MATERNAL PERSPECTIVES ABOUT BIRTH DEFECTS AND ANORECTAL MALFORMATIONS IN IBADAN, NIGERIA

BY

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DEDICATION

This work is dedicated to all those caring, in one way or the other, for children with congenital malformations worldwide

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ABSTRACT

Birth defects are structural congenital malformations that are almost always seen at birth. In countries lacking guidelines on screening for birth defects, additional responsibility is placed on parents in the early detection of these defects. Moreover, the major cause of morbidity and mortality in the treatment of children with these malformations in our environment is delayed presentation. Furthermore, there is absence of published data on the knowledge of Nigerian parents regarding birth defects and there is no information in the literature on the awareness, knowledge and attitude of parents towards early detection of birth defects and anorectal malformations.

The objectives of this study included assessing the awareness and knowledge of mothers about birth defects and anorectal malformations, ascertaining the adequacy of counselling at antenatal clinics concerning birth defects, evaluating the influence of socio-demographic factors on awareness of birth defects, and determining the relationship between maternal obstetric factors and awareness of birth defects.

This was a descriptive cross-sectional study of 365 mothers consecutively selected at the immunisation clinics affiliated to the University College Hospital, Ibadan and Adeoyo Maternity Hospital, Yemetu, Ibadan, conducted between May and July, 2012 following ethical approval. Data were collected with the use of structured interviewer administered questionnaires and information obtained on the socio-demographic characteristics, maternal obstetric history, details of antenatal care for the index pregnancy and items testing the awareness of mothers about birth defects and anorectal malformations. Descriptive and inferential statistics were performed using SPSS, version 19. Tests of association were performed using chi square statistics and p-value set at <0.05. Multinomial logistic regression was done to identify independent predictors of awareness of birth defects.

The participants were aged 17 to 42 years. The majority (98.4%) was married; 52.6% were Christians and 60.8% were unskilled workers. The participants have had between one and seven pregnancies each, and the majority (99.5%) attended antenatal care during the index pregnancy. The study found that only 35.9% and 19.5% of them were aware of birth defects and anorectal malformations respectively. During the antenatal care visit for the index pregnancy, 5.8% of the respondents received counselling about birth defects.

Factors that were found to be associated with greater awareness and improved knowledge scores of birth defects were age, religion, highest level of education, occupational class, booking at an early phase in pregnancy for antenatal care and registration in a tertiary care facility. Religion, educational status and the facility where antenatal care was received were found to be independent predictors of awareness of birth defects.

In conclusion, the study has shown that mothers in Ibadan, Nigeria have a poor level of awareness of birth defects and anorectal malformations.

Key word: birth defects, anorectal malformation, awareness, mothers

CHAPTER 1

INTRODUCTION

Birth defects are congenital malformations that are structural in nature and most often present at birth. They can be minor birth defects such as birth marks or extra digits, and major defects such as congenital heart diseases, pulmonary malformations, tracheoesophageal fistulas, anorectal malformations etc. Anorectal malformations are a spectrum of birth defects that occur in both males and females, ranging from simple, easily treatable malformations to more complex types that require multiple corrective surgeries and consequently have more severe limitations on daily living. Anorectal malformation (ARM) occurs in 1 of every 2,500 – 5,000 live births (Cuschieri, 2001 & Peña and Levitt, 2006) and is slightly more common in males. There is no racial predilection and it is seen in all the continents. Anorectal malformation is often called imperforate anus, which is a misnomer, because it is only in 5 – 10% of cases of ARM. that a truly imperforate anus exists, the overwhelming majority being "perforate" but the anus is absent and the most distal part of the gastrointestinal tract communicates with the urethra in males and reproductive tract (vagina or vestibule) in females (Lawal et al., in press).

Babies with anorectal malformations present, usually, in the immediate period after birth because the defect is a structural one and it can be easily identified by routine neonatal examination. Quite often, however, the defect is missed at birth and the baby presents a few days or weeks later (Turowski et al., 2010). The baby may present with passage of stool from abnormal openings in the perineum or passage of stool mixed with urine (Peña and Levitt, 2006).

The management of children with anorectal malformations is dependent on the type of defect. The decision of what to do is guided by the location of the most distal part of the rectum, i.e. a "low type" or "high type" of malformation based on whether the rectum lies below or above the pelvic diaphragm (Lawal et al., in press). Most babies with "low type" malformations such as perineal fistulas can be operated in the immediate newborn period, and the prognosis is very good as 100% of such babies will attain voluntary control of the act of defecation (Levitt and Peña, 2010). Those with "higher type" malformations typically undergo a diverting colostomy in the neonatal period as an

interim measure to allow the child to grow for a few weeks or months, when a definitive surgery is then performed (Levitt and Peña, 2010). Children with "higher type" defects have a poorer prognosis for faecal and urinary continence.

If the malformation is missed within the first few hours of birth, the baby is fed by the mother and taken home, and in such children, massive abdominal distension causing respiratory distress, bacterial translocation leading to sepsis, vomiting and the consequences of aspiration pneumonitis worsen the morbidity and account for a significant cause of mortality in these children (Chirdan et al., 2008 & Lukong et al., 2011). Unfortunately, the crux of the management of anorectal malformations in developing countries including Nigeria is delayed recognition and presentation to the hospital, with a higher mortality rate recorded (Chirdan et al., 2008, Ademuyiwa et al., 2009, Eltayeb, 2010 & Lukong et al., 2011). In addition, there are some types of defects in which the baby may, on gross inspection, appear to have a normal anus but on closer look or probing with a thermometer, the baby would then be seen to have an anorectal malformation (Lawal et al., 2011). Thus a cursory inspection of the anus may not be enough to exclude anorectal malformation in a newborn child.

Routine screening of newborn children for certain congenital malformations is well established in developed countries, but absent or rudimentary at best in many developing nations (Olusanya and Solanke, 2009). Screening is important, because early detection of these malformations is associated with prompt treatment and the multiplier effect of reduction in morbidity and mortality associated with the disorder, better prognosis and overall improvement in the quality of life of children afflicted with the malformation (American Academy of Pediatrics AAP, 2000 & Hoffman and Laessig, 2003). Standardised guidelines have been developed at national and international levels for routine physical examination of all newborns within the first 48hours of life (AAP, 2000 & AAP, 2004). The optimal utilisation of the process of screening, especially for structural anomalies such as ARM, which are easily detected at little or no cost, is only possible if the parents and health care professionals are carried along (Atte et al., 2006 & Arnold et al., 2006).

In the absence of specific guidelines for perineal examination in newborn children, the onus almost always fall on parents, and often, health care workers to detect babies with

ARMs. The degree of delay in presentation often reflects the level of awareness of the society in terms of birth defects, knowledge of normal and abnormal body tissues and organ-systems and the presence or absence of standardised protocol in use at the hospital/maternity centre where delivery took place. There is no information, in the literature, on the perception of parents towards screening for and early detection of anorectal malformations. In addition, knowledge is lacking on the awareness of mothers about ARM, what constitutes normal anus/abnormal anus and what can be regarded as normal functioning of the ano-rectum in the newborn period. Furthermore, there is no information in the literature on the perception of Nigerian mothers about congenital malformations.

Justification for the study

The non-existence of newborn screening protocols for anorectal malformations may be a pointer to the delay associated with the presentation to the physician of many children with the anomaly. The absence of information on the level of awareness of parents, especially mothers, about normal and abnormal anus may make it difficult to conclude on the reason why these babies are often diagnosed late.

The study will therefore serve to provide baseline information on the knowledge and awareness of mothers about birth defects in general and anorectal malformations in particular. It will, in addition, provide information on the knowledge of mothers on the possible prevention, early detection and care of these anomalies.

Aim and objectives

General aim

- To assess the perspectives of mothers about birth defects and anorectal malformations.

Specific aim

- To assess the awareness/knowledge of mothers about birth defects and more specifically, anorectal malformations
- To find out the adequacy of antenatal clinic visits in counselling on birth defects

- To ascertain the influence of socio-demographic variables on awareness of birth defects
- To determine the relationship between maternal parity and awareness of birth defects and anorectal malformations

CHAPTER 2

LITERATURE REVIEW

2.1 Congenital malformations

Congenital malformations are structural, behavioural, functional or metabolic defects present in babies at birth (Sadler, 2003). These malformations can be of major or minor types. Major structural malformations are mostly evident at birth or shortly thereafter and occur in 4 – 6% of all deliveries (Sadler, 2003 & Stevenson and Hall, 2006). These major malformations, such as congenital heart diseases, anorectal malformations, pulmonary hypoplasia, are often life threatening and constitute a significant and leading cause of neonatal, perinatal and infant mortalities (Lantto et al., 2008). Major congenital malformations were present in 79 out of 1467 live born infants (5.6%) in a cohort study of Pakistani children over a 24 months period, and the morbidity as well as mortality rates during the follow up period were noted to be higher in low socio-economic class than in high and middle income classes (Gustavson, 2005). Similarly, in a study of birth defects in Ecuador, congenital malformations were present in 72.3/10,000 live births and was responsible for 1% of the overall crude death rate in the population (Gonzalez-Andrade and Lopez-Pulles, 2010).

The definitive cause of most congenital malformations remains unknown but many agents have been associated with increased occurrence of certain congenital malformations. These include maternal smoking, ingestion of certain drugs, exposure to radiation, and certain occupations, which involve interactions with chemicals (Hemminki et al., 1981; Sadler, 2003 & Stevenson and Hall, 2006).

2.2 Anorectal malformations

Anorectal malformations represent a spectrum of structural birth defects in which there is a partial or total absence of the anorectal canal leading to the absence of a mechanism to evacuate faeces to the exterior. The spectrum of malformations in boys includes anorectal malformations: with recto-perineal fistula, recto-bulbar urethral fistula, recto-prostatic urethral fistula, recto-bladder neck fistula and imperforate anus without fistula (Figure 1.1).

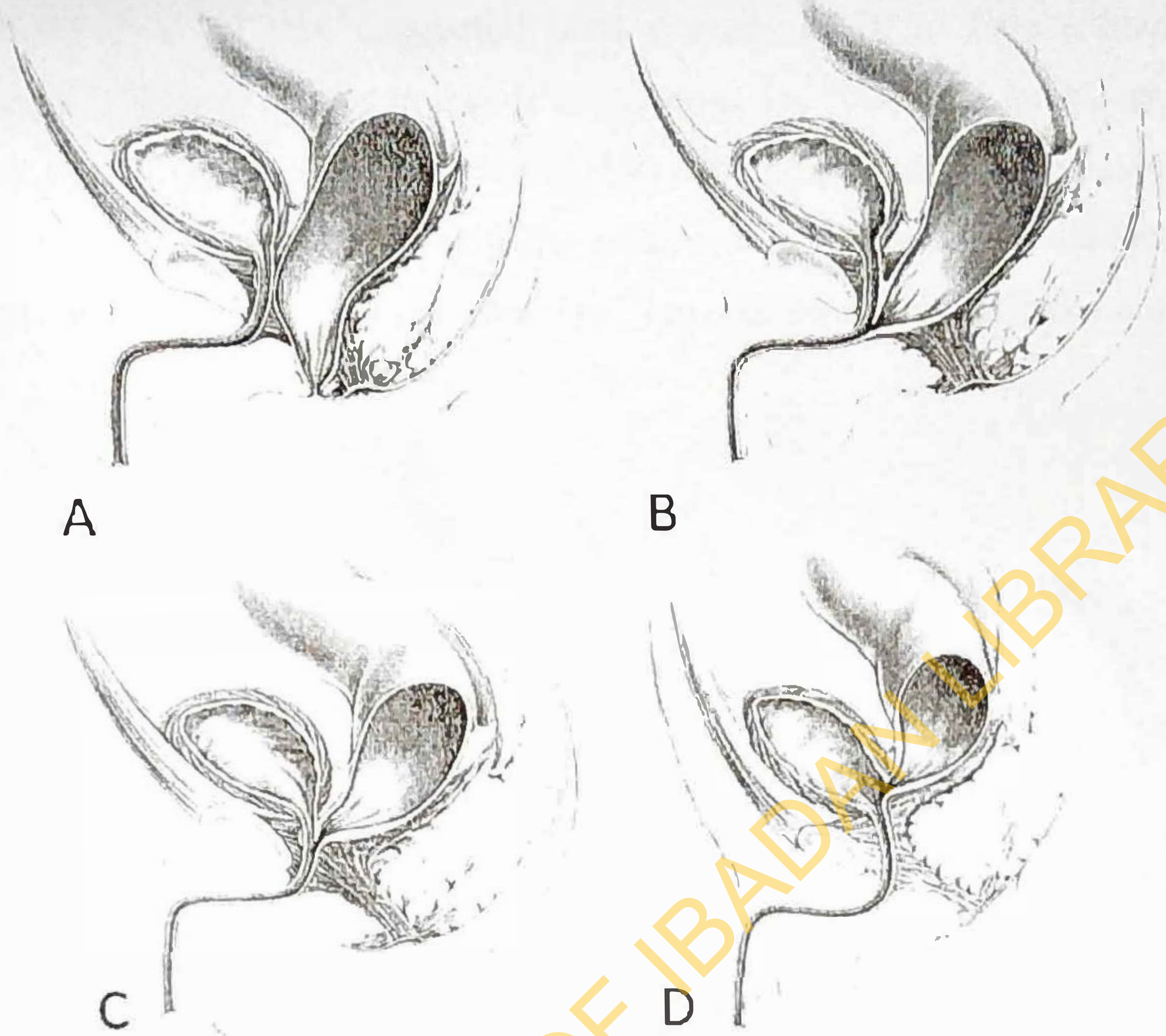


Figure 1.1. Spectrum of defects in males. ARM with: **(A)** Recto-perineal fistula. **(B)** Recto-bulbar urethral fistula. **(C)** Recto-prostatic urethral fistula. **(D)** Recto-bladder neck fistula (Courtesy Lawal et al, in press).

