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Translating SHINE: Application of community-based participatory research approaches to the cultural adaptation of a school-based water, sanitation, and hygiene intervention

Tilpasning av SHINE: Bruk av deltager-orientert aksjonsforskning i lokalt folkehelsearbeid for å kulturelt tilpasse en skolebasert vann, sanitær- og hygieneintervensjon

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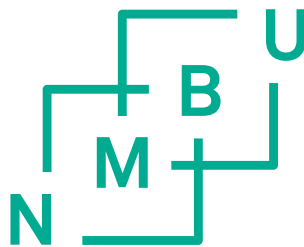
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Philosophiae Doctor (PhD) Thesis

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"Science looks for truth, practice looks for what works. What works is true, and what is true works."

-GUY W. STEUART, 1963

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I am because you are…

is the translation of the southern African philosophical concept known as *ubuntu*. I first learned about ubuntu while living in the rural community of Lefiso, South Africa and while I carry it with me always, I believe that it can help introduce everyone who has contributed to the cultivation and nourishment of my doctoral training. Therefore, in the spirit of ubuntu, I want to thank the multitude of mentors, colleagues, community partners, friends, and family who have collaborated, supported, and inspired me throughout this journey.

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To everyone who has been a part of this doctoral journey, I am brimming with gratitude.

I AM BECAUSE YOU ARE…

SUMMARY

Globally, water, sanitation, and hygiene (WASH) is a widespread public health issue because access to safe drinking water, adequate sanitation systems, and hygienic behaviors are fundamental to human health and development. Although studies have demonstrated the association between poor sanitation and hygiene to various diseases; evidence regarding the effectiveness of WASH interventions is still mixed, illustrating challenges with uptake and sustainability. Development of effective WASH interventions is dependent on having a comprehensive understanding of relevant contextual factors and determinants. Therefore, it is crucial that careful consideration of these factors is applied to intervention design, adaptation, and the assessment of outcomes. One approach which encourages local knowledge sharing regarding contextual factors, derives from the application of community-based participatory research (CBPR). Therefore, in WASH health promotion research, CBPR could help nurture and develop a culturally relevant, thus effective WASH intervention.

The purpose of this doctoral research was two-fold, first to develop an in-depth understanding of the contextual setting of the rural community of Thirumalaikodi Tamil Nadu, India, in order to contribute to and document the processes of cultural adaptation of an existing intervention using a CBPR approach, and second to contribute to the broader understanding of how health promotion interventions can be adapted and scaled using formative research. Three sub-studies were developed to help fulfill the purpose of the doctoral research (sub-study 1, 2, 3). Sub-studies included arts-based, qualitative, and quantitative approaches (photovoice, interviews, stool diaries, and survey). Students from two schools were purposively selected to participate in each study. These sub-studies contributed to the cultural adaptation of intervention components and curricula, to accommodate context, culture, and input from youth and the wider community.

The first sub-study (Book Chapter I and Manuscript II) utilized arts-based research methods to reveal students' perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors, and how several social determinants play an influential role. Book Chapter I includes a reflective discussion of the use of arts-based methods in research as a means of participant engagement as demonstrated by sub-study 1. In sub-study 2 (Manuscript III), through qualitative narrative interviews, participants revealed how adolescent girls experience menarche and menstruation, how their experiences connect to the sociocultural context; and what strategies they use to manage menstruation. In sub-study 3 (Manuscript IV), data consisted of semi-structured qualitative interviews, stool diaries and an interviewer administered survey completed by adolescent students. In this sub-

study participants discussed cultural representations and perceptions of diarrheal illness using the Bristol Stool Form Scale.

Research findings presented in this PhD dissertation highlight several important implications for future intervention adaptation and demonstrate the role of formative research and community engagement within the development and adaptation of health promotion interventions. First, norms (social and gender) are a distal influence on health outcomes. Second, cultural and religious attitudes, beliefs, and practices are linked to sanitation and hygiene-related behaviors. Next, menstruation and diarrhea are linked to various forms of stigma and taboos in this sociocultural context. Furthermore, findings indicate that open defecation, which is a common behavioral target for WASH interventions, may be perceived as taboo. Parents play an important role in health communication for participants, indicating that local knowledge is often passed down intergenerationally, which has important implications for several health challenges. Sub-study findings may be used to inform the cultural adaptation of Project SHINE (Sanitation and Hygiene INnovation in Education) among adolescents in India. Additionally, the systematic documentation of the formative research processes employed, builds upon CBPR-oriented adaptation processes as documented in health promotion literature, thus contributing to the knowledgebase of cultural adaptations of WASH health promotion interventions among adolescents in low- and middle-income settings.

SAMMENDRAG

Utfordringer knyttet til vann, sanitærforhold og hygiene (WASH) er et globalt folkehelseproblem ettersom rent drikkevann, tilfredsstillende sanitæranlegg og god hygienisk atferd er fundamentale faktorer for god helse og utvikling. Selv om studier effektivt har dokumentert sammenhengene mellom dårlige sanitære forhold og hygiene med forskjellige sykdommer, har de dokumenterte effektene fra WASH-intervensjoner vært blandede, hvilket illustrerer utfordringer med varig atferdsendring og bærekraftighet. Utvikling av effektive WASH-intervensjoner er avhengig av innsikt i relevante kontekstuelle faktorer og hva som påvirker folkehelsen, og det er derfor avgjørende at disse faktorene vektlegges i design, tilpasning, og resultatmåling av intervensjoner. En tilnærming som oppfordrer til lokal kunnskapsdeling om kontekstuelle faktorer, er deltagerorientert aksjonsforskning (community-based participatory research). I helsefremmende WASH forskning, kan deltakerorientert aksjonsforskning bidra til å utvikle kulturelt relevante og dermed effektive WASH intervensjoner.

Formålet med denne avhandlingen var todelt, først å opparbeide en grundig forståelse for kontekstuelle faktorer i lokalsamfunnet Thirumalaikodi Tamil Nadu, India, for å dokumentere en kulturell tilpasning av en eksisterende intervensjon. Dernest var målet å bidra til en bredere forståelse av hvordan helsefremmende intervensjoner kan tilpasses og skaleres ved hjelp av *formative research*. Tre delstudier ble utviklet for å besvare formålet med avhandlingen (delstudie 1, 2, 3). Delstudiene tok i bruk kunst-baserte, kvalitative og kvantitative metoder (photovoice, intervjuer, dagbøker for avføringsmønstre og spørreundersøkelser). Elever fra to skoler i Vellore-distriktet, Tamil Nadu, India, deltok i studiene. De tre delstudiene bidro til å tilpasse intervensjonens komponenter og pensum til kontekst, kultur og innspill fra elevene og lokalsamfunnet.

Den første delstudien (Bokkapittel I og Manuskript II) avdekket gjennom en photovoice-undersøkelse studentenes oppfatninger av de kulturelle og kontekstuelle faktorene som påvirker sanitære forhold og hygienerelatert atferd og hvordan sosiokulturelle faktorer spiller en viktig rolle for helse. Bokkapittel I i avhandlingen inneholder refleksjoner rundt bruken av kunst-baserte metoder i forskning. Disse metodene er virkemidler for å stimulere til deltakeres medvirkning, og et eksempel på slik medvirkning er rapportert i den første delstudien. Den andre delstudien (Manuskript III) avdekket gjennom kvalitative intervjuer hvordan tenåringsjenter opplever menarke og menstruasjon, hvordan deres opplevelser er relatert til deres sosiokulturelle situasjon, og hvordan de håndterer menstruasjon. Den tredje delstudien (Manuskript IV) besto av data fra semistrukturerte kvalitative intervjuer, dagbøker for

avføringsmønstre og en spørreundersøkelse blant tenårige studenter. I denne delstudien diskuterte deltakerne kulturelle forhold og oppfatninger av diaresykdom ved bruk av Bristol-skalaen.

Funn som blir presentert i denne doktorgradsavhandlingen kaster lys over flere viktige implikasjoner for fremtidig tilpasninger av intervensjoner og viser den viktige rollen *formative research* og lokal forankring har for utvikling og tilpasning av helsefremmende intervensjoner. Først, normer (sosiale og kjønnsmessige) har indirekte konsekvenser for helsen. Dernest viser funn at kulturelle og religiøse holdninger, tro og skikker har sammenheng med atferd knyttet til sanitære forhold og hygiene. Videre er menstruasjon og diare knyttet til flere former for stigma og tabu i denne konteksten. Funn indikerer også at det som normalt er en ønsket atferdsendring i WASH-intervensjoner, nemlig å ikke bruke naturen som toalett, kan være ansett som tabu i denne spesifikke konteksten. Deltakernes foreldre spiller en viktig rolle i kommunikasjon om helse, noe som indikerer at lokal kunnskap og læring ofte overføres mellom generasjoner, hvilket har viktige konsekvenser for flere helserelaterte utfordringer. Funn fra delstudiene kan benyttes til tilpasning av Project SHINE (Sanitation and Hygiene INnovation in Education) blant tenåringer i India. Til slutt, den systematiske dokumentasjonen av prosessen med *formative research,* bygger på deltagerorientert aksjonsforskning som grunnlag for tilpasningsprosessen slik den er dokumentert i litteraturen, og vil derfor bidra til kunnskapsbasen på kulturell tilpasning av helsefremmende WASH-intervensjoner blant unge i lav- og middelinntektsland.

LIST OF PAPERS

The PhD dissertation is comprised of the following manuscripts which will be referred to by their corresponding roman numerals throughout.

BOOK CHAPTER I

- **Gold-Watts A**; Hovdenak M; Ganesan A; Bastien S (Accepted for Publication February 2019) From arts to action: Project SHINE as a case study of engaging youth in efforts to develop sustainable water, sanitation and hygiene strategies in rural Tanzania and India. In Corbin J H; Sanmartino M; Hennessy E; Urke H, Editors, *Arts and health promotion- Tools and bridges for practice, research and training.* Springer.

MANUSCRIPT II

- **Gold-Watts A**; Aamodt G; Shanmugasundaram R; Bastien S (Manuscript) Unraveling context: A formative research photovoice study of Indian youth perspectives of sanitation and hygiene practices in the rural community of Thirumalaikodi, Tamil Nadu, India

MANUSCRIPT III

- **Gold-Watts A**; Hovdenak M; Daniel M; Gandhimathi S; Sudha R; Bastien S (Manuscript) A qualitative study of adolescent girls' experiences of menarche and menstruation in rural Tamil Nadu, India

MANUSCRIPT IV

- **Gold-Watts A**; Aamodt G; Gandhimathi S; Sudha R; Bastien S (Manuscript) Understanding adolescents' perceptions of diarrhea: A formative research study of a visual scale to measure self-reported diarrhea in low-resource settings

ABBREVIATIONS

Bristol Stool Form Scale	BSFS
Canadian Institute of Natural and Integrative Medicine	CINIM
Central Rural Sanitation Programme	CRSP
Common Sense Illness Representation Model	CSIRM
Community-Based Participatory Research	CBPR
Doctor of Philosophy	PhD
Integrated Behavioral Model for Water Sanitation and Hygiene Interventions	IBM-WASH
Joint Monitoring Program for Water Supply, Sanitation and Hygiene	JMP
Knowledge, Attitudes, and Practices	KAP
Low- and Middle-income Countries	LMIC's
Menstrual Hygiene Management	MHM
Millennium Development Goal	MDG
Neglected Tropical Diseases	NTD's
Nirmal Bharat Abhiyan	NBA
Sanitation and Hygiene INnovation in Education	Project SHINE
Sustainable Development Goal	SDG
Swachh Bharat Mission	SBM
The Ugly Indian	TUI
Total Sanitation Campaign	TSC
United Nations Children's Fund	UNICEF
Water, Sanitation, and Hygiene	WASH
World Health Organization	WHO

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CHAPTER 1: INTRODUCTION

OVERVIEW

Access to safe drinking water, adequate sanitation systems, and hygienic behaviors is fundamental to human health and development (1). However, many people around the world still lack access to basic sanitation[1] (2). Water, sanitation, and hygiene (WASH) are major contributors to the transmission of bacteria, viruses, and parasites, which cause disease and other adverse outcomes. Such diseases include diarrheal disease, parasitic infections, and urogenital infections (3-6), along with other social outcomes such as school absences and poor cognitive development, thus impeding economic development (7-9).

WASH-related outcomes including morbidity, mortality, and quality of life (1, 10-13), have therefore led to the inclusion of WASH in the Millennium Development Goals (MDGs) and Sustainable Development Goals (SDGs) (2, 14). In 2000, the United Nations launched the MDGs to reduce extreme poverty with eight, timebound targets (14). One of these targets, goal seven, was to ensure environmental sustainability. Goal seven also included an indicator that aimed to increase the global population's access to improved drinking water by 2015 (14). Although many countries were able to improve access to safe drinking water, the United Nations established the SDGs to improve and expand upon the original targets set forth by the MDGs in 2015 (14). MDG goal seven evolved into SDG goal six, ensuring availability and sustainable management of water and sanitation for all. Goal six also has a comprehensive list of indicators, which include equitable access to safe and affordable drinking water, sanitation and hygiene, ending open defecation, and increasing participation of local communities in improving water and sanitation management worldwide. Progress towards SDG six is assessed by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) through the Joint Monitoring Programme for Water Supply and Sanitation (JMP) based on survey data, which consist of Demographic and Health Surveys, UNICEF Multiple-Indicator Cluster Surveys, World Bank Living Standards Measurement Surveys, WHO World Health Surveys and national censuses (15). Working towards achieving these indicators could lead to improved WASH, which would help prevent over two million deaths per year globally (16), however, some argue that targets lack clarity in approaches monitoring access to drinking water and sanitation (15, 17).

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[1] According to WHO/UNICEF's Joint Monitoring Program for Water Supply, Sanitation and Hygiene (JMP), basic sanitation is defined as the use of improved facilities which are not shared with other households (2).

Although studies have effectively demonstrated the link between poor sanitation and hygiene to various diseases such as soil-transmitted helminth infections, intestinal protozoa infections, and diarrhea (3, 18-28), evidence regarding the effectiveness of WASH interventions is mixed (26, 29-36). Systematic reviews have identified methodological gaps and issues with measurement methods applied, data assessing long-term impact, and consensus/standardization of constructs (e.g. sustained adoption) which hinder intervention implementation and sustainability (35, 37, 38). One way to address these challenges is through the increased participation of local communities (inclusion of community insights), thereby fostering ownership and ensuring cultural relevancy. Health promotion principles of participation and empowerment encourage involvement and participation of target groups (e.g. future intervention participants) in intervention planning and adaptation processes (39). Moreover, since effective WASH interventions must be developed on the basis of a sound understanding of sociocultural contextual factors and determinants (38, 40, 41), careful consideration of relevant factors is important for intervention design, adaptation, and the assessment of outcomes. This highlights the necessity of understanding contextual, behavioral and environmental determinants, and incorporating community input to increase intervention effectiveness in health promotion research (40). Therefore, methodological flaws could be addressed with community input as proposed by SDG goal six indicators (e.g. Target 6.b – Participation of Local Communities: support and strengthen the participation of local communities in improving water and sanitation management) (42).

In addition, it is important that aspects of the sociocultural context are considered when designing WASH interventions in the Indian context. For example, the subjects of filth, purity, pollution, and the perceived cultural acceptance of dirt are discussed in academic literature as facilitators of poor sanitation and hygiene (43-46). Despite the government's concerted efforts to improve sanitation conditions (47-49), the country continuously struggles with a '*sanitation crisis*'. However, India's achievements should not go unrecognized, since the country managed to achieve MDG targets to halve the proportion of the population without access to safe drinking water and basic sanitation by 2015 (14). Nonetheless, efforts to increase sanitation coverage still fall short and challenges such as open defecation persist nationwide (50). Studies suggest the prolongation of sanitation and hygiene-related health challenges are caused by failures in public health policy and funding of programs. These activities have focused on building infrastructure rather than addressing the underlying determinants that influence WASH-associated behaviors (47, 51-54). This highlights the significance of understanding determinants and contextual factors when designing or adapting effective health promotion interventions. Thus, to address these issues, it is important to encourage collaboration, engagement,

and participatory approaches that can improve health and developmental outcomes, including a participatory partnership with communities to address policy, public health, and action that incorporate shared meanings/definitions, values, and respect for culture (55-58).

RESEARCH GAPS

A review of the literature identified several key research gaps, which this dissertation aims to contribute to as highlighted below. These gaps include:

- Insufficient guidance on how to adapt school-based WASH health promotion interventions to increase cultural relevance, appeal, and effectiveness;
- A need for studies which demonstrates how formative research can be utilized to culturally adapt an existing intervention to a new setting and target population (local community);
- Lack of comprehensive non-stigmatizing WASH health promotion interventions in India that focus on improving WASH-related behaviors and involves the participation of the local community including community-identified priorities and needs;
- Methodological gaps pertaining to measurement methods and constructs applied in current school-based WASH interventions.

In this PhD dissertation, I addressed these gaps by conducting formative research to culturally adapt an existing WASH health promotion intervention to a new setting. Adaptation is a crucial component of implementing health promotion interventions in a new context (59-62). A central function of the adaptation process is to translate and tailor the original intervention design, including strategies, activities, materials, and delivery to the target population to improve health and social outcomes of interest. An adaptation can assist in enhancing the relevance, uptake, sustainability, and effectiveness of a health promotion intervention (59). This doctoral research also focused on gaining a rich and in-depth understanding of the sociocultural context in order to systematically adapt and implement Project SHINE (Sanitation and Hygiene INnovation in Education) to the rural Indian context. In addition, this PhD dissertation presents the adaptation of Project SHINE from the Tanzanian to the Indian context to demonstrate how formative research conducted, utilized a community-based participatory research (CBPR) approach, and can contribute to the cultural adaptation of WASH health promotion interventions.

PROJECT SHINE

The impetus for this research originated from a previous pilot study in Tanzania. In 2014, researchers from the University of Calgary and the Catholic University of Health and Allied Sciences designed, implemented, and evaluated Project SHINE (entitled Neglected voices, neglected diseases) to ignite youth-driven innovation in sanitation solutions for Maasai pastoralists in the Ngorongoro Conservation

Area, Tanzania (63). SHINE was originally developed as an alternative to stigmatizing approaches used in other prominent WASH interventions that promote "shame" or "social stigma" as a means for behavior change (64-66). Instead, SHINE centers on an assets-based approach that incorporates CBPR and various arts-based methods throughout all phases. The primary objectives of this multi-pronged theory-based intervention were to "build the capacity of youth and communities to develop and sustain health promotion activities to prevent parasitic infection" (67 p. 6) Researchers also aimed to:

- Assess knowledge, attitudes and practices (KAP) concerning parasitic infection among secondary school students (63);
- Identify barriers and facilitators for efforts aimed at mitigating parasitic infection in the Ngorongoro Conservation Area (63);
- Engage secondary school students in the development of sanitation and hygiene prototypes and health promotion strategies to reduce parasitic infection by hosting a sanitation science fair (63); and
- Evaluate the school-based projects and involve the wider community in developing a plan to sustain health promotion activities (63).

Intervention strategies included: 1) participatory training workshops with secondary school science teachers and a local women's group, 2) community events, 3) school lessons and extra-curricular activities, 4) a SHINE club, and 5) a sanitation science fair which involved students and the wider community in the development and evaluation of sanitation prototypes and health promotion strategies (63) (See Figure 1 for a conceptual model of the original SHINE intervention). Project SHINE is also bolstered by health promotion principles to foster the engagement of adolescents in research processes and support young pioneers in health promotion.

FIGURE 1. CONCEPTUAL MODEL OF ORIGINAL SHINE INTERVENTION (63)

After the process and impact evaluation of the original SHINE study was completed with promising results (63, 68, 69), researchers sought to demonstrate the benefits of Project SHINE in other contexts with similar health challenges. The decision to implement the intervention in southern India was based on the need for innovative and non-stigmatizing approaches such as the application of participatory science and social entrepreneurship in WASH health promotion interventions in India, demonstrated interest by the local community, and a partnership between the University of Calgary and the Sri Narayani Hospital and Research Center (e.g. schools, a hospital, and spiritual leadership). Since the project employs a CBPR approach, the establishment of a long-term relationship with the local community was fundamental prior to implementation. Moreover, given the similarities in WASH determinants between rural India and Tanzania, it was decided that after a rigorous cultural adaptation, Project SHINE would be implemented in the rural southern Indian community of Thirumalaikodi.

The guiding theoretical framework for the development of the original SHINE intervention included the Integrated Behavioral Model for Water, Sanitation and Hygiene (IBM-WASH) (70). IBM-WASH is a synthesis of existing behavioral models typically used for WASH-research (70). Project SHINE was also informed by several other theoretical constructs in order to ensure effectiveness. SHINE intervenes on the interpersonal, intrapersonal, and community levels of the socioecological model (71) in order to equip and empower students and communities to develop strategies to prevent diarrheal disease and other negative health outcomes associated with poor access to water, sanitation conditions, and hygiene practices (63). The socioecological model is a health-promotion framework organized by multiple levels of influence that demonstrate an individual's interactions with their physical and sociocultural environment (72) or can be seen as the interdependence between factors of a health problem (73).

Furthermore, Project SHINE also leverages constructs from both Social Cognitive Theory (74, 75) and the Health Belief Model (76-78). The Health Belief Model demonstrates a pathway from knowledge and beliefs about a health concern to behavioral change (63, 73). The intervention also utilizes two of Social Cognitive Theory's key constructs: role modeling and outcome expectancies to empower youth to promote healthy behaviors in their communities and challenge social norms (73). Although these theories informed the development of the original SHINE intervention, they were not used in the development of formative research sub-studies described in this PhD dissertation.

RATIONALE FOR RESEARCH AND RESEARCH AIMS

Although rural India shares several WASH-related health challenges with rural Tanzania, the two are distinct contextual settings. Therefore, through several formative research sub-studies, the research presented here focuses on developing an in-depth understanding of the sociocultural context to foster insights into local cultural beliefs and traditions, health behaviors, and community-identified priorities. Data from the formative research sub-studies were used in a cultural adaptation process to prepare for future intervention implementation.

The purpose of this doctoral research was two-fold, first to develop an in-depth understanding of the contextual setting of the rural community of Thirumalaikodi Tamil Nadu, India to contribute to and document the processes of cultural adaptation of an existing intervention, and second to contribute to the broader understanding of how health promotion interventions can be adapted using formative research. Therefore, this doctoral research systematically documents the formative research processes that informed the cultural adaptation of a school-based WASH health promotion intervention to a new setting. Moreover, to guide this research, the research team used a CBPR approach, which recognizes the importance of the relationship between researchers and community members in the co-creation of knowledge (79). This research had three specific aims:

AIM 1
To explore students' perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors through arts-based approaches such as photovoice (Book Chapter I and Manuscript II).

AIM 2
To explore how adolescent girls in the rural community of Thirumalaikodi, Tamil Nadu, India experience menarche and menstruation; how their experiences connect to the sociocultural context; and understand what strategies they use to manage menstruation (Manuscript III).

AIM3
To understand cultural representations and perceptions of diarrheal illness among adolescent students from the rural community of Thirumalaikodi, Tamil Nadu, India and to explore whether the Bristol Stool Form Scale is suitable for use with local adolescent students from this community (Manuscript IV).

The school environment is perceived as a well-suited and cost-effective setting for reaching youth (during their formative years), their parents, and the larger community in health promotion interventions. This is because schools have an established network of educators and students and continuous programming. However, school-based interventions must be tailored through formative

research processes to increase cultural relevance, appeal, and effectiveness. Therefore, this PhD dissertation focuses on the application of formative research for developing an in-depth understanding of the contextual setting to inform the cultural adaptation of an existing WASH health promotion intervention (e.g. Project SHINE) to a new setting.

SUB-STUDY 1 OVERVIEW

For sub-study 1 (photovoice), an arts-based, participatory method, photovoice was employed with adolescent students on their personal experiences and perceptions associated with WASH-related behaviors (Aim 1). This sub-study utilized photography to increase knowledge and understanding of youth perspectives of local WASH-related contextual factors. Sub-study 1 also focused on engaging adolescent students in a group process of critical reflection and dialogue, in response to a need for an in-depth understanding of youth perspectives of the context, to assist in the adaptation and translation of the intervention. The main research question for this sub-study was: what are the cultural and contextual factors that influence water, sanitation and hygiene-related behaviors for adolescent students?

SUB-STUDY 2 OVERVIEW

In sub-study 2 (Menstrual Hygiene Management/MHM), semi-structured qualitative interviews were conducted with adolescent female students who had obtained menarche (first period) on their experiences with menarche and menstruation (Aim 2). In this sub-study, the research team sought to develop a supportive research environment in which participants were positioned as experts, and through qualitative narrative interviews, participants shared their lived experiences regarding menarche and menstruation. Sub-study 2 was conducted based on preliminary findings of stakeholder interviews, which revealed that MHM is an important WASH-related concern among stakeholders at the local level. Therefore, the research team sought a rich and in-depth understanding of local youth perspectives on the topic, in order to include community-identified health concerns in future intervention content. Research questions for this sub-study included: 1) how do adolescent girls describe their experiences of menarche and menstruation; 2) how do those experiences described by adolescent girls link to the sociocultural context and 3) what strategies do adolescent girls use to manage menstruation?

SUB-STUDY 3 OVERVIEW

Finally, for sub-study 3 (Bristol Stool Form Scale/BSFS), data consisted of semi-structured qualitative interviews, stool diaries, and an interviewer administered survey completed by adolescent students. Based on the need for an in-depth exploration of alternative methodological approaches and data

collection instruments to investigate diarrheal disease, the research team sought to explore the use of a visual tool which could be well-suited (i.e. age-appropriate) for use among adolescent students to help manage sensitive issues such as diarrhea (Aim 3). Sub-study 3 also enabled student participants to explore and reflect upon the usage of a visual tool and their lived experiences identifying and reporting diarrhea (cultural representations and perceptions of diarrheal illness) to help identify culturally appropriate language and/or research tools for future intervention use. Research questions for this sub-study included: 1) how do adolescent students perceive and represent diarrhea and 2) how do adolescent students in low-resource settings perceive the Bristol Stool Form Scale (BSFS) when self-reporting stool form in WASH-interventions?

These aims contributed to the cultural adaptation of SHINE India's intervention components and curricula to accommodate context, culture, and input from the community. Table 1 depicts specific aims and corresponding research questions which guided this PhD dissertation.

TABLE 1. RESEARCH QUESTIONS TO ACHIEVE SPECIFIC STUDY AIMS

Overall Aim	Specific Aims	Sub-study	Manuscript	Research questions
To develop an in-depth understanding of the contextual setting of the rural community of Thirumalaikodi Tamil Nadu, India in order to initiate the cultural adaptation of Project SHINE.	To explore students' perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors through arts-based approaches such as photovoice.	1	Book Chapter I Manuscript II	What are the cultural and contextual factors that influence sanitation and hygiene-related behaviors of adolescent students?
	To explore how adolescent girls in the rural community of Thirumalaikodi, Tamil Nadu, India experience menarche and menstruation; how their experiences connect to the sociocultural context; and understand what strategies they use to manage menstruation.	2	Manuscript III	How do adolescent girls describe their experiences of menarche and menstruation? How do those experiences described by adolescent girls link to the sociocultural context? What strategies do adolescent girls use to manage menstruation?
	To understand cultural representations and perceptions of diarrheal illness among adolescent students from the rural community of Thirumalaikodi, Tamil Nadu, India and to explore whether the Bristol Stool Form Scale is suitable for use with local adolescent students from this community	3	Manuscript IV	How do adolescent students perceive and represent diarrhea? How do adolescent students perceive the BSFS when self-reporting stool form?

DISSERTATION STRUCTURE

This PhD dissertation presents results from three sub-studies that address specific aims and the research purpose. Chapter 2 focuses on background and significance by providing an overview of WASH-related health challenges, contextual background, an outline of CBPR, theoretical underpinnings, and the adaptation conceptual framework which informed this research. Chapter 3 provides an overview of the research strategy, materials, and methods used in this doctoral research including sub-study designs,

recruitment, data collection, and analytic approaches applied. Chapter 4 includes further detailed descriptions of findings. Then, Chapter 5 provides a summary of key findings, research challenges, and limitations. Chapter 6 discusses research contributions, implications for future research, and concluding remarks. Lastly, Chapter 7 includes Book Chapter I and all other manuscripts.

The PhD dissertation includes a critical discussion concerning the importance, potential, and challenges of arts-based methods and community engagement strategies (Book Chapter I) that were included in the methods used in the formative research phase to explore youth perspectives on WASH determinants (Manuscript II). A sub-study on menstrual hygiene management (MHM) (Manuscript III), was conducted in order to understand adolescent girls' experiences of menarche and menstruation. The research team also conducted a sub-study on the perceptions of diarrhea (Manuscript IV) to explore reliable tools for obtaining data on self-reported diarrhea (a primary outcome of the main SHINE intervention) among adolescent schoolchildren.

The PhD study contributes to the SHINE India intervention and health promotion literature in several ways. First, this doctoral research provides an in-depth understanding of the various contextual factors and determinants that influence WASH-related KAP in the targeted setting. Second, this doctoral research helped the research team employ approaches that increase cultural relevance, appeal, and effectiveness of the intervention. Next, this research demonstrates how to use formative studies to guide the cultural adaptation of an intervention. In addition, the study also contributes to the broader scientific literature related to data collection tools for self-reported diarrhea incidence in low-resource settings among adolescent schoolchildren. Finally, this PhD dissertation contributes to the knowledge-base and future development of CBPR health promotion interventions of this nature.

CHAPTER 2: BACKGROUND AND SIGNIFICANCE OF RESEARCH

In this chapter, WASH-related diseases, determinants, and interventions will be discussed; followed by a contextual introduction to India, which will include the country's profile, an outline of WASH-related challenges, summary of determinants, and government/grassroots initiatives. Finally, the study context will be presented, which will include a description of the SHINE India pilot research project.

WATER, SANITATION, AND HYGIENE-RELATED DISEASES

Access to safe drinking water, adequate sanitation systems, and hygienic behaviors are fundamental to human health and development, therefore improvements in WASH have the potential to reduce morbidity and vulnerability to disease worldwide (1). Yet in 2017, three out of ten people did not use

safely managed drinking water and an estimated six out of ten lacked access to sanitation services (80). Poor sanitation conditions, limited access to safe drinking water, adequate sanitation systems, and poor hygiene behaviors can lead to several negative health outcomes such as diarrheal disease, dehydration, parasitic and urinary tract infections (3, 4, 81, 82). Furthermore, poor access to safe drinking water, adequate sanitation systems, and hygienic behaviors is linked to impaired cognitive learning, school absences, and poor social development (7, 8, 83, 84).

Although many of the aforementioned health challenges are both preventable and treatable, diarrheal disease is still one of the deadliest diseases globally, causing approximately 1.6 million deaths in 2016 (85). Furthermore, among all infectious diseases worldwide, diarrheal disease is the third leading cause of mortality and morbidity among all age groups (85-88). However, the population most affected by diarrheal disease are children under five in low- and middle-income countries (LMIC's) (89, 90). Among this group, diarrheal disease is the second leading cause of death (91). Additionally, when diarrhea is chronic and prolonged, it can cause malnutrition which can lead to other diseases, like pneumonia (92). Furthermore, poor access to safe drinking water, adequate sanitation systems, and hygienic behaviors may lead to stunting (via intestinal helminth infections) and impaired cognitive function (93-95).

Systematic reviews and meta-analyses have suggested that improving WASH can reduce diarrheal disease globally (26, 29, 96). Moreover, other scientific research suggests that access to safe drinking water; adequate sanitation; and hygienic behaviors not only prevent diarrheal illness, but other diseases such as guinea worm, waterborne outbreaks (e.g. typhoid, cholera, and cryptosporidiosis), intestinal helminthiases, giardiasis, schistosomiasis, and trachoma (3, 18, 19, 97-99).

DIARRHEAL DISEASE

Globally, there are approximately 4.7 million episodes of diarrhea that occur daily, including 100,000 cases of severe diarrhea and 1,600 deaths (100). The WHO defines diarrheal disease, "as the passage of three or more loose or liquid stools per day (or more frequent passage than is normal for the individual)" (10). Most commonly, diarrhea is a symptom of intestinal tract infections and these infections are generally caused by bacterial, viral, or parasitic organisms that can be transmitted via feco-oral transmission pathways and/or contaminated food or drinking water due to poor hygiene and sanitation (10, 101). Less often, diarrhea is caused by food allergies or intolerances, chemical or toxin exposures (11). According to a systematic review, it was estimated that 70% of deaths attributed to diarrheal disease were caused by 13 pathogens (101), demonstrating how a majority of cases are

connected to select pathogens such as rotavirus (17.8% of all deaths), enteropathogenic E. coli (14.0%), enterotoxigenic E. coli (7.3%), calicivirus (8.2%), and Shigella (6.4%) (101).

Although diarrheal disease-attributed deaths have been reduced (mortality) there have been only moderate reductions (15%) in diarrheal episodes (morbidity) since 1990 (81). Researchers suggest, an emphasis on therapeutic treatments (e.g. oral rehydration therapy, zinc, and nutrient supplementation) may explain these discrepancies (11). Hence, in order to improve both morbidity and mortality, future interventions must target transmission pathways by reducing exposure routes (102). Therefore, it is important to understand pathways which include a complex combination of environmental and behavioral determinants that may be influenced by seasonality, WASH-infrastructure, practices, and culture (11, 103).

Transmission of WASH-related Diseases (Diarrhea)

As mentioned previously, a broad understanding of the transmission pathways of WASH-related diseases is crucial for the development and adaptation of effective health promotion interventions. There are several epidemiological and clinical explanations of diarrheal disease such as acute (dehydrating) diarrhea, acute inflammatory (bloody) diarrhea and dysentery, and persistent diarrhea lasting fourteen days or more (82). However, for this study, we explored self-reported diarrheal illness, which leans more on the anthropological understandings of illness and an individual's cognitive beliefs and subjective perceptions regarding diarrheal illness. This understanding was selected because there is a lack of conceptual clarity regarding diarrhea, which will be elaborated upon further in sub-study 3 and Manuscript IV.

Although human excreta are dangerous to human health (1), disease can also be transmitted from animal excreta (104). Infectious agents share similar transmission pathways (e.g. via feco-oral transmission routes) with various direct or indirect methods, such as person-to-person transmission mediated through feces-contaminated fingers or objects (direct method), contaminated food or water in or outside the home (indirect method), or via agricultural fields that are irrigated with or contaminated by sewage (indirect method) (105). Because fresh human/animal feces can contain viral pathogens, bacterial pathogens, protozoan cysts, and helminth eggs when released from an infected person/animal (106), feco-oral transmission can be particularly harmful. Furthermore, neglected tropical diseases (NTDs) also share feco-to-oral transmission routes. Therefore, effective WASH health promotion

interventions could also lead to reductions in trachoma, soil-transmitted helminthiases, and schistosomiasis (1).

RISK FACTORS OF DIARRHEA

The many risk factors associated with WASH-related diseases such as diarrhea, include demographics, socioeconomics, water, sanitation, or hygiene factors and behaviors (23, 26, 107-111). Although not directly relevant to this PhD dissertation, diarrhea risk is also associated with immunodeficiency, seasonal weather patterns, and/or humanitarian crises. Table 2 inventories several risk factors associated with diarrhea.

TABLE 2. RISK FACTORS FOR DIARRHEAL DISEASE IN LOW- AND MIDDLE-INCOME COUNTRIES

Risk Factor	Example	Source
Demographic factors	Age	Bauza et al. (107), Sinmegn Mihrete et al. (112)
	Education	Alebel et al. (113); Avachat et al. (114); Tumwine et al. (111)
Socioeconomic factors	Crowded household conditions	Etiler et al. (115)
	Low-income	Ganguly et al. (108); Houweling and Kunst (116)
Water-related factors	Water availability	Bartram and Cairncross (97); Esrey et al. (117); Seimetz et al. (118)
	Water storage practices	Kapwata et al. (119)
	Water retrieval practices	Adane et al. (120)
	Water quality	Clasen et al. (121); Fewtrell et al. (26); Reller et al. (122);
Sanitation factors	Improper waste disposal	Gil et al. (123); Jung et al. (23); Majorin et al. (124); Wijewardeneet al. (125)
	Latrine availability/use	Alebel et al. (113); Ramlal et al. (109)
	Lack of sewage system	Dzwairo (126); Esrey et al. (18)
Hygiene Behaviors	Handwashing behavior	Alebel et al. (113); Cairncross et al. (110); Curtis and Cairncross (28); Ejemot-Nwadiaro et al. (127); Fewtrell et al. (26); Luby et al. (128)
	Domestic hygiene	Curtis et al. (129); Ghosh et al. (130); Jung et al. (23); Tumwine et al. (111)
	Food storage practices	Curtis et al. (129)

DEMOGRAPHIC FACTORS

Studies indicate that specific demographic factors such as age and education may influence risk of diarrheal disease, and several studies have found that diarrhea prevalence is highest in young children (107, 112). For example, a 2014 study in North West Ethiopia, determined that age was significantly associated with diarrheal morbidity, and risk of diarrheal morbidity was higher in specific age categories (e.g. 6–11 months and 12–23 months) (112). In addition, rates are influenced by level of education of the mother (111). For instance, another study in Maharashtra, India, also found that mothers with lower educational status were more likely to have children at higher risk for having diarrhea (114).

SOCIOECONOMIC FACTORS

Other factors such as socioeconomic status and household conditions (that are commonplace in low-income households), also have a significant influence on diarrhea risk. In a systematic review and meta-analysis identifying risk factors of diarrhea morbidity of children under-five in India, Ganguly et al. (108) found that low socioeconomic status was significantly associated with diarrhea risk. Moreover, other studies suggest that household conditions that are characteristic of low-income families such as poor housing structures and crowded conditions also affect risk. In a 2003 study in Turkey, which focused on identifying factors that influence the diarrheal incidence among infants, housing type and crowded houses (housing shared amongst several families) were associated with higher risk of diarrhea (115). Moreover, in a non-systematic review of socioeconomic inequalities which influence child mortality in LMIC's, authors also linked diarrhea risk to low socioeconomic status (116).

WATER-RELATED FACTORS

Studies have also revealed that a host of water-related factors influence diarrhea risk. Bartram and Cairncross (97) suggest that access to a clean water supply promotes proper hygiene and sanitation and is therefore beneficial in preventing diarrheal diseases. For example, Esrey et al. (117) suggest that water availability can reduce transmission of diarrhea-causing agents, demonstrating how water availability influences diarrhea rates among all age groups. Additionally, access to safe water sources also contributes to the prevention of diarrheal diseases since the availability of clean water is likely to impact the frequency of handwashing behavior (118). Water storage practices also influence diarrhea risk. In one study from rural South Africa, it was revealed that unsafe water storage practices are statistically significant risk factors of diarrhea (119). Furthermore, water retrieval practices (water retrieved from water storage containers using vessels without a handle) were associated with diarrhea according to a study conducted in Ethiopia (120). Moreover, a randomized control trial conducted in rural Guatemala, revealed that households who received a special vessel to conduct flocculant-disinfectant water treatment were more likely to have clean water (water that met the WHO's guidelines for bacteriologic quality) and reported fewer episodes of diarrhea among children than the control (122). Lastly, a systematic review and meta-analysis revealed that water quality interventions (interventions which address water treatment) are effective in reducing illness, further demonstrating the influence of water quality on diarrheal disease risk (26).

SANITATION-RELATED FACTORS

Evidence from a range of studies also suggest that sanitation-related factors influence diarrhea risk. For example, studies report that sanitation-related factors such as improper waste disposal practices, latrine

use or availability, and a lack of a sewage system increase the risk of diarrhea. For example, in 2004, a literature review of child feces disposal practices in LMIC's, improper child feces disposal practices were associated with a 23% increase in the risk of diarrheal illness (123). Another analytical review on the relationship between shared sanitation facilities and diarrheal diseases presents evidence that shared sanitation (unimproved according to JMP (2)) is associated with diarrheal diseases (109). Finally, the impact of improved sanitation on diarrhea has also been studied, and a review indicated that improvements in sanitation (e.g. toilets) can reduce risk of disease (18). Furthermore, lack of an adequate sewage system may also contribute to diarrhea risk. For example, Dzwairo (126) discusses how pollution from pit latrine sanitation, increases the prevalence of diseases such as diarrhea.

Hygiene-related behaviors

Additional studies pinpoint the contribution of hygiene-related factors to diarrhea risk. These studies find inter-linkages between diarrhea and hygiene such as handwashing behavior, domestic hygiene, and food storage practices. According to a systematic review and meta-analysis on WASH interventions in LMIC's, Fewtrell et al. (26) suggest diarrheal cases may be reduced with improved hygienic practices such as handwashing behavior. Additional evidence also indicates that handwashing with soap at critical times can reduce diarrhea risk by approximately 30% (28, 127). Furthermore, a non-systematic review indicates that proper food storage practices and domestic hygiene are useful measures to prevent the spread of diarrheal pathogens, hence lower diarrhea risk (129).

It is worthwhile to note that risk factors are related to other WASH-related diseases. For example, in LMIC's NTDs lead to losses in disability-adjusted life years (131). Additionally, other research has established a relationship between poverty, water, and poor sanitation (97, 132). This relationship has also been linked to other WASH-related health outcomes such as menstrual hygiene management (MHM) (84), thus illustrating how these health concerns may disproportionately affect LMIC's with higher rates of poverty.

ECONOMIC AND SOCIAL IMPACTS OF WASH-RELATED DISEASES

As previously mentioned briefly, WASH-related diseases can burden both households and health systems having the largest impact on the poor and marginalized (97). Therefore, an investment in WASH interventions may help achieve health equity throughout communities, globally (133). In 2006, the World Bank published a report suggesting that hygiene promotion interventions such as handwashing with soap were the most cost-effective health intervention (134). Also, health outcomes such as

stunting, impaired cognitive function (93, 94), poor MHM (9, 135), and malnutrition (136, 137) may lead to poor school performance, school absences and/or delayed entry into the labor market. This can have a significant economic impact on interpersonal, intrapersonal, and societal levels. Therefore, improving WASH is beneficial at both the household and macroeconomic levels (138).

INTERVENTIONS TO PREVENT WASH-RELATED DISEASES

Given the complexity of transmission pathways, risk factors, and behavioral and environmental determinants of WASH-related disease, interventions that aim to improve WASH-related health outcomes are difficult to implement, assess, and maintain (34). The following section describes existing public health interventions that aim to prevent transmission of WASH-related diseases such as diarrhea and address other social and cultural dimensions that are instrumental in mitigating adverse WASH-related health and social outcomes.

WASH interventions are often implemented at the individual, household, school, or community-level. Furthermore, WASH interventions can focus on infrastructure, behavior, or compliance measures such as improving the quality and access to drinking water; safe food storage; handwashing with soap; toilet use, and the sanitary disposal of human excreta (including sewage treatment) (25, 34, 139, 140). Given the multitude of different types of WASH interventions, in the following sections I will discuss examples of WASH interventions that are commonly implemented in health promotion research.

INFRASTRUCTURE-BASED WASH INTERVENTIONS

Infrastructure-based WASH interventions often focus on construction of toilets, sanitation infrastructure such as sewage systems, or water treatment facilities to change behavior or improve health and social outcomes and tend to require more capital investment from governments, funding agencies, communities, or individuals (54). Once built, infrastructure-based interventions involve further maintenance, which require additional financial and/or human capital. Without maintenance, all progress (initial investment) will dissolve (139).

Currently there is limited evidence supporting the sustained impact of infrastructure-based interventions (25, 26, 30, 34, 38). Therefore, further research must be conducted to understand best practices in building and maintaining sanitation infrastructure. One hybrid intervention that is infrastructure-based, known as community-led total sanitation was originally inspired by a social mobilization approach to community development and primarily focuses on eradicating open defecation (141). However, community-led total sanitation has been subject to criticism regarding the ethical

implications of the techniques used to elicit behavior change. Some argue that approaches 'shame, insult, or embarrass' (142) the community, while others argue that it raises the collective consciousness of the detrimental harms of open defecation (65). Although these strategies have sparked controversy, some justify that the use of the shaming techniques encourages participants to construct a latrine, while others argue that this can also be characterized as coercion (141).

BEHAVIORAL-BASED WASH INTERVENTIONS

Dissimilar to infrastructure-based WASH interventions, behavioral-based WASH interventions often focus on behavior change strategies. Many WASH-related diseases are influenced by actions or decisions made by caregivers, healthcare providers, or individuals. Therefore, behavioral-based WASH interventions address transmission of WASH-related disease through health behavioral change-driven strategies (32, 36, 41, 143-146). These interventions have been implemented in schools, households, communities and healthcare facilities. Furthermore, knowledge, attitudes, beliefs, norms, and self-efficacy can also be targeted in behavioral-based WASH interventions (147, 148).

SCHOOL-BASED WASH INTERVENTIONS

Although school-based WASH interventions can be both behavioral or infrastructure-based, several have aimed to improve WASH-related knowledge, attitudes and behaviors of students, their family members, and the wider community (31, 35, 37). Unlike other settings, schools already are widely seen as cost-effective and conducive for reaching large numbers of teachers and students, family, and the wider community. Furthermore, school-based interventions are also important because they provide an opportunity to build leadership, interpersonal skills, and self-efficacy among students. Thus, showcasing youth's potential to model and advocate for healthy behaviors within their household and community, and disseminate knowledge (149, 150). For example, in one study in Tanzania on school-based health education which included a focus on hygiene, children discussed how they can effectively communicate health messages on hygiene practices to their families (151). Although, in many contexts students can be positive purveyors of knowledge, in some contexts, school-based WASH interventions can be particularly challenging in terms of how information is conveyed from the student to household, due to preferred knowledge dissemination methods, power dynamics, gender, and/or prevalent generational hierarchies (152). This demonstrates a need for more research in this area to understand if and how youth can be positioned as agents of change within school-based WASH interventions.

COUNTRY PROFILE: WASH IN INDIA

In India, WASH is a widespread public health challenge. Indians account for approximately one-third of the 2.3 billion people worldwide who do not have access to improved sanitation in their home (2). Furthermore, of the 892 million who practice open defecation globally, approximately 45% reside in India (2). According to UNICEF (153), only 33% of Indian households treat their drinking water. Furthermore, estimates suggest that approximately 40% of the population defecates in the open (2), which is often related either to a lack of adequate infrastructure (154) or preference for the practice (155). Despite the government's efforts to build sanitation infrastructure, only 34% of the population use safely managed sanitation[2](2). Moreover, the Indian Public Health Association indicated that only 53% of the population washes their hands after defecation, 38% wash their hands with soap before eating, and only 30% wash their hands with soap before preparing food (153). Additionally, India's rapid urbanization and increase in consumerist culture generates 62 million tons of waste each year, in which less than 60% is collected, and only 15% processed (156, 157). Other sanitation issues include the practice of improper disposal of household waste, coupled with infrequent waste collection or insufficient infrastructure (158). These aforementioned factors all contribute to the current sanitation crisis nationwide.

