

## ORIGINAL ARTICLE

# Beliefs related to the dying process and its impact on end-of-life care in the Marma community of Bangladesh: A qualitative study

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## ABSTRACT

**Background:** Marma indigenous community in Bangladesh has a unique culture with its religion, culture, language, and tradition. To provide appropriate healthcare and end-of-life support, healthcare providers must know their beliefs and customs near and after death. We explored the beliefs related to the dying process and its impact on end-of-life care in the Marma community of Bangladesh.

**Methods:** This cross-sectional qualitative study used an open-ended interview schedule for in-depth interviews. Twenty-six interviewees were selected purposively from the Marma community of Bandarban district to represent a population of different ages with varied experiences and religious knowledge. After each in-depth interview, all field notes and audio records were transcribed verbatim, and qualitative content analysis was done to construct the themes.

**Results:** After analysis, the generated theme indicated a 'reflection of previous Karma (the sum of a person's actions)' within the Marma community. This theme is based on three categories: 'state of the body and mind', 'care of a dying person', and 'beliefs on the dying process'.

**Conclusion:** Death is inevitable for all of us, but suffering in death is not desired. Like other communities around the world, the Marma community also holds its own beliefs and practices regarding end-of-life care related to death. The death of a person in his own house is considered a good death within the Marma community. In the traditional death ritual practices of the Marma community, palliative care in the form of end-of-life care has the potential to enhance the quality of life, alleviate suffering, and enable a peaceful passing with dignity.

**Keywords:** Beliefs, death and dying, end-of-life care, Marma community, Bandarban, Bangladesh

## INTRODUCTION

End-of-life care includes supportive care and medical treatment provided in the few days prior to death.<sup>1</sup> Religion is one of the important factors that directly affect the customs of death. Other factors are ethnicity, race, education, occupation, social status, community practices, and availability of health care services.<sup>2-4</sup>

Approximately 1.8% of Bangladeshi population are indigenous 'Adivasis' including native ethnic minorities of 29 communities and are estimated to be over 2 million. Marma is the second largest indigenous community in Bangladesh living in Bandarban, Rangamati, and Khagrachari hill districts with a population of about 3,50,000 as of 2019.<sup>5,6</sup>

The culture of the Marma is unique with its religion, language, tradition, and culture. They speak the Marma language, and the majorities are Theravada Buddhists.<sup>7,8</sup> The beliefs regarding death and the dying person's care have not been adequately explored in the Marma community. So, this study explored the beliefs related to the dying process and its impact on end-of-life care within the Marma community of Bangladesh.

## METHODS

This study was conducted from December 2019 to September 2021 in Bandarban district. A qualitative semi-structured open ended questionnaire was developed by a discussion with a palliative medicine expert, an Anthropologist, Sociologist, and

## HIGHLIGHTS

1. We explored the various factors that influence the death and dying process and its impact on end-of-life care of the Marma community in Bangladesh.
2. The generated theme indicated a 'reflection of previous Karma (the sum of a person's actions)' within the Marma community.
3. Death of a person in his own house is considered a good death.
4. In the traditional customs of Marma, providing palliative care in the form of end-of-life care may improve quality of life and suffering, which will help in peaceful passing away with dignity.

Epidemiologist consisting of eight open-ended questions. Then a pilot study was done in the study area to check the feasibility and finalize the prepared questionnaire. Three in-depth interviews (IDIs) were conducted with a Buddhist monk, social activist, and cultural activist. The interviews covered the issues of experience of observing of dying process of near ones, care of the dying patient at the end of life, the concept of a good death and bad death, existing beliefs and customs related to the dying process, and death events. After piloting, the audio recorded interviews were

analyzed the underlying meaning, both requiring interpretation but differing in depth and abstraction. Meaningful phrases related to the study's aim were identified as the meaning units. These condensed meaning units were then coded and organized into subcategories. The subcategories were grouped into main categories. Finally, a theme was developed.

## RESULTS

Among the participants, 16 were men and 10 were women, while 62% resided in urban areas and 30% were from rural areas, and the remaining individuals were from Buddhist monasteries. Their age ranged from 18-75 years.