The anomalies seen in girls include: ARM with recto-perineal fistula, ARM with recto-vestibular fistula, ARM with recto-vaginal fistula, cloaca malformation and imperforate anus without fistula (Figure 1.2).

Girls may present with passage of stool from the vagina or vestibule, and in the most severe type of ARM in females, there may be just a single opening in the perineum into which opens, the rectum, the urethra and the vagina (Figure 1.3).

The malformations are usually obvious soon after birth or present as a result of failure to pass meconium within the first few hours of life. These anomalies are often associated with major life threatening anomalies (Peña and Levitt, 2005). Associated anomalies are present in 40 – 64% of children with anorectal malformations (Cuschieri, 2001 & Ratan et al., 2004). These include urinary tract malformations in 30 to 70% (Rich et al., 1988 &

Ratan et al., 2004), spinal and vertebral malformations in 8 to 40% (Boemers et al., 1999 & Ratan et al., 2004), congenital heart diseases in 10 to 20% (Ratan et al., 2004), tracheoesophageal fistulas in 6 to 10% (Ratan et al., 2004) and female reproductive tract anomalies in 8 to 30% (Ratan et al., 2004). The proportion of associated malformations tend to be higher in children with the rectal stump ending above the level of the pelvic diaphragm, and lower in those with "low" types of anorectal malformations.

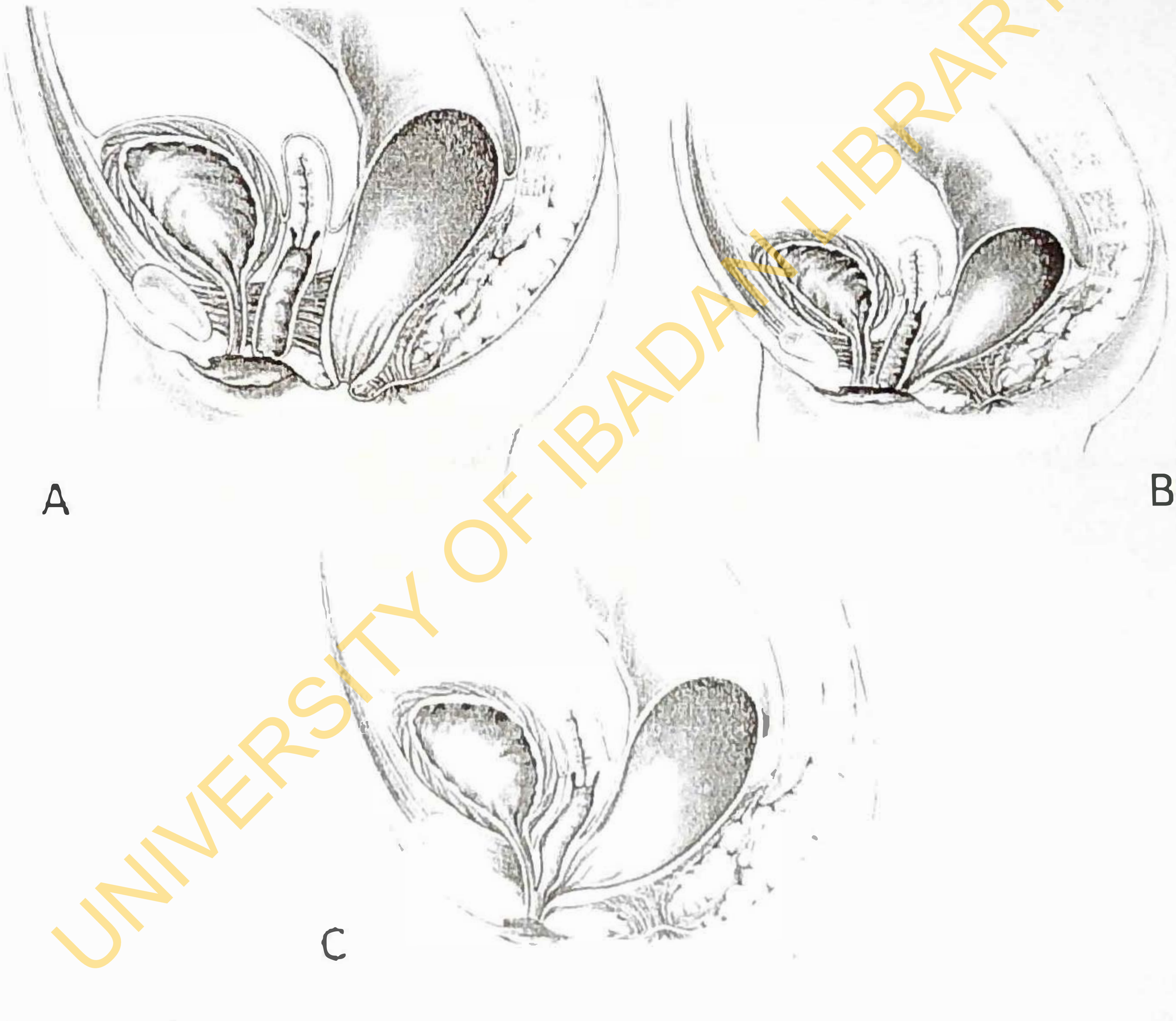


Figure 1.2. Spectrum of female defects. **(A)** Female Recto-perineal fistula. **(B)** Recto-vestibular fistula. **(C)** Cloaca (Courtesy Lawal et al. in press).

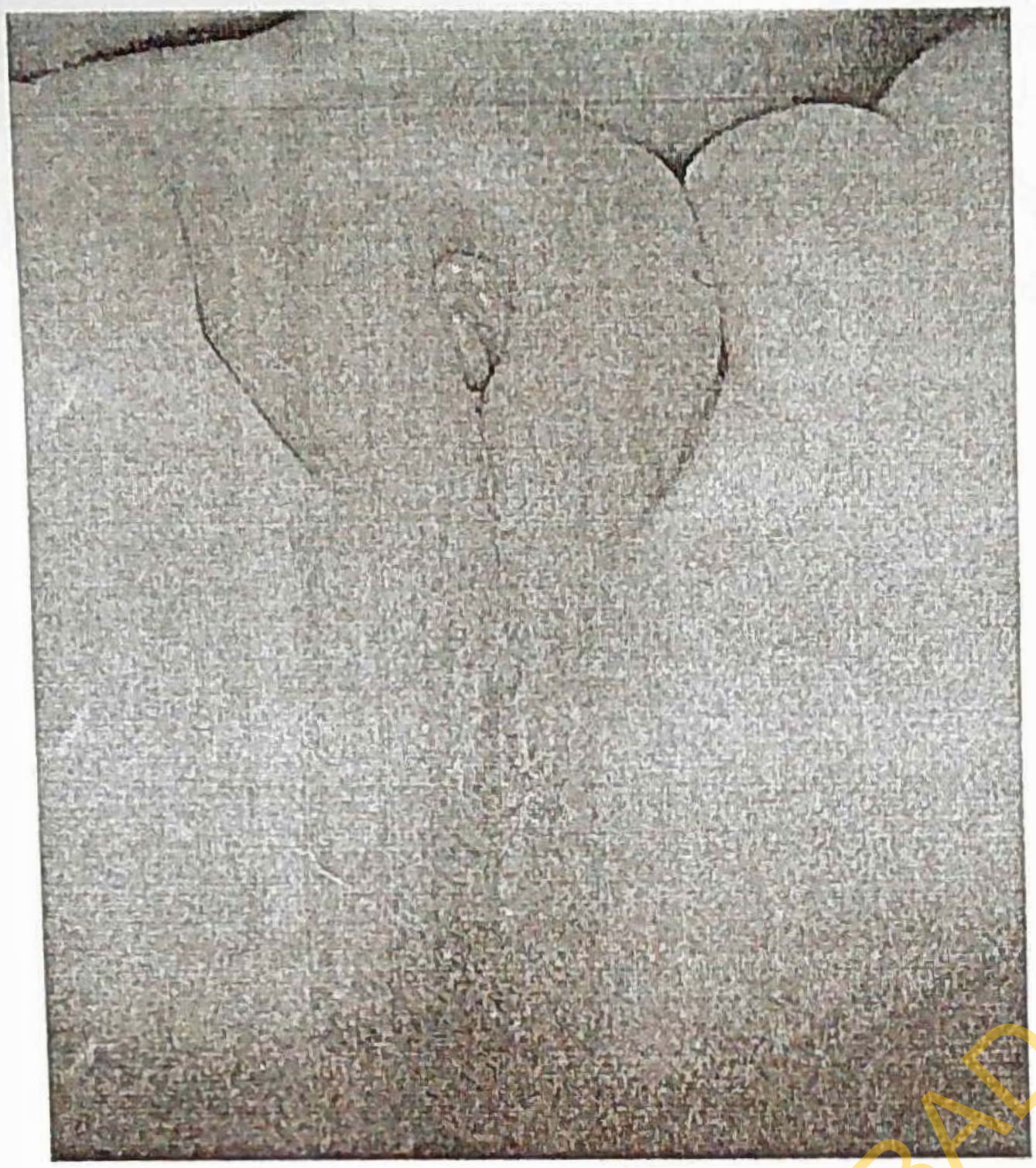


Figure 1.3. Newborn female with a single perineal opening (Cloaca malformation)

2.3 Delayed presentation in anorectal malformations

Delayed presentation or delay in diagnosis of anorectal malformations may, possibly, be due to many reasons, which include; false assurance of normal anus when the child passes meconium within the first day or two of life, inadequacy in the quality of neonatal physical examination conducted by the physicians or midwives, lack of awareness by parents of what constitutes normal and abnormal anus, rarity of certain types of ARM in which the anus appears "normal" on cursory inspection. None of these reasons, however, have been investigated as a possible cause of delay in presentation or diagnosis of ARM (Lindley et al., 2006).

Delayed presentation of patients with anorectal malformation is quite common in Africa. In a review of 104 patients admitted with ARM in Assiut, Egypt, over a period of three years, 20 (19.2%) presented after 48 hours of birth (Eltayeb, 2010). Similarly, in a retrospective evaluation of patients managed for anorectal malformations at the Ahmadu Bello University Teaching Hospital, Zaria, Nigeria over a 20 year period, the age at presentation ranged from 1 day to 9 years with a median of 8 years (Lukong et al., 2011)

Adejuyigbe and others (2004), likewise, in a review of 86 patients treated for ARM at the Obafemi Awolowo University Teaching Hospitals Complex, Ile-Ife, Nigeria, over a period of 17 years reported a median age at presentation of three days, with a range of 1 day to 15 years. Nearly 85% of the patients in that series presented after 24 hours of birth leading to a high mortality of 30%.

The problem of delayed presentation of these patients appears not to be limited to the developing countries. Twenty-one percent of 99 patients with ARM treated at Our Lady's Hospital for Sick Children and the Children's University Hospital in Dublin, Ireland, over a ten year period presented after 48 hours of birth with the malformation (Turowski et al., 2010). In that study, the patients who presented late were seen 3 to 43 days after birth with ARM. Similarly, in a retrospective review of 75 children who were treated for anorectal malformations over a 10 year period at the Alder Hey Children's Hospital in Liverpool, England, a delayed diagnosis was made in 31 patients (42%) – delayed diagnosis was considered to be one made 24 hours or more after birth (Lindley et al., 2006). Children who were diagnosed late in that study presented between two and 16 days of age and in many of the patients, there was no visible anus, yet the diagnosis was not made until quite late (Lindley et al., 2006). In addition, there were significantly more complications in the delayed diagnosis group compared to the group that was diagnosed early [10 of 31 versus 5 of 44], although there were no statistically significant differences between the groups comparing the type of lesion, presence or absence of perineal opening and the presence of associated malformations (Lindley et al., 2006).

2.4 Newborn screening

Screening is the presumptive identification of unrecognised disease or defect by the application of clinical examinations, laboratory tests or other procedures, which can be rapidly applied (National Health and Medical Research Council NHMRC, 2002). It can either be population based involving the entire population or targeted (pro-active) screening that aims to identify members of an "at risk" population. Screening of children for congenital malformations and other birth defects, ideally, commences in the new born period. The basic principle of newborn screening is hinged on the presence of a clinical

examination or diagnostic test that is feasible, readily available, affordable, beneficial to the child and his/her family as well as the society, and is cost effective (AAP, 2000).

Based on the approach used, screening programmes are grouped into four categories: biochemical screening such as for phenylketonuria, hypothyroidism, sickle cell anaemia; screening involving objective measurements such as hearing and vision screening; screening involving physical examinations such as congenital hip dislocation, congenital heart disease, anorectal malformations and; screening involving an understanding of child development such as motor disorders and autism (Hall and Stewart-Brown, 1998). The technique of physical examination is best suitable for congenital malformations that may be gross and visible even to the untrained eye, e.g. cleft lips, limb defects such as amelia, phocomelia or hidden and only recognised when sought for e.g. congenital heart diseases, congenital dislocation of the hips, anorectal malformations, Hirschsprung disease etc.

The history of screening dates back to the discovery of the genetic basis of phenylketonuria by Asbjörn Fölling in 1934 (Penrose and Quastel, 1936) and development of a protocol for the screening of newborn children for phenylketonuria by Robert Guthrie in the 1960s (Guthrie and Susi, 1963). Many states and countries subsequently passed legislations governing frameworks for the screening of newborn children (Kallen, 1989). The protocol of screening, the procedure, technique of consenting, information dissemination as well as the legal framework varies from one state to another and across different nations (Kallen, 1989, Kim et al., 2003, Hoffman and Laessig, 2003, Fant et al., 2005 & Davis et al., 2006). Screening may detect as many as one inherited metabolic, endocrine and haematologic disorder in 500 to 1000 newborn American children (Green et al., 2006). The major benefit of newborn screening is the reductions in neonatal and infant morbidity and mortality through early detection of rare diseases and early treatment (Fant et al., 2005). It has also led to saved health care costs of billions of dollars in the U.S.A. because the early detection and prompt treatment reduces the disabilities and debilities associated with delayed diagnosis (Hoffman and Laessig, 2003).