In order to address previously discussed risk factors for diarrhea, context-specific WASH-associated determinants of health must also be identified. According to the Centers for Disease Control and Prevention, determinants of health are "factors that contribute to a person's current state of health" (159). In the Indian context, determinants of health linked to WASH-related diseases are both behavioral and environmental. Previous research studies suggest that WASH-associated behavioral determinants can be attitudes, social norms and beliefs relating to perceived susceptibility to diarrheal disease, preference for open defecation, and other conflicting habitual practices (160-162) and WASH-associated environmental determinants are related to access to WASH facilities and the availability of soap (160, 163, 164). Table 3 presents a summary of scientific literature that describes or discusses WASH in India, providing a brief overview of various behavioral and environmental determinants that influence WASH-

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[2] According to WHO/UNICEF's Joint Monitoring Program for Water Supply, Sanitation and Hygiene (JMP), safely managed sanitation refers to the use of improved facilities which are not shared with other households and where excreta are safely disposed or transported and treated off-site (2).

related disease in this context (e.g. attitudes, beliefs, conditions of the physical environment, availability of services, and the social environment).

TABLE 3. ENVIRONMENTAL AND BEHAVIORAL DETERMINANTS OF WASH-ASSOCIATED DISEASES IN INDIA

Determinant	Factor	Examples	
Behavioral Determinants	Attitudinal	Attitudes toward open defecation	Banda et al. (162); Dreibelbis et al. (160); Novotný et al. (165)
		Perceptions of latrine attributes	Banda et al. (162); Burra et al. (166); Rashid and Pandit (167)
		Perceived convenience in decisions to use available facilities	Banda et al. (162); Biran et al. (164); Caruso et al. (168); Dreibelbis et al. (160)
		Attitudes regarding water treatment and quality	Banda et al. (162); Joshi et al. (169); Verma et al. (170)
	Beliefs and Behaviors	Cultural roots of open defecation practices	Banda et al. (162); De (171); Spears and Thorat (172)
		Traditional practices	Banda et al. (162), Sahoo et al. (173)
		Social norms about WASH behaviors	Banda et al. (162); Biran et al. (174); Dreibelbis et al. (160); Jewitt (175); Novotný et al. (165); (161); Shakya et al. (176); Tagat and Kapoor (177)
Environmental Determinants	Conditions of the Physical Environment	Availability of soap	Biran et al. (178); Dobe et al. (163); MacRae et al. (179)
		Water availability	Dobe et al. (163); Rashid and Pandit (180); Routray et al. (50)
	Availability of Services	Access to WASH facilities	Biran et al. (164); Dearden et al. (181); Hirve et al. (182); MacRae et al. (179); Sudeshna and Aparajita (183); van Eijk et al. (184)
		Waste disposal facilities/services	Berendes et al. (185); Nath (186); Prasad and Ray (187); Sudeshna and Aparajita (183)
	Social Environment	Inequality/status	O'Reilly and Louis (54)
		Socioeconomic status	Dobe et al. (163); Khanna and Das (188); Novotný et al. (165)
		Literacy/education	Bawankule et al. (189); Coffey et al. (190); De (171)

BEHAVIORAL DETERMINANTS

The influence of behavioral determinants (attitudes, social norms, and beliefs) on WASH-related diseases, is well documented throughout WASH literature focusing on India. Furthermore, behavioral determinants influence WASH-related social and health outcomes such as safe drinking water, school attendance, and latrine uptake or use. For example, one study in the Nelvoy village of the Vellore district in Tamil Nadu, documented attitudes regarding local defecation practices. In this study, Banda et al. (162) revealed that even though 31.8% of households interviewed had functional toilets, only 67.9% of those households actually used them. Participants indicated that customs and concerns related to smell were reported as main reasons for not using the toilets (162), which also aligns with other studies which report on attitudes toward open defecation (160, 165), latrine use (160, 164, 168), and latrine attributes (166, 167) throughout India. The study also revealed that public latrines that have been constructed by the government and intended for women, were also rarely used due to their cost (a monthly fee was required) and a lack of water onsite (162). This finding was also consistent with other research in the Indian context, that emphasizes the importance of cleansing acts post defecation (173). Banda et al.

(162) also revealed that study participants had a preference for open defecation because it was perceived as a non-stigmatized traditional practice/custom or a social activity. These findings are also consistent with other research that investigates attitudes, normative beliefs, and traditional practices (160, 171, 172). Regarding defecating outside, according to Banda et al. (162), participants elaborated by explaining, 'why dirty the house, when the weather outside is so fine?' (p. 1127). Here, the study elaborates on several behavioral determinants (attitudes, social norms, and beliefs) that are relevant to understanding WASH-related disease in the Indian context.

Other studies from the Indian context, indicate that attitudinal factors influence practices regarding water treatment and quality. In a study in an urban slum of Rohtak district in the Indian state of Haryana (near Delhi), 83.5% of respondents reported that they drink untreated water (no filtering, boiling, or chlorination) (170). Furthermore, Joshi et al. (169), also reported similar findings indicating that many rural inhabitants do not treat drinking water. Additionally, Banda et al. (162), revealed how many individuals believe water from a bore well or water that is clear in appearance is perceived as clean, which implicates the frequency with which they engage in water treatment practices. In this study, only 12 (12.4%) of respondents considered water as a source of diarrhea, illustrating a belief held by this community. Other determinants such as social norms have also played a major influence in WASH-related behaviors (160, 165, 174-177).

Environmental Determinants

Specific physical and social environmental effects, and the availability of services are also known environmental determinants in WASH literature in India. For instance, there is a growing body of evidence that illustrates the relationship between environmental determinants and school attendance. For example, a descriptive, cross-sectional study from West Bengal, presents various determinants of menstrual hygiene management (183). In this study, determinants for school absences were a lack of a proper disposal facility for sanitary napkins (75%) and lack of continuous water supply for washing (67.5%) at school (183). This example illustrates how access to WASH facilities (164, 181, 182, 184) and the availability of waste disposal facilities/services (185-187) influences poor WASH-related social and health outcomes.

There are also several studies that link conditions of the physical environment to WASH-associated diseases in India. In the 2013 study in West Bengal, on proper handwashing practice, Dobe et al. (163) reported that determinants such as water availability, availability of soap, and location of handwashing station were statistically associated with hygiene behaviors (e.g. handwashing with soap). These findings

were also consistent with other literature that emphasizes the importance of the availability of water and soap for performing proper WASH behaviors (50, 163, 178-180).

Several studies report that various social environmental determinants such as education, religion, and caste also influence access to and use of latrines in India, demonstrating these determinants as important factors, which influence WASH behaviors. For example, in a study that documented characteristics of households who adopted improved sanitation (toilets), participants who were wealthier or their economic status increased over the study period, educated, or non-Hindu adopted improved sanitation more frequently than individuals less wealthy, less educated, or Hindu (190). Other studies also suggest that socio-economic status and education are associated with WASH-behaviors such as latrine adoption (163, 165, 171, 188, 189). Furthermore, other literature links inequality to WASH-related diseases. O'Reilly and Louis (54) discuss how structural inequalities perpetuate and support inequitable access to environmental and social resources that are often linked to WASH-related diseases. Although there is a myriad of environmental determinants associated with WASH-related diseases throughout scientific literature published about the Indian context, the focus in this sub-section has not been to conduct a systematic review of the WASH literature in India, but rather to highlight the most salient studies that are pertinent to the focus of this PhD dissertation.

HISTORICAL AND SOCIOCULTURAL CONTEXT: SANITATION, STATUS, AND RITUAL PURITY

Recognition of historical and sociocultural factors are also important for understanding WASH in the Indian context. Influential activist, leader of the Indian independence movement against British rule, and historical figure, Mahatma Gandhi (born 1869) famously remarked that, "sanitation is more important than political independence", signifying the vital role of sanitation within the Indian historical and sociocultural context. In India, conceptions of cleanliness and ritual purity are extraordinarily complex and often applied to objects, situations, and people (191). Most notably, physical cleanliness is not homologous with ritual purity. Ritual purity may take precedence over physical cleanliness, thus defying fundamental components of germ theory of disease[3] (192). For example, Khare (192) explains that a drain which removes household waste can be physically clean yet ritually polluting. Therefore, it is important to unpack beliefs regarding differences between ritual impurity and physical dirtiness. This

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[3] Germ theory of disease is based on the awareness of the physical existence of germs and suggests that disease is caused by the presence and actions of specific micro-organisms within the body.

also is most often illustrated by individual's preference to maintain the purity and cleanliness of their domestic household rather than improve cleanliness or prevent pollution in public spaces (191, 193-195).

SANITATION AND CASTE

Historically, in India, conceptions of purity and pollution were established, maintained, and reinforced through the social construction of caste. The caste system is endogamous, hereditary, and often tied to cultural concepts of purity, cleanliness, and pollution (196-199), which influence behaviors, duties, and privileges (45, 154). This stratifying structure based on ancient religious texts from the Hindu religion called the *Vedas*, classifies people into five hierarchically ranked castes or groups known as *varnas* (Appendix B) namely the *Brahmans, Kshatriyas, Vaishyas, Shudras*, and *Avarnas*[4] who are also considered *Dalits* or 'untouchables'.

In 1950, the Indian government outlawed the caste system; its legacy, however, has continued to perpetuate inequalities and discrimination, which have profound implications for sanitation and health (200-202). According to the country's 2011 census, 16% of the population is classified as a scheduled caste and 8% of the population is classified as scheduled tribe. This amounts to approximately 300 million people (203). Since this system of social stratification justifies through religious doctrine a belief that upper castes are superior or more pure than those belonging to lower castes (191, 204), caste is often closely associated with socioeconomic status and other sociodemographic characteristics (205) that affect behavioral and environmental determinants discussed previously such as living conditions, socioeconomic status, and educational attainment (200, 205). Those in the most disadvantaged castes tend to live in rural areas with limited access to resources, healthcare, and sanitation facilities (200). Additionally, the notion that certain castes or actions are considered pure, while others are polluted, enforces beliefs that specific groups (often *Dalits*) have inherited by birth the duty of cleaning streets, collecting garbage, or emptying latrines full of human excreta (157, 197).

Literature has frequently documented and debated how ritual purity, pollution, and caste have contributed to India's sanitation crisis (45, 206). For example, open defecation, a practice that challenges ideas of pollution or contamination in a literal sense, is culturally accepted because it does not undermine caste (154). Instead, it reinforces caste because *Dalits* (those responsible for cleaning up

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[4] Aravarnas historically excluded from ranked castes and include those known as untouchables, *Dalits*, scheduled tribes.

dirt or polluting substances) must clean the "filth", reinforcing caste divisions and systems of hierarchy (207). Although caste is an outdated term today, the practice of cleaning ritually impure spaces (e.g. latrines) is still considered degrading and may be stigmatized due to historical associations (45, 154). Therefore, history has reinforced divisions such as social class, in addition to shaping many current societal norms. Furthermore, the physical environment in both private and public space serves as a reminder of this historical legacy (45, 194, 195).

Religious conceptions of purity and pollution deem bodily excretions (e.g. feces/defecation and menstrual blood) as polluting; therefore, these excretions have the potential to contaminate bodies and objects they encounter, despite one's caste. Therefore, habits and beliefs related to purity and cleanliness are often reflected in beliefs and/or practices related to pollution, purification rituals, and post-defecation cleansing (50). Because human excreta are considered ritually impure or filthy, bathing or cleaning clothes are common post-defecation practices (199). Therefore, water must be available within a latrine in order to perform required cleansing acts (e.g. *dhua dhoi* or anal cleansing) post defecation (173). It is also important to note that within higher castes touching or entering a latrine can be ritually polluting (50, 199). In addition to enforcing caste, the belief that handling human excreta is ritually polluting can be problematic for many sanitation measures that encourage safe disposal of child feces (208). Furthermore, complex purification rituals or water availability may prevent individuals from using available toilets (50).

Studies have also described cultural taboos and beliefs that are associated with cleanliness, purity, and pollution. A study on open defecation in Odisha, India reported that participants even considered the mere presence of a toilet in the house a sin. They believed that because idols and pictures of Gods were in the house, and the toilets would make the space impure and unfit for the divine (50). Moreover, in India, some Hindus consider menstruation an unclean or impure phenomenon (209-211) which can be traced back to Indra's slaying of Vritras from Vedic times. Here, guilt derived from killing a *Brahman* manifests every month in a woman's menstrual cycle (212, 213). Scholars have linked the belief that menstrual blood is polluting to menstrual related-shame, stigma, taboos, and restrictions (209, 210, 214). For example, findings from a study revealed that respondents believed menstrual blood was dirty, and menstruating women should be prohibited from visiting temples (215).

STRATEGIES TO PREVENT WASH-RELATED DISEASE: INDIAN CONTEXT

With several WASH-associated health concerns affecting many Indians, the country has prioritized improving WASH conditions for decades. Since independence, India has worked to mitigate the

country's sanitation challenges with several initiatives such as the Central Rural Sanitation Programme (CRSP), the Total Sanitation Campaign (TSC), Nirmal Bharat Abhiyan (NBA) and the Swachh Bharat Mission (SBM) (52) in addition to other informal grassroots activities such as The Ugly Indian (TUI) (158).
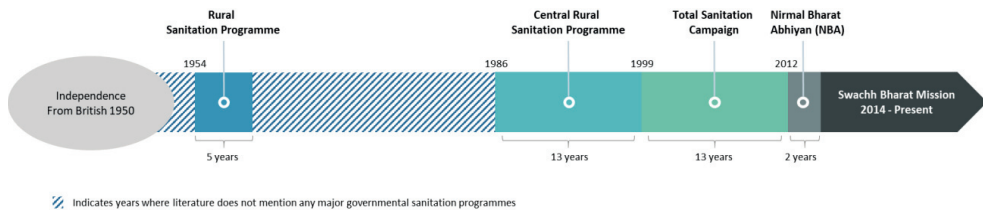
FIGURE 2. INDIAN WASH STRATEGIES TIMELINE

POST-COLONIAL INDIA

In 1954, four years after independence, the government of India introduced the Rural Sanitation Programme. This program was a component of the First Five Year Plan of the Government of India (47). Figure 2 illustrates a timeline of sanitation initiatives in India post-independence.

CENTRAL RURAL SANITATION PROGRAMME

In 1981, the Indian census revealed that rural sanitation coverage remained at 1% (47). Therefore, in 1986, the government tried to improve sanitation through the Central Rural Sanitation Programme (CRSP). CRSP aimed to increase sanitation coverage in rural areas through a subsidy-based and supply-driven approach. CRSP mainly focused on the construction of household toilets in remote areas; however, the program ignored behavioral determinants related to latrine use (52). Consequently, when the program was discontinued in 2001, only 22% of India's rural population gained access to toilets (52).

TOTAL SANITATION CAMPAIGN

In 1999, as CRSP failed to meet targets, it was replaced by the Total Sanitation Campaign (TSC). This initiative teamed community-led and demand-driven approaches with the construction of infrastructure, aiming to make rural areas "open defecation free" (52). During the TSC, subtle changes were made in order to make the program more participatory than past sanitation initiatives. For example, the TSC included information, education and communication, human resource development, and capacity building activities. These activities were especially targeted at people in rural areas. The program also offered financial incentives for construction of latrines at the household level and the

Nirmal Gram Puraskar[5] (award) at the community level for achievements in sanitation coverage (47, 216).

TSC guidelines indicated that subsidies were intended for 'backward' families and that the subsidy would only be reimbursed after the toilet was completed. However, households were strongly dependent on subsidies for toilet completion (51-53). This would eventually lead to the program's failure. Other failures included the latrine design and uptake. During the TSC tenure, rural households with toilets increased (217), however, it was also reported that many rural toilets did not work (218). Also, a national survey found that up to 50% of the newly constructed latrines were not being used (including latrines in villages designated open defecation free) (52).

Furthermore, there were additional issues pertaining to the design and construction of toilets (50) and inefficient implementation (53). Research has reported various critiques of the single model technology used in subsidy-based interventions promoted by governments (52). For example, the toilet built as part of the TSC program was often a single cubicle, pour flush toilet with no roof or water provision, and often without a door (53). This model was deemed insufficient or unfinished by several participants in a study in Odisha, India (50). Additionally, the non-involvement of community in toilet design to suit the needs and preferences may have contributed to lack of uptake (50). Studies suggest that non-involvement in choosing sanitation technology may reinforce and maintain open defecation practices (52, 219).

In the study in Odisha, India, many participants explained that the TSC toilets lacked water provision needed for cleansing acts (e.g. anal cleansing), flushing, and purification rituals which contributed to poor uptake (50). They also reported that they expected uptake to increase when latrines included water provisions (50). A study in Tamil Nadu, also reported similar results (162). Participants discussed how water is needed in post-defecation cleansing rituals; therefore, lack of water in toilet design reduces uptake and use (162). One study reported that individuals are twice as likely to increase safe excreta practices when water is present in a toilet facility versus those who must use a public water source (219). A global review of scientific literature also suggests that reliable water availability influences latrine uptake (220). Post-defecation rituals may be more conveniently or easily performed

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[5]The Nirmal Gram Puraskar is an award/incentive given to communities who have been classified as 'fully sanitized and open defecation free' (48).

near water bodies (e.g. rivers) (50, 221). Therefore, water accessibility is an important structural factor that must be addressed in toilet construction and design. Various oversights in design and implementation highlight the failures in the TSC, thus paving the way for India's future WASH initiatives.

NIRMAL BHARAT ABHIYAN

In 2012, the Indian government converted to a short-term strategy, the Nirmal Bharat Abhiyan (NBA). Households living below the poverty line and other impoverished families became eligible for increased financial subsidies for installing toilets (e.g. individual household latrines) (222). The program also adopted community-led approaches aiming to achieve 100% open defecation free villages (48). Although the NBA was launched to increase sanitation coverage in rural areas by incentivizing construction of household latrines, programmatic failures involving funding blunders led to construction delays (47).

SWACHH BHARAT MISSION

Since 2014, India has adopted the Swachh Bharat Mission (SBM) (223) (Clean India). It was launched on Gandhi's birthday, October 2, in 2014 with the intention of making India 'clean' by achieving universal sanitation coverage. The government hoped to make Gram Panchayats[6] open defecation-free and improve the levels of cleanliness in rural areas by Gandhi's 150th birthday in 2019 (47, 158). This initiative aims to eradicate the country's sanitation challenges through the application of a more comprehensive strategy (223). The SBM not only aims to improve WASH conditions with new infrastructure, but also utilizes health awareness and education. Additionally, the initiative prioritizes innovative and cost-effective technologies and community-led total sanitation programs for WASH issues (223), putting sanitation and hygiene at the forefront of India's public health agenda.

Notably, the SBM campaign uses Gandhi as a symbol. Not only do crucial milestones in the campaign pay tribute to the historical figure, but his iconic eyeglasses are the official logo. The use of this icon borrows from the '*Gandhigiri*' movement which promotes work for collective good (158). Doron (2016), hypothesizes that these glasses cast a moral gaze, buttressing allegiance and support for the program (158). Likewise, the SBM promotes civic responsibility, morals, and values by encouraging citizens to

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[6] A Gram Panchayat is the local traditional government at the village/town-level.

fulfill duties to create an improved future nation similar to the way Gandhi battled the British Empire (158).

The SBM also includes a national campaign, that promotes a healthy school environment through technical and human development in school settings throughout India, known as Swachh Vidyalaya (Clean Schools) (224). The aims of Swachh Vidyalaya are to "ensure that every school in India has a set of functioning and well maintained water sanitation hygiene facilities"; "make a visible impact on the health and hygiene of children through improvement in their health and hygiene practices, and those of their families and the communities"; and "improve children's health, school enrolment, attendance and retention" to facilitate a new generation of healthy children (224 p. 1). In addition, the campaign hopes to achieve these aims through improvements of school curricula and teaching methods (224). The Swachh Vidyalaya campaign also emphasizes healthy school environments that protect children from illness and exclusion (224). For example, Swachh Vidyalaya guidelines state that "children who are healthy and well-nourished can fully participate in school and get the most from education. Therefore, hygiene education in schools helps promote those practices that would prevent water sanitation-related diseases as well as encourage healthy behavior in future generations" (224 p. 1), demonstrating that an emphasis on WASH in schools can have a positive effect on the school setting or environment, thereby improving school enrollment and reducing school absences. These positive outcomes positively contribute to economic growth in the long-term (225, 226).

GRASSROOTS MOVEMENTS/ALTERNATIVE STRATEGIES

The Ugly Indian (TUI) is an anonymous collective that organizes volunteer clean-up projects throughout India. Their philosophy is grounded in the question, 'Why is India so filthy?', which is also the title of their viral TED talk (227). The movement suggests that accumulation of 'filth' stems from a deficit of civic responsibility and cultural attitudes (158). Unlike other approaches, implemented by the government, TUI takes a 'no nonsense approach' (158) and encourages others to take action and clean their neighborhoods (158). With the motto, *kaam chalu mooh bandh* (stop talking, start doing) (227), the movement tries to bring communities together, often through social media, to address an issue. Another movement includes the social marketing campaign, '*No Toilet, No Bride'* or *'No loo, No I do' (228),* which was initiated by state officials in the north Indian state of Harayana in 2005. This campaign aimed to promote household-level latrine ownership by "encouraging families of marriage-age girls to demand that potential suitor's families construct a latrine prior to marriage (228 p. 269). Furthermore, this campaign demonstrates the significance of gender and sanitation, emphasizing women's concerns

regarding privacy and safety in latrine ownership and may have influenced such Bollywood films such as *Ek Prem Katha* (Toilet: a love story).

CONTEXT OF RESEARCH

STUDY LOCATION
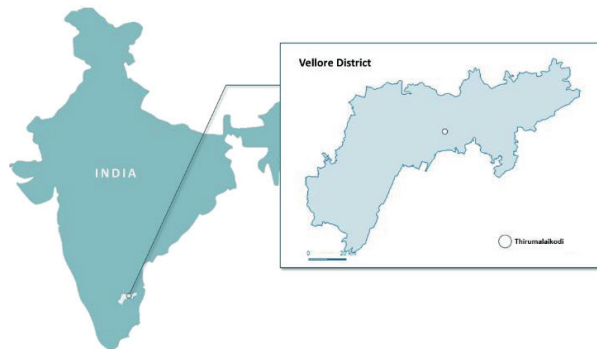
FIGURE 3. MAP OF VELLORE DISTRICT, TAMIL NADU, INDIA

Thirumalaikodi Village (also known as Malaikodi) is situated within the town of Ariyur, located in the Vellore district in the southern Indian state of Tamil Nadu (see Figure 3 for map). There is little information published about Thirumalaikodi itself. However, it is well known for its spiritual significance and referred to as Sripuram because of its proximity to the golden temple inside the Sripuram complex. The temple is devoted to Sri Lakshmi Narayani and the Sripuram complex is also home to spiritual teacher, Sri Sakthi Amma or Narayani Amma. The spiritual significance of the setting is important in understanding traditions, beliefs, and practices within this context.

Study participants primarily reside throughout the Vellore district. The Vellore district is made up of 858 villages including Thirumalaikodi village in Ariyur town. The 2011 Census reported that the total population of Ariyur is 5002 (2,546 males and 2,456 females) (229). In the 2011 Census, Ariyur was majority Hindu (85%). Other inhabitants were also Muslim (13%), Christian (3%), Sikh (0.01%), and Jain (0.1%) (230). The census for Ariyur, also reported that the adult literacy rate was 84% (91% males and 77% females) which is higher than the state of Tamil Nadu's average of 80.09% (229).

In India, SES classification often takes into account employment, occupation, and caste (231, 232). In Ariyur, 22% of the population identified as Scheduled Caste while 0.06 % identified as Scheduled Tribe (see Appendix B for description of caste) compared to 22% and 2% respectively in the Vellore district

(229). According to Census data, 1966 people were engaged in employment with 80% of workers describing their work as main work (classified as employment or earnings over a period of 6 months or more) while 20% were involved in marginal activity providing livelihood for less than 6 months (229).

TABLE 4. DEMOGRAPHIC CHARACTERISTICS FOR STUDY CONTEXT (230)

	Ariyur Town Total	Vellore District Total
Population	5,002	3,936,331
Scheduled Caste	1,084	860,212
Scheduled Tribe	3	72,955
Literacy	83.92%	79.17%
Total Workers	1,966	1,689,330
Main Worker	1,573	1,360,185
Marginal Worker	393	329,145

SCHOOL CONTEXT

Although India already included WASH at schools in the national SBM agenda (Swachh Vidyalaya), concrete strategies to encourage behavior change are still somewhat unclear (226). In the Swachh Vidyalaya handbook, only recommendations are provided without concrete guidance (224). For example, Swachh Vidyalaya supports behavior change through the incorporation of hygiene messages into the textbook curriculum, supplementary reading materials, activity-based learning methodologies or school assembly sessions (224), however, strategies proposed lack tangible guidance, clarity, and focus (226).

Although a substantial body of research regarding WASH-related diseases commonly focuses on infants (children under 5), only recently, studies have emerged that focus on adolescents in LMIC contexts (163, 233-235). This demonstrates research gaps in the WASH literature and the need for additional research studies focused on adolescents (28, 233, 236). It is also important to recognize the necessity of adolescent health and development in achieving the SDG's, which address sanitation, education, and achieving gender equality (e.g. SDG four, five and six) (237). Although adolescents are not the most vulnerable group for many WASH-related diseases, adolescents still do suffer from consequences such as poor social development, school absences, and reduced school enrollment (84, 163, 225, 238-240). Furthermore, adolescence is an important time for habit formation. Finally, the focus on adolescents throughout this PhD dissertation, highlights the importance participatory and inclusive approaches to research that encourage, empower and enable adolescents to become change agents in health promotion (63).

The rationale for focusing on adolescent students as the target population for this doctoral research was twofold. First, the original Project SHINE intervention in Tanzania used school-based participatory science education and social entrepreneurship with adolescents to develop and promote healthy communities (63). Bastien et al. (63) state that, "engaging youth as change agents in health promotion recognizes that their experiences and perspectives are of value and gives them voice to articulate concerns" (p. 15-16). Thus, further enabling youth to develop effective tools and skills that create local, sustainable, and culturally relevant strategies to improve social cohesion, connectedness, and community health. Secondly, given that this study utilizes a CBPR approach, community stakeholders were consulted when deciding which segment of the population should participate. Although Project SHINE could be implemented among different age groups, stakeholders suggested sixth, seventh, and eighth standard should be selected, because SHINE could be easily incorporated into the existing state curriculum.

Finally, the school is an ideal setting to implement Project SHINE because there are many natural entry points to incorporate WASH-related activities and health promotion education. School-based interventions can help improve WASH-related practices which are sustained outside of school; therefore, the school is an important point of outreach to households in improving sanitation (241). For example, students eat lunch at school daily, which provides an opportunity to teach and incorporate healthy sanitation and hygiene practices into their routines. Improving behaviors throughout daily routines at school, may also assist in an overall improvement of hygiene practices and contribute to healthy habit formation (242). Moreover, previous studies have suggested that adolescent girls are vulnerable to dropping out or prone to school absences when schools are ill equipped to meet their needs (e.g. menstruation) (84, 243). Therefore, adequate WASH facilities and health promotion education are needed to equip adolescents with WASH-related knowledge and resources (244).

SHINE India

The SHINE India pilot study, which this PhD dissertation is a part of, was carried out from October 2016 until July 2018. The aim of SHINE India was to improve WASH-related KAP among students in sixth, seventh, and eighth standard, as well as encourage adolescents to become health promoters and changemakers within their community, through development of life and leadership skills. At the schools involved in this study, at the time of research, there was not an active curriculum focused exclusively on WASH education, however some topics such as anatomy and water are covered in the science curriculum (e.g. Tamil Nadu Matriculation Board curriculum). The study was a two group, non-

equivalent control group pilot study, with a design that includes a pretest-posttest with one follow-up. The primary outcomes of interest were self-reported diarrheal incidence; WASH-related KAP; and leadership and self-efficacy.

As mentioned in Chapter 1, this PhD dissertation presents three sub-studies which contributed to the development of an in-depth understanding of the local contextual setting to initiate the cultural adaptation of Project SHINE to the southern Indian context (SHINE India). Thus, exemplifying the use of formative research processes to adapt a school-based WASH health promotion intervention. Table 5 provides an overview of all research activities that contributed to the entire SHINE India study, which included formative research (Phase 1), program implementation, and process and outcome evaluation (Phase 2). The table also specifies which sub-studies will be discussed in further detail in this dissertation.

TABLE 5. OVERVIEW OF RESEARCH ACTIVITIES INCLUDED IN OVERALL PILOT STUDY: SHINE INDIA

	Study Design	Presented PhD Dissertation	Other Unpublished Work
		Formative research	
Phase 1	Qualitative Quantitative Mixed-methods	✓ Photovoice photo discussion sessions with students from Group 1 ✓ In-depth interviews with students from Group 1 ✓ Diaries with students from Group 1 ✓ Survey with students from Group 1	× In-depth interviews and focus group discussions with stakeholders × Survey piloting with adolescents × Participatory research mapping with students from Group 1
		Implementation of the Intervention	
			Group 1 (intervention activities) × Teacher training × School curriculum × Health events × Sanitation science fair
		Evaluation Research	
Phase 2	Qualitative process evaluation		× Focus group discussions with students from Group 1 × Focus group discussions with teachers from Group 1 × Teacher logbooks with teachers from Group 1
	Quantitative outcome evaluation		Group 1 (intervention activities) × Baseline survey × Post-test survey × Follow-up survey Group 2 (usual curriculum) × Baseline survey × Follow-up survey

PHASE 1: FORMATIVE RESEARCH

The three formative sub-studies presented (Book Chapter I and Manuscripts II-IV) were designed to address the aims stated in Chapter 1. Formative research can be used to fill knowledge gaps and generate contextual insights to be applied for future health promotion intervention adaptation (245).

For instance, formative research can be crucial in generating a rich and in-depth understanding of the various social, cultural, economic, political, and other factors unique to the target population (245-247). Furthermore, formative research helps guide the development or adaptation of an intervention since initial findings can illustrate and describe the sociocultural context, thus assisting in the development of culturally relevant strategies, ensuring community-identified health concerns and needs are met, and local capacity utilized (245). Therefore, it is widely accepted that health promotion interventions are most likely to be effective when formative research is conducted, thus tailoring intervention strategies to the sociocultural context of the target population (59).

Additionally, Biran et al. (248), Curtis et al. (249), and Yeager et al. (250) argue that formative research is crucial for the adaptation of WASH interventions because it helps generate an understanding of existing WASH-related practices and directs attention to target community-identified health concerns to instigate behavior change. Furthermore, formative research processes have been applied to school-based interventions that are well documented throughout health promotion literature (249, 251, 252). Accordingly, in this doctoral research, the formative research phase is of particular focus, through three descriptive sub-studies which were conducted in order to explore various aspects of the sociocultural context of the target population.

As part of the cultural adaptation process, sub-studies sought to address Phase 1 of the SHINE India pilot study (formative research phase) and employ arts-based, descriptive qualitative and quantitative methods to help develop breadth and depth of understanding. Information gathering from sub-study participants was crucial to facilitating an in-depth understanding of youth perspectives and experiences, which are essential for tailoring and adaptation processes. Thus, this PhD dissertation demonstrates and describes how formative research processes assist health promotion researchers, practitioners, and planners to apply findings to develop or adapt intervention strategies to the targeted population and context using CBPR principles.

INFORMAL OBSERVATIONS AND REFLECTIONS FROM THE FIELD

In this section, I will use my firsthand experiences from the field to describe the context. Time spent in the field (approximately 7 months) helped provide these insights, however, it is important to note that these insights were not systematically collected nor analyzed. Rather, insights were informally captured through fieldnotes and journal entries.

SPIRITUAL LIFE— CENTRAL INFLUENCE

Spirituality is a central component of daily life in this context. For example, spiritual leader and guru, Sri Sakthi Amma founded the schools in the area and has also initiated other social welfare programs, therefore education at the school reflects many of Sri Sakthi Amma's spiritual beliefs and values. Although many of these spiritual beliefs and values are based in Hinduism, Amma cultivates a spiritually inclusive environment that espouses a variety of spiritual and religious forms. Schoolchildren engage in daily practices of yoga, meditation, Vedic chanting, traditional dance, and martial arts at school. Throughout time spent in the field, I also engaged in and practiced in everyday spiritual life including attending festivals, religious ceremonies, and spiritual discourses.

ACADEMIC ACHIEVEMENT RESPECTED AND PRIORITIZED

In addition to an emphasis on spirituality, academic achievement was also prioritized among adolescents who attended intervention schools. The schools in Thirumalaikodi are English medium schools because, in India, all tertiary education is taught in English. Therefore, students are encouraged to speak English throughout the day, starting from age 4 (kindergarten). The school is also academically centered with its students and staff earning several accolades throughout the duration of my fieldwork (e.g. district academic, science fair, and state-level abacus championship awards, among others). Additionally, students were strongly motivated by academic achievement, which was reflected by the school's six-day school week, where students would attend from 8:30 am until 4 pm. This is important to emphasize because a vast majority of these students were the first in their families to read and write and their education has been financially sponsored by scholarships or donations facilitated through the temple. In both schools, educational achievement (especially on state board or central board exams) was also prioritized since the advancement of these students will have a significant impact on the lives of the students and their families.

SCHOOLS ACCOMMODATE NON-TRADITIONAL EDUCATIONAL APPROACHES AND PRACTICES

Although standard state board or central board education was provided to students, schools also welcomed other extracurricular or alternative initiatives. For example, one school employed the Chrysalis program and both schools hosted a Scouts club [7]. Moreover, both schools had Green Sakthi clubs in their classrooms starting at fifth standard. Green Sakthi club was developed from Sri Sakthi

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[7] The Chrysalis Program was founded in India and utilizes participatory teaching techniques to "awaken a child's mind to bring out their full potential" (253) and the Scouts club is a global organization that encourages the development of life and leadership skills (254).

Amma's love of nature and helps educate children at the school about the importance of the environment and how to care for it. Daily Green Sakthi club activities also include planting trees, watering plants, and picking up litter on school grounds (255).

WASH CONTEXTUAL DESCRIPTION

Both schools had generally good WASH facilities onsite including segregated toilets and running water, however there was no soap available at handwashing facilities. According to JMP, schools with water available are considered to have 'basic' service (256). However, it should also be noted that although piped water was available at the school, students did not filter water before drinking and at both schools, water sources were located a distance from toilets (which do not create an enabling environment for proper handwashing behavior). Handwashing facilities were approximately 50 yards from the toilet block, making washing inconvenient. Furthermore, JMP, also stipulates that schools with handwashing facilities with water available, but no soap, are considered to have 'limited' service (256). Finally, JMP suggests that schools with improved sanitation facilities which are single-sex and usable are classified as having 'basic' service (256). It is also worthwhile to note that at the schools there were approximately 1 toilet for every 75 students (972:13) compared to national guidelines which recommend 1 toilet for every 40 students (224). Also, at the time of research, there were no trash bins located in the restroom for girls to safely and securely dispose absorbents during menstruation. Rather, a trash pile was located centrally in the main schoolyard. Furthermore, not all girls' toilets had a door, ensuring one's privacy, although they were placed in a separate room than the boys' toilets. However, after research activities concluded from this doctoral research project, the schools fundraised to build new toilet blocks and there were further plans to include a safe and secure place for female students to dispose of menstrual absorbents. Furthermore, I observed that students at the school wore a uniform daily, and on alternate days of the week, students had to wear white school uniforms. For newly menstruating girls who must wear white, this may enhance their fear that they might have an accident during menstruation (especially when the water source is not located in a private area).

Engaging with the community by living with a local family can promote understanding of family life, local customs and practices, however this was not a viable option during fieldwork. Instead, I stayed in a local guesthouse and observations of daily life at home were limited. However, I was able to visit a few homes of Vellore residents during fieldwork to observe different ways of how households collect and store water. Households utilized several different techniques and often reported water scarcity during recent years. From the few homes I visited, it appears that at home, residents of Thirumalaikodi either

collected their drinking water from a local public tap or order drinking water from a local vendor. Purchased drinking water costs ₹25 (approximately .29 Euro in March 2020) to be delivered, and generally lasts a household for two to three days. Although a majority of households purchased their drinking water from local vendors, they often collected water for bathing, washing clothes, and food from a local pond or natural water source. Collected water was often transported and stored in plastic containers with a lid, but not treated further, however some treated this water with chlorine. Throughout the community, washing hands was also a common practice before and after eating, however few handwashing stations or households used soap. Instead soap was prioritized for washing clothing, bodies during bath time, or dishes.

Throughout my fieldwork I also learned about several home remedies that are often used to treat diarrhea that are often developed from Ayurvedic medicinal practices or homeopathic remedies, which are two forms of holistic healing systems or medicinal practices that were commonly employed in this setting by community members. Based on informal discussions with community members, some reported that households in this area either have their own toilet or live in close proximity to a public toilet, therefore occurrences of open defecation are rare, however they acknowledged that open defecation often occurs in more rural and remote areas in close proximity to the Vellore district also referred to locally as the 'Hilly' region.

THEORETICAL FOUNDATIONS, ADAPTATION CONCEPTUAL FRAMEWORKS, AND COMMUNITY-BASED PARTICIPATORY RESEARCH

This section presents the specific theoretical underpinnings, adaptation conceptual frameworks, and research approach employed in this doctoral research.

COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

Participatory research, action research, action inquiry, and participatory action research are variations of different partnership approaches within the social sciences that are applied to engage the community or target group in a research project; however, in public health, the partnership approach most commonly used is CBPR (257). CBPR does not exclusively reference a particular study, design, or methodology. Rather, CBPR represents an approach towards research that dictates how research is designed and conducted (257, 258). This approach critiques traditional positivist research paradigms that seek objective truth (259). Instead, CBPR draws from critical theory, interpretive, and postmodern paradigms that give way to more reflective and pluralistic modes of inquiry (259).

WHAT IS CBPR?

CBPR differs from many other traditional top-down approaches in research (260) because both researchers and community are valued as equitable partners in knowledge generation (56). In CBPR, researchers must surrender the role of 'expert' and share power with community partners, to cultivate genuine partnerships (257). Additionally, partners must actively contribute to research processes by sharing expertise, community wisdom, and insights. This promotes an environment of co-learning (57), which may include educational processes of empowerment and critical consciousness (261) that influence both research processes and outcomes.

CBPR is guided by nine fundamental principles (Table 6) (57). This doctoral research was guided by these principles, particularly principles one through seven (56).

TABLE 6. NINE FUNDAMENTAL PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH (57)

Number	Key Principle
1	CBPR recognizes community as a unit of identity
2	Build on strengths and resources within the community
3	Facilitate collaborative, equitable partnership in all phases of the research
4	Promote co-learning and capacity building among all partners
5	Integrate and achieve a balance between research and action for the mutual benefit of all partners
6	Emphasize local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease
7	Involve systems development through a cyclical and iterative process
8	Disseminate findings and knowledge gained to all partners and involving all partners in the dissemination process
9	Establish a long-term commitment to the process

Although, CBPR may involve various study designs or research methodologies, one key characteristic, participation, is fundamental (262). In addition, CBPR also adheres to health promotion principles of participation and empowerment as stipulated in the Ottawa Charter for Health Promotion (39). Unlike conventional research, CBPR aims to foster collaborative and equitable partnerships, which recognizes the community as experts, thus facilitating collaboration and local insights throughout the research process (263) to encourage mutually beneficial initiatives. Knowledge gained from studies that apply a CBPR approach can be utilized as a powerful tool to incite social change to improve health outcomes; therefore, it is important to understand who defines knowledge and its intended purpose (258, 262).

One aim of CBPR is to increase knowledge and understanding of a given phenomenon. Mayfield-Johnson (2011) discusses the work of Jewkes and Murcott (1998) when she says that, "...with health viewed as resource originating from people within their social context rather than from the healthcare system, participation is seen as critical to reduce dependency on health professionals, to ensure cultural sensitivity of programs, to facilitate sustainability of change efforts, and enhance health in its own right"

(264, 265 p. 69). Although there are several research methods used in CBPR such as photovoice, participatory research mapping, questionnaires, and semi-structured qualitative interviews, their common thread is genuine community engagement, shared decision-making and community relevance (257).

Partnerships also produce research processes that are culturally grounded, thus improving the quality of research (260). This strengthens the potential to address community-identified health challenges through culturally informed approaches. Researchers most often come from an 'outside' (266) perspective (e.g. different country, socioeconomic background, ethnicity, and culture) than their community partners. This may lead to power imbalances or tensions (57, 267-269). Therefore, it is important for researchers to develop a sense of self-awareness and skills to work within a multicultural context (257) when participating in CBPR studies. This can be achieved through cultural humility (270), reflexivity, and positionality (261).

Cultural humility is an ongoing process of self-reflection and self-critique (270). For public health researchers to understand other cultures, they must engage and commit to understanding their own patterns of racism, classism, or sexism that may contribute to power imbalances in partnerships. Cultures must be understood and respected for a successful partnership to work (261, 267). This helps to establish and maintain mutually beneficial, respectful, and non-paternalistic partnerships in CBPR (257, 270).

Often, communities experience health challenges that are associated with socio-structural and physical environmental determinants of health. In regard to WASH, this includes poverty, inadequate housing, and access to water (257). Given that effective health promotion interventions cannot consist of a one-size-fits-all approach, community input can help researchers design or adapt culturally relevant interventions to the local context. However, there has been a shift in how health researchers investigate complex challenges, which includes in-depth understanding of context. Often, context is best understood by insiders who have firsthand experience and knowledge. Here, knowledge generated using a CBPR approach may be more culturally relevant than knowledge derived from an outsider's perspective (e.g. outside researchers) (271).

ENGAGING THE COMMUNITY

Scholars have defined community engagement as, "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people" (272 p. 7). One fundamental component of

CBPR, is the conceptualization and application of 'community' in the study context (56, 273). In this study, both geographic and communities of identity (school-based) were included (56, 273). The town of Ariyur in the district of Vellore (where the intervention schools are located), shares the cultural attribute of religion (230). In addition, in this study, community partners were selected based on their involvement with relevant organizations and institutions in the community of Thirumalaikodi. These organizations served the community and operated within close proximity to the school. However, some individuals selected were not native to the region or had recently relocated (less than 10 years).

Ongoing engagement with community partners is an essential part of CBPR. Participatory interventions that focus on partnership approaches and engagement in multiple phases of research are more likely to achieve desired programmatic goals (57). In this context, several intersecting pathways helped facilitate community engagement. For this study, the research team used the traditional pathways of engagement to cultivate partnerships. These methods of engagement were employed to respect cultural customs and daily routines. As outsiders, it is important to respect traditional systems when navigating engagement processes in a culturally sensitive and humble manner. Furthermore, authentic engagement, a key feature of the CBPR approach (274) is important for conducting ethical research (275), especially when conducting research with marginalized groups (e.g. youth/adolescents) (276-278).

ADAPTATION CONCEPTUAL FRAMEWORKS TO GUIDE INTERVENTION ADAPTATION

This PhD dissertation signifies an initial step in adapting a WASH health promotion intervention (e.g. Project SHINE) to a new population and context. Given that the adaptation employs a CBPR approach, the involvement of the local community in tailoring the intervention to fit with the community's primary health concerns, resources, and capacity was prioritized. This may enhance the effectiveness of the SHINE India intervention, and also increase the likeliness of maintenance and sustainability (258). Although there are several frameworks and models developed to assist in facilitating intervention adaptation (279), we determined that a multidimensional approach which focused primarily on the application of Mckleroy and Wingood's Map of Adaptation Process (59), Cultural Sensitivity Framework (280, 281) combined with a CBPR approach (282) would be best suited for an in-depth cultural adaptation because of its systematic inclusion of formative research, which is intended to determine, 'the extent to which an intervention is compatible with and responsive to the needs identified by the priority population"(283) (p. 126).

MAP OF ADAPTATION PROCESS

McKleroy et al. (59) developed an adaptation framework known as the Map of Adaptation Process. The framework was developed by a multidisciplinary team, informed by community health, education, social work, participatory research, and community empowerment principles. The Map of Adaptation Process helps guide the adaptation process through the application of a systematic approach, including feedback loops, to ensure tailoring to target population (59). Here, adaptation is defined as a "process of modifying an intervention without competing with or contradicting its core elements or internal logic" (59 p. 62); therefore, excessive and exorbitant changes are discouraged. Guidelines for the Map of Adaptation Process (59) consist of five main steps: *assess, select, prepare, pilot, implement*; however, sequence, timing and order are flexible (feedback loops indicated by curved arrows). Figure 4 depicts the Map of Adaptation Process however, since, steps 3, 4 and 5 were beyond the scope of this dissertation they will not be discussed further. This framework helped guide the cultural adaptation of SHINE to fit with behavioral and environmental determinants, capacity, collaboration and cultural preferences of the community of Thirumalaikodi (284).

SELECT
- Select intervention to adopt or adapt

ASSESS
- Target population, behavioral determinants, potential EBIs, stakeholder input, potential collaborations, and capacity to implement the intervention

PREPARE
- Adapt intervention
- Pre-test adapted intervention

PILOT
- Plan for implementation
- Pilot test

IMPLEMENT
- Implement adapted intervention
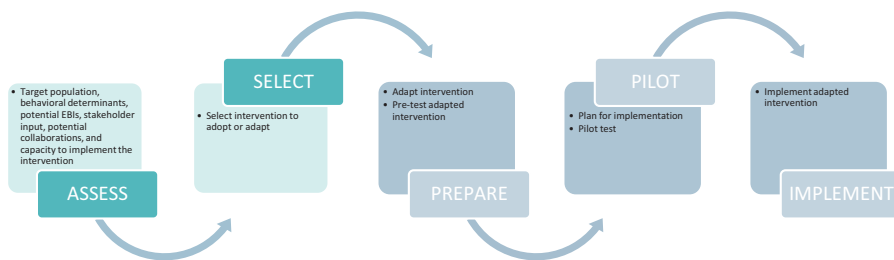
FIGURE 4. MCKLEROY AND WINGOOD'S MAP OF ADAPTATION PROCESS

CULTURAL SENSITIVITY FRAMEWORK

According to Resnicow et al. (280), programmatic activities can be culturally informed when characteristics and life experiences are incorporated into the intervention. Furthermore, in order to culturally adapt an intervention, 'surface' and 'deep structure' areas must be first identified through formative research, then modified or tailored. 'Surface' refers to elements in culture that are 'observable' or 'visible'; therefore surface level modifications in intervention adaptation are connected to fit, acceptance, or face validity with intervention participants (e.g. program language, names, intervention messages, materials, activities, and the way in which the intervention is delivered) (280). Meanwhile, 'deep structure' modifications encompass elements of a culture that may be perceived as invisible (e.g. social, psychological, environmental, and historical factors that influence WASH-related

behaviors) (280). To address 'deep structure' or non-visible elements, adaptations must attempt to incorporate theory-based mediators such as cultural norms, attitudes, or behaviors into an intervention since they have a close association with health-related motivation and beliefs (280, 285). In this study, data collected in the formative phase, attempted to address such types of adaptation which will be described in further detail in Chapter 6. However, it is important to acknowledge that since groups are heterogeneous, even with extensive formative research, it is difficult to address all deep structural elements. Given these limitations, we hope that formative research conducted and presented in this PhD dissertation addresses deep structure elements to increase program efficacy, sustainability, and impact and demonstrates how formative research contributes to the cultural adaptation of a health promotion intervention (280, 281).

