

Facial Disfigurement Stigma: Women Affected by Noma in Selected Districts of Gondar Zone, Amhara Region of Ethiopia

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Abstract

Noma is an infectious disease that results in impairment, severe facial disfigurement, and morbidity. And yet, despite its devastating medical and social effects, the disease has been a neglected clinical and social burden. The objective of this study was to explore the social consequences of living with disfigurement caused by Noma; manifested in various forms of social rejection and exclusions. A qualitative descriptive design was employed in which data was collected from female Noma survivors (FNS), family members, community members, and government authorities in selected districts in the Gondar area of Ethiopia. using structured and semi-structured interviews. Results show that stigma and discrimination due to facial disfigurement caused by Noma negatively affected the mental and physical health of the female Noma survivors and their families. In particular, it inhibited the Noma survivors from making independent life choices, ripped their aspirations and opportunity in education and condemned them to lifelong poverty and misery. Also, results in self and social exclusions, degradation of family and social positions. Myths surrounding Noma are prevalent in the study area. Female noma survivors are burdened with complex and multi-dimensional challenges due to gendered norms, inattention, and misconceptions about Noma. This unfairness and discrimination against them is yet unchallenged.

Keywords: Noma, discrimination, disfigurement, female noma survivors (FNS), social stigma

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1. Introduction

The face is the visiting part of an individual's general constitution which performs multiple tasks as indicated in some studies. Jack *et al.* (2015) describe the face as a powerful tool in social communication providing information regarding one's identity, sex, age, race, physical health, attractiveness, emotional state, social position, and communicative gestures'. Similarly, Leopold and Rhodes (2010) further argue that the face is the most important visual stimulus where humans interact and fluency with faces offers great social advantages. However, disfigurements on the face could happen at any stage or period of human development hampering the above physiological, psychological, social, and individual functions. According to Rumsey and Harcourt (2004), disfigurement is 'The state of having one's appearance deeply and persistently harmed through physical trauma or illness leaving distortion, malformation or perceived abnormality of their body features'. The major theme of this study is disfigurement caused by an illness called Noma.

Noma or *Cancrum oris* is a facial flesh-eating disease caused by a gangrenous bacterial infection that ravages the face and results in serious facial deformity (trismus, oral incontinence, impaired speech, excessive salivation, malodorous breath, etc.) and death if left untreated (Enwonwu *et al.*, 1995; Jain and Ranka, 2017). It is a little known, non-communicable and neglected disease that usually starts in early childhood and is associated with severe poverty, malnutrition and infection that has been dubbed to an alternative name 'the face of poverty' (Behanan *et al.*, 2004). Noma has disappeared from developed nations, yet is most prevalent in sub-Saharan Africa and there are few cases in Asia and Latin America. The disease has not been widely reported, but approximately 140,000 new cases are diagnosed annually with a mortality rate of about 8.5% (Srouf *et al.*, 2008; WHO, 2016).

The accurate prevalence rate of Noma in Ethiopia is not known, but Ethiopia is still part of the region called the World Noma Belt, the part of Africa that stretches from Senegal in the west to Ethiopia in the East (Marck *et al.*, 2013). Despite the initiatives of international charitable organizations,

such as the Dutch Noma Foundation, Facing Africa, Medicines sans Frontiers, project Harar and few local hospitals, Noma is neither in the list of Neglected Tropical Disease (NTD) nor has gained proper attention in Ethiopia (Health Sector Transformation Plan, 2015). The prevention and treatment of Noma is not a priority in the countries where it is prevalent, revealing that it is still neglected by the medical community, government authorities, donors and the public (Leila. *et al*, 2015).

Stigma is a dynamic process of devaluation or intense social disapproval that significantly discredits an individual in the eyes of others within a particular cultural setting (Wood, 2004). It is a global phenomenon constructed and reinforced in a language, then characterized by labelling, stereotyping, separating and status loss (Philips, 2010; Wail and Regmi, 2016). When stigma is acted upon either by omission or actions against the stigmatized, the result is discrimination. Stigma and discrimination are interwoven, legitimizing and reinforcing each other resulting in psychosocial problems, (Fingeret *et al.*, 2012; Rumsey *et al.*, 2004), poor quality of life, illness, decreased life expectancy and diminished access to healthcare (Benoit and Shumka, 2009; Patrick *et al.*, 2007). Often stigmatized individuals face similar constraints in managing social interactions irrespective of the type of stigma they face. Facial attractiveness or disfigurement stereotypes are amongst the defining elements of social stigma and discrimination against a person, particular of the way they look, usually adhering to gender norms (Sophia, 2010). Some studies noted that the physical appearance of a woman is considered as more important than that of a man in determining 'beauty' standards, life outcomes and interpersonal relationships (Jackson, 1992; Bessenoff, 2007).