However, in the last decades of the second millennium, many public health systems faced major developments, which included keeping up with recent advances in testing technology, responding to emergent infections, combating the resurgence of old diseases

such as tuberculosis, control of immigration and cross-border infection, curtailing the HIV/AIDS pandemic and surviving in the face of budgetary cuts (AAP, 2000). These led the American Academy of Pediatrics to set up a task force in 1999 to review the system of newborn screening with a view to making appropriate recommendations to overhaul the system and addressing the variability amongst different programmes (AAP, 2000 & AAP, 2010).

The recommendations addressed aspects that are crucial to the maintenance of an effective newborn screening programme in view of challenges posed by recent advances in maternal and child care, genetics and embryology, and improvement in advocacy and considerations of ethical and medico-legal issues. These crucial areas are: newborn screening public health infrastructures, role of the family, role of professionals, oversight of newborn screening systems, research, surveillance and funding (AAP, 2000 & Lloyd-Puryear et al., 2006). Major recommendations included better definition of the role of the family in the process of newborn screening, greater involvement of the parents and ensuring adequacy of information made available to them prior to the screening (AAP, 2000 & Lloyd-Puryear et al., 2006).

2.5 Parents and screening for congenital malformations

2.5.1 Role of parents in screening for malformations

The role of family members in the screening of newborn children has been recognised to be important for the success of any newborn screening programme (Arnold et al., 2006 & Kai et al., 2009). The American Academy of Pediatrics, in recognition of this role, has recommended the education of parents as one of the priority areas to be improved upon to ensure optimal output from screening protocols (AAP, 2000). Despite this, there is no clear definition of the quality and quantity of information, manner of transmitting the information to parents, and bearer of responsibility in more than 50% of surveyed screening programmes in the United States of America (Kim et al., 2003). Kim and others (2003), in their study of "the communication practices between state newborn screening programs" subsequently advised that a harmonious relationship be clearly defined between parents, primary care physicians and concerned health care professionals to ensure a better education of parents on the screening of newborns.

2.5.2 Awareness of screening for birth defects

There often is a wide gap in the knowledge of parents about different types of congenital defects that are detectable by screening. In a study of 388 American mothers, resident in Chicago, Illinois, concerning their knowledge and attitude about screening for sickle cell disease (SCD) and cystic fibrosis (CF), whereas 96% were aware of SCD, only 33% were aware of CF, despite similarities in the inheritance pattern of the two conditions (Lang et al., 2009). Similarly, the mean knowledge scores in those who are moderately or very familiar with the disorders were significantly higher than in those who are less familiar with SCD and CF (Lang et al., 2009). In that study, a higher knowledge base of SCD or CF was associated with: being 27 years or older; being married; having a college degree; having private health insurance; and being non-African American.

In a study conducted on 350 Greek women who had at least one child, previously, 181 (51.7%) had adequate knowledge of prenatal diagnosis and only 70 (20%) knew that ultrasound scan could be used for the diagnosis (Mavrou et al., 1998). Zahed et al. (1999) in a study of 90 Lebanese couples at risk for congenital malformations, specifically chromosomal and genetic disorders, reported that 22 couples (24%) were aware of the existence of screening tests for the conditions despite being at high risk, because of consanguinity. Conversely, 65% of 345 adults attending the outpatient department of a privately owned tertiary hospital in Karachi, Pakistan were aware of prenatal screening with 80% of them mentioning ultrasound scan as the only method of screening that they know (Arif et al., 2008). In that study, 23.5% of the respondents were aware of amniocentesis.

Although women while attending antenatal clinics may be aware of the importance of ultrasound scanning, this does not necessarily translate to knowledge of prenatal screening or birth defect. Chan et al. (2008) in a study of 285 pregnant women of Chinese origin reported that even though 90% reported that they understood the purpose of the ultrasound examination, only 34% could provide the correct answer about the role of ultrasound scanning in prenatal diagnosis.

2.5.3 Educating parents about screening for congenital malformations

The education of parents involves using a combination of oral, audiovisual and educational materials to enhance the assimilation of information and proper integration of the received message, to ascertain an acceptable level of understanding of the reasons for screening, the types of examination or testing to be done, the possible results, need for further testing and management of the detected congenital malformation.

There are numerous educational materials available for parents to read or view on newborn screening in some parts of the world (Huang et al., 2005 & Kai et al., 2009). Posters, pamphlets and brochures are the most widely used for educational purposes, stating the need, timing, technique of screening and the possibilities obtainable (Huang et al., 2005). Posters are pasted in clinics, maternity centres and hospital corridors, and brochures as well as pamphlets are given to would be mothers and women attending antenatal clinics or those on admission during labour. However, over 80% of these brochures contain a large amount of information that is not familiar to most mothers, especially new mothers (Arnold et al., 2006). Over half of these brochures: use inappropriate fronts, inappropriate illustrations, are not focused in message delivery, contain material above the average reading level for adults and large amount of non-specific information (Fant et al., 2005 & Arnold et al., 2006).

Although 50 of 51 states/territories (including Puerto Rico) in the USA have standardized written educational materials, for families, on newborn screening (Fant et al., 2005), parents have been found to have relatively little knowledge about the process and almost none of 51 parents in a focus group were familiar with the term "newborn screening" (Davis et al., 2006). Even though many of the parents in that group were given newborn screening brochure during their peri-partum stay in hospital, very few either read or remembered the information contained therein (Davis et al., 2006). Almost all the parents concluded that the best form of information dissemination on screening should be by a combination of brochures and an accompanying oral education, to be administered and conducted respectively during the third trimester (Davis et al., 2006).

2.5.4 Sources of information about birth defects

The major avenues through which information about birth defects are obtained by mothers include; from physicians and other health workers, from the media, from friends and from family members. Mavrou et al. (1998) found that the sources of information about birth defects according to Greek mothers are; the doctor and mass media (39.4%), doctors only (3.4%), mass media only (1.7%), abnormal family member or friend (1.5%) and others (5.7%). Bener et al. (2006) in a survey of 1480 antenatal clinic attendees in Qatar focusing on their knowledge, attitude and practices on folic acid supplementation to prevent birth defects reported that the majority (63.4%) – of those who had ever heard about folic acid – got their information about folic acid from physicians. In that study, the other sources of information about the usefulness of folic acid to prevent birth defects were; print media (21.7%), pregnancy related books (21.2%), nurses (18.6%), pharmacists (12.3%), family/friend (10.6%) and TV/radio (9.3%).

2.5.5 Factors influencing awareness of birth defects by parents

Mavrou et al. (1998) while studying 350 Greek women reported that greater awareness and better knowledge of congenital malformations were associated with: older age, better education, higher family income, and residing in cosmopolitan environment. The authors in that study noted that 61% of women aged 35 years and above had adequate knowledge of birth defects compared to 30% of women aged 18 to 24 years. In addition, 73% of those in the upper socio-economic class had adequate knowledge of the malformations whereas 29% of the women in the lower socio-economic class had similar knowledge. Furthermore, there was a 73% increase in knowledge of birth defects for every three years of additional education by the women in that study. In a study conducted in Australia on 200 mothers with new born babies who had just undergone post natal screening, it was reported that 43.5% had ever (truly) heard about genetic diseases, 24.5% knew what "carrier" meant, 30% knew about genetic screening while only 3.5% knew that the test they came for was actually to detect Phenylketonuria (Suriadi et al., 2004). In that study, multivariate analysis showed that ethnic background, English as first language, level of education and knowledge of having a genetic condition in the family were significant independent predictors of high level of knowledge of birth defects.

2.5.6 Factors influencing acceptance of screening by parents

The acceptance of a specific screening test by parents is influenced in large part by the amount of information given to the parents during the counselling session, socio-cultural factors, educational background, and religious beliefs (Zahed 1999). Li et al. (2008) in a study comparing women who accepted to undergo prenatal screening tests and those who declined in California, USA found that women who accepted the tests were more likely to; have discussed the tests with their friends and family members, and rate the information provided by health care workers during counselling as useful. The major hindrance to accepting prenatal screening in that study was scepticism and distrust of the usefulness and accuracy of the screening test results (Li et al., 2008).

In a study evaluating factors affecting acceptability of screening tests in a high risk Lebanese population, educational level and socio-economic status were found to be important variables while religious belief was not a significant influence (Zahed et al., 1999). In that study, 85% of the respondents with high level of education accepted screening compared to 51% of those with a low level of education. Additionally, 72% of the participants in that study who were of a high socio-economic status accepted prenatal screening whereas 49% of those from a low socio-economic class were willing to accept the tests.

The less than optimal acceptance of screening for birth defects is not restricted to countries without formal screening programmes alone. Rostant et al. (2003) in a survey of 633 Australian women conducted one month after childbirth, in a country where routine screening in recommended for all pregnant women, found that as many as 21% either did not have a screening done or were not sure if that was done where they had antenatal care. In that study, 24% and 50% had never heard about maternal serum screening or chorionic villus sampling respectively. The authors, in a principal component analysis showed that three factors in the questionnaire contributed the most to acceptable knowledge scores, adequacy of information, overall value of the test and confidence in the test results (Rostant et al., 2003).

2.5.7 Awareness of mothers about prevention of certain birth defects

The role of folic acid in the prevention of neural tube defects has been extensively studied as this has been found to be cost effective with reproducible therapeutic outcomes. Daily consumption of 400 micrograms of folic acid at least one month before conception and through the first trimester of pregnancy has been shown to prevent the occurrence and recurrence of neural tube defects (Wu et al., 2007).

In spite of the benefits, studies have shown great variations in knowledge and awareness of the role of folic acid supplementation by women of reproductive age group. Wu et al. (2007) in a survey of 508 women conducted in Honduras showed that 277 (55%) did not have any knowledge of folic acid supplementation. Women who were aware of the usefulness of folic acid to prevent birth defects in that study were likely to be in their twenties, have two prior pregnancies and have at least a seventh grade level of education. In a similar study carried out in Beijing, China, 248 (35.8%) out of 693 women had ever heard of folic acid – with 205 (29.6%) participants aware that folic acid is taken to prevent neural tube defects (Ren et al., 2006). Bener et al. (2006) likewise reported that 54% of 1480 Qatari women attending antenatal clinics had ever heard about folic acid. In that study, only 14% knew that folic acid was given to prevent birth defects. Furthermore, logistic regression analysis showed that women who had high school or university level of education were 4 and 8 times more likely than illiterate mothers to know about the use of folic acid to prevent birth defects (OR: 2.59 – 5.65 and 5.65 – 12.53 respectively).

2.6 Role of health-care professionals in the screening process

Health care providers are important for the success of any programme aimed at the early detection of diseases and anomalies, and are therefore the bedrock of most screening protocols. They are involved in the preparatory phase for the screening, the actual screening and examination as well as being available to offer counselling based on the outcome of such screening (Hayeems et al., 2009 & Kai et al., 2009). In addition, some of the health care providers will continue the management of the newborn that has been detected to have a congenital malformation.

The different groups of health care workers involved in the screening and early detection of diseases often exhibit variations in the amount and depth of information that they have.

or give out to parents. These include nurses, midwives, obstetricians, paediatricians, paediatric surgeons and general practitioners. Nurses and midwives have been shown to be most likely to perceive a professional responsibility to informing parents whereas obstetricians are the least likely to do so (Hayeems et al., 2009). Even though physicians agree that newborn screening should be mandatory, majority rarely or never had discussions with parents about such screening, and the reasons they give are insufficient time, inadequate compensation, not being up to date on the conditions being screened and (Hayeems et al., 2009).

Davis et al, in a focus group study of 78 health care providers on awareness of parents about newborn screening, found that even though all the health care providers were aware that parents received information brochure on screening, none was surprised that parents were told very little (verbally) and many assumed that the parents were just not interested in learning more (Davis et al., 2006). None of the 54 physicians in that group was aware of what the nurses and midwives tell the families about the process of screening and none had ever read the brochure provided by the state agency in charge of newborn screening (Davis et al., 2006). Even when these educational materials are made available, the oral explanation by physicians is often found wanting as they use jargon words and medical terminologies that many of the parents are unfamiliar with and subsequent explanations prolong this educational experience (Farrell et al., 2008). Other sources of miscommunication that been reported are non-directive nature of counselling, cultural insensitivity, problems of translation and problems related to trust (Browner et al., 2003).

2.7 Newborn physical examination

Certain congenital malformations that can be detected by physical examination, often do not have well detailed formal screening programmes (Liske et al., 2006). The routine physical examination of such malformations e.g. congenital heart diseases and anorectal malformations is considered to form a critical part of newborn screening (Knowles et al., 2005). For example, the presence of congenital heart defect is assessed during the initial newborn physical examination, and if indicated, a repeat examination carried out at 6 – 8 weeks of life (Knowles et al., 2005). The newborn physical examination, if carried out as it ought to be done, should be able to detect almost all types of anorectal malformations.

Thus, the American Academy of Pediatrics has developed guidelines for the routine examination of every newborn child within one hour of delivery (AAP, 2004 & AAP, 2010).

CHAPTER 3
METHODOLOGY

3.1 Study design

This was a descriptive cross-sectional study conducted between May and July, 2012

3.2 Study site

The study was carried out at the University College Hospital, Ibadan and Adeoyo Maternity Hospital, Yemetu, Ibadan. Ibadan is the largest city in Sub-Saharan Africa, with a land mass covering 3,123 square kilometres and a population of 2,550,593.

The University College Hospital, Ibadan, is an 800 bedded federal government funded hospital with specialists in over 50 different clinical departments and institutes, providing the major source of referral for the care of major debilitating diseases such as congenital malformations in the South-Western part of Nigeria. The Immunisation Unit of the University College Hospital, located at the General Out-patients' Department of the hospital is the major centre catering for the administration of vaccines to children between the ages of 1 day to 5 years. The routine (National Programme on Immunisation recommended) immunisation of children under-5 years takes place on Wednesdays and Thursdays each week.