### Qualitative analysis

The theme emerged as 'reflection of previous Karma (the sum of a person's actions)' based on three categories 'state of body and mind', 'care of the dying person', and 'beliefs regarding the dying process' (TABLE 1).

**TABLE 1** Themes generated from the qualitative analysis of the interviews

| Theme        | Reflection of previous Karma (the sum of a person's actions) |                                |                                       |
|--------------|--|--------------------------------|---------------------------------------|
| Category     | 1. State of the body and mind                                | 2. Care of a dying person      | 3. Beliefs on dying process           |
| Sub-Category | 1.1. Irritation  | 2.1. Familial                  | 3.1. Terminal appearance              |
|              | 1.2. Tranquility   | 2.2. Neighborhood              | 3.2. Good deeds and achieving Nirvana |
|              | 1.3. Hallucination   | 2.3. Religious/ spiritual care | 3.3. Detachment                       |
|              |  |                                | 3.4. Rebirth                          |

transcribed from Marma language to Bangla language. The principal investigator checked the qualitative data and modified the questionnaire after consulting with experts, including Psychologists, Anthropologists, Buddhist spiritual leaders (Buddhist monks), Marma cultural leaders, Journalists, and Palliative Medicine experts.

The 26 interviews covered the experience of observing of dying process of near ones, care of the dying patient at the end of life, the concept of a good death and bad death, existing beliefs and customs related to the dying process, and death events. Each interview ranged from 30-75 minutes.

Participants' responses were transcribed verbatim in Bengali. Qualitative content analysis was employed, where manifest content involved describing the visible and apparent elements of the text, while latent content

### 1. State of body and mind

Interviewees witnessed various bodily expressions throughout the dying phase, especially at the time prior to death, such as restlessness, yelling, lack of breath, frothing and dribbling of saliva, tongue protrusion, and eyeball rolling. This category is further subdivided in three sub-categories irritation, tranquility and hallucination.

#### 1.1. Irritation

Before dying, some people develop larger protruding eyes, run or become restless, and ultimately collapse to death. Within the Marma community, there is a perception about mean (anyone who spent their life doing ill works) people that they are despised by all and they show angry expressions during the dying phase. An

interviewee explains, *“People who live their lives with hatred make different faces such as angry faces, make noise, shout or grab others during their death.”*

### 1.2. Tranquility

In contrary to irritation, interviewees observed that some people had a peaceful death where the person was calm and quiet in bodily expressions throughout the dying phase, especially at the time prior to death,

According to one interviewee, *“People show various symptoms before their death. In most cases when the person was old, I found them having a peaceful death.”*

Another farmer stated, *“Some people pass away while conversing. Some even pass away while in their sleep.”*

### 1.3. Hallucination

Most of the time, a psychological outburst occurs alongside physical symptoms during death. It may reflect one's mental state during the dying process. One may become more distressed and hallucinate in the final hours of life. A farmer described, *“Anyone who sees animals such as cows, pigs, dogs, goats, and so forth before they die, they have the probability of being born as an animal in the next life. A person will see the fire of hell before they die if they are going to hell. I have even witnessed some people saying, hug me, I am afraid of these delusions.”*

Another interviewee supported saying, *“In certain situations, a tiger appears in the mind of the dying person shortly before death to bite them, and then someone arrives to take them away.”*

## 2. Care of a dying person

Majority of the people had been reported to suffer in the final stages of their lives. It could occur physically, psychologically, or both. The Marma people care for the dying patient in both ways. They are deeply concerned in providing care and comfort to the dying patient so that they can pass away peacefully.

### 2.1. Familial

Physical care is beneficial during the dying process. Traditional techniques of care play an essential part most of the time. In explaining this process, an

interviewee narrated, *“I saw the granddaughter of a person sitting beside her and massaging the grandmother's chest. For some time, the dying person looked around and could sense our presence. Eventually, she left us.”*

A senior female citizen opined about end-of-life care as, *“We try to rub baked herbal medicine in various parts of the body in the traditional Marma ways in order to bring comfort in the last stages of a dying person.”*

### 2.2. Neighborhood

Togetherness of family members and relatives plays an important role during the dying phase of a person. If a person can say goodbye to everyone, the person might leave with a satisfied and peaceful mind. A cultural activist explained, *“All the family members and relatives visit the dying person. They spend as much time as they can with the moribund. They stay close so that the person is able to say final goodbye. It will be a good sign of death if he dies in front of his close ones.”*

### 2.3. Religious/spiritual care

The dying phase is crucial in the Marma community because it decides the rebirth. They are concerned about the nature of death and try to comfort the dying one in many ways. Buddhist chants before death, pious work in life, and donations in religious places are believed to make a peaceful exit.