CBPR APPROACHES TO ADAPTATION

Intervention adaptation is crucial to ensure that programmatic activities meet the cultural and contextual needs of the community (285). Programs are often poorly adapted when input from community is ignored; therefore, we included CBPR approaches to assist in the adaptation process. A CBPR approach to intervention research offers a means to co-develop or adapt an intervention that accommodates local cultural beliefs, values, and contexts. Therefore, the research team determined that CBPR is a suitable approach for engaging communities in the research process and influencing intervention adaptation.

This doctoral research applied a CBPR approach to build researcher-community partnerships and shape the scope of research, data collection activities, interpretation, and further application of research findings. This integration may also help optimize the future likelihood of intervention sustainability and effectiveness (282). Furthermore, authentic partnerships were imperative to the adaptation process to genuinely incorporate community insights into programmatic activities, methods, and delivery. Throughout the research process, stakeholders and participants shared their expertise as cultural insiders. Moreover, community partners helped us navigate cultural nuances and contributed to the development and implementation of SHINE India. This partnership led to equitable engagement in research, which is crucial to data collection, adaptation, and future testing using culturally relevant tools.

CONCEPTUAL FRAMEWORK FOR ADAPTATION

Figure 5 depicts the composite and enhanced framework used in this PhD dissertation. This conceptual framework is informed chiefly by the Map of Adaptation Process (59) combined with CBPR principles

(282). As mentioned previously, although prepare, pilot, and implement (Steps 3, 4, and 5) are also main components of the Map of Adaptation Process (59), they are not illustrated in the following depiction since these components are not included in the formative phase of this research. In applying this conceptual framework to the study design, we focused on 1) a conceptual framework that guides the adaptation of an intervention to fit with the target population's behavioral and environmental determinants, capacity, and preferences/needs (284) and 2) engage and incorporate community insights/experiences into programmatic activities to enhance cultural appropriateness and acceptability of the adapted intervention (282). While the conceptual framework displayed below, shows the different components of the cultural adaptation used in this research, the following chapters will focus primarily on sub-studies 1, 2, and 3.
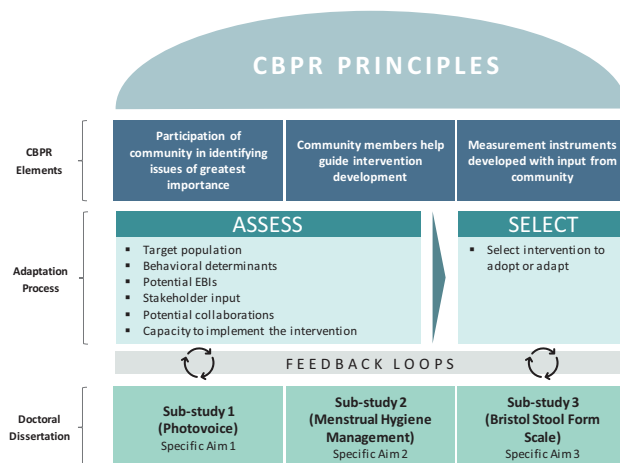
FIGURE 5. CONCEPTUAL FRAMEWORK USING MAP OF ADAPTATION PROCESS AND CBPR PRINCIPLES

As discussed, intervention adaptation involves a systematic process of modifying methods, programmatic activities, or practices to increase relevance, suitability, appropriateness and fit for the target population/community (59). In the case of this PhD dissertation, the adaptation process was carried out to increase suitability and cultural relevance for adolescent students in the community of Thirumalaikodi. Adaptation frameworks applied facilitated the intervention modifications of Project SHINE (described in Chapter 6) and could lead to both surface and deep structural changes (280, 286).

Feminist Perspective (Sub-Study 2)

Sub-study 2 (MHM) was informed by a feminist perspective. Although feminist research stems from a multitude of approaches and standpoints, this study is grounded in the notion that feminist research explores gendered contextual influences, gender inequalities, empowers women, and advocates for social change (287, 288). According to McHugh and Cosgrove (287), feminist research "…does not accept societal assumptions about the nature of women, gender, or about the differences between men and women" (p. 19). Discourses pertaining to gender are central to the feminist perspective applied in this research (287-289), because feminist research explores how women and men are treated differently in society and how various disparities of power may be used to alienate, oppress, or marginalize women (290). Gender is a socially constructed interpretation of man or woman that is often culturally and historically informed, and shapes codes and norms (291-293), therefore, it must be understood within the social structure in which it was constructed, negotiated, maintained, and reproduced (294). Furthermore, Butler (295), argues that gender is not essential or natural, but rather forged through continuous gendered performances. Understanding gender as performative provided an entry point into understanding the complexities of gendered experiences.

A feminist perspective firmly recognizes the importance and validity of women's experiences (296 p. 53) meaning that women's experiences must be focused on and addressed throughout the research process (288, 297). McHugh (288) explains that feminist research is distinctly not about, but for women and developed to transform a sexist society (287, 298). Therefore, given that sub-study 2 (MHM) focuses on adolescent girls' experiences of menarche and menstruation we felt that this application of this perspective was a suitable approach (288). Use of a feminist perspective helped to shed light on gender-specific sanitation challenges and needs. Furthermore, the application of a feminist perspective informed our understanding of adolescent girls' experiences of menarche and menstruation, how gender is constructed, negotiated, maintained, and reproduced, and how these experiences connect to, and are shaped by the sociocultural context (289, 290, 295).

Common Sense Illness Representation Model (Sub-study 3)

Each individual makes sense of health and illness differently; therefore, understanding these unique representations, how they are constructed, and conveyed is crucial to the development of tools that help measure outcomes in public health interventions. In this doctoral study, the research team decided to use constructs of a theoretical model borrowed from health psychology to cultivate our understanding of illness representations of diarrhea among adolescents in this context. This model was

applied to the design and analysis of sub-study 3 (BSFS), manuscript IV. The Common Sense Illness Representation Model (CSIRM) is an explanatory model that assists in the exploration of illness representations (299, 300). The CSIRM helps explain how information is processed to determine one's health. The CSIRM is composed of three types of information (300-302). The first type of information is lay information, which is translated or processed by an individual. This information is based on former cultural knowledge of illness (302). Second, there is external information, which is information that comes from a source that is perceived to be significant by an individual (e.g. parent or doctor) and often derived from the social environment (302). Finally, there is information that develops from an individual's own constructs of illness representation, such constructs often develop from current experiences with an illness (302). This third type of information also includes knowledge obtained from previous effective strategies for coping with an illness and can be influenced by an individual's personality type and culture (303). Hagger and Orbell (2003) explain that "it is the perception and interpretation of the different sources of information that leads to the construction of the illness representation" (302 p. 142); therefore, this combination of information helps individuals 'make sense of' or construct a representation.

Researchers have connected the CSIRM to several illness cognition dimensions also known as the representation of the health threat that include cause, consequences, identity, and timeline (304) (see Figure 6). These specific dimensions highlighted in Figure 6, helped inform sub-study 3 (BSFS) development and analysis which I will return to in Chapter 3 and 4. The *cause* dimension is connected to beliefs related to factors causing illness or disease. These can be biological, emotional, environmental, or psychological. For example, biological causes may be connected to germs or viruses (305), and environmental ones could be classified as pollution or chemical (305, 306). The *consequence* dimension represents beliefs related to the overall impact on an individual's quality of life or functional capacity. For example, many assess this dimension according to their inability to perform certain tasks based on illness (302). Then the *identity* dimension relates to labeling the illness (e.g. 'I think I have diarrhea') and knowledge of symptoms ('diarrhea hurts my stomach') (302). The *timeline* dimension refers to beliefs about 'course of illness' and 'time scale' of the associated symptoms (my diarrhea is chronic vs intermittent). Finally, the *control/cure* (299) describes coping behaviors and efficacy of treatment (302).
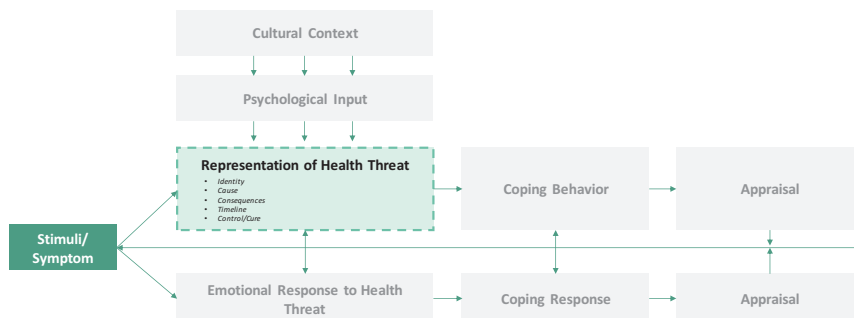
FIGURE 6. COMMON SENSE ILLNESS REPRESENTATION MODEL

In sum, this dissertation was conducted using the conceptual framework depicted in Figure 5 while sub-studies were informed by CBPR principles, a feminist perspective, and constructs from the CSIRM. In the next chapter, research methodology will be presented.

CHAPTER 3: RESEARCH STRATEGY, MATERIALS, AND METHODS

This chapter describes the study designs and sampling strategies used in sub-studies 1-3, followed by a more in-depth description of data collection and analysis methods used in each sub-study.

STUDY DESIGN

This PhD dissertation was written and designed as part of the SHINE India pilot as described in Chapter 2, however; this dissertation describes only the formative research which pertains to the three sub-studies.

STUDY DESIGN AND METHODS

This study contributed to the knowledge base of how arts-based methods and CBPR can be used to culturally adapt sanitation and hygiene interventions in school settings. Furthermore, the sub-studies presented in this PhD dissertation demonstrate how formative research is crucial to the process of adapting a health promotion intervention to ensure cultural relevance and appropriateness. To accomplish this, three sub-studies were conducted that utilized qualitative and mixed-methods research designs. For all sub-studies, constructivism was the central research paradigm which guided this work. Constructivism is based on the position that knowledge is subjective (307) and "reality is viewed as socially and societally embedded" in the mind (308 p. 7). Creswell and Clark (309) state that a constructivist philosophical orientation to research indicates that "the understanding or meaning of

phenomena, formed through participants and their subjective views. When participants share their understandings, they speak from meanings shaped by social interaction with others and from their own personal histories. In this form of inquiry, research is shaped 'from the bottom up'" (p. 40).

In sub-study 1 (photovoice) and 2 (MHM), qualitative methods were employed which are suitable for gaining an in-depth understanding of culture and a given phenomenon (308). Although sub-study 3 (BSFS) was largely based on constructivism, pragmatism also played a central role, which allows for the use of multiple methodological approaches (mixed-methods) and honors both subjective and objective knowledge (309). Since Aims 1-2 leaned towards a more exploratory nature, inductive methods were selected, which positions participants as experts (310, 311), while Aim 3 employed a deductive approach. In sub-study 3 (BSFS), a mixed-methods design was used to assess acceptability of the BSFS and to triangulate findings. According to Creswell (312), mixed-methods designs provide a "blending of data, [which] it can be argued provides a stronger understanding of the research problem or questions" (p. 215).

Formative research can involve data collection activities that enrich future intervention adaptation and implementation regarding cultural appropriateness, effectiveness, and suitability for the chosen target group (245). Furthermore, formative research can employ both qualitative and quantitative methods to assist researchers in providing further insights regarding target population of the intervention (313). Therefore, as part of the formative research process, three sub-studies applied qualitative (interviews, photo discussion sessions) and quantitative methods (survey, diary) to inform the development of the intervention, such as curricula, and extra-curricular activities. Furthermore, sub-studies utilized methods and tools (e.g. arts-based research methods, narrative interviewing techniques, and image-based tools) that were also considered to be age- appropriate to elicit the perspectives of youth.

In the first sub-study, arts-based methods such as photovoice were employed with students at school 1. The second sub-study used in-depth semi-structured qualitative interviews while the third sub-study used a mixed-methods approach. Table 7 provides an overview of the three sub-studies described in this PhD dissertation, their design, data sources, sample, analysis, methods and corresponding manuscripts.

TABLE 7. OVERVIEW OF RESEARCH DESIGNS AND DATA COLLECTION METHODS USED IN SUB-STUDIES

Study	Specific Aim	Study Design	Data Sources	Participants	Analysis	Manuscript
Sub-study 1	To explore students' perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors through arts-based approaches such as photovoice	Qualitative Photovoice	Photo/Focus Group Discussion	Purposive sample of students at	Conventional Content Analysis	Book Chapter I

				intervention school (n=10)		Manuscript II
Sub-study 2	To explore how adolescent girls in the rural community of Thirumalaikodi, Tamil Nadu, India experience menarche and menstruation; how their experiences connect to the sociocultural context; and understand what strategies they use to manage menstruation.	Qualitative Interviews	Semi-structured interviews	Purposive sample of female students at 2 intervention schools (n=10)	Thematic Analysis	Manuscript III
Sub-study 3	To understand cultural representations and perceptions of diarrheal illness among adolescent students in rural Tamil Nadu, India to improve the validity of measures of self-reported diarrhea.	Mixed-methods	Survey Stool Diary Semi-Structured Interviews	Purposive sample of students at intervention school (n=15) Concurrent interviews of same students (n=10)	Directed Content Analysis/ Descriptive statistics	Manuscript IV

For this doctoral research, qualitative methods such as photovoice and semi-structured interviews were used to explore adolescent perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors; experiences of menarche and menstruation; and cultural representations and perceptions of diarrheal illness; while quantitative methods helped to investigate the acceptability of the BSFS as a tool for diarrhea self-report in WASH research in low-resource settings. Additionally, use of arts-based research methods (e.g. photovoice) were used as tools for engagement, inquiry, awareness raising, and action. Furthermore, application of the aforementioned methodological approaches helped to gain insights into which intervention components must be adopted or adapted to best fit the needs of the community.

A CBPR approach helped orient research activities to engage community members in research processes (257). As mentioned previously in Chapter 2, core principles that foster equitable partnerships, capacity building, co-learning, and action were integrated throughout all research activities. For example, photovoice engages with participants to co-create knowledge. While design of research aims, instruments in sub-study 2 (interview guides) and 3 (interview guides, questionnaire, and diary) were designed with input from local stakeholders, thus grounded in the local expertise and experiences of community stakeholders. Moreover, community stakeholders were involved throughout multiple stages of the research process from study development to write up, thus further emphasizing CBPR fundamental principle 3: "facilitate collaborative, equitable partnership in all phases of the research "(57). For example, in sub-study 2, input from stakeholders influenced research priorities and provided cultural guidance. Similarly, in sub-study 3, stakeholder input helped shape research priorities, contributed to the formulation of data collection tools. Multiple local stakeholders also participated in

the academic manuscript preparation process on Book Chapter I and Manuscripts II-IV, demonstrating how community members were fully engaged throughout the research process in all sub-studies.

As a first step, during the formative research component of the intervention, the research team worked to engage with the community to develop the knowledge-base to understand behavioral and environmental determinants associated with WASH and the contextual setting, as well as assess potential unintended consequences of the intervention. This was essential for laying the foundation for intervention adaptation and translation, and for generating interest in the project. In this phase, the research team learned about the community's priorities and capacity, determinants, and unique health challenges.

Another component of formative research phase was semi-structured interviews with community stakeholders to learn about community capacity, context, WASH-associated determinants, and health challenges. Key informants were purposively sampled and asked to participate in a 45-minute interview. Individual interviews were an appropriate data collection method for this topic because they minimize the risk of embarrassment and created channels for transparency. However, findings from these interviews will not be reported in further detail in this PhD dissertation.

RECRUITMENT OF SCHOOLS AND PARTICIPANTS

A multi-stage sampling strategy was used in the overall study (for a visual representation of the sampling strategy, (see Figure 7) to select participating schools. First, three schools were recruited to participate in the larger SHINE study. However, only the two schools (Group 1) participated in the research activities discussed in this dissertation. The research team used convenience sampling to recruit schools to participate in the study and recruitment of schools was primarily influenced by proximity to the temple and research donors[8]. Schools were also targeted because they were private, which increased accessibility and freedom to implement Project SHINE in the standard curriculum. After schools were selected, students from specified grades or standards were selected to participate. Convenience sampling was used during these stages because it allowed the research team to recruit pre-existing groups of students. The main SHINE intervention recruited the 6, 7, and 8th standards to participate since the SHINE intervention is consistent with the existing national curriculum for these

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[8] CINIM financially supported data collection activities described in this PhD dissertation, however they had no influence over research design, analysis or interpretation of research findings.

standards. For other sub-studies associated with SHINE and described in greater detail later in this PhD dissertation, the research team primarily used purposive sampling strategies.
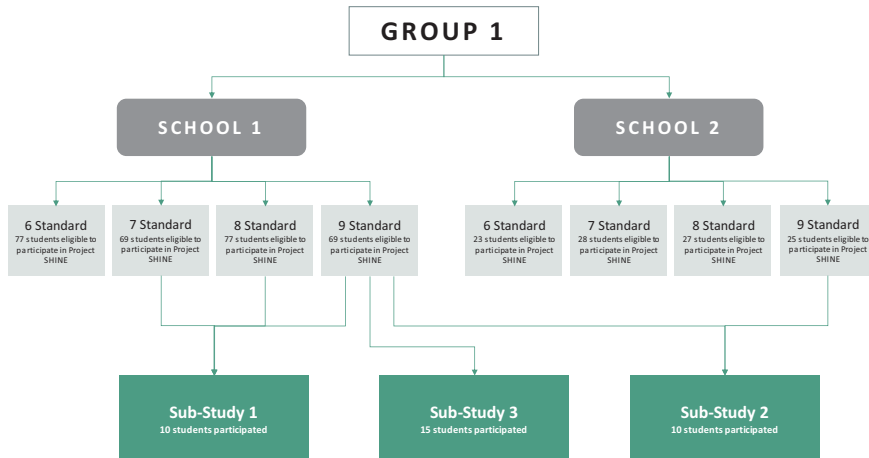
The main PhD supervisor and colleagues from the University of Calgary initially established partnerships with school 1 and 2, and the local hospital which facilitated initial stages of recruitment. However, during the course of the project, the PI (PhD student) worked intensively with school leadership, including school principals, correspondents, local project coordinators, and teachers during the recruitment processes of students. Ongoing engagement with community partners is an essential part of CBPR and community partners were often identified through a snowballing/referral strategy. In addition to building relationships in a formal space, the research team also engaged with the community in informal environments independent of the project. This meant attending temple rituals and ceremonies daily, going to various religious or cultural celebrations throughout the community, and partaking in additional activities at the school.

For each sub-study a purposive sampling strategy was employed, to select a sample that met specific criteria. Criteria were predetermined before each separate recruitment process and often determined by research aims of interest (314). In each sub-study that involved students, participants were recruited at school through the local project coordinator/community liaison that was assigned to the project by each intervention school principal. Project coordinators/community liaisons were two local schoolteachers (one at each intervention school). Through this role they facilitated sampling efforts to make sure that participants were properly informed and able to raise any concerns/feedback regarding

research activities. Project coordinators/community liaisons would inform students about each study by explaining that researchers from Project SHINE were interested in speaking to them about their experiences and their participation was entirely optional. If a student indicated interest, they were invited to participate and asked to obtain written consent from their parent or caretaker. Furthermore, the project coordinators/community liaisons would also often privately ask students who met sampling criteria to participate in the study. Criteria for each sub-study are outlined below in Table 8:

TABLE 8. SUB-STUDY 1, 2, 3 RECRUITMENT CRITERIA

	Sub-study 1 (Photovoice)	Sub-study 2 (MHM)	Sub-study 3 (BSFS)
Recruitment Criteria	• Current student at School 1 • In 7, 8, or 9th standard • Willing to take photographs of their community and/or experiences • Comfortable expressing themselves in English • Open to sharing their experiences within a group of peers • Obtained written parental consent • Assented to participate	• Current student at School 1 or 2 • Female/attained menarche • In 9th standard • Comfortable expressing themselves in English • Open to sharing their experiences • Obtained written parental consent • Assented to participate	• Current student at School 1 • In 9th standard • Comfortable expressing themselves in English • Open to sharing their experiences • Obtained written parental consent • Assented to participate

There were, however, limitations in the setting that had implications for the sampling strategy and may have introduced bias into the sample. Since the intervention schools were English language schools and the PI spoke English and not Tamil, a majority of data collection activities were conducted in English with the exception of the survey used in sub-study 3 (BSFS), which was administered by two local nurses. In light of this, students had to be comfortable communicating in English freely to participate in the study. This may have introduced sampling bias. However, to mitigate this challenge, the research team recruited students from 9th standard (a class where a majority of students are comfortable expressing themselves freely in English) for sub-studies 2 (MHM) and 3 (BSFS) to increase the number of those eligible to participate.

ENGAGING THE COMMUNITY: STRATEGIES AND PROCESSES

Community engagement is a continuous process (275) because relationships are often established before the study is developed and are maintained beyond the lifespan of the study (315). Often, relationships extend beyond the scope of the study, and researchers may engage with a range of actors/gatekeepers/stakeholders within the community (275). When seeking entry into the community for this study, it was important for the research team to map out the main stakeholders/gatekeepers. Initially, a local stakeholder assisted in the compilation of a stakeholder directory. The same stakeholder organized meetings and supervised introductions to all stakeholders in the directory. She also explained

basic formalities, culture, and customs of the context. In this context, there are many unspoken 'rules' or social conventions that vary or may not be formally documented. This knowledge conferred on the research team the ability to show proper respect for local values, beliefs, traditions, and customs, and engage in what is locally considered polite/appropriate conduct (e.g. greetings, appropriate attire, proper gestures, removing shoes upon entering offices/homes/temples).

The assembly of the stakeholder directory provided the team with a general understanding of local social structures and inventoried key decision-makers. However, throughout the research project it became increasingly clear that decision-making powers might be confounded by other circumstances. For example, tasks may be delegated when decision-makers are engaged in other matters. Therefore, although distinct hierarchies exist, there are complex decision-making pathways that depend on situational circumstances. As an outsider, it was vital to become familiar with and knowledgeable of these hierarchies and pathways to engage stakeholders and effectively facilitate research activities using a culturally sensitive approach and feedback loops. Throughout the study, the research team tried to engage with the community using culturally informed techniques, especially when seeking permission, assistance, feedback or providing updates on study progress (e.g. feedback loops).

As mentioned previously in Chapter 2, when designing an intervention, community engagement can ensure its cultural relevance and appropriateness as well as increase its acceptability and likelihood of completion of desired outcomes (274, 316). The initial meetings were focused on acquiring permission to engage in research activities and implement SHINE India. Meetings were also used as an opportunity to obtain feedback, learn more about the setting, and discuss intervention details such as the appropriate age-group of participants and timeline. These meetings were crucial in progressing toward the final and key step, which was to receive a blessing (endorsement) from the spiritual leader, Amma. It would not have been possible to plan the project without this blessing. Additionally, a blessing from Amma built credibility and trust in the research team and project (275); the absence of a blessing could have signified project disapproval or termination.

The main PhD Supervisor, Dr. Bastien explained the study to the spiritual leader and asked for a blessing after receiving *theertum*[9]. It was granted and both main PhD supervisor and the PhD-candidate received

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[9] In the Hindu religion, *theertum* is Blessed or holy water often contains spices such as cardamom, saffron, and *tulsi* (holy basil). It is typically used during *puja* to wash the temple deity, then distributed to devotees as *prasadam* (consecrated offering consumed by worshippers after worship) (318).

shawls and pens to signify appreciation. Once granted permission from the spiritual leader, official planning and engagement commenced. This blessing increased community investment and commitment to the project.

Stakeholder inclusion in the research and implementation processes was also key to community engagement. Community engagement can be used to provide input on data collection instruments or intervention design adaptation (317). In order to engage with local researchers, stakeholders, and community members to share decision-making regarding research processes, the PI met with a local medical epidemiologist who acted as cultural advisor. Additional processes or feedback loops were also implemented to engage community stakeholders such as recruiting school principals to review and provide feedback on the main SHINE pilot study questionnaire in addition to recruiting local nurses to review study instruments and assist in data collection activities. Participants were also actively engaged in the research process. Photovoice participants were invited to become co-investigators in Sub-study 1 data analysis. The PI also organized frequent individual meetings with teachers, principals, and gatekeepers to obtain feedback and inform about project progress. Frequent meetings with stakeholders were intended to help foster genuine partnerships, generate trust, and ownership of the research project.

However, it is important to recognize that the community is made up of a multitude of voices, some of which may not be reached through engaging with stakeholders or decision-makers. Community members such as parents or elders were not directly involved in the formal stakeholder engagement process, although the research team did attempt to ameliorate this through participation in daily activities in the community. Thirumalaikodi is a community with strong spiritual ties and participating in this aspect of community life was central to ensuring community engagement. Outside of building relationships in formal spaces, the research team also engaged with community members in informal environments independent of the research project activities. This meant attending daily *puja* at the temple, going to various religious or cultural festivals throughout the community, participating in local *seva*[10] and participating in additional activities at the school.

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[10] *Seva* is known as self-less service in the Sripuram community or service for others in which one does not expect anything in return. In this context, *seva* activities often served greater humanity, the community, or the physical/natural environment (318).

As previously discussed, at schools 1 and 2 a local project coordinator/community liaison was selected by the school principal to facilitate study logistics. The liaison typically organized research activities, acted as an interpreter, or helped explain authorization pathways within the context. This was especially important because, although gatekeepers endorsed the project, each activity needed further approval at the start of each field visit by the school correspondent, then further authorization when a timetable was proposed.

POSITIONALITY AND REFLEXIVITY: POSITIONING OF THE RESEARCHER

Academic researchers' power and privilege often derives from traits associated with identity (261). This power and privilege shapes one's positionality which influences community partnerships and research processes. Muhammad et al. (2015) discuss how power-sharing can help build effective academic and community partnerships which is vital to CBPR and cultural humility (263, 267). Genuine partnerships encourage reflection on a community's real-life experiences (56, 257, 263), thereby providing researchers a space to enhance their understanding of issues that are important to the community. However, without engaging in processes of self-reflection and self-critique, there is potential to create power differentials in both academic knowledge generation and relationships between community and academic partner/researcher (261). Given the selected approach to research, it was imperative for me to reflect on issues associated with power, identity and positionality throughout this PhD study. Here I will discuss power, positionality, and my process of self-reflection.

Positionality is comprised of one's identity, personal experiences, motivation, commitment, and values (261). In all research and community partnerships, there are external and internal power dynamics (259). However, to avoid community marginalization and foster collaboration, it is crucial to operationalize both reflexivity and positionality.

INSIDER-OUTSIDER RELATIONSHIP

Researcher and community relationships are complex and shaped by identity, ability to understand, and access (319). The notion of insider-outsider was formulated on the basis of researchers' identity vis-à-vis their relationship to a particular community and setting (320). In an insider-outsider relationship, the insider is the group of interest and the outsider is the researcher. Moreover, insiders often share a background or identity with the community or setting and have access to local knowledge that outsiders do not (261). Therefore, we included 'insiders' (e.g. nurses, school principals, local project coordinators, participants) in research activities as co-researchers such as data collection, analysis, and writing and

preparation of manuscripts for knowledge sharing. This was important because insiders treat shared knowledge with a unique kind of respect and may feel more accountable to their communities (261).

IDENTITY

Throughout this PhD dissertation, I often refer to the community as a unit of identity. However, like communities, an individual's identity may not be homogenous. Identity can be fluid, complex, and dynamic changing over time and context (261). An identity is based on a complex formula of ascribed and achieved characteristics. Ascribed characteristics are features of the identity which are attributed to our race/ethnicity, cultural background, skin color, sexual orientation, ability, or gender (261). Achieved characteristics relate to our 'achievements' such as education, profession, or social position (261). Finally, identity can be shaped by both our own and other's perceptions, among other factors such as membership in a dominant or subordinate group (261).

Muhammad et al (2015) state that it is crucial to include individuals in academic research whose identities (such as gender, race/ethnicity, sexual orientation, or class) can intersect with community partners to guide knowledge generation, build trust, and demonstrate a value in diversity (261). This stems from the idea that academic researchers from diverse backgrounds in regard to color, disabilities, gender, and sexual orientation generate knowledge differently based on their previous/everyday life experiences and identities (261). This can also be a valuable tool in community engagement, data collection, and knowledge sharing. As a biracial (Black and Jewish) American woman, I would never assert an Indian identity, or profess that I can provide an insider perspective into the context. However, based on my ascribed identity, I am familiar with experiences of oppression or discrimination that may parallel some individuals in India. Furthermore, such experiences may compel me to become attuned to specific practices or beliefs that oppress or marginalize such individuals. This informed my interactions with community partners, co-researchers, and participants in addition to my interpretation of research data.

However, as I reflect on positions and identity, I can also acknowledge how discourses of power and privilege within my achieved identity may affect research activities and partnerships. The identity and positionality of a highly educated researcher from a western country can have a significant influence on community engagement, research goals, knowledge generation, and sharing (261). Throughout data collection, the research assistant, Marte Hovdenak and I reflected on our positionality in terms of insider-outsider relationship and its effect on research processes and validity. We committed ourselves to understanding a culture and respecting local traditions/way of life. From these reflections we tried to

experience everyday life routines of some of the community members in a culturally respectful manner to help us understand the 'space between' insider-outsider perspectives and perceive, interpret, and portray participants authentically. We also tried to collaborate with partners in a mutually-beneficial relationship or meet outside of formalized research activities during occasions such as *puja*[11]. These efforts helped increase engagement and trust in our partnership. However, throughout research activities there was still room for more group reflection on how positionality affected our inner group dynamics. In future research studies, I would include more group reflections about the role of power and privilege within the research team.

SUB-STUDY 1 (PHOTOVOICE): BOOK CHAPTER I AND MANUSCRIPT II
Data Sources and Analysis

Arts-based research breaks away from traditional research paradigms to construct alternative ways of knowing (322). The research team was interested in understanding the lives and realities of student participants and determined that photovoice was an effective method to incorporate the students' perspectives and their real-life experiences into intervention adaptation. Therefore, sub-study 1 utilized the arts-based method, photovoice. Photovoice is a CBPR method, in which people are provided with cameras to take pictures that reflect their experiences and uses photographs to trigger critical reflection on issues that are important to participants (323). According to Wang & Burris, two key developers of the photovoice methodology, the three main goals of photovoice are to 1) allow community members to take photographs that reflect their experiences, 2) engage people in dialogue about community issues, and 3) reach influencers to stimulate change (323). In this context, where hierarchy and social structure is valued, students were not typically encouraged to engage with authority figures in discussion. Therefore, this participatory method in which photographs would trigger discussion and critical reflection was used to attempt to break down hierarchical structures and empower adolescents to share ideas and make social change in their community.

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[11] *Puja* (*pooja* in Tamil) is a Vedic ritual performed either in the temple or home that is based in nature and gives offerings to the divine (318). At the temples in Sripuram, *puja* is performed by Sri Sakthi Amma or priests in the temples. The ones involved in performing the puja chant mantras or hymns in Sanskrit while deities are anointed with sandalwood paste, *kum kum* (vermillion), fresh flowers, coconut water and sometimes given offerings of fruit or rice. Also, during the puja, incense sticks and a handheld *deepam* (lamps) are waved in a circle moving in a clockwise direction three times. After a break the deity is dressed and adorned with more fresh flowers. This is followed by additional rituals with *deepam* and incense. The puja ends with *pranaam* (bowing with head touching the ground) in front of the deity (318).

The purpose of this study was to explore students' perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors through arts-based approaches such as photovoice (Aim 1). Additionally, sub-study 1 helped engage youth participants in a creative process of critical reflection and dialog to inform and integrate students' voices in the SHINE India intervention adaptation and subsequent social action. For sub-study 1, data collection took place from June-July 2017. Students were purposively sampled and recruited by the local project coordinator/community liaison at their school. In total, three boys and seven girls attending school 1 in 7, 8, and 9th standards were recruited to participate. Participants first attended one information meeting. The purpose of the information meeting was for participants to become familiar with the photovoice study and method. Participants were also taught the ethics of photography, apprised of how data and identities would be protected, trained how to use digital cameras and how to obtain informed written consent when taking photographs of people.

After the initial information meeting, participants separated into single-sex groups to ensure they were comfortable when talking about sensitive topics in front of their peers for subsequent sessions. Participants then completed seven photo assignments throughout the duration of the study. Then, after each photo assignment, each group would come together to share their photographs in a photo-discussion session. All photo-discussion sessions followed a similar format in both male and female groups, lasted approximately one-hour, and were facilitated by the PI. However, since the groups were conducted separately, photo assignments that were generated by participants varied. Before each photo-discussion session, participants would select one-two photographs to share with a short explanation of why they took the photo. After all participants shared their photographs with the group, the entire group voted anonymously for one photograph to discuss in-depth using the SHOWED technique (324).The SHOWED technique (324) is a Freirean-based inductive questioning technique that is used to "trigger" critical dialogue (325, 326). Moreover, this technique can help participants reflect and identify concerns and strengths related to each photo-assignment and make linkages between photographs, their own unique personal experiences, and social action (327).

After each photo-discussion session, participants would then develop the next photo assignment for their group by connecting keywords or concepts with the guidance of the PI. Since both groups attended the initial information meeting together, they followed the same photo assignment for the first photo-discussion session.

After several photo-discussion sessions, both groups began to generate similar topics and discussions. Therefore, I determined that no new information was being generated which indicated we had reached data saturation. In total fourteen photo-discussion sessions, and one wrap-up meeting were held over a three-week period. All sessions were conducted in English; however, a translator (project coordinator/community liaison) was present during the information meeting.

DATA ANALYSES OF BOOK CHAPTER I AND MANUSCRIPT II

Data from photo-discussion sessions were audio recorded, transcribed verbatim, and then analyzed. Data analysis was conducted using qualitative research software, Atlas.ti, 2017 and conventional content analysis were used for the analysis of photo-discussion session text (328). Conventional content analysis helps reduce data conceptually to describe a particular phenomenon through the development of categories and concepts (328, 329). The process includes three main phases: preparation, organization, and reporting. Preparation includes data collection activities and making sense of the data. During organization, we (PI and photovoice participants) coded, created categories, and abstracted data (329). Finally, reporting included describing results. I decided to use conventional content analysis to capture the direct insights of study participants without 'imposing' preconceived ideas or theoretical perspectives (328), see Table 9 for example.

TABLE 9. AN EXAMPLE OF THE ANALYSIS PROCESS IN SUB-STUDY 1

Main Theme	Sub-theme	Code	Illustrative quote
Norms in transition	Linkages between cleanliness and godliness	Cultural Beliefs Notion of cleanliness/purity Consequential outcomes	*Somebody [said] if our home is clean then only the God will give us more blessings* (Male Participant).

In the final wrap-up meeting, the PI presented the initial codebook to participants and facilitated a code verification exercise with participants to ensure reliability. Participants coded parts of transcripts, contributed codes they felt were missing, and provided additional general feedback. Next, the PI continued the analysis process with the revised codebook through second-cycle coding (330) and two additional member-checking sessions to ask participants follow-up questions and develop themes. Students also met to develop an action plan to create social change in their community informed by their learnings from participation in the research project.

SUB-STUDY 2 (MHM): MANUSCRIPT III
Data Sources and Analysis

Qualitative research is important because it provides context and fosters understanding (331). Sub-study 2, used qualitative narrative interviews (332) to explore experiences of menarche and menstruation among adolescent girls at School 1 and 2 (Aim 2). Since the aim of this sub-study was to understand the experiences of adolescent girls, we determined that qualitative narrative interviewing techniques were suitable because of the approach's capacity to encourage participants to tell their personal stories (25). Therefore, the research team employed qualitative methodologies to enhance our understanding of the context and associated determinants, reveal relationships, and provide insights on potential entry points for knowledge transfer with the future aim of increasing the overall knowledge-base of MHM among this population in this context (331).

In this sub-study, the research team employed CBPR principles by incorporating community stakeholder input into several phases of research and by discussing research priorities with local stakeholders. The study was also informed by the previous research conducted by the University of Bergen Master's student Marte Hovdenak[12] of a similar nature[13] which was conducted from September-November 2017 (333). Research questions, aims, and interviews were duly informed by previous work conducted by Hovdenak which included a small-scale photovoice study on MHM and in-depth interviews with female adolescent students, health experts, and female teachers at the school (333). Research conducted by Hovdenak (333) was also informed by CBPR principles, thus recognizing the expertise and partnership of community members throughout the research process.

Data collection for sub-study 2 occurred from June-July 2018. For this sub-study, with the help of the two community liaisons (one at each school), ten participants were selected purposively to fulfill the investigative purpose of understanding adolescent girls' experiences with menarche and menstruation. Moreover, in this sub-study, student participants attended both School 1 and School 2 and were in ninth standard.

All interviews in sub-study 2 lasted for approximately 30-45 minutes and were guided by five central questions with probes. Interviews first explored constructions of gender, stories of menarche, and

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[12] Marte Hovdenak was a research assistant for sub-study 2 (MHM).

[13] The objective of Marte Hovdenak's previous work for her master's thesis was to understand the experiences of adolescent girls in school in Thirumailaikodi (also locally referred to as Sripuram), Tamil Nadu surrounding their menstruation, and how they cope with MHM (333).

closed with discussions about experiences relating to menstruation. In this study, during the initial interview, participants were asked if they would like to engage in a follow-up interview. Therefore, three participants also participated in a follow-up interview where they were asked to engage in a participatory research mapping exercise that mapped where and what type of information they obtained about MHM (however, these maps are not described in further detail in this dissertation).

Interviews were audio recorded and transcribed verbatim (334), but participants had the option to turn off the audio recorder at any time. Therefore, three participants declined to be audio recorded in sub-study 2. However, the research team still obtained permission from the participants to take detailed notes throughout the interview. In total, seven out of ten participants consented to have their interviews audio recorded.

DATA ANALYSES OF MANUSCRIPT III

The research team used Attride-Stirling (335) thematic analysis approach for data analysis in sub-study 2. This approach was selected based on its suitability to reveal patterns and relationships between themes. For this sub-study, data were analyzed using a multi-stage analytic process using qualitative data analysis software Dedoose. The analysis process included reading verbatim transcripts, reflections, and notes; generating codes and themes, thematic mapping, defining, and mapping themes (335). First, data were coded inductively then, codes (basic themes) were mapped and condensed into organizing and global themes (335). Through this process, meaningful segments of text were extracted to identify patterns and overarching themes to demonstrate the 'richness of the phenomenon' (336). Analysis was also informed by a feminist perspective (290, 293, 295), which helped identify gender-specific sanitation challenges and needs. Table 10 presents an example of how codes were developed into themes using thematic analysis.

TABLE 10. AN EXAMPLE OF THE ANALYSIS PROCESS IN SUB-STUDY 2

Global theme	Organizing Themes	Basic Themes (Codes)	Illustrative quote
Negotiating 'womanhood': transitions and challenges	Gender norms and restrictions	Beliefs Gender Norms Cultural traditions Restrictions	We have to keep one knife under the pillow. [The] knife [has] steel properties. My grandmother told that, ghosts will attack in periods times. (Participant 5)

Initial themes were then mapped and condensed into main themes that will be discussed in further detail. Furthermore, to increase rigor of analysis, the PI and research assistant engaged in an inter-coder

reliability exercise in which two members of the research team coded a transcript then discussed how codes were applied.

SUB-STUDY 3 (BSFS): MANUSCRIPT IV
Data Sources and Analysis

There is a research gap pertaining to how adolescents perceive and self-report diarrheal illness. Furthermore, there are several methodological issues associated with the various research tools currently used to evaluate the impact of WASH interventions in low-resource settings. This sub-study explores subjective interpretations of diarrheal illness, which differ from the medical classifications discussed in Chapter 2. This is important because subjective interpretations surrounding the definition of diarrhea may introduce limitations in self-reporting (337-339) and are often informed by the cultural context. In part, this study aims to understand more about adolescent definitions of diarrhea. Therefore, the research team designed sub-study 3, to inform the development of self-report measures of diarrheal illness of outcome measurement tools for the main Project SHINE to improve future study validity.

According to Bowen et al. (340), acceptability studies are crucial for determining whether an approach should be used in a future intervention. This study was implemented to explore whether the acceptability of proposed data collection tools (BSFS) to investigate self-reported diarrheal illness as a primary outcome were culturally appropriate and acceptable for future intervention use (e.g. satisfaction, perceived appropriateness, and fit). The BSFS in WASH research could be a promising objective assessment tool for the assessment of stool form (consistency). The scale uses visuals to classify different categories of stool ranked 1-7 (with Types 1 and 2 indicating constipation and Types 6 and 7 leaning towards diarrhea (341)) (see Appendix C for the BSFS). Therefore, the research team conducted a small-scale descriptive study to explore the acceptability of its use in low-resource settings among adolescents.

Acceptability was a predetermined focus of sub-study 3 to direct attention to how potential SHINE India participants will perceive and experience measurement tools (340). Therefore, we explored whether the proposed measurement tools were suitable for program participants (e.g. investigation of ease of application, opinions about experience, and attitudes regarding use) (see Table 11). Using a convergent parallel mixed-methods study design, the research team employed a combination of qualitative and quantitative approaches to address the complexities of the sub-study's aims and expand insights (312, 342).

Although sub-study 3 was a descriptive study, application of a CBPR approach was essential for the selection of appropriate data collection tools (282, 343). For this sub-study, community partners (e.g. nurses, teachers, and the school principal) reviewed the BSFS and agreed that visuals were age-appropriate and easy to understand thus receptive for improving survey responses in future research activities. Nurses and community stakeholders were also consulted when formulating language choices to align with the cultural context. First, the research team discussed the tool with community partners; next, partners reviewed instruments and guides to be used in sub-study 3; and finally, the research team incorporated the feedback provided. For example, several commented on the use of specific words such as 'diarrhea' or 'stool', which were subsequently changed to 'loose motion' or '*kakka*' (local terms). Therefore, in this sub-study, community input was incorporated to several phases of research, including research question development, study design, and data collection.

TABLE 11. FOCUS AND OUTCOMES OF INTEREST IN SUB-STUDY 3 ADAPTED FROM BOWEN, KREUTER (341)

Area of focus		Outcomes of interest	
Acceptability	▪ Opinions about experience ▪ Attitudes regarding use	▪ Satisfaction ▪ Perceived appropriateness ▪ Fit within cultural context (cultural appropriateness)	

The application of mixed-methods also helped to triangulate and merge data (312) to gain a more comprehensive understanding of the research issue. We employed semi-structured interviews, surveys, and stool diaries with the intended target population to understand how the BSFS would assist in self-reported stool. Quantitative and qualitative data were collected concurrently, then data underwent separate analysis processes, and finally results were merged during interpretation. Data were collected from October 2017 to July 2018.

For the qualitative component of sub-study 3, 20-40-minute semi-structured interviews were conducted with ten students (seven females and three males). Interviews aimed to elicit insights on cultural representations and perceptions of diarrheal illness and the acceptability of the BSFS as an assessment tool to self-report diarrhea. Here, acceptability was explored through interview questions regarding attitudes and opinions about experiences filling out stool diaries which applied the BSFS. The sub-study was also guided by Leventhal's CSIRM (344) (Figure 6), which primarily helped shape questions asked in the qualitative component and analysis (345). Interviews were audio recorded with consent of participants. One participant expressed discomfort being recorded during their interview, so the audio

recorder was subsequently shut off. Data collection continued until data saturation was achieved (no new information was being generated).

Quantitative data were collected through interviewer administered face-to-face surveys (n=14) and one-week stool diaries (n=14). The interviewer administered survey was developed based on previous literature that explores illness perceptions and the BSFS. The survey included 19 questions which were both structured and open-ended and consisted of the following: demographic information which included age, diet, and water source (questions 1-4). We also asked participants to rate their own recent stools using the BSFS (questions 5-7, 9-10, and 17). Question 8 helped assess the BSFS feasibility. Similar to a validation study conducted by Guled (346) which assessed whether the BSFS can be used as an outcome measure with mothers rating their child's stool, we asked specific questions which required participants to use the BSFS to describe which stool type was considered healthy or unhealthy for children, adults, and adolescents of the participant's age (questions 11-16). Questions also included dimensions of the CSIRM such as *consequence* (question 18), and *cure* (question 19). See Appendix D for the data collection instrument used to capture survey data.

In addition, participants completed daily stool diaries for one-week which used the BSFS (Appendix C) to assist in the standardization of illness representation. Stool diaries employed a simple task of recording daily bowel movements (frequency) and type (form) according to the BSFS. Although to my knowledge a stool diary like the one used in sub-study 3 has not been previously used in WASH research involving adolescents, similar stool diaries have been used in research regarding fecal incontinence, irritable bowel syndrome and constipation (347-350) (see Appendix F for stool diary). Quantitative methods also helped to determine acceptability of using the BSFS in the future SHINE India intervention evaluation through the assessment of survey question non-response and participant retention.

DATA ANALYSES OF MANUSCRIPT IV

For the qualitative analysis, data were analyzed using directed content analysis (328), which employs the deductive use of theory to guide analysis. This approach is particularly efficacious when exploring multifaceted and sensitive topics such as diarrhea (329). Here, the CSIRM provided a foundation for the initial codebook and coding scheme (351-353). Furthermore, BSFS acceptability and attitudes regarding the BSFS were segmented and coded. Interviews were conducted, coded, and analyzed using qualitative data analysis software Atlas.ti 7. Text transcripts were segregated into meaning units which were identified and categorized using predetermined categories/themes (informed by the CSIRM and the

BSFS). All text that did not correspond with any of the predetermined categories were given a new code. See Table 12 for example.