The Adeoyo Maternity Hospital (AMH) is one of the oldest hospitals for maternal care in Nigeria. It served, in the past, as the temporary site of the University College Hospital, Ibadan. The AMH, owned by the state government, is a general hospital with a bias towards maternal and child care. It caters for the teaming population of Ibadan city; with a large proportion from lower socioeconomic groups. The hospital has an immunisation unit that is under a Chief Nursing Officer and routine vaccines are administered on Mondays, Tuesdays and Fridays.

3.3 Target population

Women in the reproductive age group with newborn children

3.4 Study population

Women presenting at the immunisation units affiliated to the University College Hospital, Ibadan and Adeoyo Maternity Hospital, Ibadan. The two hospitals were selected to have a mix from the various socioeconomic groups in the city.

3.5 Sample size determination

The sample size was calculated using the formula $n = \frac{Z\alpha^2\, p\, q}{d^2}$

Where: n is the sample size

α is the level of significance = 5%

$Z\alpha = 1.96$

p is prevalence

q = 1-p

d is how much deviation that will be important clinically, d = 5%

Prevalence (of awareness of parents about metabolic congenital anomalies from previous study – Lang et al , 2000) = 33%

$$n = \frac{(1.96)^2\, 0.33(1-0.33)}{(0.05)(0.05)}$$

$$= 340$$

Thus minimum sample size = 340 mothers

A total of 170 mothers were scheduled to be recruited from the University College Hospital and 170 mothers from the Adeoyo Maternity Hospital, Ibadan.

3.6 Sampling technique

Consecutive mothers presenting at the immunisation clinics of the General Out-Patients Department (UCH) and Adeoyo Maternity Hospital and who gave their consents were recruited until the required sample was obtained.

3.7 Selection criteria

Inclusion criterion

Mothers, with children under 12 months, who gave their consent, were included in the study.

Exclusion criterion

Mothers who came for immunisation of children older than 12 months of age

3.8 Data collection procedure

Data was collected with the use of interviewer administered questionnaires (Appendix I). Data was collected by the investigator on: socio-demographic data such as mother's age, occupation, marital status, level of education, religion, number of children in the family and other related questions.

The mother's age was dichotomised according to the mean, for cross tabulation. Occupation was recorded and classified into classes I, II and III (Esan et al, 2004). Marital status was recorded as single, married or separated.

The highest level of education was dichotomised into those with secondary education or less and those with post secondary education (NCE, polytechnic or university education).

Gravidity and parity were obtained by asking about the number of pregnancies till date and number of children till date respectively. For the purpose of cross tabulation, gravidity was categorised into those who were primigravida (only one pregnancy so far) and those with more than one pregnancy (multigravida). Parity was dichotomised according to the mean number of children.

The participants were asked about antenatal details of the (last) pregnancy; whether they attended antenatal clinic for the pregnancy that resulted in the child birth or not – recorded as Yes or No. They were also asked for the location of the antenatal clinic that they attended. For the purpose of analysis, the location of antenatal care was dichotomised into; tertiary hospital and other hospitals (to include general hospitals, PHC centres and private clinics).

The utilization of ultrasound scanning during the pregnancy was assessed by; number of scans performed, if they were told the findings and what the findings were.

The mothers' awareness/knowledge of birth defects and anorectal malformations were assessed using a combination of open and closed ended questions. They were asked if they were aware of birth defects; if the defects could be prevented, detected, inherited or treated; and if they knew that folic acid supplementation could be used to prevent certain birth defects. A congenital malformation awareness score (CMAS) was created using the responses from these five questions (Questions 26 – 30 in the questionnaire); a "Yes" attracted a score of 1 while "I don't know" and "No" led to a score of 0 (i.e. a minimum score of 0 and a maximum score of 5). The CMAS was then dichotomised into those with a score of 1 or higher and those with a score of zero (0). Details of the newborn examination were asked; time it was done and if findings were communicated to the mother.

The mothers were shown three pictures of the perineum of babies; one of a girl with anorectal malformation (and recto-perineal fistula), another of a boy with anorectal malformation (and recto-perineal fistula) and a third picture of a girl with a normal perineum. The number of pictures correctly identified were recorded and dichotomised into those who identified at least one picture correctly and those who could not identify any of the pictures correctly, for the purpose of cross tabulation.

The babies, who were brought for immunisation, were examined at the end of the interview to exclude anorectal malformations.

A pre-test was done by administering the questionnaire to 20 mothers who presented to the Paediatric Surgery Clinic of the UCH, Ibadan to circumcise their sons to ascertain the comprehensibility of the questionnaire and the ease of administration.

The questionnaire was translated into Yoruba language and back translated into English language to confirm comprehensibility and retention of intended questions.

3.9 Data management and analysis

Data collected were collated, computed and subjected to statistical analysis using SPSS version 19. Results were presented using tables and charts.

Categorical data were summarised by frequencies, percentages and proportions, while continuous data were summarised using means, standard deviations, medians and ranges. Tests for association between socio-demographic variables and awareness of birth defects

and anorectal malformations were done using Chi-square statistics. Further bivariate analysis was done between awareness of birth defects and awareness of anorectal malformations and; the number of children (previous boys and girls), number of previous pregnancies, number of months of pregnancy when the mother registered for antenatal care, location of antenatal care, the CMAS and the number of pictures correctly identified as depicting normal anal location using Chi-square statistics. Significant variables (at a p-value of 0.2) in the bivariate analysis were entered into a multivariate model to identify likely predictors of awareness of birth defects/anorectal malformations. All the variables were taken in a single step for the logistic regression.

3.10 Ethical considerations

3.10.1 Statement of confidentiality

No personal identifiers such as name was used in the questionnaire such that the answers could be linked back to their source i.e. confidentiality of all responses given was maintained. Data were coded into a computer that was password protected and encrypted with McAfee antitheft software program to ensure maximal confidentiality.

3.10.2 Beneficence to participants

After completion of each interview, health talk was given so as to correct wrong impressions on birth defects and anorectal malformations. Advice was also given on how to prevent birth defects. Babies with anorectal malformations that were detected during the interview were referred to the appropriate specialist and followed up.

3.10.3 Non maleficence

Mothers who were not willing to participate did not suffer any discrimination with immunisation of their wards; neither did they suffer harm or loss.

3.10.4 Ethical approval

Ethical approval was obtained from the joint University of Ibadan/University College Hospital Ethical Committee (Appendix II).

3.10.5 Approval and consent from participants

Assent was obtained from the Head of Department, UCH Immunisation Clinic and the Chief Medical Superintendent, Adeoyo Maternity Hospital, Yemetu, Ibadan. Informed consent was obtained from each participant before the interview (Appendix III).

CHAPTER 4

RESULTS

4.1 Socio-demographic characteristics of the study population

A total of 365 mothers participated in the study, comprising of 181 (49.6%) mothers recruited at the GOPD Immunisation Unit of the University College Hospital, Ibadan and 184 (50.4%) from the Immunisation Unit of the Adeoyo Maternity Hospital, Ibadan.

The participants were aged 17 to 42 years with a mean of 29.5 (± 5.1) years. The majority (359, 98.4%) was married and the rest (6, 1.6%) were single. A total of 192 (52.6%) participants were Christians and 173 (47.4%) were Muslims.

The majority (222, 60.8%) of the respondents were unskilled workers, the others being skilled workers (107, 29.3%) and dependants (36, 9.9%).

Table 4.1 shows that 47.9% of the mothers had a secondary school level of education or less and 52.1% had post secondary education.

Table 4.1 – Highest level of education attained by the study participants

Level of education	Number (%)
None	2 (0.5)
Primary	40 (11.0)
Secondary	133 (36.4)
NCE	21 (5.8)
Polytechnic	70 (19.2)
University	99 (27.1)
Total	**365 (100.0)**

NCE – National Certificate of Education

4.2 Obstetric characteristics of the study participants

4.2.1 Gravidity and parity of the study participants

The participants have had between 1 and 7 pregnancies with a mean of 2.3 (± 1.2) pregnancies. They have had 1 to 6 children with a mean of 2.2 (± 1.2) children. The majority (233, 63.8%) has had two or more children and 132 (36.2%) just had their first child.

The index children (for immunisation) were aged between 3 days and 11 months, mean of 2.5 (± 2.9) months. A total of 190 (52.1%) of the children for immunisation were boys and 175 (47.9%) were girls.

4.2.2 Antenatal care details of the (last) pregnancy

The majority (363, 99.5%) of respondents had antenatal care for the index pregnancy while 2 (0.5%) did not receive any form of antenatal care. The distribution of the location of the antenatal care is as shown in Table 4.2.

Table 4.2 – Location where antenatal care was received by the respondents

Location	Number (%)
Tertiary hospital	131 (35.9)
General hospital	168 (46.0)
Primary Health Care Centre	7 (1.9)
Private clinic	41 (11.2)
Mission homes	15 (4.1)
Traditional birth attendant	1 (0.3)
None received	2 (0.5)
Total	365 (100.0)

The participants registered for antenatal care between the 1st and 8th months of pregnancy with a mean gestational age at registration of 4.7 (± 1.5) months (Figure 4.1).

Figure 4.1 – The gestational age at registration for antenatal care (N = 363)

4.3 Awareness about birth defects and anorectal malformations

4.3.1 Awareness of the participants about birth defects

The majority (234, 64.1%) of the respondents was not aware of birth defects while 131 (35.9%) were aware of birth defects. Examples of birth defects given by those who were aware of these anomalies included; Central Nervous System malformations e.g. hydrocephalus and spina bifida, limb anomalies e.g. amelia, congenital talipes equinovarus deformity, congenital heart diseases, craniofacial malformations e.g. cleft lip and palate, choanal atresia and anorectal malformations.

Table 4.3 shows where the respondents first heard about birth defects.

Table 4.3 – First source of information about birth defects among the respondents

Source	Number (%)
From Doctor/Nurse	27 (20.6)
From posters in hospitals	6 (4.6)
From mass media	47 (35.9)
From internet	1 (0.8)
From friends	13 (9.9)
From books	16 (12.2)
Could not remember	21 (16.0)
Total	**131 (100.0)**

4.3.2 Knowledge of the participants about birth defects

Among the study participants; 68 (18.6%) mothers knew that birth defects could be prevented, 46 (12.6%) knew that they could be inherited, 69 (18.9%) knew that birth defects could be treated, 46 (12.6%) knew that birth defects could be prevented using folic acid and 60 (16.4%) knew that certain tests could be used to assist in prenatal diagnosis of these defects. The congenital malformation awareness score (CMAS) developed from the five preceding responses ranged from 0 to 5. The majority (284, 77.8%) had a score of 0, while 81 (22.2%) had a score of 1 or higher (Table 4.4).

Table 4.4 – Congenital malformation awareness score (CMAS) of the participants

CMA Score	Number (%)
0	284 (77.8)
1	6 (1.6)
2	10 (2.7)
3	21 (5.8)
4	20 (5.5)
5	24 (6.6)
Total	**365 (100.0)**

4.3.3 Awareness of the participants about anorectal malformations

The majority (294, 80.5%) was not aware that a child could have an anorectal malformation while 71 (19.5%) mothers were aware of anorectal malformations. A total of 29 (7.9%) and 27 (7.4%) mothers were aware of ARM with recto-urethral fistulas or ARM with recto-vestibular fistulas respectively.

The picture of a girl with anorectal malformation and recto-perineal fistula was correctly identified by 66 (18.1%) respondents and that of a boy with a similar malformation was correctly identified by 71 (19.5%) respondents. The total number of pictures (of three) that was/were correctly identified is as shown in Table 4.5.

Table 4.5 – Total number of pictures of the perineum (out of three) correctly identified by the respondents

Number of picture(s) correct identified	Number of respondents (%)
0 (None)	175 (47.9)
1	118 (32.3)
2	34 (9.3)
3	38 (10.4)
Total	**365 (100.0)**

4.4 Antenatal care visits and counselling about birth defects

Each of the mothers had between 0 and 6 ultrasound scans performed during the (last) pregnancy, median of 2. The majority (338, 92.6%) was informed of the findings by the sonographer who performed the ultrasound scan examination. A total of 305 (83.6%) were, in addition, informed by their obstetrician/midwife of the details of the ultrasound scan while 58 (15.9%) were not informed by their health care giver on presentation of the result to him/her.

Twenty-one (5.8%) mothers received information about birth defects during the antenatal care visits in the last pregnancy; with a nurse/midwife being the source of the information to 13 (61.9%) mothers, a doctor to 5 (23.8%) and another health care worker to 3 (14.3%).

The majority (357, 97.8%) did not use folic acid before they knew they were pregnant. Only eight (2.2%) respondents used folic acid pre-conception, of which six thought that it was for the prevention of anaemia and two knew that it was for the prevention of neural tube defects. The pre-conception folic acid was self prescribed by seven of eight women; the last had a pharmacist prescribe the medication to her.

4.5 Comparison of participants from the two study sites

4.5.1 Comparison of socio-demographic characteristics of participants from the two study sites

A higher proportion of the participants from Adeoyo Maternity Hospital (AMH) were 30 years or younger compared to those recruited at the UCH, Ibadan of the same age group (72.8% vs. 50.3%, $p < 0.001$). A higher proportion of the respondents from UCH were Christians compared to those from AMH (70.7% vs. 34.8%, $p < 0.001$). The proportion of participants from UCH who had a post secondary level of education (82.9%) was higher than that of the participants from AMH with a similar level of education (21.7%), ($p < 0.001$). Majority of the participants from AMH were unskilled workers compared to their counterparts recruited at UCH (85.3% vs. 35.9%, $p < 0.001$). The participants from the two sites were not significantly different in terms of their marital status ($p>0.05$). (Table 4.6).