Most of the literature available on Noma focuses on clinical descriptions, whereas little has been said on the extent of discrimination against survivors (Waili and Regmi, 2016). This paper aims at exploring the facial disfigurement stigmatization experiences of female Noma survivors (FNS) and factors associated with stigmatization. It also presents how female survivors are treated and regarded by their family members, the community they live in and the responsible government authorities.

2. Research Methods

2.1. Study Context

This study was undertaken in four rural districts, namely Belesa, Koladiba, Addis Zemen and Ebenat, found in Gondar Zone of the Amhara region. The districts were purposively selected primarily based on the convenience in accessing female Noma survivors in adjacent geographic areas, sharing similar socio-cultural norms, and also for convenience in verbal communication with respondents without the need for translations. The region is one of Ethiopia's region where women's health has been adversely affected by poverty and established gender norms are culturally dominant (Ethiopia poverty assessment, 2014). Such factors, not only increase the risk of and susceptibility to Noma, but also could potentially affect perceptions, attitudes, treatments and intensity of stereotypes towards the noma survivors.

2.2. Study Participants and Data Collection

This study employed a qualitative descriptive research design since the qualitative assessment is suitable for analysing sensitive issues in general, effective in identifying intangible factors like beliefs, opinions and norms and allows flexibility to have a free and open conversation with participants (Cook et al., 2013). The descriptive approach offers the opportunity to gather rich descriptions of the phenomena and lays the ground for future studies (Connolly and Reilly: 2007). Data was collected from female Noma survivors, their families, community members and selected regional government offices. Semi-structured in-depth interviews were administered for the first three study groups and structured interviews for government representatives. Data from Noma survivors and families were audio-recorded. Field notes were taken from community members and government representatives.

Initially, using the database of Facing Africa Noma (a British charity that provides complex facial reconstructive surgery for Noma survivors in Ethiopia), eight female survivors were identified. The survivors who lived in rural and semi-rural areas were of varying age (17 – 68 years old),

marital status, educational level, treatment experience (operated or not) and slight geographic characteristics. A purposive sampling technique was applied to ensure participant variation in terms of the above variables. The in-depth interview questions for these groups focused on sharing experiences, perceptions, feelings, challenges and coping systems with regard to living with facial disfigurement. Individualized interviews were used to gain confidence of respondents, avoid any overlapping interests and fear of being further discriminated or punished for giving their opinion. Besides, we gave the survivors a chance to speak out their experiences without interruption.

We approached sixteen family members affiliated to the survivors. As much as possible we considered different variables in these groups, too (male and female, closely/not closely affiliated relatives, caregivers, different livelihoods, education levels, age range, e.t.c.). In-depth interviews were used to explore psychosocial challenges encountered by family members due to having a disfigured kin. Similarly, we selected twenty-five individual members of the nearby community (close neighbours, leaders of religious and social community-based institutions) to find out perceptions, positive supports and challenges in the community concerning the female Noma survivors and their families. We investigated the values attached to female attractiveness by examining the contributions made by traditional adages in reinforcing particular forms of social status, gender roles and expectations.

Finally, structured interviews were administered to four officials (two females and two males), whose role varied from senior management to expert working in three regional governmental organizations namely, Women and Child Affairs, Labour and Social Affairs, and the Health Bureau. We chose these organizations purposively as they were responsible for the economic, social wellbeing and health, respectively, of female Noma survivors. These organizations provided information about their intervention and level of support to female Noma survivors.

2.3. Data Analysis

Thematic data analysis was employed as it helped in discovering patterns in data sources and making sense of the narratives in identifying themes and

fulfilling the aims of a specific study (Braun and Clarke: 2013). The authors transcribed all the data (recorded and field notes) from Amharic to English. After deep reading of the data, coding took place manually by classifying and identifying descriptive terms, phrases or categories of themes that fitted the aim of the study, i.e. exploring and describing the situation (Marshall, 2003). We used such themes to summarize, adjust information for analysis, interpretation and developing findings.

2.4. Ethical Considerations

The study was conducted after securing approval of the proposal by Addis Ababa University Centre for Gender Studies. Study participants were informed about the purpose of the study and verbal and written (signatures) consents were obtained before the interview was undertaken. In the case of minor participants, the presence of a guardian or a parent, at least at the initial phase of the interview, was ensured. To minimize the possibility of intrusion by the interviewer and protect the autonomy of the participants, their own words and expressions were used in the study. The participants were informed verbally that they had the right to refuse to answer or terminate their participation at any point in the interview or audio recordings. Respondents were also informed that information or pictures they gave to be solely used for academic.

