Lived experiences of arsenic-related psychosocial distress in rural Bangladesh

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ABSTRACT

Arsenic occurs naturally in the groundwater across much of Bangladesh, with millions exposed through drinking water. It has wide-ranging health effects, including skin lesions, cancers, heart disease, and cognitive impairment. There is also emergent but limited literature on its effects on psychosocial well-being. This paper advances the understanding of the relationship between arsenic exposure and psychosocial distress. An exploratory qualitative study was undertaken, where interviews were conducted with 23 members of an affected community in a village in southwestern Bangladesh. Results show that arsenic exposure is linked both directly and through mediated pathways to psychosocial distress. There are significant impacts on the participants' lives, including inability to access safe water, lack of agency, chronic pain and discomfort, difficulty performing everyday tasks, lost productive time, issues of marriageability, among others – all of which contributed to psychosocial distress, both individually and compounded together. The findings indicate a need for more comprehensive understanding of arsenicosis when designing safe water interventions.

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1 | INTRODUCTION

For Bangladesh, the presence of arsenic in the groundwater is one of the largest public health disasters, with a wide range of implications. In my years of professional experience in the water, sanitation and hygiene (WASH) sector, I observed how arsenic was acknowledged by most as an issue of public health and human rights that requires urgent attention, and yet got relegated to the side lines when it came to implementing water supply interventions. Moreover, much of the narrative rests on the scale of the issue and the sheer numbers involved, but not what it means for people to actually live with chronic arsenic poisoning. One impact which is not often discussed in the literature, and even less often in the development discourse, is the effect it can have on the psychosocial well-being of those living in affected areas.

This paper will discuss how the issue of how arsenic arose in Bangladesh, review some of the existing literature on the adverse effects it can have on people and society, and most importantly, discuss the results of a qualitative study conducted in an affected community to further the understanding of the ways in which arsenic can affect psychosocial well-being.

A few decades ago, the high prevalence of diarrhoeal disease was a major concern in Bangladesh. This was mainly due to the reliance of a large part of the population on surface water containing pathogenic organisms. The Bangladesh government's Department of Public Health Engineering (DPHE)[1], along with UNICEF, installed shallow tubewells across more than half the country in the 1970s and 1980s (Smith, Lingas and Rahman, 2000). The campaign was successful, and by the early 1990s there were an estimated 2.5 million tubewells in rural areas, providing about 95% of the population with what was thought to be safe drinking water (Human Rights Watch, 2016).

Unfortunately, since arsenic was not known to be an issue in the region, no testing was performed. Child mortality decreased following the programme, although it is questionable whether this was solely due to pathogen-free water (Caldwell *et al.*, 2003). This is because around the same time as the proliferation of tubewells, several other life-saving public health interventions were implemented on a large-scale, including vaccines, antibiotics and oral rehydration therapy – the last of which played a major part in reducing diarrhoeal deaths (Caldwell *et al.*, 2003). The installation of shallow tubewells across the country inadvertently exposed millions of people to arsenic. Arsenic is naturally found in groundwater in many other parts of the world including India, Taiwan, Vietnam, China, Mexico, Chile, Argentina, and the

[1] DPHE are responsible for water supply and sanitation services rural areas and small towns in Bangladesh.

US. However, the most widespread arsenic contamination is in Bangladesh, and this is considered to be the largest mass poisoning to ever occur (Yu, Harvey and Harvey, 2003).

The British Geological Survey (Kinniburgh and Smedley, 2001) assessed tubewells across Bangladesh and found that 25% of sampled tubewells contained over 50µg/L of arsenic (the Bangladesh standard). Moreover, 9% exceeded 200µg/L and 1.8% exceeded 500µg/L. Among the tubewells surveyed, 9% were deep tubewells (more than 150m in depth) and the rest were shallow. Contamination was mainly among shallow aquifers, of which 27% contained over 50µg/L arsenic, and 46% contained over 10µg/L, which is the WHO standard (Kinniburgh and Smedley, 2001). It is estimated that about 35 million people have been exposed to water containing over 50µg/L arsenic and 57 million people to water with over 10µg/L arsenic (Kinniburgh and Smedley, 2001).

Since the exposure to arsenic through groundwater is a slow and gradual process – that is, an example of chronic rather than acute poisoning – it can result in many long-term, chronic health conditions, which will be discussed in more detail in the following section. An under-researched outcome of arsenic exposure is that of psychosocial distress. The goal of this study was to gain an in-depth understanding of the relationship between arsenic exposure through groundwater and psychosocial distress, by looking at the experiences of health issues, social structures and economic conditions in a village in southwest Bangladesh.

In order to do this, it is important to understand what is meant by the term psychosocial distress. It is not a simple task to define this term, since it varies across different academic fields, cultures and geographies. To simply define the words linguistically, *psychosocial* refers to the "interrelation of social factors and individual thought and behaviour" (Oxford English Dictionary Online, 2018b) and *distress* is defined as "extreme anxiety, sorrow, or pain" (Oxford English Dictionary Online, 2018a). Psychosocial distress is a phenomenon being studied within many fields of public health as well as in emergency response, in order to understand the emotional and social dimensions of these issues. According to the Inter-Agency Network for Education in Emergencies (2014) – a consortium of UN agencies, NGOs, donors, governments, etc. – "the term psychosocial underscores the close connection between psychological aspects of our experience (e.g., our thoughts, emotions, and behavior) and our wider social experience (e.g., our relationships, traditions and culture) … However, many psychosocial problems do not require clinical treatment but are rooted in stigmatisation, lost hope, chronic poverty, uprooting, inability to meet basic needs, and inability to fill normal

social roles …" For the purpose of this study, this understanding of the concept of psychosocial distress will be applied, since it is broad enough to encompass the complexities of distress felt as a result of living with chronic arsenic poisoning.

In recent years, many scholars have begun to study psychosocial distress specifically as an outcome of water insecurity and a lack of access to adequate sanitation facilities (Wutich and Ragsdale, 2008; Stevenson *et al.*, 2012; Sahoo *et al.*, 2015; Bulled, 2016; Thomas and Godfrey, 2018). It should be noted that these studies interchange the terms "emotional distress" and "psychosocial distress" to describe similar experiences, which will be further elaborated upon in the next section. This study builds upon existing research and methodologies, and seeks to fill gaps in the literature and broaden the understanding of psychosocial distress as an outcome of arsenic exposure. In this paper I will review some of the existing literature on arsenic and its adverse effects on health and its social and financial implications, assess currently used methodologies for studying psychosocial distress in the context of water, and detail my own objectives, methodology and results. This will be followed by a discussion of the results, the limitations of the study, and the final conclusions drawn from it.

2 | OBJECTIVES

Overall aim: To advance the understanding of the relationship between arsenic exposure and psychosocial distress, by studying lived experiences within the context of southwestern Bangladesh.

Research questions:

1. What are the local idioms of distress in relation to arsenic exposure?
2. In what ways does arsenic exposure manifest in psychosocial distress?
3. How do household finances and gender issues intersect with arsenic exposure and its effects?

3 | A REVIEW OF THE LITERATURE ON ARSENIC AND ITS ADVERSE EFFECTS

Arsenic is a naturally occurring metalloid in water, soil and air, and can also come from anthropogenic sources such as mining and electronics manufacturing (Hughes, 2002; Naujokas *et al.*, 2013). It poses a serious threat to human health, with an estimated 100 million people across the world exposed to high amounts of arsenic through drinking water (Tyler and Allan, 2014). Arsenic has a variety of other adverse effects on human health, which will be discussed

in this literature review. In this section I will present a key range of impacts relating to arsenic exposure, including its adverse effects on health and well-being, social structures, and household finances. Following that, I will focus more on the available literature on psychological and social impacts, along with an analysis of research methodologies currently being used to study water-related psychosocial distress.

Adverse physiological health effects of arsenic exposure

Arsenic exposure can lead to various adverse health outcomes. Many of the physiological effects have been studied widely across the world, with many studies having been conducted in Bangladesh as well. Some of the available literature on the health effects of arsenic are described below and summarised in Table 1.

Dermatological: Cutaneous lesions are one of the most common effects of arsenic exposure. They can occur as early as six months of exposure (Das and Sengupta, 2008) or take up to 6 to 9 years to manifest (WHO, 2005). Skin lesions include melanosis (hyperpigmentation or hypopigmentation) or keratosis (thickening of the skin which appear as papules or nodules) (WHO, 2005). Melanosis is a common early manifestation of arsenicosis, whereas keratosis is a sensitive marker for advanced stages (Das and Sengupta, 2008). These skin lesions are non-malignant until a sudden increase in size or bleeding in the keratotic lesions, at which point it can transform into malignancies (Naujokas *et al.*, 2013).

Cancers: Arsenic affects almost every organ in the body. Various ecological, case-control and cohort studies show that arsenic is associated with cancers of the lung, bladder, kidney, skin, liver and prostate (International Agency for Research on Cancer, 2012). As mentioned earlier, skin cancers can result from transformations of skin lesions into malignant carcinomas due to chronic exposure to arsenic. Squamous cell carcinoma and basal cell carcinoma are the most common types of skin cancer resulting from chronic arsenic exposure (Naujokas *et al.*, 2013).

Cardiovascular disease and others: A study from Taiwan shows association between arsenic exposure and carotid atherosclerosis (Huang *et al.*, 2009). A prospective cohort study in Bangladesh found a dose-response relationship between arsenic exposure and mortality from ischaemic and other heart diseases (Chen *et al.*, 2011). Association was also found between arsenic exposure and hypertension (Abhyankar *et al.*, 2012).

Arsenic suppresses the immune system and has been shown to be associated with higher mortality from pulmonary tuberculosis (Smith *et al.*, 2011). A study from Bangladesh also shows that arsenic exposure during pregnancy is associated with increased infectious disease

morbidity among infants (Rahman *et al.*, 2011). Exposure to arsenic from water has also been shown to be associated with diabetes (Chen *et al.*, 2007).

Cognitive impairment: A cross-sectional study conducted by (Wasserman *et al.*, 2004) found that exposure to arsenic from drinking water was associated with reduced intellectual function among 10 year olds, after adjusting for confounders such as sociodemographic covariates and manganese. Arsenic in water was associated with reduced scores on the Wechsler Intelligence Scale for Children in a dose–response manner (i.e. children exposed to arsenic levels over 50μg/L achieved significantly lower scores than children exposed to levels below 5.5μg/L). A further cross-sectional study (Wasserman *et al.*, 2007) with 6 year old children, reported similar results, although the associations were weaker than in the previous study. Similar impacts have been reported in adults, including poorer cognitive function and lower education levels were associated with higher arsenic levels (Gong *et al.*, 2011). In a longitudinal study by (Hamadani *et al.*, 2011), where they looked at urinary arsenic twice during pregnancy and twice in childhood, found adverse effects of arsenic exposure on IQ in 5 year old girls, but not in boys.

Table 1: Summary of physiological health effects of arsenic exposure

Health issue	**Details**	**Reference**
Dermatological	Melanosis	Das and Sengupta (2008); WHO (2005)
	Keratosis	
Cancer	Squamous cell carcinoma and basal cell carcinoma (from keratotic skin lesions)	Naujokas et al. (2013)
	Lung, bladder, kidney, liver and prostate cancers	International Agency for Research on Cancer (2012)
Cardiovascular disease	Carotid atherosclerosis	Huang et al. (2009)
	Ischaemic and other heart diseases	Chen et al. (2011)
	Hypertension	Abhyankar et al. (2012)
Cognitive impairment	Lower intelligence scores among children	Wasserman et al. (2004 & 2007); Hamadani et al. (2011)
	Lower intelligence scores among adults	Gong et al. (2011)
Others	Immune system suppression	Smith et al. (2010)
	Increased mortality from pulmonary tuberculosis	Smith et al. (2010)
	Increased infectious disease morbidity among infants	Rahman et al. (2011)
	Diabetes	Chen et al. (2007)

Linkages between arsenic exposure and household finances

A study from Bangladesh showed a negative correlation between household income and arsenic exposure (Curry *et al.*, 2000). Other studies show similar results: people from a lower socioeconomic status stand a higher chance of being exposed to arsenic and are affected worse (Ahmad *et al.*, 2007). This may likely be related to factors such as poor nutrition and the nature of their occupation (e.g. manual labourers drink more water) (Polya and Middleton, 2017). Current literature shows strong links between poverty and arsenic-related health effects. A systematic review of the socioeconomic effects of arsenic exposure shows that it increases the economic burden on the poor (Brinkel, Khan and Kraemer, 2009). Most arsenic-affected people do not end up getting treated due to financial constraints, which leads to further financial issues since they lose income-earning opportunities, and moreover, seeking treatment and/or a safe water source also incurs further costs (Chowdhury *et al.*, 2006). Ahmad *et al.* (2007) found that 58.6% of the sampled population went through economic problems as a result of arsenicosis, 53.7% experienced a decrease in their level of efficiency at work, 42.7% experienced financial loss, 21.9% could not afford medicine and/or nutritious food, and 15.9% were unable to get a suitable job.