Table 4.6 – Comparison of socio-demographic characteristics of the participants from the two study sites

	Study sites				
Socio-demographic characteristic	**UCH** No (%)**	**AMH** No (%)**	**Total** No (%)**	χ^2	**p value**
Age (years)					
≤ 30	91 (50.3)	134 (72.8)	225 (61.6)	19.623	**<0.001***
> 30	90 (49.7)	50 (27.2)	140 (38.4)		
Total	181 (100.0)	184 (100.0)	365 (100.0)		
Marital status					
Single	1 (0.6)	5 (2.7)	6 (1.6)	2.645	0.104
Married	180 (99.4)	179 (97.3)	359 (98.4)		
Total	181 (100.0)	184 (100.0)	365 (100.0)		
Religion					
Christianity	128 (70.7)	64 (34.8)	192 (52.6)	47.260	**<0.001***
Islam	53 (29.3)	120 (65.2)	173 (47.4)		
Total	181 (100.0)	184 (100.0)	365 (100.0)		
Educational status					
Secondary or lower	31 (17.1)	144 (78.3)	175 (47.9)	136.634	**<0.001***
Post-secondary or >	150 (82.9)	40 (21.7)	190 (52.1)		
Total	181 (100.0)	184 (100.0)	365 (100.0)		
Occupational class					
1 – Skilled	90 (49.7)	17 (9.2)	107 (29.3)	95.023	**<0.001***
2 – Unskilled	65 (35.9)	157 (85.3)	222 (60.8)		
3 – Dependant	26 (14.4)	10 (5.4)	36 (9.9)		
Total	181 (100.0)	184 (100.0)	365 (100.0)		

* - Statistically significant, ** - Column percentages presented, χ^2 – Chi square

4.5.2 Comparison of maternal obstetric characteristics of participants from the two study sites

The proportion of respondents recruited at UCH who were primigravida, i.e. had only one pregnancy so far (42.0%) was higher than the proportion of respondents from AMH who were primigravida (30.4%) ($p = 0.022$). Comparatively, a higher proportion of the participants from AMH booked for antenatal care at 5 months or later in pregnancy than the participants from UCH who booked for antenatal care at a similar gestational age (72.0% vs. 37.6%, $p < 0.001$). The participants from both study sites were not significantly different in terms of their parity (Table 4.7).

Table 4.7 – Comparison of maternal obstetric characteristics of the participants from the two study sites

	Study sites				
Characteristic	**UCH**	**AMH**	**Total**	**χ^2**	**p value**
	No (%)**	**No (%)****	**No (%)****		
Gravidity					
Primigravida	76 (42.0)	56 (30.4)	132 (36.2)	5.276	**0.022***
Multigravida	105 (58.0)	128 (69.6)	233 (63.8)		
Total	181 (100.0)	184 (100.0)	365 (100.0)		
Number of children					
≤ 2	126 (69.6)	113 (61.4)	239 (65.5)	2.714	0.099
≥ 3	55 (30.4)	71 (38.6)	126 (34.5)		
Total	181 (100.0)	184 (100.0)	365 (100.0)		
GA at booking					
< 5 months	113 (62.4)	51 (28.0)	164 (45.2)	43.381	**<0.001***
≥ 5 months	68 (37.6)	131 (72.0)	199 (54.8)		
Total	181 (100.0)	182 (100.0)	363 (100.0) ***		

* - Statistically significant, ** - Column percentages presented *** - two participants did not receive antenatal care

4.6 Socio-demographic variables and awareness/knowledge of birth defects

Table 4.8 shows that the proportion of participants who were older than 30 years and were aware of birth defects (45.0%) was higher than the proportion that was 30 years of age or younger who were aware of birth defects (30.2%), p = 0.004. A higher proportion of Christian respondents were aware of birth defects than Muslim respondents (47.4% vs. 23.1%, p < 0.001). The proportion of participants who had a post secondary level of education and were aware of birth defects (55.3%) was higher than the proportion of participants who had a secondary or lower level of education and were aware of birth defects (14.9%), p < 0.001. Majority of mothers who are skilled workers were aware of birth defects compared to dependants or unskilled workers (66.4% vs. 41.7% vs. 20.3%, p < 0.001). There was no association between awareness of birth defects and marital status.

Table 4.8 – Socio-demographic variables of the participants and awareness of birth defects

Socio-demographic variable	Awareness of birth defects: Aware No (%)	Not aware No (%)	Total No (%)	χ^2	p value
Age (years)					
≤ 30	68 (30.2)	157 (69.8)	225 (100.0)	8.191	**0.004***
> 30	63 (45.0)	77 (55.0)	140 (100.0)		
Total	131 (35.9)	234 (64.1)	365 (100.0)		
Marital status					
Single	1 (16.7)	5 (83.3)	6 (100.0)	0.980	0.322
Married	130 (36.2)	229 (63.8)	359 (100.0)		
Total	131 (35.9)	234 (64.1)	365 (100.0)		
Religion					
Christianity	91 (47.4)	101 (52.6)	192 (100.0)	23.305	**<0.001***
Islam	40 (23.1)	133 (76.9)	173 (100.0)		
Total	131 (35.9)	234 (64.1)	365 (100.0)		
Educational status					
Secondary or lower	26 (14.9)	149 (85.1)	175 (100.0)	64.638	**<0.001***
Post-secondary or >	105 (55.3)	85 (44.7)	190 (100.0)		
Total	131 (35.9)	234 (64.1)	365 (100.0)		
Occupational class					
1 – Skilled	71 (66.4)	36 (33.6)	107 (100.0)	67.222	**<0.001***
2 – Unskilled	45 (20.3)	177 (79.7)	222 (100.0)		
3 – Dependant	15 (41.7)	21 (58.3)	36 (100.0)		
Total	131 (35.9)	234 (64.1)	365 (100.0)		

* - Statistically significant

The proportion of participants who were older than 30 years and had a congenital malformation awareness score (CMAS) greater than zero (30.0%) was higher than the proportion that was 30 years of age or younger with a similar score (17.3%), $p = 0.005$. A higher proportion of Christian respondents had a CMAS greater than zero than Muslim respondents (31.8% vs. 11.6%, $p < 0.001$). The proportion of participants who had a post secondary level of education and had a CMAS greater than zero (36.8%) was higher than the proportion of participants who had a secondary or lower level of education and had similar scores (6.3%), $p < 0.001$. Mothers who are skilled workers were more likely to have higher CMAS than dependants or unskilled workers (48.6% vs. 22.2% vs. 9.5%, $p < 0.001$). There was no association between CMAS and marital status (Table 4.9).

Table 4.9 – Socio-demographic variables of the participants and congenital malformation awareness score (CMAS)

	CMAS				
Socio-demographic Variable	**CMAS = 0** **No (%)**	**CMAS > 0** **No (%)**	**Total** **No (%)**	**χ^2**	**p value**
Age (years)					
≤ 30	186 (82.7)	39 (17.3)	225 (100.0)	8.019	**0.005***
> 30	98 (70.0)	42 (30.0)	140 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Marital status					
Single	5 (83.3)	1 (16.7)	6 (100.0)	FET	1.000
Married	279 (77.7)	80 (22.3)	359 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Religion					
Christianity	131 (68.2)	61 (31.8)	192 (100.0)	21.527	**<0.001***
Islam	153 (88.4)	20 (11.6)	173 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Educational status					
Secondary or lower	164 (93.7)	11 (6.3)	175 (100.0)	49.259	**<0.001***
Post-secondary or >	120 (63.2)	70 (36.8)	190 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Occupational class					
1 – Skilled	55 (51.4)	52 (48.6)	107 (100.0)	64.052	**<0.001***
2 – Unskilled	201 (90.5)	21 (9.5)	222 (100.0)		
3 – Dependant	28 (77.8)	8 (22.2)	36 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		

* - Statistically significant, FET – Fisher's Exact Test

4.7 Socio-demographic variables and awareness of anorectal malformations

A higher proportion of participants who were older than 30 years of age could correctly identify the perineal pictures of babies with ARM than those younger than 30 years of age (59.3% vs. 47.6%, p = 0.029). Mothers with post secondary education were more likely to be aware of anorectal malformations than those with lower levels of educational achievement (57.4% vs. 46.3%, p = 0.034).

There was no association between awareness of anorectal malformation as determined by correct recognition of perineal picture of babies with ARM and; marital status, religion, and occupational class (Table 4.10).

Table 4.10 – Socio-demographic variables of the participants and awareness of anorectal malformations

	No of perineal pictures correctly identified				
Socio-demographic Variable	**None No (%)**	**At least 1 No (%)**	**Total No (%)**	**χ^2**	**p value**
Age (years)					
≤ 30	118 (52.4)	107 (47.6)	225 (100.0)	4.758	**0.029***
> 30	57 (40.7)	83 (59.3)	140 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Marital status					
Single	2 (33.3)	4 (66.7)	6 (100.0)	0.522	0.470
Married	173 (48.2)	186 (51.8)	359 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Religion					
Christianity	92 (47.9)	100 (52.1)	192 (100.0)	0.000	0.991
Islam	83 (48.0)	90 (52.0)	173 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Educational status					
Secondary or lower	94 (53.7)	81 (46.3)	175 (100.0)	4.483	**0.034***
Post-secondary or >	81 (42.6)	109 (57.4)	190 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		

4.7 Socio-demographic variables and awareness of anorectal malformations

A higher proportion of participants who were older than 30 years of age could correctly identify the perineal pictures of babies with ARM than those younger than 30 years of age (59.3% vs. 47.6%, p = 0.029). Mothers with post secondary education were more likely to be aware of anorectal malformations than those with lower levels of educational achievement (57.4% vs. 46.3%, p = 0.034).

There was no association between awareness of anorectal malformation as determined by correct recognition of perineal picture of babies with ARM and; marital status, religion, and occupational class (Table 4.10).

Table 4.10 – Socio-demographic variables of the participants and awareness of anorectal malformations

	No of perineal pictures correctly identified				
Socio-demographic Variable	**None No (%)**	**At least 1 No (%)**	**Total No (%)**	**χ^2**	**p value**
Age (years)					
≤ 30	118 (52.4)	107 (47.6)	225 (100.0)	4.758	**0.029***
> 30	57 (40.7)	83 (59.3)	140 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Marital status					
Single	2 (33.3)	4 (66.7)	6 (100.0)	0.522	0.470
Married	173 (48.2)	186 (51.8)	359 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Religion					
Christianity	92 (47.9)	100 (52.1)	192 (100.0)	0.000	0.991
Islam	83 (48.0)	90 (52.0)	173 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Educational status					
Secondary or lower	94 (53.7)	81 (46.3)	175 (100.0)	4.483	**0.034***
Post-secondary or >	81 (42.6)	109 (57.4)	190 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		

Occupational class					
1 – Skilled	45 (42.1)	62 (57.9)	107 (100.0)	4.320	0.115
2 – Unskilled	116 (52.3)	106 (47.7)	222 (100.0)		
3 – Dependant	14 (38.9)	22 (61.1)	36 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		

* - Statistically significant

4.8 Maternal obstetric variables and awareness/knowledge of birth defects

The proportion of respondents who booked for antenatal care at a tertiary hospital and were aware of birth defects (66.4%) was higher than the proportion that booked at other hospitals and was aware of birth defects (19.0%), $p < 0.001$. A higher proportion of mothers who booked for antenatal care before the fifth month of pregnancy were aware of birth defects than those who booked at 5 months or later (49.4% vs. 25.1%, $p < 0.001$). There were no associations between awareness of birth defects and the number of pregnancies or birth to date (Table 4.11).

Table 4.11 – Maternal obstetric variables of the participants and awareness of birth defects

	Awareness of birth defects				
Variable	**Aware**	**Not aware**	**Total**	**χ^2**	**p value**
	No (%)	**No (%)**	**No (%)**		
Gravidity					
Primigravida	51 (38.6)	81 (61.4)	132 (100.0)	0.678	0.410
Multigravida	80 (34.3)	153 (65.7)	233 (100.0)		
Total	131 (35.9)	234 (64.1)	365 (100.0)		
Number of children					
≤ 2	93 (38.9)	146 (61.1)	239 (100.0)	2.747	0.097
≥ 3	38 (30.2)	88 (69.8)	126 (100.0)		
Total	131 (35.9)	234 (64.1)	365 (100.0)		
Location of ANC					
Tertiary hospital	87 (66.4)	44 (33.6)	131 (100.0)	81.718	**<0.001***
Other hospital	44 (19.0)	188 (81.0)	232 (100.0)		
Total	131 (36.1)	232 (63.9)	363 (100.0) **		
GA at booking					
< 5 months	81 (49.4)	83 (50.6)	164 (100.0)	22.950	**<0.001***
≥ 5 months	50 (25.1)	149 (74.9)	199 (100.0)		
Total	131 (36.1)	232 (63.9)	363 (100.0) **		

* - Statistically significant, ** - two participants did not receive antenatal care, ANC – Antenatal care, GA – Gestational age

Table 4.12 shows that the proportion of respondents who booked for antenatal care at a tertiary hospital and had a CMAS greater than zero (36.6%) was higher than the proportion that booked at other hospitals and had similar scores (14.2%), $p < 0.001$. A higher proportion of mothers who booked for antenatal care before the fifth month of pregnancy had CMAS greater than zero compared to those who booked at 5 months or later (28.0% vs. 17.6%, $p = 0.017$). There were no associations between the CMAS and the number of pregnancies or births to date.

