



## Having a child with orofacial cleft: Initial reaction and psychosocial experiences of Ghanaian mothers



Adwoa Bemah Bonsu<sup>a,\*</sup>, Veronica Millicent Dzomeku<sup>a</sup>, Felix Apiribu<sup>a</sup>, Solomon Obiri-Yeboah<sup>c,e</sup>, Benjamin Asamoah<sup>b</sup>, Kofi Boamah Mensah<sup>e</sup>, Akosua Agyenim-Boateng<sup>a</sup>, Anita Kusi Appiah<sup>a</sup>, Peter Donkor<sup>d,e</sup>

<sup>a</sup> Department of Nursing, Kwame Nkrumah University of Science and Technology, Private Mail Bag, University Post Office, Kumasi, Ghana

<sup>b</sup> Department of Sport Science, Kwame Nkrumah University of Science and Technology, Private Mail Bag, University Post Office, Kumasi, Ghana

<sup>c</sup> Dental School, Kwame Nkrumah University of Science and Technology, Private Mail bag, University Post Office, Kumasi, Ghana

<sup>d</sup> Department of Surgery, School of Medical Sciences, Kwame Nkrumah University of Science and Technology, Private Mail Bag, University Post Office, Kumasi, Ghana

<sup>e</sup> Komfo Anokye Teaching Hospital, P. O. Box 1934, Kumasi, Ghana

### ARTICLE INFO

#### Keywords:

Qualitative research  
Ghana  
Experiences  
Mother  
Orofacial cleft  
Child

### ABSTRACT

**Background:** Orofacial cleft are the most prevalent congenital deformity of the orofacial region. The birth of a child with orofacial cleft elicit emotional trauma in mothers.

**Objectives:** The study explored the reactions and psychosocial experiences of Ghanaian mothers' having children with cleft lip or/and palate in the Kumasi metropolis.

**Methods:** The study employed a qualitative exploratory descriptive design to realize its objectives. Purposive sampling method was used and data saturation was achieved with 12 informants aged 18 years to above 40 years. All interviews were audio-taped and transcribed. Data analysis was done concurrently applying the techniques of thematic analysis.

**Results:** Mothers' described their initial reaction to the birth of the child as unexpected event with culminated experiences such as shock and disappointment, leading to rejection of the child. Mothers' experienced emotional reactions such as sadness, anxiety and worry. Also, feeding challenges were experienced. Perceived and actual stigma were expressed which led to social isolation. They received support from their spouses and health professionals. Six main themes emerged were unexpected event, nutritional challenges, emotional reactions, participation restriction, losses and support.

**Conclusion:** Mothers need supportive care from husbands, families and healthcare providers. There is also the need to educate the general public on orofacial cleft.

### 1. Introduction

Orofacial cleft (OFC) are the most pervasive congenital defects of the orofacial region worldwide (Stock & Feragen, 2016). In the present study, orofacial cleft (OFC) will be used to denote cleft of the lip, palate, or both lip and palate. The incidence and prevalence of OFC significantly differ across ethnic groups and geographical areas globally with Africa reporting the lowest with 0.7 per 1000 live births (Kosowski, Weathers, Wolfswinkel, & Ridgway, 2012; Loh & Ascoli, 2011). The low prevalence of OFC reported in Africa may be attributed to a high proportion of births occurring in areas that are remote from structured healthcare systems leading to unreliable data on the incidence of the condition. Ghana lacks OFC registry, however, earlier community based studies reported a relatively high prevalence of 5.0

per 1000 live birth in the year 2007 and 6.3 per 1000 live birth in 2010 (Agbenorku, Agbenorku, Sefenu, Matondo, & Osei, 2007; Agbenorku, Agbenorku, et al., 2011; Donkor, Bankas, Agbenorku, Plange-Rhule, & Ansah, 2007). A recent study in the Ashanti Region of Ghana reported 36 OFC out of 2744 live births from eleven selected health facilities from October 2009 to September 2010 (Agbenorku, Yore, Danso, & Turpin, 2013). This shows that congenital anomaly of the orofacial is evidently on the increase in Ghana.

Studies confirm that child born with OFC face problems with physical, behavioural, psychosocial, emotional, mental, and cognitive functioning (Loh & Ascoli, 2011; Stock & Feragen, 2016). However, these challenges are successfully managed currently due to advances in technology and the availability of specialists including maxillofacial and plastic surgeons, paediatricians, audiologists, dentists and

\* Corresponding author.

E-mail addresses: [bbemahc2000@gmail.com](mailto:bbemahc2000@gmail.com) (A.B. Bonsu), [kofimensah227@yahoo.co.uk](mailto:kofimensah227@yahoo.co.uk) (K.B. Mensah).

orthodontists, speech therapists, psychologists, otolaryngologists, nurses, and social workers working in multidisciplinary team to address abnormal facial appearance, impairment in speech and other related problems (Johansson & Ringsberg, 2004; Kosowski, Weathers, Wolfswinkel, & Ridgway, 2012).

Giving birth to a child with OFC is distressing for mothers and it is known to be associated with severe emotional and psychosocial consequences, which have been well documented in many countries (Behal, Khan, & Utreja, 2016; Johansson & Ringsberg, 2004). Every parent who has a child with OFC looks forward to its repair to enhance their physical appearance. In high income countries, the majority of children have their OFC repaired in early childhood due to the availability of medical services, funding opportunities and increased awareness among clients. However, the story of the OFC child from low and middle income countries including Ghana differ (Agbenorku et al., 2011).