3. Findings and Discussion

3.1. Beauty Perceptions

Despite this famous phrase, “Beauty is in the eyes of the beholder” telling us beauty is an individual taste, there is a consensus that what determines ‘attractive’, ‘beautiful’, or ‘normal’ are learned from one's culturally presented ideals (Michael, 1991). Crawford and Unger (2004) noted that often studies on attractiveness ignored disfigured people and portrayed disfigurement as something to get rid of and attractiveness as a sign of being fit and healthy. The consistency and stability of images of men and women may lead people to believe that there is a social consensus about images and gender. Harplin *et al* (2004) indicated that the physical appearance of women had important social consequences than that of men.

Considering this, participants were asked to describe what an ideal “normal” or “attractive” woman should possess. Accordingly, very light-skinned (*qey*) or slightly brown (*teyim*), large eyes, white gapped or ungapped teeth, straight or sometimes high bridged (*gorada*) nose, long or medium-sized hair with *shrubu* (cornrows) style, hippy, tall, average in weight, height or reasonably short etc. were attributes mentioned by the majority of the respondents. Additionally, one Noma survivor and two community members said:

“Beautiful is someone who has not missed any facial parts”

(FNS, age 43)

“...quiet, shy or submissive in public or for her husband”

(Male neighbor, age,47)

“Being young is beauty for a woman”

(Neighbor, age 62, Female)

Looking at these descriptions, clearly facial attractiveness is one of the key determinants of overall ratings of physical beauty, and deviations are implicitly not welcomed. Again, these traits implicate as signals of biological health, sexual selection, and power relations. Likewise, some Amharic proverbs replicate the importance of body image as a pre-requisite of social status and ways of behaving. E.g. ‘*melk setiegn, moya kegorebet emarallehu*’ (may God give me beauty, I can learn cooking skills from neighbours), *melk tifunn beseme yidegifu* (giving a nice name will help an ugly person to compromise his/her ugliness), *qey sew melk ayfejim* (being light-skinned is by itself is beauty), *yeset bera yebeklo denbara* (a bald woman is like a startled mule). Some adages display gendered exploitative and restrictive norms deliberately affiliating a woman only to domestic activities like *set lebet wefcho leduket* (as a woman is to home, so is a mill to powder), *yeset motwa bemajetwa* (a woman’s death is in her kitchen). Yet when it comes to men, adages focus more on power dynamics, work, vitality, well-formed body and manifestations of strength. E.g *Mawrat new setinat, mesrat new wondinet* (to talk is womanly and to work is manly), *set bitawik bewend yailk* (though a woman proposes, a man decides), *Keset tebdel yewond kosmana yishalal* (a skinny man is better than a huge woman). Similarly, Yohannis 2007 and Jemaneh (2000) stressed that local

media advertisements and secular Amharic songs portray women mostly based on physical appearance, the sexual division of labour and roles in domestic tasks than in the public sphere; where women's contributions have been undervalued and their work is rather considered as leisure.

Such trends of standardization exhibit a consensus on the designation of women and communicate the society's masculine favored (patriarchal) ideology, reinforcing socially established realities and expectations. In her book, "The Beauty Myth", Wolf (2002), contends that images of beauty are used against women as a means of social control where women are expected to possess some objective beauty measures and men must want such women. This entails that a woman is to be treated, measured and provided with social acceptance based on looks and affirms that deformity is incorrect, bad and abnormal.

3.2. Manifestations of Social Disapprovals

Noma survivors and their families face various challenges regarding self and social functioning, roles and participation in family and public life, stereotypes, and practices in different aspects of their lives, body image adaptation and coping strategies.

3.2.1. Awareness and perceptions about Noma and the place for the Noma Survivors

Despite the unusual and extremely disfiguring nature of Noma and its physically debilitating features, the majority of the respondents in this study showed a predominant tendency of not perceiving Noma as a disease. Facial disfigurement due to Noma was treated and associated mainly with traditional beliefs.

Respondents used the following phrases to describe Noma; the work of evils, being cursed (*ergeman*), fate (*Eta fenta*), punishment for ancestral wrongdoings (*Yehatiat kefiya*), the will of God (*Yegzer fikade*), going out of home accidentally during a solar eclipse (*Michee/chegno*), animal bites, falling from high cliffs, and eating some foods during pregnancy. Four of the interviewed Noma survivors explained how they became disfigured as such:

“When I was a baby, my mom left me at the direction of the solar eclipse in the morning, then I got this scar on my face” (FNS, age 68)

“A bat has peed on me while I was asleep” (FNS, age 55)

“I do not know what happened to me, maybe it is a disease called *kunchir*” (FNS, age 37)

“An unknown insect is responsible” (FNS, age 27)

Also one of the mothers of the interviewed Noma survivors stated the cause of her daughter contracting the disease as “a result of refusal to receive ancestral spirits” (*Yezar menfese*). Also, there was a tendency by respondents to confuse Noma with other known facial disfiguring diseases like cleft palate, leishmaniasis, or leprosy.

