decided all my kids to wait two years old. He says, “It’s a controversy, I can’t tell you it causes [autism] and I can’t say that’s the cause, but I have to give to you the warning.”

Trust in vaccinations other than MMR was another topic that was brought up frequently by participants, and many conversations turned to COVID-19 as I interacted with parents at the height of the pandemic. In the summer of 2020, before the development of the COVID vaccines, participants told me that they were afraid of COVID and intended to get the vaccine as soon as possible. At this time, Alia told me: “You know, I used to reject the flu vaccine, but this time, if they find an effective [COVID vaccine], I definitely...I will get [it].” However, when I interviewed parents in January 2021 after the release of the first COVID vaccines, they seemed more hesitant to accept it. Some parents cited lack of trust in a vaccine that was “too new” or had not been thoroughly and convincingly researched. When discussing the COVID vaccine in 2021, Layan told me:

Covid vaccine - I feel horrible about that. I don't know, because social media now... everything people upload it. There's a doctor who got [the COVID vaccine] and he died after two weeks. He was very healthy [before the vaccine]. Another lady had seizures. You still have to wear a mask [after the vaccine], you still can get the COVID, and you know, we don't know how people's bodies are gonna react to it. We don't know a lot about it, so I don't feel comfortable taking it.

In Layan's case, stories of death and seizures following the COVID vaccine reached her via social media and greatly impacted her trust in the vaccine. She felt that she was lacking necessary information on the effects of the COVID vaccine and that people did not know enough about the vaccine due to what was perceived as a dearth of research on safety and efficacy. Similarly, during my interview with Damsa in January 2021, she stated that she felt it was best to wait to get the vaccine until she could be provided with more proof of its safety. She told me: "I know technology change a lot, but it doesn't change that fast! I wouldn't give my kids or myself corona vaccine right now until I know - maybe a year later but not now." This shows that although many parents lend some trust to science and medical systems, they also believe that their trust should be earned through more research and science communication.

DISCUSSION

A social ecological model allows us to examine the issue of vaccine hesitancy within an immigrant and refugee community at various levels, from individual experience to engagement with broader social systems. While Somali parents have often been framed as a hesitant community who has been targeted with disinformation (Dyer, 2017), this research shows that they are actually very discerning in their vaccine decision-making, doing extensive personal research and consulting with trusted friends, family, and community to make vaccination-related decisions. Similarly, medical trust in this community is not a simple binary of trust versus distrust. Instead, many parents use their personal experiences with healthcare providers to determine their trust in the healthcare system, and many who place their trust in healthcare providers do so only provisionally, until they can do their own research and seek second opinions.

Like many parents, Somali parents in this study draw from their personal experiences and research to make decisions about vaccination. Leach and Fairhead (2007, p. 65-66) suggest that doing personal research is encouraged both by other parents and by doctors for vaccination as well as other aspects of child rearing. This necessity to take “personal responsibility” for the health of oneself and one’s family is expected within a U.S. profit-driven medical system in which patients are positioned as consumers (Tomes, 2016). For immigrant and refugee populations in particular, conducting oneself as a consumer patient who comes armed with knowledge and negotiates treatment within a neoliberal health framework may represent one way to pursue biopolitical citizenship (Ayo, 2012). While it has been argued that medical systems act as disciplining institutions for immigrants and refugees, Aihwa Ong (1995) finds that Khmer refugees engage in “a complex type of contestation that both invites medical attention and yet repels it” (p. 11). The ways in which Somali refugees view doctors and scientific research with respect while simultaneously using personal scientific research to verify or challenge their doctors’ recommendations may be one example of such a complex contestation.

Far from making their decisions about vaccination in isolation, the Somali parents I spoke with explained that support (or lack of support) from their families played an important role in their decision-making. Indeed, parents noted that a sufficient amount of social support was needed in order to decide to get the vaccine, which they worried may lead to a need for increased support to raise a disabled child. While many parents stated that they had a lot of social support in Somalia from their families, many felt that they lost that social support post-migration. McMichael and Manderson (2004) discuss the ways in which Somalis in Melbourne give social relations meaning by comparing them to their previous experiences of social worlds in Somalia. Similarly, although some Somali parents discussed the importance of relying upon friends and

the local Somali community for social support, they also agreed that there was more support available “back home” where relationships with family, friends, and neighbors had been more firmly established across generations.

Parents in Southern California often used information they learned from the broader diasporic Somali community in their vaccine decision-making, and they explicitly framed other parts of the diaspora (Minnesota, The UK, etc.) as their extended community. Many participants explicitly stated that they learned about the association between autism and MMR vaccination from Somali community members both within and outside of the Southern California region. This is in line with Brunson’s (2013) work suggesting that vaccination decision making is often highly influenced by parents’ social networks. While the Somali community is far from monolithic, the spread of information about vaccination suggests a highly interconnected social network spanning the globe. As of 2006, there were approximately 527 Somali websites on the Internet, many of which were community and political sites where Somalis could interact (Issa-Salwe, 2006). Studies of social media usage by Somalis have also revealed the popularity of social media as a means of interaction with other Somalis and expression of national identity – especially among Somali youth (Dhaha and Igale, 2013). Technology is thus a powerful tool for spreading information and maintaining connections throughout the Somali diaspora and may be one method of exchanging stories and information surrounding MMR vaccination. This also suggests that social media may be a key means of reaching community members for the dissemination of information about disease risk and vaccines.

Previous studies have shown that Somali refugees cite many reasons for their vaccine hesitancy, including concerns about autism and the number, timing, and contents of vaccines (Jama et al., 2018; Christianson et al., 2020). With regard to autism, many Somali parents

explicitly state that they are concerned that the MMR vaccine will cause their children to stop speaking or to be unable to learn to communicate, which is particularly concerning due to Somalis' rich oral tradition and the fact that Somali language is so tied to Somali identity (Ahmed, 2002; Valentine et al., 2009). Additionally, Claire Decoteau (2017) finds that Somali experiences of racial and national exclusion as well as their questioning of the Western biomedical mainstream have contributed to vaccine hesitancy and the development of embodied health movements which challenge biomedical hegemony. Although some Somali parents ultimately refuse MMR vaccination, many instead opt to delay vaccination until after children have begun to speak (Jama et al., 2018), thus leading to a trend of under-vaccination. Due to the highly contagious nature of the diseases that MMR vaccine protects against, it is necessary for at least 90% of individuals to be vaccinated in order to preserve community immunity (Sadarangani, 2016). Thus, under-vaccination increases community risk for exposure to measles, mumps, and rubella. While this study has paid particular attention to the context of vaccine decision making among Somali refugees, it must be stated that this is far from the only community to express hesitancy to vaccinate with MMR. For example, MMR vaccine hesitancy is also prominent in Orthodox Jewish communities in the UK who also lack trust in medical systems (Kasstan, 2020). However, as noted by Kasstan (2020), the concerns of religious minority groups around vaccination are not wholly unique but are often a reflection of national vaccine anxieties.

Somali parents act as advocates for themselves and their children within a healthcare system in which they often have negative experiences (Svenberg et al., 2011). While some parents reported positive experiences in the healthcare system, many reported negative experiences, often related to xenophobia and racism. The negative experiences that parents had

with the medical system were often quite serious, as shown by the stories of attempts by doctors to force unwanted and unnecessary surgeries and sterilizations. These experiences may impact overall parental trust in the medical system and their subsequent vaccination decision-making (Hornsey et al., 2020). While parents did not explicitly link their previous medical experiences to MMR vaccination, some interviews took place during the COVID-19 pandemic, and many did note that their lack of trust in the Western medical system strongly correlated with their lack of trust in the COVID-19 vaccination. Many parents stated that the COVID vaccine was “too new” and did not have enough research backing it up, thus showing they once again did not implicitly trust the medical system but instead hoped to have the vaccine’s safety supported by research which they could evaluate themselves. This is similar to the vaccine hesitancy observed in Black communities in the UK, who have expressed hesitancy toward the COVID-19 vaccine due largely to lack of trust in the medical system (Razai et al., 2021).

CONCLUSION

This study shows that vaccine decision-making for Somali parents is a complex process that is impacted by many factors at different levels of personal experience and social interaction. Previous research has suggested the Somali parents are hesitant to vaccinate their children with MMR due to perceptions that the vaccine causes autism (Bahta and Ashkir, 2015; Christianson et al., 2020; Decoteau, 2017). While this is true, it is also the case that there are a number of other factors that go into vaccine decision-making, including personal research, lived experience, family support, interactions with the diasporic Somali community, and interactions with the medical system. If it is the intention of medical and public health systems to increase vaccine confidence and uptake within racialized refugee populations, it is necessary to account for the complexities associated with vaccine hesitancy and delay and to understand the necessity to

engage in collaborative health management with these communities. Collaboration is especially important in populations experiencing forced migration and the resultant health surveillance and control that significantly impacts their experiences with medical systems. This has significant implications for vaccination of marginalized communities, especially during the COVID-19 pandemic. While this exploration was mostly focused on reasons for MMR vaccine hesitancy, the social and political context surrounding COVID-19 vaccination will undoubtedly present unique barriers to vaccination uptake.

The social ecological model is useful for helping to identify different levels at which to intervene in particularly complex issues such as vaccine hesitancy. For instance, at the community level it is clear that information is being spread through social media, which could mean that social media could be a useful tool for debunking disinformation and creating educational campaigns. Additionally, at the institutional level it may be valuable for doctors to embrace the fact that parents are doing their own research and to engage with them through the research by suggesting particular literature to read or citing relevant work in their communications with patients. It would also be useful for healthcare systems to employ full time community health workers (CHW) or other patient navigators rather than just the required translators. While translators provide a valuable service, issues with healthcare at the institutional level include issues such as navigation and medical racism that extend far beyond simple language barriers. Consideration of these levels of intervention would be valuable not only for MMR vaccine, but for concerns associated with the COVID-19 vaccination as well.

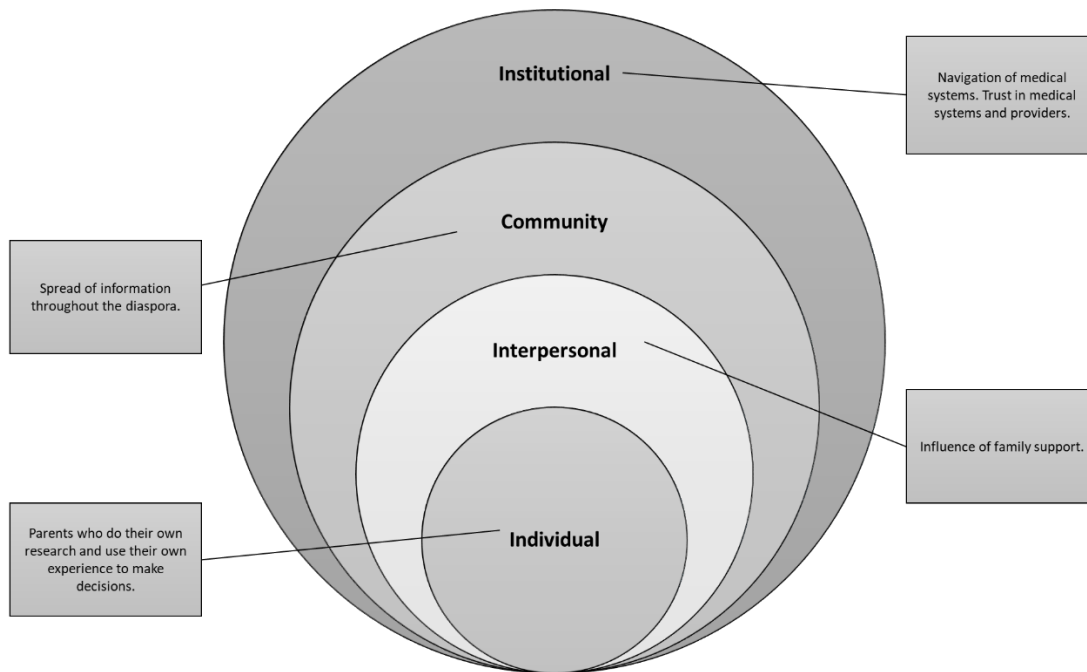


Figure 2.1: The Social Ecological Model of Parental Vaccine Decision Making. This figure illustrates the different levels of the social ecological model that I am using as a framework for understanding parental vaccine decision making. The individual level is concerned with personal parental research and experiences used to make decisions. The interpersonal level is concerned with family support. The community level includes the spread of vaccine information throughout the broader Somali diaspora. Finally, the institutional level is largely concerned with trust in and navigation of medical systems.