It is important to note that only those who have visible symptoms such as skin lesions are identified as arsenic patients by the Bangladesh government (Human Rights Watch, 2016), even though chronic exposure to arsenic has many more adverse effects on health, as shown in this literature review. Moreover, the effect of arsenic on socioeconomic conditions are studied mainly based on visible symptoms of arsenicosis as well. There is a distinct lack of research on the socioeconomic outcomes of more intangible effects like psychosocial distress.

Effect of arsenic exposure on psychosocial well-being

According to the WHO (1946), health is considered "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". The psychological and social implications of arsenic exposure are a crucial and important dimension to consider when assessing its impacts. However, there is limited literature on the effects of arsenic on psychosocial well-being. The few studies available demonstrate the need for further research.

A study in Inner Mongolia compared an arsenic affected-village with an arsenic-free village, where the General Health Questionnaire (GHQ) – a quantitative screening instrument that assesses mental well-being (Goldberg and Hillier, 1979) – was administered (Fujino *et al.*, 2004). The study showed that the mental health of participants in the arsenic affected village

was significantly worse, although the cause of the distress was not directly attributed to the arsenic. A study conducted in Chapainawabganj district (n=147), an arsenic hotspot in Bangladesh, also used the GHQ to show mental health scores were significantly worse among those who were affected by arsenic (Keya, 2004, cited in Brinkel *et al.*, 2009). A cross-sectional study (n=4,099) conducted in four arsenic-affected districts in Bangladesh, using the same tool, showed that drinking from untested tubewells and having arsenicosis were associated with lower mental health scores (Chowdhury, Krause and Zimmermann, 2015). Moreover, in a case-control study, arsenicosis patients reported higher levels of depression, insufficient sleep, loss of appetite, etc. than controls (Khan *et al.*, 2006, cited in Brinkel *et al.*, 2009).

Social instability and ostracism are among the major issues faced by those who are exposed to arsenic: Conflict arose from social friction over contaminated water. Ostracism arose from those who are unaffected tending to avoid arsenic victims; arsenic victims sometimes being wrongly identified as leprosy patients; children of arsenic victims not being allowed to attend social/religious functions (Chowdhury *et al.*, 2006). Ostracism further compounds the health issues of arsenic victims: they are often denied water from neighbours' tubewells, or not allowed to bathe in the village pond (Brinkel *et al.*, 2009).

Many people have superstitious beliefs about arsenicosis, such as it being a curse or the work of evil spirits or the devil – as a result, many do not end up receiving any form of medical treatment (Chowdhury *et al.*, 2006). Breakdown of marriages and/or family relations is also common: many people get divorced or separated due to one partner being affected by arsenic; it can be difficult to find a spouse for an arsenic victim; other families are reluctant to establish marital relationships with families who have members with arsenicosis (Brinkel *et al.*, 2009; Sarker, 2010). A qualitative study conducted in southwestern Bangladesh also found similar themes of ostracism and discrimination among those affected by arsenicosis (Hassan, Atkins and Dunn, 2005).

Through an ethnographic study in Bangladesh, Sultana (2009) talks about how exposure to arsenic leads to changes in gender relations. For men the concern was more ideological or cultural: having an arsenic contaminated tubewell was concerning because it meant the women and girls in the household would have to travel out to public spaces to collect water. Women, on the other hand, were concerned with the logistics of having to travel longer distances and the unease of having to use someone else's water source. In some households, familial hierarchies and power dynamics mean that women and girls are sometimes forced to continue

collecting water from an unsafe source because it is nearer. As Sultana (2009) states "... water collection is one of the domestic duties through which women are able to leverage outside mobility." Thus water (whether contaminated with or free of arsenic), can have an effect on gender-water relations.

Based on the same ethnographic data, Sultana (2011) finds that people expressed different forms of suffering in relation to water – suffering because of water (due to lack of access to safe water) and suffering from water (due to the various impacts arsenic poisoning has on their lives, including ill health). They also reported social conflicts arising as a result of sharing water sources, which included instances of arguments, shouting, verbal insults, humiliation and feeling belittled, among many others. Sultana (2012) found various sources of psychological and social stress, including physical health, marriage issues, ostracism and stigmatisation, as well as loss of livelihood and impoverishment.

Specific studies on water and sanitation-related psychosocial distress

Wutich and Ragsdale (2008) looked at the effects of water insecurity (in general; not in terms of arsenic) and the resulting emotional distress, in an urban squatter settlement in Cochabamba, Bolivia. The authors studied culturally grounded expressions of water-related emotional distress, which were then converted to binary data and measured on a scale. They found four emotions were particularly prevalent in relation to water insecurity: fear, worry, anger, and being bothered. Stevenson *et al.* (2012) looked at the effects of water insecurity and its effects on psychosocial stress among women in a region in Ethiopia. This was a mixed methods study, and the qualitative phase identified stresses of water collection, opportunity costs of water collection, water-associated illnesses, using water frugally, using water from undesirable/unsafe sources, relationships with husbands and neighbours, and feeling shame, to be commonly indicated sources of psychosocial stress resulting from water insecurity. In addition, the quantitative phase of the research shows that water insecurity was positively correlated with psychosocial distress measured on a binary scale. The study utilised the Self-Reporting Questionnaire (Beusenberg and Orley, 1994) modified and validated for Ethiopian populations.

Another study on water insecurity and emotional distress (Bulled, 2016), this one conducted in rural South Africa, used a version of the scale to measure emotional distress developed by Wutich and Ragsdale (2008), modified for the particular community being studied. The findings of this study show that participants experienced worry, fear and annoyance over the

quality of the water, feeling embarrassed about their water situation (in comparison to neighbouring villages), and feeling anger towards people who use water inappropriately (Bulled, 2016). Another recent study, conducted by Thomas and Godfrey (2018) in a small town in Ethiopia, used the same scale to measure emotional distress (but modified for the Ethiopian context). They found the most common dimensions of distress expressed as feeling bothered about having to collect water, being afraid of running out of water, fearing power cuts that could lead to loss of water supply, and being upset with a family member about water usage (Thomas and Godfrey, 2018).

Sahoo *et al.* (2015) looked at psychosocial distress in relation to sanitation. Using the grounded theory approach, this qualitative study found that that sanitation practices meant much more than just defecation and urination – it included carrying water, washing, bathing, menstrual management, and changing clothes. When carrying out these activities, women reported three types of stressors: environmental, social, and sexual. These stressors in turn were influenced by the woman's life stage, living environment, and access to sanitation facilities. Environmental barriers, social factors and fears of sexual violence led to sanitation-related psychosocial stress. The two studies by Sultana (2011, 2012) mentioned above, specifically studied the effect of arsenic exposure on various aspects of people's lives in several affected districts within Bangladesh. The earlier study utilised qualitative (ethnographic) data to study emotional geographies in various arsenic-affected regions, and the later used mixed methods to study the geography of health and well-being in arsenic-affected areas. Although neither of these studies explored psychosocial distress explicitly, the range of the findings encompassed various instances of psychosocial distress.

Although none of the above studies focus specifically on psychosocial distress as a result of arsenic exposure, they provide valuable insight into the current status of research on emotional or psychosocial distress in relation to WASH. These studies lend themselves well to extrapolate and adapt methodologies to study psychosocial distress as an outcome of arsenic exposure. A summary of these studies and the corresponding sites and methodologies is shown in Table 2 below. The next section will further discuss how these various pieces of research influenced the methodology of this study.

Table 2: Summary of specific studies on water-related emotional/psychosocial issues

Author(s)	Year	Study site	Setting	Subject matter	Methods
Wutich & Ragsdale	2008	Cochabamba, Bolivia	Urban	Water insecurity and emotional distress	Mixed methods
Sultana	2011	Various districts, Bangladesh	Rural	Arsenic in groundwater and emotional geographies	Qualitative (ethnography)
Sultana	2012	Various districts, Bangladesh	Rural	Geography of health and well-being in arsenic affected areas	Mixed methods
Stevenson et al.	2012	Amhara, Ethiopia	Rural	Water insecurity and women's psychosocial distress	Mixed methods
Sahoo et al.	2015	Odisha, India	Both	Sanitation-related psychosocial distress among women	Qualitative (grounded theory)
Bulled	2016	Limpopo, South Africa	Rural	Water insecurity and emotional distress	Quantitative
Thomas & Godfrey	2018	Oromia, Ethiopia	Peri-urban	Water-related emotional distress	Quantitative

4 | METHODOLOGY

The goal of this study was to gain an in-depth understanding of the lived experiences of psychosocial distress among those exposed to arsenic in groundwater. It was not to quantify the prevalence or the extent of arsenic-related psychosocial distress, or compare to any form of baseline of psychosocial distress. The use of psychosocial distress measures in development sectors is an emerging field with limited comparable data. Wutich and Ragsdale (2008) used a scale which was grounded in local idioms of distress, and Bulled (2016) and Thomas and Godfrey (2018) subsequently used modified versions of this scale. Stevenson *et al.* (2012) employed an internationally-used self-reporting questionnaire in the quantitative portion of the study. Although these studies broke new ground in studying psychosocial distress, the issue with using such methods is that they are not comparable since the operational definition of emotional or psychosocial distress is different in each study, and moreover, they are all related to water insecurity in general, rather than a specific contaminant such as arsenic.

As a result, this study relies more upon the approaches employed by the ethnographic study by Sultana (2011), the grounded theory study by Sahoo *et al.* (2015) and the qualitative portion of the study by Stevenson *et al.* (2012). Although Sultana (2011) does not study psychosocial distress specifically, it does look at many social and emotional aspects of living in arsenic-

contaminated areas in Bangladesh. The Sahoo *et al.* (2015) study, although related to sanitation and not contaminated water, takes place in a culturally similar setting and more importantly, takes an open-ended approach to understanding psychosocial stress. The approach allows the issue to be understood in-depth and with all its complexities and nuances, rather than reducing it down to a binary scale as the methodologies mentioned in the previous paragraph did.

Thus, an exploratory study using qualitative methods was employed to study the phenomenon of arsenic-related psychosocial distress. This approach allows the researcher to generate and develop theory from the data (Davies, 2011), rather than taking a confirmatory approach and use data to test existing theories.

Epistemological and ontological considerations

Since this study aims to understand particular aspects of human behaviour, actions and perceptions, the epistemological stance taken by this research is one of interpretivism, especially that of the hermeneutic-phenomenological tradition which seeks to understand and interpret human behaviour (as opposed to explaining it) from the points of view of those being studied (Lindseth and Norberg, 2004; Bryman, 2012). With regard to its ontological position, this research takes a constructionist approach to the nature of social phenomena, that is, they are constructed and continually modified by social actors (Bryman, 2012). The flipside of this – that is, a positivist epistemological stance and an objectivist ontological stance – is not conducive to studying lived experiences. This is because the study participants are members of an affected community navigating complex social relationships, interactions with the environment, difficult health issues, and all the related emotional issues that come with them. In other words, they are human beings with subjective experiences – and within the boundaries of the research questions that frame this study, these experiences need to be understood rather than objectively quantified. Thus, the hermeneutic-phenomenological lends itself well to studying lived experiences (Lindseth and Norberg, 2004).

Field site

In order to be able to interview members of an arsenic-affected community, the selection criteria for the field site was for it to be an area with a high level of arsenic contamination. Another consideration was the availability of support from BRAC (an international NGO based in Bangladesh that I previously worked for). Since BRAC regional field staff have in-depth local knowledge, I utilised their help in navigating the area – both geographically and also to

be mindful of the regional norms and political leanings. The first site chosen did not work out and consequently a different site was chosen.

The sub-district (*upazila*[2]) of Matlab South in Chandpur district was initially chosen since it has some of the highest arsenic concentrations (Figure 1a), with the district mean being the highest in the country at 366µg/L (Kinniburgh and Smedley, 2001). Based upon advice from colleagues at BRAC and REACH (a research project on water security led by the University of Oxford), four villages were visited. However, among the approximately 15 people approached in various locations within these villages, every one of them mentioned that they had no issues with arsenic – they did not have problems accessing arsenic-free water, neither they nor people they knew had visible signs of arsenicosis, and therefore it was not a matter of concern to them. It was apparent that there were many tubewells that had previously been tested and marked unsafe, but many residents seemed to have invested in their own deep tubewells. The local DPHE office was reached out to for advice on potential sites but could not be contacted.