TABLE 12. AN EXAMPLE OF THE QUALITATIVE ANALYSIS PROCESS FOR SUB-STUDY 3

Meaning unit	Codes	Category
First of all, we need to [tell] my… our, parents, because they are taking care of us. our parents or grandmas will be using some of the medicines to cure it (Participant 1).	Communication with others Culture Family	Cure/control

Survey responses were entered into Excel, Office 365 (Microsoft) and then basic statistical analyses were performed using SPSS software version 25 (SPSS Inc, Chicago, Illinois). Qualitative responses to survey questions were converted into quantifiable categories for analysis. This was done by grouping responses into similar categories. For qualitative responses to survey questions, the original interviewer wrote all answers on a paper version of the survey. I then took the qualitative material and transcribed it into text. Next, I developed categories which involved coding survey responses and finally assigned units to codes (354). See Table 13 for an example of how qualitative answers were grouped into categories.

TABLE 13. AN EXAMPLE OF QUANTITATIVE CODING OF QUALITATIVE SURVEY RESPONSES

Original question	Qualitative Responses	Category	Unit
What color is healthy stool?	Yellow Pale yellow Dark yellow	Yellow	1

We used descriptive statistics to summarize variables and organize salient information on cultural representations and perceptions of diarrheal illness and application of the BSFS. Stool frequency was calculated for each participant, by dividing the first recorded bowel movements by the total number of days a participant filled out in the diary. Furthermore, stool form was calculated for each participant by averaging their total scores reported in the diaries (type).

ETHICAL CONSIDERATIONS

The protocol for this research was approved by the Regional Committee for Medical and Health Research Ethics (reference number: 2017/156), Norwegian Centre for Research Data (reference number: 53162), and ethical evaluation from National Research Ethics Committee for Social Sciences and Humanities (reference number: 2017/169) in Norway, as well as the Institutional Ethical Review Board and Institutional Ethics Committee (reference number: 30/25/02/17) at the Sri Narayani Hospital and Research Centre and the Sri Narayani College & School of Nursing in India (See Appendix E for documentation of ethical clearance).

Confidentiality Measures

Each meeting or interview was held in a location selected by our community liaison partner. Locations were a private space where there was minimal risk for others to overhear conversations or see the participant(s). In order to minimize the consequence of a breach of confidentiality, audio files were deleted from recorders after transcription. Additionally, after transcription, all transcripts were de-identified, and transcripts were stored on password-protected computers.

Processes ensuring confidentiality of data were thoroughly explained in consent forms, in-person, and again before interviews and focus-group discussions were conducted. The research team also attempted to ensure that confidentiality was protected during discussions by giving participants the option to choose to be referred by pseudonyms or numbers, if desired.

Consent and Assent Procedures

This study involves children as research participants which requires that unique protocols are followed since children are incapable of providing informed consent to participate in research activities. Therefore, we implemented a multilayer consent process to ensure that their rights were protected. First, we established a partnership with the local schools to gain permission to conduct the PhD study on school premises. This partnership established a cooperation that was culturally respectful and collaborative (with involvement of local community liaison/project coordinators). Next, we used an active parental written consent procedure, so that parent/caretaker(s) were able to consent or refuse to have their child participate. We achieved this by distributing a detailed information sheet and invitation to an information meeting to all parents and caretakers. Consent forms were available in English and Tamil and were translated and back translated to ensure accuracy. The research team and school also extended an invitation to parents to ask further questions about the study in an information meeting. The aim of the information meeting was for parent/caretaker(s) to ask questions about the study/process. However, only 6 parents from School 1 attended the information meeting. At the information meeting in which parents did attend, the research team went over the information sheet to explain the project and give parent/caretaker(s) the opportunity to ask questions. In addition, parent/caretaker(s) were informed again of their right to refuse to allow their child to participate and their right to withdraw their child from the study at any time without consequence (this information was also included in the information sheet). For all parent/caretaker(s) who did not attend the information night, the school principal was available to answer questions via phone. Personal phone calls gave parent/caretaker(s) who lived far away, did not have the money to travel to the school, or who were not comfortable asking questions in English, an opportunity to have a one-on-one conversation with a

trusted member of the community about the study. If a parent/caretaker(s) was not literate, participants were asked to read the information in the letter and refer them to speak with the school principal or research team where they would be able to get more information (all contact information was included in the form).

All sub-studies also obtained informed written assent from participants. In all assent procedures, the research team made it clear that there was no expectation that participants would take part in the corresponding research activity or sub-study, and that their decision to not participate or withdraw would have no potential consequence. Individual consent/assent forms were formulated for each research activity, implying that participants must engage in consent processes multiple times to participate in separate research activities. Finally, as part of the informed assent process, investigators reminded participants that they were free to withdraw from the study, leave the room, terminate audio recording, or refrain from contributing at any time during all data collection activities.

In the photovoice study, participants were trained in ethics of photography and research and carefully instructed that informed written consent and parental consent/assent for minors must be obtained anytime they took a photograph of a person's face or any other identifiable feature. They were subsequently given consent forms and required to obtain written consent when taking photographs of people.

OTHER ETHICAL CHALLENGES

In sub-study 1 (photovoice), the act of photography is not only a tool for reflection, but for research, skills development, self-confidence, and curiosity (355). In addition to these beneficial outcomes, it is equally important to reflect on potential power imbalances that are interlinked with the medium and photovoice process. One way photography perpetuates power imbalances is when the visual content of a photograph is objectified and revealed without context (356). Susan Sontag (1977) discusses these power dynamics within photography when she describes a camera as 'a tool of power'. This may lead to individuals' misinterpreting reality and perpetuating other misconceptions or stereotypes (357). Additionally, visible identifiers can connect individuals to the image, which has several ethical implications. Therefore, consent processes are shaped by power imbalances. These processes protect the individual in the photographs and the photographers from harm. If proper protocols are not followed, there may be problematic ramifications such as unwanted attention, scrutiny, alienation, or shame. Photovoice mitigates power imbalances by establishing rigorous consent processes and methodological procedures that aim to provide context and reflection of visual images. Most

importantly, participants are encouraged to take photos and narrate experiences from their own everyday lives providing a subjective perspective and context (356).

CHAPTER 4: PRESENTATION OF MANUSCRIPTS

SUB-STUDY 1 (PHOTOVOICE): BOOK CHAPTER I AND MANUSCRIPT II

The aim of sub-study 1 was to explore students' perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors through photovoice. Participants revealed that several social determinants play an influential role in sanitation and hygiene-related behaviors that determine the sanitary conditions of one's private space (in the household or domestic settings) and public spaces (outside of domestic settings/in communal environments). This relationship is mediated by norms, attitudes, or beliefs. Main findings focused on three themes related to sanitation and hygiene-related behaviors with an underlying focus on the physical environment.

Theme 1, "causes and consequences" of our analysis focused on both students' observations and perceptions of what causes normative sanitation and hygiene-related behavior, and their positioning of these behaviors as negatively affecting the physical environment and health of the community. Two sub-themes emerged ("'bad habits': litter(ing) as a descriptive norm" and "'why should we care?' displaced responsibility and passivity") that involve descriptive norms such as littering. Moreover, themes describe how these behaviors are reinforced and maintained by attitudinal indifference. Participants frequently discussed how descriptive norms influence habits that contribute to the sustained practice of poor sanitation and hygiene-related behaviors such as littering. Furthermore, participants described how attitudinal indifference and structural factors such as a lack of sanitation infrastructure supported littering or waste disposal behaviors.

Theme 2, "norms in transition" addressed contextual factors associated with culture, religion, and household dynamics that influence sanitation and hygiene-related behaviors. Under this theme, we identified two sub-themes: "linkages between cleanliness and godliness" and "gender-role paradigm shifts". Here, participants shared how various cultural or religious beliefs promote positive domestic hygiene practices in private space (in the household or domestic settings) demonstrating how cleanliness and hygienic practices are interlinked with religious beliefs in this context. However, despite these cultural and religious hygiene promoting practices, modern-day responsibilities may not align (especially for women).

Participants discussed various strategies to facilitate action and social change regarding sanitation and hygiene. The third theme, 'strategies for behavior change' revealed underlying factors associated with sanitation and hygiene-related knowledge and social norms. There were two sub-themes under this theme which included: "generational beliefs and knowledge gaps: achieving health literacy" and "future change agents". In this context, it was revealed that knowledge was often transferred intergenerationally. However, the lack of general knowledge and education about WASH among older generations contributed to cycles of misinformation, knowledge gaps, and poor sanitation and hygiene-related behaviors. Therefore, participants offered their own suggestions to minimize these challenges which included knowledge dissemination, media advocacy, and policy initiatives.

This sub-study contributed to Book Chapter I, where process and methodologies were rigorously reflected upon. As arts-based research methods gain momentum, academic researchers and practitioners must also engage in continuous processes of self-reflection and self-evaluation (57, 260). In Book Chapter I, we aimed to discuss and critically reflect upon how the use of CBPR arts-based method, photovoice was incorporated into the formative research phase as 1) a tool for knowledge translation[14] and action and 2) a process of promoting meaningful and equitable partnerships in CBPR. Here, we sought to develop a supportive research environment where participants were positioned as experts and photography was used to stimulate knowledge production, participation, and co-learning (323). This arts-based method enabled student participants to identify and represent (359) their community and lived experiences to help us understand WASH-related contextual factors and facilitate the interpretation, adaptation, and translation of Project SHINE to the local sociocultural context. Furthermore, Book Chapter I illustrates the similarities and differences across the Indian and Tanzanian contexts, while simultaneously unpacking the methodological dilemmas and experiences in practice concerning participant engagement, community partnerships, power and empowerment.

SUB-STUDY 2 (MHM): MANUSCRIPT III
In sub-study 2, we aimed to explore how adolescent girls in the rural community of Thirumalaikodi, Tamil Nadu, India experience menarche and menstruation; how their experiences connect to the sociocultural context; and understand what strategies they use to manage menstruation. Findings

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[14] Knowledge translation is a process of contextualization and application, which according to the Canadian Institutes of Health Research promotes the synthesis, dissemination, exchange, and ethically-sound application of knowledge to improve health outcomes (358).

revealed that menarche often marks the beginning of the transition from girl to womanhood. It inaugurates both the physical changes of puberty and reinforces the social construction of gender, pressuring girls to restrain, restrict, and self-impose gendered attitudes and beliefs that are culturally perceived as 'feminine'. In addition, participants shared both positive and negative experiences of menarche and menstruation. Moreover, participants revealed that they were explicitly taught to follow 'rules' or cultural codes which restrict behavior, social relationships, and personal conduct. In response, girls developed coping mechanisms to manage menstruation such as internally and externally imposed withdrawal and isolation.

This global theme describes conflicting emotions participants experienced in response to menarche and menstruation. Two organizing themes were also identified: 'positive experiences' and 'distressing experiences'. Participants described positive experiences associated with menarche as closely tied to menarcheal rites of passage or a celebration described locally as a 'function' which are prevalent in this context. During the function, girls described how they were honored and celebrated by their family and friends. Although girls discussed several positive experiences during menarche, participants also reflected on how menstruation negatively affects their everyday life provoking distressing experiences, such as various attitudes and beliefs which support taboos (e.g. women are haunted by ghosts or can potentially cause harm to plants during menstruation).

The theme, 'negotiating womanhood: relationships and behaviors' captures how participants were taught to follow various 'rules' or cultural codes which shape gender norms as newly menstruating women. According to participants, gender norms restrict specific behaviors, social relationships, and personal conduct. Throughout interviews, study participants described several 'rules' or codes which entailed specific ways of dressing, acting, and interacting which can be further interpreted as a 'gendered performance'. These gendered performances also affected adolescent girls' relationships with others. In addition, participants shared that they did not know about menstruation until they attained menarche; however post-menarche 'rules' or cultural codes were taught and prioritized (often through mothers or grandmothers). Girls also described how their identity transitioned into womanhood after menarche, which promote shifts in their identity.

Another theme we identified, 'social navigation strategies while menstruating' captures the various mechanisms participants develop to cope and manage menstruation in this sociocultural context. We further identified two organizing themes, which include 'concealment and secrecy' and 'self-imposed

isolation'. Participants discussed the strategies they utilized to conceal menstruation from peers and family, which included secrecy and isolation. These strategies are often fueled by embarrassment and shame. Moreover, participants discussed other strategies, which included internally imposed withdrawal and isolation to cope with menstruation. This type of self-imposed withdrawal affected both their academic achievement and psychosocial wellbeing.

SUB-STUDY 3 (BSFS): MANUSCRIPT IV

The aim of sub-study 3 was to understand cultural representations and perceptions of diarrheal illness among adolescent students in rural Tamil Nadu, India to improve the validity of measures of self-reported diarrhea. The study was designed as a mixed-method study.

In the qualitative portion of this study, we sought to increase understanding of diarrheal illness and reporting practices from the perspective of those experiencing it. Our findings were categorized according to the CSIRM constructs (dimensions). For the identity dimension, the participants included physical characteristics, symptoms, and beliefs about the cause of diarrheal illness.

Furthermore, CSIRM constructs include beliefs about the consequences of the condition for an individual. Regarding the consequence dimension in our study, participants discussed both physical symptoms of diarrhea and other ramifications, which they related to their inability to participate in certain activities, attend school, or communicate with others based on the burden of diarrheal illness. Moreover, participants discussed stigmatizing qualities of diarrheal illness which affected their participation or performance in school and/or relationships. Participants also shared several diarrheal treatment methods and coping behaviors when discussing the cure dimension of the CSIRM. Various methods involved diet modifications, medical and naturopathic treatments, and communication with others about illness. Another category relating to the study's aims pertained to the BSFS and was also extracted from interviews with participants. Interviews revealed that participants had mixed opinions regarding stool diaries with an application of the BSFS.

The quantitative findings aimed to summarize and organize salient information on perceptions of diarrheal illness and explore the acceptability of the BSFS as a tool for self-reporting in WASH interventions involving adolescent participants.

We asked the participants to self-report their bowel movements and stool form (frequency and consistency) using the BSFS. Furthermore, 100% of participants reported that they were able to match different types of stool to the pictures on the chart. Students were then asked to use pictures to

describe their most recent stool and 64% selected Type 3, 21% selected Type 4, and 14% selected Type 6. Participants also used the BSFS to assess healthy stool for different populations. Here, 71% of participants ranked Type 4 as healthy stool for someone of their age (13-14) and 78.6% ranked Type 7 as unhealthy stool.

Furthermore, participants discussed various cures for diarrhea. We found that ten out of 14 students (71%) suggested that medical/healthcare strategies were a good cure (e.g. taking tablets, visiting the doctor, or hospital), 50% recommended home remedies, while 21% of participants asserted that changes in dietary intake would help cure diarrhea.

Results from stool diaries show that the participants recorded 111 stools over a seven-day period (participants averaged 7.92 bowel movements per week (ranging from 7-10) or 1.1 stools per day. In sum, Results from surveys and diaries indicate that participants most commonly reported stool type, was Type 3 at 63% (surveys) and Type 4 at 38% (diaries) and, diarrhea (Type 6 and 7) is an irregular occurrence. In addition, the quantitative component of sub-study 3 demonstrated that all participants were able to understand the BSFS and apply the scale to their own bowel movements

CHAPTER 5: DISCUSSION

This chapter discusses the main findings of the three sub-studies that comprise this PhD dissertation, research study trustworthiness, and challenges and limitations.

SUMMARY OF FINDINGS

Findings demonstrate how community members and project participants can contribute knowledge and understanding to help guide intervention adaptation, thereby assuring greater cultural relevance. Research conducted provided insight into behavioral and environmental determinants of diarrheal risk, capacity, preferences, challenges, and needs of the target population (i.e. adolescent schoolchildren in Thirumalaikodi, India). Findings presented in Chapter 4, also provided an in-depth understanding of participant experiences and provides a foundation for cultural adaptation by exploring 1) perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors through arts-based approaches; 2) how adolescent girls experience menarche and menstruation; and 3) the acceptability of the BSFS for self-reported diarrhea. The first sub-study (photovoice) as discussed in Chapter 4, demonstrated how arts-based research methods could be used to engage with youth and help explore contextual factors that influence sanitation and hygiene-related behaviors and descriptive

norms (Book Chapter I and Manuscript II). For the second sub-study (MHM), findings revealed that menarche and menstruation designate cultural codes which shape gender norms (Manuscript III). The final sub-study (BSFS), revealed diarrheal-taboos, local methods to cure or control diarrhea, and how diarrheal illness can lead to absenteeism or withdrawal from school and social activities (Manuscript IV). For the following sections, I provide a synthesized discussion which presents overarching key findings to inform the cultural adaptation of Project SHINE.

Similar themes emerging from sub-studies 1-3 include: 1) norms distal influence on health outcomes; 2) cultural and religious attitudes, beliefs, and practices linked to sanitation and hygiene; 3) stigma and taboos; and 4) parents play an important role in health communication for participants. Key findings from formative research sub-studies described in this section are also key to future intervention adaptation that will be described in further detail in Chapter 6.

There were disparate findings and themes stemming from the sub-studies which pertain to WASH and gender, and other WASH-related practices such as open defecation. For example, in sub-study 2 (MHM), we used a feminist perspective (287, 288, 297) to explore and pinpoint gender-specific sanitation challenges and needs. Gender-related experiences were an obvious focus given that the study centered on adolescent girls' experiences of menarche and menstruation. However, in sub-study 1, participants discussed a relationship between gender and WASH differently, prompting discussion on environmental sanitation and how historically women are responsible for domestic hygiene of the household. Therefore, a feminist perspective informed our understanding of these experiences and how gender is constructed, negotiated, maintained, and reproduced, in this context (294).

Although the two sub-studies discussed gender differently, both findings still generated rich reflection and insights regarding gender roles in this context. Other inconsistencies focused on open defecation and toilet use. For instance, in sub-study 1 (photovoice), one participant reflected on the defecation practices (open defecation) of a family in his neighborhood, however also in sub-study 1 (photovoice) and in sub-study 3 (BSFS), participants discussed how open defecation was something that only people who live outside their community and participate in agricultural work or engage in. Inconsistencies regarding open defecation could indicate that open defecation is not common in this community, or alternatively, reflect social desirability biases or stigma connected to open defecation (e.g. participants sharing what they perceive is good/correct to not disappoint the interviewer).

KEY FINDING 1: DISTAL INFLUENCE OF NORMS ON HEALTH OUTCOMES (SUB-STUDIES 1 AND 2)

Findings from sub-study 1 (photovoice) and 2 (MHM) reveal that social and gender norms affect risk factors for diarrheal disease such as hygiene behaviors which may influence health and social outcomes. As discussed in Chapter 2, norms have important implications for intervention adaptation since they are associated with health-related motivation and beliefs (280, 285). In sub-study 1 (photovoice), participants often discussed littering as a descriptive norm (what one perceives is commonly performed), generating poor sanitation and hygiene habits. They expressed the idea that littering was exacerbated by attitudinal indifference and a lack of waste management systems or sanitation infrastructure. Littering behavior studies have also shown that the presence (or absence) of litter reinforces behaviors in specific spaces (360-362). Individuals are more likely to litter in previously littered environments because the mere presence of litter indicates that such behavior is commonly practiced in that space (360, 362, 363). Therefore, these descriptive norms influence attitude-behavior relationships (360, 361, 364), which is consistent with the perceptions of behaviors discussed in sub-study 1 (photovoice). Norms discussed by participants in sub-study 1 differed from norms identified in context-specific WASH literature. For example, other research on WASH-related social norms from the Indian context, focuses primarily on open defecation and latrine use which was discussed little in this context (160, 162, 175).

Sub-study 2 (MHM) findings revealed that social norms such as gender norms which we understood as 'rules that govern the attributes and behaviors that are valued and considered acceptable by men, women, and other gender minorities' (294 p. 2441) influenced experiences of menarche and menstruation by restricting behavior, social relationships, and personal conduct. Other research has also reported similar norms. Furthermore, a systematic review and qualitative meta-synthesis by Hennegan et al. (365) discusses how gender norms influence attitudes, beliefs, and behaviors that affect adolescent girls' experiences of menstruation. Gender norms were not discussed explicitly in sub-study 3, however some participants discussed sharing illness with a particular parent (often the mother), which may shed light on gender roles within the household.

KEY FINDING 2: CULTURAL AND RELIGIOUS ATTITUDES, BELIEFS, AND PRACTICES LINKED TO SANITATION AND HYGIENE (SUB-STUDIES 1 AND 2)

Sub-studies 1 (photovoice) and 2 (MHM) also revealed how various cultural and religious factors influenced behaviors that have implications for sanitation and hygiene behavioral factors for diarrheal risk. These can be further compared to regional notions of purity, filth, cleanliness discussed in Chapter 2 (196-199). In sub-study 1 (photovoice), findings revealed that cultural and religious practices

motivated and maintained specific sanitation and hygiene-related behaviors (e.g. sweeping and domestic hygiene), unlike cultural taboos that perpetuate an idea of the practice of cleaning as degrading work (45, 157). According to participants, emphasizing ties of cleanliness and religion could be an effective way of transferring domestic hygiene behaviors to public space. This was further demonstrated in Tagat and Kapoor (177) research on 'sacred nudging' which describes how various cultural and religious beliefs and practices could be used as a catalyst for changing WASH-related behaviors in India. Here, findings indicate an in-depth exploration of WASH-related religious and cultural beliefs helps us recognize the uniqueness and complexity of the context and understand how a one-size-fits all approach is insufficient (177).

The findings of sub-study 2 (MHM) provided important insights concerning experiences of adolescent girls with menarche and menstruation. Findings revealed how experiences of menstruation are also often influenced by cultural beliefs (e.g. such as the perception that menstruation is dirty or ritually polluting). Participants discussed cultural and spiritual rituals and practices such as bathing rituals or a 'head bath' performed to alleviate physical symptoms associated with menstruation and ensure purification, hygiene, and cleanliness. Furthermore, participants stated how they did not attend temple or enter the *puja* room at home during menstruation since according to religious beliefs they are incapable of withstanding divine energy. This is consistent with other research that links cultural and religious attitudes, beliefs, and practices to MHM. Hennegan et al. (365) found that although explicit cultural restrictions varied by region, religion, and caste, girls universally experienced various forms of cultural and religious attitudes, beliefs, and practices that would significantly influence their experiences with menstruation. For example, findings from a multi-site study reveal that respondents reported they believed menstruating women should not visit temples or religious sites because of their impure state (366).

Findings of sub-study 3 (BSFS) did not include insights on various cultural and religious factors which influence sanitation and hygiene-related behaviors, however these factors were not probed explicitly. Instead sub-study 3 focused on cultural understandings of diarrhea with the exploration of diarrheal illness representations, which included local methods to cure diarrhea that one may argue are culturally or religiously grounded.

KEY FINDING 3: STIGMA AND TABOOS (SUB-STUDIES 1, 2, 3)

According to Goffman (367), stigma is an, "attribute that is significantly discrediting" (p. 3). Identifying and describing different types of stigma must be considered when designing intervention content and assessment tools. Findings reveal how menarche and menstruation and diarrheal illness are linked to various forms of stigma. Sub-study 2 (MHM) confirms previous research on stigmatizing attitudes and beliefs that may affect menstruating girls (368) which can have a distal effect on their future educational, economic, and social development (145, 369). In sub-study 2 (MHM), participants reported that improper disposal of menstrual absorbents would attract wild animals (physical stigma), that ghosts would haunt women during menstruation (tribal stigma), and that a menstruating body can potentially cause harm to plants (physical stigma) demonstrating local stigmatizing beliefs or taboos in this context. Furthermore, participants discussed efforts to hide from family and peers during menstruation signifying its stigmatizing condition. In other literature the link between menstruation and stigma is based on the belief that menstruation is considered disgusting, dirty, or ritually polluting (370, 371). Furthermore, other literature on menarche and menstruation documents the stigmatization of menstruation, describing taboos regarding the visibility of menstrual blood or the notion that menstruating women are perceived polluting or dangerous (368, 372, 373).

The third sub-study (BSFS) sheds light on various cultural understandings of diarrhea as well as additional barriers and benefits to the BSFS to measure diarrhea incidence in future interventions. Findings from sub-study 3 (BSFS) revealed how participants were embarrassed to talk about diarrheal illness with others because they perceive diarrhea as disgusting, foul smelling, unclean, or bad (e.g. physical stigma). Therefore, participants expressed a general discomfort with the subject matter and often attributed their apprehensiveness to speak about diarrheal illness to shyness. According to De Leeuw (374) beginning at age 12, adolescents become less suggestable and increasingly more susceptible to peer pressure and group norms. Therefore, this renders privacy especially important for individuals of this age which could help explain why adolescent participants indicated that they were not fond of providing indication of illness (e.g. that they had diarrhea), rather appear normal. Taboos associated with diarrheal illness were similar to menstrual-related taboos presented in sub-study 2 (MHM), which caused girls to conceal or hide when they are menstruating. In sub-study 3 (BSFS) participants also shared their general discomfort with the subject matter and preference for concealing the illness, staying at home during bouts of diarrhea. Here the stigmatizing qualities of diarrhea advocate strategies of secrecy to provide protection from bullying and shame. Furthermore, students linked frequent toilet use and diarrheal illness, explaining that as an illness with intermittent symptoms,

a student may experience limited control over where and when they can go to the bathroom. Here, participants shared that instead of using a toilet that they deemed unfit or unhealthy, they elected to stay home during bouts with diarrhea to minimize the perceived risks (using a dirty toilet, discovery, or teasing from peers). The necessity of using an unsanitary toilet facility may also further stigmatize diarrhea because in India, toilets are seen as dirty or impure (157, 375).

Silence is a valuable part of communication in qualitative research that can be a form of response that indicates a participant's lack of knowledge, comfort level, cultural norms, or interviewers' skills to illicit participant responses (376, 377). Charmaz (378) argues that researchers should also pay attention to silences to understand implicit meanings which can further contribute to understanding a phenomenon in qualitative inquiry (379). Despite open defecation being the focus of the government-initiated WASH campaigns (as discussed in Chapter 2) and the focus of a wealth of public health literature throughout the region (50, 168, 217, 380-382) it was rarely discussed among participants and often framed as a challenge for other communities in more rural settings. Furthermore, in discussions with stakeholders which are not formally included in this PhD dissertation, but significantly informed my understanding of the sociocultural context, open defecation was frequently discussed as either no concern of the local community or indicated as inappropriate to teach about in school (with exception of a focus group conducted with health professionals whose patient reach extends beyond the Vellore district). Given this feedback, I did not probe open defecation explicitly throughout the sub-studies with adolescents. Moreover, since the topic was rarely brought up by participants and acknowledged as an issue for other communities suggests that open defecation is taboo in this context. These findings demonstrate implications of stigma, taboo, and strategies applied/developed by participants to conceal stigmatized conditions (e.g. menstruation and diarrhea).

KEY FINDING 4: PARENTS PLAY AN IMPORTANT ROLE IN HEALTH COMMUNICATION FOR PARTICIPANTS (SUB-STUDIES 1, 2, 3)

Local knowledge is often community-based and unique to a particular culture (383). Both sub-study 1 (photovoice) and 2 (MHM) revealed that intergenerational knowledge transfer plays an influential role in conveying health behaviors to adolescents regarding MHM and sanitation and hygiene-related behaviors (384, 385). Findings reveal how local knowledge and beliefs were transferred intergenerationally from parents and/or grandparents to study participants.

In sub-study 1 (photovoice), participants shared how knowledge and beliefs relating to traditional medicinal remedies, handwashing behaviors, the perceived use and efficacy of chlorine tablets, domestic hygiene practices, and littering were often passed down through generations. This was confirmed by previous research which suggests WASH-related knowledge and beliefs are passed down through generations. For example, in one study about personal hygiene practices in Indonesia among mothers, women reported that information about nail cutting was passed down generationally (386). Other research regarding intestinal worms in Bangladesh found health-related misconceptions were passed through elders or relatives (387). Finally, research regarding pro-environmental practices of adolescents, reported that parents are key influencers on behavior (388, 389).

Participants in sub-study 2 (MHM) described how information about menstruation was also often passed along intergenerationally through their mother, grandmother, or other relatives. Similarly, other studies have yielded results suggesting that insufficient knowledge about puberty, reproductive health, and menstruation is transferred to adolescent girls by their family members leaving them poorly informed and ill equipped to cope with menstruation (211, 213, 215, 390).

Finally, findings from sub-study 3 (BSFS) revealed the importance of communication with parents when initiating diarrheal control strategies or coping behaviors. Many participants emphasized the importance of telling their parents when they were suffering from the illness, because parents often played the role of caretaker and were well positioned to assist in the control or cure dimension of diarrheal illness based on knowledge and previous experience (intergenerational knowledge transfer of local knowledge systems). However, few stated that they were uncomfortable speaking to their mothers about diarrhea as they grew older. These findings are inconsistent with one study that investigated levels of agreement between parental and adolescent reports of illness suggesting that parents are unaware of illness status of their children (391). However, another study suggests that high levels of parent-adolescent agreement are associated with cultures that support familism[15] (392) indicating that this may be a unique finding for this population.

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[15] Familism is an ideological belief which prioritizes the needs of the family.

TRUSTWORTHINESS

Since the research sub-studies in this PhD dissertation where mainly guided by a constructivist paradigm and utilized qualitative research methods, I will discuss trustworthiness in-depth. Lincoln and Guba (393) (1985) conceptualized trustworthiness in qualitative research as criteria including credibility, dependability, and confirmability (307). Here, trustworthiness substitutes for quantitative concepts of validity, reliability and objectivity (393, 394). It can also be understood as the degree to which researchers' interpretation matches participants 'construction of reality' (395). In order to increase trustworthiness of data as well as authenticity, engagement, and shared power, the research team built processes into study design such as prolonged engagement, triangulation, and member-checks or respondent validation into research sub-studies. Furthermore, throughout this doctoral research I created coding schemes, memos, matrices, and utilized qualitative data analysis software (Atlas.ti and Dedoose) to help facilitate an audit trail so that steps conducted in all qualitative analyses are traceable and replicable (396). These measures contributed to data dependability and confirmability.

Critiques of trustworthiness underscore how the concept applies positivist principles to qualitative practice. Trustworthiness implies that a phenomenon can be verified with reliable research methods and practice. However, in qualitative research, standardized research methods may not always produce 'quality' research (395). For example, member-checks may be flawed because a participant may fail to recall the context in which they shared a specific feeling, experience, or fact. Also, participants may feel obliged to cooperative with a researcher's initial interpretation (395). Addressing these critiques led to the application of a CBPR approach, which aims to share power between research and participant to generate knowledge.

Sampling for sub-study 3 (BSFS) was guided by the Aim 3 which was exploratory in nature therefore small-scale study was designed and small sample was also used for the quantitative portion of the study. This makes it difficult to assess quantitative concepts of validity, reliability and objectivity (393, 394) for this sub-study. However, we do acknowledge these limitations and that results from this research is not generalizable.

PROLONGED ENGAGEMENT (SUB-STUDY 1, 2, 3)

Prolonged engagement is a technique that helps establish credibility with participants (393, 397, 398). In order to ensure rigor and trustworthiness in all three sub-studies, the research team incorporated prolonged engagement. This meant that the same research team members (e.g. PI) conducted semi-structured interviews over the course of the research project, spent extended time in the field (over 7

months), and participated in many daily life activities throughout the community and beyond the scope of the research project to build rapport, relationships, and trust with participants.

MEMBER-CHECKING PROCESSES (SUB-STUDY 1)

Member-checking is a technique used to improve credibility and confirmability of study (397, 398). In sub-study 1 (photovoice), the research team collected follow-up data through member-checks. Member-check sessions included discussions about preliminary interpretations, follow-up questions, codebook confirmation, or coding activities. Member-check sessions consisted of separate discussions using standard semi-structured interview techniques. Since interview questions were developed from preliminary data analysis activities (e.g. memos and interpretation), the purpose of the member-check sessions was to enhance understanding and fill in gaps in data. In sub-study 1 (photovoice), member-checks occurred in a group setting to foster an environment of collaborative thinking and critical reflections. The group setting also encouraged participants to discuss together their feelings, attitudes, and ideas about the PI's preliminary interpretations. In addition, the group environment provided a platform for participants to reach consensus or disagree.

INTER-CODER RELIABILITY (SUB-STUDY 1, 2)

Inter-coder reliability is a strategy that helps ensure reliability or agreement during the analysis process (399). In sub-study 1 (photovoice), participants played an active role in the analysis process. Three months after photo discussions sessions, participants came together and received a copy of the codebook. Then the PI conducted a brief lecture on qualitative research and analysis. Afterwards participants were given individual quotes and asked to apply codes. Participants were encouraged to apply as many codes as they saw fit to each section of text. The purpose of this exercise was to see how participants applied and understood codes. After the exercise, participants discussed the codebook, addressing which codes should be eliminated and whether any codes need to be added. This exercise informed final codebook formulation.

Furthermore, in the analysis process of sub-study 2 (MHM), an inter-coder reliability exercise was employed to establish consistent meaning among researchers in application of codes (399). First, the research team developed a codebook, then transcript was coded independently by researchers. After coding one transcript independently, the coders met to discuss findings and gaps in the codebook. A new codebook developed based on discussion and definitions fine-tuned followed by a second round of coding until no new themes emerged.

In order to achieve credibility, dependability, and confirmability the research team triangulated data. Multiple data sources, methods, and researchers were involved throughout the research process (398, 399). Triangulation of methods also helps elicit various understandings derived from differing perspectives and methods in which to frame validity of results. In sub-study 3 (BSFS), we used semi-structured interviews, survey, and stool diaries to triangulate data and broaden understanding of the perspectives and experiences of adolescents in the sociocultural context.

CHALLENGES AND LIMITATIONS OF THIS RESEARCH

The following section includes reflections pertaining to challenges in the field and other limitations of this doctoral research. Furthermore, it is important to acknowledge that there are also challenges and limitations that arise from partnership approaches such as CBPR that must be considered (56, 400).

ISSUES OF KNOWLEDGE GENERATION AND POWER

It is important to unpack and understand privilege from all sides. As an outsider, I did not feel like it was my place to challenge systems. However, hierarchies did determine which voices were heard and how stories were told. Leadership often dictated this and while one may assume that these hierarchical systems are intended to protect the community and not silence non-conforming opinions, it is also important to consider that hierarchies could be in place to maintain the status quo. Throughout this doctoral research, we tried to work within these hierarchical structures to co-create knowledge and not challenge it.

It is also important to reflect on positions within the team and community partners. Throughout this research process, I tried to recognize constraints of social structures and hierarchy in order to understand associated challenges and promote shared decision-making and ownership. However, it must be acknowledged that given our different identities and positions, each individual's agenda may have been misaligned and was not always clearly defined. Community partners have other jobs while the PI was solely devoted to the doctoral study. Therefore, it is difficult to authentically share ownership when commitment and investments deviate.

I also found that access to information was easier during informal interactions with participants or community members. However, since I was not able to live with a local family or conduct research activities outside of school grounds during fieldwork, opportunities to learn about the contextual setting and the community's everyday lives were sometimes limited. However, I tried to engage with the

community by visiting the school, local vendors, and other communal environments such as the temple where I participated in puja and other community activities on a daily basis. Furthermore, some students in sub-study 2 (MHM) and 3 (BSFS) declined to be audio recorded during the interview process, while others continued to exchange information after interviews concluded. I felt non-taped discussions or disclosures were useful in building trustful relationships and gaining an understanding of the sociocultural context. Here the CBPR approach can be liberating, since students felt free to ask me questions about personal experiences (e.g. my own experience when I attained menarche), thereby diminishing power imbalances and increasing equity within the partnership. However, these informal interactions, when the recorder was shut off were disclosed in confidence and not used as data. The research team maintained confidentiality for those communications even if that meant excluding valuable insights in reported data. However, conversations did inform experiences and the knowledgebase that stimulated the analysis process.

Even though the research team was strongly invested in the community, it was also important to publish results in peer-reviewed journals. However, teachers and students were more concerned with test scores on board exams. Therefore, implementing tasks that may be perceived by some as superfluous was challenging. In those instances, we struggled to create an environment that accommodated everyone's priorities, needs, and wants.

COMMUNITY ENGAGEMENT

Although stakeholder engagement is important for cultivating trusting relationships, sharing power, building capacity, co-learning processes, identifying strengths and resources, and addressing community identified needs and health challenges, there are challenges associated with the time burden required from stakeholders and community members. Therefore, the research team often tried to ease this burden through collaborative processes that were respectful of their time and other commitments. This often-had implications for planning project activities (e.g. schedules). However, establishing respect and understanding was essential to a genuine, mutually beneficial partnership. Therefore, in order for researchers to engage in CBPR research they must develop a sense of self-awareness, flexibility, humility and skills to work within a multicultural context. Expecting a 100% commitment from the community, without a willingness to be flexible, humble or respectful could have led to power imbalances and jeopardized the partnership.

Despite stakeholders demonstrated interest in the study by participating in formative research activities as participants, automatic acceptance and understanding of the utility and processes of academic research should not be taken for granted (275). Some stakeholders expressed frustration with processes such as language translation (English to Tamil), distribution of questionnaires, and consent procedures. These activities may not have been perceived as directly benefiting the community, therefore purposeless. In planning future projects, it will benefit the engagement process to explain research purposes and importance to all community members in-depth. This may improve the perception that research activities are equally as important as more tangible outcomes (e.g. intervention alone). This type of forum may also help inform stakeholders about future research activities to help plan and reduce the burden of additional workload.

In this study, although researchers initiated intervention selection (e.g. choosing to adapt Project SHINE), a CBPR approach solidified a commitment to collaborative partnerships throughout the process. This ensured involvement of community in health issue selection and intervention adaptation processes (e.g. waste management/disposal was included, and open defecation was excluded). Additionally, the use of CBPR helped improve validity and reliability of instruments used in research activities (i.e. BSFS). For example, the school principal provided input on language used in consent forms and survey and local nurses assessed various sub-study instruments (stool diaries, surveys, and interview guides). Finally, participants were actively engaged in the research process as co-researchers. Students were invited to become co-investigators in sub-study 1 (photovoice), thus improving reliability in interpretation of photovoice involved in data analysis and contributing to understanding of findings (266).

Time Constraints and Commitments

Another key fixture of CBPR is long-term engagement. Prior to undertaking a CBPR project, academic researchers must engage with communities and build long-term partnerships (400, 401) which can challenge various time and budgetary constraints that comprise a doctoral research fellowship. Although CBPR scholars have not assigned a numeric value to 'long-term', Israel et al. (400) indicates that projects can take 'decades' illustrating how the development of collaborative partnerships long exceeds the constraints of the PhD (e.g. 3 years). Therefore, for this study it was critical to build upon existing relationships formed previously by Dr. Bastien and colleagues from the University of Calgary in the community of Thirumalaikodi. Israel et al. (400) also suggests that partnerships in CBPR must extend beyond a single research project which may conflict or last beyond the purview of a doctoral fellowship.

Therefore, it is important that commitments to the community are consistently reflected upon, evaluated, and considered when engaging in a CPBR research project. Since my final field visit in July 2018, I have managed to continuously communicate and engage with members of the community demonstrating my commitment to the CBPR approach to facilitate both research project related and unrelated projects.

POWER IN WRITING/REPRESENTATION

Historically, cultures have dominated other groups through means of knowledge-based repression (261). In writing this PhD dissertation and manuscripts, I had more power and privilege given my previous training/background and push to fulfill requirements of the PhD. Meanwhile, community members had other job expectations, which made it challenging to include everyone in the writing process equitably (e.g. manuscript development). It is also important to acknowledge that there is also an unequal distribution in regard to incentive in producing an academic publication. Academic researchers must produce publications as part of their job contract, while there is little incentive for community members to devote time and resources to the process. Finally, in terms of the manuscript writing and development the research team had an advantage in terms of capacity. On campus, there are academic writing courses and trainings, access to other academic literature, in addition to an easily accessible writing center.

This represents how incentives and resources lead to unequal power dynamics in writing and representation of findings. Since academic writing is not the preferred method of knowledge sharing in all contexts, the research team sought other methods of research dissemination or knowledge translation such as the sanitation science fair and photo exhibition. In the writing process, I tried to avoid (402) the idea of participant 'ventriloquism'[16] by presenting a critical analysis of the history and context and at least one community partner's input in each publication to properly contextualize research (261).

LANGUAGE

In many ways, culture often merges with language. Wong and Poon (2010) suggest, culture 'is not a self-enclosed, uninfected entity with stable coherent meaning [but] a way of life structured by language,

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[16] Ventriloquism is when a researcher avoids using the first person in analysis, to simulate a portrayal of an 'objective' truth.

discourse and power relations' (403 p.152). Language was an unforeseen limitation throughout this doctoral research because although the schools that participated identified as English language schools, English was often students second language. Here, power differentials between researchers and participants were introduced through language and translation. Currently there is a lack of research devoted to these issues. However, it is important to be transparent and reflect upon communication and comprehension challenges which influence research.

There is a common assumption that participant communication accurately expresses their thoughts, perceptions, and experiences. However, it is critical to acknowledge that communication in a second language during data collection may affect the participants' ability to express themselves freely and accurately. Not all bilingual people are comfortable communicating and expressing themselves in a research setting. Therefore, it is also important to highlight methodological issues introduced by language in cross-cultural research. For example, the underlying power differentials in language. According to poststructuralist and post-colonialist scholars, words have been used to dominate and marginalize populations (404). It is also necessary to reflect on the potential invisibility of language challenges in this context, which may cloud the capacity of a bilingual person to clearly communicate lived experiences. Language also may have introduced bias into recruitment strategies, since only participants who are able and willing to communicate and articulate their experiences in English were selected to participate (397). Furthermore, language may have influenced analysis and interpretation of data which is why research activities which ensured trustworthiness of data such as member-checks were essential. It is also important to acknowledge that sub-studies also incorporated creative, age-appropriate, and collaborative research methods (arts-based methods, visual tools) to develop relationships, and promote communication apart from language to help mitigate challenges with language and understanding which may have been experienced by study participants.

ENGAGING YOUTH IN CBPR

Although literature often focuses on youth health issues, youth themselves are often excluded from research processes (405). CBPR is intended to be an empowering process (263) that provides a platform for a community to share input; identify strengths and resources; express concerns and needs; and build capacity in order to address health concerns (259), yet the approach still presents several challenges and limitations. In this doctoral research, we incorporated youth throughout several phases of the research process to provide an opportunity to tap into youth perspectives. Jacquez et al. (271) suggest CBPR is an effective approach for engaging youth because research generated by youth is more likely to be

accepted by youth (406). Therefore, initial youth input and engagement promoted the cultural relevance, appeal, and effectiveness for the participants (271). Given the added benefit of youth-generated contextual knowledge, the incorporation of youth into CBPR partnerships yielded more meaningful and valid results (407). Here youth participated in developing research questions, data collection, analysis, and dissemination or knowledge translation. However, CBPR methods encourage participants to initiate social change/action in their communities by connecting with policymakers and gatekeepers, this may not always be feasible, realistic, or lead to the desired/intended results. Furthermore, a singular focus on social change/action could also be discouraging for the long-term success of a project (408). In this context, hierarchical social structures that value seniority shape systems and cultural norms that influence how youth are perceived, seen, and heard. Therefore, these social structures may also prevent students from having access to power within society. Thus, provoking the question: to what extent can youth participants share their "voice"? Therefore, goals and expectations for research activities must also carefully acknowledge these challenges and limitations within the context.

Another limitation is that all of CBPR's fundamental principles were not always able thoroughly integrated into every single research activity. Instead, CBPR principles were incorporated where the research team deemed relevant. In a methodological review of mixed-methods CBPR research (409), authors discuss how CBPR principles may not always be consistent with all data collection activities. In the doctoral research, CBPR principles influenced each sub-study, however it is important to note that not all principles of CBPR could be incorporated with all data collection activities. In particular this applies to three principles, namely; Principle 1: CBPR recognizes community as a unit of identity; Principle 8: Disseminate findings and knowledge gained to all partners and involving all partners in the dissemination process; and Principle 9: Establish a long-term commitment to the process). For example, data collection activities were not necessarily relevant to forming a CBPR partnership, however these partnerships were essential to identifying relevant stakeholders, building trust, and assessing various power dynamics at play. Furthermore, in sub-study 2 (MHM) and 3 (BSFS) a participatory data analysis process which engaged partners was not explicitly employed due to time constraints of fieldwork. Therefore, it is important to clarify that although CBPR principles informed phases of research, they were not explicitly integrated into all data collection activities.

A final limitation includes key elements of the overall purpose of this doctoral research: to develop an in-depth understanding of the contextual setting of the rural community of Thirumalaikodi to initiate the cultural adaptation of Project SHINE. Some argue that an intervention adaptation cannot retain the original program's claim of evidence base (284, 285, 410). However, this is difficult to determine because core elements of an intervention are often not evaluated separately (411). Therefore, it is important to also include a tailored evaluation for the adapted intervention. In this case we have explored the acceptability of data collection tools with community input to improve validity of selected measures. Key findings provided important considerations for future intervention adaptation. Findings also informed curriculum adjustments (deep surface) presented in Figure 8 which is intended to guide future practitioners in the adaptation process. However, it is also important to acknowledge and consider study limitations. A cultural adaptation is not necessarily generalizable to other populations. Despite these limitations, findings still make an important contribution to future intervention development and research on cultural adaptation.

CHAPTER 6: CONLUSION

In the following chapter implications for future research are summarized and recommendations are made for future program implementation and research such as the SHINE India cultural adaptation (based on the application of adaptation frameworks discussed in Chapter 2).

IMPLICATIONS FOR FURTHER RESEARCH AND RECOMMENDATIONS

Although there is a wealth of adaptation literature in health promotion, little is published on the systematic process of culturally adapting WASH health promotion interventions which target adolescents. Therefore, this PhD dissertation contributes to the growing field of adaptation literature in health promotion and the ongoing research and cultural adaptation of Project SHINE which is explained in further detail in this section. Moreover, based on the key findings described in Chapter 5, I have identified a few areas that require future research or action.

Systematic application of formative research with a CBPR approach assisted in the cultural adaptation of SHINE to the Indian context. As discussed previously, formative research included 3 sub-studies which were described throughout this PhD dissertation and provided insight into experiences and perspectives of the target population. Furthermore, formative sub-studies helped identify key elements for intervention adaptation and encouraged the research team to collect data using different methods and

sources, uncover community-identified challenges and needs, and shed insights on the proposed intervention study (SHINE India). Furthermore, frequent stakeholder engagement enabled feedback loops and continued intervention development and tailoring.

It is anticipated that the formative research presented in this PhD dissertation, may also contribute to the development of future WASH interventions. Formative research can be used to culturally adapt an existing health promotion intervention to another setting. Each of the specific aims addressed were informed by the overall aim of this study and provided further contextual insights, exemplifying formative research processes in cultural adaptation, in addition to informing future intervention and research activities. Furthermore, in contrast with other top-down approaches or strategies which are based on eliciting embarrassment, disgust, and shame, this PhD dissertation demonstrates how participant perspectives and experiences highlight the uniqueness of a context, thereby affirming how one-size-fits-all approaches are limited or insufficient. To summarize, this PhD dissertation builds upon existing research, approaches, and principles within CBPR and health promotion, further contributing to the literature on cultural adaptation processes of WASH health promotion interventions.