A local leader expressed her beliefs on the care of the dying one as, *“There were many aged people around her (my mother) and everyone started talking. We could sense that there was not much time for my mother. So, we immediately started sharing the good deeds done by her. Good deeds included making the novice ceremony of her sons, donating stairs for the temple, hoisting the flag, etc. While being reminded this way, she started mumbling Buddha Buddha and gave up his last breath.”*

Most people and religious leaders have explained the importance of chanting. A Monk persuaded, *“According to our Buddhist principles, since Buddha's accent, chanting (Maitrisutra) is recited to the dead pilgrims. The purpose of this work is to remember the words of religion and virtue before death.”*

### 3. Beliefs on the dying process

Multiple factors influence the beliefs of the Marma community about the dying process. It comprises the presentation of the dying, care of the dying, the presence of family, the lifestyle of one's entire life, environmental factors, and religious activities.

#### 3.1. Terminal appearance

Work during life can shape the nature of the dying process as well as their life after death. Interviewees from various socioeconomic groups shared their opinions on a presentation during the dying process.

A female participant who had prior experience with caring for the dying shared her opinions as, *"Some people stick out their tongues, while others often roll their eyes again and again. As a result, people typically say two things. Firstly, it is considered that the dying person deceived individuals while being alive and caused harm to others by telling lies, so their tongue protruded. Secondly, it is believed that if they killed animals or were engaged in slaughtering animals, they have their eyes turned upside down."*

Another respondent substantiated, *"The dying is said to go to hell if they defecate or urinate while dying. It is believed that passing through the bottom means carrying a lousy exit."*

Again, while explaining their belief in the dying phase, another person mentioned, *"People who earn a living by slaughtering animals display signs of agitation, such as running around, shouting, and catching during the dying phase."*

Contrary to the above scenario, calm and quiet people are considered to have a peaceful exit from the earthly life as a monk described his belief as, *"If a person has done good things and has not harmed others, they will have a tranquil expression on their faces."*

People believe the last breath exits from the human body in many ways. The exit points indicate good or bad things. The upper portion of the body is considered a good way and the lower is considered bad. A villager described, *"We think those who die peacefully and without much agony have a better existence after*

*death. Those whose final breath comes out from the mouth, through the eyes, and so on, we believed, may directly enter Nirvana."*

Nirvana is a transcendent condition in which the person is freed from the consequences of karma and the cycle of death and rebirth. There is also no misery, desire, or sense of self. It stands in for Buddhism's ultimate objective. Sometimes the presentation of the dying process includes psychological components such as an acute confusional condition, delusion, and so on. A villager explained, *"If a person sees an animal before death, they may experience rebirth as an animal; if they see fire, they may go to hell; it is believed that they will rebirth as a human being if a human being is seen."*

#### 3.2. Good deeds and achieving Nirvana

It is considered that the work of a person is never destroyed. It will remain and transform into another life. Eventually, a person has to pay for what they have done in life, whether good or bad. The ultimate goal of a person in the Marma community is to achieve Nirvana through doing good deeds in life. It became clear from the statement of a traditional healer, *"The two things that must be believed are action and karma..... If a person has done anything wrong in the past, it will have an effect in their recent birth. Accordingly, if a person greets someone correctly, the response will also be positive."*

A school teacher stated her observation of her father in the dying phase, *"We are Buddhists and we believe in a lot in good deeds. The novice ceremony of the son is considered as a very virtuous deed that is the key to heaven. In the dying state, the good deed is repeated in the ears of the people. Again, at times pictures of the Buddha are shown. People believe that if you do something decent or good, the person will go in a good way as he leaves and thus achieve Nirvana."*