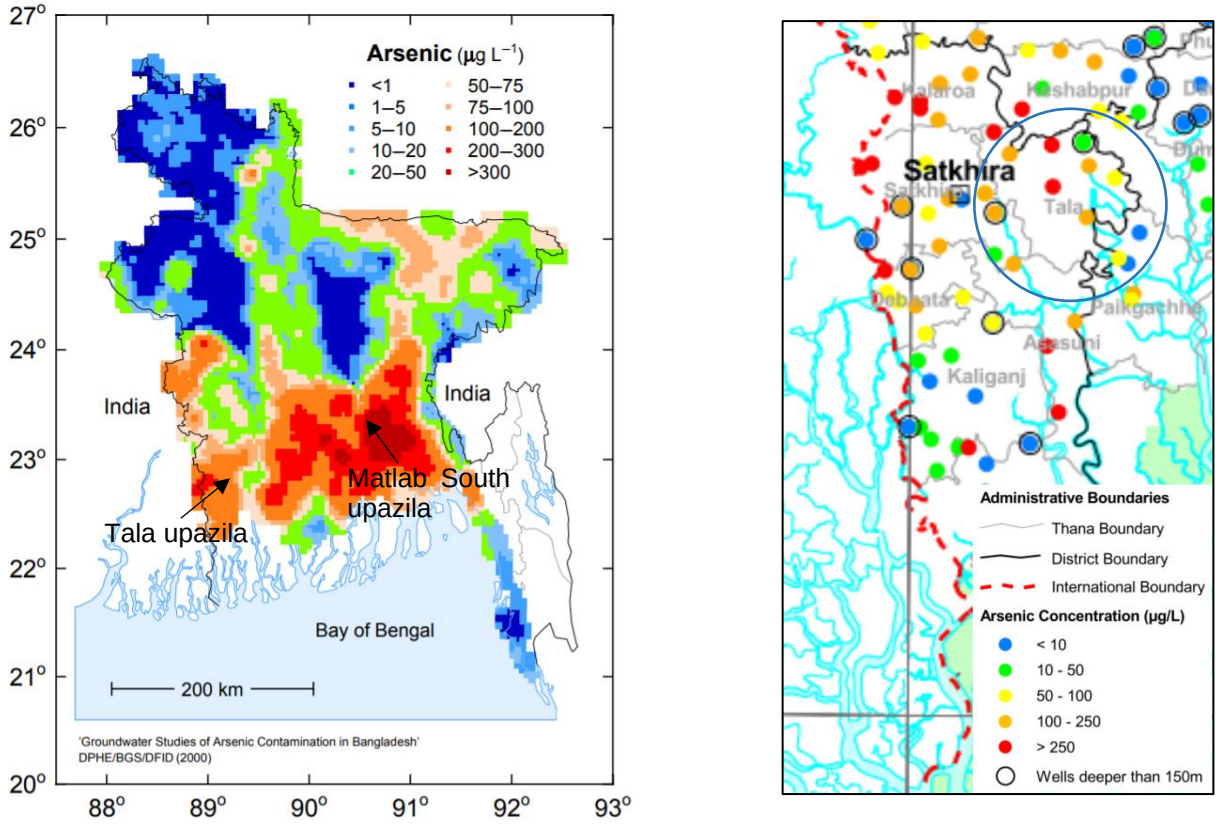
Based on further discussions with BRAC, it was decided that Tala sub-district (*upazila*) in Satkhira district could serve as a study site. With a district mean of 133µg/L, the area is less contaminated than Chandpur but still among the twelve highest (Kinniburgh and Smedley, 2001), and the residents there were known to be negatively affected by the presence of arsenic. The local DPHE office had some records of people living with arsenicosis in the area, especially in one particular village[3]. This village, consisting of 278 households, was thus selected as the study site. The area is mainly agrarian, with most residents farming the land for crops such as jute.

[2] The administrative tiers in Bangladesh are as follows: country, division, district (*zila*), sub-district (*upazila*, formerly *thana)*, and union. The union is the lowest tier of local government, and is divided into nine wards consisting of a cluster of villages (Directorate General of Health Services, 2012).

[3] (a) The village will not be identified by name on ethical grounds, in order to protect the anonymity of the study participants. (b) It should be noted that BRAC has not provided any water-related interventions in this village, only sanitation facilities had been provided in the past.

Figure 1: (a) Regional distribution of arsenic in Bangladesh groundwater (indicating locations of Tala and Matlab South upazilas); (b) Point-source arsenic map zoomed in on Tala, Satkhira (Kinniburgh and Smedley, 2001)

(a) *(b)*



Sampling and selection criteria

Inclusion criteria: Adult men and women living in a defined area contaminated with arsenic (the study village), with or without visible symptoms of arsenicosis.

Exclusion criteria: Anyone who does not have the ability to consent to being interviewed or those who may be put at risk by being interviewed.[4]

The sampling technique used was purposive, based on a snowball sampling technique. That is, study participants are selected strategically or purposively, such that their experiences are relevant to answering the research questions, and subsequently the snowball technique allows the initial participant(s) to identify other potential participants who have had relevant experiences (Bryman, 2012). After defining the sampling frame, the snowball seed was identified through convenience sampling. The consent process was started and the interview was conducted (more details on these processes are given in the subsections below). Following

[4] One household was excluded because the women did *purdah* (not interacting with men other than their husbands or blood relations). Since I was being guided by two male colleagues, we judged based on our knowledge of the local culture that approaching them, even by myself, may put them at risk of being reprimanded by male family members.

each interview, I asked the participant to introduce me to their immediate neighbours. Other residents requested to be interviewed after hearing of the study. This was taken as an opportunity to build rapport with the community, but they were told that several households would be visited over the next few days to speak to each respondent separately. The general aim was to reach approximately 10% of the households in the village (i.e. 27-28 interviews), but with the intention to stop when data saturation was reached, that is, when no new information emerges from collecting further data. Saturation was eventually reached at 23 interviews.[5]

In addition, some high-level individuals who had several years of experience working in the water sector in Bangladesh (government and non-government), with expertise on arsenic mitigation, were reached out to conduct key informant interviews. This was done in order to triangulate the information collected from the interviews with the affected community members, and to gain an understanding of how those working in policy and implementation view the issue of arsenic-related psychosocial distress. Three people granted appointments and agreed to be interviewed[6].

Interview design

For the interviews with the community members, an in-depth interview (IDI) guideline (Appendix 1) was developed to help carry out the data collection process. The questions were developed based on the research questions and the issues which commonly came up in the literature review above. The questions were kept as open-ended as possible, but with prompts to encourage further conversation when necessary. In an exploratory qualitative study such as this, it is crucial to have set guidelines in order to ask questions which cover as many topics relevant to the research questions as possible, while still allowing enough flexibility to the interviewee to relate their experiences openly and in detail (Bryman, 2012).

The questions were designed to cover a range of topics related to arsenic in the groundwater, which would lead to discussions about health, finances, social and emotional issues. The overall sequencing of questions was to ask about their general well-being, where they obtain their water from, how the presence of arsenic affects the collection and consumption of water, whether they face social conflicts arising from the presence of arsenic, if they face health issues as a result of arsenic, if arsenic incurs extra financial costs on their family, and their perceptions

[5] It should be noted that in some of the households approached, there were no people available because they were away from the village, for medical care and other purposes. Thus, some perspectives may not have been captured in the study.
[6] However, one did not consent to audio recording.

of the risks posed by arsenic. These questions were asked with the intention of finding possible pathways or stressors relating to psychosocial distress, keeping enough openness for the participants to express feelings of distress in their own way. Some basic demographic questions on age, family size, education and occupation were also asked at the end of the interviews.

A semi-structured interview guideline (Appendix 2) was also designed for the key informant interviews. The questions they were asked were customised according to their experiences, and were similarly open-ended to allow for in-depth discussions.

Data collection

In-depth interviews with members of the affected community were conducted between 13th and 18th July, 2018. Before beginning each interview, a description of the study was given and written or oral consent was taken. Each interview was approximately 20 minutes long. It was an iterative process, where the way of asking questions, their contents, and the order they were asked in, were reflected upon and modified. Each respondent was different in their own way, and therefore the interviews somewhat varied accordingly. Hence it should be noted that results of each interview are therefore not comparable to each other, but rather separate subjective experiences, which were later collated to find themes and patterns (more details on this will be discussed in the next subsection). Sensitivity was the key issue at all times, since many of the topics in discussion were quite emotional.

All interviews were conducted in simple, conversational Bengali (of which I am a native speaker). This is important since interpretation of subjective experiences is central to qualitative research (Van Nes *et al.*, 2010). Since language is one of the primary ways of relaying experiences, and translation involves a certain level of interpretation (Van Nes *et al.*, 2010), being a native speaker can add a layer of validity to the research. The location of interviews was designed to make the respondent comfortable about the interview and build rapport with them. Most of the interviews were conducted on the front porches or courtyards of the houses, as per the respondents' preferences. Audio recordings of the interviews were taken on a smartphone. Throughout the process the participants' tone, body language and use of expressions were noted in order to add to the understanding of their emotional response to the subject at hand.

Data analysis

In order to properly understand the information relayed by the study participants and to study the patterns in their experiences, the interviews were first transcribed and translated into

English. The hermeneutic-phenomenological approach was applied in the data analysis: hermeneutic because it involves text interpretation (i.e. coding the textual data and finding emergent patterns) and phenomenological because it involves extracting meaning from the textual data to understand the lived experiences of the participants (Lindseth and Norberg, 2004). Analytic memos were made for each interview. Open coding was done by going over each line of the transcript, and emerging patterns were noted. A codebook was developed based on the patterns that arose in the data (Appendix 3). Thematic analysis was done by assessing repeating patterns, looking at similarities and differences between experiences, and noting local idioms of expression. These allowed identification of themes in the data. The process was iterative, whereby I revisited and re-examined the data at various points when overlaps and pathways between different themes emerged.

Ethical considerations

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: SOGE 18A-68). Information about the research was verbally presented, and written informed consent (Appendix 4) was taken from each participant before they were interviewed. For those who could not read or write, the information was read out loud to them and oral consent was taken. It was ensured that the participants understood what the study was about, and were given a chance to ask questions if they had any. They were made to understand that there would no harm nor any benefits such as compensation for participating. They were assured they could stop the interview at any time or refuse to answer any question if they chose to do so. Permission to take audio recording of the interview was also taken during the informed consent process. They were assured that all data would be anonymised and their privacy would be maintained strictly.

Moreover, it was crucial to conform to cultural and social norms. The timing of the interviews was according to the local residents' usual daily schedule. On each day, I went to the village once in the morning at approximately 09:30 and left around midday (which is when they normally start cooking) and again in the afternoon around 14:00, concluding at approximately 17:00 (the end of the workday when they usually socialise and rest). Other small but important considerations included wearing culturally appropriate dress, and being cognizant of the duration of the interviews since many of them were stepping away from their household chores and even their farm work in order to be interviewed.

5 | RESULTS

In-depth interviews were conducted with 23 respondents, each from a different household in the village. Basic demographic data is presented in Table 3 below. Results show that emotional response to arsenic-contaminated water was both direct and indirect. That is, there were sources of distress because of the very presence of arsenic in the groundwater, and there were sources of distress which were consequences of arsenic consumption. In a majority of cases, psychosocial distress resulting from arsenic was mediated by the effect it has on physical health – either the respondents' own health or that of their family members. And although health emerged as a very prominent mediator, there were also other consequences of arsenic consumption – such as loss of productivity, extra financial costs, death of family members or neighbours, and issues of marriageability, among many others – which acted as pathways between arsenic exposure and psychosocial distress as well. The participants expressed distress through various verbal expressions, including "*chinta*" (worry), "*dushchinta*" (anxiety), "*koshto*" (suffering), "*betha*" (pain) and "*durbolota*" (weakness). There was also a sense of frustration and resignation which was implicit in the way they spoke about their issues and in their body language. The following subsections will expand on the above themes and demonstrate, through salient quotes, the lived experiences of arsenic-related psychosocial distress.

Table 3: Demographic and health data

Indicator	Result
No. of respondents	23
Sex	15 F 8 M
Age (average)	49
No. of household members (average)	5.4
Household position	6 primary income-earners 17 others
Education	11 none 9 primary 3 secondary
Occupation	11 farmers 10 housewives 1 civil service 1 retired
Visible arsenicosis	17
Has family member with visible arsenicosis	21

Lack of access to safe water

Arsenic contamination was quite widespread in this area. Among the respondents interviewed, nearly every household had a shallow tubewell in or near their homestead and all of these had been tested and marked red, according to them. Arsenic was first discovered in this village between 10 and 20 years ago. Two options for safe water were mentioned: (1) a pond sand filter, provided by an international NGO[7], was reported to have been out of order for several years; and (2) three deep tubewells, installed by the government, and in working condition – one in a school yard, one by the side of a road, and one situated in a family's courtyard.