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Chapter 3

SHIFTING PRIORITIES AND NEOLIBERAL IDEOLOGIES IN REFUGEE HEALTH INTERVENTION DESIGN

ABSTRACT

In this article, we explore the design of a vaccine education intervention for Somali refugees in the US. Originally conceived of as a culturally and linguistically appropriate project to be co-designed by refugees, funder demands for a “social enterprise” led to future iterations being developed for a “generic” audience. We explore epistemological negotiations and shifting priorities that shaped intervention design, highlighting how non-profits engage neoliberal ideologies such as “social enterprise” and “design thinking” while attempting to meet community needs. We argue that social enterprises can be useful for non-profits only if they facilitate meeting the needs of communities they serve.

INTRODUCTION

In 2017, a small grassroots non-profit organization called Somali Community Group (SCG) (all names of people, projects, and organizations are pseudonyms) launched the Somali Tallaal (“vaccination”) Project. The project was imagined as a culturally and linguistically appropriate response to plummeting vaccination rates among Somali refugees in the United States. Run by current and former refugees, SCG is a small, grassroots non-profit situated in Southern California. Based on many years of community-based research, SCG has learned that due to varied literacy among community members, image-based learning has the most significant impact on community education (Quinzon, 2017). Thus, they set out to create a visual intervention that would incorporate a significant amount of community co-design. An important step in designing this intervention was recruiting an interdisciplinary intervention team, which included the president of SCG, a physician and design thinking expert, a community health and

engagement expert, two business development experts, and an anthropologist (the first author). This team engaged in intervention design, strategic planning, and facilitation of design workshops and engagements with the Somali community.

Because the intervention team was seeking an “innovation grant” from a foundation funding novel approaches to health issues, the team chose virtual reality (VR) as an appropriate mode of image-based education for the project. While VR has been available since the early 1990s, recent improvements in VR technology have led to a renewed interest in the technology and a view of VR as the next stage of experiential technological innovation (Chesher, 1994; Hu-Au and Lee, 2017). In addition to being seen as an innovative method for visual learning, VR technology was chosen because research suggests that it provides enriching, immersive learning experiences which are easy for participants to absorb and recall (Merchant et al., 2014), and research suggests it is a potentially powerful tool for behavioral health interventions. We examine the development of the intervention with attention to epistemological negotiations and shifting priorities as SCG negotiated the project with the funder. While the funder required the development of a social enterprise, and SCG was open to using a social enterprise model, we found that tensions arose in reconceptualizing the project in such a way. Although social enterprises are theoretically capable of promoting social good and meeting community needs, the focus on profit generation and incorporation of neoliberal values risks alienating the communities that social enterprises are meant to serve. We explore these issues through this article and provide recommendations for how community-based organizations might negotiate social enterprise models in a neoliberal funding context.

Stories for a “Culturally Appropriate” Intervention

While Abdi can be serious as part of his job as president of the non-profit organization SCG, he also has a warm smile and infectious laugh that convey his good humor regardless of circumstances. Today, we are holding a design workshop to develop storylines for our pediatric vaccination education platform, which uses virtual reality (VR) to educate the Somali community about vaccination and dispel rumors associating the MMR vaccine with autism. In attendance at the workshop is the entire intervention team, as well as a technology expert and a research intern who is a member of the Somali community. The team has broken up into small groups to work on ideas for the VR storyline, and Abdi is telling a story to the first author and technology expert Idan:

You know the story of Yusuf from the Quran? It's the story of a guy who was the favored brother. His brothers all got together and threw him into a well. Then they brought sheep's blood to their father and said, 'a wolf ate Yusuf!' Eventually some travelers came to the well and when they got water, Yusuf came up! They brought him to the market and sold him! He became a prophet. They don't know that he will be a prophet.

Allah blessed him with foresight, like interpreting dreams. He went through stages and at the end became the most trusted minister of Egypt. He warned them about droughts and other things. Eventually, he forgives his brothers. So basically, in the Islamic faith, we believe that people have trials, but with faith, support, and empathy you can overcome.

Abdi notes that this story illustrates how powerful storytelling is to the Somali community, and how storytelling that relates to faith is especially valuable. He believes that we should use a quote from the Quran in our VR content in order to make it relatable to the community. We all agree that it will be beneficial to include Somali characters in our storyline, easily recognizable through their clothing, such as hijabs. We also discuss that it would be ideal to have part of the storyline take place in a Somali home with traditional Somali food on the table. Abdi goes on to say that a particular challenge in developing our VR content and changing community members' minds about vaccination is that there is a lack of trust in medicine among

the Somali community. He launches into another story to illustrate:

There was a man in the community who had a stroke and was in a coma. [The medical team] wanted to take his organs! I went to translate for his family, and [the medical team] told me that the man had a doctor and I had to check with him. So, I got Dr. Bahar senior [a well-known doctor in the Somali community] to say not to take his organs. Eventually [the man] started moving his fingers! He came out of it! He watched his kids grow up, and he is a community member today!

While Abdi acknowledges that there is generally respect for doctors within the Somali community, and that indeed there are some trusted physicians, he notes that there is also distrust due to language barriers, a lack of cultural awareness displayed by doctors, and the over-all difficulty of navigating the complex and profit-driven medical system. This mixture of respect and distrust means that it is particularly complicated to approach vaccination issues within the Somali community and to appear as an expert while simultaneously engendering trust. These are the kinds of conversations that the design workshop focused on addressing in order to determine how to develop content for the Somali community that would be educational, culturally appropriate, and mindful of their unique positionalities with regard to medical systems.

Pitching a “Generic Product”

Just seven months later, the intervention team finds themselves gathered around a large table in a sunny hospital conference room, discussing the future of the project. Huddled around a conference phone, the team is on a call with Valerie, a local pediatrician who they hope will serve as an advisor on the project. Steven, the intervention team’s resident physician and design thinking expert, launches into a description of the project and what we are attempting to do. He explains to Valerie that vaccine hesitancy is a major problem in the Somali population and that we are looking for innovative solutions to this issue using VR. After some discussion, Valerie asks about the future of the project. Steven confidently responds, “our plan for the future will be to make it much more generic. For a Hispanic, African American, Caucasian population.”

Later the same day, speaking with a hospital innovation officer, Steven reiterates a similar sentiment: “We’re planning to test with the Somali community, but also planning to make it generic in the future - by probably September of this year to have generic content for other communities.” The idea behind the generic product, the team agrees, is to strip the VR content of all cultural and religious signifiers; to make it palatable to a “general” audience. The way that the intervention team talks about the project has also changed, as they have begun to discuss the intervention as a “product” rather than an educational health intervention. The focus has shifted from design workshops and community engagement to the development of a business model. Although the team plans to go ahead with development of the Somali-specific VR as a “pilot” project, the intervention has become a product to be marketed to governmental and healthcare entities, and its future is no longer culturally specific.

How did dialogue surrounding the vaccination project transform so dramatically, from discussion of designing culturally meaningful stories with the community to development of a product stripped of all cultural referents? How did a design workshop for a Somali-specific educational intervention transform into a meeting about a “generic” product with mass appeal? In this article, we examine how a non-profit organization frames and grapples with the challenges of designing and developing a behavioral health intervention while mediating the needs of the target refugee population and demands of funders. We focus on the design thinking approaches implicated in the development of a VR-based story for vaccine promotion and how the story is impacted by collaboration and conflict both within the intervention team and between the intervention team and the project’s funder. In particular, we attend to tensions created by pressure from funders to develop the intervention as a health education “product” using a social

enterprise model. While the social enterprise approach presents a potentially sustainable, scalable model for the non-profit, it risks derailing their focus on goals that prioritize the good of the communities they serve over generating profit. Additionally, we explore the ways in which the future of the intervention shifts from a community co-designed, culturally specific intervention to a “generic” product to be marketed to large healthcare organizations.

METHODS

Data for this article were drawn from two years of participant observation (2018-2020) with the intervention development team in Southern California. During this time, the first author was employed as a qualitative researcher on the intervention project and worked to ensure the inclusion of community engaged methods. She attended weekly project meetings, met with funders, conducted interviews and focus groups with the Somali community and experts working within the community, wrote and administered surveys, engaged in business development and content design workshops, and attended events such as health fairs related to the project. While the first author’s input was instrumental in deciding upon the community engagement methods early in the project, she remained a part of the project in more of an advisory capacity as the project’s focus shifted from community engagement to the development of a business model.

For ethnographic research on this project, the first author took detailed field notes during all participant observation activities. She also conducted semi-structured interviews with each of the five members of the intervention team over the course of the development of the project. Interview questions focused on the project team members’ roles, as well as the logistical and ethical issues surrounding the intervention. Interviews were transcribed and coded using MAXQDA software by the first and second authors.

Participants were made aware of participant observation at the beginning of the project and were notified that data collected would become part of a research project. All participants signed informed consent forms prior to interviews and were informed that they could opt out of any questions they did not feel comfortable answering. Ethical approval for this study was provided by the Institutional Review Board at UC San Diego (Protocol #: 171434).

Setting

Since the 1990s, civil war in Somalia has led to mass displacement of millions of people, with over 120,000 Somalis resettling in the United States since 1991 (USAID Bureau for Democracy, 2004; Zong and Batalova, 2017). Upon resettlement in the Global North, many Somalis have been faced with the widespread diagnosis of autism; a developmental disorder that was unfamiliar to them prior to migration (Decoteau, 2017). One study in Minnesota found that 1:32 children in Somali communities in the U.S. are diagnosed with autism in comparison to the state average of 1:48 children (Henneberry, 2013). The search for answers about the high prevalence of autism in their communities has led a number of Somali parents to discover anti-vaccination resources via the internet, and these parents have been subsequently targeted by anti-vaccination activists (Dyer, 2017). Despite abundant evidence that vaccination does not cause autism, Somali parents remain concerned because no one has been able to tell them what *does* cause this disability (Decoteau, 2017).

However, misinformation about vaccination is far from the sole reason for vaccine anxieties expressed throughout the Somali diaspora. Somali refugees also lack access to linguistically appropriate health education, express fear and distrust of the United States's profit-driven medical system, and express community desires to enact agency in healthcare decision-making after experiencing forced migration and various forms of biological and social control

(Dyer, 2017; Decoteau, 2017; Campeau, 2019). These vaccine anxieties have resulted in decreased rates of measles, mumps, and rubella (MMR) vaccination among Somalis in the United States (Dyer, 2017; Decoteau, 2017; Campeau, 2019). In Minnesota, which has the highest Somali population in the United States, the Somali MMR vaccination rate decreased from 92% in 2004 to 42% in 2014 (Dyer, 2017), leading to an outbreak of measles in 2017 (Sun, 2017). Because there is a significant amount of communication and movement between diasporic Somali communities in the United States, ideas about childhood autism and vaccination have spread to various Somali communities throughout the globe, including to Southern California.