#### 3.3. Detachment

Attachment is the leading cause of suffering. To relieve all kinds of attachments at the end of life, the togetherness of family and relatives plays an important role. After saying goodbye to everyone, a person might

leave with a satisfied and peaceful mind. A cultural activist explained, “*Muichongre’ means guard in the Marma language. The person has to say final goodbyes. He is guarded when he dies so that he can die peacefully.*”

Sometimes the dying person remains restless, so some special customs are practiced to calm the dying person. The hair of the novice ceremony is considered sacred; an immediate novice ceremony is often arranged if the dying person’s son has not accepted a monk’s life. One respondent explains, “*Many times, I have seen that no matter how much care is practiced, death does not happen easily. In such cases, someone from the family accepts the life of a monk as a more pious deed. This is observed according to the rituals of our Buddhist customs.*”

#### 3.4. Rebirth

The dying phase is crucial in the Marma culture since it determines a person’s rebirth implications. As a result, the care of a dying person is determined by their beliefs. They are concerned about the nature of death and attempt to comfort the dying in a variety of ways. Buddhist chants, pious work, and commemorating offerings at sacred places are said to bring about a tranquil departure. A person’s professional life leads to rebirth. The previous employment of a person influences where they are born and what life they will have. According to one respondent, “*Those of us who have faith in the afterlife believe that if the mind of the dying person can be kept calm, they will gain a good fortune. So, the family and relatives try to follow this ideology from the place of humanity.*”

## DISCUSSION

### ***The process of dying***

A dying individual and their family members experience physical and psychological distress during the dying process. The findings highlight two contrasting physical manifestations: irritation and tranquility. The terminal phase, characterized by an irreversible decline in functional status leading to death, can vary in duration, lasting from a few hours to days, and in rare cases, weeks.<sup>10</sup> Pitorak also found that the worsening of

specific symptoms indicates the onset of the terminal phase, including changes in breathing, profound weakness and fatigue, refractory delirium, and cold skin, among others. Recognizing the dying phase enables proactive planning for patient care, preparing the family, patient, and staff, and facilitating discussions about end-of-life preferences, location of death, and anticipated symptom management.<sup>10, 11</sup>

Among the signs and symptoms observed in dying individuals, as many as 70% of patients experience respiratory distress in the final six weeks of life. The prevalence, severity, and associated distress of respiratory distress increase as the time of death approaches.<sup>12, 13</sup> Lawlor et al. discovered delirium in up to 88% of patients when carefully screened during their terminal phase.<sup>14</sup> While witnessing the agitated delirium of a dying individual can be distressing for family members, caregivers, and healthcare professionals, the patient’s distress associated with their thought-disordered states of hypoactive delirium should not be underestimated.<sup>15, 16</sup>

### ***Taking care of the dying patient and end-of-life care***

Most people worldwide suffer from symptoms of the final stages of their lives, either physically, psychologically, or spiritually, and sometimes even mixed. The Marma also have similar sufferings while caring for a dying patient besides their deep concerns with the religious components for a peaceful pass away. Wairuatanga, which means spirituality, is a crucial element of the Māori community of New Zealand in coping. The challenges experienced during the end-of-life journey included diagnosis, treatment, dying process, funerals, bereavement, and unveilings.<sup>17</sup> In addition, spiritual practices help solve issues and ease depression and anxiety.<sup>17</sup> Hermann, in his study, also revealed the importance of spiritual care of the dying person, which included the need to experience nature, a positive outlook, and companionship.<sup>18</sup> In another study, participants discussed visitors’ choices, environmental preparation, and decisions for a dying family member before death. They also described the practice of calling a priest for the last rites when a loved one may be dying, although the dying person might hesitate because this sacrament might somehow assure the death.<sup>19</sup>

### ***The beliefs on the process of dying and death***

Multiple factors influence the beliefs on the process of dying of the Marma community. The Marma community believes that their work shapes the nature of their death and life after death. Communities around the world have various beliefs regarding how their death is shaped. Asian (Chinese) families feel they are assuring death if the loved one is in a room with the number “4” in it; since this number is associated with death in their culture.<sup>19</sup> They also wary of having the ill person’s feet facing the door because they believe the dead are carried out of the room with their feet first. In their culture, bad karma causes sickness and death.<sup>19</sup>