Choices to use water were influenced by perception of the water quality and health impacts. Several respondents had been informed by doctors that the deep tubewells contained high salinity levels and would cause heart problems, and therefore advised them not to drink from those. Some residents also claimed that arsenic had infiltrated the deeper layers of soil under the deep tubewells and those were contaminated as well. The accuracy of these claims could not be substantiated, however, two of the key informants did mention that it was possible. According to one, it is sometimes common for DPHE to install deep tubewells without test boring and therefore not confirming the presence of an impermeable clay layer to prevent arsenic from infiltrating deeper. Another mentioned the lowering of the groundwater table to be the reason behind this.

Among the respondents, more than half had openly admitted to drinking from the shallow tubewells within their housing compounds which were confirmed to be contaminated with arsenic. Several respondents said they drank from the deep tubewells, although as mentioned, many were doubtful whether these were even safe. A few respondents mentioned the presence of high salinity in these deep tubewells. Moreover, a small minority of respondents who mentioned drinking from deep tubewells eventually also admitted to just drinking from arsenic-contaminated tubewells in their homes when they felt too weak or tired to go further away to collect water.

> *"Sometimes we even drink from the shallow tubewell at home. For example, when I come back from having toiled in the field all day and I'm too tired to go further to the deep tubewell to get water, I just drink from this one. So of course we get affected badly*

[7] It could not be determined exactly which organisation; the respondents simply mentioned that foreign NGO workers were involved.

because of this. A lot of people in my extended family have died because of arsenic." – Woman, 60 (IDI#15)

Most respondents had initially changed their water source when they first found out about the arsenic, but the change was not sustained. Some respondents mentioned switching to the pond sand filter, and a majority said they started using the deep tubewells that got newly installed at the time (some mentioned both), and one respondent said they never switched. Some respondents mentioned that they supplemented their supply of water by harvesting rainwater during the monsoon, and a small minority mentioned that they sometimes buy water. A few respondents admitted to reverting back to using the water source that they used originally – which in all cases were the shallow tubewells in or near their homes. The main reasons given were because the water sources stopped working or, in the case of the deep tubewells, were said to contain high levels of salinity and/or arsenic that had seeped down.

"They've installed a few deep tubewells here that are not supposed to have arsenic, but those cause heart problems. So if people want to save themselves from one illness, they switch tubewells, but then they are faced with another illness." – Woman, 30 (IDI#17)

Thus, arsenic caused them to modify or change their water collection behaviour, but the presence of salinity or purported seepage of arsenic in the newer water sources resulted in them reverting back to using contaminated shallow tubewells, since they are closer in proximity. Furthermore, more than half mentioned using their water source for all purposes. A small minority admitted to using deep tubewells for just drinking and cooking and the shallow tubewells at home for all other purposes, or mainly using deep tubewells just for drinking and shallow tubewells for all other purposes (including cooking). This indicates that people are not only directly drinking arsenic-contaminated water, but also cooking with it due to a lack of recognition of the risks involved. One of the key informants touched upon this issue as a lacking in the awareness-raising around risks of arsenic.

The issues of safe water access faced by this community were echoed by the key informants: all three recognised overall water quality and sustainability of water sources as the main issue in the water sector Bangladesh, with arsenic being a major barrier to access. Two mentioned falling groundwater table as an issue that is further compounding the arsenic problem. This lack of access to safe water that is free of arsenic and other contaminants seemed to be an evident source of distress in this community, as most of the participants expressed a sense of

resignation at not having much of a real choice when it came to obtaining safe water, because it had become a matter of choosing between different contaminated sources.

Lack of agency

An unexpected topic which came up during the interviews was the topic of previous researchers, doctors, government officials and NGO workers who had come to the village previously. All respondents were aware of previous research that had taken place, and the interventions that followed. This involved testing the water sources (which happened several times over the years), testing of hair, nail and blood samples, and installation of the pond sand filter and deep tubewells. The respondents also mentioned doctors coming to the village and providing them with medicine such as ointments for symptomatic relief, along with advice on nutritious food intake as a way of managing arsenicosis. A few of them also mentioned that some people suffering from arsenicosis were taken to Dhaka (the capital) by these researchers or doctors for treatment for short periods.

Among a majority of the respondents there was a sense of frustration about the lack of any solution to their problems despite the large number of people such as researchers and doctors that have come around, and the number of times they have come and gone.

> *"A lot of people have come around to take our interviews like you. They've even taken our hair and nail samples. Our area is probably the worst affected in Bangladesh. But nobody could provide us with a solution for safe water. They come and give us some medicine like a bit of ointment, but then what? We're tired of talking about this because there is no solution. I don't mean you, but the people who come here to test the water, and test us. They've even taken a couple of people to Dhaka for treatment and sent them back after a few days. Medicines don't really work." – Man, 42 (IDI#9)*

> *"Lots of people come to this village, test the water, and give us medicine. But to no avail. It doesn't really work. We've seen so many doctors, but it's no use - we still haven't gotten better. Some people say it's never going to get better. People have come to test the water about five or six times. They've told us we can't drink this water, we should only drink from the deep tubewell. But it doesn't make a difference … People come every once in a while to test the water and they tell us there is arsenic in it, and we shouldn't drink it. Then they also leave and never come back again. That's just how it keeps going."*
> *– Woman, 30 (IDI#20)*

This lack of agency over safe water sources (and the corresponding lack of agency over their health) was a very clear stressor for them. It incited strong reactions and a sense of frustration and irritation about it, compounded by the fact that researchers and others repeatedly come and go but never bring any tangible solutions. This situation was also touched upon by the key informants who all recognised a critical lack of coordination between the various stakeholders working in the water and sanitation sector. There was the general perception that every organisation works in their own way, that there is not much communication between them, and in fact a reluctance to share data and information with one another. One of the key informants mentioned a lack of prioritisation and commitment from the government and one mentioned that the use of donor funding towards safe water supply is not optimal. This perspective on the issue provides an explanation as to the repeated but inadequate interventions experienced by the members of this community.

Social cohesion and friction

All but one household shared their tubewell with others. Those who use the tubewells in their homesteads share with the surrounding 2-3 households, and those who use the communal deep tubewells shared with various households. The most common problem cited by the respondents was queueing for water. A small number of respondents also mentioned that when they collect water from a neighbour's tubewell, the neighbours sometimes get irritated at people constantly coming to their tubewell and might not allow them to use it. One respondent seemed to take this issue to heart, and it seemed that the tension between them and their neighbours was higher than the usual. However, over half of the respondents mentioned that there were no problems in sharing the tubewells. According to them, this village is so widely affected by arsenic that everyone is going through the same issues when it comes to accessing water, and therefore there is a level of understanding between them.

> *"No [there are no problems], because there is so much arsenic in this area, a lot of people are affected by it. Most people drink water from the deep tubewell in the school or the one by the side of that road." – Man, 80 (IDI#11)*

Most of the respondents reported getting along well with their neighbours. The majority of the respondents mentioned they have a good relationship with their neighbours, and a small number said the relationship was good but not always perfect. The main reason for this,

according to the respondents, is the fact that they are all affected by the arsenic in some way or another, and therefore everyone understands what the other is going through.

> *"Because all of us are victims of arsenic on a daily basis … we all have members in our families suffering because we are using this contaminated water. No one is the odd one out, that's why it doesn't cause any problems between one another. Arsenic is the common root to everyone's problems here."– Woman, 55 (IDI#2)*

This community seems to present an overall sense of social cohesion based on their shared negative experiences, which is in contrast to the common discourse of ostracism around water sharing and interactions with neighbours. However, this does not preclude the fact that some respondents still did experience some level of friction with their neighbours when it came to sharing of water sources, even though they are fewer in number. It is possible that this may have been a more widely prevalent issue than captured in these interviews. The respondents may not have opened up completely about these issues because they were aware that I was also interviewing their neighbours. Regardless, there is evidence of some tension with regard to sharing water sources.

Gender issues

Gender norms and gender-based differences came up both implicitly and explicitly in the results. Among the respondents interviewed, it was evident that women were mostly responsible for collecting water. In more than half the households it was the wife's responsibility. Husbands also collected water, but mainly to help out at times. There were only two households where the husbands were primarily responsible for fetching water. Other members of the family responsible for collecting water were daughters and daughters-in-law. A small minority of respondents mentioned that all members of the family contributed to this task. For those that collected water from outside their homesteads, the time taken ranged from 10-30 minutes (roundtrip).

With regard to marriage, it was evident that the majority had experienced problems when it came to getting their children married. Over half the respondents mentioned problems in arranging marriages, either as first-hand experiences or as a general occurrence they have come across. From their responses, it was clear that they preferred to marry outside of the village as a norm, but faced problems because of the presence of arsenic. It is apparently a common occurrence for families from other villages to meet them and for everything to go well until

those families find out about the arsenic in the village. In some cases, they have the misconception that arsenic is contagious, and at other times they know moving into this village will inevitably mean drinking arsenic-contaminated water. In contrast, some respondents mentioned not having experienced any problems or having heard of such things occurring.

> *"A lot of people don't want to get married into this village. If they see our hands and feet, they won't want their daughters to get married into our families. I've seen it happen. Some wives have even left their families because of arsenic. They don't want to stay here." – Man, 50 (IDI#19)*

One respondent mentioned that her husband did not live with her or talk to her, but it was not clear whether this was in any way related to her having arsenicosis. Another respondent also mentioned knowing a girl with arsenicosis from this village being married off to a family in another village.

> *"There is a girl with arsenicosis from this village who got married off to another family. Her husband doesn't talk to her, or let her go anywhere. She lives like a prisoner. They don't even let her cook because they don't want to eat food that she prepared. They make her do outdoor work." – Woman, 55 (IDI#5)*

In general, when it came to issues of marriage, the discourse mainly centred on women (i.e. potential brides) – on "giving away" their daughters to be married into families in other villages, and "bringing in" women to be married to men in this village. Moreover, most of the women interviewed were ones who came from other villages to this one to be married – and nearly all of them mentioned their old villages not having issues with arsenic. These issues were echoed by one of the key informants, who mentioned meeting a group of women as long back as 1996, in a village in a similar geographical setting as this one, among whom the major concern was that nobody would want to marry them. This informant had since encountered many other people over the years who had the same concern.

Discussion on the respondents' opinions of who they think are the worst affected by the presence of arsenic produced interesting and varied results. The majority mentioned specific persons – with most of them pointing out to a family who lost several members, and a few mentioning themselves. When prompted about which groups of people are most affected, similar numbers of respondents mentioned men, women, and the elderly. There were a couple of women among those who mentioned men to be the most affected, and a couple of men

among those mentioned women to be the most affected. A few considered everyone to be equally affected because they believed arsenic did not distinguish between men and women.

The main reason that the particular family was mentioned was because they lost several income-earning members, leaving them in a financially disadvantaged state. Many considered the elderly to be the worst affected because arsenic has debilitating physical effects, and they are already frail. Those who considered men to be the worst affected, the general idea was that more men were affected by arsenicosis than women, and in fact the people who died due to arsenic-related causes in this village were all men. Many also considered arsenic to be harder on men, because they believe men have to work harder. On the contrary, the few who mentioned women considered women the ones who work harder and therefore feel the burden disproportionately.

> *"Men suffer more. They have to work outside for a long time. We can take rest, but they can't. More men have arsenicosis and more have died because of it." – Woman, 60 (IDI#14)*

> *"Women are affected worse. They work in the fields, then they have to come back home and cook for their families, do household chores. So they suffer more. Men can come home, take a bath, say their prayers then get some sleep. Women can't do that."*
> *– Woman, 40 (IDI#22)*

This is an interesting example of differing perspectives. Some respondents, like the ones quoted above, perceived the gendered experiences of arsenic poisoning. Yet others believed that everyone was affected equally; or they did not consider it to be a matter of gender but rather one of age; or even that it was a matter of the severity with which specific families have been affected. Thus, it is an instance where the perception is one where the lines of gender demarcation can sometimes be blurred.

Physical health effects

Visible arsenicosis was common among participants and their families. Overall, nearly all respondents had an emotional response to their and their families' health issues, as shown in their choice of words, their tone and body language when describing their health problems. All respondents with visible arsenicosis reported that they were currently feeling unwell due to a variety of arsenic-related physical discomforts (and two respondents without visible arsenicosis also mentioned feeling unwell due to other health issues). All the respondents who had

arsenicosis presented with dermatological symptoms, especially a scaly hardening of the skin (keratosis). There were a couple of people who also had smaller areas of non-hardened lesions.