Only respondents with relatively better educational status (excluding government institution representatives) mentioned that, though they did not have any clue about what it exactly was, they understood it as a disease rather than as a curse. A similar study by Sokoto Hospital (the only hospital in Africa dedicated to treating Noma) in northwest Nigeria, indicated that among the local communities, Noma was highly associated with *bad spirits* and given a name as: “*ciwon iska*”, meaning “*the disease of the wind*” implying that it had culturally asserted meaning (Farley et al., 2020). This conception of diseases has been reported to affect people’s perceptions of Noma and health-seeking behaviours.

Owing to such beliefs, ten of the interviewed family members had sought consultations from traditional healers or community to halt the problems caused by Noma. The lack of knowledge about the mere existence of this disease has contributed to the lack of trust in modern treatment and affected their health care decisions. In some situations, the intervention of the traditional healers worsened the condition and sometimes seeking modern surgical treatment was perceived as dangerous because of the risk of incurring punishment of God. Some accepted it as fate.

Customarily women and girls in the study places are assigned and restricted to roles and responsibilities in child nurturing, preparing food, preparing

ceremonial events like making coffee and serving it to visitors and neighbours, fetching water from rivers/wells, going to market and flour mills and other domestic chores (Attali, 1985). Similarly, it is important to note that productive or reproductive tasks assigned to women affected by Noma were highly subjective to the definitions of attractiveness, disfigurement and reactions from the community they belong to. Noma survivors were judged and given humiliating nicknames that reflected their deviations. Thus, these nuances gave rise to more complex and strict restrictions on their social, sexual, and productive roles unlike the unaffected women in their community.

3.2.2. The self-image of the female Noma survivors

Strahan *et al.*, (2008) and Chan (1990) indicated that our perceptions, responses and interaction with others, as well as personal attitudes, were shaped to a larger extent by our cross-cultural variations. Sociocultural norms for ideal beauty standards pushed women to base their self-worth more strongly on appearance and to feel more concerned about the perceptions of others and less satisfied with their bodies. Such misconceptions were at the top of the Noma victims' knowledge about the disease and led them to feel they were different from the ideal beauty images.

“I feel like I am the ugliest woman in our village, there is no one like me” (FNS, age 22)

“I do not have full lips and cheek, beautiful is someone who has not missed any facial parts” (FNS, age 43)

Not only that they thought that they were unattractive or unappealing, they also believed that they missed some human and, particularly, feminine qualities. It was so difficult for some of the survivors to explain how the disease coloured their lives. Frequent bullying, being gestured at and being given nicknames like; *elephant face*, *hyena face*, *mentally ill*, *disabled* (*Korata* or *Godolo*), *ugly* (*Masteya*), etc. were part of their everyday life. These insults made them develop negative self-perception, emotional distress, hopelessness and very limited interest and confidence in social interactions and powerlessness to challenge the given negative designations.

“Going to markets, churches or schools is worse since there is a need to stay there for a long time and the people around are all staring, laughing and bullying” (FNS, age 17).

“The feeling of being ashamed of and uncomfortable resulted in my avoidance of public life” (FNS, age 28)

The severity of social and self-stigma that Noma survivors experienced varied across different age and generational categories. Relatively older Noma survivors (aged 68 and 55) stated the severity of the social or self-stigma they experienced varied across their life span. In their early years, though they encountered bullying from other peer children, they gave less meaning to their disfigurement and its self and social implications. However, the most difficult phase in life for the female Noma survivors was their youth and adulthood (between 15-40), when they began to be more conscious of their environment, themselves and were able to grasp what happened to them or what made them different. Also, it is a critical time, when it mattered greatly for a girl’s beauty to get high attention and feedbacks from others. It is a period of self-development, life choice-making and asset building. However, most Noma survivors who were in or passed this stage felt sad, and considered themselves as losers due to limitations exerted by the society not to let them enjoy and decide on matters concerning their lives. At older ages, the female Noma survivors themselves and villagers tended to adapt and ignored the facial appearance. Instead some kind of help and respect was provided and only reduced levels and types of discrimination were witnessed. Thus, with respect to age, the level and types of discrimination on interviewed female Noma survivors were slightly different, though they still fell in the same category of ‘discrimination’.

On the other hand, three Noma survivors who had the chance to have corrective facial surgery (offered by foreign medical charities) stated that their main reason to undergo such procedure was their look. A General Plastic Surgeon Consultant stated that corrective surgery for Noma remained inaccessible in Ethiopia mainly due to the government's unreadiness to tackle Noma. He further affirmed that Noma was forgotten

and not widely known even among the medical community. Nishikawa (2015) and Cadogan *et al.* (2011) contend that corrective surgery may restore facial identity and functioning when compared with the pre-correction state. Yet, it does not always guarantee a “normal” face and improve the psychological burden. One of the survivors believed that surgery improved her looks but she still wore a scarf to cover the scar, since she could not process the previous traumatizing experience:

“Even after the surgery, I cover my face. I feel ashamed to take the clothing off, in case people gaze, laugh at me, or bully me.” (FNS, age 17,)

The second one felt happy about her post corrective surgery looks and stated;

“I consider that I am reborn. My family, and relatives are reacting positively and giving me confidence not to hide my face anymore” (FNS, age 28)

However, a third one who had a very complex disfigurement believed that the result of the surgery did not improve her looks to her expectation. It rather worsened her situation:

“I am still left with a swelling and a big scar. Also, destructive comments of others discouraged me in proceeding further with the surgery” (FNS, age 37)

Though the responses by the two survivors reflected difficulty to overcome previous traumatizing experiences, family members and survivors did not deny that patient acceptability after reconstructive surgery had improved. However, the authors believe that unrealistic expectations of what plastic surgery could achieve in terms of repairing looks or body functioning had contributed to their dissatisfaction. Besides, failure to quickly adapt to the new facial appearance and the absence of any comprehensive psychosocial rehabilitative supports aggravates the burdens. In this regard, Costa *et al.* (2014) described how the repair of self-concept and psychological rehabilitation were lengthy and gradual process. Hence, it is possible to say the probability of lifelong challenges of a Noma survivor, irrespective of medical intervention status, is still high.

3.2.3. Positions of the Family members

Significantly, family members were found playing as double agents. They could engage in the discriminatory acts knowingly or unknowingly or act as a protective family member. When community members isolate them for having a ‘cursed’ child or being related, they, in turn, put pressure on and discriminate against their own Noma survivor family member.

“I was told to stay/hide in a stable, kitchen or outdoors when a stranger came to our house and I remember what my mom used to say to me “Wolade tachenegifyallesh” meaning, your looks can cause a pregnant woman abort (FNS, age 68)

“I was considered and repeatedly reminded by my cousin how useless and a cause of misery I was for the family” (FNS, age 17)

“I used to set up coffee ceremonies but not attend them as my employer (my aunt) told me, my face would scare other people, and that might keep customers away from her small restaurant” (FNS, age 43).

“I was told that I had a mental problem and needed to stay helping my mom at home and dad in the field, while my other siblings, at least went school” (FNS, age 22)

In some places, villagers believed that the whole family was cursed. Some Noma survivors were openly denied employment opportunities for the fear of Noma being contagious. On some occasions, family members were told to keep away from certain social activities, such as cooking, serving food; they did not invite them to social events, rejected marriage with them, and provided them with food in isolation. Parents, siblings, and children of the Noma survivors were, at least, targets of verbal and psychological attacks. As such one of the mothers stated her painful experience:

“Some neighbours use my daughter's disfigurement as a means of attacking us during some conflicts with the family and make us feel ashamed in the presence of others making us powerless and submissive and unable to stand for ourselves” (Mother of FNS, age 52)

Few of the interviewed family members and relatives admitted that they were ashamed of the Noma family member. In an extreme case, one of the survivors' brother said the following:

“I changed my residence area to a different place where no one recognized me. I saw people laughing, bullying and giving her (Noma survival sister) nicknames. However, I did not dare to defend her even though it hurts to see. I used to feel very embarrassed even to say that she was my sister until she had her facial reconstructive surgery” (Brother of FNS, age 24)

Such persistent social challenges on the family inevitably and eventually eroded their social cohesion and led them to narrowly limit their range of social interactions within immediate family members, which resulted in what has been termed as ‘social death’ (Talley, 2014).

In contrast, from some rational minds in the family and community, few Noma survivors enjoyed a relative privilege of protection and support. Supports were given in terms of encouraging the survivors to seek medical help, to go to school and public places, defending them against those discriminatory acts. The husband of one of the survivors who had constructive surgery said:

“I have convinced my wife to have the surgery, despite giving up on any hope that her face can be reformed but some people discouraged us not to waste time and accept the destiny. I stayed with her in the hospital for over three months during the procedures and our neighbours were ploughing my field” (Husband of FNS, age 38)

Some of the families migrated to other places and, in most circumstances, resorted to violent means to protect their Noma survivor member. As a result, family members experienced strained relationships with their community members or even amongst family members.

3.2.4 Intimacy and Marital Relationships

Intimate personal relationships involve feelings of emotional and physical closeness and connectedness with another person. A growing literature

documents the importance of physical attractiveness in intimate relationships. For instance, a study by Amelia *et al.* (2017) pointed that women who were perceived to be physically attractive were more likely to be in dating, marital and sexual relationships as attractiveness traits were associated with "good gene" in terms of health and reproductive value.

Despite the prevailing assumption that Noma survivors are not supposed to be interested in having a relationship or having a family, two of the survivors were currently married and one was a widow. The rest of the interviewed survivors never got married nor started any serious relationships. However, four of them had children born out of wedlock following instances of rape (by extended family members, neighbours, strangers) and a few were taken advantage of due to their financial positions.