A vital next step in this research process is to document Phase 2 (program implementation, and process and outcome evaluations) which entails piloting the adapted intervention and assessing the process (e.g. program reach, dose, and fidelity) and impact of the intervention in the selected setting of Thirumalaikodi, India. Other future research that builds upon this initial formative work may also include a thorough evaluation of the adapted intervention's core components, a full-scale validation study of the BSFS, or an in-depth exploration into if and how the deployment of cultural adaptation processes and CBPR approaches enhanced intervention effectiveness and sustainability.

Findings from sub-study 1 (photovoice) revealed that several social determinants play an influential role in sanitation and hygiene-related behaviors that determine the sanitary conditions of private and public spaces. This relationship is further mediated by norms, attitudes, or cultural/religious beliefs. In follow-up meetings, adolescent participants indicated further interest in using learnings from photovoice to teach others in the community about WASH. They discussed using culturally and contextually accepted approaches such as theater and social media (e.g. WhatsApp and Facebook) to transfer knowledge/health promoting messages. Therefore, in March 2019 student participants wrote and acted in a drama about WASH challenges identified for their peers and teachers at school. Participants also discussed another future initiative which would focus on social marketing strategies such as the application of social media for disseminating health promoting messages. Future research may involve

assessing the impact and potential reach of such youth-driven strategies or further evaluation of participant's experience and engagement in the action component of this project.

Findings from sub-study 2 (MHM) revealed that information about MHM was often disseminated to girls by their grandmothers and mothers. These findings set the foundation for future research which explores perceptions and descriptions of grandmothers' and mothers' knowledge of MHM, how they obtained their knowledge. Therefore, seeking an in-depth understanding of various generational attitudes and beliefs throughout all layers of this sociocultural context. Furthermore, it would be interesting to explore what and how men and boys are taught about menstruation in order to develop a more inclusive school curriculum that recognizes the importance of gender and sanitation. As well as providing an additional entry point for addressing the stigma and taboo that surround menstruation.

Findings from sub-study 3 (BSFS) demonstrated that the BSFS was an acceptable tool to assist in self-report of diarrheal illness among adolescents in this context. Next steps could include translation of the BSFS to the local language of Tamil. Further research may also include a validation study of the instrument with a larger sample size. Finally, other future research could pertain to the overall SHINE India pilot study by assessing the acceptability and satisfaction of all adapted intervention components and an investigation of the health and social outcomes (e.g. diarrhea and school absences).

SHINE India Cultural Adaptation

This PhD dissertation contributes to the knowledgebase of how CBPR can be used to culturally adapt sanitation and hygiene interventions in school settings. In addition, this research demonstrates how leveraging community input can inform research and implementation strategies (data collection tools, processes). As documented throughout this dissertation, sub-studies (1, 2, 3) helped identify potential areas to facilitate a cultural adaptation of Project SHINE to the Indian context. Based on existing adaptation literature and study aims, we determined that a combination of adaptation frameworks was best suited for a comprehensive cultural adaptation using a CBPR approach. Therefore, the research team incorporated elements of the MAP of Adaptation Process (59, 412) and the Cultural Sensitivity Framework (280), and a CBPR approach to achieve these aims. See Figure 8 for a visual representation of the adaptation process used.
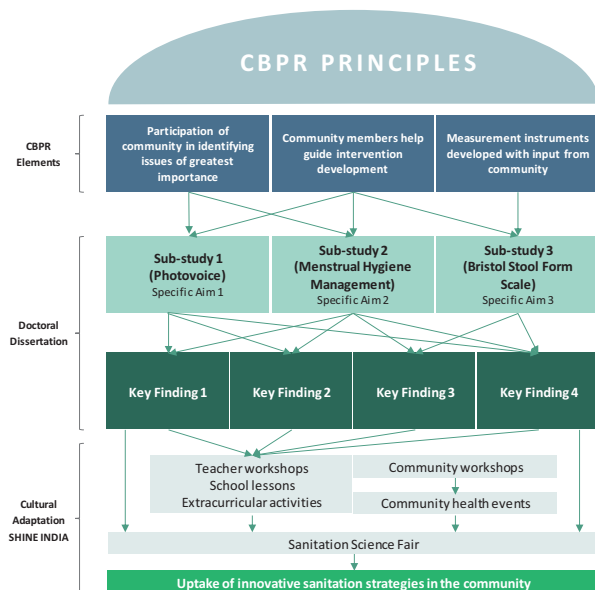
Formative work which was informed by a CBPR approach also illustrated how research which is grounded in lived experiences and perceptions of the target community (e.g. adolescent students) can enhance adaptation and translation processes (257, 413). Stakeholder interviews and student's photo discussion sessions (sub-study 1) often included discussions of littering behaviors which revealed the cultural importance of the physical environment, environmental sanitation, and waste management. This can help inform the translation of specific lessons in the original SHINE curriculum to have a more explicit focus on physical environment and environmental sanitation (SHINE India intervention manual). Moreover, throughout India, many people do not use toilets and defecate in the open because toilets are considered dirty and perceived as defiling to clean (45). Feedback from stakeholders and teachers indicated that key content from the original SHINE intervention was not suitable for the local contextual setting regarding open defecation. Additionally, student participants failed to discuss open defecation (although it was not specifically probed) therefore this omission demonstrated that open defecation was not a prioritized health concern of the community, taboo, or perhaps culturally unacceptable to discuss at school. However, students discussed other WASH challenges (e.g. littering, domestic hygiene, and water availability) and suggested they could help with cleaning and other household chores therefore transforming social norms (sub-study 1). This could influence the inclusion of a lesson that includes proper hygienic cleaning practices such as cleaning toilets and reusing waste. Moreover, findings from

the stakeholder interviews and sub-study 2 (MHM) revealed that information concerning MHM is not effectively shared among young girls which leads to taboos inciting shame, and fear of menstruating bodies. Therefore, activities regarding MHM could be added to address this issue.

The formative research phase also explored perceptions of diarrhea, with self-reported diarrhea being a main outcome of the SHINE India study. These findings are consistent with other research that suggests adolescences perception of health is different from adults and use of picture-based tools may be useful in increasing validity of self-report among this age group. Notably 100% of students expressed that the BSFS was easily understood, however some still felt uneasy about sharing health information, regardless of format.

Adaptations of health interventions often include program modifications that may entail omissions or additions, modifications in intensity/dose, in addition to tailoring to cultural context (410). Based on sub-study key findings and stakeholder input, I have identified areas to adjust content, methods, and timing. Table 14 depicts how key findings from the presented research could inform changes in the SHINE India curriculum most notably 1) de-emphasis on open defecation, 2) inclusion of elements to culturally and religiously ground the curriculum, 3) inclusion of MHM curriculum and supporting materials. Table 14 systematically categorizes revisions that can be made to intervention strategies in the future (no change, surface change, deep change, removed, added) according to Resnicow et al. (280) and demonstrates how elements of formative research could inform adaptations to the SHINE India curriculum.

TABLE 14. EXAMPLES OF POTENTIAL INTERVENTION ADAPTATIONS FOR SHINE INDIA

Element	Description of Original Element	Description of Adaptation	Change Type	Key Finding	Data source
SHINE Manual	NA	Add cultural and spiritual visuals/text in between chapters that are distinctly relevant to the context.	Deep Change (Added)	1, 2	Photovoice, Stakeholder interviews, Interviews
Activity 3: Toilet Cleaning and Maintenance	NA	Activity focused on the importance of cleaning and maintaining toilets/sanitation facilities at school and at home. *adapted from IRC International Water and Sanitation Centre (414)	Deep Change (Added)	1, 2, 3	Regional Literature, Photovoice, Interviews, Stakeholder interviews
Activity 4: Menstrual Hygiene Management	NA	Activity to raise awareness among students about menstruation and the importance of menstrual hygiene management. *adapted from SODIS (415)	Deep Change (Added)	2, 3, 4	Stakeholder interviews, Interviews, Regional Literature
Activity 5: Glo Germ	Handwashing activity which shows germs.	Change order in curriculum Addition of facts and myths	Surface Change	2, 3	Photovoice,

					Regional Literature
Handwashing Experiment					
Activity 6: Sanitation Spectrum	Sanitation Spectrum activity helps people to understand different sanitation situations that may exist in their community and how to improve conditions.	Remove because of explicit focus on open defecation.	Deep Change (Removed)	3	Photovoice, Interviews, Stakeholder interviews
Activity 10: Transmission Routes	This is a lesson plan to educate students about fecal-oral transmission.	Change order in curriculum. Change illustrations to match south Asian context. Add information about water quality. Addition of facts and myths.	Surface Change	4	Photovoice, Stakeholder interviews, Interviews, Regional Literature
Activity 12: Rotten Eggs	Activity to understand why some eggs sink and some float, using physics/math to understand density.	Eggs not commonly eaten in local households (vegetarian), Addition of facts and myths.	Deep Change (Removed)	2	Photovoice, Stakeholder interviews, Interviews, Survey
Sanitation Science Fair	Science fair to showcase projects related to water, sanitation and hygiene in relation to human and animal health.		No Change	1, 4	Photovoice, Stakeholder interviews, Interviews, Regional Literature

It is also recommended that further adaptation should include additional adjustments in local examples and translated to local language of Tamil.

CONCLUDING REMARKS

This doctoral dissertation contributes to a growing body of research on how formative research can be utilized to culturally adapt an existing intervention to a new setting; non-stigmatizing participatory WASH health promotion strategies; culturally relevant data collection tools for self-reported diarrhea among schoolchildren in low-resource settings; and the knowledge-base and future development of CBPR health promotion interventions of this nature.

The following summarizes key findings from sub-studies, which exemplified cultural adaptation processes and provide an in-depth understanding of the research context thus laying the foundation for adaptation.

Norms distal influence on health outcomes: Participants discussed how descriptive norms influence attitude-behavior relationships which affect environmental sanitation and health. Furthermore, gender norms were explicitly taught to girls as newly menstruating women (often by grandmothers or mother) which restricted their behavior, social relationships, and personal conduct.

Cultural and religious attitudes, beliefs, and practices linked to sanitation and hygiene: Various cultural and religious factors motivated and maintained specific sanitation and hygiene-related behaviors (e.g. sweeping and domestic hygiene). Also, according to participants, emphasizing ties of cleanliness and religion could be an effective way of transferring domestic hygiene behaviors to public space.

Experiences of menarche and menstruation were also often influenced by cultural beliefs that encouraged cultural and spiritual rituals and practices to alleviate physical symptoms associated with menstruation and ensure purification, hygiene, and cleanliness.

Stigma and Taboos: Menstruation and diarrhea are linked to various forms of stigma and taboos in this sociocultural context. Participants were embarrassed to talk about diarrheal illness with others because they perceive diarrhea as disgusting, foul smelling, unclean, or bad (e.g. physical stigma). Furthermore, despite open defecation being the focus of WASH literature and research in India, the topic was rarely brought up by participants and acknowledged as an issue for other communities suggesting that open defecation is taboo in this context.

Parents play an important role in health communication for participants: Local knowledge passed down through intergenerational knowledge transfer and played an influential role in conveying health behaviors to adolescents regarding MHM and sanitation and hygiene-related behaviors. Moreover, participants revealed the importance of communication with parents when initiating diarrheal control strategies or coping behaviors, because parents often played the role of caretaker and were well positioned to treat diarrheal illness based on knowledge and previous experience.

In conclusion, this doctoral research contributes to a growing knowledgebase of health promotion intervention adaptation research, through the detailed and descriptive account of a cultural adaptation of the school-based WASH intervention: SHINE India. Furthermore, this doctoral research explores the sanitation and hygiene-related experiences and behaviors among adolescents, an understudied population in WASH research. Finally, it sheds light on WASH-related norms, stigma, local knowledge sharing practices to culturally adapt an intervention to improve health and social outcomes among intervention participants in the future and further demonstrating how CBPR can help adapt intervention components to focus on community-identified behavioral and environmental determinants, capacity, preferences, and needs of the target population/future intervention beneficiaries.

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FROM ARTS TO ACTION: PROJECT SHINE AS A CASE STUDY OF ENGAGING YOUTH IN EFFORTS TO DEVELOP SUSTAINABLE WATER, SANITATION, AND HYGIENE STRATEGIES IN RURAL TANZANIA AND INDIA

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Keywords: water, sanitation, and hygiene; participatory; arts-based; intervention; youth

Abstract

Arts-based methods are used increasingly in health promotion efforts—and particularly within community-based participatory research (CBPR) approaches—in order to meaningfully engage, uncover, and amplify local voices to elicit social change. However, there are still important knowledge gaps to be addressed. In this chapter, we critically reflect on our experience in implementing a CBPR intervention called Project SHINE (Sanitation and Hygiene INnovation in Education). Project SHINE addresses water, sanitation, and hygiene challenges among youth and communities in rural Tanzania and India. In Tanzania, we describe our use of several arts-based methods to engage participants in dialogue. These methods include a sanitation mural, a time capsule incorporating reflective pieces and drawing, digital stories, and a sanitation science fair that included youth-driven knowledge translation strategies to reach the wider community in health promotion efforts. Project SHINE was subsequently adapted and implemented in rural India. During the adaptation process, a photovoice sub-study was implemented in order to increase knowledge and understanding of youth perspectives and engage them in a process of critical reflection and action to create social change in the community. Drawing upon our experiences from the field, we examine the opportunities and challenges associated with arts-based methods to catalyze action in health promotion research and practice. We conclude by highlighting important considerations for design and implementation of future studies using these approaches in other settings.

2.1 ARTS-BASED ENGAGEMENT IN RESEARCH: PROJECT SHINE

Through creative and collaborative processes, arts-based methods have been used to varying degrees within health promotion research and evidence-based public health interventions (Delgado, 2015; Israel et al., 2005; Leavy, 2015). Art is fundamentally communicative and expressive (Barone & Eisner, 2012), thus capable of inciting collaboration, perspective, emotion, dialogue, and/or action. Studies have demonstrated that arts-based methods, when applied to research approaches, can be used to develop community partnerships, manage sensitive issues, involve community members in the interpretation of data, and as a dissemination tool to communicate knowledge and empower participants to catalyze change in their communities (Delgado, 2015; Lambert & Hessler, 2018; Lohan et al., 2015; McEwan et al., 2013; Vindrola-Padros et al., 2016). Additionally, arts-based methods hold the potential to promote communication beyond language and encourage close collaboration between academic researchers and community participants throughout the research process.

There are several different art forms often used in arts-based research, including the performing arts such as music, spoken word, and drama; visual arts such as painting, drawing, design, and crafts; community and cultural affairs such as festivals, fairs, and events; literature, poetry, and

creative writing; and online, digital, or electronic arts (Cahnmann-Taylor & Siegesmund, 2018; Delgado, 2015; Lambert & Hessler, 2018). These arts-based methods can be applied to research approaches in various ways (Coemans & Hannes, 2017; Qingchun Wang et al., 2017), thus reflections on the application and effects of arts-based methods are key in continuing to develop this field of research. The arts-based methods discussed in this chapter were used as tools of inquiry, awareness raising, adaptation, and knowledge translation. Knowledge translation is a process of contextualization and application (Campbell, 2012; Graham et al., 2006), which according to the Canadian Institutes of Health Research promotes the "synthesis, dissemination, exchange, and ethically-sound application of knowledge" to improve health outcomes (Straus et al., 2009). Throughout this chapter, we will reflect on several distinct features of arts-based methods as (1) a tool for awareness raising, knowledge translation, and action and (2) a process of promoting meaningful and equitable partnerships in community-based participatory research (CBPR) within the frame of Project SHINE (Sanitation and Hygiene INnovation in Education) in India and Tanzania.

Implemented in two countries, Project SHINE is a school-based intervention that aims to improve water, sanitation, and hygiene (WASH)-related knowledge, attitudes, and behaviors among students, teachers, and local communities. In addition to supporting participatory approaches in the classroom, SHINE encourages youth to become health promoters and change-makers within their communities through the development of life and leadership skills. Unlike other WASH interventions that may employ techniques that promote "shame" or "social stigma" as a means for behavior change (Bartram et al., 2012; Kar & Chambers, 2008; Pattanayak et al., 2009), Project SHINE uses an assets-based approach that incorporates CBPR and various arts-based methods throughout all phases of the research as a tool for awareness raising, knowledge translation, and action to promote meaningful engagement for participants and community members.

Throughout the intervention in Tanzania, art was used as a means to facilitate dialogue and promote knowledge-sharing and meaningful participant engagement. Arts-based health promotion activities such as open defecation mapping, a sanitation mural, a sanitation time capsule, digital stories, songs, and a sanitation science fair were incorporated throughout the intervention. These activities were used in formative research, implementation, and knowledge translation phases of the intervention and promoted participant inquiry and reflection, youth mobilization, and leadership focused on water, sanitation, and hygiene in the community.

During our adaptation to the southern Indian cultural context, the medium of photography was incorporated into the formative research phase through the CBPR process of photovoice. Here, we sought to develop a supportive research environment in which participants were positioned as experts and photography was used to stimulate knowledge production, participation, and co-learning (Caroline Wang & Burris, 1997). This arts-based method enabled student participants to identify and represent (Caroline Wang et al., 1998) their communities and lived experiences in

order to help us understand WASH-related contextual factors and facilitate the interpretation, adaptation, and translation of Project SHINE to the local cultural context.

2.2   SHINE TANZANIA: AN APPLICATION OF THE ARTS TO CREATE A BROAD PLATFORM FOR YOUTH EXPRESSION AND ENGAGEMENT

SHINE Tanzania was developed and implemented in 2014 (see Fig 2.1) as a pilot study to engage students in two secondary schools and the wider community in the development and evaluation of strategies to improve water, sanitation, and hygiene. The focus of the intervention was grounded in community concerns regarding the impact of parasitic infection on child health and from local hospital records, which indicated that fecal-oral transmitted diseases including helminth infections and protozoa are prevalent in the region. SHINE Tanzania was first implemented in a Maasai pastoralist community in the Ngorongoro Conservation Area (NCA) in rural and remote Tanzania. It was a collaboration between academic researchers and students from the University of Calgary, Canada and the Catholic University of Health and Allied Sciences, Tanzania, as well as through a long-term partnership with communities of Maasai pastoralists in the Ngorongoro Conservation Area (NCA) of Tanzania. The transdisciplinary research team included members with expertise in diverse fields—ranging from education, psychology, and anthropology to global health, veterinary medicine, and bioengineering—who work within a One Health paradigm (Zinsstag et al., 2011), which focuses on the interrelationships between humans, animals, and the environment.[1]
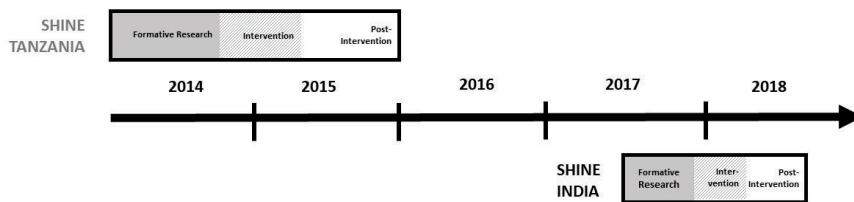
Fig 2.1 Project SHINE Timelines[2]

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[1] The initial grant to develop Project SHINE was provided by Grand Challenges Canada through the Stars in Global Health competition. The focus in Project SHINE emerged based on concerns expressed by the local communities in the NCA regarding the effect of parasitic infection on child health and hospital records, which indicated that helminth infections (parasitic worms) and protozoa contribute to a substantial burden of disease in the community. The community engagement process in the intervention development is described in detail in the conceptual paper for the study (Bastien et al., 2016).

[2] Dr. Sheri Bastien was the principal investigator (PI) on the initial Project SHINE in Tanzania and the main supervisor on Project SHINE in India.

The study design has been described in full elsewhere (Bastien et al., 2016), as has the process and outcome evaluation of the intervention (Hetherington et al., 2017). In the intervention, a sequenced suite of participatory arts-based methods were used, including: open defecation mapping (2.2.1), a sanitation mural (2.2.3.1), a time capsule (2.2.3.2), songs, the capstone event of the sanitation science fair (2.2.2), and subsequent digital stories (2.2.3.3) to engage youth in reflecting on their experience with SHINE.

2.2.1   Open Defecation Mapping

During the formative research phase, which involved qualitative research both in schools and in the wider community (see for instance Henderson et al., 2016), we wanted to engage youth in an icebreaker activity that would raise the potentially sensitive issue of open defecation in a non-threatening way. We refrained from asking about individual practices and instead asked about how the community and physical environment were structured and what common WASH practices were. This approach simultaneously contributed to our understanding of the broader community context and of WASH behaviors. Using poster paper and markers, we invited the students to draw a map of their village, indicating *bomas* (houses) where people and animals sleep, water sources, and places where animals and people commonly defecate. We then asked them a series of questions, such as what different water bodies are used for (washing clothes, drinking water for humans and livestock), what happens when it rains, if flies are common in the area, how they understand contamination, and what they perceive to be "safe" water. This led to a reflective discussion on health and how participants understand the causes of diarrheal disease. This exercise also provoked laughter among the students, who were at first tentative to draw on the paper but once they understood the purpose became animated and engaged.

2.2.2   Sanitation Science Fair – Culturally Relevant Knowledge Translation Strategies

The development and evaluation of the sanitation science fair has been described in detail elsewhere (Bastien et al., 2017); however, in brief, it was designed to engage and empower youth and communities in the development and evaluation of locally relevant and sustainable health promotion strategies to improve sanitation and hygiene. Student teams were separated into three broad categories (e.g., water, sanitation, and hygiene) and with the guidance of biology teachers and the research team developed sanitation science fair projects, which were showcased at a One Health sanitation science fair in November 2014. Approximately 400 Form 3 students participated from two secondary schools. Then, an evaluation team consisting of a broad cross-section of community members was tasked with identifying promising projects that were particularly relevant given the community context and which held potential for social entrepreneurship[3]. The wider community was invited to attend the science fair, and there were

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[3] A tangible outcome of the project is that a community-based soap social enterprise has been formed through this process. More information about the group and their soap is available here: **https://www.project-shine.net/**.

between 500 and 1000 in attendance at the two schools, which included representatives of the Pastoralist Council (local government), local education authorities, traditional leaders, and out-of-school youth.

Each project included a knowledge translation component, which focused on the public health implications of the science fair project findings for the wider community. Through discussions with our local community partners regarding what would be culturally relevant techniques to transmit knowledge in the local Maasai context, students used approaches such as songs, which were an engaging means to involve students actively and reflexively in applying and translating what they had learned throughout the SHINE intervention to the wider community. One such example is a team of students that developed an experiment to test how many folds in a cloth were needed in order to filter water. Based on their findings, they developed a song to teach to women that could be sung while collecting water.

2.2.3   SHINE Arts-Based School and Community Event

As part of the knowledge translation activities post-intervention, a one-day event was organized at the school to engage youth and community members in a series of arts-based approaches to elicit perspectives on what participating in Project SHINE meant to them. The day was organized around a series of facilitated stations whereby youth, teachers, and community stakeholders— including the evaluation team from the sanitation science fair—circulated to each station to participate in an activity and contribute to broadening our understanding of the impact of the study from their perspective. The stations included: (1) posters with visuals developed by the Bachelor of Health Sciences students from the University of Calgary to depict the main findings of the study and to gather perspectives to help interpret the findings; (2) a sanitation mural whereby participants were invited to paint what their experience with SHINE meant to them; (3) a Foldscope[4] station that provided another opportunity to prepare and look at locally collected samples of water, soil, and plants collected from the schoolyard; and (4) a digital storytelling station. The highlights from the selected facilitated stations are elaborated on below.

2.2.3.1   Sanitation Mural

The sanitation mural was used as a visual method through the project to elicit student perspectives on what participating in Project SHINE meant to them. We provided a white sheet and a selection of paints and brushes on a table and asked participants to illustrate by any means what their SHINE experience meant to them (Fig 2.2 and 2.3). The canvas was ceremoniously initiated by a traditional leader and member of the SHINE evaluation team giving a speech and

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[4] Foldscope is an origami-based microscope that costs less than a dollar to produce and was used in the project as an example of frugal innovation to unlock the creativity and curiosity of students in relation to the development of low-cost water, sanitation, and hygiene strategies. Students made a song about Foldscope that can be accessed here: https://vimeo.com/137421188. The main Foldscope website: (**www.foldscope.com**)

painting the first stroke. Students and the wider community used words, phrases, and pictures to highlight the essence of the project, and it was later showcased in the school and formed part of the time capsule.

Fig 2.2 Students and teachers collaborating on the development of a sanitation mural

In discussion with students and teachers, it became clear that painting was not an activity they had engaged in previously, but which they enjoyed tremendously.

2.2.3.2 Time Capsule

A time capsule is a historic cache of information or items that can be used both as a memory that participants can look back and reflect on at a later date and as a method of communicating with people in the future, to share perspectives, hopes, and dreams from an earlier time period. Within Project SHINE, this assignment was given in a Civics class and framed as a means to get students to think about what they envision in the future for their community and the changes they might like to see in the next five years. The assignments consisted of a worksheet with a series of questions, including what their vision for a healthy Maasai community consisted of and what they perceived their role in achieving this to be. Prompts to guide the reflection included: access to clean water and toilets/ latrines; food; access to a doctor/hospital/healer; and physical, social, and spiritual health. The worksheet also included a section where they could use the arts and draw their vision. The sheets were completed by SHINE participants and, together with the sanitation mural and science fair posters, were put into a container that was buried under the ground at the school. After five years have passed, the intention is that the Project SHINE time capsule will be opened, and the students and community will be able to discuss and reflect on the changes that have taken place.

2.2.3.3 Digital Stories

Storytelling is deeply engrained in Maasai culture, and in order to tap into this mode of expression to capture and convey what it meant to participants to be involved in the project, digital stories were created in partnership between the research team and participants. Digital storytelling permits participants to build narratives about their experiences through different mediums such as video, audio, imagery, music, or text (Lambert & Hessler, 2018). It was explained to participants that we wanted to use a technique that was culturally relevant to the Maasai to share the SHINE story to the wider world, and that using visual means and digital stories might be a useful tool for reflecting and sharing participant experiences.

The photos that were taken of the sanitation science fair by students with disposable cameras were printed and shared with students. In addition, photos taken by the research team were included among the options students could select from for the digital stories, so that there was a wide range of photographs to choose from to represent participant memories and experiences. Storyboarding sessions were facilitated by members of the University of Calgary team with guiding questions to help students organize the sequence of photos and develop captions for the digital stories.

Fig 2.3 Sanitation mural from SHINE Tanzania

When this activity was completed, those who wished their experiences and reflections to be captured on film were taken to an adjacent room for filming. Upon their return to Canada, the University of Calgary students, with the assistance of a filmmaker, finalized the digital stories and stored and shared them on USB devices to all participants and to the school as a token of appreciation for their participation in the study and to serve as a memory of the project[5]. Although not all or even most students are likely to have a computer on which they can view the

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[5] The digital stories are available online here: https://vimeopro.com/user2374415/project-shine

photos, they do have access to computers on the school premises, and the digital stories can be shared with parents at school meetings.

2.3   FORMATIVE RESEARCH: APPLICATION OF PHOTOVOICE IN THE ADAPTATION OF PROJECT SHINE TO AN INDIAN COMMUNITY

Throughout India, poor sanitation and hygiene is a widespread public health challenge. Indians account for one-third of the 2.3 billion people worldwide who do not have access to improved sanitation in their home (World Health Organization & UNICEF, 2014), and this is a leading contributor to the diarrheal disease burden of children under five (Boschi-Pinto et al., 2008). Given India's vulnerability to diarrheal disease and other sanitation-related challenges, solutions that incorporate the country's social, cultural, and environmental context are in great demand. Project SHINE was a relevant health promotion intervention that contributed to the country's existing efforts to improve WASH-related health outcomes for communities. However, given India's rich cultural heritage and distinct historical legacy, a rigorous adaptation and translation process from the Tanzanian context was needed.

SHINE India evolved from mutual interests in water, sanitation, and hygiene conveyed by leadership from the locally based Sri Narayani Hospital and Research Centre in Sripuram, Thirumalaikodi, and Dr. Bastien facilitated the partnership. Once a partnership was formally established, an academic research team was formed including PhD and master students from Norwegian academic institutions (Norwegian University of Life Sciences and University of Bergen), local schools, community stakeholders, and spiritual leadership. Implemented from June 2017-July 2018 in the rural community of Sripuram, Thirumalaikodi within the Vellore District of Tamil Nadu (see Fig 2.1 for timeline), in SHINE India, arts-based research methods were incorporated into the study design as a critical component of the formative research phase and adaptation framework. The study protocol was approved by the Norwegian Centre for Data Research (reference number: 53162) in Norway and the Institutional Ethics Committee/Institutional Review Board at the Sri Narayani Hospital and Research Centre (reference number: 30/25/02/17) in India. As an initial step, a month-long photovoice sub-study was conducted at a local school, which aimed to engage adolescent students in a group process of critical reflection and dialogue to assist in the adaptation and translation of the intervention to the local cultural context. Rooted in the tradition of documentary photography, photovoice provided adolescent students with cameras so that they could accurately capture and share their community's assets, challenges, and needs in relation to issues concerning water, sanitation, and hygiene (Caroline Wang & Burris, 1997). These photographs, accompanied by critical discussion and reflection, helped inform changes to the SHINE India adaptation that was subsequently implemented in their school.

Artistic expression when applied to CBPR approaches can trigger discussions that facilitate the co-creation of knowledge between researcher and participant. Although there are several

approaches that can develop a researcher's understanding of the cultural context, we felt that using an arts-based method not only could help co-create knowledge, but could also encourage and promote genuine partnerships, participation, and engagement through discussion and intimate sharing. In order to embark on this process, we needed to understand students' everyday lives. Figure 2.4 demonstrates how photovoice was utilized in the formative research and adaptation processes to help increase the cultural relevance, appropriateness, and appeal to student participants (Viswanathan et al., 2004).
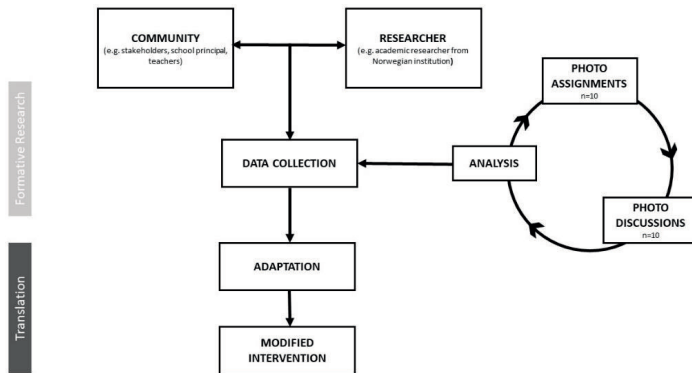
Fig 2.4 Adaptation Framework for Project SHINE India Using Arts-Based Method: Photovoice (Adapted from Mckleroy et al., 2006)

2.3.1 *Photovoice: An Effective and Engaging Tool for Adapting the SHINE Intervention*

In the photovoice sub-study, a purposive sampling strategy was used to recruit participants. Here, the school principal and teachers recruited 10 students (three boys and seven girls) aged 13-15 through classroom announcements and the distribution of project brochures. The research team, school principal, and a local project coordinator worked closely with participants throughout the sub-study. The project coordinator was a local schoolteacher and attended school with the students daily. She was also available to discuss any issues about the project if students were uncomfortable or unsure how to communicate with the principal investigator[6]. The project coordinator was not present in photo discussion sessions (PDS) so that students would not associate the photo discussions with a school assignment and would be able to communicate

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[6] PhD candidate Anise Gold-Watts was the PI in SHINE India.

freely. Additionally, the project coordinator had regular meetings with the school principal to provide updates on the photovoice sub-study progress and student feedback.

Participants attended one information meeting, seven PDS, and one wrap-up meeting over a three-week period. They were formally introduced to the photovoice sub-study in the initial information meeting, which the local project coordinator co-facilitated with the principal investigator. The main purposes of this information meeting were (1) for participants to become acquainted to the photovoice process and method, and (2) to build rapport between the participants and the principal investigator prior to in-depth PDS. Participants were also taught about photography ethics (see Fig 2.5), how data and identities would be protected throughout research activities, and how to obtain informed written consent when taking photographs of people. They also had the opportunity to ask questions in English or their native language, Tamil.

Fig 2.5 Photography ethics: Implications and procedures

Susan Sontag discusses ethical implications embedded within the artistic medium of photography when she describes the camera as "a tool of power" (Sontag, 2001); therefore, the first photovoice training included a discussion on photography and ethics. The technical processes involved when taking photos can offer a "permanent record" (Price, 1994) or an "authentic" visual representation of the photographer's reality (Ball & Smith, 1992; Collier & Collier, 1986). However, when viewing a photograph, an individual may interpret or react to a photograph differently than the photographer intended (Killion, 2001). Consequently, it is important that both researchers and participants discuss and reflect upon the power of taking pictures before they mutually decide to engage in a photovoice project. Since visual content can be easily objectified when revealed without context (Cooper & Yarbrough, 2010; Frosh, 2001), SHINE India participants were encouraged to take photos and narrate experiences from their own everyday lives (Cooper & Yarbrough, 2010). Also, in this project, we discussed the importance of "storytelling" or providing context when sharing photographs. Guided by a handout and a short exercise in which students went through an example, the photovoice facilitator (PI) modeled how contextual descriptions can complement a photograph (such as descriptions of what the picture conveys and why the photographer chose to take this photo) to prevent misunderstandings and/or other misconceptions (Frosh, 2001; Sontag, 2001). Additionally, participants were carefully instructed that informed written consent must be obtained anytime they took a photograph of a person's face or any other identifiable feature because visible identifiers can easily connect individuals to an image, which has several other ethical implications in research. These consent processes were established to protect both the individuals in photographs and the photographers themselves (student participants) from harm, thus preventing issues such as unwanted attention, involuntary participation, marginalization, embarrassment, or shame.

In this information meeting, participants were trained on how to use digital cameras. The group talked about their prior understanding of photography. Discussing the group's prior knowledge

about the medium was an important step before distributing cameras, and it helped the facilitator structure the rest of the meeting based on the students' experience levels. A major concern from students was: is sanitation photogenic? The group had little to no experience using a camera, so we showed the group examples related to different research questions to help them conceptualize future assignments. During an explanation on the photovoice method, students browsed *Visual Voices: 100 Photographs of Village China by the Women of Yunnan Province* (Wu, 1996) to see examples of photos from another photovoice project in China. After flipping through the book and seeing the different ways that these women photographed their community, students felt reassured and excited for the first photo assignment. It is important to consider that many students will reference advertisements or portraiture as the type of photographs that are customary in their environment. Here, it was crucial to bring examples of other ways to take photographs that illustrate reality or everyday life (e.g., newspaper clippings, postcards, books) so that students could see examples of different types of photography. We also discussed how to take photographs and photo aesthetics such as lighting, focus, and composition.

Once participants indicated that they understood the process, the first PDS were scheduled, and participants separated into single-sex groups to ensure that they were comfortable when talking about sensitive topics in front of their peers. After each photo assignment, each group would come together to share their photographs. All PDS followed the same procedure in both male and female groups; however, since the groups were conducted separately, the photo assignments generated differed. It is also important to note that participants were included and involved in the research question development processes, helping to ensure that the study genuinely addressed community-identified needs and interests.

Prior to each PDS, participants would select one or two photographs that they had taken for that day's photo assignment that they would like to share with the group. When the session started, each participant would share their selected photographs with the group. After all participants had shared their photographs, the entire group would vote on one photograph to discuss in depth.

Table 2.1 SHOWED Method

(Hergenrather et al., 2009)

What do you **See**?
What is **Happening**?
How does this relate to **Our** lives?
Why does this situation/strength exist?
How can we become **Empowered** by our new understanding?
What can we **Do**?

To facilitate these in-depth discussions, we used an inductive pneumonic questioning technique known as the SHOWED method (Table 2.1) (Shaffer, 1985). This method is based on Freirean processes of listening, dialogue, and action (Freire, 1973; 2000) that were used to "trigger" critical dialogue and reflection (Wallerstein, 1994). During discussions, the initial questions elicited critical dialogue first through description (See, Happening), then personalization (Our), while subsequent questions probed

further critical analysis (Why), problem-posing (Empowered), and action (Do) (Wallerstein, 1994).

It can be argued that the central focus of these discussions was not the photographs themselves, but the critical dialogue that ensued. For example, in one PDS a participant shared a photograph (see Fig 2.6) of a bush plant which generated an in-depth discussion about hygiene habits such as waste disposal and traditional health practices.

Fig 2.6 Photovoice Assignment 4: What Habits Do People Have That Are Not Hygienic?

Participants explained how this bush plant was not beneficial for their community because it grew thorns, produced no food, and did not have any medicinal value; therefore, people would dump waste on or around it. Then students began to discuss strategies for improving the community. For example, they spoke about how they could cut down the bush to prepare the land for planting medicinal herbs. This would perhaps sway people's attitudes about dumping their waste there.

2.3.2 *Shared Power: From Critical Dialogue to Action*

From the PDS, the academic research team identified key themes and applied them to a blend of adaptation frameworks traditionally used to translate evidence-based health promotion interventions such as Intervention Mapping (Bartholomew et al., 1998) and the Map of Adaptation Process (McKleroy et al., 2006). Using the photovoice data, these frameworks guided the intervention adaptation and knowledge translation of the SHINE school curriculum from Tanzania to the Indian cultural context. For example, students' photographs and discussions often revealed the cultural importance and sacredness of the natural/ecological environment, environmental sanitation, and waste management, which helped inform the translation of specific lessons in the SHINE Tanzania curriculum to have a more explicit focus on environmental sanitation and the natural environment for SHINE India. The adapted curriculum with the input

from the photovoice sub-study was disseminated to over 300 students in two schools in the SHINE India intervention in the local community of Sripuram, Thirumalaikodi.

2.3.2.1 Project SHINE India Adaptation

The main outcome of the photovoice project was to make changes in the SHINE India curriculum. Throughout India, many people do not use toilets and instead defecate out in the open because toilets are considered dirty and it is seen as defiling to clean an impure space (Lüthi, 2010) such as a toilet. Students suggested in the PDS that they could help with cleaning and other household chores, therefore transforming social norms. According to social cognitive theory, social modeling is a powerful method of health behavior change (Bandura, 1998; Glanz et al., 2008). Inspired by photovoice student participants, we decided to include a lesson in the intervention that included proper hygienic cleaning practices such as cleaning toilets and reusing waste.

2.3.2.2 Photovoice Photograph Exhibition

Similarly to SHINE Tanzania, as part of the main intervention, students and teachers held a sanitation science fair where they came up with projects related to water, sanitation, and hygiene. Many students constructed models and performed demonstrations for their science fair projects. Parents, community members, and students from other classes were invited to tour the projects. In addition to the science fair, photovoice students decided that they would like to include their photographs in a display. This small photo exhibition was suggested by the local project coordinator and discussed during the final group meeting. Students saw an exhibition as an opportunity to display their work to their peers and community as well as promote awareness about key issues discussed during the project. The gallery of photographs and captions was displayed outside the sanitation science fair so that all attendees could view it before they entered the main science exhibition.

2.4 REFLECTIONS, CONSIDERATIONS, AND LESSONS LEARNED

As arts-based research methods gain momentum, academic researchers and practitioners must also engage in continuous processes of self-reflection and self-evaluation (Minkler, 2005; Minkler & Wallerstein, 2003). Although these methods exhibit the potential to communicate and elicit discussion beyond traditional research praxis through various data collection and knowledge translation methods, we must also reflect on further methodological and epistemological limitations. Each SHINE intervention was implemented within distinct social, cultural, and environmental settings and populations. The following reflections illustrate the similarities and differences across these contexts while simultaneously unpacking the methodological dilemmas and experiences in practice concerning participant engagement, community partnerships, power, and empowerment.

2.4.1 Meaningful Processes of Participant Engagement in Participatory Arts-Based Research

Ensuring meaningful participant engagement was essential throughout both the formative research and implementation phases of both SHINE interventions. The inclusion of arts-based methods within SHINE contributed to broader and more authentic engagement of participants and community members because of the methods' capacity for equitable participation that encourages personal expression and sharing of one's lived experiences (Finley, 2008). Often, this type of engagement contributed to critical reflection processes that addressed sensitive or stigmatized concerns (Switzer et al., 2015) and acted as an entry point for participants to engage in discussions concerning potentially sensitive health issues, such as open defecation and its effects on community health. Additionally, in the SHINE photovoice, students shared photographs of their everyday lives and spoke openly about their personal experiences with hygiene-related illnesses and disease in their community. Thus, contributing to the depth and richness of our understanding of the contextual setting. Moreover, in many instances, arts-based methods such as the sanitation mural in Tanzania facilitated an open dialogue and ensured that participant experiences and expertise remained at the center of the inquiry, while also helping balance power dynamics by providing opportunities for participants to share their perspectives in a way that resonates and is most relevant to their culture and context. However, engaging with arts-based methods is not without challenges, and upon reflection of our own positionalities and experiences, it is important to acknowledge and deconstruct the complexities of employing arts-based methods in health promotion research.

In both settings, a foundational component of the project was the collaborative efforts put forth by academic researcher-community partnerships; therefore, stakeholder inclusion in all phases of research was fundamental to the SHINE approach. While participatory arts-based methods were incorporated throughout the project to encourage authentic participation and equitable partnerships, we also collaborated with students, teachers, and the wider community beyond these methods in various forums such as think tanks, workshops, and focus groups in which participants, stakeholders, and researchers met and exchanged knowledge. In Tanzania, a think tank approach to engaging community stakeholders at the local hospital, schools, and wider community included traditional leaders, traditional birth attendants, out-of-school youth, and parents in all phases of the piloting of SHINE, which supported equitable participation and community ownership of the intervention. While think tanks generated a space for community participants to articulate potential concerns about the intervention at each stage, the platform also encouraged the development of community-driven mitigation strategies, thus exemplifying co-learning processes between academic researchers and community collaborators in which local knowledge and skill helped navigate challenges and structures that the research team might lack. Additionally, the evaluation teams for the sanitation science fairs, which consisted of a broad spectrum of community stakeholders, were highly engaged in the process of selecting culturally relevant strategies for improving WASH and subsequently served as an advisory board for the project. Their participation constitutes another means whereby the project incorporated a diverse cross-section of stakeholders with an aim to contribute to the overall sustainability of the project.

Although Project SHINE was deeply committed to developing equitable partnerships, it is also important to consider that systems of oppression, structural hierarchies, and power imbalances exist at the local community level, which may influence community-researcher partnerships. In India, although we held regular meetings with community stakeholders/gatekeepers who were involved with the local community-based organizations, hospital, schools, and spiritual leadership, it is important to acknowledge that while diverse in their position and expertise, our collaborating partners do not represent all voices within the community. Although we may envision comprehensive community participation and representativeness, it may not be feasible within a complex community structure. Stakeholders can represent and communicate many concerns; however, we must not assume they are able to represent the entire community (Wallerstein & Duran, 2006). The community is composed of a multitude of voices, and stakeholders/gatekeepers may not adequately represent certain segments of a community, such as the elderly and other hard-to-reach groups. Although we hoped to include the community in shaping the research project, in order to ensure that the project addressed community-identified needs, it is important to recognize and reflect upon how each community has dynamic and complex historical, political, and cultural forces that shape knowledge and power. In SHINE India, community members such as parents and local elders were not directly involved in our formal stakeholder engagement process, though we did attempt to ameliorate this with informal interactions throughout our daily activities in the community. Sripuram, Thirumalaikodi is a community with a strong spiritual legacy, and engaging in this aspect of community life was central to our own investment in the partnership. This included daily participation in *puja*[7] and regular participation in *seva*[8] activities. We also chose to wear locally appropriate clothing and follow cultural norms and rituals regarding traditional activities. Participation in these activities was essential to showing our commitment and engagement in the community. However, formalized stakeholder meetings were especially important arenas of knowledge exchange, allowing us to report on current project activities and receive feedback on our progress. As these formal processes failed to reach certain segments of the community, such as the elderly or parents, we felt it was essential for the research team to build relationships outside of formalized space. To do so, we attended temple daily, attended school-based and religious or cultural celebrations, and greeted parents in the schoolyard to foster further engagement, trust, and mutual respect with community members.

2.4.2 The Potential for Arts-Based Methods as a Tool for Empowerment and Catalyst for Social Change

One of the main aims of Project SHINE has been to encourage youth through the development of life and leadership skills. Powerlessness is a social determinant of health, and thus empowerment

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[7] Puja is a devotional practice, or act of worship.
[8] Seva is selfless service, which is a core principle in Hinduism and an important aspect of life in Sripuram.

is essential to improving health outcomes. The World Health Organization (WHO) distinguishes between individual and community empowerment, defining individual empowerment in terms of an ability to make decisions and control one's personal life, while community empowerment is defined as collective action to "gain influence and control over the determinants of health and the quality of life in their community" (World Health Organization, 1998). The goals of Project SHINE are both to aid in the participants developing life skills that lead to greater autonomy over their own health, and also to develop leadership skills that allow them to take part in leadership and civic engagement activities in the long term. With arts-based methods such as photovoice, time capsules, and murals, SHINE aimed to create a participatory platform that would foster engagement, ownership, and self-determination among the participants, which in turn will encourage the development of various life skills as well as self-confidence in their role as change makers in their communities (Wilson et al., 2007).

Project SHINE was developed as a CBPR project that creates a platform for data collection, art, and youth empowerment. Nevertheless, we should not assume that participation is inevitably empowering for the participants or co-collaborators, especially given the social structures surrounding youth participants. Action is a foundational component of CBPR, with participants engaging with stakeholders, gatekeepers, and policymakers to create social change. However, Strack et al. (2004) state that it is important to bear in mind that arts-based methods such as photovoice are a "process," and empowerment may not be completely realized by participants by the conclusion of a project or research study. Empowerment is a personal journey and likely a lifelong project for most people, and thus cannot be reduced to a simple measurable outcome of participation in a year-long study. Therefore, it is important to understand the value of processes of reflection and dialogue as a crucial first step in personal growth processes that lead to mobilization and empowerment, especially when working with youth who are currently experiencing intense experiences of personal growth and change (Strack et al., 2004).