Institutional context

To address these vaccination fears and the spread of misinformation about vaccination, SCG set out to apply for an innovation grant from a funding foundation that centers health equity in Southern California. The funder's board is racially and ethnically diverse and includes medical technologists, physicians, policy specialists, entrepreneurs, and attorneys, among other business professionals and philanthropists. In addition to innovation grants, the funder provides operational funding for community-based organizations, engages in impact investing, and provides emergency response funds for emergent community health needs.

Core to the foundation's activities is a "venture philanthropy" approach, wherein philanthropic pursuits are undertaken using the strategies of venture capitalism (Van Slyke and Newman, 2006). Venture philanthropy has been used in the development of social enterprises, which "adopt a business model typical of commercial enterprises and a social mission typical of non-profits" (Di Lorenzo and Scarlata, 2018). In other words, social enterprises focus on the acquisition of profit while attempting to alleviate social problems such as poverty and inequality.

The goal of the foundation’s innovation grant was to develop a sustainable social enterprise model using “innovative” approaches.

While SCG was comfortable with the prospect of innovation, they found it much more difficult to adjust from the traditional non-profit model of community-based assistance to a social enterprise model requiring consideration of profit margins in addition to addressing the community’s needs. In their application for the grant, SCG had highlighted both the innovative use of VR and community-engaged methods, but it was while negotiating the contract with the funder in 2018 that they became aware of the expectation that they also develop a social enterprise, finding a way to generate profit with their VR intervention.

COMPETING EPISTEMOLOGIES

While the Somali Tallaal Project was initially developed out of a shared vision to create a culturally and linguistically appropriate educational intervention for a racialized refugee population, epistemological tensions arose within the intervention team, as well as between the intervention team and the funder. These tensions arose due to different ideas about suitable methodologies for the project, definitions of “validation,” and the competing knowledge claims of “published science” and “the community.”

Randomized clinical trials (RCTs) have become the “gold standard” of global and public health projects (Adams, 2016a), and interventions are now frequently designed as research projects using RCTs (Biruk, 2012). In the context of the Somali Tallaal Project, the funder highly valued an “evidence-based” approach but explicitly did not wish to fund an RCT at the beginning of the project. The Somali Tallaal Project team, on the other hand, had an RCT in mind when initially developing the idea for the project. Because one of the lead investigators on the Somali Tallaal Project is a physician, it made sense to the project team to use his expertise to

design a trial. As the project progressed, the funder sought greater evidence that their investment in the project would yield an effective product and insisted upon testing more akin to an RCT. As a result, the Somali Tallaal Project team found it necessary to shift their methodological approach to respond to changing funder expectations.

The funder also insisted upon seeing quantitative metrics and “legitimate ways” of testing the validity of content, unsatisfied with community co-design and ethnographic evaluations of content alone to determine whether it would resonate with the community. In public and global health, funding often relies upon the ability to report quantitative metrics to funders to demonstrate the legitimacy, efficacy, and scalability of interventions (Adams, 2016b). This desire for metrics has led to non-profit interventions being developed as research projects that seek to quantify certain aspects of human behavior and to gloss over those aspects of behavior that cannot be easily quantified (Biruk, 2012). Within the context of the Somali Tallaal Project, there were ongoing tensions between the funder’s desire for metrics and the project team’s desire for deeper ethnographic data. Additionally, approaches common in the technology sector such as A/B testing the content were proposed by the funder to hold more value than the ethnographic work that the intervention team was doing to produce and evaluate the content. Commonly used in user experience research, A/B testing is a method that involves showing two versions of a single variable to a user and assessing which version has a greater effect. In the context of the Somali Tallaal Project, funders wanted to see an A/B test of two potential VR storylines, which contrasted with the intervention team’s methodology of using qualitative approaches to iteratively develop a single storyline.

In the development of the intervention, the Somali Tallaal Project team frequently had their project framing questioned by the funder. For instance, foundation board members took

exception to the use of the word “validation” to refer to the intervention team’s process of testing content with the Somali community. To the board, many of whom are specialists in the business and technology sectors, “validation” refers to the production of statistically significant quantitative data related to the effectiveness of the content to alter vaccination behavior. For the Somali Tallaal Project team, “validation” refers to the process of qualitatively evaluating content and materials through the process of in-depth interviews and focus groups with a small number of participants and assessing the potential of the content to impact perceptions surrounding vaccination. Not only do these approaches differ in terms of qualitative versus quantitative approaches, but they differ with respect to the intended impact of exposure to the intervention content.

The Somali Tallaal Project team also differed internally in their perspectives on whether to include information about autism in the educational content. In a meeting with the technology partner responsible for building the VR, the intervention team’s physician Steven stated, “We shouldn't include any information about autism. We have information from an autism research center that we shouldn't discuss autism and vaccination at the same time at all because it might strengthen the association.” However, the community engagement expert and the first author had heard the opposite from the Somali community in our interactions with them. The community engagement expert, a Somali public health professional named Naifa, responded: “[During community engagements] the conversation of autism was hard to avoid. The script didn’t explicitly talk about it. People [in the Somali community] accept vaccination, but as soon as MMR as a concept and as a vaccine is introduced, it's already automatically linked to autism whether we include it in the script or not. Based on that, the community ‘knows’ autism and MMR are linked. We had to talk about the research to indicate that MMR is *not* connected to

autism.” Thus, while research from other contexts suggested that mentioning autism would be harmful to the team’s aim of encouraging vaccination, engagement with the community revealed the opposite to be true. This represented a conflict between “published science” and what communities were saying, and it is important to understand how interventionists reconcile these competing knowledge claims, especially if we are to understand and rectify power differentials in community-engaged research (Lake and Wendland, 2018). Because the Somali Tallaal Project team recognized the importance of centering the community’s perspective in the final VR storyline, they ultimately agreed to include a brief discussion of autism as part of the content.

APPLYING DESIGN THINKING TO THE SOMALI TALLAAL PROJECT

Design thinking has been used widely in public health and humanitarian design, with many individuals and organizations hailing it as an innovative way to address difficult-to-tackle community health problems and to develop sustainable social enterprise models (Brown and Wyatt, 2010; Ramos et al., 2015; Redfield, 2016; Agafonow, 2019). Tim Brown, the former CEO of global design firm IDEO, is well-known for his contributions to the field of design thinking. Brown’s approach is fundamentally human-centered and focused on the idea of empathy through ethnographic methods (Brown, 2009). However, recent critiques of design thinking have suggested that this approach often lacks the reflexivity of the social sciences upon which it draws inspiration for its methodologies, and instead of truly centering the voices of communities or clients, it puts the designer or “design team” in the position of being the expert(s) in charge of interpreting community and client needs and desires (Kimbell, 2011). Additionally, design for public health and humanitarian ends in particular has been critiqued as a form of “soft cultural imperialism,” which entails “the soft insertion of market values and biases into communities at an individual, personal level” (Johnson, 2011, p. 463). Finally, design

thinking is linked to neoliberalism in its emphasis on market values and its shifting of “the onus of responsibility away from the state and/or society at large to the at-risk communities themselves” (Cook, 2019, p. 16).

The Somali Tallaal Project team endeavored to combine design thinking principles with community-based research in the development of their vaccine education intervention. While the term “design thinking” has been widely used in a number of disciplines for decades, it has recently risen in popularity and has become clearly associated with ideas about innovation (Irani, 2018), making it a logical choice for the creation of a project to be funded by an innovation grant. Some of the central methodologies associated with design thinking include ethnography, iterative testing, and prototyping. An early step toward the incorporation of design thinking into the intervention team’s methodology was their participation in a design thinking workshop, led by resident design thinking expert and physician Steven. During this workshop, the team discussed how to leverage design thinking to solve a behavioral health problem. Steven referred to community-engaged approaches as “radical collaboration” and framed design thinking for the team as an iterative, human centered way to provide people with an experience that could impact their health behaviors. According to Steven, “If you give the right experience, that person will stop smoking, will lose weight, will immunize their children.” In this way, design thinking was framed optimistically as a way to solve intractable public health problems.

Building upon design thinking ideas and previous community-based research within Somali and other refugee communities (Johnson et al., 2009), the community engagement specialist, Naifa, and the first author held a series of focus group discussions and design workshops with the Somali community to create the content of the intervention. Through these experiences, the community iteratively co-designed a culturally and linguistically appropriate

storyline for the VR experience. In some cases, direction from the Somali community changed the intervention team's pre-existing assumptions about content development. For instance, while the intervention team initially imagined a story wherein a Somali community health worker (CHW) would convey information to the audience via VR, the community focus group discussions revealed a strong preference for receiving information from a doctor character who resembled a trusted physician within the community, as community members highly valued the expertise of certain doctors. In addition to testing with the community, we tested our storyline with a panel of experts including physicians, researchers, and business specialists who could speak to the accuracy, viability, and utility of our final VR experience.

When the storyline was finalized, it was once again tested with the community through a series of focus group discussions and surveys. Participants were asked what they liked and disliked about the story and whether it had the potential to impact their vaccination behaviors. Participant feedback was aggregated and used to develop a final iteration of the storyline. This story was sent to the intervention team's technology partner for development into a VR experience. First, the Somali Tallaal Project's technology partner created a 2-dimensional video animation to act as a prototype for the VR. This prototype was subsequently tested with the community through surveys and focus group discussions. Participant feedback was then incorporated into the final VR experience, which consists of watching a pregnant hijab-wearing Somali mother expressing her concern about vaccination to the audience. In this initial scene, the mother is in her home with her family, and Somali food can be seen on the table. In expressing her concern, the mother discusses what it means to have a healthy child and how her healthcare related decision-making is related to her faith. The experience then shows the mother at a doctor's office in conversation with her Somali-speaking doctor. Within this experience, the

mother has a chance to ask the doctor all of her questions about vaccination, including addressing her concerns about whether vaccination can lead to autism. Thus, Somali parents are experiencing through the immersive VR a potentially ideal doctor's visit in which they do not feel rushed, can have all of their questions answered, and can be treated as equals by their Somali-speaking doctor. This experience notably diverges from the real-life medical experiences of many Somali refugees (Pavlish et al., 2010). The VR experience is available as a 360-degree video that can be viewed on a smart phone, a computer, or through a VR headset so that it can be widely accessible.

While the funder's expectation that SCG develop a social enterprise were in line with their central venture philanthropy approach, the Somali Tallaal Project team was somewhat unprepared for the prospect of business development when they received the grant. In the eyes of the project team, the grant would simply enable them to develop innovative educational materials. Instead, it became necessary for them to quickly pivot to the design and development of a business plan upon receipt of the grant. Design thinking also played a role in the development of the business plan, with emphasis placed on ideas of potential community impact from the social enterprise and following in the steps of other organizations that have used design thinking in their social enterprise models. Business development, like community-based research, was focused on a series of meetings, workshops, and consultations with experts; however, the design of the business plan did not incorporate the direct involvement of the Somali community beyond the two Somali members of the Somali Tallaal Project team. Another major shift that took place during the business development process was that the Somali Tallaal Project team was no longer merely discussing a VR experience, but a VR *product*. A new business expert was brought onto the team at this time to help with business development and financial

projections. Rather than discussions of community engagement, the emphasis within the Somali Tallaal Project team meetings was now placed on determining factors such as minimum viable product (MVP), return on investment (ROI), and internal rate of return (IRR).