Purpose and the motive of marrying or having children from Noma survivors was found interesting. As one of the husbands of the married Noma survivor explained, the way he got married was due to the comparative advantage he gained. He said, "*I married her because she was cheap in terms of paying dowry. Unlike my first wife who was 'not defective' and costed me 10 cattle as a dowry to marry her, I was not expected to pay more than 2 cattle to marry my present wife because she is defective*" (Husband of FNS, age 44).

His Noma wife stated that her husband was supportive of her and her kids but still felt that he had a clear preference over the other 'normal' wife. During social events and parties, for example, he preferred to be seen with the other 'normal' wife. She also mentioned that the other wife and her kids sometimes teased her for the same reason. In another instance, the motive of a husband for marrying a Noma survivor was driven by religious purpose. Accordingly, he said: "*By marrying the Noma survivor, I can serve GOD and get blessings for my soul*" (Husband of FNS, age 38).

However, some of the survivors reported having had a relationship or sexual intercourse with someone from a lower social class or a person with a more critical disability. For instance, leprosy is another disease where

individuals affected have traditionally been rejected by their family and community members due to a belief that leprosy is a curse, fate, or divine punishment (Edessa, 2016). With this respect, an old Noma surviving widow affirmed that she got married to a man who had leprosy just because both were considered to have leprosy and were left with no choice but to beg for a living, robbing their freedom and opportunity to share resources in their community.

Similarly, children of the Noma survivors also suffered from clear discriminations and deprivation of parental love, nurturing and care just because of their mother's condition. A daughter of a survivor's clearly stated:

“Though I and my brother knew who our father is, we are not using his name as he denied fatherhood and custody when we were young. To the worst, our father feels ashamed to have kids from our mom and by any means, he does not like to be seen with us or her.”

(Daughter of FNS age, 19)

The authors of this study also witnessed male Noma survivors to be in a relatively better position to choose a partner, access resources and win social acceptance. However, female survivors were paying a higher price for attempting to engage in normal social interactions. Even those who were not married yet also seemed to feel that they must be content to be married to any willing partner and were unlikely to marry when compared to their 'normal' siblings and are mocked more by their partners in relationships.

3.2.5 Ownership and Control of Property and Livelihoods

Agriculture is the main economic activity in the study areas and land is the basic source of employment, assets creation, health, wellbeing, social identity and security systems. Notwithstanding variations in involvement across age, social class, type of crops, and production cycle, women make up almost fifty percent of the agriculture labour force in sub-Saharan Africa. In the study area, land preparation, weeding, harvesting, threshing, herding and storing have been some of the women's responsibilities in addition to herding animals, preparation of food and caring for children. However, their contribution to agriculture is underrepresented and seen as subsidiary or less

important to what men do. This has resulted in the belief that women could not lead or act as a fully independent agent to agricultural production, management, ownership, control and decision-making powers (Melese, 2011 cited in Belay *et al.*, 2016).

The challenges of female Noma survivors go beyond ignoring women's role and is highly influenced by the designated social identity. One of the survivors was denied her right to own land, a right enjoyed by her siblings, just because she was considered as unfit and lifetime dependent who needed someone's care. Similarly, the siblings themselves also participated in the systematic exclusion of the Noma survivor member while sharing inheritances. For instance, the exclusion was manifested through giving less fertile and small plots to the female Noma survivor; and becoming an agent to the survivor and taking advantage on management. Thus, even though an inheritance is one way of owning the major asset (land), it was difficult for female survivors to enjoy or share it equally with siblings due to reduced bargaining power. Furthermore, the decision-making structure was highly skewed to the husband of the married Noma survivors and were dominated by their husbands in management and ownership of properties during the marriage. This situation supports what Wolf's (2002) claimed as beauty associated myth was a reflection of power imbalance where the man used the deformity of the women as a weakness and dominates her.

Additionally, even if they wanted to engage in other income-generating and business activities, they would not be able to attract customers. Owing to prejudice, potential customers would be unwilling to consume their products/work. Two of them stated that they had tried to engage in selling local alcoholic beverages such as 'Tella' and 'Areke' or food items which could attract many customers, but were forced to change to other petty jobs like selling non-food items i.e. firewood and charcoal to survive.

“Except families or few close neighbours, people are not interested to eat the food I cook or even drink the Tella I made. Because they think it (Noma) would be transmitted to them. Instead, they prefer other neighbours who produce similar beverage” (FNS, age55).