Over half the respondents mentioned they have a near-constant itching or burning sensation on their skin, and this is made worse when they go out in the sun, in water (either when bathing or under rain) and when sweating. Several mentioned being in a lot of pain in relation to this. It is especially painful on the palms of the hand and the soles of the feet, which rendered simply holding things or walking barefoot (a cultural norm) extremely difficult. Itching and burning seemed to be less of a problem among whom the dermatological symptoms were seemingly less severe, as observed by the researcher as well as mentioned by the respondents themselves. Several respondents also mentioned feeling physically weak overall, and becoming easily tired. Some respondents also mentioned symptoms such as gastric issues, dizziness, lack of appetite, palpitations, difficulty breathing and difficulty sleeping. Two respondents mentioned having been diagnosed with serious heart problems and one had been diagnosed and treated for cancer.

> *"My hands and feet hurt. I have palpitations in my chest. I am suffering, I am suffering a lot. It's hard to describe this suffering. I can't sleep at night. There are innumerable problems in my body.' – Woman, 70 (IDI#4)*

> *"We have to fight against this illness constantly in order to survive." – Man, 42 (IDI#9)*

Participants also felt strongly emotional about their family members' health issues. All but two respondents mentioned having family members affected by arsenicosis. Most had between 1-2 family members affected, except for one who had four and another who had six affected. The latter in fact lost her husband and three sons to arsenicosis-related health issues, and her eldest daughter-in-law is currently being treated for cancer in Dhaka. Another respondent also had a husband with cancer who had undergone chemotherapy in Dhaka for three months, but treatment was currently stopped because they could not afford it anymore. With regard to symptoms, most mentioned ones similar to the above – mainly dermatological symptoms, burning sensation and pain.

> *"My younger son has arsenicosis – those lesions are all over his body. We've got very little land and property so he's gone away to find work. He's gone quite far away, leaving his kids behind. My husband also has arsenicosis. He can't walk or move very well, he is always in a lot of pain." – Woman, 60 (IDI#7)*

"I had three sons, I've lost them all. My husband has also passed away. There is hardly anything left of my family, I'm just going on living like this." – Woman, 70 (IDI#4)

Not only does arsenicosis affect various small but crucial aspects of their everyday life (more of which will be discussed in the next subsection), but many also mentioned it makes them more easily prone to other illnesses (several mentioned frequent occurrences of fever or flu-like symptoms) and that it takes longer for medicines to take effect on them and for them to get better. This demonstrates how complex the experiences of ill health due to arsenic can be, and in fact a majority of the respondents expressed distress at being chronically ill, and constantly in pain and discomfort. The most common descriptor used was "suffering" (*koshto*).

"Water is life. But we don't have that life, can you imagine how much we suffer?" – Woman, 30 (IDI#20)

"The government doesn't really give us any medicines. We are dying and nobody can see us." – Woman, 50 (IDI#6)

Physical health problems were a clear source of distress and anguish for the participants, since being in chronic pain and discomfort gets in the way of them living their lives normally. Among the key informants, all three spoke about the negative health implications of arsenic exposure, but the physiological effects of arsenic took primary focus. The psychological implications of being in chronic pain does not seem to be a consideration that is taken into account in terms of the health response to arsenic. The key informants mentioned the Upazila Health Complexes being designated to identify arsenicosis patients and provide rudimentary treatment and advice. This explains some of the sense of frustration and hopelessness felt by the respondents (demonstrated especially well by the last quote above) – they are chronically ill but there isn't much that even healthcare providers can do for their physiological issues, and much less for their emotional well-being since that is not even taken into account.

Impediments on daily life

Arsenic has a significant effect on the respondents' and their families' daily lives – mainly involving their income-earning work and/or their household chores. The majority of respondents mentioned their work is negatively affected because of arsenic, and a few mentioned that although it affects their work they accept the situation as it is, since they have no other choice but to keep working. One mentioned that they were unable to work at all. This was mainly due to their arsenicosis-related health issues – major complaints were getting very

easily tired, short of breath and being physically too weak to exert much. In addition, they repeated the issues they have with the painfulness on their palms and feet and how that makes most tasks quite difficult.

Since most of the respondents and their family members are farmers, their work is quite physically demanding. Moreover, their household chores – such as collecting water, cleaning their livestock, cleaning the house and yard, cooking, etc. – also require exertion and time spent exposed to the elements. As mentioned before, the heat of the sun and the act of sweating also add to the physical pain they experience.

> *"We are farmers, and our work is very physical. But if our bodies are weak, how are we supposed to work and survive? I am the only income-earning member in a family of five. If I can't work, I cannot feed my family. We are just going on like this… I sometimes do the household chores too, like taking care of the animals and cooking. Because we have arsenicosis in our family, whoever is feeling a bit better on a particular day does all the work and the other takes rest." – Man, 42 (IDI#9)*

> *"It has a huge effect. For example, I cannot work outside in the sun for very long. When I'm out in the sun I feel really bad, I feel dizzy. It's difficult to stay under the sun for more than 10 minutes at a time … I'll work for an hour and take rest for half an hour. This is how I manage. So it takes longer for us to finish our work." – Man, 33 (IDI#10)*

The respondents also talked about how certain aspects of their everyday lives were affected that seem small, but can have a significant impact. For example, being unable to wear a blouse underneath the *saree* (as it is traditionally worn) because it is too irritating and painful to the skin, being unable to hold a pen, bathing in the pond or climbing a tree. Thus, being unable to work properly, perform their daily chores, or even partake in mundane or ordinary activities – that is, crucial aspects of their everyday lives which cannot be lived normally – is a major stressor for them. These obstacles are a source of stress in and of themselves, but also because they have negative financial implications, which will be discussed in more detail in the next subsection. It should be noted, however, that a small minority of respondents did mention that arsenic did not affect their daily lives much at all.

Financial issues

The presence of arsenic has had an impact on the household financial situation of the study participants. Loss of productive time was a major concern among many of the respondents.

They mentioned getting ill quite often and having to take a few days off every month, and moreover, working much less efficiently than they would have, had they not had arsenicosis. Many respondents mentioned having to take to frequent breaks during the workday to take rest. As mentioned earlier, physical exertion, sweating and exposure to the elements – very common phenomena in an agricultural setting – are quite painful for them.

A few respondents also mentioned having extra costs related to water – either to buy water from the market, or in contributing to the repair or installation of a new source. A couple of respondents mentioned spending money on point-of-use filters for pathogen removal (this was confirmed through observation as well). A majority of the respondents had healthcare costs as a result of having been affected with arsenicosis, and three respondents also had quite major costs due to them or their family members having to be treated for cancer in Dhaka. The most common costs were for doctor's visits and buying medicine. Some also mentioned trying to spend a little more on nutritious foods since they have been advised by doctors that better nutrition will help cope with arsenicosis. Some respondents did mention that they were at times given free medicine, but this was sporadic and came with hidden costs.

> *"Doctors advised us to have more vitamins and minerals like iron, etc. and grow more fruits and vegetables. And we were also given vouchers to get free medicine from the hospital. However, to go collect those free medicines, it takes a lot of time and money – transportation costs can be 50-100 taka, it also takes up the whole day, so we can't even work for that entire day. We are poor people, not earning money even for one day is very problematic for us. Therefore, people couldn't afford to go collect the free medicines more than once. You must have heard of the saying 'water is life'. We need to use it for survival, and this is how we are leading our lives." – Man, 38 (IDI#3)*

A majority of the respondents mentioned that they constantly worry about their financial situation – worrying about losing productive time, not being able to work efficiently, and about how they will be able to afford anything if things continue as they are. A couple of respondents mentioned worrying about how they will support their children's future if they don't have enough money, and those who had taken out loans were worried about how to pay them back.

> *"I get sick very easily. My arms and legs are weak, my entire body hurts… I saw a doctor in Tala, and I was okay for a while. But now it's getting worse again. Where will I get the money for all this? We cannot afford to miss even a day's work. Where will I get money and how will I afford medicine? I worry about this every single day. I ask God*

when will my illness get better, when will we be financially better off? I worry about this all the time." – Female, 60 (#14)

"We have to buy medicines. We are poor people, we can't always eat well. We don't have any land or property of our own… I worry about how to afford things. About how we will pay our loans, how we will earn money. I'm constantly worried about this." – Female, 60 (IDI#15)

A few families had to take more drastic measures to be able to cope with the extra costs, especially those who required more costly treatment (such as chemotherapy in Dhaka) and those who had several arsenicosis-affected members in the household. A couple of families had sold property and assets, and some had taken loans. The respondent mentioned earlier who had lost her husband and three sons (that is, income-earning members of the family), used to have a sizable area of land but had since sold everything off and was mainly living on welfare along with her daughter and daughters-in-law. There were a small number of respondents who did mention that they were not worried about money – they had come to accept the fact that money comes and goes and that these extra expenses were just a normal part of their lives.

One of the three key informants talked about the financial implications of arsenicosis. They mentioned having worked with arsenicosis patients who were faced with such situations, including one extreme case where a man had to have his legs amputated, could no longer continue to work and was driven to begging in order to support his family.

Perceptions of risk

Respondents' perception of the risk posed by arsenic was a pattern that showed up in many of the interviews. Every respondent was aware of arsenic as a contaminant in the groundwater, which mainly enters the body through drinking water from contaminated tubewells, and causes a host of health issues. A few also mentioned arsenic entering plants through the soil. Some were aware of the pathway from skin lesions to cancer, since people they knew had experienced it. However, something that was hardly mentioned was the risk to children. Some did acknowledge the future risk if they continued drinking the arsenic-contaminated water, but there was not much mention of current risks. Because they observed the visible effects of arsenic poisoning on themselves in adulthood, their perception seems to be that children are not currently at risk.

"The younger people in the family are fine. Arsenic doesn't really show up among the younger people. It starts showing among those who are a bit older."- Male, 50 (IDI#19)

Moreover, some had also made the observation that their family members and other relatives who had moved away to Dhaka, either did not have arsenicosis or had less severe symptoms. Some believed that if they are able to start drinking from an actually safe source – and not the questionable deep tubewells they have in their village – their symptoms would likely get better. However, there were some that were quite sure that once they had been affected by arsenicosis they would not get better.

"Once arsenicosis happens, drinking safe water will not help. Once it enters your body there is no cure." – Woman, 55 (IDI#5)

A majority of the respondents who were asked what the most problematic issue in the area was, considered it to be either arsenic or water quality in general, and nearly all respondents mentioned that their lives would be much better if arsenic had not been present in their area.

"Everyone would have been healthy. Arsenic has caused a lot of problems for people in this area. The problem is with the water. Water has caused all these problems. The soil is now poisonous."– Woman, 30 (IDI#23)

When asked about the severity of the arsenic issue in comparison with other large-scale problems in the area such as floods and cyclones, the respondents still considered arsenic to be the bigger problem because they consider it to be a more permanent problem that has become a fixture in their lives.

"Floods are a disaster that happen every once in a while, but arsenic has become intertwined with our lives. Floods come when there is too much rain and the river overflows. But arsenic has entered our lives permanently by contaminating our tubewells. It poses the biggest risk to our lives. When floods come, we go to the shelters and the government and NGOs provide us with food and other goods. But those of us who are affected by arsenic have to live with it, and suffer through it." – Woman, 30 (IDI#17)

Overall, the respondents were well aware of the negative effects of arsenic (albeit with some crucial gaps in knowledge such as risks of cooking with arsenic-contaminated water). It was clear that they perceived the great risks it poses and the general mechanisms by which it affects people. However, it is interesting to see that they are not much concerned with regard

to the present risk to children, indicating that they perhaps do not have much knowledge on the effect arsenic can potentially have on a child's developmental abilities.[8]

Anxiety over death and the future

A topic that repeatedly came up during the interviews was an overhanging feeling of anxiety about arsenic and the toll it can take on families. A number of respondents were afraid and anxious about premature deaths – either their own or of their family members who also have arsenicosis. This was mainly because they have seen so many people in their community pass away in an untimely manner because of arsenic. A large number of people mentioned experiencing deaths of neighbours, a few mentioned deaths of relatives or extended family members, one man who had lost a brother-in-law, and of course the woman who lost her husband and three sons.

> *"We have a lot of anxiety about arsenic. We worry about what will happen next. So many people in this village have died because of arsenic. I worry about everyone in the family. If one person dies, how will the rest survive? These anxieties are always there." – Man, 33 (IDI#10)*

Some were worried about how their children will be taken care of if they were to die, and some were also worried about their children's future if they continued drinking arsenic-contaminated water, including if they would be able to get them married.

> *"I worry about my children. If they get affected, I will have problems getting them married. If they get spots on their faces or bodies, people are going to be repulsed by them. So I worry a lot about that. I constantly hope that they are not affected by this illness." – Woman, 30 (IDI#17)*

Many were anxious about being able to access safe water, and how long they would have to continue drinking water containing arsenic, and a few were worried about the situation in general. A small minority of respondents did mention, however, that they did not feel worried or anxious about arsenic, mainly because they did not see a point in being worried all the time.