While photovoice and other CBPR methods encourage participants to make contact with policymakers to create change in their communities, this may not always be a realistic goal, and a singular focus on this can be discouraging for the long-term success of a project (Johnston, 2016). Both SHINE interventions were implemented in settings that had distinct social structures. In India, hierarchical social structures that value seniority shape systems and cultural norms that influence how youth are perceived, seen, and heard. In this context, social structures may also prevent students from having access to power within society. This leads to the question: to what extent can youth participants share their "voice"? In many countries around the world, youth are unable to vote or participate in civic organizations without consent from an adult. Even to participate in Project SHINE, all students needed to obtain parental consent. As we managed goals and expectations of the project, we also acknowledged that adolescents often must act through proxy and reflected upon local systems of power and processes of empowerment. However, this is not to suggest that empowerment cannot be achieved through skills development and feelings of self-confidence and self-worth; rather, it is to remind us that

researchers must acknowledge potential benefits and limitations of methods in order to effectively facilitate and support project participants. Additionally, researchers engaged in arts-based CBPR research should be cautious when raising expectations of project participants. In the SHINE PDS, participants brainstormed solutions for identified challenges without limitations, such as a discussion on potential sanitation enforcement strategies that are punishable by fines, or imprisonment for individuals who are seen dumping waste in the community's water sources. However, society, power structures, corruption, and resources may limit participant control of everyday life and their abilities to implement such strategies.

2.4.3 Tapping the Potential of Arts-Based Methods for Unlocking the Creativity and Curiosity of Youth in Health Promotion Interventions

Arts-based methods were also integrated into SHINE to provide a platform for youth as social actors, future educators, scientists, and leaders and to enable them to express themselves in diverse ways that would resonate with their culture and context. The linguistic complexity of the setting was one factor in adopting a participatory arts-based method within the project. Although English is the language of instruction at secondary schools in Tanzania, as well as in our partner schools in India, it is not the participants' first language in either setting. Moreover, given the strong community focus within the project, the predominately oral culture among Maasai pastoralists, and potentially low literacy levels, including a more diverse spectrum of possibilities for expression within the project was important in terms of inclusion of diverse perspectives and modes of expression, as well as ensuring a broader reach and overall sustainability of the project.

We found students to be positively engaged in this component of the project, and it was frequently mentioned that they lack a similar creative outlet within their school setting. Community members reflected that it is important that the knowledge created as part of the project be shared beyond the walls of the classroom and spread to the wider community, speaking to the potential of arts-based methods in health promotion to span the divide that often exists between schools and communities. Teachers similarly expressed appreciation for the inclusion of arts-based methods in the project, yet discussion indicated that within the national curriculum there is insufficient focus and space devoted to the arts. Similarly, the inclusion of arts such as dance and theatre in SHINE India's knowledge translation and dissemination activities resonated with the local culture, where such performing arts are a common part of community life. After the photovoice sub-study, three students wrote and directed a short skit about the importance of water (a key takeaway from the photo discussion sessions and a community-identified health concern), while other students choreographed a dance about handwashing (see Fig 2.7 below). Participants expressed that they felt happy sharing their knowledge and experiences with their peers through art.

Fig 2.7 Students in SHINE India engage in performing arts to teach peers about the importance of water (left) and handwashing (right)

2.4.4   Can Arts-Based Methods Alleviate Power Imbalances?

Power imbalances can exist within community-researcher, young-elder, and other superior-subordinate relationships that are replicated and reinforced by history, politics, culture, and tradition (Muhammad et al., 2015). In many ways, the inclusion of arts-based methods in Project SHINE was intended to mitigate power differentials in the research process. As mentioned above, the SHINE Tanzania intervention was implemented in a context of considerable linguistic complexity. The incorporation of arts-based methods was crucial to giving a broad and diverse platform for youth expression. Additionally, literacy levels among both students and community members could not be assured; therefore, providing a medium that nurtured personal expression and sharing was essential for equitable engagement.

However, despite efforts to minimize power differentials, we acknowledge several difficulties of establishing truly equitable partnership. In the SHINE India project, the photovoice process aims to overcome imbalances in power in the relationship between participant and researcher; however, this is especially difficult when working with youth in a setting where distinct social structures are prominent. To overcome this, we tried to develop a supportive environment where we could learn together, with participants and their experiences as the focal point of all interactions. Although we had certain time constraints, we focused on building rapport and allowing space in all our conversations with participants for questions and debate. We discussed the participants' roles as co-researchers and the instrumentality of their experiences and concerns to the development of the research project. Through looking at the photographs and discussing the various issues they identified within their community, we started to develop new knowledge and understanding of the local context together. The cultural significance of the natural environment quickly emerged as important to the participants, alongside concerns about generational divides regarding the importance of ecological preservation. Exploring these ideas and concerns was essential to the adaptation of the SHINE curriculum to the Indian context. We continuously tried to communicate the implications and impact of the research and the importance of the participants' involvement. However, power imbalances between participants also posed a challenge to the equitability of the PDS experience. Janes (2016) discusses how in

some ways CBPR can preserve power differentials in community-researcher partnerships despite the approach's claims to prevent and/or mitigate oppressive research practices. As only one photo is selected and discussed, dominant members of the group can end up controlling the direction of the discussion, and certain participants may not have their voices heard. To prevent this, we selected the photo for discussion through an anonymous vote and developed group norms aimed at creating an open, inclusive, and supportive environment in which everyone felt comfortable expressing their opinion during the initial photovoice meeting.

Through the application of a CBPR approach, the research project brought academic researchers, communities, and students together to exchange knowledge and disseminate findings. However, a research project developed with the intention to encourage equitable partnerships can also contribute to the very power dynamics it seeks to disrupt (Janes, 2016). We hope to expose additional tensions related to power within this type of work to encourage a push toward more reflexive and transparent research praxis. As we build meaningful partnerships with community collaborators, it is crucial that we try to understand how research skills are applied in the local context, so these skills and capacity can be leveraged outside the research project to ensure that the project is mutually beneficially throughout the entirety of the research process. In Project SHINE, although participants were excited about the intervention itself, we experienced difficulties recruiting community collaborators to contribute to the academic writing processes (i.e., we have not been able to reach a teacher who was deeply involved in implementing SHINE Tanzania to co-author this chapter). Mindful of the potential threat of tokenism (Arnstein, 1969)—which would consist of merely including names to give the appearance that we engaged the community—we used this opportunity to reflect and learn more about local ways of communicating and disseminating information, which often included visual and performing arts such as theater, song, and dance (described in previous sections). As collaborative partners, we should also explore alternative methods of dissemination, since academic publications may not represent "currency" to local counterparts or be accessible to collaborating communities. By limiting knowledge translation to the confines of academic tradition, we sustain the power and privilege of academics and diminish inclusive and equitable practices of the CBPR approach. Therefore, it is necessary to critically reflect on such challenges and limitations in an attempt to build the academic researcher's capacity to become more adept in understanding alternative communication methods and knowledge translation.

2.4.5 Conclusion

In Project SHINE, arts-based methods were used at various stages of the intervention to engage youth, teachers, and the wider community not only in the development of culturally relevant and sustainable strategies to improve water, sanitation, and hygiene, but also more broadly to promote youth leadership and to provide an additional avenue or platform for expression within the project. This demonstrates how arts-based methods can be integrated into health promotion interventions to increase authentic engagement, encourage empowerment processes, increase understanding, translate knowledge, and aid in knowledge translation to the wider community.

However, from a methodological standpoint, systematic and thoughtful inclusion of arts-based methods at all phases of the research—alongside more traditional methods such as in-depth interviews, focus group discussions, and surveys—is a promising strategy for meaningfully engaging youth and communities and enhancing triangulation within a study. The use of arts-based methods also allowed the researchers to gain a deeper understanding of the cultural contexts we were working in through engaging with personal and communal forms of artistic expression and encouraging active listening and continuing reflection throughout the process. In many ways, the incorporation of the arts was a continuous organic process which made it challenging to evaluate their effect and impact. Therefore, we recommend that similar interventions aiming to reach youth should systematically plan and sequence the incorporation of arts-based methods into an evaluation. This would help further strengthen legitimacy of methods and allow for effective and systematic evaluation of processes and outcomes.

Although each SHINE intervention incorporated different arts-based research methods during different phases of research to help achieve research project objectives under a CBPR frame, future iterations would need to develop meaningful indicators and apply systematic evaluation frameworks in order to realize the full potential of arts-based methods when applied to research. However, throughout these two interventions, we witnessed participants sharing their personal insights, reflections, and experiences through creative expression, which—despite criticisms of voice, power, and empowerment—did inspire a sense of responsibility to the community and improve our understanding of the health issues that were important to the community. Moreover, the inclusion of arts-based methods has fostered alternative methods of knowledge translation that markedly challenge us as academic researchers to disrupt and critique traditional academic praxis and work toward more equitable and creative approaches in future projects. Although the use of methods differed, their inclusion lead to unique partnership engagement, knowledge sharing, and learning, demonstrating how these methods can be utilized in health interventions as a tool for education, knowledge translation, and action.

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UNRAVELING CONTEXT: A FORMATIVE RESEARCH PHOTOVOICE STUDY OF INDIAN YOUTH PERSPECTIVES OF SANITATION AND HYGIENE PRACTICES IN THE RURAL COMMUNITY OF THIRUMALAIKODI, TAMIL NADU, INDIA

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ABSTRACT

Water, sanitation, and hygiene are issues of substantial public health importance. Community-based participatory research approaches such as photovoice can help explore and identify determinants, which influence sanitation and hygiene-related behaviors. The main aim of the present study was to use photovoice as part of the formative research process to increase understanding of youth's perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors in Thirumalaikodi, India. Over a three-week period, ten participants in seventh, eighth, and ninth standard participated in an information meeting, seven photo discussion sessions, and one wrap-up session. In each photo discussion session, participant groups selected one "trigger" photograph and through a structured discussion using SHOWED pneumonic questions (a series of questions that ask participants to describe and reflect upon a chosen photograph), generated a new understanding of issues related to water, sanitation, and hygiene. All sessions were audio recorded and transcribed verbatim. Conventional content analysis was used to analyze photo discussion session text. Findings revealed that factors such as social structure, education, and culture influence behaviors that determine the sanitary conditions of an individual's private and public space. Furthermore, participants described how descriptive norms generated practices (e.g. littering) that were reinforced and maintained by limited access to waste management systems, attitudinal indifference, and generational beliefs. Findings yielded an in-depth understanding of youth's perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors. This study also contributes to the research literature on the application of participatory approaches in intervention adaptation processes.

Keywords

INTRODUCTION

Poor hygiene behaviors and inadequate sanitation conditions are linked to several negative health outcomes such as parasitic worm infections, diarrheal disease, malnutrition, and stunting (Walker et al., 2012, Cumming and Cairncross, 2016, Hall et al., 2008). Furthermore, studies demonstrate that there is an association between sanitation and hygiene and other outcomes such as impaired cognitive learning, school absences, and poor social development (Lau et al., 2012, Freeman et al., 2012). Therefore, improving water, sanitation and hygiene (WASH) has been an integral part of the global health agenda. Evidence suggests that theory-based health promotion interventions which address determinants may lead to improved behavioral and health outcomes (Glanz and Bishop, 2010). Historically, WASH interventions were focused on infrastructure, for instance hardware solutions including water treatment technologies, handwashing facilities, and improved toilets to increase latrine use (Peal et al., 2010). However, it has become increasingly recognized that there is a need for more comprehensive approaches to effectively address WASH challenges and achieve intended health outcomes (Dreibelbis et al., 2013).

India has prioritized improving sanitation infrastructure for decades, yet India is still a top contributor to the diarrheal disease burden, globally (United Nations Children's Fund (UNICEF) and World Health Organization (WHO), 2009). Moreover, approximately 40% of the population defecates in the open (World Health Organization (WHO) and United Nations Children's Fund (UNICEF), 2017), which is often related to a lack of adequate sanitation infrastructure or preference for the practice (Doron and Raja, 2015). Additionally, India's rapid increase in population and urbanization generates an overwhelming 62 million tons of waste each year, in which less than 60% is collected and only 15% processed (Press Information Bureau, 2016). With several WASH-associated health concerns affecting the country, the government has worked to mitigate these sanitation and hygiene challenges with several initiatives such as the Central Rural Sanitation Programme, the Total Sanitation Campaign, and the Swachh Bharat

Mission. However, despite these initiatives working towards successfully expanding sanitation coverage, behavior change outcomes are still poor (Clasen et al., 2014, Bhattacharya et al., 2018).

Evidence regarding the behavioral and health impacts of other WASH interventions is still mixed (Watson et al., 2017, McMichael, 2019). Some studies report significant effects on behavioral and health outcomes; however, others demonstrate modest impact. For example, studies on handwashing have found that perceived health benefits, attitudes, and other contextual factors influence handwashing behavior (Friedrich et al., 2017, Dobe et al., 2013), while studies on waste management have found that access to trash collection services, normative beliefs, perceived responsibility and age were all determinants of waste disposal practices and littering behaviors (Bauza et al., 2019, Arafat et al., 2007). This illustrates that factors that influence sanitation and hygiene-related behaviors are not well understood, highlighting the need for further research.

There is also a need to investigate behavioral determinants across different settings and populations to inform the development of culturally and contextually relevant interventions. One approach to explore behavioral determinants is through community-based participatory research (CBPR). CBPR approaches, such as photovoice can help broker participant-researcher relationships to uncover the cultural and contextual factors that influence determinants of sanitation and hygiene-related behaviors, which may enhance intervention effectiveness and sustainability (Cornwall and Jewkes, 1995). Although there are several studies that have used the photovoice methodology to explore the personal experiences, perceptions, and challenges of youth, there are comparatively few photovoice studies that focus on water, sanitation, and hygiene and none in the southern Indian context. Furthermore, to our knowledge, no study has explored youth perspectives of the underlying mechanisms of behaviors (behavioral determinants) in order to adapt and tailor intervention strategies to youth in the Indian context. This formative research will fill an important gap in the knowledge base both with respect to how CBPR can

be used to elicit youth perspectives on WASH, and on how findings can be used to inform the development and adaptation of a culturally relevant WASH health promotion intervention.

The purpose of the present study was to explored students' perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors through photovoice. This knowledge will contribute to the adaptation s of Project SHINE (Author et al, 2016) (Sanitation Hygiene INnovation in Education) to the local context of Thirumalaikodi, Tamil Nadu.

METHODS

Study Area and Participants

The present study is a part of Project SHINE. For more information about Project SHINE see www.project-shine.net. This study was implemented at a private English medium school (first-twelfth standard) in the rural community of Thirumalaikodi, which is in the Vellore district in the southern Indian state of Tamil Nadu. Thirumalaikodi is well known for its spiritual significance because of its proximity to the Sri Lakshmi Narayani golden temple. The Vellore district is made up of 858 villages and 36 towns, with a total population of 3.9 million (Directorate of Census Operations Tamil Nadu, 2011). In Vellore, 22% of the population identified as Scheduled Caste while 2% identified as Scheduled Tribe, which are both 1% more than the populations of the entire state of Tamil Nadu (20% and 1% respectively) (Directorate of Census Operations Tamil Nadu, 2011). Participants in this study were male and female students, aged 13-15 years in seventh, eighth, or ninth standard (grade) and primarily resided throughout the Vellore district.

Recruitment

Using a purposive sampling strategy, the school principal and teachers recruited ten students that met the following inclusion criteria: (1) currently enrolled as a student at the school, (2) in seventh, eighth, or ninth standard, (3) willing to take photographs of their community and/or experiences, (4) comfortable

expressing themselves in English (the language of instruction at the school), (5) open to sharing their experiences within a group of peers. The study was conducted at the school selected for future intervention implementation of Project SHINE. Additionally, one student dropped out after the sixth photo discussion session (PDS) due to scheduling conflicts.

A relationship between study participants and the researcher team is essential to establish trust and rapport in CBPR and was key to producing quality data in this study. Although there was no formal relationship between researchers and participants prior to data collection, we hoped to promote trust and respect through informal exchanges such as an introducing the research team to students and teachers at the all school assembly and additional classroom introductions and/or visits prior to data collection.

Data Collection

Photovoice is a method in which individuals are provided with cameras to take pictures, so they can represent, reflect upon, and communicate their personal experiences (Wang and Burris, 1997). According to Wang and Burris (1997), two pioneers of the photovoice method, the three main goals of photovoice are to: 1) allow participants to take photographs that reflect their experiences, 2) engage participants in dialogue about community issues, and 3) reach influencers to stimulate change. The method was developed on the basis of feminist theory, Freirean principles, and documentary photography (Wang and Burris, 1997). In this study, photovoice was used as an approach to engage youth in the formative phase for the Project SHINE intervention adaptation. Participants took photographs that captured cultural and contextual factors that influence sanitation and hygiene-related behaviors, as well as highlight their community's strengths, challenges, and needs through a group process of critical reflection and dialogue.

Data collection took place from June-July, 2017. Participants attended one information meeting, seven PDSs, and one wrap-up meeting over a three-week period. All sessions were conducted in English; however, a translator fluent in Tamil was present during the information meeting to help facilitate and answer clarifying questions. The purpose of the information meeting was to acquaint participants with the study and photovoice method (Sutton-Brown, 2014). In this meeting, participants were taught the ethics of photography, discussed how data and identities would be protected, trained how to use digital cameras, and how to obtain informed written consent when taking photographs of people (Wang and Burris, 1997). After the information meeting, participants were separated into single-sex groups, to ensure that they would be comfortable talking about sensitive topics with peers.

All PDSs followed the same procedure in both groups, however since groups were conducted separately, photo assignments generated by participants varied. All PDSs were facilitated by AGW and lasted for approximately 1-hour. Prior to each PDS, participants were requested to select one or two photographs to share with the group and discuss why they took the photo. After all participants shared their photographs, the entire group voted anonymously for one photograph to discuss in-depth using the SHOWED technique (Shaffer, 1985). SHOWED (Shaffer, 1985) is a Freirean-based inductive questioning technique that is used to "trigger" critical dialogue. The technique helps participants make linkages between the photographs discussed and each individual's own personal experiences (Sutton-Brown, 2014). Furthermore, SHOWED guides participants to discuss and reflect upon potential action (Sutton-Brown, 2014).

At the end of each session, participants developed their next photo assignment by connecting keywords or concepts, with the guidance of AGW. Since both groups attended the initial information meeting together, they followed the same photo assignment for the first PDS (see Table 1 for photo assignments by group). After seven PDSs, it became apparent that both groups were generating similar topics and

discussions, indicating we had reached data saturation. In total, 14 PDSs were conducted (seven for each group).

Table 1. Photo assignments developed by participants in each group

Photo Assignment	Male Group	Female Group
1	What is sanitation and hygiene?	What is sanitation and hygiene?
2	How do people get disease from poor sanitation and hygiene?	How does pollution effect waste?
3	What makes something unhygienic?	What factors can we improve to make India a more developed country?
4	How do diseases spread from water?	What habits do people have that are not hygienic?
5	What are good and bad hygiene habits?	What habits do I have to keep myself hygienic?
6	Where do people get their sanitation and hygiene information?	Where do we learn about our health information?
7	How can we make sure food and water are clean?	What are the traditional practices related to sanitation, hygiene, and health?

Data Analyses

Each PDS was audio recorded, transcribed verbatim, and transferred to a qualitative research software, Atlas.ti, 2017. We used an inductive approach and conventional content analysis, to analyze PDS text to capture the direct insights of study participants without 'imposing' preconceived ideas or theoretical perspectives (Hsieh and Shannon, 2005). There were several stages within the analysis process. First, AGW immersed herself in the text by reading through transcripts to become familiar with the data (Tesch, 2013), then, after reflection, developed the initial codebook through an open-coding process (Hsieh and Shannon, 2005). Codes were then organized into parent codes and sub-codes which comprised the initial codebook (Patton, 2002).

After the initial codebook was completed, in the wrap-up meeting, AGW presented the codebook to the study participants. Participants then engaged in a code verification exercise to ensure inter-coder reliability. In this exercise, participants coded parts of transcripts, added codes they felt were missing, and contributed general feedback. Next, AGW continued analysis with second-cycle coding using the

revised codebook (Saldaña, 2015). Meaning units with similar content were then organized into sub-themes and with further interpretation, AGW merged sub-themes to generate overarching main themes. AGW also conducted two additional member-checking sessions to ask participants follow-up questions and further refine themes. Participants then used subsequent sessions to develop an action plan to create social change in their community.

Ethical Approval

The study protocol was approved by the Norwegian Centre for Data Research (reference number: 53162) in Norway and the Institutional Ethics Committee/Institutional Review Board at the Sri Narayani Hospital and Research Centre in India (reference number: 30/25/02/17). Due to the age of participants, students were required to provide assent and active written consent of a parent or caretaker to participate in the study.

RESULTS

Throughout the PDSs, critical dialog amongst participants revealed that several determinants play an influential role in sanitation and hygiene-related behaviors, that determine the sanitary conditions of one's private space (in the household or domestic settings) and public spaces (outside of domestic settings/in communal environments). This relationship is mediated by norms, attitudes, or beliefs. Some of the excerpts presented have been edited or paraphrased for readability and grammatical correctness, including removal of distracting phrasing and identifying information. All major changes are indicated by square brackets.

Causes and consequences: nexus between descriptive norms, behavior, and outcomes

This theme describes both participant's observations and perceptions of what causes normative sanitation and hygiene-related behaviors, and their positioning of these behaviors as negatively affecting the physical environment and health of the community. Two sub-themes emerged ("'Bad

habits': litter(ing) as a descriptive norm" and "'Why should we care?' displaced responsibility and indifference").

'Bad habits': litter(ing) as a descriptive norm

Norms influence behavior, which often determines what is socially acceptable. Additionally, normative influence is guided by what one perceives is commonly performed (descriptive norms) or approved of (injunctive norms). Participants described how descriptive norms influence habits that contribute to the sustained practice of poor sanitation and hygiene-related behaviors such as littering. Both male and female participants shared their perceptions of littering behavior as a "bad habit" or "dirty", demonstrating that littering is a descriptive, yet unaccepted norm. For example, one photo (Figure 1) taken by a participant depicts a polluted stream that triggered a discussion about waste disposal habits. One participant shared:

> *The people are following [the] negative things of man. If a person puts garbage in waterbodies, another person will think, why should we not put [garbage] in waterbodies? [Then] many people [will] follow them and it becomes a habit…* (Male Participant).

As illustrated by this excerpt, although this participant describes this behavior as common, it is conveyed as negative and therefore an unacceptable behavior. In addition, the participant suggests that when people act out behaviors, they perceive are commonly practiced, it becomes habitual, posing harm to the physical environment and health of the community.

Figure 1. Participant photo of a former local water source

In a separate PDS, another participant echoes similar sentiments when she describes a photograph she

took near her home:

> This is the backyard of my home [next to] a government school. [The] government school land is
> [used for] waste dumping. Now mosquitos, rats, snakes come this side. The monkey go[es]
> there… All the ones in my house, we are [upset] all because of this. They have [facilities] but they
> didn't use [them]. They are using this place (Female Participant).

This quote further illustrates how improper waste disposal is a common yet unaccepted behavior

throughout the community, and reflects how such practices pose various health threats to neighboring

residents.

'Why should we care?' displaced responsibility and indifference

Besides the reported perception that others commonly practice littering, participants also discussed

how attitudinal indifference supported such behaviors. Participants described people as being

"careless", "lazy", "not interested", "not worrying about others", or thinking "why should we care?"

regarding the physical presence of waste in public spaces and corresponding behaviors (e.g. littering and

waste disposal). However, although PDSs revealed that several participants perceived attitudinal

indifference or 'laziness' as facilitating littering behaviors, structural factors such as sanitation

infrastructure were also identified as playing an influential role. One participant shared:

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> *They want to put their garbages in the [dumpsters], which [are] a little bit far away from their homes. [However], they're putting garbages in this place near [their] home* (Male Participant).

In this account, the participant describes how indifference, lack of infrastructure influence improper waste disposal behaviors. Moreover, participants discussed how, in order to practice sanitation and hygiene-related behaviors, there needed to be efficient and reliable sanitation or waste management infrastructure (e.g. sewage systems and waste collection). However, participants revealed that sanitation infrastructure was often neglected or poorly maintained, thus making habitual sanitation and hygiene-related behaviors arduous.

One participant also reflected on how community members weigh their civic responsibilities when engaging in sanitation and hygiene-negligent behaviors that cause environmental harm:

> *They are not interested to do it. They are thinking, 'Why should we do [it]?' This is not our duty. So, they are not thinking of the future* (Female Participant).

This excerpt highlights tensions in local perceptions, civic responsibilities, illustrating a discrepancy in awareness, beliefs, and values among community members. Participants shared their regard for the physical environment and personal beliefs about how proper sanitation and hygiene behaviors can benefit both the physical environment and health, while also discussing, how others may not consider duty to the physical environment as beneficial to the overall community (e.g. physical environment and health), demonstrating variations in core beliefs and values.

Norms in transition

The theme, "norms in transition" explores participant's reports of malleable contextual factors associated with culture, religion, and household dynamics that influence sanitation and hygiene-related behaviors. We identified two sub-themes under this theme, which were, "linkages between cleanliness and godliness" and "gender-role paradigm shifts".

Linkages between cleanliness and godliness

Participants spoke about how in some households, sanitation behaviors within private space are influenced by sociocultural or religious rituals that promote positive domestic hygiene practices. In both discussion groups, participants shared the religious and cultural importance of keeping their home clean. The photo in Figure 2 was taken for the male group's photo assignment 5 (Table 1 and was described as representing a sweeping ritual before sunset.

Figure 2. Participant photo of a mother cleaning their home (private space)

Participants elaborated, that their homes will be cleaned regularly to respect deities. Participants also explained that keeping one's home clean, would bring other benefits such as the deity entering the home and granting blessings to the dwelling's inhabitants. This demonstrates a close relationship between domestic hygiene and local cultural or religious beliefs. One participant explained that to promote hygienic practices, it would be beneficial to emphasize spiritual benefits of the practice to ensure maintenance.

> *If we say that it is [about] hygiene, they will clean it for one day or two days…But if we say that God gives us more blessings, means that they will do it regularly* (Male Participant).

This demonstrates how cleanliness and hygienic practices are interlinked to religious beliefs in this context. Gods may enter the home to give blessings to the inhabitants upon the condition that the home is kept clean. Moreover, participants suggest that to motivate sustainable behavior change, it is

important to understand the cultural and religious linkages of purity and cleanliness of the Divine, in this cultural context.

Gender-role paradigm shifts

Participants revealed that despite cultural and religious traditions, individuals experience multiple demands throughout their daily life making it difficult for them to engage in hygienic practices that affect sanitation within (private space) and outside (public space). In several PDSs, participants perceived employment as a top priority, which involves demanding schedules, commutes, and stamina. These responsibilities may not correspond with traditional domestic hygiene practices or duties. Male participants spoke about women joining the formal workforce, which largely affects traditional households. This change in societal gender norms has permeated into household dynamics and domestic hygiene (e.g. housework or chores).

Both groups reported a shift in attitudes towards domestic hygiene, however, male participants specifically discussed how they observed a decline in women engaging in housework, rather prioritizing work outside the home, thus illustrating a shift in domestic priorities. Meanwhile, in the female group, participants shared how successful career ambitions influenced their own sanitation and hygiene-related attitudes and behaviors. The group discussed how much they value their personal hygiene because they are determined to get a good education, which is a key step for future achievements. One participant reflected:

> *[I value] my future and my job. [If] a person is healthy, then only he can work. So, sanitation is good [for] him. Every day, we are coming to school, we are working, we should [be clean] and come. It's our duty. If we are getting germs that directly affect us, then [the] next day we will not be coming* (Female Participant).

Despite these differing perspectives, both groups allude to different roles women play in the broader discourse on sanitation and hygiene. The male group discussed how emerging opportunities have taken women outside the home and shifted traditional household dynamics, while girls discuss how they value

sanitation because it supports education and successful job prospects. The female group perceived that without adequate sanitation and hygiene behaviors, one will be susceptible to disease, unable to attend school, and deprived of educational opportunities, which may prevent the further pursuit of a successful career.

Strategies for behavior change

The application of the SHOWED technique also "triggered" participants to discuss strategies that facilitate action. These 'strategies for behavior change' addressed many underlying cultural and contextual factors associated with beliefs, norms, values, sanitation and hygiene-related knowledge. Two sub-themes that emerged included: "generational beliefs and knowledge gaps: achieving health literacy" and "future change agents".

Generational beliefs and knowledge gaps: achieving health literacy

Given the influence of norms on sanitation and hygiene-related behaviors, participants shared how they perceived knowledge and education as significantly affecting sanitation and hygiene related-behaviors. Participants also reflected upon processes of knowledge sharing among older and rural populations, demonstrating the prominence and value of local health knowledge. One participant shared:

> *From a small age, it's their habit, they won't think. They are [raised] in such a way. Maybe because of their elders, they didn't teach them* (Female Participant).

Here, participants describe how this generational knowledge transfer contributes to knowledge gaps and poor sanitation and hygiene-related behaviors.

Future change agents

Participants proposed several strategies to improve the community's sanitation and hygiene-related challenges that incorporated (1) education: "we can advise them", "create awareness"; (2) media advocacy: "distribute this news to all of them through WhatsApp or Facebook", "make advertisements"; (3) policy: "government should put an order that those who are polluting those waterbodies will be

punished severely", "request to the government to clean", "go to each houses in the streets and check the cleanliness"; and (4) others: "build a safety wall to protect the water", "form a group to go clean", "keep cameras and watch the people who are putting wastes in the area". Although approaches varied, participants expressed hope in younger generations, wishing to educate their peers. One participant explains:

> *The education department should put a rule to every school that they have to teach teenage*
> *students about hygiene, sanitation, [and] health. Regarding that, if they teach the teenage*
> *students, maybe [they can be] aware and they can advise to [their] neighbor and illiterate people*
> (Male Participant).

This demonstrates how participants believe knowledge and school-based educational interventions can contribute to improving overall sanitation, hygiene, and health.

Participants often took photos of litter in public spaces, which prompted discussion about littering behaviors (causes, consequences, and solutions). The photo in Figure 3 was taken to represent individuals improperly disposing waste in public space.

Figure 3. Participant photo of litter

One participant revealed how attitudinal indifference reinforced or maintained improper waste disposal in their community while suggesting alternative strategies to this unfavorable behavior.

> *They think they can throw the rubbish... the trashes there… But if they plant the tree, it is good for them, but they are not thinking* (Female Participant).

Throughout PDSs, participants shared how they valued the physical environment by discussing the medicinal significance of specific plants and nature's importance with comments such as, "trees are good for us" and "plants will help". Here, this participant suggested that instead of improperly disposing waste, an unused space can be delegated for planting trees, which provide health benefits to the community.

PDSs also revealed how participants view their role in contributing to a solution. Participants discussed how they can take action to help reform attitudes and beliefs regarding domestic hygiene and contribute to changing household dynamics regarding sanitation and hygiene-related behaviors in private space:

> *We are grownups, we are fourteen now. We can do the work, it is not very tough. So, we can do that work, we can help the parents to do this work…We can clean it* (Female Participant).

In another PDS that focused on food hygiene one participant shared:

> *We want to wash the vegetables and we can help our mother or our grandparents or our relatives who [are] preparing food at that time* (Male Participant).

Both groups acknowledge a shift in responsibility and describe personal ownership to make change.

DISCUSSION

To the best of our knowledge, this is the first photovoice study which explores perceptions of the cultural and contextual factors that influence sanitation and hygiene-related behaviors conducted among adolescents in India. Findings reveal that sanitation and hygiene-related behaviors are often influenced by determinants such as education, culture, gender, and other dimensions of everyday life. Furthermore, these determinants shape norms, attitudes, and beliefs that govern behavior.

Norms influence behavior according to several behavioral change theories. As previously revealed by PDSs, littering was described as an important, yet complex challenge in the community. Participants

discussed how the accumulation of litter may lead to environmental contamination and increase risk of other health hazards (e.g. promote areas that are hospitable for flies, monkeys, mosquitos, rats, and snakes) that caused poor health outcomes (Anderson, 1964, Schultz et al., 2013).

In low- and middle-income countries such as India, inadequate sanitation infrastructure can contribute to the influx of litter, waste, and environmental contaminants into the public space and local drinking water resources (Narain, 2012, Williams et al., 2019). In this study, participants described littering as a descriptive norm (what one perceives is commonly performed), which generated poor sanitation and hygiene habits. According to the Theory of Planned Behavior, this finding shows how infrastructure or perceptions of control (Ajzen, 1985) have a complex relationship with sanitation and hygiene-related behaviors. Similarly, other research has discussed the relationship between sanitation and hygiene-related behaviors and infrastructure. For example, in Kenya, other infrastructure-related factors such as having water inside versus outside the home, influenced handwashing behaviors (Schmidt et al., 2009), while another study in India highlighted the complex relationship between toilet ownership and use (Coffey et al., 2014).

Participants also reflected upon how littering behaviors could be reinforced and maintained by attitudinal indifference. Littering was made to seem more socially acceptable, through displacement of civic responsibilities. Participants described how they observed individuals modelling negative behaviors (e.g. littering) without consequence, therefore, encouraging others to adopt. Various studies on littering behaviors have shown that the presence (or absence) of litter can help locate behaviors to specific spaces (Liu and Sibley, 2004, Cialdini et al., 1990, Krauss et al., 1978). Individuals are more likely to litter in previously littered environments because the mere presence of litter indicates that such behavior is commonly practiced in that space (Cialdini et al., 1990, Krauss et al., 1978). These descriptive norms influence attitude-behavior relationships (Liu and Sibley, 2004, Cialdini et al., 1990), which is consistent with the perceptions of behaviors discussed in PDSs.

It is also important to reflect upon context and beliefs when assessing and understanding behavior. When one engages in a perceived harmful behavior such as littering, contextual factors (e.g. culture and religion) can influence one's beliefs, justification, and choice. The findings of the study revealed that cultural and religious practices incentivize specific domestic hygiene-related behaviors. Here, we link sanitation and hygiene-related behaviors to existential, spiritual, or religious beliefs. In India, notions of purity, filth, cleanliness, and hygiene are uniquely complex because of cultural taboos and beliefs (Gupta et al., 2016, Doron and Jeffrey, 2018). Participants discussed how specific sanitation and hygiene-related behaviors were motivated and maintained by spiritual beliefs, unlike cultural taboos that perpetuate an idea of the practice of cleaning as degrading work (Doron and Jeffrey, 2018). However, it was not discussed if cleaning included ritually impure spaces such as toilets. According to participants, emphasizing ties of cleanliness and religion could be an effective way of transferring domestic hygiene behaviors to public space.

Despite religious traditions, participants also revealed that throughout the community, individuals experience multiple demands making it difficult for them to engage in sanitation and hygiene-related behaviors within and outside the home. In their communities, career ambitions were not necessarily congruent with traditional household duties. These demands may have shifted in recent years, as a result of several factors, such as an increase in more industrious, stressful and time-consuming jobs. Despite an overall decline in the female workforce in India, participation has been increasing among specific groups such as women with education (Mehrotra and Parida, 2017). This largely affects the household, since historically, women in India were responsible for household chores (Singh and Mukherjee, 2018). Therefore, the shift in societal gender norms has permeated into household dynamics and domestic hygiene behaviors. Perspectives that emerged in PDSs reveal how the cultural and contextual dimensions of sanitation and hygiene are shifting, and gender norms are a major factor.

Local knowledge is often community-based, implying that the family are instrumental in knowledge transfer. It is unique to a particular culture and often informs behaviors pertaining to health and the environment (Ellen and Harris, 1997). Participants discussed local knowledge and beliefs regarding traditional medicinal remedies, handwashing behaviors, the perceived use and efficacy of chlorine tablets, domestic hygiene practices, and littering. Participants shared how knowledge and beliefs were often passed down through generations. Other studies confirm that influential attitudes and beliefs can be transferred intergenerationally. For example, in one study about personal hygiene practices in Indonesia, women reported that information about nail cutting was passed down generationally (Usfar et al., 2010). While other research regarding intestinal worms in Bangladesh, suggest health-related misconceptions were passed through elders or relatives (Bath et al., 2010). Finally, research regarding pro-environmental practices of adolescents, report that parents are key influencers of behaviors (Collado et al., 2019).

Moreover, participants recommended initiatives that address school-based education, media advocacy, policy, and infrastructure. These strategies are also consistent with existing interventions that address sanitation and hygiene-related challenges. According to participants, knowledge influenced people's ability to perform a health behavior and their perception of associated risk. Despite these norms or habits, participants described motivation to improve the environment through modelling and policy. Hence, research findings suggest that future activities probe change on the interpersonal, community, and society levels. For example, participants suggested enforcing economic/judiciary penalties for littering. Similarly, in Nigeria, the government has taken steps to influence attitudes towards environmental sanitation, through the implementation of a sanitation court, where those who are accused of engaging in environmental pollution (e.g. water, air, and littering) are prosecuted (Pandve, 2008).

Strengths and limitations

There are several strengths and limitations in this study that must be acknowledged. Strengths included a participant and researcher relationship that fostered knowledge-sharing and meaningful participant engagement throughout the study. Participants also acted as co-investigators, as they developed research questions through photo assignments, provided data, analyzed, and coded transcripts, thus generating new knowledge, which improved the quality and validity of the research. Additionally, this helped us to gain a better understanding of which issues participants deem important.

Another strength involved, the application of the photovoice method which helped us to incorporate contextual elements and health challenges that were meaningful to participants in the future intervention adaptation and design. For example, we learned that waste and waste disposal behaviors (e.g. littering) were major concerns of participants. However, it would be remiss to neglect to mention how participants discussed other sanitation and hygiene-related behaviors such as handwashing, food hygiene, and toilet use. Nonetheless, discussions overwhelmingly focused on waste management, therefore the data presented in this manuscript reflects those findings. This may also be influenced by a local initiative at the school, Green Sakthi, which aims to deepen student's relationship with nature through weekly activities such as planting trees and picking up litter in the schoolyard. However, this was not probed explicitly, therefore, it is not possible to determine the extent of this influence.

The SHOWED method's final question (What can we Do?), helped participants reflect on potential action steps. The action steps discussed included art-based activism (e.g. drama) and media advocacy. Future research concerning a large-scale evaluation of intervention activities proposed could demonstrate such strategies effectiveness, and youths' role in cultivating change within their community. In the context of this study, the action component resulted in participants creating a photo exhibition that showcased their work to their peers and greater community. In addition, participants were motivated to include a more culturally relevant approach; therefore, they wrote and acted in a theatrical drama to promote

awareness about key issues reflected upon in PDSs. Additionally, findings from this study were used to adapt Project SHINE's curriculum and programmatic activities, which were subsequently implemented in their school.

However, participants did not explicitly discuss open defecation throughout the PDSs. This is a limitation because open defecation is a major public health concern and the main focus of the national Swachh Bharat Mission. We can neither determine reasons for its omission without further research devoted solely to the topic. However, given this was a CBPR study; we were focused on issues important to the participants to learn more about their realities and associated health challenges.

The study had other limitations, such as potential sampling bias, since the majority were female participants (seven girls versus three boys). In addition, the study took place in a private English-medium school, although many of the students are the first generation to attend school in their family. However, we would like to emphasize that results are not meant to be generalizable to other contexts and this formative work was intended to inform an adaptation of Project SHINE for implementation at the study participant's school.

Furthermore, PDSs were conducted in English, which is the primary language of instruction at the school, however it is not the native language of participants. This may have influenced communication and analysis of data. Therefore, a translator helped facilitate the initial information meeting and we conducted member-check sessions to enhance our understanding and fill gaps by discussing preliminary interpretations and asking follow-up questions.

CONCLUSION

In summary, this photovoice study engaged participants and researchers in a formative research process that generated youth perspectives, explored determinants, the contextual setting, and various mechanisms of sanitation and hygiene-related behaviors. This fostered an understanding of these

cultural and contextual factors to increase cultural appropriateness for the adaptation, translation, and

development of health promotion strategies within the SHINE India intervention and exemplified how

formative research processes using a CBPR approach can be utilized for intervention adaptation in

health promotion research.

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MANUSCRIPT III

A QUALITATIVE STUDY OF ADOLESCENT GIRLS' EXPERIENCES OF MENARCHE AND MENSTRUATION IN RURAL TAMIL NADU, INDIA

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Abstract

Background: In low- and middle-income countries, women and girls experience several menstrual hygiene management-related health and social challenges such as urinary tract infections, social stigma, and school and workplace absenteeism.

Purpose: In this study, we sought to explore how adolescent girls in rural Thirumalaikodi, Tamil Nadu, India experience menarche and menstruation, how their experiences connect to the sociocultural context, and what strategies they use to manage menstruation to inform the adaptation and development of Project SHINE, a school-based water, sanitation, and hygiene intervention.

Methods: We conducted semi-structured qualitative interviews with adolescent girls in 9th standard (grade) from June-July 2018. Data were analyzed using a thematic network approach.

Results: Findings revealed that menarche inaugurates biological transitions of puberty and cultural codes that shape gender norms. Gender norms in turn generate, maintain, and reproduce stigmatizing attitudes, beliefs, and practices that influenced the development of coping mechanisms at home and at school. The resulting adaptations to the intervention consisted of two activities (school lesson and an extracurricular activity) that address knowledge gaps and popular myths regarding menstrual hygiene management in this context.

Conclusions: This study demonstrates the importance of qualitative research in unpacking adolescent girls' personal experiences with menarche and menstruation. Findings also show how formative research can contribute to the adaptation and development of contextually and culturally relevant health promotion strategies.

Keywords: Menstrual hygiene management; adolescent; gender norms; water, sanitation, and hygiene; India

Introduction

Adolescence marks a time of physical, emotional, cognitive, and behavioral growth and development. In particular, during the time of adolescence, girls experience the onset of menarche, signifying a transition from girl to woman (1). However, for girls in India,

adolescence can be especially challenging because menstruation is often linked to cultural beliefs, traditions, and stigma (2). Whilst there has been increased focus on the importance of incorporating menstrual hygiene management (MHM) within health promotion interventions aiming to address water, sanitation, and hygiene (WASH) challenges, there is a need to develop a better understanding of what approaches are effective and in which contexts. This is an issue of substantial public health importance, given that adolescent girls especially, may face a variety of MHM-related health and social challenges such as urinary tract infections, reproductive tract infections, social stigma, shame, and school absenteeism (3-7) pertaining to insufficient puberty education, sanitation coverage, and access to menstrual absorbent materials (8-10). The development of effective health promotion interventions to address MHM, includes menstrual education and access to absorbents, soap, clean water, and private sanitation facilities (toilets and place for absorbent disposal) (11). These elements allow for the safe, supportive, and dignified management of menstruation to maintain health (12, 13). Therefore, it is critical for WASH health promotion interventions to address the complex relationship between gender and sanitation, as well as the sociocultural context in order to develop interventions and strategies that improve MHM in low- and middle-income countries (LMICs) (14, 15).

In India, the topic of MHM is often linked to stigma, taboos, and restrictions, possibly stemming from the belief that menstrual blood is polluting (16-18). Studies have found that women and girls report not attending work or school because of menstrual-related cultural customs or taboos (19). This can have profound distal effects on their education, economic, and social development (20, 21), which further demonstrates the necessity for WASH health promotion programming that prepares adolescent girls for the emotional, social, and physical changes in their body.

In 2010, India mandated that education was a fundamental right of every child with the installment of the Right to Education Act, however a widespread lack of clean, private and safe sanitation facilities and menstrual education throughout the country continues to undermine this right for many adolescent girls (8). In recent years, the Indian government has recognized the importance of proper MHM for the educational attainment of adolescent girls and accordingly has developed initiatives to address MHM by improving sanitation in schools (8). Such initiatives are included within the nation's key sanitation strategy: Swachh Bharat Abhiyan (Clean India Mission) in the form of the National Guidelines on Menstrual Hygiene Management which provide 'action' and 'technical' guides to ensure schools have gender-segregated toilets to fulfil the need for privacy, and support adolescent girls during menstruation (22). Systematic reviews have demonstrated that the availability of adequate sanitation facilities can improve school enrolment and retention among adolescent girls (23-25) however, adolescent girls still face several challenges regarding menstruation, including sociocultural beliefs and taboos that influence adolescent girls' understanding of menstruation and management strategies (8, 26-29). For example, existing research on beliefs about menstrual blood (as impure or polluting) affects how girls manage menstruation and encourage various restrictive practices (8, 18, 26-28). In a study from Tamil Nadu it is suggested that restrictive practices and taboos are perceived to maintain religious purity (29). Such restrictions and taboos include isolation and restrictions on participating in daily activities, using separate supplies (such as using separate vessels or a separate mat for sleeping), being banned from puja room (where ceremonies take place), not touching flowers, or being in contact with men (29).

Despite expanding literature on MHM, there is still a lack of understanding of the complexities of this topic. MHM is often influenced by social and cultural beliefs that shape

attitudes toward menstruation, which must be considered when designing WASH health promotion interventions and programs. In addition, there is a need for an increased understanding of local menstrual beliefs and practices to help understand various constraints, restrictions, and pressures in a particular sociocultural context (30). According to a systematic review and meta-synthesis of qualitative literature on women and girls' experiences of menstruation in LMICs, there is also a limited understanding of individual personal experiences, due to the fact studies tend to rely on focus group discussions, which often divulge more collective experiences (10). Therefore, further research on adolescent girls' personal experiences with menstruation may shed light on important sociocultural insights that can lead to more effective and sustainable health promotion intervention planning and adaptation (31).

This study was informed by preliminary findings of other formative research activities (e.g. curriculum assessment and semi-structured key-informant interviews with stakeholders), which are not included in this manuscript and suggest that MHM is an important WASH-related concern among stakeholders from local healthcare and educational institutions. Therefore, this formative study engaged adolescent female students, positioning them as experts to understand experiences of menarche and menstruation, in order to adapt a school-based WASH health promotion intervention: Project SHINE (Sanitation and Hygiene INnovation in Education) (32).

RESEARCH OBJECTIVES

The objectives of this formative research were to explore 1) how adolescent girls in the rural community of Thirumalaikodi, Tamil Nadu, India experience menarche and menstruation; 2) how their experiences connect to the sociocultural context; and 3) what strategies they use to manage menstruation. These contextual and cultural insights are essential to adapt Project SHINE to the southern Indian context.

THEORETICAL GROUNDING

The use of a theoretical lens helped shape the research questions, data collection, and analysis (33). The study was informed by a feminist perspective, to shed light on gender-specific sanitation challenges and needs. The incorporation of the feminist perspective also allowed for exploration of gender-related experiences and the lived experiences of women. Feminist research aims to understand and challenge how individuals experience the world and through this understanding help facilitate change for marginalized or vulnerable groups, such as adolescent girls in India (33, 34). The feminist perspective was used in this study to explore the following conceptual ideas: 1) menarche and menstruation are a biological event that only women (girls) can experience and 2) recognition of the societal constructions of gender. Thus, in this study a feminist perspective is used to highlight the importance of the sociocultural context and its influence on adolescent girls' experiences of menarche and menstruation.