Table 4.12 – Maternal obstetric variables and congenital malformation awareness score (CMAS)

	CMAS				
Variable	**CMAS = 0**	**CMAS > 0**	**Total**	**χ^2**	**p value**
	No (%)	**No (%)**	**No (%)**		
Gravidity					
Primigravida	102 (77.3)	30 (22.7)	132 (100.0)	0.034	0.853
Multigravida	182 (78.1)	51 (21.9)	233 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Number of children					
≤ 2	183 (76.6)	56 (23.4)	239 (100.0)	0.616	0.433
≥ 3	101 (80.2)	25 (19.8)	126 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Location of ANC					
Tertiary hospital	83 (63.4)	48 (36.6)	131 (100.0)	24.271	**<0.001***
Other hospital	199 (85.8)	33 (14.2)	232 (100.0)		
Total	282 (77.7)	81 (22.3)	363 (100.0) **		
GA at booking					
< 5 months	118 (72.0)	46 (28.0)	164 (100.0)	22.950	**<0.001***
≥ 5 months	164 (82.4)	35 (17.6)	199 (100.0)		
Total	282 (77.7)	81 (22.3)	363 (100.0) **		

* - Statistically significant, ** - two participants did not receive antenatal care, ANC – Antenatal care, GA – Gestational age

Table 4.12 shows that the proportion of respondents who booked for antenatal care at a tertiary hospital and had a CMAS greater than zero (36.6%) was higher than the proportion that booked at other hospitals and had similar scores (14.2%), $p < 0.001$. A higher proportion of mothers who booked for antenatal care before the fifth month of pregnancy had CMAS greater than zero compared to those who booked at 5 months or later (28.0% vs. 17.6%, $p = 0.017$). There were no associations between the CMAS and the number of pregnancies or births to date.

Table 4.12 – Maternal obstetric variables and congenital malformation awareness score (CMAS)

	CMAS				
Variable	**CMAS = 0**	**CMAS > 0**	**Total**	**χ^2**	**p value**
	No (%)	**No (%)**	**No (%)**		
Gravidity					
Primigravida	102 (77.3)	30 (22.7)	132 (100.0)	0.034	0.853
Multigravida	182 (78.1)	51 (21.9)	233 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Number of children					
≤ 2	183 (76.6)	56 (23.4)	239 (100.0)	0.616	0.433
≥ 3	101 (80.2)	25 (19.8)	126 (100.0)		
Total	284 (77.8)	81 (22.2)	365 (100.0)		
Location of ANC					
Tertiary hospital	83 (63.4)	48 (36.6)	131 (100.0)	24.271	**<0.001***
Other hospital	199 (85.8)	33 (14.2)	232 (100.0)		
Total	282 (77.7)	81 (22.3)	363 (100.0) **		
GA at booking					
< 5 months	118 (72.0)	46 (28.0)	164 (100.0)	22.950	**<0.001***
≥ 5 months	164 (82.4)	35 (17.6)	199 (100.0)		
Total	282 (77.7)	81 (22.3)	363 (100.0) **		

* - Statistically significant, ** - two participants did not receive antenatal care, ANC – Antenatal care, GA – Gestational age

4.9 Maternal obstetric variables and awareness of anorectal malformations

There were no associations between awareness of anorectal malformations, by correctly recognising perineal pictures of babies with ARM, and; number of pregnancies till date i.e. gravidity, number of children till date i.e. parity, location of antenatal care and gestational age at booking (Table 4.13).

Table 4.13 – Maternal obstetric variables of the participants and awareness of anorectal malformations

Variable	No of perineal pictures correctly identified				
	None	At least 1	Total	χ^2	p value
	No (%)	No (%)	No (%)		
Gravidity					
Primigravida	65 (49.2)	67 (50.8)	132 (100.0)	0.139	0.709
Multigravida	110 (47.2)	123 (52.8)	233 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Number of children					
≤ 2	115 (48.1)	124 (51.9)	239 (100.0)	0.008	0.928
≥ 3	60 (47.6)	66 (52.4)	126 (100.0)		
Total	175 (47.9)	190 (52.1)	365 (100.0)		
Location of ANC					
Tertiary hospital	55 (42.0)	76 (58.0)	131 (100.0)	2.907	0.088
Other hospital	119 (51.3)	113 (48.7)	232 (100.0)		
Total	174 (47.9)	189 (52.1)	363 (100.0) **		
GA at booking					
< 5 months	76 (46.3)	88 (53.7)	164 (100.0)	0.304	0.581
≥ 5 months	98 (49.2)	101 (50.8)	199 (100.0)		
Total	174 (47.9)	189 (52.1)	363 (100.0) **		

* - Statistically significant, ** - two participants did not receive antenatal care, ANC – Antenatal care, GA – Gestational age

4.10 Predictors of awareness/knowledge of birth defects

4.10.1 Predictors of awareness of birth defects amongst socio-demographic variables

Christian mothers were (nearly) twice as likely as Muslim mothers to be aware of birth defects (OR = 1.79, 95% CI: 1.07, 2.99, p = 0.027). Participants with post secondary level of education were three times more likely to be aware of birth defects than those with lower educational achievements (OR = 3.16, 95% CI: 1.63, 6.06, p < 0.001). Age group and occupational class were not found to be significant predictors of awareness of birth defects (Table 4.14).

Table 4.14 – Logistic regression analysis of relationship between socio-demographic variables and awareness of birth defects

Variable		OR	95% CI	p value
Age group	> 30 years ≤ 30 years	1.213	0.722 – 2.041	0.466
Religion	Christianity Islam	1.787	1.070 – 2.985	**0.027***
Educational status	Post-secondary or higher Secondary or lower	3.155	1.634 – 6.061	**0.001***
Occupational class	1 – Skilled workers	1.993	0.871 – 4.559	0.102
	2 – Unskilled workers	0.640	0.276 – 1.485	0.299
	3 – Dependants			

*Statistically significant

4.10.2 Predictors of knowledge of birth defects amongst socio-demographic variables

Christian mothers were more likely than Muslim mothers to have a good knowledge of birth defects (OR = 2.06, 95% CI: 1.11, 3.80, p = 0.021). Participants with post secondary level of education were three times more likely to have a higher congenital malformation awareness score than those with lower educational achievements (OR = 3.48, 95% CI: 1.46, 8.31, p = 0.005). Age group and occupational class were not found to be significant predictors of knowledge of birth defects (Table 4.15).

Table 4.15 – Logistic regression analysis of relationship between socio-demographic variables and knowledge of birth defects using CMAS

Variable		OR	95% CI	p value
Age group	> 30 years	1.237	0.689 – 2.221	0.477
	≤ 30 years			
Religion	Christianity	2.058	1.114 – 3.802	**0.021***
	Islam			
Educational status	Post-secondary or higher	3.477	1.455 – 8.306	**0.005***
	Secondary or lower			
Occupational class	1 – Skilled workers	2.451	0.970 – 6.173	0.058
	2 – Unskilled workers	0.676	0.247 – 1.852	0.446
	3 – Dependants			

*Statistically significant

4.10.3 Predictors of awareness of birth defects amongst maternal obstetric variables

Participants who booked for antenatal care at a tertiary hospital were eight times more likely to be aware of birth defects than those who booked at other facilities (OR = 8.13, 95% CI: 4.36, 15.15, $p < 0.001$). The number of children and month of registration for antenatal care were found not to be significant predictors of awareness of birth defects (Table 4.16).

Table 4.16 – Logistic regression analysis of relationship between maternal obstetric variables and awareness of birth defects

Variable	Categories of variable	OR	95% CI	p value
Number of children	≤ 2 ≥ 3	1.026	0.556 – 1.891	0.935
Location of ANC	Tertiary hospital Other hospital	8.130	4.362 – 15.151	**<0.001***
GA at booking	< 5 months ≥ 5 months	1.375	0.756 – 2.502	0.297

*Statistically significant, ANC – Antenatal care, GA – Gestational age

4.10.4 Predictors of knowledge of birth defects and maternal obstetric variables

Participants who booked for antenatal care at a tertiary hospital were three times more likely to have a congenital malformation awareness score greater than zero compared to those who booked at other facilities (OR = 3.23, 95% CI: 4.36, 15.15, $p < 0.001$). The number of children and month of registration for antenatal care were found not to be significant predictors of awareness of birth defects (Table 4.17).

Table 4.17 – Logistic regression analysis of relationship between maternal obstetric variables and knowledge of birth defects, using congenital malformation awareness score - CMAS

Variable	Categories of variable	OR	95% CI	p value
Location of ANC	Tertiary hospital Other hospital	3.226	1.894 – 5.495	**<0.001***
GA at booking	< 5 months ≥ 5 months	1.305	0.762 – 2.232	0.332

*Statistically significant. ANC – Antenatal care, GA – Gestational age

4.11 Newborn physical examination

The majority (222, 60.8%) of participants were told that their babies were examined shortly after birth while 143 (39.2%) were not informed that this was done. A total of 186 (51.0%) respondents had examined the anus of their babies; at an interval of 1 to 28 days after birth (median of 2 days). The technique utilised for the examination of the anus included: inspection only (169, 90.9%), insertion of thermometer (6, 3.2%), insertion of finger (3, 1.6%), insertion of menthol (2, 1.1%), insertion of cotton bud (2, 1.1%), and instillation of warm water (2, 1.1%). The babies of the respondents passed faeces between the first and fifth day of life (median of 1 day).

4.12 Examination findings

Two babies were found to have anorectal malformations during the study; one was a two month old female with ARM and recto-perineal fistula and the other was a five day old with ARM and recto-vestibular fistula. Both mothers were primipara and the children were referred to paediatric surgeons for the correction of the defects.

CHAPTER 5

DISCUSSION

The early detection of birth defects, through screening, is associated with prompt treatment, reduction in morbidity and mortality and better survival based on improvement in the quality of life of affected children (American Academy of Pediatrics AAP, 2000 & Hoffman and Laessig, 2003). In the absence of well established guidelines for screening of birth defects, such as in Nigeria, a great responsibility is placed on parents who, in addition to the efforts of health care workers, will have to be partners in ensuring early detection of birth defects if present in any newborn child. There is no better person that is qualified to detect any of these anomalies that are missed in the immediate newborn period before the child is sent home than a mother who spends the most time with a child at this phase of life.

Socio-demographic characteristics of the participants

The mothers recruited for the study were aged 17 to 42 years, which is well within the expected reproductive age group of 15 to 45 years that most women become mothers. They were mostly married, reflecting the influence of the Yoruba culture in which setting the study was conducted, that encourages procreation in marital relationships.

The mothers recruited from Adeoyo Maternity Hospital tended to be younger, Muslims, had lower levels of educational achievement and were unskilled workers. On the other hand, those from the University College Hospital were more likely to be older, Christians, had higher levels of educational attainment and were skilled workers. This could be attributable to the socioeconomic diversities of the clients attending the two hospitals. The Adeoyo Maternity Hospital is a state government controlled secondary health care facility that caters for women residing in the metropolitan area of Ibadan, majorly populated by people of low socioeconomic class. On the other hand, clients attending the University College Hospital, a tertiary health care centre, are mostly in the middle socioeconomic stratum of the society. This could also be responsible for the earlier date at booking for antenatal care among mothers from the University College Hospital, Ibadan.

Awareness/knowledge of mothers about birth defects and anorectal malformations

The present study revealed poor awareness of mothers about birth defects as only 35.9% of the participants were aware of these defects. Furthermore, 19.5% of the study participants were aware of anorectal malformations and 7.4% were aware of a type of anorectal malformation in females – i.e. anorectal malformation with recto-vestibular fistula. This is similar to the findings of Lang et al. in a study of 388 residents of Chicago, Illinois, USA, where only 33% of the mothers had ever heard about cystic fibrosis, the predominant metabolic defect affecting the American population (Lang et al., 2009). This suggests that poor level of awareness of birth defects, in various forms, is a universal problem. It thus brings to fore the concerns of the American Academy of Pediatrics when it constituted a task force to review the effectiveness of screening programmes and as one of its recommendations, the education of mothers about birth defects was a key suggestion to ensure the success of screening for birth defects (AAP, 2000). Furthermore, the poor level of awareness about birth defects is likely to have a more negative effect in developing countries where protocols and guidelines for screening and early detection of birth defects are lacking.

The predominant sources of information about birth defects for mothers who were aware of those in this study were the mass media and doctors/nurses. This finding is similar to what was reported among Greek mothers in which doctors and the mass media were the major sources of information about birth defects to 39.4% of them (Mavrou et al., 1998). Bener et al. (2006) also found that doctors and the print media were the predominant sources of information about the prevention of birth defects in a survey of 1480 Qatari women. The importance of the mass media as a leading source of information about birth defects is probably attributable to the coverage enjoyed by television, radio and the print media as sources of enlightenment and education for the populace with most homes having one form or the other of these.

Antenatal care visits and counseling on birth defects

All but two of the participants in the present study registered for antenatal care during the index pregnancy and performed an average of three ultrasound scans each. This suggests a high level of awareness of the populace about the place of ultrasound scanning in

pregnancy. Enakpene et al. (2009) in a survey of 222 women in Ibadan, Nigeria found that women readily of their own volition request for antenatal ultrasound scanning. The major reasons given by the women for presenting for the ultrasound scan in that study were to check for foetal viability (64.7%) and to determine the baby's gender (22.6%). However, none of the 222 women requested for ultrasound scanning to screen for birth defects in their babies.

The findings on ultrasound scan were explained to 92.6% of the women by the sonographer in the present study. Additionally, 83.6% received explanation about the result of the ultrasound scan from their doctor or midwife. These suggest that the interaction between the women and the sonographer or doctor/midwife is a good source of information about the state of the foetus, i.e. viability, estimating date of delivery and determination of sex.

On the other hand, only 5.8% of the participants in the study received information about birth defects during the antenatal care. Not only does this suggest inadequacy of information from health care workers about screening for birth defects, it shows the lack of guidelines on information to be made available to expectant mothers in Nigeria. Where those guidelines are in place, parental education by health care workers have been found to be instrumental to the success of newborn screening for birth defects (Kim et al., 2003).

In the present study, only 8 (2.2%) participants used folic acid pre-conception, of which two knew that it was recommended for the prevention of neural tube defects and to be administered to women planning to get pregnant. Additionally, overall, 12.6% of the mothers knew that folic acid could be used to prevent birth defects, even though most did not take it prior to conception. Similarly low proportions have been reported from other countries. Ren et al. (2006) noted that 29.6% of women studied in Beijing, China were aware that folic acid could be used to prevent neural tube defects. Bener et al. (2006) in a study of 1480 women in Qatar found that only 14% knew that folic acid could be given to prevent birth defects. The poor level of awareness of the use of folic acid in the prevention of neural tube defects suggests the inadequacy of education and enlightenment on prevention of birth defects. It may thus be necessary to include such information in

health education campaigns and as part of the information given to attendees of antenatal care clinics.