According to the beliefs held by Catholics and Buddhists, it is considered unnatural for children to die before their parents. The Buddhist belief is associated with karma, where it is believed that children may pass away at an early age as a result of not having accumulated enough good deeds in their past life.<sup>20</sup> Additionally, in Indian beliefs, there are specific favorable and unfavorable times for dying. Families from Eastern India may consult a pundit (priest) who consults a special book to determine an auspicious time for death.<sup>21</sup> On the other hand, Native Hawaiians believe that every individual possesses mana (divine power) that resides in their iwi (bones) upon death. They believe that the iwi must be buried in the ground to transmit their mana.<sup>2</sup>

Santal ethnic community in Bangladesh believes that deceased individuals will ascend to heaven in the afterlife.<sup>22</sup> The Mro community also shares the belief that everyone’s destination is heaven, although they acknowledge the presence of evil spirits that may obstruct their path.<sup>22</sup> In contrast, the Marma community adheres to different beliefs, as they follow dogmas based on their past way of life and Karma, with their ultimate goal being the attainment of Nirvana.

Conversely, the Pankhua community in Bangladesh has a conviction that everything possesses a spirit and that everything is interconnected.<sup>22</sup> On the other hand, the Marma community believes that their actions are enduring and remain intact, undergoing a transformation from one form to another.

### ***Limitations***

Due to the utilization of COVID-19 protective equipment, it was difficult to accurately observe sudden, brief facial expressions and body language. Although we focused on equal participation of both male and female, gender balance could not be achieved in the case of the interviewees as in the cultural perspective of the Marma community, women are not involved in death customs and sensitive religious activities. In rural areas, despite being a Marma, the investigator faced local Marma language problems while interviewing. Participants can only talk with their mother tongue (Marma language) and the local Marma language is difficult to understand. This language barrier was solved with the help of two expert community people while conducting interviews. Due to the COVID-19 pandemic, funeral ceremonies were arranged in more restricted ways with less participation of community people. So, the investigator did not get the opportunity to observe the death rituals which was done in the community. Short staying in the Marma community is also another limitation for which the dying process was not directly observed by the investigator. Only Bandarban Sadar Upazila of Bandarban district was selected purposively for the study, which does not represent the whole Marma community of three districts in Bangladesh.

### ***Conclusion***

Within the Marma community, the location and circumstances of death determine whether it is perceived as positive or negative. While passing away in one’s own home is regarded as a desirable death, individuals may still endure difficulties during their final moments. In order to uphold traditional customs, providing palliative care in the form of end-of-life support can contribute to a peaceful and dignified transition.

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### **Author Contributions**

Conception and design: WWM, AMRB, NA, MAH. Acquisition, analysis, and interpretation of data: WWM, MIIT, MAH. Manuscript drafting and revising it critically: WWM, AMRB, MIIT,

MKC, NA, MAK. Approval of the final version of the manuscript: WWM, AMRB, MIIT, MKC, NA, MAK. Guarantor accuracy and integrity of the work: WWM.

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### Conflict of Interest

The authors have no conflict of interest to declare.

### Ethical Approval

Ethical permission was obtained from the Institutional Review Board of Bangabandhu Sheikh Mujib Medical University (Memo no: BSMMU/2020/11137). Written informed consent was obtained from all eligible participants who willingly agreed to participate in the study. The participants were informed about the sensitive nature of the interview topic but assured that it would benefit the community. They were also assured that their data would be kept anonymous and confidential. Each participant had the right to withdraw from the interview at any time.

Participating in the study posed no risk of physical or social harm. However, discussing the death events of loved ones could potentially cause psychological trauma. In such cases, participants were given the option to pause, stop the interview, and withdraw from the study. The first author, a registered physician with expertise in palliative medicine, was prepared to provide psychological support to participants in the event of psychological trauma.

No identifying information was included in the study. The collected information was used solely for research purposes, and anonymity and confidentiality were maintained throughout all stages of the study.

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