Because of its creation of an expert design team with many non-Somali members and incorporation of largely Western design thinking principles, the Somali Tallaal Project had the potential to be an example of a non-reflexive design project. Additionally, although the Somali community was included in the design of the VR storyline, the use of VR as the delivery platform was decided upon prior to consultation with the Somali community, and the imposition of this technology on the community due to its fit with the “innovation grant” could be seen to represent a form of soft cultural imperialism (Johnson, 2011). The Somali Tallaal Project team grappled with these concerns throughout the development of the project, and rather than positioning themselves as expert translators of the Somali experience, the team consulted with influential Somali community leaders who were experts in their own experiences and well-connected to the experiences of the Somali community at large. Although the Somali Tallaal Project team originally envisioned delivering VR content using specialty VR goggles, these community experts informed the project team that this would not be the most accessible option for the community. However, the community experts informed the team that most people had access to smart phones or computers, making 360-video a more appropriate platform for distributing educational content. Additionally, the two Somali members of the Somali Tallaal Project team and the first author continuously encouraged reflexivity during team meetings and regularly scheduled check-ins with the Somali community and the aforementioned community leaders. While these solutions were imperfect and incomplete, they represented a step toward more community-engaged design of interventions.

COMPETING PRIORITIES: COMMUNITY INTERESTS VS. SOCIAL ENTERPRISE MODELS

One feature that united all intervention team members, regardless of background, was their desire to help and to be part of what one team member called “a greater cause.” This desire to be part of a greater cause was unfortunately frequently overshadowed by prioritizing the development of a revenue-generating social enterprise model. While in theory, social enterprise models and helping others are not mutually exclusive, the social enterprise model was in practice not always aligned with the intervention team’s community engagement strategies and overarching desire to ameliorate health disparities in a racialized refugee population.

Social enterprise models, which are becoming increasingly popular in the non-profit sector, have been largely associated with neoliberalism because they represent the privatization of services for the “public good” and also the “marketization” of such services (Eikenberry and Kluver, 2004; Gerrard, 2017). Although social enterprises in the non-profit sector come with some degree of autonomy from funders, they can also result in the centering of profit over the centering of the community. Additionally, the logics of social enterprise can become suffused within the workings of the non-profit, leading the organization to encourage neoliberal models of self-help within the communities they serve (Gerrard, 2017). This “trickle down” of neoliberal self-help ideals may indeed empower certain sectors of the population, but they may also leave those with the greatest need ineligible for assistance from non-profits, just as they are rendered ineligible for assistance from government entities.

Although the funder’s expectations included the prioritization of the development of a revenue-generating social enterprise, it was not clear about how the VR intervention could or should generate profit. As such, the Somali Tallaal Project team was tasked with determining

how to “market” the VR “product” and to whom they might sell such a product. The expectation to develop a social enterprise was initially not entirely welcome by everyone on the Somali Tallaal Project team. Mona, an entrepreneur and business expert on the intervention team noted, “When we were negotiating the contract, I was very defensive.” She explained that she was not prepared to engage in such “transactional” interactions or to prioritize revenue generation as someone affiliated with a non-profit. Similarly, Steven felt that the funder’s priorities were initially at odds with the spirit of the project. He stated, “[A] community engagement public health project is what we were granted and what we won. And then it changed into product development. I see it as taking a square peg and putting it into a circle.” He went on to say, “I was very uncomfortable with it - and this dates back four years - when a venture capitalist was part of our team and we just didn’t understand one another.”

However, eventually, the Somali Tallaal Project team members came to embrace the new model. Mona explained her change of heart: “It was challenging at first, but I think it was the best thing that could have happened as well.” Ultimately, she felt that the social enterprise model represented a way to expand the possibilities of the non-profit to affect change within the communities they serve. Steven also changed his opinion of the shift in priorities, stating, “I think [the shift has] actually been its strength - I think it's taken us out of our comfort zone, brought on people into a team that would not have otherwise been there.” Similarly, Abdi felt that the social enterprise model represented a possibility for positive change in the non-profit sector. When asked about the shift to a social enterprise model, Abdi said, “As long as the funding doesn't dictate and say ‘you have to do it this way,’ or does not push...as long as the non-profit has the flexibility of being creative and innovative and the solution is fitting with the mission and the community has a say, I think it's a very good concept.” His statement suggests

that he views social enterprise models as potentially useful as long as certain conditions which uphold the values of the non-profit are met. Similarly, Naifa felt that social enterprise could be useful for scaling and sustaining the project, as long as the project continued to fulfill the non-profit's duty to the community. She stated: "I think also like, even though we're like having more of a monetary goal like need to get more of an enterprise model, I don't think it's a terrible thing. In fact, it might help us be able to scale those in a sustainable way. But I think, I think there has to be a balance between being mindful of the enterprise component and then being mindful of like the intention, which is to empower communities and improve their health outcomes."

FROM "CULTURALLY SPECIFIC" TO "GENERIC PRODUCT"

The shift to a social enterprise business model produced tensions for the intervention itself, which was originally conceptualized as culturally and linguistically appropriate VR content for the Somali community. While this goal of cultural and linguistic appropriateness was central to the values of the non-profit in serving the community and was one of their primary areas of expertise, it was at odds with the desire of the intervention team to create a sustainable business model. Specifically, they decided to create many different kinds of content – in addition to the VR story on MMR vaccine promotion – that could be more broadly marketed. The team hoped that in future, they could create an entire library of health topics using VR, including diabetes management, pediatric health and nutrition education, and other health issues faced by the Somali community.

It quickly became clear that developing this entire educational library using the same lengthy process of community co-design and community testing would take too much time and cost too much money to be sustainable for a social enterprise. It also became clear to the intervention team that such specialized products may not be widely marketable. Thus, the

intervention team set their sights on the eventual development of a “generic” VR storyline which could appeal to people from various racial, ethnic, and religious backgrounds and which could be translated into more commonly used North American languages such as English and Spanish. This generic product would include “ethnically ambiguous” characters and would do away with the Somali language, references to Islam, and cultural dress that were part of the Somali-specific MMR content. Although the intervention team is continuing with the development of the Somali-specific MMR education platform as planned, it is now viewed as a “pilot project” for the social enterprise. The necessity to move forward to design a “generic product” with wider revenue-generating potential as the next step moves the intervention team further away from the original goal of producing a wide array of culturally and linguistically specific VR experiences that appeal to particularly underserved populations.

While a “generic” product with more mass appeal is certainly more widely marketable than a very culturally specific product that caters to one portion of the overall population, removing the rigorous process of research, community engagement, and community testing from the development of “generic” content may severely impact the efficacy of the intended intervention. With MMR for instance, there are specific populations that experience vaccine hesitancy or refusal, and their reasons for doing so are varied (Reich, 2016). Many parents who refuse vaccines or are hesitant to vaccinate their children are white, upper middle-class mothers. Their reasons for not vaccinating are often related to a feeling of personal expertise in their children’s “unique” bodies and experiences, which allows them to question the recommendations of their doctors (Reich, 2016). In contrast, children from low-income Black families are often under-vaccinated due to lack of access to health care and distrust of medical systems due to experiences of medical racism (Reich, 2016; Samudzi, 2017). While the intention here is not to

assume that each community discussed is homogenous, a “generic,” one-size-fits-all approach to public health education that addresses MMR vaccine hesitancy or refusal may not be appropriate for every community and indeed may leave out those that are most marginalized. In fact, this generalizing approach stands in opposition to the general trend in public health toward cultural adaptation of interventions, which is based in evidence that cultural adaptation creates more effective interventions and more positive health outcomes for marginalized populations (Barrera et al., 2013).

DISCUSSION

In this article, we have explored how a non-profit approached development of a health education intervention while grappling with competing epistemologies, priorities, and models. While the Somali Tallaal Project’s central aims were initially to use community-based methods to create a culturally and linguistically appropriate storyline, priorities shifted due to funder expectations to develop a profit-driven social enterprise model that would ultimately result in a “generic” product to be widely marketed to healthcare organizations beyond the Somali community. We demonstrate the ways that non-profits experience the conflict between the ethics of community engagement and the neoliberal expectations of funding foundations whose core focus is on venture philanthropy.

At the outset, the Somali Tallaal Project team’s goal was to develop a culturally specific VR storyline based on community research that could appeal to Somali refugees in their healthcare decision-making. The modality of VR was chosen in response to a funding foundation’s call for “innovative” projects to solve healthcare problems. In this way, the project was already being shaped by the funder from the time of its inception, reflecting SCG’s reaction to the idea of what it means to get funding in a neoliberal context. The choice of VR as an

innovative approach reflects a set of values – often explicitly or implicitly expressed by funding foundations – that privilege a faith in technological solutions to health problems. This same faith in technology has also been seen in the context of broader global health interventions and has been critiqued as an attempt to provide “quick technological fixes” to social and institutional problems (Cueto, 2013, p. 33). Nonetheless, SCG felt that through community-engaged approaches, they could create an appropriate educational experience that harnessed the immersive nature of VR to provide Somali parents with experiences that may otherwise elude them due to lack of access to services in their primary language (Pavlish et al., 2010).

We demonstrate that as the project continued to be developed, its methodologies were also determined by the funder. Although the project began with community-based research as its core methodology, the necessity to develop a social enterprise model saw these methods take a backseat to the process of business development. While it cannot be said that community input was completely devalued, it became a lower priority than the potential for profitability. This prioritization undeniably shaped the project as well as the future of the project, which transformed from the development of a culturally specific “library” of health education topics to the development of a “generic product” which could be widely marketed to the “average” North American. While the “generic” product was said to be for a “Hispanic, African American, Caucasian population,” words such as “average” and “generic” – used repeatedly by the Somali Tallaal Project team to refer to their broader North American audience – may act as subtle referents to whiteness. Whiteness, as has been argued by Haraway (1989/1992), Berg (2008), and others, is often considered to be an “unmarked” category without “culture,” or a self-evident natural baseline against which to compare all other categories. Despite the initial aim of the project to cater specifically to a Black refugee population with specific social concerns, the

product for a “generic” audience wipes away all references to “culture” to become palatable for a white majority population. In this way, the initial aim of the project to be “culturally specific” becomes antithetical to the ultimate goal to develop a widely marketable “generic” product that can appeal to white majority consumers. The upshot of this is that the methodologies of CBPR and community co-design become decentered from the future goals of the project. Indeed, there has been no discussion of using these methodologies to create the “generic” product. Instead, it has been proposed that cultural signifiers will be stripped away from the product to give it more mass appeal.

This “generic” versus “cultural” approach has significant implications for debates about “cultural competence.” While culture is a complex and shifting concept, assumptions that individuals or organizations can have “cultural competence” and can therefore provide “culturally appropriate” interventions relies upon ideas of a static concept of culture that is ascribed to the racialized “other” (Tascon and Gatwiri, 2020). The intention of SCG was never to oversimplify the concept of culture, but to instead use the framework of cultural humility, which centers self-reflection and self-critique (Tervalon and Murray-García, 1998). Through their focus on cultural humility, SCG emphasized issues of power in their development of the intervention, creating an immersive experience that allowed Somali community members to be part of an equitable interaction between a Somali-speaking doctor and a patient who poses questions to the doctor. This does not necessarily reflect the reality of Somali refugees’ interactions with the medical system, which are often impacted by xenophobia, racialization, and linguistic barriers (Terrana, 2021). While this focus on cultural humility and community engagement may have produced a useful intervention for the Somali community, the prospect of creating a “generic”

product with mass appeal toward the “average” American *without* the use of community engagement speaks to the unmarked and “un-cultural” nature of whiteness.