[8] Participants were not directly asked if they knew about arsenic and its effects on cognitive development in children since the topic at hand was already sensitive, and therefore it did not seem ethical to introduce another stress-inducing topic within the context of the interview.

6 | DISCUSSION

The interviews with the members of this affected community generated rich and compelling data. The results provide a view into their experiences of living with chronic arsenic poisoning and the effects it has on their psychosocial well-being. This section will discuss the results within the framework of the research questions, compare the findings of this study with that in the existing literature, and discuss the limitations of this study and its methodology.

What are the local idioms of distress in relation to arsenic exposure?

The first step to understanding subjective lived experiences of psychosocial distress is to understand idioms of distress grounded in local culture. As mentioned before, the study participants expressed this explicitly through various verbal expressions, and implicitly through facial expressions, tones and body language. The most commonly used idioms are similar to the findings from the ethnographic study in arsenic-affected areas of Bangladesh by Sultana (2011), which also mirrors some of the implicit emotions felt by participants in this one, including feelings of worry, anxiety and frustration.

Themes of pain and suffering were prevalent across most of experiences relayed by the study participants. What is interesting to note is that accounts of physical pain (of arsenicosis-related issues) was inextricably linked to emotional pain and suffering. This is likely due to the fact that the physical pain they feel as a result of skin lesions is not only constantly present, but very easily exacerbated by phenomena that are very common to their lifestyle and circumstances, such as sweating and being out in the sun, or even simpler activities such as touching objects. Moreover, most of the respondents had keratosis on their hands and feet – appendages that are fundamental to most physical tasks. This phenomenon of strongly interlinked physical and emotional pain is a novel finding that is largely absent from the discourse, as evidenced by the literature review in this paper. Even in an ethnographic study that looked at lay understandings of the physiological effects of arsenicosis, the resulting interrelation of pain and distress was not studied (Islam, 2014).

In what ways does arsenic exposure manifest in psychosocial distress?

It is evident from the results of this study that arsenic exposure is linked both directly and indirectly (i.e. through mediated pathways) to psychosocial distress. These will be elaborated upon in this section and later summarised through a visual representation of the pathways in Figure 2.

Arsenic has a direct effect psychosocial distress because it prevents access to safe water. This initiates a change in behaviour – that is, switching water sources. Both in this case and as shown in other studies, this usually means collecting water from further away when wells closer to their homes are tested and marked unsafe (Sultana, 2009, 2011). However, in this village there was the added complexity of uncertainty about the water quality of the deep tubewells which are supposed to be arsenic-free. As a result, many residents resort to using water sources which they definitely know to be unsafe, since they are closer in proximity. Moreover, using unsafe water sources that are nearby is not simply a matter of convenience, but also one of physical capability. Arsenicosis makes it very difficult and painful for them to perform tasks that are physical in nature, and therefore using nearby tubewells (regardless of contamination status) is a coping mechanism. In their study on water insecurity and psychosocial stress, Stevenson *et al.* (2012) found the stresses of water collection, opportunity costs of water collection, and using water from undesirable or unsafe sources, to be common sources of psychosocial stress., This study adds to the understanding of barriers to access through its examination of unsafe water being a direct source of psychosocial distress

The lived experiences of this community show that there are various pathways of mediation between arsenic exposure and psychosocial distress. The most dominant pathway appears to be through the effect that arsenic has on physical health. With regard to the physiological effects, the experiences of the participants of this study are in alignment with current literature. Skin lesions including keratosis, which every participant with arsenicosis presented with, are an indicator of long-term exposure to arsenic (Das and Sengupta, 2008). Not only can these turn malignant (Naujokas *et al.*, 2013), but arsenic can result in other types of cancers as well (International Agency for Research on Cancer, 2012). Although determining the aetiology of the cancers affecting the residents of this village was beyond the scope of this study, it is not unlikely for them to be associated with the arsenic exposure.

Other symptoms experienced by the participants included weakness, insufficient sleep, palpitations, breathlessness and loss of appetite – many of which were among the symptoms found to be significantly higher in arsenicosis cases in a case-control study in Bangladesh (Khan *et al.*, 2006, cited in Brinkel *et al.*, 2009). Moreover, gastrointestinal issues and chronic bronchitis (of which breathlessness is a symptom) which were also mentioned by the participants, can be associated with arsenic toxicity (Mazumder, 2001). It is important to note that these are also common somatic manifestations of psychosocial distress (Drapeau, Marchand and Beaulieu-Prevost, 2012). These physical symptoms, along with the painfulness

and burning sensation felt as a result of the skin lesions, have a major impact on the daily lives of the people living in this village, and is a source of constant stress for them. This also ties in with issues of lost productive time, added healthcare costs, and the resulting stress from these financial issues (which will be discussed in more detail below).

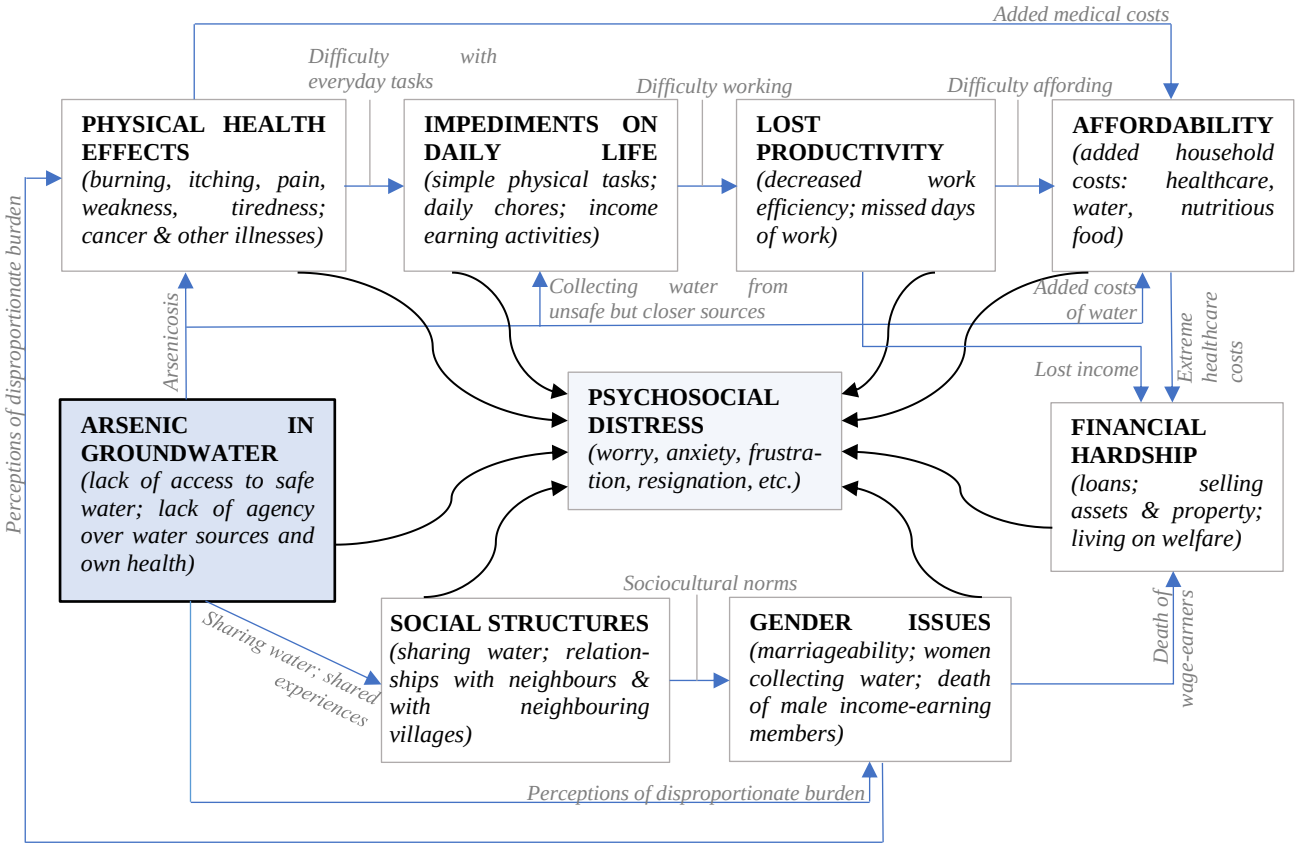
Interestingly in this village, ostracism from neighbours was not experienced by any of the respondents, which is different from the existing literature where people affected by arsenic often experience various forms of discrimination (Brinkel *et al.*, 2009; Hassan *et al.*, 2005; Sultana 2011; Sultana 2012). The main reason behind this is the fact that arsenic is so widespread in this particular village that everyone has been affected to a similar extent, more or less. Thus there was a sense of community and social cohesion resulting from shared negative experience among them. However, there was also some tension between some of the neighbours regarding sharing of water sources, which is a theme that occurs commonly in the literature, both in terms of arsenic as well as water security in general (Wutich and Ragsdale, 2008; Stevenson *et al.*, 2012; Sultana, 2011).

How do household finances and gender issues intersect with arsenic exposure and its effects?
With regard to finances, the major issues cited by the respondents were increased healthcare costs, loss of productive time, and decreased work efficiency, with a few even resorting to taking loans and selling property. This is in agreement with the literature with shows that arsenic exposure can increase the economic burden on the poor (Brinkel *et al.*, 2009), incur financial losses, decrease work efficiency and make it difficult to afford medicine (Ahmad *et al.*, 2007). These financial constraints add another layer to their already-existing anxieties about arsenic, and the issue of lost productive time also ties back to the effect on their daily lives.

It is clear from the participants' experiences that living in an arsenic-affected area can be quite gendered. Women bore the disproportionate burden of collecting water, spending anywhere between 10-30 minutes doing it, depending on where they live. Marriageability of sons and daughters was a key issue, both in terms of visible manifestations of arsenicosis on the body and in terms of living in a contaminated area. As mentioned before, much of the discourse around marriage involved the situation revolving around the women (giving them away bringing them in to the village). And in fact, most of the women interviewed had themselves left their non-arsenic affected villages to come live in this contaminated area after marriage. Yet, when it came to their perception of the most affected group due to arsenic, only a few mentioned women. Many did not see being affected by arsenic as a gendered issue at all, since in their experience the ill effects of arsenic did not differentiate between the genders. Thus, the

presence of arsenic both reinforces existing gender norms while simultaneously blurring gender differences, which is in agreement with findings from Sultana (2009). Moreover, gender and financial issues overlap when the men, who are primary income earners, are ill or have passed away. Figure 2 presents a framework summarising the pathways by which the various psychosocial stressors can act.

Figure 2: Framework of various psychosocial stressors and how they relate to one another



It was evident from the information collected through the interviews, as well observation of tone and body language, that the study participants felt a range of emotions regarding their situation – frustration, resignation, anxiety, worry and anguish – all of which can be interpreted as different forms of distress. They felt anxiety over everything from being able to access safe water, their own health, their families' health and finances to the looming presence of death around them. This is in agreement with the literature which shows mental health scores were significantly worse among those who were affected by arsenic (Keya, 2004, cited in Brinkel *et al.*, 2009; Fujino *et al.*, 2004; Chowdhury *et al.*, 2015). This study adds a further layer of in-depth understanding of the effect of arsenic on psychosocial well-being, beyond the quantitative scores shown in the literature.

Psychosocial distress being mediated through pathways of different stressors can be seen in the study from Odisha, India on sanitation-related psychosocial distress (Sahoo *et al.*, 2015). Findings from Sultana (2012) show that suffering due to physical health, medical costs, problems of marriageability (especially among women), loss of livelihood and death are among the perceived problems faced by arsenicosis patients. Many of these themes have also emerged in this study as psychosocial stressors, however, the findings of this study further demonstrate pathways and combinational effects of various psychosocial stressors.

Limitations of the study

The methodology adopted for this study was indeed conducive to studying lived experiences of psychosocial distress as a result of arsenic poisoning. It allowed for a rich, in-depth and nuanced understanding from the point of view of those affected. Moreover, the exploratory nature of the methodology meant it was broad enough to capture the breadth of these issues. However, there are several limitations to qualitative research, the most prominent of which is the issue of generalisability. It is important to recognise that the point of most qualitative studies is not to produce data or evidence that can be extrapolated to other situations, but to gain a nuanced understanding of the subjective realities of a specific group of people in a defined area.

Having said that, the study was conducted in area with very widespread contamination of arsenic. The experiences of psychosocial distress is likely to be quite different in an area with more sporadic arsenic contamination. Issues such as ostracism and social conflicts over water sharing could be more evident in such areas. Ostracism and discrimination were not captured in this study because they did not manifest as dominant themes in the lived experiences of this particular group of people exposed to arsenic. Repeating this type of study in a few different typologies, with regard to study sites, could lend to a rich source of in-depth qualitative data on arsenic-related psychosocial distress in various settings.