Socio-demographic variables and awareness of birth defects

Participants in the present study were more likely to be aware of birth defects if they; were older than 30 years of age, were Christians, had post secondary education or were skilled workers. The findings on their congenital malformation awareness scores, reflecting their knowledge about birth defects, mirror this. Furthermore, religion and highest level of education attained were found to be significant predictors of awareness of birth defects or a better knowledge score on birth defects. Mavrou et al. (1998) in a study conducted in Greece reported that better awareness and higher knowledge scores of birth defects were found in older women, those with better education, higher family income and residents of cosmopolitan areas. Lang et al. (2009) similarly found older age and having a college degree to be among predictors of a higher knowledge score of sickle cell disease or cystic fibrosis in a survey of American women. Other predictors of higher scores in that study were having private health insurance and not being African-American. Older age is presumably associated with greater experience of life and the interactions women have with their friends and neighbours may lead to having heard about birth defects in conversations or through other sources. Better educational achievements and being a skilled worker are likely to expose the women to greater access to the media or internet. The mass media, corroboratively, was found to be the leading source of information about birth defects in the present study.

Maternal obstetric characteristics and awareness of birth defects

In this study, women who booked for antenatal care at a tertiary hospital and those who booked early (less than five months of gestation) were more likely to be aware of birth defects and have higher scores on evaluation of their knowledge about birth defects. Additionally, the facility where antenatal care was done was found to be a predictor of awareness of birth defects or higher knowledge scores.

These observations and inferences may be linked to the socioeconomic factors responsible for the choice of facility to book for antenatal care. Women of the middle

socioeconomic class are more likely to book at a tertiary hospital or a facility where the quality of care available is above and beyond what obtains in a poorly funded and not so well maintained secondary health care facility (Iyaniwura and Yussuf, 2009). Oladokun et al. (2010) reported from a cross sectional study of 796 antenatal clinic attendees that early booking in pregnancy is likely to be associated with women who are more educated, professionals and those with fewer previous pregnancies.

In conclusion, the present study has shown that mothers in Ibadan, Nigeria have a poor level of awareness about birth defects and anorectal malformations. There is a gap in the counselling given to pregnant women attending antenatal care facilities in the setting. Health promotion aimed at prevention, early detection and prompt treatment of birth defects can be achieved by improving the transmission of information to mothers at antenatal clinics and educating the populace through mass media and health care workers.

REFERENCES

Adejuyigbe, O., Abubakar, A. M., Sowande, O. A., Olayinka, O. S. and Uba, A. F. 2004. Experience with anorectal malformations in Ile-Ife, Nigeria. *Pediatric Surgery International* 20: 855-858.

Ademuyiwa, A. O., Sowande, O. A., Ijaduola, T. K. and Adejuyigbe, O. 2009. Determinants of mortality in neonatal intestinal obstruction in Ile Ife, Nigeria. *African Journal of Paediatric Surgery* 6: 11-13.

Aite, L., Zaccara, A., Trucchi, A., Nahom, A., Iacobelli, B. and Bagolan, P. 2006. Parents' informational needs at the birth of a baby with a surgically correctable anomaly. *Pediatric Surgery International* 22: 267-270.

Arif, M. O., Fatmi, Z., Pardeep, B., Ali, T., Iqbal, H., Bangash, H. K., Pervaiz, R., Altaf, H. and Baba, J. A. 2008. Attitudes and perceptions about prenatal diagnosis and induced abortion among adults of Pakistani population. *Prenatal Diagnosis* 28:1149-1155.

American Academy of Pediatrics 2000. Serving the family from birth to the medical home. Newborn screening: a blueprint for the future - a call for a national agenda on state newborn screening programs. *Pediatrics* 106: 389-422.

American Academy of Pediatrics 2004. Hospital stay for healthy term newborns. *Pediatrics* 113: 1434-1436.

American Academy of Pediatrics 2010. Hospital stay for healthy term newborns. *Pediatrics* 125: 405-409.

Arnold, C. L., Davis, T. C., Frempong, J. O., Humiston, S. G., Bocchini, A., Kennen, E. M. and Lloyd-Puryear, M. 2006. Assessment of newborn screening parent education materials. *Pediatrics* 117: S320-325.

Bener, A., Al Maadid, M. O., Al-Bast, D. A. and Al-Marri, S. 2006. Maternal knowledge, attitude and practice on folic acid intake among Arabian Qatari women. *Reproductive Toxicology* 21:21-25.

Boemers, T. M., Beek, F. J. and Bax, N. M. 1999. Review. Guidelines for the urological screening and initial management of lower urinary tract dysfunction in children with anorectal malformations--the ARGUS protocol. *BJU International* 83: 662-671.

Browner, C. H., Preloran, H. M., Casado, M. C., Bass, H. N. and Walker, A. P. 2003. Genetic counseling gone awry: miscommunication between prenatal genetic service providers and Mexican-origin clients. *Social Science & Medicine* 56:1933-1946.

Chan, L. W., Chan, O. K., Chau, M. C., Sahota, D. S., Leung, T. Y., Fung, T. Y. and Lau, T. K. 2008. Expectation and knowledge of pregnant women undergoing first and second trimester ultrasound examination in a Chinese population. *Prenatal Diagnosis* 28:739-744.

Chirdan, L. B., Uba, F. A., Ameh, E. A. and Mshelbwala, P. M. 2008. Colostomy for high anorectal malformation: an evaluation of morbidity and mortality in a developing country. *Pediatric Surgery International* 24: 407-410.

Cuschieri, A. 2001. Descriptive epidemiology of isolated anal anomalies: a survey of 4.6 million births in Europe. *American Journal of Medical Genetics* 103: 207-215.

Davis, T. C., Humiston, S. G., Arnold, C. L., Bocchini, J. A., Jr., Bass, P. F., 3rd, Kennen, E. M., Bocchini, A., Kyler, P. and Lloyd-Puryear, M. 2006. Recommendations for effective newborn screening communication: results of focus groups with parents, providers, and experts. *Pediatrics* 117: S326-340.

Enakpene, C. A., Morhason-Bello, I. O., Marinho, A. O., Adedokun, B. O., Kalejaiye, A. O., Sogo, K., Gbadamosi, S. A., Awoyinka, B. S. and Enabor, O. O. 2009. Clients' reasons for prenatal ultrasonography in Ibadan, South West of Nigeria. *BMC Women's Health* 9: 12.

Eltayeb, A. A. 2010. Delayed presentation of anorectal malformations: the possible associated morbidity and mortality. *Pediatric Surgery International* 26: 801-806.

Esan, T. A., Olusile, A. O., Akeredolu, P. A. and Esan, A. O. 2004. Socio-demographic factors and edentulism: the Nigerian experience. *BMC Oral Health* 4(1): 3.

Fant, K. E., Clark, S. J. and Kemper, A. R. 2005. Completeness and complexity of information available to parents from newborn-screening programs. *Pediatrics* 115: 1268-1272.

Farrell, M., Deuster, L., Donovan, J. and Christopher, S. 2008. Pediatric residents' use of jargon during counseling about newborn genetic screening results. *Pediatrics* 122. 243-249.

Gonzalez-Andrade, F. and Lopez-Pulles, R. 2010. Ecuador: public health genomics. *Public Health Genomics* 13: 171-180.

Green, N. S., Dolan, S. M. and Murray, T. H. 2006. Newborn screening: complexities in universal genetic testing. *American Journal of Public Health* 96: 1955-1959.

Gustavson, K. H. 2005. Prevalence and aetiology of congenital birth defects, infant mortality and mental retardation in Lahore, Pakistan: a prospective cohort study. *Acta Paediatrica* 94: 769-774.

Guthrie, R. and Susi, A. 1963. A Simple Phenylalanine Method for Detecting Phenylketonuria in Large Populations of Newborn Infants. *Pediatrics* 32: 338-343.

Hall, D. M. and Stewart-Brown, S. 1998. Screening in child health. *British Medical Bulletin* 54: 929-943.

Hayeems, R. Z., Miller, F. A., Little, J., Carroll, J. C., Allanson, J., Chakraborty, P., Wilson, B. J., Bytautas, J. P. and Christensen, R. J. 2009. Informing parents about expanded newborn screening: influences on provider involvement. *Pediatrics* 124: 950-958.

Hemminki, K., Mutanen, P., Saloniemi, I. and Luoma, K. 1981. Congenital malformations and maternal occupation in Finland: multivariate analysis. *Journal of Epidemiology and Community Health* 35: 5-10.

Hoffman, G. L. and Laessig, R. H. 2003. Screening newborns for congenital disorders. *WMJ : official publication of the State Medical Society of Wisconsin* 102: 45-50.

Huang, M. C., Lee, C. K., Lin, S. J. and Lu, I. C. 2005. Parental consent for newborn screening in southern Taiwan. *Journal of Medical Ethics* 31: 621-624.

Iyaniwura, C. A. and Yussuf, Q. 2009. Utilization of antenatal care and delivery services in Sagamu, south western Nigeria. *African Journal of Reproductive Health* 13: 111-122.

Kai, J., Ulph, F., Cullinan, T. and Qureshi, N. 2009. Communication of carrier status information following universal newborn screening for sickle cell disorders and cystic fibrosis: qualitative study of experience and practice. *Health Technology Assessment* 13: 1-82, iii.

Kallen, B. 1989. Population surveillance of congenital malformations. Possibilities and limitations. *Acta Paediatrica Scandinavica* 78: 657-663.

Kim, S., Lloyd-Puryear, M. A. and Tonniges, T. F. 2003. Examination of the communication practices between state newborn screening programs and the medical home. *Pediatrics* 111: E120-126.

Knowles, R., Griebsch, I., Dezateux, C., Brown, J., Bull, C. and Wren, C. 2005. Newborn screening for congenital heart defects: a systematic review and cost-effectiveness analysis. *Health Technology Assessment* 9: 1-152, iii-iv.

Lang, C. W., Stark, A. P., Acharya, K. and Ross, L. F. 2009. Maternal knowledge and attitudes about newborn screening for sickle cell disease and cystic fibrosis. *American Journal of Medical Genetics. Part A.* 149A: 2424-2229.

Lantto, M., Renko, M. and Uhari, M. 2008. Trends in childhood mortality from 1969 to 2004 in Finland. *Acta Paediatrica* 97: 1024-1029.

Lawal, T. A., Chatoorgoon, K., Bischoff, A., Pena, A. and Levitt, M. A. 2011. Management of H-type rectovestibular and rectovaginal fistulas. *Journal of Pediatric Surgery* 46: 1226-1230.

Lawal, T. A., Peña, A. and Levitt, M. A. (In Press). Pediatric colorectal disorders – Hirschsprung disease, anorectal malformations and rectal prolapse. *American Academy of Pediatrics: Textbook of Pediatric Care*. T. K. McInerny, H. M. Adams, D. E. Campbell, D. M. Kamat, T. G. DeWitt, J. M. Foy. Eds. 2nd Edition.

Levitt, M. A. and Peña, A. 2010. Imperforate anus and cloacal malformations. *Ashcraft's Pediatric Surgery*. G.W. Holcomb & J.P. Murphy. Eds. 5th Edition. Philadelphia, PA: Saunders Elsevier. 468-490.

Li, D. K., Karlberg, K., Wi, S. and Norem, C. 2008. Factors influencing women's acceptance of prenatal screening tests. *Prenatal Diagnosis* 28:1136-1143.

Lindley, R. M., Shawis, R. N. and Roberts, J. P. 2006. Delays in the diagnosis of anorectal malformations are common and significantly increase serious early complications. *Acta Paediatrica* 95: 364-368.

Liske, M. R., Greeley, C. S., Law, D. J., Reich, J. D., Morrow, W. R., Baldwin, H. S., Graham, T. P., Strauss, A. W., Kavanaugh-Mchugh, A. L. and Walsh, W. F. 2006.

Report of the Tennessee task force on screening newborn infants for critical congenital heart disease. *Pediatrics* 118: e1250-1256.

Lloyd-Puryear, M. A., Tonniges, T., Van Dyck, P. C., Mann, M. Y., Brin, A., Johnson, K. and Mcpherson, M. 2006. American Academy of Pediatrics Newborn Screening Task Force recommendations: how far have we come? *Pediatrics* 117: S194-211.

Lukong, C. S., Ameh, E. A., Mshelbwala, P. M., Jabo, B. A., Gomna, A., Akiniyi, O. T. and Nmadu, P. T. 2011. Management of anorectal malformation: Changing trend over two decades in Zaria, Nigeria. *African Journal of Paediatric Surgery* 8: 19-22.

Mavrou, A., Metaxotou, C. and Trichopoulos, D. 1998. Awareness and use of prenatal diagnosis among Greek women: a national survey. *Prenatal Diagnosis* 18:349-355.

National Health and Medical Research Council. 2002. Childhood health screening and surveillance: a critical review of the evidence. Report prepared by Centre for Community Child Health, Royal Children's Hospital Melbourne for the National Health and Medical Research Council. ii + 229pp.

Oladokun, A., Oladokun, R. E., Morhason-Bello, I. and Adedokun, B. 2010. Proximate predictors of early antenatal registration among Nigerian pregnant women. *Annals of African Medicine* 9: 222-225.

Olusanya, B. O. and Solanke, O. A. 2009. Maternal and neonatal factors associated with mode of delivery under a universal newborn hearing screening programme in Lagos, Nigeria. *BMC Pregnancy and Childbirth* 9: 41.

Peña, A. and Levitt, M. A. 2005. Pediatric surgical problems. *Colon and Rectal Surgery*. M.L. Corman. Ed. 5th Edition. Philadelphia, PA: Lippincott Williams & Wilkins. 555-603.

Peña, A. and Levitt, M. A. 2006. Anorectal malformations. *Pediatric Surgery*. J.L. Grosfeld, J.A. O'Neill, E.W. Fonkalsrud and A.G. Coran. Eds. 6th Edition. Philadelphia, PA: Mosby Elsevier. 1566-1589.