Although priorities shifted, the importance of design thinking remained central to the creation of the Somali Tallaal Project throughout both the community engagement and the development of the social enterprise model. While design thinking has been a valuable approach for public health and humanitarian design, it has also been critiqued for its lack of reflexivity, its neoliberal approach, and its status as a form of soft cultural imperialism (Kimbell, 2011; Johnson, 2011; Cook, 2019). With these critiques in mind, the Somali Tallaal Project team worked to incorporate refugee community members’ expertise into their model. Although this model is theoretically a good compromise, this article comes with the caveat that this approach is still being negotiated and we are not yet certain of its outcomes. However, we argue that the approach would be most effective if refugees were given more leadership roles in refugee design projects and were consulted at the early stages of projects prior to deciding upon particular platforms (e.g. VR) and approaches. In addition, engagement of the refugee community could have been a part of the design of the business model, which incorporated design thinking but did not include the perspectives of the broader refugee community. Nevertheless, this will only be effective if funding foundations see the value in refugee leadership and place refugee voices and needs above Western ideals about medicine, technology, and innovation (Adams, 2016b; Cueto, 2013).

CONCLUSION

Community-based research is an ideal model to use for the development of interventions – particularly for communities that have been structurally oppressed (Johnson et al., 2009).

However, the Somali Tallaal Project demonstrates how – in the face of decisions about which approaches will generate the greatest profit – community-centered methodologies often get left behind, and considerations for structurally vulnerable populations become of secondary importance or removed altogether. While social enterprise models in theory are supposed to be designed to place the community’s needs at the heart of the enterprise, this project shows that it is not always the case that the community remains at the center of profit driven models.

Additionally, interventions that make use of neoliberal ideologies such as “social enterprise” and “design thinking” may risk alienating the communities they are supposed to serve, foregrounding values of innovation and technology over the needs of the community. If non-profits wish to incorporate social enterprise models into their toolkits while maintaining a focus on target communities, they should have the flexibility to create these social enterprises using community-based research and design in earnest. While these approaches may take longer due to the necessity for in-depth community collaboration, they are important to keep the community’s needs at the center of all the non-profit does. While approaches that take a greater investment of time may reduce profit margins, the profits are ultimately still greater than what non-profits typically receive and may be funneled back into serving communities in need. This is just one way that social enterprise can work for non-profits and for structurally vulnerable communities that are otherwise not served by the majority of interventions and public services.

Funders should also take into consideration the ways in which their neoliberal values may limit the possibilities of social enterprise. Rather than funding projects based primarily on their status as “innovative” or “technological,” funders should ensure that the needs and voices of marginalized communities are foregrounded in the programs that they fund – even if this means moving away from the use of particular methodologies that privilege Western biomedical and

scientific approaches. We do not suggest that social enterprises are a panacea for social and economic issues faced by marginalized communities, nor do we suggest that social enterprises can be entirely decoupled from neoliberal values within the context of our modern capitalist system. Instead, we suggest that social enterprise models are only useful insofar as they allow for community identification of priorities and trajectories of the social enterprise and do not displace community needs in favor of profit generation or a focus on neoliberal values.

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Chapter 4

DEVELOPMENT OF A CULTURALLY AND LINGUISTICALLY SENSITIVE VIRTUAL REALITY EDUCATIONAL PLATFORM TO IMPROVE VACCINE ACCEPTANCE WITHIN A REFUGEE POPULATION

ABSTRACT

Objectives: To combat misinformation, engender trust, and increase health literacy, we developed a culturally and linguistically appropriate virtual reality (VR) vaccination education platform using community-engaged approaches within a Somali refugee community.

Design: Community based participatory research (CBPR) methods including focus group discussions, interviews, and surveys were conducted with Somali community members and expert advisors to design the educational content. Co-design approaches with community input were employed in a phased approach to develop the VR storyline.

Participants: 60 adult Somali refugees and 7 expert advisors who specialize in healthcare, autism research, technology development, and community engagement.

Setting: Somali refugees participated at the offices of a community-based organization in San Diego, California, as well as at a community health fair and online. Expert advisors responded to surveys virtually.

Results: We find that a CBPR approach can be effectively used for the co-design of a VR educational program. Additionally, cultural and linguistic sensitivities can be incorporated within a VR educational program and are essential factors for effective community engagement. Finally, effective VR utilization requires flexibility so that it can be used among community members with varying levels of health and technology literacy.

Conclusion: We describe using community co-design to create a culturally and linguistically sensitive VR experience promoting vaccination within a refugee community. Our

approach to VR development incorporated community members at each step of the process. Our methodology is potentially applicable to other populations where cultural sensitivities and language are common health education barriers.

INTRODUCTION

Over 300,000 refugees enter the United States every year. While refugee resettlement has increased over time, events as recent as 2015 mark one of the largest exoduses of forced human migration, sparking a crisis as countries struggle to cope with the influx and the social and economic demands that coincide with human resettlement (Nicolia et al., 2015). What is largely missing in the public discussion is an appreciation that refugees face extraordinary challenges throughout their migration process from origination to destination. One challenge in particular – the access to proper healthcare - is critical, both for those that have been resettled in the past and those who have recently arrived (Kumar, 2020). The other challenge is to collect and monitor healthcare data that can be accessed and disseminated to resettled communities for public health monitoring (Westgard et al., 2020). In recognition of these challenges, important questions range from how to efficiently meet the healthcare demands of a growing population that is effective and sustainable to providing an engagement that uses culturally specific resources that simultaneously enhances health education and drives an increased level of trust in the local healthcare system (Shadmi et al., 2020).

Upon resettlement in Western countries, many Somali refugees were faced with the widespread diagnosis of autism, a developmental disorder which was unfamiliar to them prior to migration (Decoteau, 2017). On one hand, among a community cluster of resettled Somali children in Minneapolis, the prevalence of autism has exceeded 3% and has eclipsed the national average of 1.9% (Henneberry, 2013). On the other hand, this specific refugee community was

targeted by anti-vaccination activists and the propaganda that vaccination is a cause of autism. This misinformation led to concern by Somali parents and distrust in the healthcare system, which has resulted in a propensity for vaccine hesitancy and non-acceptance (Decoteau, 2017; Henneberry, 2013; Dyer, 2017). A lack of effective messaging towards what does cause autism and the dissemination of anti-vaccination propaganda were successful in decreasing vaccination rates in the Somali refugee population in Minnesota from 92% to 42% over the span of a decade (Dyer, 2017; Hviid, 2019).

Effective healthcare education relies on various principles for building essential skills, including communication, assessing the accuracy of information, decision making, planning, goal setting, and self-management (Nabulsi et al., 2007). At its core, health education must be simple, retained, and must be assimilated within those factors relevant to a given individuals biases and acceptances towards the delivered message (Nabulsi et al., 2007). New digital innovations such as virtual reality (VR) has emerged as a tool to provide an enriching and immersive learning experience that promotes absorption in both acute conditions such as anxiety and post-traumatic stress disorder, and chronic conditions such as tobacco cessation as well as for medication compliance (Merchant et al., 2014; Psotka, 1995; Riva et al., 2016; Zhou et al., 2014). The ability for VR to increase information retention and to change health behaviors by engaging users in a non-healthcare environment makes VR a potentially valuable platform for visual health education. Therefore, our primary aim was to develop a customized, culturally and linguistically appropriate VR educational program specifically focused on pediatric vaccinations, and to leverage community based participatory research models and community co-designs to build, test, and deploy VR at the community level among a group that are known to be vaccine hesitant or vaccine resistant.

METHODS: STUDY DESIGN

The Somali Tallaal Project (Tallaal is Somali for vaccination)² is a community innovation program to design, deploy, and utilize new healthcare innovations with an inclusive model of community engagement. Within the current program, community-based participation was incorporated along three complementary approaches (Bhavnani et al., 2016). These include:

- 1) To define the health care access barriers in a resettled refugee community with a focus on pediatric vaccination.
- 2) Incorporate a community-based participatory model to develop the virtual reality content with community member co-design.
- 3) Develop a virtual reality technology that is customized with cultural, linguistic, and religious sensitivities to provide appropriate health education.

Qualitative feedback was derived through focus group discussions, interviews, and surveys developed by the investigators and was completed by community members and experts for analysis during each phase of technology development. Focus groups and interviews were conducted by Najla Ibrahim and Samantha Streuli. Najla Ibrahim is a Somali woman who holds an MPH degree and is an expert in community public health issues. Samantha Streuli is a white woman who is a PhD candidate in anthropology at UC San Diego and who has been working with the Somali community for three years. The majority of focus group and interview participants were unknown to Samantha and Najla prior to the research project, though some were acquaintances from previous work within the Somali community.

² Pseudonym, as are all names of projects and organizations herein.

Ethics Approval Statement

This study was approved by The University of California San Diego Institutional Review Board (Protocol #171434).

Patient and Public Involvement

The Somali community was involved in the research from its inception and were regularly consulted as the research was developed. Focus groups and interviews with the community informed the development of research questions, which prioritized the experiences and interests of the Somali community. We consulted with community members and community leaders when designing and conducting the study and developing survey, focus group discussion, and interview questions to determine outcome measures. Somali community members were also involved in the recruitment to the study, as much of the recruitment happened via word-of-mouth. The results of the study will be presented to participants and other community members, who will be further consulted via focus groups on how to best disseminate results.

Participants

Inclusion/Exclusion Criteria

We identified groups of Somali individuals for community participation and VR co-design. Participants were required to be members of the Somali community in San Diego, California who were over the age of 18 and were either 1) Somali refugees; 2) Somali immigrants; or, 3) US-born Somali Americans. We selected a group of 7 expert advisors to assist in the development of VR. These advisors included: 1) researchers or other experts in autism and/or vaccination; 2) physicians serving the San Diego Somali community and in pediatric health; 3) leaders within the Somali community.

Setting

San Diego County is the 3rd largest metropolitan area in California and the 12th largest resettlement area in the United States. The organization responsible for the development and execution of the program is Somali Community Group (SCG), a fiscal sponsor for the East African Collaborative of 8-community organizations that aims to outreach, educate, and enroll refugees and immigrants in health insurance programs. This specific community predominantly resides in City Heights, a subdivision of San Diego County that has a population of 75,000 individuals. Socioeconomic statistics of this region includes a median household income of \$39,330 (national median \$55,322), 40% are immigrants and/or refugees, with 31% having an education level of a bachelor's degree or greater (City Heights Demographics and Statistics).

Recruitment

Somali individuals were recruited via telephone and through word-of-mouth by Somali Community Health Workers (CHWs) and peers. Our target participants were: a) parents of children between 0-2 years of age, b) pregnant, or c) planning to become pregnant in the next two years; however, we included those Somali community members interested in issues of autism and/or vaccination regardless of parental status. All participants consented to have their names and contact information collected for future correspondences. This information was securely stored in an encrypted file and only used to re-contact participants who agree to be re-contacted. The research objectives, research participants' rights, and description of how data would be used were explained to all participants prior to participation. All participants provided verbal consent, which was approved by The University of California San Diego Institutional Review Board (#171434).

Expert advisors were identified by the Somali Tallaal Project leadership team according to their particular areas of specialization. Advisors signed consent forms to participate in the iterative development of educational content.