Gender must be understood within the social structure in which it was constructed, negotiated, maintained, and reproduced (35). These social structures are supported by gender norms which are "rules that govern the attributes and behaviors that are valued and considered acceptable by men, women, and other gender minorities" (35). Butler (36), argues that gender is not essential or natural, but rather forged from continuous gendered performances. Understanding gender as performative provided an entry point into understanding the complexities of gendered experiences. Moreover, the application of a feminist perspective informed our understanding of adolescent girls' experiences of menarche and menstruation, how gender is constructed, negotiated, maintained, and reproduced, and how these experiences connect to, and are shaped by the sociocultural context.

Materials and Methods

SETTING AND SAMPLE

The study presented in this paper, was part of the formative research phase in the process of adapting Project SHINE and took place in the village of Thirumalaikodi which is located in the Vellore district of the southern Indian state of Tamil Nadu. Two schools from Thirumalaikodi village were selected to participate in the study based on expressed interest in Project SHINE demonstrated by the local community. A sample of 10 adolescent girls in ninth standard (grade nine), who averaged 14 years from two schools in the rural community of Thirumalaikodi were invited to participate in semi-structured qualitative interviews from June-July 2018. Adolescent girls were the selected target group for this study because of their unique position to reflect upon their experiences with menarche and menstruation. Furthermore, adolescent girls in India are especially vulnerable to a range of adverse health and social outcomes such as urinary tract infections, reproductive tract infections, social stigma, shame, and school absenteeism (4, 27).

In this study, adolescents who attend school in Thirumalaikodi, primarily reside throughout the Vellore district, and commute to school six days a week either by foot, autorickshaw, motorbike, or school bus. Both schools selected for this study were English-medium private institutions however, a majority of the schoolchildren enrolled at these schools are the first in their family to read and write. Furthermore, and most notable, the temple and local spiritual leadership play a large role in education at the schools, thus reflecting local spiritual beliefs and values. For example, yoga, meditation, Vedic chanting, and traditional dance are regularly practiced at school. Additionally, at the time of research, there was not an active curriculum focused on MHM at either school.

Although there is little information published about Thirumalaikodi, information regarding the Vellore district itself (including both rural and urban areas), is more broadly

available. In the district of Vellore, there are approximately 3,9 million people who reside in 22 Town Panchayats and 858 villages (37). According to the Indian census, in Vellore, 22% of the population identified as Scheduled Caste, while 2% identified as Scheduled Tribe, there is a literacy rate of 79%, and 57% of the population reported that they are not engaged in any type of employment (37).

A purposive sampling strategy was employed to recruit participants for the study, which focused on the inclusion of girls who had already begun menstruating and included similar characteristics of future SHINE intervention participants (e.g. enrolled at the same school, similar age and locality). Verbal and written information about the purpose of the study was provided to girls before participating. First, adolescent girls were informed of the study through the research project's local community liaisons (two schoolteachers) at each school. Community liaisons informed students about the study by explaining that, researchers from Project SHINE were interested in speaking to them about their experiences with menstruation and their participation was entirely optional. If they indicated interest, they were invited to participate and asked to obtain written consent from their parent or guardian. Selection criteria for participation included the following: 1) must currently attend school in ninth standard, 2) be comfortable expressing themselves in English, and 3) attained menarche (onset of menstruation). Given that interviews were conducted in English (the primary language of instruction at the school) and not other local languages (e.g. Tamil or Telugu), adolescent girls were informed that interviews would be conducted in English prior to agreeing to participate. Although students were purposively sampled to mirror the future SHINE intervention's potential participants at the school, due to the nature of the study, representativeness was not prioritized. Instead, participants were purposively sampled to meet selection criteria to generate rich, in-depth qualitative data of

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participant's lived experiences.

A strong, researcher-participant relationship that established trust and rapport was key to sampling and data collection in this study. There was no existing relationship between researchers and participants at the time of data collection, however, the research team worked to cultivate trust and respect through other informal exchanges. For example, AGW and MH were introduced to students by the school principal at an all school assembly and frequently visited the school prior to data collection. Furthermore, the research team utilized assent forms and brochures to provide a clear understanding of the research project's main aims to nurture trust between researchers and participants. For example, assent forms and a study brochure were given to students which explained the specific aim of this study and provided additional information on confidentiality.

ETHICAL CONSIDERATIONS

Ethical approval was obtained by the Norwegian Centre for Data Research (reference numbers: 53162/54618) in Norway and the Institutional Ethics Committee/Institutional Review Board at the Sri Narayani Hospital and Research Centre (reference number: 30/25/02/17) in India. Due to the age of participants and the nature of the discussions, the research team set up several measures to ensure participants and parents fully understood the study requirements before agreeing to participate. First, assent from minors and written parental/caregiver consent was obtained. Then interviews were conducted in secured rooms at the school to ensure the privacy of participants (only participants and researchers were present during interviews). In order to protect participants' confidentiality, they were also reminded of their right to withdraw from the study at any time, the right to decline to answer questions, as well as their right to choose to turn the audio recorder off at any time throughout the interview.

DATA COLLECTION

A qualitative, phenomenological approach with narrative interviews was employed (38), so that questions were developed to help prompt participants to tell their personal stories. Semi-structured qualitative interviews were conducted by the first and second author (AGW and MH), both female researchers with experience in qualitative research methods who had previously spent several months in the community. Since the interviews dealt with a potentially sensitive topic, the research team received cultural guidance from local experts on MHM prior to data collection (e.g. appropriate framing and terminology). Interviews lasted for approximately 30-45 minutes and were guided by a five-question interview-guide. Interviews first explored constructions of gender, then participants were asked to share stories of their first period, followed by discussions about various experiences relating to menstruation. After the completion of ten interviews and three follow-ups, we determined that little new information was being generated therefore we had reached data saturation.

Semi-structured interviews were audio recorded and transcribed verbatim; however, participants had the option to turn off the audio recorder at any time, and three declined to be audio recorded (7 out of 10 participants consented to have their interviews audio recorded). During transcription, identifying information was removed to maintain the confidentiality of participants (e.g. names, dates, and places). For all interviews that were not audio recorded, the interviewer took detailed notes to capture experiences.

DATA ANALYSIS

Data were analyzed using Attride-Stirling (39) thematic analysis approach in conjunction with Dedoose software for managing qualitative data. First, we (AGW and MH) coded the data inductively. Then, codes (basic themes) were mapped and condensed into organizing and global themes, which will be discussed in further detail (39). In addition, in order to increase rigor, we

engaged in an inter-coder reliability exercise in which two members of the research team (AGW and MH) coded the same transcript, compared codes, and discussed their application of the codes, to ensure that there was a common understanding of codes, how they were defined, and applied. Analysis was also informed by a feminist perspective (36, 40, 41). The outcome of the analysis is shown in Table 1.

Results

Table 1 outlines the thematic map that comprises this study's findings (as presented below). The illustrative excerpts displayed are provided to highlight themes; however, they have been edited for readability. Edits included the removal of identifying information, paraphrasing, and enhancement of grammatical correctness since interviews were conducted in the participant's second language. For example, "I not listen" was changed to "I [do] not listen". Changes are indicated by square brackets.

TABLE1. THEMATIC MAP OUTLINING THE DEVELOPMENT/EVOLUTION OF CODES TO GLOBAL THEMES

Global Themes	*Organizing Themes*	*Basic Themes (Codes)*
Emotional duality of menstruation	Positive experiences	Rite of passage celebration
		Knowledge and understanding
	Distressing experiences	Taboos
		Psychological distress in different contexts
Negotiating 'womanhood': transitions and challenges	Gender norms and restrictions	Learning from mothers and grandmothers
		Impact on religious practices
	Accepting adult responsibilities	Loss of childhood identity
		Relationships in transition
Social navigation strategies while menstruating	Concealment and secrecy	Maintaining outward appearances
		Do not tell
	Self-imposed isolation	Non-participation at school
		Avoiding public spaces

MENSTRUAL PARADOX: THE EMOTIONAL DUALITY OF MENSTRUATION

Girls reported both positive and negative experiences of menarche and menstruation, this theme describes the conflicting emotions participants discussed. Often, positive experiences were associated with menarcheal rites, or a celebration described locally as a 'function' in which girls are honored by their family and friends over the course of several days. While this ritual may serve several purposes (e.g. relaying that a girl is now ready for marriage), the narratives presented by the participants focused on the celebratory nature of the experience. At menarche, girls also reflected retrospectively upon concerns, fears, and distress felt regarding the biological and social changes they endured. Therefore, we developed two organizing sub-themes which included 'positive experiences' and 'distressing experiences'.

POSITIVE EXPERIENCES

Adolescent girls described the *function* as a "happy" and "enjoyable" experience. They spoke about several practical components of the function, such as rituals and traditions performed, however, it was emphasized that missing school, receiving gifts (e.g. new dresses, saris, and gold), and seeing their extended family were their favorite aspects. One participant further elaborates:

> When we have periods, they will conduct the function, [with] our family [and] relations. They kept one basket on my head and then they [poured] water [on] me and a good moment happened, and I was so happy. A girl, I think, sometimes will be happy, sometimes I feel bad, but it is also a positive thing (Participant 10).

This excerpt illustrates how the function was a celebratory event for the girls as they express their elation with the activities and traditions that transpired.

Although many positive experiences centered on the function, one participant described the time of menarche in more general terms, as a natural event and opportunity for informing and promoting understanding:

> … Girls should not be scared of this, it's just a part of their life. If they get depressed on this, how will they face all the [other] situations…Because every girl will be getting this, [wherever] she is from, whatever the caste or whatever the country. She will be getting it. So, she should not think like, 'what will they think [about] it?' If it is spotting, she should be conscious and use the napkins. It should be in a proper size and everything. Nowadays everything is just developing, even the napkins are the correct size of the panty, so [there is] nothing to worry about. So, girls should not feel afraid for coming to school or wherever they're going (Participant 5).

Here the participant described menstruation as a naturally occurring phenomenon among all girls. She normalizes menstruation (confronting negative discourses of fear and shame), by highlighting that experiences of menstruation transcend socially stratifying structures such as nationality and caste. She also discusses the proper use of menstrual absorbents to avoid spotting and to feel comfortable in school, further reflecting upon how innovations are currently being developed to meet needs of girls, thus positively influencing MHM.

DISTRESSING EXPERIENCES

Girls also shared how menstruation adversely impacted their everyday lives through attitudes and beliefs that perpetuate taboos that incite concerns, distress, or fear. Often, participants entwined menstruation with distress. Distress may also reference psychological indicators such as sadness and stress. For example, girls were reportedly told that improper disposal of menstrual absorbents would attract wild animals, thus revealing when they were menstruating to others (a distressful thought). They were also told that ghosts haunt women during menstruation. One participant describes how she manages the ghosts by sleeping outside during menstruation, while others discussed the importance of carrying a copper nail to thwart them away. Such taboos may

lead to restraint and feelings of distress, or concern. This was illustrated in the following:

> We should not water plants… if we maintain a distance between the plant it is OK. [However] we should not touch, because, the plant will suddenly shrink, because it can't tolerate the heat [from] us. Women during that particular three to five days (during their period), we have more heat. It is prove[n] in science (Participant 5).

This participant describes how cultural beliefs regarding the heat tolerance of plants foster concerns that her menstruating body can potentially cause harm; therefore, she refrains from touching plants during the first days of her menstrual cycle.

NEGOTIATING 'WOMANHOOD': TRANSITIONS AND CHALLENGES

Often girls discussed how they were taught to follow various "rules" or cultural codes as newly menstruating women. These norms restrict behavior, social relationships, and personal conduct, which lead to the formulation of the global theme, 'negotiating 'womanhood': transitions and challenges' with an organizing themes, 'gender norms and restrictions' and 'accepting adult responsibilities'.

GENDER NORMS AND RESTRICTIONS

Throughout interviews, study participants described several "rules" or codes which entailed specific ways of dressing, acting, and interacting which we classified under the organizing theme, 'gender norms and restrictions'. Girls frequently reported engaging in gendered performances, which encompass acting 'feminine', abiding by "rules" or cultural codes, and engaging in appropriate conduct in their new identities as women. One participant shared that "rules" were often introduced at menarche when she shared that, "many rules was there when the first periods occurs (Participant 7)". For example, during their period girls described practicing

bathing rituals (e.g. head bath [1]), being restricted from spaces such as the *puja*[2] room at home and temples, refraining from cooking food for others, being segregated from other members of the household, and being instructed to use a designated plate for eating. One participant shared that during this time, she "will pray in my home itself, but not enter in the puja room (Participant 6)".

Several participants described not knowing about menstruation until they attained menarche. For example, one participant shared that she did not know she even had her period until after two days when her mother did her laundry, demonstrating a lack in basic menstrual-related knowledge. Although several participants did not expect the biological changes they would endure, "rules" or cultural codes were prioritized post-menarche. Girls reported that family members, especially their mothers or grandmothers, often taught them "rules" or cultural codes when they attained menarche, which governed attitudes, beliefs, and practices. One participant shares how these "rules" or cultural codes shape gender norms when she explains:

> She gave information about how to be proper, how to sit, and how to behave. We have to be studious, we have to remain a gap, and if we share something, you must think twice. You can't share everything to everyone (Participant 10).

Participants mentioned several examples of how gendered norms impacted religious practices. Norms often influenced the manner in which girls adapted as newly menstruating women. The

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[1] Traditional bathing of the head and hair done during menstruation, practiced both for hygiene and to alleviate symptoms associated with menstruation.

[2] Ritual acts of devotion and worship.

following excerpt describes how restrictive gender norms may have further implications when one participant shares:

> On my third time, when I got [it] I was not [aware of] the 28 days gap. We were out, and suddenly [while] traveling I got [my period]. I was not prepared for it. So, my trip was fully disturbed. Because of this, I should not go to temples. We had a plan of going to four temples the next day. [But], 'til the fourth day, until the period is controlled, we should not go to temple or worship God. [So] the trip cancelled, [and] because of me, no one went. Everyone was with me, so it disturbed me. Firstly, when I hear the news that we're not going to go anywhere, we have to stay at home, I was a little bit stressed. Like, what is this? [I think] because of me everyone is going to get moody. So, I thought if I would have stayed in my home, everyone will be enjoying. And second, I was disturbed because I could not go and experience all the places, like what we planned (Participant 5).

This quote illustrates how externally enforced restrictions of not being able to attend the temple can also be distressful when she describes her desire to attend the family trip, but the entire family was forced to turn around because she was not allowed to enter temples. Furthermore, this participant emphasizes the guilt she felt when she blames herself for the trip's cancellation and wishes that she had stayed home so the rest of the family could go.

ACCEPTING ADULT RESPONSIBILITIES

As girls enter womanhood, they describe shedding their childhood identity. In many ways, childhood is connected to freedom, and post-menarche "rules" establish codes of conduct to be followed that promote a separation between genders or gendered behaviors. Several participants discussed how gender roles were enforced after menarche, which promotes shifts in their identity. One participant describes the transition as an advancement into adulthood when she says,

> When I was small, my mother [would] clean all things. I [was] enjoying the small age. Then when I'm coming on ninth standard, and I get periods, oh, why, it's very difficult. I feel

difficulties, after that periods. Before periods, I was really enjoying that age and I was playing with everybody, boys… girls. And, before periods I will wear normal [clothing], now I have to cover everything (Participant 6).

Other participants echoed similar sentiments by elaborating on how the adoption of cultural codes enforces gender norms that restrict behaviors in womanhood:

It completely changed. When I was before the age (of menarche), I had all rights to go here [and] there and there [were] no restrictions. After the age of adolescences, restrictions were, not about talking to someone, but it was physically. Like, you can't go everywhere you want. You will need a guide to guide you, 'til you complete your teenage [years]. So, a little bit of restrictions [were] raised. And I also had responsibility in my home. And contact to males, like gents, we have to have a gap (Participant 5).

Both excerpts illustrate the transition of identity after menarche. The participant describes changes as a swift descent from freedom to the staunch adherence to various cultural codes. She expresses her difficulty in dealing with this transition and loss of freedom.

Participants revealed that gender norms had a profound influence on their conduct, which affected relationships with others. Moreover, participants suggested that the relationships most affected were their relationship with men in their lives such as neighbors, friends, cousins, and their father. One participant shares these relationship changes after menarche:

Yes, my life has changed totally when [the] first period occurs, and my mom, and my sister, my grandmother, all said you should not play with boys, you should not go outside regularly, you should not play with all, but you should not talk to all. You should be in limit, and the fathers also be in their limit. Before they are very friendly with us, but [when] the period occurs they will not [be] friendly with us [any]more. I felt very sad of that. I felt very sad. My brother, my father, all are separated, [there is a] little bit distance [between] us and them (Participant 7).

Here, this participant talks about the vast transition her life underwent after menarche, most notably the enforcement of gender-influenced attitudes, beliefs, and practices (e.g. separation

between genders). The participant expresses dismay and sadness that she will no longer be able to maintain relationships with important people in her life because of their gender (e.g. brother and father). The same participant continues:

> [Before], we can talk, we can enjoy, we can go anywhere, we can play, we can do anything with our father. But [when] periods occurs, all things will stop, and [a] limit is there. [A] little bit [of] distance also will be there. When we are sitting, we can feel the distance of our father and it feels so bad too. Mainly the olden [generations] they are following these rules and taking to our modern world. It is not good, I think so. We can't separate and limit, it's not nice, I feel very bad (Participant 7).

SOCIAL NAVIGATION STRATEGIES WHILE MENSTRUATING

The global theme, 'strategies to navigate menstruating body' describes various coping mechanisms that participants developed to cope and manage menstruation. We identified two organizing themes, which include 'concealment and secrecy' and 'self-imposed isolation'.

CONCEALMENT AND SECRECY

Participants frequently shared how their periods were a private matter, not to be shared with others. One participant explains, "Whether we have periods or not, we should not tell others. It's embarrassing (Participant 1)." Participants also developed personal approaches to conceal menstruation, which included secrecy and isolation. One participant describes how she copes with menstruation by concealing it from peers and family:

> But my friends cannot identify whether I have periods or not. One basic thing ma'am, girls are keeping black *bindi*, [when] they have periods. …And in our family, also, girls we should keep

only black [during] our period days. We should not keep that sandal, *kum kum*[3], any of that. Only black *bindi*. I don't like. My friends are teasing. So, whether [I have] periods or not, I don't tell (Participant 1).

Here, the participant describes the routine practice of women wearing a black *bindi*[4] during menstruation. However, when she is menstruating, she avoids wearing this *bindi* to conceal or hide her menstrual status from others, including her grandmother. She also discusses the embarrassment she feels when she gets her period mainly because of teasing and taunting from peers, alluding to the implications of cultural practices on her psychosocial wellbeing. Therefore, she has developed a strategy of secrecy that helps her cope with the shame and stigma she experiences during menstruation. By choosing not to wear her black *bindi* she resists this cultural practice. However, it is unclear if this resistance is rooted in denial of the auspiciousness of the practice, or if she has prioritized protecting herself and concealing her menstruating body. Either way, this excerpt illustrates an example of an approach to concealing menstruation and how participants may feel uncomfortable sharing their menstruation with others.

SELF-IMPOSED ISOLATION

Participants also discussed internally-imposed withdrawal and isolation as an approach to cope with menstruation. Withdrawal can lead to feelings of loneliness, failure to develop healthy attachments to others, and failure to participate in various community, academic and work activities. Throughout interviews, participants described self-inflicted withdrawal from school, social environments, and relationships. One participant reveals:

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[3] *Kum kum* is a red powder composed of lime and tumeric that is commonly applied to the center of one's forehead

[4] A *bindi* is a marking applied to the center of the forehead, traditionally placed on the sixth chakra, or third eye.

[At] school we don't discuss this. When someone is so sad, in this time, in our school, my good friends, they'll just sit alone, they'll not mingle into the group. They just sit alone, and they just feel sad. I personally will ask what happened, they'll say, "I got periods". Why are they not coming out? They are afraid if they stand, something will happen on their dress. So, they are personally disturbed. In this way, they are disturbed mentally, physically. They can't concentrate even on studies (Participant 5).

Here, the participant describes a lack of openness around the topic of menstruation among her peers. Girls at school will withdraw from activities (due to fear of spotting on their clothes). This withdrawal and isolation during menstruation impacts both academic achievement and psychosocial wellbeing. For example, one participant describes an experience with her period at school:

[During my] first period, my teachers [asked] me, "Why are you late?" [However] I'm not seeing [my teacher], I'm thinking about, why [is] this problem coming now! I'm thinking about that only. For that class, I [do] not listen, [I am] confused. When I go home, and [read], I'm confused. I can't learn the lesson. In that time, I am not listening [in] class. That time I say [to myself] why is God doing like this? I am thinking about that only. That time I'm [scared], very [scared] (Participant 2).

The participant discusses having difficulty focusing in school when she has her first period, which affected her school performance and ability to fulfil class assignments. Here, her inability to cope with menstruation leads to distress and fear.

Participants also discussed how restrictive gender norms also influenced internally-imposed withdrawal. One participant describes:

When I get periods, I avoid going to shops. Because many of the male guys will [be] in that place and then I don't know how to be still a girl. I want to become a brave woman so, that I can be maintaining my distance with all of those [men] who are aged. When I am in [my] home, I feel so lonely, because always I am home. I do not like to [be] with men, like aged. I think it's dangerous for me. Something will happen. So that I did not go (Participant 10).

This excerpt describes the internally-imposed protective measures or strategies she has developed to avoid contact with adult men. Moreover, she suggests that brave women are able to properly maintain a distance with men, describing contextual cultural codes, thus demonstrating how her construction of bravery or fearlessness is still significantly informed by gender norms.

Another participant shares how internally-imposed protective measures potentially impact academic achievement and school attendance:

> I used to say [to] my friends, like, "This is just a part of life, so we should not get depressed on this particular thing." But other girls are really afraid of coming to school, whether someone will see us, or something will look odd… (Participant 5).

Here, this participant illuminates how motivation to conceal menstruation from others affects other aspects of everyday life.

Discussion

This study revealed that adolescent girls' experiences of menarche and menstruation are largely shaped by cultural codes and gender norms, which further influence gendered attitudes, beliefs, and practices that construct and maintain conceptions of womanhood that alienate, isolate, and restrict.

Among participants in this study, menarche attainment was perceived as both positive and distressing. Positive aspects reported focused on the traditional practices associated with menarche (menarcheal rites). Girls described how they felt happy or joyful because of celebratory menarcheal rites of passage into womanhood, during which, family members gave the girls gifts of clothing and gold. An emphasis on the positive aspects of menarche is at odds with other studies that often characterize menstrual-related experiences as negative, thus demonstrating the complexities and paradoxes within adolescent experiences of menarche and

menstruation. This finding is also consistent with other literature that documents menarche as a celebrated rite of passage (42). However, these rites still exist within an overall discursive positioning of menstruation, which highlights distressing experiences. Researchers have previously explored experiences of women and girls with menarche and menstruation through a feminist lens, and how these experiences may shape their identities and role as women (15, 43-45). Furthermore, feminist research highlights how negative experiences with menarche and menstruation may be influenced by the sociocultural and historical context which heavily influences cultural attitudes and beliefs (43).

Girls also reported several cultural codes that influenced their personal experiences. These cultural codes encompassed cultural and spiritual rituals and practices such as bathing rituals or a 'head bath', which would alleviate physical symptoms associated with menstruation and ensure purification, hygiene, and cleanliness. In addition, several participants described how they did not attend temple or enter the puja room at home during menstruation, revealing that these beliefs inform practices in their everyday lives. It was also explained locally, that girls were prohibited from attending temple, since they are believed to be incapable of withstanding divine energy. Furthermore, participants discussed avoiding contact with plants, as well as other practices such as sleeping outside to manage ghosts, refraining from cooking for the household, or using a designated plate for eating, which demonstrates how culturally informed attitudes, beliefs, and practices influence adolescent girl's personal experiences with menstruation. Other research from Tamil Nadu and different contexts and cultures has suggested that cultural codes post-menarche also promote similar gender norms and rituals. For example, findings from a multi-site study reveal that respondents reported they believed menstruating women should not visit temples or religious sites because of their impure state (46). Another study from Tamil

Nadu, also suggests that restrictive rules influence dietary habits such as avoiding non-vegetarian foods (e.g. meat, fish, and eggs) at menarche (47).

Girls developed mechanisms to manage menstruation such as internally-imposed strategies to cope with or conceal menstruation, which often included secrecy, isolation, and withdrawal. Indications that menstruation should be kept secret, suggests that menstruation is perceived as an embarrassing or shameful occurrence by some study participants. Throughout interviews, girls discussed their efforts to conceal menstrual bleeding. For example, one participant shared how she refused to wear a black *bindi* to suppress any visual cues, which may disclose that she is menstruating to others. *Bindis* are an auspicious mark or dot that is traditionally worn by Hindu women, however in this context, we observed women of different faiths performed this practice daily, to protect the Sixth Chakra or Third Eye. Thus, demonstrating the cultural and spiritual significance of *bindis* in this context. Other studies in Indian contexts, also described MHM practices that are motivated by a desire to conceal or hide menstrual blood. A study in Mumbai, also discusses concealment. This study revealed that girls dried menstrual cloths under their clothes in order to conceal menstruation from male family members, while another study in Odisha reports that women use discretional strategies to eliminate lingering traces of menstrual blood when washing their clothes (48, 49). However, as illustrated by the example of the black *bindi*, girls emphasize the importance of concealing strategies to prevent others from knowing they are menstruating. Feminist scholars discuss how experiences with menarche and menstruation among adolescent girls are frequently characterized by secrecy and concealment and fueled by cultural beliefs that suggest menstrual blood is impure (43, 50-52).

These cultural codes also had profound influences on familial relationships between genders (e.g. father/daughter or sister/brother). At menarche attainment, girls were separated from the household in the lead up to their function (menarcheal rite), which foreshadowed changes in participants' relationship with men in their families. Girls also discussed how they felt post-menarche, when cultural codes restricted their relationships with men, which led to social withdrawal and isolation. Here, study findings reveal how social constructions of gender shaped menstrual-related cultural codes and/or 'menstrual etiquette' (53) that lead to gendered performances that maintain idealized distinctions between masculine and feminine (54).

Participants also discussed how post-menarche, they were instructed (often by family members) to modify conduct, relationships, and clothing to successfully transition into womanhood. As one participant stated, it was explicitly communicated that as a woman, it was now important to act 'proper' to maintain respect. Respect is important in this context and often entails respectful ways of greeting others, dress, gestures, and ritual. This is reflected in other research about menstruation. Garg, Sharma (16) discuss how adolescent girls are told they must avoid behaviors, restrict interactions with men, dress modestly, and not touch religious texts or visit holy places. This further illustrates how menarche launches a transition into womanhood, which considerably impacts the lives of adolescent girls.

Throughout interviews, girls also discussed their experiences with menstruation in the context of the school. At school, various restrictions linked to menstruation may be discursively positioned to generate negative attitudes around what it means to be a girl, demonstrating how gender norms are affected during adolescence. Furthermore, participants discussed how they were uncomfortable talking to friends about menstruation because they feared menstrual-related bullying. In addition to teasing and gossip associated with menstruation, girls discussed how

menstruation affected their social relationships and their ability to engage in school. This is consistent with other research on menstrual-related bullying, which demonstrates how fear of teasing is interlinked to menstrual odor or leakage (55). Moreover, other research reports that a lack of understanding from male classmates fosters an unsupportive social environment at school (56).

Feminist research which explores experiences with menarche and menstruation focuses on how such experiences are constructed, negotiated, maintained, and reproduced through various social interactions that evolve from sociocultural representations and practices (43). Excerpts presented in this study demonstrate this link between experiences with menarche and menstruation and the local sociocultural context. Several participants described knowing little or nothing about menstruation pre-menarche. One participant shared how she did not know she was having her period until after the second day, when her mother discovered bloodstains in her underwear. Several participants described information about menstruation being transferred inter-generationally through their mother, grandmother, or other family members. Other research has yielded similar findings, which suggest that insufficient knowledge about puberty, reproductive health, and menstruation is transferred inter-generationally, leaving adolescent girls poorly informed and ill-equipped to cope with menstruation (57-59).

Insufficient knowledge also may contribute to perpetuating negative interpretations of womanhood, leading to isolation, shame, and fear (27). Based upon the type of knowledge emphasized and transferred by family members, we discern that this information contributes to the discursive positioning of menstruation as something negative. Drawing from the work of feminist scholar Lovering (51), instead of labelling girls as 'ignorant', and faulting the mother or teachers for menstrual knowledge gaps, in this study, we also tried to reflect upon and consider

how other factors may profoundly influence knowledge production and transfer. For example, adolescent girls may lack knowledge about menstruation because the sociocultural context positions menstruation as problematic, thus difficult to discuss with others. Furthermore, knowledge transfer may be minimal because cultural and historical beliefs make it embarrassing or taboo to discuss menarche, menstruation, and/or menstrual blood. Commonly, adolescents learn about menstruation from others, however it was revealed that menstrual hygiene education at school was limited. For example, some programs that addressed MHM at the schools where research was conducted were no longer running at the time of data collection.

There are several strengths and limitations of this study. Prolonged engagement is a technique that helps establish rapport, strong relationships, and credibility among participants (60). First, researchers attempted to establish rapport by spending time volunteering at the school, and by attending local festivals and events; however, due to the sensitive nature of this study, some participants still felt uncomfortable sharing their experiences and declined permission to have interviews audio recorded. However, efforts were made to ensure participants felt safe by explaining confidentiality procedures and securing a private room to conduct interviews. It is important to acknowledge some of the researchers' status as outsiders to the community and the power imbalance that entails, as well as the effect this could have had on data collection. Therefore, it was crucial that we incorporated local capacity and expertise into the research design and manuscript writing processes, to establish a cooperation that was culturally respectful, collaborative, and mutually beneficial (61). The added value of the research team's personal experiences from the field also informed and helped develop findings, however, we recommend a more rigorous integration of informant feedback (e.g. member checks) to help build a more rich, nuanced, and complete understanding of the context. Strengths also included

the application of an intercoder reliability exercise to enhance consistency in coding among researchers, which also strengthened rigor of findings.

However, there were also some limitations with the study. Interviews were conducted in English, which, while the primary language of instruction at the school, is not the first language of the participants, and could have affected some participant's ability to fully express their personal experiences. Language could have also influenced the clarity and flow of communication and analysis. It is also vital to acknowledge that the methods employed, and the sample selected may limit the ability to generalize findings to other contexts and populations. Nevertheless, this was not the purpose of this formative work, rather we tried to recruit a sample that would mirror future intervention participants. We hope this study provides rich contextual insights into this population, in addition to exemplifying how formative research can be used in the cultural adaptation process for school-based WASH health promotion interventions. However, we recognize the value of further exploration of adolescent girl's experiences of menstruation and menarche with the inclusion of a more diverse sample (e.g. inclusion of participants from a diverse locality). Furthermore, this study utilized a feminist perspective, identifying it as an important lens for research regarding MHM. However, since male and female adolescents have very different experiences regarding menstruation, data from adolescent boys were not collected, thus limiting insights on adolescent boy's menstrual knowledge gaps and commonly held beliefs. Therefore, we recommend further qualitative research (e.g. interviews, focus group discussions, or use of other participatory methods) to include those perspectives.

Findings from this formative work were used to inform the adaptation and development of school-based WASH health promotion intervention activities. This adaptation process utilized a combination of adaptation frameworks such as Mckleroy and Wingood's Map of Adaptation

Process (62) and Rescinow's Cultural Sensitivity Framework (63). Based on findings, we adapted Project SHINE to include additional intervention components that address insufficient knowledge of menstruation, social support networks, and various attitudes and beliefs that perpetuate stigma and taboos at school.

In making adaptations to the original SHINE curriculum, we sought to specifically address information gaps and popular myths regarding MHM in this context. First, it was critical that intervention content be adjusted and include additional participatory activities focused on MHM, to coordinate with Project SHINE's participatory nature (32). For example, a peer-to-peer MHM activity was introduced which employed age-appropriate visual aids such as the Menstrupedia comics to address information gaps and other interactive teaching strategies (e.g. role play) to enhance social support networks that promote a supportive school environment. Additionally, another educational lesson with a special focus on MHM was included which utilized interactive games that aim to debunk specific menstrual-related myths and taboos that are prevalent in this sociocultural context (e.g. girls have the potential to contaminate/harm plants during menstruation). Tailoring and changes also addressed prevalent beliefs and practices that may be harmful to adolescent girls.

Conclusion

This study highlights menarche and menstruation experiences of adolescent girls in rural India with a specific focus on generating an in-depth understanding of the local sociocultural context. Findings suggest that menarche inaugurates biological transitions of puberty and cultural codes or restrictions that cultivate rigid gender roles and norms. Furthermore, gender norms also generate, maintain, and reproduce stigmatizing attitudes, beliefs, and practices that influenced the development of coping mechanisms related to MHM at home and at school. In addition, this study demonstrates the importance of qualitative research in unpacking adolescent girls' personal

experiences, which contributes to rich formative research for the adaptation and tailoring of

WASH health promotion interventions to suit the local context.

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Data Availability Statement

The datasets generated for this study are available on request to the corresponding author.

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UNDERSTANDING ADOLESCENTS' PERCEPTIONS OF DIARRHEA: A FORMATIVE RESEARCH STUDY OF A VISUAL SCALE TO MEASURE SELF-REPORTED DIARRHEA IN LOW-RESOURCE SETTINGS

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Abstract

Introduction: Although water, sanitation, and hygiene interventions are effective in reducing diarrhea, there are methodological issues regarding the research tools used to evaluate their health impact. Moreover, there is limited research on individuals' subjective interpretations of diarrheal illness, which may introduce further limitations in relying on self-reported data. Therefore, we conducted a study which aims to understand adolescents' perceptions of diarrheal illness in rural Tamil Nadu, India. Next, we wish to explore the acceptability of the Bristol Stool Form Scale to assess self-reported diarrhea in water, sanitation, and hygiene interventions involving adolescent participants in low-resource settings.

Materials and Methods: The study was conducted as part of the formative research phase in the cultural adaptation of Project SHINE, a school-based educational water, sanitation, and hygiene intervention in Thirumalaikodi, Tamil Nadu, India. A convergent parallel mixed-methods study design with a purposive sampling strategy was used. Qualitative data included ten in-depth interviews with student participants aged 13-14. Quantitative data were collected through interviewer administered face-to-face surveys (n=14) and one-week stool diaries (n=14). Each data set was analyzed separately and compiled during interpretation of findings.

Results: Across all data sets, diarrhea was reported to be perceived as unhealthy and an irregular occurrence among participants. Participants also reported diarrheal-taboos, local methods to cure or control diarrhea, and discussed how diarrheal illness can lead to absenteeism or withdrawal from school and social activities. Moreover, participants were able to understand and answer questions about their stool using the Bristol Stool Form Scale, suggesting that is an acceptable tool.

Discussion: Visual tools demonstrate promise in improving self-reported diarrheal illness among adolescents in low-resource settings in India. However, until we address diarrhea-related taboos, it will be difficult to address methodological issues in the assessment and reporting of diarrheal illness among adolescents.

1   Introduction

Diarrheal disease is often caused by bacterial, viral, or parasitic organisms, often due to unsafe drinking water, inadequate sanitation, or poor hygiene (1-4). Globally, three out of ten people do not use safely managed drinking water and an estimated six out of ten lack access to sanitation services (5). The population most affected by diarrheal disease are children under five in low- and middle-income countries (6, 7), however children older than 5 years, adolescents, and adults also experience more than 2.8 billion episodes of diarrhea per year (8), demonstrating how diarrheal disease affects the mortality and morbidity of individuals in all age groups (9, 10). Furthermore, even though few studies have been conducted on the health and social

consequences of diarrhea among adolescents, researchers connect diarrheal disease among adolescents to school absences and hospitalization (8, 11).

In countries such as India, diarrheal disease claims the lives of approximately 300,000 children under 5 each year (12). Furthermore, India has one of the largest populations globally, which lack access to clean drinking water and sanitation coverage (13). As of 2015, 66% of the population in India still lacks access to basic sanitation and 22% lack access to basic drinking water (13), illustrating how water, sanitation, and hygiene (WASH) continues to be a major public health challenge in this context.

Systematic reviews have demonstrated that WASH interventions are effective in reducing diarrheal disease (14, 15); however, there are still lingering methodological issues pertaining to the research tools used to evaluate health impact in low-resource settings. In WASH interventions, data collection tools to investigate diarrheal disease often include objective measurements such as stool collection (assessing enteric pathogens), observation (caregiver reports of frequency/consistency), and self-report. However, stool collection is costly, requires expertise, facilities, storage, and has several other logistical limitations (16), while caregiver reporting can be unreliable (17). Furthermore, evidence of the impact of WASH interventions on child health is mixed, since, many studies rely on self-reported symptoms, which can be susceptible to biases (recall, social desirability, and measurement error) (16, 18, 19). Despite evidence suggesting that self-reported outcome measures are unreliable, studies investigating the impact of WASH interventions continue to rely on them.

There is also a lack of conceptual clarity concerning diarrhea (17, 19-22). Several definitions of diarrhea exist to assist with the diagnosis. Researchers and practitioners tend to use the World Health Organization's (WHO) definition, which is based on a study of children in Bangladesh (22). The WHO defines diarrhea as three or more loose or watery stools in 24 hours (23). However, individuals may have different subjective interpretations surrounding the definition of diarrhea, which introduces methodological challenges in self-reporting (16, 21, 24). Subjective interpretations of diarrhea may be informed by their unique cultural context; therefore, it is difficult to determine a single unanimous understanding of diarrhea between researchers, practitioners, and study participants. Finally, such discrepancies in understanding of diarrhea may also have profound consequences on how the impact of an intervention is understood, where diarrhea is a primary outcome.

In a recent review of 55 WASH interventions with the intended purpose of reducing diarrheal disease, 36 studies applied the WHO definition (25). Despite the widespread use of the WHO definition, there is still limited research exploring cultural and contextually influenced diarrheal illness representations (19). Researchers must acknowledge these limitations when using self-report instruments in WASH research, given that diverse representations and perceptions of diarrheal illness held by the population of interest may introduce measurement errors. This demonstrates a need for in-depth exploration of alternative methodological approaches and data collection instruments to investigate diarrheal disease in various contexts.

Further exploration of illness representations reported by children and adolescents are also important for assessing WASH studies involving adolescents. Studies have shown that health assessments by adolescents are susceptible to measurement error, because their illness representations may be influenced by accelerated physical and psychosocial developmental changes (26-29). Therefore, perceived health status is enhanced if adolescents perceive data collection tools as acceptable and helpful in self-reporting.

The present study addresses understanding of diarrheal illness and corresponding self-report challenges among this age-group, addressing the knowledge gap concerning. It is important to note that this study focuses on diarrheal illness rather than diarrheal disease, because illness is a more subjective interpretation of ill-health, rather than objectively, pathologically, or medically defined and measured disease (30-33). Furthermore, illness representations are cognitive beliefs that an individual develops to structure their perceptions about an illness, which often include multidimensional components that identify symptoms, severity, duration, and cause of an illness (34). Here, we apply the Common Sense Illness Representation Model (CSIRM) (34), which is an explanatory model to assist in the exploration of individual's illness representations (35, 36).

In an effort to improve approaches for measuring self-reported diarrheal illness among adolescents for a school-based WASH health promotion intervention and to exemplify youth-focused intervention adaptation processes, we conducted a small-scale descriptive study as part of the formative research phase in the cultural adaptation of Project SHINE (Sanitation and Hygiene INnovation in Education) (37).

To the best of our knowledge, this is the first study that investigates diarrheal illness representations using the Bristol Stool Form Scale (BSFS), among adolescents. The aims of this study are two-fold. Firstly, to understand cultural representations and perceptions of diarrheal illness among local adolescent students from the rural community of Thirumalaikodi, Tamil Nadu, India. Secondly, to explore whether the BSFS was suitable for local adolescent students from this community (acceptability).

2   Materials and Methods

2.1   Study Design

In this study, we employed a convergent parallel mixed-methods study design (38). Creswell and Clark (38) explain that this design enables the researcher to develop a more 'complete understanding' of a given phenomenon. Quantitative and qualitative data were collected concurrently, then data underwent separate analysis processes. This study was also based on criteria for studies which explore acceptability articulated by Bowen, Kreuter (39) and as such there is greater emphasis on the qualitative component presented in this manuscript.

2.2   Study Setting

The study was conducted from October 2017 to July 2018 at one school (grades Kindergarten-12) in Thirumalaikodi, a village in the Vellore district in the southern Indian state of Tamil Nadu. The Vellore district has a population of approximately 3.9 million with a majority being Tamil speaking and Hindu (40). Other predominant languages are English and Telugu. The district is

primarily rural and is made up of 858 villages and 36 towns each under the authority of 22 Town Panchayats (40). Additionally, located within the area is spiritual leader, Sri Sakthi Narayani Amma and the Sripuram spiritual park devoted to Sri Lakshmi Narayani informing the community's strong cultural and spiritual values.

2.3   Sampling/Recruitment

All participants were enrolled at the school in which the future Project SHINE intervention took place. Project SHINE is a health promotion intervention that aims to improve sanitation and hygiene-related knowledge, attitudes, and practices among students and teachers through the application a community-based participatory research (CBPR) and participatory science (37). Therefore, adolescent study participants were representative of future SHINE intervention participants. Since Project SHINE is a CBPR intervention, it is important that participant and community input was considered in the adaptation of intervention content and evaluation tools, to ensure cultural appropriateness. Adolescents were selected to participate in this study, as part of the formative work conducted jointly with youth, the target population of the future SHINE intervention, to promote knowledge co-creation, and to increase understanding of local youth perspectives. The school was selected based on interest expressed by the local community, and a partnership between researchers and local institutions (e.g. schools, hospital, and spiritual leadership).

Schools and students included in this study were selected according to the following recruitment strategy: First, the school was selected from the set of schools invited to participate in the larger intervention study. We obtained approval to conduct research activities and to implement the intervention from gatekeepers and local leadership. The school principal subsequently assigned a local community liaison (a schoolteacher), to work with the research team and was responsible for coordinating recruitment, collecting diaries from participants, and scheduling the survey and interviews.

Secondly, a purposive sampling strategy was employed to recruit participants for the study. The community liaison was assisted by ninth standard class teachers to invite students to participate in the study who met following selection criteria: (1) currently enrolled at intervention school; (2) in ninth standard; (3) comfortable expressing themselves in English; (4) open to sharing experiences about diarrhea and health; and (5) willing to provide assent to participate and obtain written parental/caregiver consent.

Teaching staff at the school informed students about the purpose of the study before inviting students to participate. Efforts were made to ensure similarity between study participants and future intervention participants because findings from this study would inform survey development, which all intervention students would then complete. Therefore, the research team focused recruitment criteria on participants who attended the same school, on ensuring an equal distribution of sex (although more girls than boys agreed to participate) and geographical background (all from the Vellore district). In total, 15 students agreed to participate. Of the 15 students who agreed to participate, one was excluded from the survey and diary data collection

activities since they were absent from school during the time the survey was conducted. Table 1 shows the participants' demographic characteristics.

Table 15. Participants' demographic data; adolescents' perception of diarrhea study, Tamil Nadu, India.

Variables		Number of participants	Percentage
Sex	Female	9	64.3 %
	Male	5	35.7 %
Age	13	4	28.6 %
	14	10	71.4 %
Education level	Grade 9	14	100 %
Water Source (at home)	Tap or piped	8	57.1 %
	Rainwater	0	0 %
	Lake or pond	0	0 %
	Water truck	1	7.1 %
	Water vendor	1	7.1 %
	Dug well	0	0 %
	Tube well or borehole	7	50 %
Diet	Vegetarian	0	0 %
	Non-vegetarian	14	100 %

*Three participants reported more than one water source

Prior to data collection activities, the research team conducted additional research activities with other groups of students at the school. This means that although there would be a level of awareness about the project in general, none of these students had participated in any other project activities. Therefore, in order to build trust between researchers and study participants, the research team utilized assent processes and an introduction meeting (which explained aims of this research study and provided additional information on confidentiality) to nurture rapport between researchers and participants.

2.4   Bristol Stool Form Scale (BSFS)

Stool form is an essential criterion for the assessment of diarrheal illness (23, 41). Visual and descriptive tools that evaluate stool consistency may help improve and standardize measures and potentially improve self-reported diarrheal illness among adolescents (42). One such visual tool, the BSFS, was developed by Lewis and Heaton (43). The BSFS ranks images of stool on a scale of 1-7 based on consistency from Type 1 (separate hard lumps) to Type 7 (watery). Type 6 and Type 7 are classified as diarrhea (44, 45).

Although the BSFS was originally developed and validated in Bristol, United Kingdom for adults with irritable bowel syndrome, this study aims to explore its acceptability with a different contextual setting, population, and health challenge. As mentioned previously, the application of the BSFS in WASH research could reduce several types of error related to bias (recall and social desirability) and comprehension (standardize the definition of the disease under investigation) (19). Therefore, we set out to explore if the use of the BSFS to self-report bowel movements among adolescents was acceptable from the perspective of prospective intervention participants.

2.5   Data Collection

2.5.1 Qualitative Data Collection

Qualitative research methods were applied to obtain a better understanding of adolescents' knowledge, perceptions and practices relating to diarrheal illness (46). Semi-structured qualitative interviews were conducted with 10 students (7 females and 3 males). The aim of interviews was to gain insights on cultural representations and perceptions of diarrheal illness and the acceptability of the BSFS as an assessment tool for self-reported diarrhea. Acceptability was explored through interview questions regarding attitudes and opinions about experiences filling out stool diaries which were based on the BSFS. Participants were purposively sampled and recruited by the community liaison.

A semi-structured interview guide was prepared based on the CSIRM (34). The CSIRM is an explanatory model that assists in the exploration of 'lay views' or individual's illness representations (35, 36). Interview questions explored constructs of the CSIRM (identity, cause, timeline, consequence, cure (34) (See Table 2)) and the BSFS in order to investigate if the use of the instrument was comprehensible, culturally appropriate, and acceptable in this context (See Table 2). Questions included open-ended questions about the terminology used to describe diarrhea, symptoms, perceived causes, and control/cure (47).

Table 16. Overview of CSIRM and corresponding interview questions asked (adapted from Babooram, Mullan (48))

Construct from CSIRM	Example of questions asked
Identity	What is the difference between diarrhea and other types of poo?
Cause	How do you think someone might get diarrhea?
Timeline	Can you tell me what happens when someone gets diarrhea? What happens next?
Consequence	What kinds of problems might they have?
Control/Cure	What would they need to do to get better?