“I do not have the courage to work even as a housemaid in rural places, as people are afraid to look at me without my scarfs” (FNS age 22)

These experiences eroded their confidence to try to engage in self-run livelihood activities and were forced or preferred to be dependents on their families or relatives serving them for free throughout their lives. Such expressions supported Rumsey and Harcourt (2004) who stated that compared to facially ‘normal’ people, facially deformed people received less time and attention from others, and were less likely to get hired. Instead, Noma survivors were often seen as little more than their ‘deformity’, not full participants in society and had difficulty in doing what they like, and finding jobs that would allow them to support themselves and their family. Furthermore, even families who had a Noma surviving member faced subtle discrimination in the local market and were given lower social status in their community. Consequently, this led them to have rigid family and social roles which remained fixed throughout their lives where most interviewed survivors worked mostly in hidden and non-public places on laborious tasks like digging, farming, carrying huge loads in on-farm works.

3.2.6 Educational opportunity

Education is one of the most fundamental requirements in the modern world. A study by Adeyemo *et al.* (2016) on the impact of facial disfigurement among cleft lip and palate patients in Nigeria revealed that more than half of the participants experienced bullying and harassment at school which affected their decision to pursue higher education.

It is common even among ‘normal or unaffected’ girls in the study areas to face barriers from social norms, poverty, gender-based violence, early marriage, and teenage pregnancy hindering them to access and completion of education (UNICEF, 2018). However, the female Noma survivors and their families thought that beyond these hurdles, their condition limited their chance to pursue education and hampered alternative livelihood outside of agriculture. Constant body shaming and bullying counted as the major factors hindering Noma survivors from education, thus, condemning them to lifelong misery.

“No one in the classroom wanted to speak or sit next to me, I had to sit alone in the last rows.” (FNS, age 28)

“Most of my teachers looked at me with pity and I was not given chances to participate in the class” (FNS, age 17)

“Thinking of going to school was very depressive and not my interest at all. I tried to commit suicide by drinking a pesticide” (FNS, age 22)

The suffering of Noma survivors was not limited to active discrimination and harassment but also facing rejection by teachers due to speech impediments and communication problems; teachers perceived them as ‘mentally ill’, and expected less from the Noma survivors'. Family members also prevented them from going to school in the first place or forced them to drop out of school if the survivor somehow managed to go to school. Only three of the interviewed Noma survivors were able to go to school and the maximum grade attained was grade four.

Hence, by crushing their educational aspirations such discrimination resulted in lower achievements, limiting their chance of success and not to aim high. In this regard, interviewed government authorities neither challenged this lifetime discrimination nor arranged any education option for this group as one of the special needs groups.

3.2.7 Harmful Traditional Practices

Harmful Traditional Practices (HTPs) are those customs known to harm the physical, sexual and psychological well-being, human rights and socio-economic participation of people. Female Genital Mutilation/ Cutting (FGM/C), abduction for marriage, early forced and child marriage, polygamy, milk tooth extraction constitutes the most prevalent forms of HTPs in Ethiopia affecting women and children (DHS, 2011).

Noma survivors were also most vulnerable to multiple and cruel forms of HTP's in contrast to ‘normal’ or an affected woman in the study areas. Accordingly, with the intent of healing the wound on their face due to Noma, most of the interviewed survivor families applied unknown and

dangerous medicines/herbs and substances, including dangerous acids resulting in more pain and deformity.

“To remove my abnormally grown teeth and improve my bad look caused by Noma, my front and canine tooth were extracted” (FNS, age 55)

“I was cauterized several times in my cheeks by ‘Tatte’ (treatment by tapping skin with tip of a red-hot iron wire)” (FNS, age 37)

Such HTP’s were done with or without their consent and mostly by recommendation of traditional healers or community members resulting in worse deformity than the Noma had caused.

Likewise, as Noma is inextricable to chronic malnutrition, it is important to mention how food taboos targeting girls, pregnant and lactating women in the study area affected Noma survivors and their babies. This can be through prohibiting certain foods or the culture of men being served first with the best food. (Wollelaw *et al.*, 2018). For instance, inadequate food intake and malnutrition worsens the weakening of bodies of Noma survivors and exposes them to other health problems. When the body gets very weak, it creates inconvenience to have corrective surgeries and delays the recovering process. Also, this condemns babies of the survivors to low birth weight, mortality, stunted growth and an intergenerational cycle of nutritional problems. In the authors' view, gendered nutrition coupled with malnutrition and other factors could affect the survivor’s nutritional status eventually aggravating their condition and everything that comes out of it.

3.3 Coping Strategies

Coping strategies are actions or adjustments taken towards the self-protection and self-esteem despite a stigmatizing situation. The greatest psychosocial challenge to endure for most people with disfigurement is experiencing stigma, a low level of psychological wellbeing and learning how to cope. Coping mechanisms can be receptive, aggressive, passive, or hostile. However, a successful adjustment in disfigurement lies in the ability to interact with other people at various levels, from meeting people for the

first time to enjoying an intimate relationship (Kondo *et al.*, 2005; Millstone, 2008).