CBPR and Community Co-Design

Our CBPR approach involved community members in each step in the design, iterative testing, and development of culturally and linguistically appropriate health education content. This approach to CBPR in the Somali community builds upon public health work previously done within refugee communities (Fisher et al., 2016). We developed a community co-design methodology that uses the principles of design thinking combined with community-based research to enable participants to be directly involved in the design and creation of content and products that are developed to benefit them (Fisher et al., 2016; Israel et al., 1998). This co-design methodology was inclusive in that community members were asked to participate within content curation and to lead certain aspects of VR development.

Phased Approach to Virtual Reality Development

We merged each aspect of CBPR and community co-designs within a phased approach to VR development (Vendor: INVIVO, Toronto, Canada). These phases included:

Phase 1: CBPR approaches to assess community needs and concerns important to pediatric vaccination.

Phase 2: VR modality determination for script development. The modality consisted of the type of VR experience and the script development included the specific educational content.

Phase 3: VR Prototype and iterative feedback from storyboards, 2- and 3-dimensional animation, and visual and audio experiences that incorporate VR design elements including those factors that allow users to engage at different levels of health literacy.

Phase 4: Final VR Product and Testing

The objective within VR development was to use those tools and devices that were available to the community-at-large and to ensure cultural and linguistic sensitivities were incorporated.

Data Collection and Analysis

All data were collected electronically via tablet or computer at the time of focus group discussions, interviews, and surveys. Focus group discussions and interviews were either recorded and transcribed, or extensive notes were taken on a computer in the event that groups or individuals declined to be recorded. Analyses were conducted thematically and iteratively using the content of the surveys, focus group discussions, and interviews during the phased approach for VR development. This approach utilized five steps: 1) familiarization, 2) coding, 3) theme development, 4) defining themes and, 5) reporting (Miles & Huberman, 1994). During the process of familiarization, all sections of the interviews, focus group discussions, and surveys relating to the experience of utilizing VR were extracted. Coding was performed using MAXQDA software. Emergent themes from each phase of development were defined and reported in order to inform the subsequent development phases.

The primary data coder was SAS. To ensure a rigorous evaluation of the data, a subset of transcripts was also coded by AM. In order to achieve consensus on codes, AM and SAS engaged in recurring discussions on the coding process. The analysis was further tested during discussions with expert advisors. The consensus was reviewed and approved by all investigators. Specific quotations were chosen by SAS to represent emergent themes in the data.

RESULTS

This program began in April 2019 and product testing is ongoing. Figure 4.1 illustrates the phased approach to development and iterative testing. In total, 67 individuals (7 advisors, 60 Somali community members) provided feedback during each phase of VR development and participated within the community-co design.

Community-based Participation

The first step in our community engagement process was to hold a series of 3 focus groups exploring topics of interest to the Somali community including vaccination, autism, pediatric health, and technology (n = 18 Somali community members). Based on this initial feedback from the community, the project team held a design workshop to create a series of 3 story ideas for the VR. These ideas were then brought to the Somali community in the form of another design workshop where the community evaluated the suitability of the provided stories and suggested changes. 4 Somali community members (2 Somali community health workers, 1 Somali woman, and 1 Somali man) participated in this design workshop to develop the general framework of a story. Information learned from the community was then used to develop a first iteration of a script. This script was then tested for cultural and linguistic suitability and vaccine-promotion potential with 17 Somali women from ages 26-78 and was followed by a discussion with a prominent male community leader to again assess the cultural and linguistic appropriateness of the content to promote vaccine education. Finally, a 2-dimensional prototype of the VR animation was developed with a Somali voiceover (Figure 4.2) and was tested with 24 community members in order to determine the effectiveness of the messaging in promoting vaccination and to assess cultural and linguistic elements of the storyline.

Phased Approach to Virtual Reality Technology Development

Phase 1: CBPR approaches to assess community needs and concerns important to pediatric vaccination

The Somali community focus group discussions were broken up into three separate sessions, each of which focused on a particular area of community interest (Table 4.1). The first focus group discussion was centered on health concerns of the community, and participants cited autism as a major concern, as well as language barriers that pose a significant problem when engaging with the medical system. In addition, participants brought up issues of trust which were tied to poor communication.

The second focus group discussion explored issues of pediatric health. Participants provided information about pregnancy, childbirth, pediatric care, and parenting. The central theme of this focus group discussion was issues of trust within the medical system, with many mothers indicating that while they highly valued their doctors' opinions, they also preferred to do their own research. Mothers relayed to us their desire to receive health education in their own language from a trustworthy doctor.

The third focus group discussion was centered around issues of vaccination and technology. Participants once again indicated issues surrounding trust in medical systems and their desire to make their own educated health decisions. Additionally, participants stated that they would like to receive more detailed information about how vaccinations work. For instance, one participant stated: "If they could show how the vaccine works in the child's body and what it does – if it can be visualized." Another participant asked for further explanation of the risks and benefits of vaccination, saying: "That before the vaccines are given to our children, for it to be

explained to us what the risks are - the sided effects, and the benefits. When we compare the two, then make a decision.”

Themes that emerged from interviews with 3 Somali parents also included concerns about autism, medical trust, and the desire to learn more about vaccination.

Phase 2: VR modality determination for script development

Modality determination: The project team consulted extensively with Somali CHWs to determine an appropriate modality, and chose 360-video due to the ability of this format to be experienced using virtual reality headsets, smart phones, or computers in order to make this VR program widely accessible to all members of the Somali community.

Script development: Open-ended survey responses from Somali community members regarding the three potential storylines indicated that an older Somali male doctor would be most suitable to deliver health information in our story, as this character would evoke feelings of trust and respect. Somali community members favored a scene where a Somali mother could be shown talking to her doctor – this way they could see themselves as a character in the VR story and could see their questions and concerns being addressed directly. The open-ended survey responses from community advisors indicated a preference for a storyline with a strong focus on family and supported the story concept of a Somali mother asking questions to a trusted physician. This information was used to develop the initial script.

Six members of the expert advisory board reviewed the initial script. Advisors were asked to answer a series of six open-ended questions and provided insightful answers that assisted with script development (Table 4.2). Specifically, when advisors were asked for their overall impressions of the story, they stated: “Overall, I like how the story flows and the way in which the educational components are presented.” One advisor noted: “I like the simplicity of

the conversation with its effective focus on the key messaging of the value of the timely vaccination to help raise healthy kids.”

We conducted a community focus group discussion during the script review process to engage the community. Community members were asked to assess how culturally appropriate the storyline was, what they would like to change, how impactful the story was, and how they would personally design the content. During this focus group discussion, participants agreed that the story was clear and easy-to-follow; however, as additional questions were asked about story flow, the feedback turned to autism. We found that even when we did not mention autism, the false association between autism and the measles, mumps, and rubella vaccine (MMR) came up as a topic of discussion. Many community members said that they were concerned about autism and the MMR vaccination. One woman asked: “if MMR doesn’t cause autism, why did I see my child stop talking immediately after getting the MMR?” The participants agreed that the VR must address the autism question, and that they would prefer to learn this information from a doctor character in the VR storyline.

Community members were also asked to take a brief survey after reviewing the script. This survey included questions about attitudes toward vaccination as well as vaccination planning. Notably, there was an 18% increase in participants who endorsed being “very comfortable” with MMR vaccination following script exposure. Additionally, those who said they were “not at all comfortable” with MMR vaccination decreased by 12% following script exposure. There was also a 17% increase in those who stated they would allow their child to receive the MMR following script exposure (Table 4.3).

Phase 3: VR Prototype and iterative feedback

Three expert advisors provided feedback on the storyboard and prototype that focused on where characters were positioned (i.e. husband next to wife), color scheme, and highlighted the need to describe the immune system's function in order to retain scientific accuracy in the communication of vaccination information.

The prototype (Figure 4.2) was tested with the Somali community in the context of an in-person focus group discussion and surveys that took place both in-person and online. Participants in the focus group discussion were asked a series of open-ended questions about their experience with the prototype. The primary focus of this discussion was analysis of the storyboards and stylistic elements of the VR experience (e.g., color preferences, imagery, portrayal of characters). Participants indicated that they highly valued the Somali voiceover and preferred to include the discussion of autism in the final VR storyline, as its exclusion would raise more questions for the community. The participants also felt that the father character in the VR storyline seemed somewhat excluded and should be standing near his wife to signal support.

All participants who reviewed the prototype agreed that the inclusion of culturally appropriate characters and a Somali voiceover maximized the educational experience. 13/24 (54%) participants stated that the prototype made them either more comfortable or much more comfortable with vaccination than they were before exposure to the prototype. 20/24 (83%) participants stated that they would recommend MMR vaccination to members of their community following exposure to the prototype. Additionally, 21/24 (88%) said they planned to vaccinate their children following exposure to the prototype.

VR design factors: The key VR design elements that were incorporated within each phase of VR development include passive, non-intrusive experiences, a dynamic and interactive visualization, and prompts that promote the user towards self-reflection.

Phase 4: Final Product and Testing

The final product is a four minute 360-video animation available in Somali and English languages. It can be viewed online using a tablet, a smart phone, or with VR goggles. Settings include a Somali home populated by a family, and a doctors' office. In the animation's introduction, we meet the expectant mother who states that she is expecting her first child and is trying to make decisions about vaccination. Figure 4.3 illustrates in screenshots each of the 4 chapters in the VR experience. We plan to test the final product using an A/B testing model with the Somali community wherein the A group receives the VR education and the B group receives a basic English-language educational video about vaccination. Both groups will be surveyed before and after exposure to the educational materials to assess changes in attitude toward vaccination and willingness to vaccinate.

DISCUSSION

The main results of the Somali Tallaal Project program can be summarized as follows: 1) a community participatory research model can be effectively translated for the co-design of a VR educational program with community members involved in each phase of technology development; 2) cultural and linguistic sensitivities can be incorporated within a VR pediatric immunization educational program and are essential factors for effective community engagement; and 3) effective VR utilization requires flexibility that can be used among community members with varying levels of health and technology literacy. To the best of our

knowledge, our VR development is the first such health innovation for vaccination education designed by a community of refugees known for vaccine hesitancy.

Refugee Learners – Vaccination & Autism

This community has common barriers to effective education such as a lack of information and information that is not culturally and/or linguistically appropriate to drive understanding (Kim et al., 2020). Regarding immunizations, many parents and caregivers in this community already possess medically inaccurate information. We have previously determined that within this refugee community the reason not to immunize has resulted from misinformation and the perception that vaccination results in autism. Although MMR vaccination rates have fallen in the Somali community (from 92% to 42% over the span of a decade (Dyer, 2017; Hviid, 2019)) rates of autism and pediatric learning impairments have remained high (1:32 Somali children have autism compared to the national average of 1:54) (Maenner et al., 2020; Hewitt et al., 2016). While these results do not support the link between vaccination and autism, many parents are still convinced of an association between MMR and autism. Given these results, it is important to take into consideration the mental and emotional state and the ideation that arises from associating vaccinations with autism. Within this community health engagement related to immunization requires education focused on the importance of vaccinations for newly arrived refugees, and a re-education among those who have previously elected not to immunize. In this context, we performed a community health assessment and identified the drivers for a low rate of vaccination in the Somali community ranging from cultural and language barriers, distrust in the healthcare system, and the misinformation that vaccination results in autism. Recognizing these drivers for low immunization rates in this community, our observations for the mechanisms for how VR affects behavior changes include: content that is culturally relevant, stimulates an

awareness and expectation for what vaccines do and do not do, and provides an immersive experience leading to information retention (Diemer et al., 2015).