Moreover, there are many biases inherent in qualitative studies. The most prominent among these are personal biases of the researcher, since in qualitative studies the researcher is very much an active participant rather than a fully objective observer. Every researcher inevitably brings their own personal views, notions and understanding of the world into the research process – from design and data collection to the analysis and interpretation stages. This can be controlled to an extent by acknowledging and being aware of one's self and one's positioning as the researcher through self-reflection and introspection (Norris, 2007). I came into this

research with my own experiences of having worked in the WASH sector and having an idea of the complexities faced by so many in rural Bangladesh. I controlled for any potential biases as best as possible, starting from the study design stage by keeping the interview questions as open-ended as possible, to triangulating the data using literature and information from key informants, and maintaining an iterative data analysis process. To reduce the selection bias, I chose a village which my BRAC colleagues were familiar enough with to guide me, but one which they had not worked in extensively. It is also important to note that I was guided by field staff at the managerial level (not front-line workers) who were not personally familiar with the residents.

7 | CONCLUSION

This study demonstrates that the presence of arsenic in the groundwater in a particular area can potentially affect various aspects of people's lives and impact them in a major way. This can range from the significant (such as selling property to be able to afford treatment, or being unable to get married), to the trivial (such as holding a pen or wearing a blouse) – but all of which have a substantial impact on their lives. In addition to the direct psychosocial implications of arsenic being present in the groundwater, these consequences of arsenic contamination can also manifest as psychosocial distress, as the lived experiences of this community show. These impacts can act as a pathway of stressors that lead to psychosocial distress, both individually and compounded together (as shown in Figure 2).

Much of the discourse around arsenic in Bangladesh's groundwater is numerical – it is common to hear about the 57 million people are exposed to arsenic levels above the WHO standards, the 61 out of 64 districts that are affected, or the 46% of shallow tubewells across the country that are contaminated (Kinniburgh and Smedley, 2001). The safe water narrative – both national and global – is not enough when it comes to arsenic. Indeed millions of people have been exposed to arsenic, but there is much more to drinking unsafe water and living with arsenic poisoning, as demonstrated by the experiences of the people in this particular community. This can have important implications in terms of WASH interventions in such areas. Interventions are largely focused on the technological aspects of safe water provision (which may not even sustain in the long-run, as seen in this community and even mentioned by the key informants). It may be equally important to consider a more holistic approach which takes into account the different stressors present in an arsenic-affected community.

The lived experiences of these participants demonstrate that providing a safe water source is simply not enough. Firstly because in any given community in an arsenic-affected area of Bangladesh at this point in time has been exposed to the contaminant for several years now, and while access to safe water can improve their lives immensely, it does not reverse many of the impacts they have already faced. Thorough understanding and knowledge of the psychosocial distress experienced by affected communities can help in designing better and more comprehensive interventions – unlike the sporadic and uncoordinated interventions which left this particular community quite jaded. This study also demonstrates opportunities for further research which could cover both the breadth and depth of the consequences of the one of the largest-scale public health disasters to ever occur. Lastly, the findings of this study also demonstrate the need for empathy and understanding in both interventions and in research.

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Appendix 1: Guidelines for in-depth interviews with members of the community

Aims	Questions	Follow-ups / probes
To get a general sense of their well-being. Whether they are stressed about arsenic or if they are stressed out in general.	How are you doing? আপনি কেমন আছেন?	How have things been for you in the last month or so? গত মাসখানিক কেমন চলছে সবকিছু?
	How are things going compared to your neighbours? আপনার প্রতিবেশীদের তুলনায় কেমন চলছে?	How is the neighbourhood overall? প্রতিবেশীগণ সাধারণত কেমন?
To ascertain their primary and secondary sources of drinking water. Also to see what uses they put the water to, and how they feel about using these sources.	Is there arsenic in the water here? এখানকার পানিতে কি আর্সেনিক আছে?	What do you know about the water sources in the vicinity? আপনার আশেপাশের পানির উৎস সমূহের ব্যাপারে একটু বলবেন?
	Which one(s) do you use most frequently? কোন উৎসটি সবচেয়ে বেশি ব্যবহৃত হয়?	Why is it used the most? এই উৎসটি কেন সবচেয়ে বেশি ব্যবহৃত হয়?
	What is the water from the primary source used for? প্রাথমিক উৎসের পানি কিসের জন্য ব্যবহৃত হয়?	What is the water from the secondary source used for? দ্বিতীয় উৎসের পানি কিসের জন্য ব্যবহৃত হয়?
	Who owns the primary source? প্রাথমিক উৎসের মালিক কে?	Who owns the secondary source? দ্বিতীয় উৎসের মালিক কে?
To understand what they know about arsenic, if they're drinking from arsenic-	Can you tell me a little about the arsenic in this area? এই এলাকার আর্সেনিক নিয়ে আমাকে একটু বলবেন?	What do you know about arsenic? আর্সেনিক সম্পর্কে আপনি যা জানেন তা একটু বলবেন?

Aims	Questions	Follow-ups / probes
contaminated water and if they understand the implications.	How did you first come to know about arsenic? আর্সেনিক সম্পর্কে আপনি প্রথম কিভাবে জানতে পেরেছেন?	For example: did you learn from others around you, or have people from organisations such as NGOs told you about it? যেমন: আপনার চারপাশের অন্যদের কাছ থেকে কি আপনি শিখেছেন নাকি এনজিওর মতো সংগঠনের লোকজন আপনাকে এ সম্পর্কে বলেছে?
	Once you got to learn more about arsenic, how did you respond to the issue? যখন আপনি আর্সেনিক সম্পর্কে আরও জানতে পারলেন, তখন আপনার প্রথম পদক্ষেপ কি ছিল?	Have you or anyone else done anything to avoid it or mitigate it? আপনি বা অন্য কেউ কি এটি এড়াতে বা কমানোর জন্য কিছু করেছেন?
To find out which household member(s) are mainly responsible for collecting water and whether the presence of arsenic has any effect on this. That is, does the presence of arsenic influence them to modify their behaviour from what they would consider the norm, or does it exacerbate existing norms.	Who collects the water in this household? এই বাড়ির পানি কে সংগ্রহ করে?	How does the presence of arsenic affect the collection of water? আর্সেনিকের উপস্থিতি কীভাবে পানি সংগ্রহকে প্রভাবিত করে?
To find out if there are health issues that may be attributable to arsenic. This is of course not a proper diagnostic process, just a note of what health issues are being experienced and if any of them are ones normally associated strongly with arsenic.	Can you tell me a little bit about your health? আপনার স্বাস্থ্য সম্পর্কে একটু বলবেন?	What about your family's health? আপনার পরিবারের স্বাস্থ্য নিয়ে একটু বলবেন?
	Do you think arsenic is affecting your health? আপনি কি মনে করেন আর্সেনিক আপনার স্বাস্থ্য প্রভাবিত করছে?	Can you please describe in a bit more detail? আরেকটু বিস্তারিত বর্ণনা দিবেন?

Aims	Questions	Follow-ups / probes
To find out if there are any issues with regard to social conflict due to the presence of arsenic (e.g. problems arising from sharing water sources, or one family having to switch to a water source that another family either owns or monopolises, or problems within the family itself).	How has the presence of arsenic in this area affected your day-to-day life? এই এলাকায় আর্সেনিক থাকার কারণে আপনার প্রতিদিনের জীবনে কেমন প্রভাব পড়েছে?	Are there issues with sharing water sources, or anything you have to do differently because of the presence of arsenic? যৌথ ভাবে পানির উৎস ব্যাবহার করার জন্য কি কোন সমস্যা বা আর্সেনিকের কারণে কি কোনকিছু অন্যভাবে করতে হয়?
This leads on from the previous question. The aim of this question is to find out how arsenic affects the ways neighbours interact with one another, especially if there are any visible symptoms of arsenic poisoning.	Tell me a bit about your neighbours. আপনার প্রতিবেশীদের সম্পর্কে আমাকে একটু বলবেন?	Does the arsenic affect them? তারা কি আর্সেনিক দ্বারা প্রভাবিত?
Is ostracism an issue in this area or is the presence of arsenic a shared experience that the community faces together?	What is the relationship like between neighbours in this area? এই এলাকার প্রতিবেশীদের মধ্যকার সম্পর্ক কেমন?	Does arsenic affect your relationship with your neighbours? আর্সেনিক কি আপনার প্রতিবেশীদের সাথে আপনার সম্পর্ককে প্রভাবিত করে?
	Is there arsenic in the neighbouring villages? আশেপাশের গ্রামগুলোতে কি আর্সেনিক আছে?	Do they have similar problems as this village? তাদেরও কি এই গ্রামের মতোই সমস্যাসমূহ আছে?
To understand whether they think it is men, women, children, etc. who bear the most burden due to the presence of arsenic. Whether this has a gender and/or age dimension. Whether it causes any strains on existing relationships or the formation of new ones.	In your opinion, who is the most affected by the arsenic in this area? আপনার মতে, এই এলাকায় আর্সেনিক দ্বারা সবচেয়ে বেশি ক্ষতিগ্রস্ত কে?	Why do you think this is the case? কেন সেটা মনে হয়?

Aims	Questions	Follow-ups / probes
To explore further whether arsenic affects the ability to get married and how people who move from one area to another after cope with the presence of arsenic.	Where did you grow up? আপনি কোথায় বড় হয়েছেন?	Was it far away? এটা কি দূরে ছিল?
	Did that place have arsenic? সেই জায়গায় কি আর্সেনিক ছিল?	How did you feel about moving here? এখানে এসে থাকার ব্যাপারে আপনার কি মনে হয়েছিল?
To understand whether they have worries and anxieties regarding arsenic and its effects.	Do you worry about arsenic? আপনি কি আর্সেনিক নিয়ে চিন্তিত?	What is it that worries you? কোন ব্যাপারটি আপনাকে চিন্তিত করে?
To find out whether the family has to bear any extra costs such as: investing in a water source, a point-of-use filter, healthcare costs. This can also lead in to a discussion about costs through loss of productive time (e.g. travelling longer for safe water).	Are there any costs related to arsenic that your household has to bear? আর্সেনিক থাকার কারনে আপনার পরিবারকে কি কোন অতিরিক্ত খরচ বহন করতে হয়?	What are the costs for? [*Prompts: investing in a water source, a point-of-use filter, healthcare costs; loss of productive time (e.g. travelling longer for safe water).*] খরচগুলো কি কি খাতে করতে হয়? [যেমনঃ পানির উৎস খাতে বিনিয়োগ, ব্যবহারের পয়েন্টে ফিল্টার লাগানো, স্বাস্থ্য খাতে খরচ; অথবা উৎপাদনশীল সময়ের অপচয় (নিরাপদ পানির জন্য দীর্ঘ সময় ভ্রমন)]
To understand whether these added costs affect their psychosocial well-being.	How do you feel about these extra costs? এই অতিরিক্ত খরচ সম্পর্কে আপনি কেমন বোধ করেন?	
To understand their perception of the scale and magnitude of the risk posed by arsenic.	If there was no arsenic in this area how would your life be different? যদি এই এলাকায় কোন আর্সেনিক না থাকত তবে আপনার জীবন কেমন হত?	In your opinion, what is the biggest issue in this area? আপনার মতে, এই এলাকার সবচেয়ে বড় সমস্যা কি?

Appendix 2: Guidelines for key informant interviews

Aims	Questions	Follow-ups / probes
To break the ice and begin talking about the emergence of the arsenic issue.	How long have you been working in the water sector in Bangladesh?	Can you tell me a little about the time arsenic was first discovered in the groundwater in the 1990s?
To understand their views on what takes priority in the water sector in Bangladesh.	What do you think is the biggest issue in the water sector here?	Do you think it is arsenic or are there bigger issues?
To understand their views on policies and policy implementation in relation to arsenic.	What do you think of the current policies in place regarding arsenic?	
To understand their understanding of the intangible effects of arsenic poisoning, such as emotional, social and financial issues.	As far as I know there are no policies or strategies to deal with those who have been exposed and affected by arsenic, just that the government recognizes those with skin lesions as arsenicosis patients. What about all those have effects which are not visible?	What do you think about those who are affected, but you may not be seeing visible effects on them?
To understand what they think are the gaps/lacking in terms of policy, water supply interventions and/or research.	Do you think enough is being done regarding in terms of mitigation and in terms of dealing with arsenic?	What should researchers, policymakers and implementers be focusing on?
To allow them to talk about anything that may not have been covered.	Do you have anything further to add from your experience?	