All qualitative semi-structured interviews were carried out in English by the first author (AGW) who has previous experience in qualitative research methods. Interviews were conducted at school in a private classroom, lasted from 20-40 minutes, and were audio recorded with consent of participants. As previously mentioned, during interviews, one participant indicated that they were uncomfortable being recorded and the audio recorder was subsequently shut off. Instead the interviewer (AGW) took detailed notes for this participant. Data collection continued until 10 participants were interviewed and data saturation was achieved, thus no new information generated.

2.5.2 Quantitative Data Collection

Quantitative data were collected through interviewer administered face-to-face surveys (n=14) and one-week stool diaries (n=14). The sample size was determined by the study aims which were to explore acceptability, therefore we determined a small sample would be adequate (49). Interviewer administered surveys were conducted by two female researchers from the local nursing college (SG and RS). Surveys were conducted at the school in a private classroom with blinds/door shut, thus no students were observed during the process. The survey was adapted from a previous BSFS validation study by Guled (50) to appeal to the specified research aims and target population of this study. It included questions concerning demographics, diet, and

perceptions of stool using BSFS. Participants were also asked to report on their most recent stool, according to the BSFS. Participants were then requested to complete daily stool diaries for 1-week which used the BSFS to assist in the standardization of illness representation. Furthermore, the application of the BSFS in the diaries and survey triangulated data in order to broaden our understanding of the self-reported stool form and diarrhea among adolescents in this context.

2.6   Data Analysis

2.6.1   Qualitative Analysis

In the qualitative portion of this study we sought to increase our understanding of diarrheal illness and reporting practices from the perspective of those experiencing it. Data were analyzed using directed content analysis (51), which employs the deductive use of theory to guide analysis. This approach is particular useful to explore multifaceted and sensitive topics such as ours (52). Here, the CSIRM provided a foundation for the initial codebook and coding scheme (53-55). In order to explore the BSFS acceptability, attitudes regarding the BSFS were also segmented and coded. All interviews were conducted, coded, and analyzed using qualitative data analysis software, Atlas.ti software version 7 (Atlas.ti GmbH, Berlin) by the first author (AGW). Transcription was conducted by the first and last author (AGW and SB). First, we read text transcripts to get a sense of the whole, then we segregated text into meaning units which were identified and categorized using predetermined categories/themes (informed by the CSIRM and the BSFS). Finally, all text that did not correspond with any of the predetermined categories were given a new code. An example of coding is shown in Table 3.

Table 17. An example of the qualitative analysis process

Meaning unit	Codes	Category
First *of all we need to [tell] my… our, parents, because they are taking care of us. Our parents or grandmas will be using some of the medicines to cure it (Participant 1).*	Communication with others Culture Family	Cure/control

2.6.2   Quantitative Analysis

Our quantitative investigation aimed to summarize and organize salient information on cultural representations and perceptions of diarrheal illness and the BSFS as a tool for self-reporting in WASH interventions involving adolescent participants. We used the SPSS software version 25 to analyze the data (SPSS Inc, Chicago, Illinois). Descriptive statistics were used to summarize survey questions and demographic variables.

2.7   Ethical Considerations

The study protocol was approved by the Norwegian Centre for Data Research (reference number: 2017/53162) in Norway and the Institutional Ethics Committee/Institutional Review Board at the Sri Narayani Hospital and Research Centre (reference number: 30/25/02/17) in India. Informed assent and informed active parental consent were provided for all participants.

Furthermore, since this study dealt with a sensitive topic, participants were invited to ask questions, decline to answer, or switch off the audio-recorder at any time.

3   Results

3.1   Qualitative Data

Interviews generated 29 codes which were then organized into categories according to the constructs of the CSIRM (identity, cause, timeline, consequence, cure), and the BSFS. Quotes have been edited for readability with all changes denoted by square parentheses.

Identity

Illness representations generally contain an identity component, which includes the name of the illness and identification of various symptoms that an individual believes are associated with the condition. When discussing diarrhea, participants revealed that the identity dimension included diarrheal illness' physical characteristics, symptoms, and beliefs about the cause of diarrheal illness. Diarrheal illness was defined as 'loose motion', 'going in liquid fluid', or 'fecal matter in liquid state'. However, identification of diarrheal illness often included descriptions of related symptoms such as 'stomach ache', 'feeling bored', 'can't sit', 'always be in restrooms', and 'fever' and perceived causes such as 'bacterial infection', 'vitamin deficiency', and 'consumption of unhealthy foods'. For example, one participant shared:

> *Diarrhea is the frequent stools [that] we get when we eat contaminated food, which is not suitable to our health. So [it] doesn't get digested properly (Participant 2, Female).*

This demonstrates that participant definitions of diarrhea included a combination of several CSIRM constructs (e.g. cause and consequence).

Participants also commented that in parallel with identification, communicating to others about diarrheal illness is difficult. This demonstrates how the *identification* dimension and *consequence* are closely linked. One participant shared that he dislikes talking about diarrhea because of its defining characteristics. He goes onto explain that he perceives diarrhea as, 'ugly' and having a 'bad smell' (Participant 9, Male).

Cause

Although a few participants struggled to describe the cause of diarrhea, others suggested several potential causes such as hygiene, bacterial diseases, and consumption of contaminated food, roadside water, hair, spicy food, or eating non-vegetarian food. One participant shared:

> *If they eat junk foods, what they eat [does] not [get] digested [and] vomit or diarrhea will come. [Or] when you're eating some hair. Hair goes into our stomach and causes diarrhea (Participant 4, Female).*

Here the participant discusses how consumption of certain food types (e.g. junk food) cause diarrhea.

Another participant also talks about how she believes hygiene can also cause diarrhea when she says,

> Someone might get sick when they are not having [good] personal hygiene
> (Participant 1, Female).

Here the participant discusses behavioral causes of diarrheal illness and links personal hygiene.

Timeline

It is also important to acknowledge what was difficult for some participants to discuss throughout interviews. Some participants often answered questions in a single word or avoided implicating themselves in discussions of diarrhea (e.g. avoidance of revealing personal experiences). This distanced participants from speaking about the topic in-depth. This was especially illuminated when participants discussed the timeline dimension, since this question invited further reflection on an individual's personal experience with diarrhea illness in terms of frequency and duration of diarrheal episodes. Participants' characterization of a diarrheal illness duration varied, occurring within a 1-5-day period. Some participants also specified that after 2-3 days they should seek help from a healthcare professional. Participants reports of frequency also varied ranging from 1-3 times a day to 6-7 times a day.

Consequence

Illness representation constructs include beliefs about the consequences of the condition for an individual. Here, participants revealed that the consequence dimension was multifaceted and complex. Participants discussed several physical symptoms of diarrhea in addition to other dimensions of everyday life that related to their inability to participate in certain activities, attend school, or communicate with others based on the burden of diarrheal illness.

Participants discussed how they felt uncomfortable talking to others about diarrhea including family and friends. One participant shared:

> I will feel very shy to talk about it to anyone (Participant 10, Female).

This shyness is echoed by others:

> Well [when] someone gets diarrhea means they feel they [cannot] talk freely. In
> that time, they'll have some problems… stomach pains…diarrhea, no? so they
> cannot talk freely with us. They feel shy to share (Participant 4, Female).

Here, participants discussed how they do not feel comfortable talking to others about diarrhea especially with friends at school.

Participants revealed that diarrhea was stigmatizing and influenced participation or performance in school and/or relationships. One participant shared:

> A person with diarrhea will not be normal because they might not know when we
> get stools. We have the sense it is going to come, but [with] diarrhea we might not
> know and sometimes the people may not come out of their houses in our places

> *because they will think when we go out, we can't use the proper washrooms. So, they stay inside (Participant 2, Female).*

In this excerpt, the participant describes how diarrhea threatens normalcy because of the uncertain nature of diarrheal illness. This uncertainty causes one to stay home because they will not know where and when they will be able to use a sanitary toilet.

The same participant continues to discuss how diarrhea affects their sense of normalcy:

> *We can't behave as we [did] before. First thing, a person will feel uncomfortable and he just feels if 'it' comes out, what will happen so, he can't [go] use. Some people have the habit of using washrooms only in their homes because it will be easy for them. Some people [are] using everywhere, and they get afraid of infections… what they get when they use a public toilet (Participant 2, Female).*

Here, this participant shares that when a person has diarrhea, they will feel uncomfortable and stay home in order to reduce the risk of using a public toilet which they perceive as dangerous or unhealthy.

This participant then further elaborates about why people are hesitant or afraid of using public toilets.

> *In their house they maybe have a personal toilet, but outside, every person, is using a [public] toilet which, they may feel uncomfortable to use. Even I don't use in every place. We get infections in the toilets which are public. Everyone [uses them], so after[wards] they don't keep it [as] clean as it was before. They just complete their 'work' (diarrhea) and move. They don't clean up inside. So, in India, it is a very very big problem. They just come finish their 'work' [and] go off. So, that is why people think not to come out and use public toilets (Participant 2, Female).*

Participants also spoke about how diarrhea can disturb their participation at school. One participant reflects:

> *In these break times we have the habit of going to washroom, but in the class if we start disturbing the teacher and going out and coming back, everyone will think, what are they doing? Just going for every single period, everyone will be distracted [by that] particular person, so they'll start asking questions (Participant 2, Female).*

This account suggests that consequences of diarrhea influence toilet use behaviors that may be deemed suspicious by peers.

Participants often reflected on toilet use behaviors during a diarrheal episode. Here, one participant connects the unpredictability or uncertainty of diarrhea with open defecation.

> *[In the villages] I see some of them have toilets and some of them are going in [the] forest, they have a small forest which [is] full of small small trees. They go in the forest and release their diarrhea and come home and washing it. [They go in the forest because] there house is here, and their land of cultivating is far*

away. When [it's] one kilometer [to the toilet] … [and] they got diarrhea when they [are] cultivating land they can't come to the house, so they go in [that] place (Participant 9, Male).

Diarrhea was often characterized as urgent or unpredictable (e.g. 'can't sit'). Here this participant connects symptoms to open defecation.

Control/Cure

Participants spoke of several diarrheal treatment methods and coping behaviors when discussing the cure dimension of illness representations. These methods can be classified into three categories which included diet modifications, medical and naturopathic treatments, and communication with others about illness (See Table 4).

Table 18. An overview of cures reported by participants in semi-structured qualitative interviews (n=10)

Dietary modification	Medical and naturopathic treatments	Communication
'Eat healthy foods such as soft vegetables' 'Avoid [certain] foods [like] butter, oil, and street foods like *pani pu*ri' (*Panipuri* is a deep-fried snack that is filled with water that is often sold from roadside food vendors) 'Avoid spices like chili powder' '[Eat] mostly curd' 'Avoid rice' 'Juice milkshakes, fruits, vegetables are good [to eat]' 'Eating [food] raw is good' 'Avoid all the type of sambal foods' '[Avoid] the gas foods which we eat, the carbonated things, food that has spices like *dhal*' (*Dhal* is a traditional soup made from lentils) 'Give fruit juices curd rice and *chapatt*i' (*Chapati* is a traditional flatbread dish that is commonly eaten in India) '[Eat] fruits like apples' 'Hot water we should drink' 'Avoid junk foods in night times' 'Eat cold items' 'Sugar and water is the easiest method to cure the diarrhea'	'Taking a tablet after their meal' 'Go to the hospital' '*Siddha*' (*Siddha* is a traditional medicine system which has its origins in Tamil Nadu) '*Ayurveda*' (*Ayurveda* is traditional medicine that can be traced back to the Vedic period) 'Medicinal plants' 'Serum *cumin pani*' (*Cumin pani* is a traditional remedy used for digestion) 'Syrup from the hospital'	- Parents - Doctors - Teachers

For diet, participants shared that it was important to 'eat healthy foods such as soft vegetables' (Participant 1, Female) and 'avoid [certain] foods [like] butter, oil, and street foods like *pani puri'* (Participant 2, Female). Several participants also discussed how spicy foods were the cause of diarrhea therefore many suggested that one must, 'avoid spices like chili powder' (Participant 2, Female) to alleviate symptoms. Medical treatments included both modern and traditional remedies such as, 'the hospital' (Participant 5, Male) and 'Ayurveda' (Participant 1, Female).

Furthermore, participants also discussed how communication with doctors, teachers, or parents was an essential step in treating diarrheal illness.

Although participants discussed difficulties in speaking about diarrhea, participants shared that they felt open to communicate with their parents about diarrheal illness. One participant shared:

> *Parents will get the person to the hospitals and medicines will be given and they take care very carefully. If there are any problems the parents will uh cure that (Participant 3, Male).*

Another participant explained:

> *First of all, we need to [tell] my… our, parents, because they are taking care of us. our parents or grandmas will be using some of the medicines to cure it (Participant 1, Female).*

This was further elaborated upon, describing how parents are able to help cure diarrhea.

> *We must say to our parents so that they can stop [it], they can give tablets, or give an aid to our doctor. Saying to our parents is important, but not to our friends (Participant 2, Female).*

Several participants discussed how they preferred to talk to their mother specifically about diarrheal illness. This participant explained:

> *Firstly, she is also a woman and that's the point and the second thing is that I share everything to my mother. So, it includes my personal things and personal hygiene. So, I say to my mother first, and then she gives a measure to it (Participant 2, Female).*

Some also discuss willingness/openness to communicate with doctors about diarrhea who they perceive as the gateway to effective treatment.

> *Once we say everything to a doctor, he can judge what's the problem. So, like we say the color and what state it is coming out and when how many times. So, once we say everything to a doctor in a correct manner he can give and suggest a correct medicine or something to us. So that is why it is easy to say something to a doctor (Participant 2, Female).*

One participant discussed how as he gets older it becomes more difficult to talk about illness with his mother. While another participant echoes similar sentiments:

> *If I speak about it, someone will be laughing. So … I don't like to talk of that. I will feel ashamed to say to my mother also because I am fourteen years. Up to 10 years I will say to my mother without [feeling] shy, [but] now I'm grown up, so I feel ashamed to say like this (Participant 8, Female).*

Unlike others, this participant talks about how fear of teasing prevents her from sharing when she has diarrhea with her mother.

Bristol Stool Form Scale

Another category relating to the study's aims pertaining to the BSFS, was extracted from interviews with adolescent participants. Although participants unanimously reported that the BSFS was easy to understand, their experience using the BSFS in the stool diaries was mixed. Some participants discussed how they felt uncomfortable to report stool using the form. For example, one participant shared:

> Because it is a personal thing about us, and we can't say it freely of course. So, it seems somewhat bad for me…I just feel somewhat bad to fill it, but it is our health issues, so I feel good too. Sometimes it will be so shy for me, and otherwise it's not, other things it's OK (Participant 1, Female).

In another account, one participant reflected:

> I feel shy to fill out that form. [When] mam came [with] that form, everyone [was] asking what is in that envelope. We all felt ashamed to say what [it was], because it is [about] stool. If you say that it is a stool form [that] we have to write [and] we have to mention what type is it, if we say that to our friends, they would be laughing. So, we felt ashamed to say that. (Participant 8, Female).

While some participants shared they felt shy or embarrassed to fill out the stool diaries which applied the BSFS, others reflected on the potential benefits of recording their health information:

> First, I thought, why should I do this? First thought it's something person[al] to us, so why should I give it to someone else? And later on I thought its somewhat helpful for everyone because sanitation and hygiene is so important for girls especially. So, giving out this makes something useful like this. So, first time it was something awkward to give, the next day and the next day after that I thought it was good, so I [did] it properly (Participant 2, Female).

Furthermore, another participant continues to evaluate the potential value of the diary when sharing the following excerpt.

> What's OK is we can keep a good schedule for that, when we are eating something that's bad it will be, leads to some bad response of poo. When we are somewhat eating good foods it seems normal, normal motion, so that's the good thing (Participant 1, Female).

As described previously in Table 4, participants described foods to avoid which included spicy foods, butter, oil, and other street foods. Contrastingly, good foods were classified as healthy, fresh, and often associated with vegetables. The excerpt presented here also highlights potential benefits of the implementation of a stool diary.

3.2   Quantitative Data

Table 19. Overview of variables in the survey

Variables	Categories	Number of answers	Percentage
Last bowel movement	Today	14	100
	Yesterday	0	0

	Other	0	0
Bowel movement frequency (yesterday)	1	9	64.3
	2	3	21.4
	3	1	7.1
	0	1	7.1
Bowel movement frequency (day before yesterday)	1	11	78.6
	2	1	7.1
	4	1	7.1
	5	1	7.1
Bowel movements visible	Yes	8	57.1
	No	6	42.9
Last bowel movement seen	Today	8	57.1
	Yesterday	3	21.4
	Day before yesterday	1	7.1
	No idea/no habit of looking	2	14.3
Ability to match stool on BSFS	Yes	14	100
	No		
Which type of stool according to BSFS resembles most recent bowel movement	Type 3	9	64.3
	Type 4	3	21.4
	Type 6	2	14.3
Cure dimension	Diet	3	21.4
	Medical/healthcare	10	71.4
	Home remedies	7	50

Table 20. Overview of survey results: participant perceptions of stool using the BSFS

	Perceived healthy stool for an adolescent	Perceived healthy stool for an infant	Perceived healthy stool for an adult	Perceived unhealthy stool (general)
Type 1	0 (0%)	0 (0%)	0 (0%)	2 (13.33%)
Type 2	1 (6.66%)	3 (20%)	3 (18.75%)	0 (0%)
Type 3	3 (20%)	0 (0%)	8 (50%)	0 (0%)
Type 4	10 (66.66%)	1 (6.66%)	1 (6.25%)	1 (6.66%)
Type 5	1 (6.66%)	4 (26.66%)	3 (18.75%)	0 (0%)
Type 6	0 (0%)	5 (33.33%)	1 (6.25%)	1 (6.66%)
Type 7	0 (0%)	2 (13.33%)	0 (0%)	11 (73,33%)

Participants had a mean age of 13.7 years (range 13-14) and over 60% of participants were female (Table 1) and all reported that they eat meat (non-veg). Tap or piped water was the most commonly used water source (57%) then tube well or borehole (50%), followed by water truck and water vendor (both 7%).

We asked participants to self-report their stool form/bowel movements (frequency and consistency) using the BSFS (see Table 5 and Table 6). Every participant (100%) answered questions requiring them to self-report stool form. Furthermore, all participants reported that they were able to match different types of stool to the pictures on the chart. Students where then asked to use pictures to describe their most recent stool, 64% selected Type 3, 21% selected Type 4,

and 14% selected Type 6. Participants also used the BSFS to assess healthy stool for different populations (Table 6). Ten out of 15 or 67% of participant responses ranked Type 4 as healthy stool for someone of their age (13-14) and 73% of participant responses ranked Type 7 as unhealthy stool.

Participants discussed various cures for diarrhea (Type 6 and 7) which was then classified into 3 variables (e.g. diet, medical/healthcare, and home remedies) (see Table 5). Ten out of 14 students (71%) suggested that medical/healthcare strategies were a good cure (e.g. taking tablets, visiting the doctor, or hospital), 50% recommended home remedies, while 21% of participants indicated that changes in dietary intake would help cure diarrhea.

Stool diaries gave insight into the participant's everyday stool. All participants who completed the survey rated stool for one week on the BSFS's seven-point scale and recorded how many times they had a bowel movement. Results are shown in Table 7 and display first recorded values. In total, participants recorded 111 stools over a seven-day period (participants averaged 7.92 bowel movements per week (ranging from 7-10) or 1.1 stools per day. The most common types of stool rated in surveys (last bowel movement) was Type 3 at 63%, while diaries were Type 4 at 38%. Furthermore 14% of study participants reported their last bowel movement as diarrhea (Type 6 or 7) in the survey while 10% of total stools reported in the diaries could be classified as diarrhea. In addition, eleven participants reported that they had diarrhea at least once over the one-week period, however no participants reported diarrhea (Type 6 or 7) more than 3 times in a 24-hour period which would align with the WHO's classification of diarrhea.

Table 21. Overview of total number of self-reported stool type in diaries

Stool Type	Number	Percent
Type 1	3	2.7 %
Type 2	6	5.4 %
Type 3	34	30.6 %
Type 4	43	38.7 %
Type 5	14	12.6 %
Type 6	11	9.9 %
Type 7	0	0 %

4   Discussion

This study explored cultural representations and perceptions of diarrheal illness among adolescents and the acceptability of the BSFS. We found that cultural representations and perceptions of diarrheal illness and individual health assessments that influence self-report among adolescents, are linked to attitudes and beliefs that are both individual and context-specific (e.g. individual beliefs about the consequences or cause of diarrheal illness and traditional diarrheal treatment methods). Other research has also contributed to the cultural understanding of health-related perceptions and representations maintained by local populations in low- and middle-income (56). However, understanding health and illness is vastly complex, therefore it is important to use exploratory research to uncover local perceptions among subsets of populations such as adolescents (35, 36).

In the quantitative portion of the study, all participants demonstrated that they were able to understand the BSFS and apply the scale to their own bowel movements, however results from the qualitative component reveal that taboos may influence how diarrheal illness is reported to outsiders. Participants' perception of healthy and unhealthy stool was consistent with previous research. One study previously reported that the average BSFS score for healthy adults was 3.6 (57), while the average BSFS score for the present study was 3.8. Results from the surveys showed that the most commonly reported stool type was Type 3 (63%), while the corresponding number for diaries was Type 4 (38%). This is also consistent with another study in east India which reported that the most predominant stool form reported by study participants was Type 4 (58). Furthermore, literature has demonstrated that stool frequency between 3 per week and 3 per day is normal (44). Therefore, the participants' reported range of frequency of stools per week was within an acceptable range also when compared to other research on stool frequency and form in India (58).

According to the survey results, diaries, and interviews, diarrhea (Type 6 and 7) is an irregular occurrence. Therefore, it can be interpreted that adolescents who participated in this study, do not perceive diarrhea as normal or healthy. Moreover, 73% of study participants indicated that they perceive Type 7 (watery stool) as illness-related. This is closely related to the *identity* dimension of the CSIRM which pertains to labeling the illness and knowledge of illness symptoms (36). In semi-structured qualitative interviews, participants most commonly identified diarrhea by its physical attributes ('loose motions'), however, since physical symptoms are also perceived as one possible component of an illness (27), participants often described diarrhea in symptom-related terms (e.g. fever, stomachache, and fatigue).

The *cause* dimension is connected to beliefs related to factors causing illness or disease (36). These can be biological, emotional, environmental, or psychological (59). In the survey and semi-structured interviews, participants struggled to identify causes of diarrhea. In some interviews, participants discussed various causes of diarrhea, which were connected to hygiene, diet, and bacterial diseases. In a study regarding beliefs about diarrhea causes in another village in Vellore, 43% of participants believed food caused diarrhea and 15.5% did not know the cause (60). Insufficient understanding of the actual causes of diarrhea may foster shame and embarrassment surrounding the illness. Therefore, there needs to be further exploration into discourses about diarrhea to dismantle taboos and inform a culture of accurate and unbiased reporting of diarrheal illness.

The *control/cure* dimension describes how coping behaviors and efficacy of treatment can cure an illness (36). In both surveys and semi-structured interviews, students reported similar cures such as diet, medical intervention, and traditional naturopathic treatments or 'home' remedies. Studies exploring cultural representations and perceptions of illness, often include local beliefs and cultural knowledge about illnesses, including descriptions of traditional practices that help treat or cure diarrheal illness (33, 56, 61). Consistent with literature on traditional medicine in India, cures and/or treatment strategies mentioned by participants can be linked to several ayurvedic practices that are prevalent in the area. Since ancient times, traditional beliefs have widely influenced treatments of various ailments throughout India, therefore, India has a rich

tradition in naturopathic medicine systems such as Ayurveda, Siddha, and Homeopathy. Furthermore, findings derived from this study reveal that this local context is no exception. For example, according to Ayurvedic medicine, diarrhea could be caused by a weakened digestive fire (often caused by excess *pitta*[1]) (62). In this study, participants discussed several traditional remedies to help treat diarrhea, that when compared to resources on Ayurveda, also center around medicinal plants and other energetically 'cooling' foods, such as fruits, vegetables, and 'cold items' (all *pitta*-countering) (62). Moreover, although not all students discussed Ayurvedic medicinal treatments explicitly, several of the cures suggested by participants (such as avoiding the consumption of hot, spicy, or oily foods) are perceived to further weaken digestive fire, which may aggravate the *pitta* (62). However, in the survey, 71% of participants suggested that an individual should seek medical care or pursue other healthcare-related strategies. However, what was noticeably absent in survey results was mention of communication as a *control* strategy. In the semi-structured interviews, communication (with parents) was often discussed as an initial control strategy or coping behavior. However, communication pathways were inconsistent between participants. While many emphasized the importance of telling their parents when they were suffering from diarrheal illness, some shared that they were uncomfortable speaking to their mother about diarrhea as they grow older. One participant even implied that her mother teased her if she got ill, which led to the avoidance of sharing her health status. However, many participants shared in their interviews that it was vital to share with their parents when they got ill, because they described their parents as their caretaker and well positioned to be able to assist in *control/cure* dimension of diarrheal illness based on knowledge and previous experience.

The *consequence* dimension of the CSIRM represents beliefs related to the overall impact on an individual's quality of life or functional capacity (36). For example, many assess this dimension according to their inability to perform certain tasks based on illness (36). Findings from semi-structured interviews reveal that participants perceived diarrhea as problematic because it compromises their appearance and participation in everyday activities. These prohibiting qualities that conflict with participant's perceived 'normal' everyday, included not being able to communicate with others 'freely'. Participants expressed a general discomfort with the subject matter and often attributed their apprehensiveness to speak about diarrheal illness to shyness. One participant explained that diarrhea was disgusting and therefore was not something he liked to discuss or share. However, several students shared that they were open to speaking to select individuals about diarrhea such as parents or doctors. Given these contrasts, it appears the premise of communication regarding diarrheal illness is both influenced by taboos and transactions (e.g. I will tell you if you can help me get healthy again). Since peers often are unable to assist with the *control/cure* dimension or treatment, participants appeared hesitant to share. Instead, participants shared that peers may tease them for having diarrheal illness. This is

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[1] According to *Ayurveda*, *pitta* is one of the three life forces (*doshas*) and known to regulates metabolic processes.

consistent with other research on toilet use which ascertains that bullying is associated with toilet use behaviors at school (63). Moreover, when using the BSFS it is important that researchers clearly explain to participants how accurately reporting diarrheal illness can be mutually beneficial to enhance future WASH research validity.

Willingness to communicate with others may have affected participant's engagement with the BSFS, which varied. Some participants expressed that they were embarrassed to report their stool form/bowel movements in the stool diaries, while others noted the utility of the exercise, using it as an opportunity to understand more about their own health. Moreover, participants indicated that although the BSFS was easily understood, diarrhea itself was uncomfortable to speak about. Anthropological literature that focuses on illness perceptions suggests that cultural representations and perceptions of illness are influenced by the local cultural, contextual, and social environment (30-33, 64). Therefore, it is important to reflect on participants comfort-level with the content of material (e.g. images and subject-matter), especially when relying on self-reported findings to determine intervention effectiveness.

Furthermore, in semi-structured interviews, participants discussed how toilet habits during diarrhea may influence or threaten academic participation at school. Students related frequent toilet use to diarrheal illness, explaining that as an unpredictable illness, a student may experience limited control over where and when they can go to the bathroom. Moreover, participants reported that instead of using a toilet that they deemed unclean or unhealthy, they elected to stay home during bouts of diarrhea to minimize the perceived risks (using a dirty toilet/teasing from peers). Here, the necessity of using an unsanitary toilet facility may further stigmatize diarrhea because in India, toilets are seen as dirty or impure (65, 66). Other studies have indicated that public toilets are often dirty or poorly maintained (67, 68). In addition, one study also indicated that the smell of public toilets contributed for the preference of defecating in the open (60).

Participants also discussed how they were especially uncomfortable having diarrhea at school because it might be revealed to others that they have diarrhea. Findings reveal that participants were embarrassed to reveal diarrheal illness to others (especially at school) because they perceive diarrhea as disgusting, foul smelling, unclean, or bad (e.g. physical stigma). Given these aversions, students discussed how diarrheal illness may be perceived as detrimental, prompting teasing from peers, teachers, and/or parents. Participants also shared how they worried that diarrhea at school could cause bullying, therefore they kept it a secret or stayed home. This highlights how secrecy surrounding diarrhea promotes protection from bullying and shame.

We also observed how adolescents perceived, interpreted, and reported diarrhea because of various emotional and cognitive differences (27, 69). Participants discussed how diarrhea can lead to absenteeism or withdrawal from social activities. Previous studies on adolescent illness representations suggest that definitions of illness are often compounded by one's lack of ability to do required and desired activities, such as attending school, sports, and engaging with peers (27, 34, 70). This is influenced by cognitive and developmental changes that influence adolescent's conceptualization of illness and indicators of good health. Because adolescents are

currently going through other developmental changes, they may lack cognitive understanding of a disease, that an adult may have (27).

4.1   Strengths and Limitations

There are several strengths and limitations to the study. One strength is the mixed-methods approach that was applied in order to gain an in-depth understanding of cultural representations and perceptions of diarrheal illness among adolescents. However, the convergent parallel design prohibited insights gained from one method to influence the other, which is a common characteristic in sequential designs (71).

Limitations include the small purposive sample, rather than a randomized population-based sample. As a result, we are not able to generalize the results to other adolescent populations within the Vellore district or outside. However, representativeness was not prioritized, although we tried to recruit a sample that would mirror future intervention participants. Furthermore, the small sample size also prevented us from conducting more complex quantitative analyses. However, since the study was a small-scale descriptive formative research study and more qualitatively weighted, we felt this was an appropriate sampling strategy and sample size.

Language was another limitation. All data collection activities were conducted in English. While English is the language of instruction at the school in which the study was conducted, it is not the native language of study participants. Therefore, words which complement pictures on the BSFS such as 'sausage' were not widely understood (this could also be because sausage is not part of the local diet in rural India). Although collecting data in English simplified data collection activities for the research team, language may have caused a loss of meaning in the analysis and communication complications (e.g. short verbal responses) in the qualitative component. Therefore, we recommend future translation of the BSFS to local languages in order to encourage comprehension by participants and that future data collection activities are conducted in the native language of participants. Nevertheless, we tried to mitigate these limitations through the incorporation of prolonged engagement and inclusion of local research partners in data collection activities.

5   Conclusion

The findings of this study provide important descriptive insights on adolescent illness representations in relation to diarrheal illness, in addition to reporting practices for the SHINE intervention and other WASH health promotion intervention research and literature. Findings also suggest that challenges associated with self-reported data on diarrheal illness may be connected to a general reluctance to discuss this issue among this population, thus likely influenced by taboo and stigma. This is a challenge that is rarely discussed explicitly in WASH health promotion literature, indicating that more research is needed.

6   Data Availability Statement

The datasets generated for this study are available on request to the corresponding author.

7   Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

8   Author Contributions

AGW contributed to research project development and research design; data collection, data management; data analysis; and writing and editing processes of the manuscript. GA contributed project development; research design; data analysis and editing processes of the manuscript. SG contributed to research project development, data collection, and provided input in cultural components of study design. RS contributed to research project development, data collection, and provided input in cultural components of study design. SB contributed to research project development; research design; and editing processes of the manuscript. All authors have read and approved the final manuscript.

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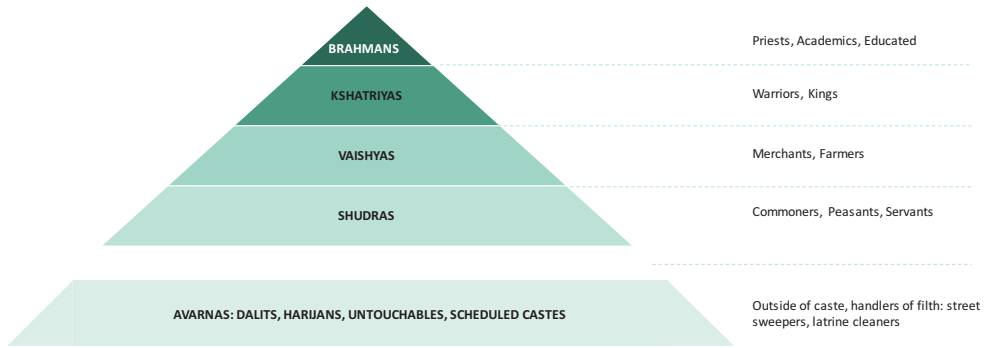71.   Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage Publications (2017).

APPENDICES

APPENDIX A. GLOSSARY

Term	Definition	Source
Water/drinking water	"Drinking water services refers to the accessibility, availability and quality of the main source used by households for drinking, cooking, personal hygiene and other domestic uses."	WHO/UNICEF Joint Monitoring Programme for Water Supply, Sanitation and Hygiene (JMP)
Sanitation	"A process whereby people demand, effect, and sustain a hygienic and healthy environment for themselves by erecting barriers to prevent the transmission of disease agents"	UNICEF. Towards better programming: a sanitation handbook. In EHP applied study 1997 (Vol. 5). EHP.
Hygiene	"Hygiene refers to the conditions and practices that help maintain health and prevent spread of disease."	WHO/UNICEF Joint Monitoring Programme for Water Supply, Sanitation and Hygiene (JMP)
Menstrual Hygiene Management	"Access to clean materials, privacy for changing materials, soap and water for bathing, and disposal facilities for materials."	WHO/UNICEF Joint Monitoring Programme for Water Supply, Sanitation and Hygiene (JMP)
Community	"A group of people or organizations defined by function (such as an industry), geography (such as a metropolitan area), shared interests or characteristics (such as ethnicity, sexual orientation or occupation), or by a combination of these dimensions, in which members share some sense of identity or connection."	Mendel P, Meredith LS, Schoenbaum M, Sherbourne CD, Wells KB. Interventions in organizational and community context: a framework for building evidence on dissemination and implementation in health services research. Administration and Policy in Mental Health and Mental Health Services Research. 2008 Mar 1;35(1-2):21-37. p. 23.
Stakeholder	"…Represent the defined community in which the research is taking place." AND Those who have interest in or who are impacted by the proposed research.	Tumiel-Berhalter LM, Watkins R, Crespo CJ. Community-based participatory research: Defining community stakeholders. Metropolitan Universities Journal. 2005. p. 92. Rabinowitz, P. (2016). Identifying and analyzing stakeholders and their interests. Retrieved from the University of Kansas Community Tool Box website: http://ctb. ku. edu/en/table-ofcontents/participation/encouraging-involvement/identify-stakeholders/checklist.
Adaptation	The process of modifying key characteristics of an intervention, recommended activities and delivery methods, without competing with or contradicting the core elements, theory, and internal logic of the intervention thought most likely to produce the intervention's main effects.	McKleroy VS, Galbraith JS, Cummings B, Jones P, Harshbarger C, Collins C, Gelaude D, Carey JW, ADAPT Team. Adapting evidence–based behavioral interventions for new settings and target populations. AIDS Education & Prevention. 2006 Aug;18(supp):59-73. p. 62.
Adolescents	Adolescence captures the notion of the growing individual who is able to take increasing responsibility, but who still needs more protection than an adult. 10–24 years corresponds more closely to adolescent growth and popular understandings of this life phase and	Sawyer SM, Azzopardi PS, Wickremarathne D, Patton GC. The age of adolescence. The Lancet Child & Adolescent Health. 2018 Mar 1;2(3):223-8. p. 1.

	would facilitate extended investments across a broader range of settings.	
Context	"...The environment in which the innovation, partnerships, and organizations are operating. It includes different dimensions that are not limited to socio-economic, political, cultural, and geographical contexts." AND "...The circumstances in which people are living. Context also refers to sociocultural variables that are (largely) shared within a society, such as values, norms, and beliefs."	Delafield R, Hermosura AN, Ing CT, Hughes CK, Palakiko DM, Dillard A, Kekauoha BP, Yoshimura SR, Gamiao S, Kaholokula JK. A community-based participatory research guided model for dissemination of evidence-based interventions. Progress in community health partnerships: research, education, and action. 2016;10(4):585. p. 6. Pick S, Poortinga YH, Givaudan M. Integrating intervention theory and strategy in culture-sensitive health promotion programs. Professional Psychology: Research and Practice. 2003 Aug;34(4):422. p. 422.
Culture	"Culture is a socially transmitted or socially constructed constellation consisting of such things as practices, competencies, ideas, schemas, symbols, values, norms, institutions, goals, constitutive rules, artifacts, and modifications of the physical environment"	Fiske AP. Using individualism and collectivism to compare cultures--A critique of the validity and measurement of the constructs: Comment on Oyserman et al.(2002). p.85.
Cultural adaptation	"The systematic modification of an evidence-based [intervention] or intervention protocol to consider language, culture, and context in such a way that it is compatible with the [target population's] cultural patterns, meanings, and values"	Bernal G, Jiménez-Chafey MI, Domenech Rodríguez MM. Cultural adaptation of treatments: A resource for considering culture in evidence-based practice. Professional Psychology: Research and Practice. 2009 Aug;40(4):361. p. 362.

APPENDIX B. CASTE SYSTEM

Caste	Description
BRAHMANS	Priests, Academics, Educated
KSHATRIYAS	Warriors, Kings
VAISHYAS	Merchants, Farmers
SHUDRAS	Commoners, Peasants, Servants
AVARNAS: DALITS, HARIJANS, UNTOUCHABLES, SCHEDULED CASTES	Outside of caste, handlers of filth: street sweepers, latrine cleaners

APPENDIX C. BRISTOL STOOL FORM SCALE

Type	Description	Image
1	Separate hard lumps, like nuts (hard to pass)	
2	Sausage-shaped, but lumpy	
3	Like a sausage but with cracks on its surface	
4	Like a sausage or snake, smooth and soft	
5	Soft blobs with clear cut edges (easy to pass)	
6	Fluffy pieces with ragged edges, a mushy stool	
7	Watery, no solid pieces, entirely liquid	

APPENDIX D: SURVEY (SUB-STUDY 3)
STRUCTURED INTERVIEW GUIDE –STUDENTS

Key:

IQ = Interview question

P: Probe

Interview Plan:

Small talk to develop rapport with participant. Describe the general set up of the interview and review confidentiality agreement.

"I would like to thank you for participating in this interview. This interview is part of ongoing research cooperation between the Norwegian University of Life Sciences, the Sri Narayani Hospital and Research Centre and the communities that live in the Vellore Area. The research project aims at building the capacity of youth and communities in the area to develop and sustain health promotion activities to prevent diarrheal disease. The reason for this interview is to get a better understanding of young people's opinions and personal experiences so that future programs can be better designed to suit your needs. I would like to ask you some questions about your perspectives and experiences. As mentioned in the consent form, all of your responses will remain confidential. I will remove any identifying information that you share in this interview, for example any names of people or places, and the way I report your answers back to my team will not allow anyone to link anything you say to your identity. While we're talking today, if you ever feel uncomfortable with a question or simply do not want to answer it that is completely fine, just let me know. Is it okay for me to record this interview?"

IQ1: What is your age?

IQ2: Can you describe your daily diet?

P: Do you eat meat?

IQ 3: Tell me about what you had to drink yesterday? Please tell me all that apply.

- ☐ Water
- ☐ Yogurt
- ☐ Animal milks
- ☐ Juice
- ☐ Tea
- ☐ Soda
- ☐ Ice

P: Is there anything else not mentioned?

IQ4: Where do you get your water? You can tell me all that apply.

- ☐ Tap or piped

- ☐ Rainwater
- ☐ Lake or pond
- ☐ Water truck
- ☐ Water vendor
- ☐ Dug well
- ☐ Tube well or borehole

IQ5: When was your last kakka (poo)?

    P: Did you see it?

    P: When was the last kakka you saw?

IQ6: How many times did you poo yesterday?

IQ7: What about the day before?

Here is a chart of 7 fake stools.

(Go through the Bristol Stool Chart with the participant and talk about what each of the different stools look like)

IQ8: Could you match them on this chart?

IQ9: Which picture closely resembles your most recent poo?

IQ10: If not, can you draw and describe the type that is missing?

IQ11: What type of stool is healthy for a child your age? (list all by numbers)

IQ12: What type of stool is health for a child under two?

IQ 13: What about an adult?

IQ14: Are there any types of stool types on this chart that might make you think that you are sick?

IQ15: What color is healthy stool?

IQ16: What color shows that someone is sick?

IQ17: In the past 7 days, have you ever had 3 or more type 6 or 7 in one day?

IQ18: Is that something that happens often?

IQ19: What else happens when someone is sick?

    P: What do you do?

Thank you for taking the time to talk to me today!

*Adapted from Guled. F. (2011). Bristol Stool Chart Validation Study.

STOOL (KAKKA) DIARY

ID Number_____

Start date_____

How would you describe your last poo?

Please fill in the table below with whichever poo type best describes your last poo. If you had more than one poo in a specific time slot, fill in the numbers separated by a comma.

	Morning	Midday	Evening
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

BRISTOL STOOL CHART

Type 1	Separate hard lumps, like nuts (hard to pass)
Type 2	Sausage-shaped but lumpy
Type 3	Like a sausage but cracks on its surface
Type 4	Like a sausage or snake, smooth and soft
Type 5	Soft blobs with clear-cut edges (passed easily)
Type 6	Fluffy pieces with ragged edges, a mushy stool
Type 7	Watery, no solid pieces, entirely liquid

cinim   SHINE

APPENDIX E: ETHICAL APPROVAL

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord			13.02.2017	2017/156/REK nord
			Deres dato:	Deres referanse:
			10.01.2017	

Vår referanse må oppgis ved alle henvendelser

Sheri Bastien
Department of Public Health Science

2017/156 Prosjekt SHINE (Utdanningsbasert sanitets- og hygieneinnovasjon): Et prosjekt orientert mot skole- og lokalsamfunn for å forbedre vann-, sanitær- og hygiene (WASH) i Sri Puram, India

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 02.02.2017. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: Norwegian University of Life Sciences
Prosjektleder: Sheri Bastien

Prosjektleders prosjektomtale (original):
In India, poor water, sanitation and hygiene (WASH) is a major public health concern, which affects diarrheal incidence and other health behaviors such as hand washing and open defecation. Given these concerns, solutions that include the country's unique social, cultural and environmental context are in demand. Project SHINE (Sanitation and Hygiene INnovation in Education) is an intervention designed to improve WASH practices through the application of participatory science and social entrepreneurship training in schools and communities. It focuses on the development of culturally appropriate strategies that utilize the community and students in all phases of research. SHINE was first implemented in Tanzania and will now be translated, adapted, implemented, and evaluated in three communities in India using a community-based participatory approach, while maintaining its core components. The school-based pilot study will include approximately 400 students in grades 7-9.

Vurdering

Framleggingsplikt
De prosjektene som skal framlegges for REK er prosjekt som dreier seg om "medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger", jf. helseforskningsloven (h) § 2. "Medisinsk og helsefaglig forskning" er i h § 4 a) definert som "virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom". Det er altså formålet med studien som avgjør om et prosjekt skal anses som framleggelsespliktig for REK eller ikke.

I dette prosjektet er formålet å intervenere i skole og samfunn i Sri Puram i India, hvor hensikten er å forbedre sanitær hygiene, kunnskap om hygiene, samt forbedre holdninger og adferd på området, ved at skole og samfunn deltar i prosjektet og på den måten får kunnskap om sanitær hygiene.

Selv om studien indirekte vil kunne gi en helsemessig gevinst faller ikke prosjektet inn under definisjonen av de prosjekt som skal vurderes etter helseforskningsloven.

Vedtak

Etter søknaden fremstår prosjektet ikke som et medisinsk og helsefaglig forskningsprosjekt som faller innenfor helseforskningsloven. Prosjektet er ikke framleggingspliktig, jf. hfl § 2.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK nord, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

May Britt Rossvoll
Sekretariatsleder

Kopi til:sheri.lee.bastien@nmbu.no

NSD

Sheri Bastien

Institutt for landskapsplanlegging Norges miljø- og biovitenskapelige universitet

1430 ÅS

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 21.02.2017. Meldingen gjelder prosjektet:

53162	*Project SHINE (Sanitation and Hygiene INnovation in Education) a school and community-based project to improve water, sanitation and hygiene in Sri Puram/rural India*
Behandlingsansvarlig	*Norges miljø- og biovitenskapelige universitet, ved institusjonens øverste leder*
Daglig ansvarlig	*Sheri Bastien*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvernombud/meld_prosjekt/meld_endringer.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 01.08.2021, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Siri Tenden Myklebust

Kontaktperson: Siri Tenden Myklebust tlf: 55 58 22 68
Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

Marguerite Daniel
Christiesgt. 13
5015 BERGEN

Vår dato: 15.08.2017   Vår ref: 54618 / 3 / ASF   Deres dato: Deres ref:

Tilbakemelding på melding om behandling av personopplysninger

Vi viser til melding om behandling av personopplysninger, mottatt 02.06.2017.
Meldingen gjelder prosjektet:

54618	A positive deviance approach to menstrual health among adolescent girls in Sri Puram, India. A photovoice study
Behandlingsansvarlig	Universitetet i Bergen, ved institusjonens øverste leder
Daglig ansvarlig	Marguerite Daniel
Student	Marte Gulbrandsen Hovdenak

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database.

Personvernombudet vil ved prosjektets avslutning, 14.06.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Dersom noe er uklart ta gjerne kontakt over telefon.

Vennlig hilsen

Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.

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SRI NARAYANI HOSPITAL
&
RESEARCH CENTRE
SRIPURAM, THIRUMALAIKODI, VELLORE - 632 055
Vellore District, Tamil Nadu, India.

Communication of Decision by the Institutional Ethics Committee / Institutional Review Board

IEC/IRB No: 30/25/02/17

Protocol title: Project SHINE (Sanitation and Hygiene INnovation in Education) a school and community based project to improve water, sanitation and hygiene	

Principal Investigator: Dr. Sheri Lee Bastien

Name & Address of Institutions:

Associate, Faculty of landscape and society, Norwegian University of Life Sciences

☑ New review   ☐ Revised review   ☐ Expedited review

Date of review (D/M/Y): 25 February 2017

Date of previous review, if revised application:

Decision of the IEC/ IRB:

☑ Recommended   ☐ Recommended with suggestions

☐ Revision   ☐ Rejected

Suggestions/ Reasons/ Remarks:

Approved. IRB recommends that Dr. Arun Risbud, MPH, will be the inhouse mentor and monitor the work of the graduate student. He will also train her to be culturally sensitive

Recommended for a period of : STUDY PERIOD

Please note *
- Inform IEC/IRB immediately in case of any Adverse events and Serious adverse events.
- Inform IEC/IRB in case of any change of study procedure, site and investigator
- This permission is only for period mentioned above. Annual report to be submitted to IEC/IRB.
- Members of IEC/IRB have right to monitor the trial with prior intimation.

Date: 03.03.2017

Signature of IRB Member Secretary

Norwegian University
of Life Sciences