VR CBPR and Co-Designs

In addition to the mechanisms for how VR affects behavioral change, several design factors must be maintained when considering who interacts with the VR technology and especially among immigrants that may have varying levels of health and digital literacy. Within our program, most community members experienced a positive interaction with VR. There are several plausible reasons for our observations. Through community co-designs, we leveraged key design factors including a non-intrusive experience (users learn in their own environment), a passive interaction (content that is visual, audio, and depicted versus reading), a dynamic storyline that builds upon previous experiences and uses known environments, and promotes self-reflection by allowing the user to introspect and contemplate during the VR experience.

Because we recognized the importance of culturally and linguistically appropriate educational materials to deal with issues of low health literacy and medical distrust, we included community-based approaches in each phase of our development. The results of focus groups and surveys conducted within the community revealed several important considerations for the development of our VR storyline. For instance, community members were much more comfortable receiving information from a trusted doctor character. Community members also felt it necessary to include direct and clear information about the lack of relationship between autism and vaccination in our storyline. This was in contrast to our expectation and that doing so would reinforce this misinformation. Following design workshops with the Somali community, we tested the program that they helped to co-design within the community in order to address its cultural and linguistic appropriateness as well as its ability to promote vaccination behavior. We

also tested the VR storyline with a team of subject matter experts who evaluated the scientific accuracy and usability of our design. In our community testing, we found that many Somali community members felt the VR storyline engendered trust, was relatable, was educational, and was convincing. Several focus group and survey participants stated that they planned to vaccinate and to recommend vaccination to others following exposure to the VR. Our testing with our panel of experts found that our content was user-friendly, easy to understand, and scientifically accurate.

While we appreciate that community co-designs are an important methodology for how a new technology is designed, a foundation of CBPR is necessary to harness community involvement. To employ CBPR, we engaged community members throughout every step of the process. Before developing the idea for the VR storyline, we engaged the community in a series of three focus groups to better understand their needs, strengths, and interest in collaboration. Focus group discussion questions were open-ended and allowed for participants to bring their interests and concerns into the conversation. Information learned from these engagements was used to begin to develop the culturally and linguistically appropriate storyline for the VR. Community members were also continuously engaged throughout the development of the VR storyline through community co-design.

It is our plan to leverage the educational curriculum as well in future deployments of VR. Due to the constraints of COVID-19, we are currently exploring the possibilities of using telehealth and other digital communication platforms to safely and effectively deploy the VR into the community. Addressing vaccine hesitancy is especially relevant within the context of COVID-19, as vaccination rates for preventable diseases have dropped significantly since the beginning of the COVID-19 crisis (Santoli et al., 2020). There are also concerns about the

potential of misinformation related to COVID-19 vaccination that is especially relevant for an underserved community that is largely excluded from vaccine clinical trials and communities that have a history of vaccine hesitancy.

Limitations

Our community feedback and focus group may represent a convenience sample for those that are more apt towards vaccine acceptance, and therefore may not completely capture all concerns among those who are vaccine hesitant. While this represents a potential selection bias, our method to include a wide range of community members as well as internal and external advisors may enhance internal validity by incorporating a heterogeneous group for community input. Community based participation and community co-designs at each stage of VR development from the initial idea through completion of a VR animation may enhance external validation by including the key components related to cultural and linguistic sensitivities within the phased approach for VR development. Finally, a perceived shift from vaccine hesitancy to vaccine acceptance at this point is subjective and requires real-world validation and prospective follow-up confirming vaccine delivery.

CONCLUSION

We employed community-based participatory approaches, and community co-design to develop an innovative vaccine educational technology with Somali refugees using VR. By combining new technology-enabled approaches with the needs, interests, and expertise of Somali community members, we have created a methodology that can address vaccination beliefs and behaviors in a vaccine hesitant refugee population. Future research will include an assessment of the efficacy of the VR platform on vaccination rates over time, as well as continued community

engagement for the development of additional VR content which can increase health literacy within underserved populations.

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Table 4.1: Sample questions and salient responses from exploratory focus groups indicated that parents were very concerned about autism and that they found it difficult to trust the healthcare system due to lack of communication in their primary language. While parents trusted certain doctors, they also highlighted the importance of doing their own research to understand their children’s health. Parents also expressed a desire to understand how vaccines work within the body and what the risks and benefits are of vaccination.

TABLE 4.1. Focus Group Questions and Responses from Somali Community	
Category and Questions for Community Members	Salient Responses
Session 1: General Health	
Examples of questions asked in focus groups	
“What are some of your community’s biggest health concerns in the U.S.?”	“Autism.”
	“One of the biggest health problems that people have that I forgot to mention is that most people don't understand a lot of English.”
“What do you find not trustworthy within the health care system?”	“Lack of good communication...especially in primary language.”
	“Health insurance!”
Session 2: Pediatric Health	
Examples of Questions asked in focus groups	
“Do you trust your doctor’s recommendations for your child’s health?”	“Yes, whatever recommendation the doctor gives me, I have to take it.”
	“I mean I always think it's obviously for a good reason, but for me, I think I always do my own research before I automatically assume that's what's best for me. If it's something very serious like [the doctor] saying for example 'you need a surgery,' that [I] automatically would be like ‘let me get another opinion from another doctor.’”
Session 3: Vaccination	
Examples of questions asked in focus groups	
“What are the topics or things that you would like to know about in relation to vaccines?”	“If they could show how the vaccine works in the child’s body and what it does – if it can be visualized.”
	“That before the vaccines are given to our children, for it to be explained to us what the risks are - the sided effects, and the benefits. When we compare the two, then make a decision.”

Table 4.2: Sample questions and salient responses from engagement with project advisors. Advisors enjoyed the clarity and flow of the storyline as well as finding it culturally relevant and appropriate. They also believed that the story had significant potential to increase vaccine knowledge.

TABLE 4.2. Questions and Responses from Project Advisors	
Questions Asked to Advisors	Salient Responses
1) What are your overall impressions of the story? What did you like the most about the story? Is there anything that you think should change in the story?	“Overall, I like how the story flows and the way in which the educational components are presented. I also think it’s a great idea to have the story centered around a meal, as it seems culturally relevant and helps make the situation relatable to users.”
	“Based on my past feedback, I am glad that this story has been selected. I like the simplicity of the conversation with its effective focus on the key messaging of the value of the timely vaccination to help raise healthy kids.”
2) Have you noticed any inaccuracies in scientific and medical facts in the story?	“No.”
	“No, from my knowledge all of the content presented is accurate.”
3) Was the story clear and easy to understand? Did the story flow naturally?	“Very clear and flowed in a way we would use in teaching in general. Very logical progression of information.”
	“Yes, the story is clear and flows very naturally.”
4) Was the story culturally appropriate? Was the cultural component balanced throughout?	“One of the things I liked about this story is the emphasis of the great Somali family bond that can be pivotal in achieving the goals of this project to leverage the great trust Somali parents put on their relative and educated community members.”
	“Yes, the story was culturally relevant and appropriate.”
5) Was the story convincing? Does it have a potential to change attitudes of vaccine hesitant parents?	“I think it gives the information about immunization, the science behind it, and does not focus on the controversies, which have not been supported by medical data.”
	“Yes. I would just make sure we really take advantage of VR when we show the visuals inside the body and how vaccine’s function within the immune system.”
6) In your opinion, does the story increase knowledge?	“Yes, it stays with the facts in a positive way, in a healthy environment with the families.”
	“It can, depending on the background of the parents and audience and their desire to benefit from such educational program.”

Table 4.3: This table shows the results of a survey of 17 Somali mothers following exposure to the initial script for the VR. + indicates % increased following exposure to the script, - indicates % decreased following exposure to the script.

TABLE 4.3: Survey following initial script exposure							
How comfortable are you with MMR vaccination?	%	How comfortable are you with MMR vaccination?	%	Would you get MMR for your child?	%	Would you get MMR for your child?	%
Very comfortable	52%	Very comfortable	70%+	Yes, I would	65%	Yes, I would	82%+
Somewhat comfortable	24%	Somewhat comfortable	18%-	I would consider it	23%	I would consider it	12%-
Not at all comfortable	24%	Not at all comfortable	12%-	I don't know	6%	I don't know	0%-
				No, I would not	6%	No, I would not	6%

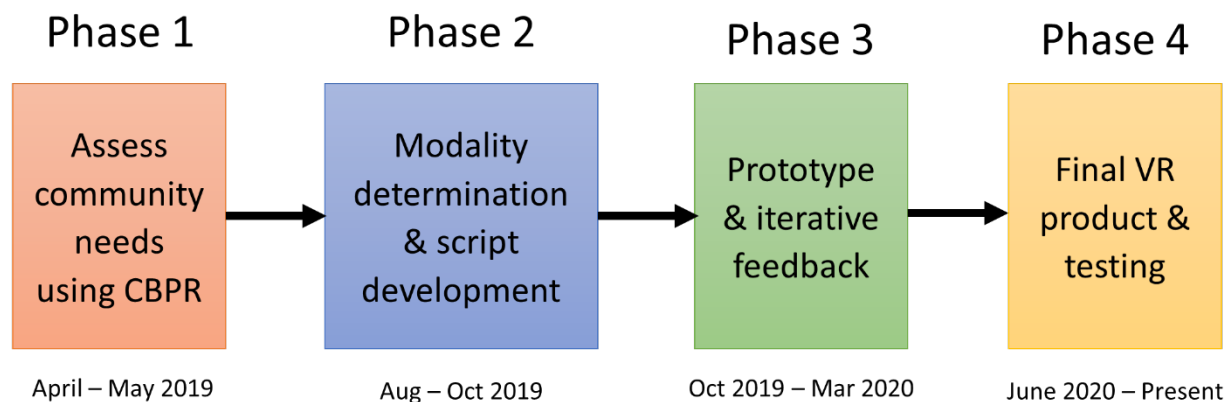


Figure 4.1: Phased approach to VR development. Assessment of community needs began in April 2019 in advance of the development of the VR. Iterative testing took place throughout 2019 and 2020, with some gaps in testing due to the restrictions of the COVID-19 pandemic. The final VR product has been completed as of June 2020 and is currently being tested with the Somali community.



Figure 4.2: Still frame from prototype. The prototype consisted of a motion storyboard with a voiceover which was translated into Somali for presentation to the community.