Appendix 3: Codebook

Code	Full form	Definition	Sub-code	Full form	Meaning
UWS	Unsafe water source	Drinking from water sources that contain, or possibly contain, arsenic and other contaminants	TAS	Tested, contains arsenic	Water source was tested, declared to contain arsenic and painted red.
			UNC	Unclear	Water source was tested, declared to be safe, but some residents claim that arsenic has infiltrated it.
			SAL	High salinity	Residents have been told about high salinity content of water source
USE	Use of different sources	Different purposes that different sources are used for	EVR	Everything	Residents who use a single water source for all purposes
			DRDT	Drinks from deep tubewell	Residents who use deep tubewell for drinking, but use (arsenic-contaminated) shallow tubewell for other purposes
			DRCKDT	Drinks and cooks from deep tubewell	Residents who use deep tubewell for drinking and cooking, but use (arsenic-contaminated) shallow tubewell for other purposes
CB	Changing behaviour	Changing their water collection behaviour due to the presence of arsenic	SW	Surface water	If they switched to a surface water source (specifically pond sand filter)
			DTW	Deep tubewell	If they switched to a deep tubewell
			RWH	Rainwater harvesting	If they use rainwater harvesting to supplement water supply
			BUY	Buying water	If they sometimes buy water
			REV	Reverting back to original source	If they have reverted back to using their old source which they now know is arsenic-contaminated

Code	Full form	Definition	Sub-code	Full form	Meaning
CW	Collection of water	Which member of the family collects the water	WF	Wife	Wife collects water
			DT	Daughter	Daughter collects water
			DIL	Daughter-in-law	Daughter-in-law collects water
			HUS	Husband	Husband collects water
			ALL	All members	All members collects water
SH	Sharing	Those who have to share the water source with other households	NP	No problems	If they do not have problems due to sharing
			QUE	Queueing	If they have to queue for water
			DA	Doesn't allow at times	If someone doesn't allow the use of a tubewell or gets irritated when others use it
			DNS	Does not share	If they do not share their tubewell at all
NBR	Relationship with neighbours	The kind of relationship the respondent has with their neighbours because of the presence of arsenic	GR	Good relationship	When the respondent has a good relationship with their neighbours
			GRNP	Good but not perfect	When the respondent has a good relationship with their neighbours, but not always perfect
			BR	Bad relationship	When the respondent has a bad relationship with their neighbours
HLT	Health	Effects of arsenic on health	FUW	Feeling unwell	If they were not doing well health-wise
			DERM	Dermatological effects	If they had skin lesions and hardening (melanosis/keratosis)
			BURN	Burning / itching	If they have a burning and/or itching sensation on their skin
			PAIN	Pain	If they feel pain overall or due to their skin condition

Code	Full form	Definition	Sub-code	Full form	Meaning
			WEAK	Weakness	If they feel weak
			DIZ	Dizziness	If they feel dizzy or light-headed
			SLP	Difficulty sleeping	If they have trouble falling asleep and getting enough sleep at night
			APP	Lack of appetite	If they have loss of appetite
			BRTH	Difficulty breathing	If they have trouble breathing or felt breathless
			GAS	Gastric issues	If they have gastrointestinal issues
			HRT	Heart problem	If they have a heart condition
			CAN	Cancer	If they have (or had) cancer
FHLT	Health of family	Whether they have any family members diagnosed with arsenicosis	DERM+	Dermatological	If a family member had dermatological symptoms along with the associated discomforts
			CAN	Cancer	If a family member had cancer
			HRT	Heart problem	If a family had a heart condition
DTH	Death	When the respondent has had one or more family member die due to arsenic-related health conditions,	IM	Member of immediate family	When they have experienced the death of one or more member of their immediate family
			EX	Member of extended family	When they have experienced the death of one or member of their extended family
			COM	Member of community	When that have experienced the death of one more member of their own community

Code	Full form	Definition	Sub-code	Full form	Meaning
		or if they have experienced the death of someone in the community			
DL	Daily life	When aspects of their daily lives are affected because of the presence of arsenic	AW	Affects work	When the ease and efficiency with which they can work is impeded
			AWKW	Affects work but keeps working	When they find it difficult to work but they just keep going because they have no other choice
			TB	Takes breaks	When they take frequent breaks as they work, or if they frequently take days off because they are unwell
			CW	Cannot work	When they cannot work at all
			NE	No effect on work	When the presence of arsenic has no effect
MAF	Most affected by arsenic	People who the respondents think are the worst off because of the presence of arsenic	SPC	Specific person(s)	If they mention specific people as the most affected by arsenic
			MN	Men	If they mention men as the most affected by arsenic
			WMN	Women	If they mention women as the most affected by arsenic
			ELD	Elderly people	If they mention elderly people as the most affected by arsenic
			EQ	Everyone	If they mention that everyone is equally affected
MRG	Marriage	Whether there are issues with getting	PGM	Problems getting married	When people from other villages don't want their sons or daughters marrying someone from this village
			NPGM	No problems getting married	When there is no experience of people not wanting to marry someone from this village

Code	Full form	Definition	Sub-code	Full form	Meaning
		married or maintaining a marriage because of the presence of arsenic	PIM	Problems in marriage	When there are problems between people who are already married
RS	Research and intervention	When they mention previous research and interventions on arsenic that has taken place in the village	RS	Research and intervention	When the respondent is aware of previous research and previous safe water supply interventions and/or symptomatic treatment of arsenic
			RSIN	Research and/or intervention to no avail	When the respondents express a sense of frustration that previous research and interventions have not led to any positive changes
FN	Finance	If they have extra costs due to the presence of arsenic	HC	Healthcare costs	When they have costs related to doctor's visits, treatment, medicine, and other related costs
			MHC	Major healthcare costs	When they have major costs related to health, such as getting cancer treatment in Dhaka
			WC	Water-related costs	When they have invested in buying water, or contributed to repairing or installing a new source
			NEC	No extra costs	When they have no extra costs due to the presence of arsenic
			LPT	Loss of productive time	When they miss work or take frequent breaks from it

Code	Full form	Definition	Sub-code	Full form	Meaning
			SP	Sold property	Those who have sold property or assets to be able to afford treatment
			LOAN	Took loan	Those who have taken loans to cope with the extra costs
			WLF	Lives on welfare	Those who live on welfare
			WFN	Worries about finances	Those who worry about finances and how to be able to afford things
			DWFN	Does not worry about finances	Those who do not worry about finances
			WKF	Worries about kids' future	Those who worry about finances in relation to their kids' future
ANX	Worry/anxiety	Worry and anxiety due to the effects and/or presence of arsenic	WD	Worried about death	If they are anxious about their own or their family members' deaths because they have experienced arsenic-related deaths around them
			ACD	Anxious about children	If they are anxious about who will take care of their children if they die
			ACF	Anxious about children's future health	If they are anxious about their children's future health if they continue drinking contaminated water
			ASW	Anxious about safe water	If they are anxious about being able to access safe water
			AG	Anxious in general	If they are worried and anxious about arsenic in general
			DNW	Does not worry	If they are not worried about arsenic
DIF	Different if no arsenic	If the respondent			

Code	Full form	Definition	Sub-code	Full form	Meaning
		mentioned that life would be quite different if there was no arsenic in the area			
BI	Biggest issue in area	If the respondent thinks is the biggest issue in the village is arsenic or water quality			

Appendix 4: Informed consent form

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PARTICIPANT CONSENT FORM
CUREC Approval Reference: SOGE 18A-68

Effect of arsenic exposure on psychosocial wellbeing in rural Bangladesh

Purpose of Study: To understand the relationship between arsenic exposure and psychosocial distress, along with the associated socioeconomic and gender issues. The study is being carried out as part of a dissertation to fulfil the requirements of an MSc in Water Science, Policy and Management at the University of Oxford

প্রধান লক্ষ্যঃ আর্সেনিকের বিস্তার ও মনোসামাজিক কল্যানের সম্পর্ক বোঝা এবং পাশাপাশি এর অর্থনৈতিক প্রভাব এবং পুরুষ ও নারী ভেদে এ প্রভাবের পার্থক্য বোঝা। এই গবেষণা পত্রটি ইউনিভার্সিটি অফ অক্সফোর্ড এর পোস্টগ্রাজুয়েট (মাস্টার্স ডিগ্রী) প্রোগ্রামের অংশ বিশেষ। গবেষণামূলক প্রবন্ধটি (থিসিস) ওয়াটার সাইন্স, পলিসি ও ম্যানেজমেন্ট এ মাস্টার্স ডিগ্রী সম্পন্ন করার জন্য জমা দেওয়া হবে।

		Please initial each box *প্রতিটি বক্সে ছোট সই দিবেন*
1	I confirm that I have read and understand the information sheet dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. আমি নিশ্চিত যে উপরে উল্লেখিত অধ্যয়নের জন্য আমি _____ তারিখের তথ্যপত্র পড়েছি এবং বুঝতে পেরেছি। আমি তথ্য বিবেচনা করার সুযোগ পেয়েছিলাম, প্রশ্ন জিজ্ঞাসা করতে পেরেছি এবং সন্তোষজনক ভাবে উত্তর পেয়েছি।	☐

2	I understand that my participation is fully voluntary and that I am free to withdraw from the study at any time, without giving any reason, and without any adverse consequences. আমি বুঝতে পারি যে আমার অংশগ্রহণ সম্পূর্ণভাবে স্বেচ্ছামূলক এবং যে কোন সময় কোনও কারণ ছাড়া এবং কোনও ক্ষতি ছাড়া আমি নিজেকে গবেষণা থেকে সরিয়ে ফেলতে পারব।	☐
3	I understand that I can refuse to answer any question if I do not feel comfortable with it. আমি বুঝতে পারি যে আমি যে কোন সময় সাক্ষাতকারটি বন্ধ করতে পারব এবং কোন প্রশ্নে অস্বস্তিবোধ করলে আমাকে উত্তর দিতে হবে না।	☐
4	I understand that research data collected during the study may be looked at by designated individuals from the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data. আমি বুঝতে পারি যে গবেষণার সময় নেয়া তথ্য প্রয়োজনে অক্সফোর্ড বিশ্ববিদ্যালয়ের মনোনীত ব্যক্তিকে দেখানো হতে পারে। আমি উক্ত ব্যক্তি/ব্যক্তিদের আমার প্রদত্ত তথ্যসমূহ দেখার অনুমতি দিচ্ছি।	☐
5	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee. আমি বুঝতে পারি যে, এই গবেষণা ইউনিভার্সিটি অফ অক্সফোর্ড এর কেন্দ্রীয় বিশ্ববিদ্যালয় গবেষণা নীতিশাস্ত্র কমিটি (University of Oxford Central University Research Ethics Committee) দ্বারা পর্যালোচিত এবং অনুমতিপ্রাপ্ত।	☐
6	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project. আমি বুঝতে পারি যে কে তথ্য দেখতে পারবে, কিভাবে তথ্য সংরক্ষণ করা হবে এবং গবেষণার শেষে তথ্য কি হবে।	☐
7	I understand how this research will be written up and published. আমি এই গবেষণা কিভাবে লিখিত এবং প্রকাশিত হবে তা বুঝতে পারছি।	☐
8	I understand how to raise a concern or make a complaint. আমি বুঝতে পারি যে আমার যদি কোন অভিযোগ থাকে তাহলে কার সাথে যোগাযোগ করতে হবে।	☐
9	I consent to being audio recorded. আমি অডিও রেকর্ডিং করার অনুমতি দিচ্ছি।	☐

10	I understand that audio recordings will be taken to ensure information collected during the interviews is not missed. আমি বুঝতে পারি যে সাক্ষাত্কারের সময় নেয়া তথ্যগুলি যেন বাদ না পরে সেটা নিশ্চিত করার জন্য অডিও রেকর্ডিংগুলি নেওয়া হবে।	☐
11	I agree to take part in the study.[9] আমি এই গবেষণায় অংশগ্রহণ করতে সম্মত হচ্ছি।	☐
12	I agree for my personal data to be kept in a secure database for the purpose of contacting me about future studies. আমি আমার ব্যক্তিগত তথ্যসমূহ ভবিষ্যতে গবেষণা সম্পর্কে যোগাযোগের উদ্দেশ্যে একটি নিরাপদ ডাটাবেসে রাখতে দেয়ার জন্য রাজি আছি।	☐

_____	_____	_____
অংশগ্রহণকারীর নাম	তারিখ	স্বাক্ষর
_____	_____	_____
গবেষকের নাম	তারিখ	স্বাক্ষর

[9] If any of the participants are unable to read, the information that is on this form will be read aloud to them and ensured that the matters are fully understood.
অংশগ্রহণকারীরা যদি পড়তে না পারে তবে এই তথ্যটি তাদের কাছে জোরে পড়া হবে এবং নিশ্ছিত করতে হবে যে তারা বিষয়টি সম্পূর্ণ ভাবে বুঝতে পেরেছে।