Although data has shown a relative increase in OFC repair in Ghana, the age of children whose OFC are repaired range from 1 to 25 months (Agbenorku, Ansah et al., 2011; Donkor et al., 2007); confirming that the majority of mothers of a child with OFC do not get the defect repaired in early childhood. This implies that many mothers are living with children with unrepaired OFC. In Ghana, only few OFC specialists exist; and are mostly found in the two biggest teaching hospitals (Winsor, 2016). The Ghana OFC Foundation therefore partnered with non-governmental organizations such as the Smile Train, Transforming Faces Worldwide, Operation Smile and many others to help with paediatric orofacial surgeries in Ghana (Newman & Agbenorku, 2014). These organizations visit Ghana occasionally for free surgeries for babies who have OFC; which are mainly done in Komfo Anokye Teaching Hospital (KATH), Kumasi and Korle Bu Teaching Hospital (KBTH), Accra, creating geographical barriers. Also, some mothers refuse to travel to these hospitals for the repair due to high travel cost and other unforeseen medical charges (Winsor, 2016). Thus, suggesting the existence of financial barrier to OFC treatment. Consequently, the majority of mothers do not get their babies OFC repaired within months after birth. However, previous research on OFC in Ghana (Antwi-Kusi et al., 2015) has not explored the experiences of mothers with OFC children although the incidence is rising. It is observed that the majority of mothers find unrepaired OFC more stressful than that of repaired OFC (Behal et al., 2016).

Notably in Africa, the birth of a child with congenital deformity is mostly accompanied by myths, cultural and traditional beliefs (Olasoji, Ugboke, & Arotiba, 2007). Hence, OFC may elicit emotional trauma in mothers in this part of the world where religion, culture, beliefs and demographic variables have been shown to have great influence in modelling the individual's reaction as well as behaviour toward OFC children. Previous studies that focus exclusively on mothers who have children with OFC explored feeding difficulties (Lindberg & Berglund, 2014; Masarei et al., 2007), perceptions about cause, social reaction and treatment of a cleft (Antwi-Kusi et al., 2015), perceptions about support (Johansson & Ringsberg, 2004) rather than on how a birth of a child with OFC affects mothers' initial emotional reaction and psychosocial life. Reports from these studies suggest that mothers who give birth to children with OFC are prone to emotional distress such as sadness, grief, shock, and worry; family avoidant behaviour and issues related to difficult infant feeding (Antwi-Kusi et al., 2015; Johansson & Ringsberg, 2004; Lindberg & Berglund, 2014). Researchers have underscored that mothers who identify their baby's deformity prenatally are able to prepare emotionally, psychosocially, financially and physically before birth. Hence, mothers grieve for a shorter period and cope positively with the child's defect (Nusbaum et al., 2008; Robbins et al., 2010).

The authors of this study observed in their clinical work that the birth of a child with OFC presents emotional and psychosocial challenges for mothers in Ghana and these require to be explored systematically to afford scientific evidence for the phenomenon within the

Ghanaian context. This study explored the experiences of mothers of children with OFC at KATH in the Kumasi metropolis with focus on their initial reaction and psychosocial experiences.

## 2. Material and methods

### 2.1. Design

The study explored and described mothers' experiences using a qualitative, exploratory, descriptive design to fully understand the reactions and psychosocial experiences of Ghanaian mothers' giving birth to a child with OFC (Mayan, 2009). This design was employed in the study to understand the emic perspective of the phenomena under study (Creswell & Poth, 2017; Delpont & Fouché, 2011). The study pursued to answer the following research question: (1) how do Ghanaian mothers react in their first meeting with the newborn child? and (2) what is the psychosocial experience of giving birth to a child with OFC?

### 2.2. Study setting

The study was carried out at the cleft clinic of KATH, a tertiary health facility located in the Kumasi metropolis of Ashanti region. The geographic location of the 1200-bed capacity hospital, the road system of the country and cosmopolitan nature of Kumasi make KATH accessible to all the areas that share boundaries with the Ashanti region and others that are further away.

### 2.3. Population and sampling technique

Mothers of children diagnosed with OFC at the cleft clinic of KATH constituted the study population. About 65 children are diagnosed with OFC yearly (KATH Cleft Records, 2017). Of these, 12 mothers who consented in writing or verbally participated in the study. Mothers were purposively sampled to include those referred or who visited the clinic for treatment. Purposive sampling ensured that mothers who had children with unrepaired OFC were enrolled to ensure that they had living experiences to share. Also, those who could communicate in either English or 'Twi' (local dialect) (languages the lead (AB) author could speak fluently) were recruited. All the mothers who willingly consented to participating completed the study, and data saturation was achieved with 12 mothers.

### 2.4. Data collection tool and procedure

Collection of data commenced from February 2017 and ended in May 2017; through individual face-face in-depth interviews using a semi-structured interview guide (Creswell, 2013). The lead author did all the interviews. The interviews focused on issues relating to having a child with OFC. Guiding questions were as follows:

*Main question:* Please can you share with me your experiences after your child was diagnosed with orofacial cleft?

*Sub-question:*

1. Please tell me how you felt when you discovered that your child had OFC.
2. Please share with me how you reacted when you first saw your baby.
3. Please share with me how you have been coping after the diagnosis.
4. Please tell me about your relationship with the child now.
5. Please share with me a typical day of your life after the diagnosis of your child's condition.
6. Is there anything you would like to share with me?

Responses were probed or redirected where necessary to ensure full understanding of the informants' experiences and also to ensure that

Download English Version:

<https://daneshyari.com/en/article/8584205>

Download Persian Version:

<https://daneshyari.com/article/8584205>

[Daneshyari.com](https://daneshyari.com)