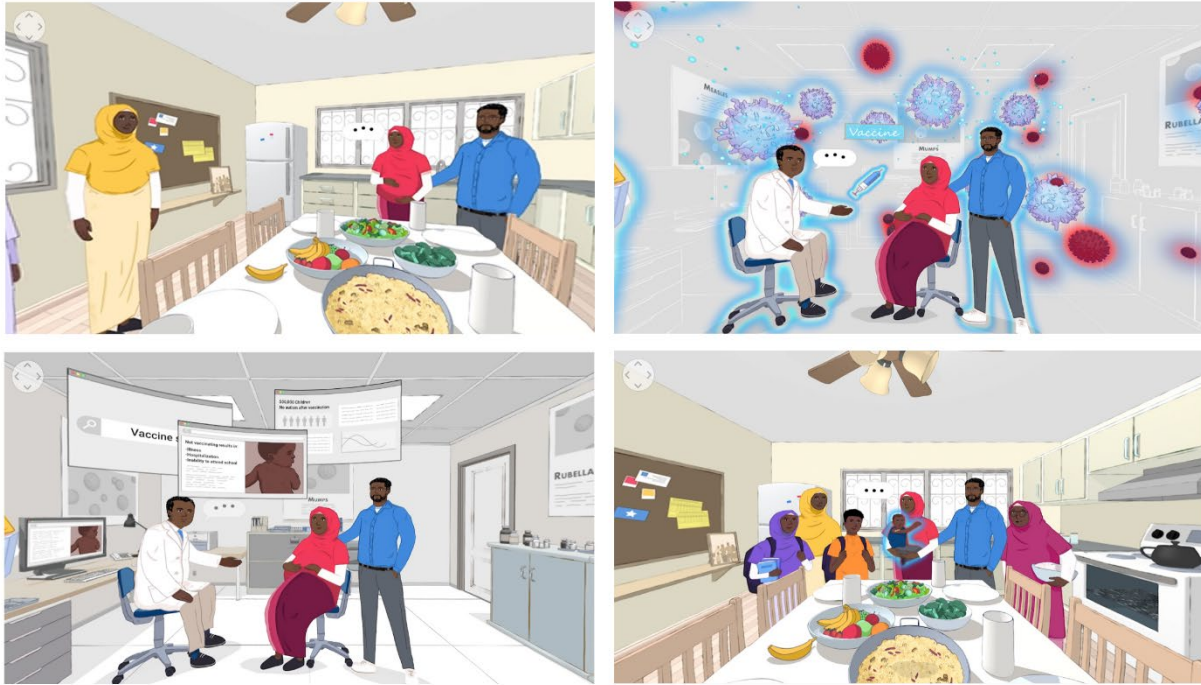


Figure 4.3: Top row: Chapters 1 and 2 of the VR story. Bottom row: Chapters 3 and 4 of the VR story. In chapter 1 of the animation, the expectant mother, her husband, and her sister visit the doctor’s office and learn about measles, mumps, and rubella (MMR). In chapter 2, the family learns how the immune system works. In chapter 3, the family learns from the doctor what the MMR vaccine does and how it works. In Chapter 4, the doctor explains to the family the risks and benefits of MMR vaccination, including a statement debunking the association between autism and vaccination. Finally, the 360-degree video concludes by showing the new mother and her family – including the new, healthy baby – and the new mother states that after learning all the facts, she has decided to vaccinate her child.

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Chapter 5

CONCLUSION

This dissertation has explored how organizational, ethical, and sociopolitical factors interact to shape the design and delivery of a vaccine-promotion intervention designed by and for Somali immigrants and refugees. My project has contributed to three central research questions: [1] What social and structural factors contribute to vaccine decision-making in a Somali population in Southern California, and how can we understand these factors through a social ecological model? [2] How does an immigrant and refugee-run nonprofit organization approach the development of a community-based, virtual reality vaccine promotion intervention that aims to be in the best interests of the community they serve, while simultaneously dealing with shifting priorities and neoliberal ideologies of funding foundations? and [3] How does community co-design of a public health intervention happen in practice, and how does this impact community perceptions of the intervention?

I answered these research questions through three complementary approaches, each of which allows a unique lens onto the research topic. In my second chapter, I examined the context of Somali vaccine hesitancy in Southern California using a social ecological model to explore the different levels of sociopolitical experiences that impact vaccine decision making and discussed the implications for vaccine hesitancy during a pandemic. The third chapter emphasized the creation of a vaccine promotion intervention from the perspective of the interdisciplinary team responsible for the strategic development of the intervention. Within this chapter, I discussed the challenges associated with the development of such an intervention, including the tensions which arose between the intervention team and the project's funder. In my fourth chapter, I detailed how the intervention team worked together with the Somali community to co-design the vaccine promotion intervention, emphasizing the importance of community-based methods in

intervention design. I show how community-based methods strengthen the intervention and create a more equitable experience for a marginalized community.

Throughout these studies, I draw on a number of theoretical frameworks including structural violence, social ecological theory, and biopolitics while also emphasizing the value of community-based research approaches.

SUMMARY OF KEY FINDINGS

Vaccine Decision-Making in Somali Immigrants and Refugees

With regard to vaccine decision-making in the Somali community in Southern California, this dissertation has shown that these decisions are always highly social and political. These results echo other studies of vaccine decision making showing that social and political factors play an important role in making these complex decisions (Leach and Fairhead, 2012). Specifically, this chapter used a social ecological model to focus on how parental research, the availability of family support, the spread of ideas throughout the diaspora, and trust in medical systems has impacted parental vaccine decision making for Somali immigrants and refugees. This work has also shown that ideas about vaccination and concerns about children not speaking are widely shared throughout the Somali diaspora, which is highly interconnected. While Somalis are not a monolith and do not all receive and act on information in exactly the same way, it is the case that social media, news networks, and Somali-specific websites likely play an important role in the spread of information about vaccination and anxieties about autism in Somali communities throughout the world. This work reveals various social levels at which future interventions can take place, and provides insight into how institutional power structures can be unsettled to result in more equitable healthcare decision making for marginalized communities.

Intervention Design and Neoliberal Ideologies in Funders

This dissertation has shown some of the complexities associated with intervention development, especially as it pertains to tensions within intervention teams and between intervention teams and the neoliberal ideologies of funders. While the Somali Tallaal Project team was focused primarily on developing a community-based intervention, their funder required that they develop a social enterprise model. This fundamentally changed the way that the project was spoken about, and it became no longer a project or an intervention, but a “product.”

Although the Somali-specific intervention was indeed created, it is the case that the team planned for future iterations of the project to be more “generic” in order to appeal more widely to various communities and to be a more profitable social enterprise. While the current model of nonprofits often relies upon conditional grant funding, their development of community-based programs and initiatives is limited by the requirements of funders. This research shows several areas of disconnection between funders and nonprofit organizations and identifies these areas of disconnection as potential future sites of negotiation and transformation where community priorities can be asserted.

Community-based Research Approaches

The final chapter of this dissertation illustrates the ways in which community co-design was leveraged to develop an intervention with the Somali refugee community. I discuss the process of community co-design with Somali immigrants and refugees, while also exploring whether community co-design does indeed result in the development of an intervention that resonates with the community. I find that co-design can serve as a valuable and powerful tool for the co-development of interventions, especially when those interventions consist of technologies that are relatively new to the community in question. For example, in testing the community co-

designed intervention, I found that a significant proportion of Somali community members experienced greater educational outcomes and increased comfort with the MMR vaccination following exposure to the intervention. This has important implications for the future development of public health interventions which center the communities they serve.

TAKEAWAYS ABOUT COMMUNITY-BASED RESEARCH

Research questions were formulated based on consultations with the community and the community-based organization. As mentioned in the introduction to this dissertation, a collaborative approach is one way to make some small amount of progress toward equity in research. To this end, I worked closely with community leaders and the nonprofit organization to develop interview guides. I worked with a Somali research assistant on data analysis and co-authored a manuscript with her, and she was regularly consulted on the project throughout. While I had hoped to work more closely with additional community members, this was made more difficult due to the constraints of social distancing during COVID-19, and I was limited to conducting phone interviews with several mothers.

Due to the constraints of COVID-19, I was unable to follow the intervention through to its testing with the Somali community, and thus do not have data about the manner in which the final intervention was experienced by the Somali community as well as the intervention team. Additionally, our iterative co-design with the Somali community consisted of relatively small sample sizes, and thus we were unable to run any meaningful statistics on the surveys we conducted with them. Despite the small sample size, the information we gathered from the community during iterative co-design was rich and detailed, resulting in a VR experience that was generally positively received by the community.

While social distancing did restrict my ability to do more interactive research with the Somali community, doing research on vaccine hesitancy during a pandemic and rapid vaccine rollout was a unique and interesting experience. Although my research was not specifically about the pandemic, I was able to see not only the ways that the community responded to MMR vaccination, but how their attitudes toward COVID-19 and the different COVID-19 vaccinations shifted as the pandemic progressed.

FUTURE DIRECTIONS

This dissertation provides valuable information on the social and political factors impacting vaccine decision-making in a Somali immigrant and refugee community. Future research on vaccination in Somali communities may examine these issues in more depth, especially as they may vary according to factors such as geographic location, time in the U.S., types of social support, and so forth. For instance, it would be very valuable to further examine the way that vaccine messaging spreads from one region of the world to another via a social network analysis. Additionally, it would be beneficial to include more men and fathers in these conversations about vaccination, as their input is undoubtedly valuable in vaccine decision making. Further studies of vaccine decision making with regard to vaccines other than MMR would be particularly valuable, especially during the COVID-19 pandemic.

In addition to providing context for vaccine decision making among Somali communities, this dissertation has examined the ways that the neoliberal ideologies of funding foundations can fundamentally shift the way that interventions are developed and/or discussed. In the future, it would be prudent to examine other types of programs and interventions in community-based organizations and the ways that they are impacted by the values of funders. A deeper understanding of these issues and the tensions between community needs and funder desires

could help to eventually shift the funding landscape so that community needs are placed at the forefront of funder concerns rather than prioritizing metrics and following technological trends (Adams, 2016; Cueto, 2013).

Finally, an interesting next step for this work would be a continued examination of the implementation of the VR intervention once it is safe to do so. This aspect of the study would have important implications for the use of technology in intervention design and would contribute greatly to science and technology studies of VR, education, and embodiment (Southgate and Smith, 2016). Additionally, working with the community to assess the VR would provide us with pertinent information about whether our community co-design did indeed result in the development of an intervention that resonates with the community and increases their knowledge on MMR vaccination.

VACCINE DECISIONS AND INTERVENTION DEVELOPMENT

In examining how organizational, ethical, and sociopolitical factors interact to shape the design and delivery of a vaccine-promotion intervention designed by and for Somali immigrants and refugees, I have learned that it is necessary to understand the complexities of vaccine decision making while also accounting for the ways that interventions are shaped by the ideals of funders. With regard to decision making, Somali parents are much like other parents in that they thoughtfully weigh their options in determining what is best for their individual child. This process is impacted by their personal research as well as their interactions with their community and their often-negative experiences within the medical system. As Black, Muslim immigrants and refugees, Somali parents' unique racialized experiences impact the way that they view vaccination. Much like white, middle-class parents born in the U.S. who are often associated with the anti-vaccination movement, Somali parents discuss doing their own research to

understand vaccination and making purposeful decisions based on the needs of their particular children (Leach and Fairhead, 2012; Sobo, 2016). However, unlike the prototypical anti-vaccination parent, Somali parents' vaccination decisions are often based on their experiences with medical racism, their connections to other members of the Somali diaspora, and their desire to exercise agency in the face of the biopolitical disciplining of their bodies as they become U.S. citizens.

In an ideal scenario, community-based interventions would take the community's needs as a starting point and engage the community in each step of intervention design and dissemination. While these steps were indeed taken in the case of the intervention described within this dissertation, it is also true that tensions that arose during the development of the intervention impacted the way that it was discussed and understood as well as the future trajectory of the intervention. As the framing of the intervention shifted to social enterprise design, the Somali Tallaal Project team worked to conceive of a more "generic" or "culturally unmarked" product after the creation of the Somali-specific experience. Thus, although social enterprise is supposed to have the best interests of particularly marginalized communities in mind, we see through this research how projects can shift to de-center those communities in favor of profit maximization (Eikenberry and Kluver, 2004; Gerrard, 2017). This is a complex situation as the profit generation via social enterprise models can also provide nonprofit organizations and other grant-reliant public health entities with some degree of autonomy in how they spend said profits, freeing them from the often restrictive and neoliberal requirements of grant funding. Therefore, while it can be said that social enterprise models feed into neoliberal ideals of funding agencies, they may also represent future freedom from those ideals. It is

important for nonprofit organizations to strategically consider how they may be able to use these models to their advantage, but only if it is not at the expense of the communities they serve.

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