Coping mechanisms employed by interviewed female Noma survivors and their families mainly targeted on public avoidance and concealment (covering the face). All of the interviewed female Noma survivors had learned to hide their injuries behind the scarf since childhood and had already succumbed to the stigma and built resilience. Keeping Noma survivors always in isolation (in a kitchen or locking in a separate room) and not letting them meet or socialize was adopted by members as a way of protection. Occasionally, families/members of the survivors changed their residence to alleviate their stress and get relief from discriminatory social, and community relationships.

Thus, in the absence of integrated psychological, medical and rehabilitative supports that could help in successful adjustment, the coping methods used to deal with the stigmatizing situations worsened and, over the long term, degraded positive self-perception, deprived social bondages and engagement in productive activities.

3.4 Institutional Responses

As a primarily concerned body for health and wellbeing of the community, the region's Health Bureau Disease Controlling Department representatives stated in shocking emotions that:

"...I have never seen or heard of such a disease or our office never came to consider the issue of Noma as public health problem"
(Government representative ≠ 2)

"For a disease to get recognition and visibility by the government, its prevalence rate highly matters" (Government representative ≠1)

On the other hand, the representative of the region's Social and Labour Bureau acknowledged the existence of the disease and said:

"We do communal supportive works in many disability issues but not on this one. I saw two or three people with that kind of face when we

run cleft palate case tracings in rural areas and thought it was a kind of cancer” (Government representative ≠ 4)

However, responses from a high ranking official at the region's Women, Children and Youth Affairs Bureau were unsympathetic and highly contrary to the mandate of the institution itself. Responses to the questions ranged from complete denial of the existence of Noma in the region to extreme defensiveness in for most of the proper interview questions.

“I do not think the pictures you are showing me are faces from this region. This is not a problem for our office to handle, and if Noma exists, it should be the responsibility of the region's Health Bureau. We are burdened and faced with other worse problems” (Government representative ≠ 3)

Though Article 55(1) of the constitution of the FDRE and Proclamation No 691/2010 empowers and mandates the above regional government institutions to formulate, lead, cooperate, follow up and ensure addressing of respective socioeconomic affairs, the responses of the representatives revealed that beyond the information gaps, even those who were aware of the problem lacked commitment and readiness to intervene; e.g. not reporting the incidence to higher authorities and provide comprehensive support or resistant to learn. In the authors, while working with the Ethiopian Federal Ministry of Health, noted that there were some unsuccessful efforts by health charities to include and sensitize the issue of Noma in the national health extension workers training manual. This missed opportunity greatly affected the reporting system and early detection.

Ziegler (2012), a human rights advocate, flagged that Noma was an evidence of clear human rights violations where victims suffered from extreme poverty, insufficient food, lack of proper medical care, sanitation, and omnipresent neglect. Thus, the authors' assessment of the intervention and level of support by these institutions in alleviating the complex burden suffered by the female Noma survivors and families were altogether inadequate. It was understood that they did not share some basic information on cross-cutting and cross-sectorial issues. Hence, Noma and

its social costs were overlooked and were not even in their agendas for intervention.

4. Conclusion and Recommendations

Due to the profound social significance of the human face, facial disfigurement can drastically affect the management of social interactions. This study revealed how multifaceted neglect along with stigma and discrimination resulted in information gap and myths about facial disfigurement caused by Noma. Female Noma survivors were often seen as “facially aberrant and unattractive”, unfit for mate choice, disabled, victimized, dependent and passive. Such labels and subsequent treatments have brought adverse outcomes to their self-concept and self-esteem, deprived them of personal development opportunities, and condemned them to lifelong poverty and suffering. Moreover, it left them invisible and powerless to challenge their status quo and were vulnerable to abuse and violence. These persistent prejudices gradually eroded their human dignity and exacerbated social withdrawal. To a lesser degree families of the female Noma survivors, too, faced challenges and felt unsupported in their efforts to live ‘normal’ lives.

Generally, Noma has not been given the visibility and political willingness it deserves and requires. Overall, this research demonstrates that the situation of female Noma survivors and their health is not only defined by them individually but also by their family and the society in which they live. Consequently, addressing the needs of Noma survivors seeks holistic and collaborative actions. Government and non-government actors have to ensure a human rights approach to reduce the discrimination and stigmatization of those suffering from Noma. Thus, our study recommends interventions aimed at dissipating the myth surrounding Noma through public awareness and availing community level supports for people affected or disfigured by Noma. Furthermore, psychological therapy, rehabilitation, and reintegration should not be overlooked to mitigate the emotional distress of post corrective surgery. Also, access to medical assistance from early detection to reconstructive surgery should be availed and prioritized, considering the ruthlessness of the disease, to prevent mortality and

progression to severe disfigurement. Further studies in the subject will help to understand the problem from a wider perspective and adds knowledge.

Conflict of interest

The authors declare that there are no potential conflicts of interest.

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Appendix

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