Penrose, L. and Quastel, J. H. 1937. Metabolic studies in phenylketonuria. *Biochemistry Journal* 31: 266-274.

Ratan, S. K., Rattan, K. N., Pandey, R. M., Mittal, A., Magu, S. and Sodhi, P. K. 2004. Associated congenital anomalies in patients with anorectal malformations--a need for developing a uniform practical approach. *Journal of Pediatric Surgery* 39: 1706-1711.

Ren, A., Zhang, L., Li, Z., Hao, L. and Tian, Y. 2006. Awareness and use of folic acid, and blood folate concentrations among pregnant women in northern China--an area with a high prevalence of neural tube defects. *Reproductive Toxicology* 22:431-436.

Rich, M. A., Brock, W. A. and Peña, A. 1988. Spectrum of genitourinary malformations in patients with imperforate anus. *Pediatric Surgery International* 3: 110.

Rostant, K., Steed, L. and O'Leary, P. 2003. Survey of the knowledge, attitudes and experiences of Western Australian women in relation to prenatal screening and diagnostic procedures. *The Australian and New Zealand Journal of Obstetrics & Gynaecology* 43:134-138.

Sadler, T. W. Ed. 2003. Birth defects and prenatal diagnosis. *Langman's Medical Embryology*. 9th Edition. Philadelphia, PA: Lippincott Williams & Wilkins. 149-168.

Suriadi, C., Jovanovska, M. and Quinlivan, J. A. 2004. Factors affecting mothers' knowledge of genetic screening. *The Australian and New Zealand Journal of Obstetrics & Gynaecology* 44:30-34.

Stevenson, R. E. and Hall, J. G. Eds. 2006. Human malformations and related anomalies. *Human Malformations and Related Anomalies*. 2nd Edition. Oxford: Oxford University Press. 3-84.

Turowski, C., Dingemann, J. and Gillick, J. 2010. Delayed diagnosis of imperforate anus: an unacceptable morbidity. *Pediatric Surgery International* 26: 1083-1086.

Wu, D. Y., Brat, G., Milla, G. and Kim, J. 2007. Knowledge and use of folic acid for prevention of birth defects amongst Honduran women. *Reproductive Toxicology* 23:600-606.

Zahed, L., Nabulsi, M., Bou-Ghanim, M. and Usta, I. 1999. Acceptance of prenatal diagnosis for genetic disorders in Lebanon. *Prenatal Diagnosis* 19:1109-1112.

APPENDIX I

QUESTIONNAIRE

MATERNAL PERSPECTIVES ABOUT BIRTH DEFECTS AND ANORECTAL MALFORMATIONS IN IBADAN, NIGERIA

This questionnaire is designed to assess your knowledge, attitude, perception and perspective about birth defects in newborn children. All the responses that you give will be taken into confidence and cannot be traced back to you. The responses will help in formulating policies towards promoting early detection and treatment of congenital malformations in Nigerian children. Thank you.

Section A

1. Serial number .....
2. Location of Interview – **1)** GOPD **2)** AMH
3. Age last birthday ..... years
4. Occupation .....
5. Marital status – **1)** Single **2)** Married **3)** Separated
6. Highest level of education – **1)** None **2)** Primary **3)** Secondary
   4) NCE **5)** Polytechnic **6)** University **7)** Others .....
7. Religion **1)** Christianity **2)** Islam **3)** Others .....
8. Total number of pregnancies till date .....
9. Total number of children till date .....
10. Number of previous boys .....
11. Number of previous girls .....

Section B

12. Index baby's age ..... day's
13. Baby's gender – 1) Male 2) Female
14. Did you have antenatal care for the pregnancy (of the index baby)?
    1) Yes **2)** No
15. If answer to 14 was Yes, where did you have the antenatal care?
    1) Tertiary hospital **2)** General hospital **3)** PHC/Local Govt Facility

4) Private clinic 5) Others (specify) .....

16. At what month of pregnancy did you register for antenatal care? ..... month

17. How many ultrasound scans did you do during the pregnancy? .....

18. Were you told the findings of the ultrasound scan by the sonographer?

1) Yes 2) No

19. Were you told the findings of the ultrasound scan by your doctor?

1) Yes 2) No

20. Do you know about birth defects? 1) Yes 2) No

21. If the answer to 20 was Yes, what are birth defects?

.....

.....

.....

22. Where did you first hear about birth defects?

1) From your doctor 2) From your nurse/midwife 3) From posters in hospitals 4) From the mass media 5) From the internet 6) From friends 7) I can't remember

23. Mention three (3) examples of birth defects that you know

.....

.....

.....

24. Did anybody tell you about birth defects during the last pregnancy?

1) Yes 2) No

25. If answer to 24 was Yes, who told you?

1) Doctor 2) Nurse/Midwife 3) Other health workers

26. Did you use folic acid before you got pregnant?

1) Yes 2) No

27. If answer to 26 was Yes, who prescribed it for you?

.....

28. Can birth defects be prevented? 1) Yes 2) No 3) Don't know

29. Can birth defects be inherited? 1) Yes 2) No 3) Don't know

30. Can birth defect be treated? 1) Yes 2) No 3) Don't know

31. Can some birth defects be prevented by taking folic acid just before pregnancy?

1) Yes 2) No 3) Don't know

32. Are there tests that can be done to detect birth defects while pregnant?

1) Yes 2) No 3) Don't know

33. Mention any three (3) of these tests that you know?

.....

.....

.....

Section C

34. Are you aware that a baby can be born without an anus?

1) Yes 2) No

35. If Yes, how life threatening would you rate the problem on a scale of 1 (very mild, not life threatening) to 10 (very severe, life threatening) .....

36. Are you aware that a boy can be born passing stools in urine?

1) Yes 2) No

37. If Yes, how life threatening would you rate the problem on a scale of 1 (very mild, not life threatening) to 10 (very severe, life threatening) .....

38. Are you aware that a girl can be born passing stools through the vagina?

1) Yes 2) No

39. If Yes, how life threatening would you rate the problem on a scale of 1 (very mild, not life threatening) to 10 (very severe, life threatening) .....

40. Are you aware that a baby can be born with a "hole in the heart"?

1) Yes 2) No

41. If Yes, how life threatening would you rate the problem on a scale of 1 (very mild, not life threatening) to 10 (very severe, life threatening) .....

42. Are the pictures shown to you those of babies with normal perineum or with birth defects?

Picture A:

1) Normal 2) Abnormal 3) I don't know

If abnormal, what is the abnormality .....

Picture B:

1) Normal 2) Abnormal 3) I don't know

If abnormal, what is the abnormality .....

Picture C:

1) Normal 2) Abnormal 3) I don't know

If abnormal, what is the abnormality .....

43. Were you told that your baby was examined shortly after birth?

1) Yes 2) No

44. What did the doctor/nurse/midwife tell you about the examination findings?

.....

.....

45. How long after birth did you examine your baby's anus? ..... day (s)

46. How did you carry out the examination of your baby's anus?

.....

.....

47. After how many days following birth did your baby first pass faeces? ..... day (s)

Section D: Examination findings

	BIRTH DEFECT FOUND		
REGION	**YES**	**NO**	**TYPE OF DEFECT, IF YES**
HEAD AND NECK			
CHEST			
ABDOMEN			
PERINEUM			
LIMBS			
SPINE AND BACK			

Thank you

IWE IBEERE NIPA IMO ATI IHA TI AWON IYA KO SI AISAN ABIMO OMO ATI BIBI OMO LAINI ILE IYAGBE NI ILU IBADAN NI ORILEDE NAIJIRIA

Iwe ibeere yi wa lati ye imo ati iha ti e kosi bibi omo ti ko ni ile iyagbe ati awon aisan abimo omo miran ni inu awon omo oojo ati ni kekere. Gbogbo esi ti e ba fun wa yio je ni oro asiri ti a ko ni so fun enikeni wipe eyin ni e fo esi be. Eyi yio ran itoju awon omo lowo ni orilede Naijiria paapaa nipa ti bi a se n tete mo ti omo ba ni aisan yi ati lati tete gba itoju ti o peye. E se pupo.

Ipele A

1. Onka ti iwe yi je .....
2. Agbegbe ti ati se ibeere – 1) GOPD 2) AMH
3. Ojo ori yin je ..... (ni odun)
4. Ise ti e n se .....
5. Nipa ti olokode – 1) omidan ni mi 2) adelebo ni mi 3) ati wa ni ototo
6. Iwe ti mo ka ti o ga julo – 1) Mi o ka rara 2) Ile iwe alakobere 3) Ile iwe giraama 4) Ile iwe ti awon oluko 5) Ile iwe ti eko imo ero 6) Ile iwe giga ti unifasiti 7) Omiran .....
7. Esin 1) Elesin Kristi 2) Elesin Islam 3) Omiran .....
8. Eemelo ni eti feraku ni apapo .....
9. Omo melo ni edumare fi jinki yin .....
10. Omo okunrin melo ni o wa ni arin won .....
11. Omo obinrin melo ni o wa ni arin won .....

Ipele Bii

12. Ojo ori omo ti e n to lowo je ..... (ni ojo)
13. Se okunrin ni tabi obinrin – 1) Okunrin 2) Obinrin
14. Se e gba itoju alaboyun nigba ti e ni oyun omo yi? 1) Beeni 2) Beeko
15. Ti o ba je beeni, ni ibo ni eti gba itoju yi? 1) Ile iwosan giga ti unifasiti 2) Ile iwosan to gbogbo gbo 3) Ile iwosan ti ijoba ibile 4) Ile iwosan ti aladani 5) Omiran .....
16. Ni osu wo ninu oyun yii ni e fi oruko sile si ile iwosan na? Osu .....

17. Ayewọ alaworan ti omo ninu oyun melo ni ese? .....

18. Se awon oga ti won se ayewo alaworan yi so esi re fun yin?

1) Beeni 2) Beeko

19. Se dokita ti o n se itoju alaboyun so esi re fun yin? 1) Beeni 2) Beeko

20. Se e mo nipa aisan abimo omo? 1) Beeni 2) Beeko

21. Ti eba mo nipa aisan abimo omo, iru awon aisan wo ni a man pe bee?

.....

.....

.....

22. Ni ibo ni e ti gbo nipa aisan abimo omo'? 1) Ni odo dokita mi 2) ni odo noosi mi 3) ni iwe ti aka ni ogiri ni ile iwosan 4) ni ori ero amohunmaworan tabi asoromagbesi 5) ni ori intaneti 6) ni odo awon ore mi 7) mi o le se iranti

23. E da oruko meta ninu awon aisan abimo omo

.....

.....

.....

24. Nje enikeni so fun yin nipa aisan abimo omo nigba ti won n se itoju alaboyun fun yin'?

1) Beeni 2) Beeko

25. Bi o ba je wipe beeni, ta ni eni ti o so fun yin'?

1) Dokita onisegun 2) Noosi tabi agbebi 3) Onise ilera omiran

26. Nje e lo ogun foliki asidi siwaju ki e to feraku? 1) Beeni 2) Beeko

27. Bi o ba je wipe beeni, ta ni o ko ogun foliki yii fun yin?

.....

28. Nje aisan abimo omo see dena de? 1) Beeni 2) Beeko 3) Mi o mo

29. Nje arsan abimo omo maa n ran lati iya tabi baba de omo? 1) Beeni 2) Beeko 3) Mi o mo

30. Nje itoju wa fun aisan abimo omo? 1) Beeni 2) Beeko 3) Mi o mo

31. Nje awon aisan abimo omo orisi kan see dena de pelu ogun foliki asidi ti a ba lo siwaju ki a to feraku? 1) Beeni 2) Beeko 3) Mi o mo

32. Nje awon ayewo kan wa ti alefi mo ti abiyamo ba ni aisan abimo omo ninu oyun?

1) Beeni 2) Beeko 3) Mi o mo

33. E da oruko meta ninu awon ayewo yii ti eba mo?

.....

.....

.....

Ipele Sii

34. Nje e mo wipe osese ki won bi omo ti ko ni ni ile iyagbe? 1) Beeni 2) Beeko

35. Bi o ba je beeni, bawo ni aisan yi se ri nipa ti mumu emi ni egodo lori iwon lati ookan (ti ko ni wahala rara pelu omo) si ewa (eyi ti ole mu emi omo lo ni waran sasa) .....

36. Nje emo wipe won le bi omo okunrin ti yio ma ya igbe ni inu ito?

1) Beeni 2) Beeko

37. Bi o ba je beeni, bawo ni aisan yi se ri nipa ti mumu emi ni egodo lori iwon lati ookan (ti ko ni wahala rara pelu omo) si ewa (eyi ti ole mu emi omo lo ni waran sasa) .....

38. Nje emo wipe won le bi omo obinrin ti yio ma ya igbe lati ile omo?

1) Beeni 2) Beeko

39. Bi o ba je beeni, bawo ni aisan yi se ri nipa ti mumu emi ni egodo lori iwon lati ookan (ti ko ni wahala rara pelu omo) si ewa (eyi ti ole mu emi omo lo ni waran sasa) .....

40. Nje emo wipe won le bi omo ti yio ni iho ni inu okan re?

1) Beeni 2) Beeko

41. Bi o ba je beeni, bawo ni aisan yi se ri nipa ti mumu emi ni egodo lori iwon lati ookan (ti ko ni wahala rara pelu omo) si ewa (eyi ti ole mu emi omo lo ni waran sasa) .....

42. Nje awon aworan ti ali han yin wonyi je ti omo ti o pe tabi omo ti o ni aisan abimo omo?

Aworan A:

1) Omo ti o pe 2) Omo ti o ni aisan abimo omo 3) Mi o mo

Ti o ba je ti omo ti o ni aisan abimo omo, kin ni kope ni inu aworan naa

.....

Aworan B:

1) Omo ti o pe 2) Omo ti o ni aisan abimo omo 3) Mi o mo

Ti o ba je ti omo ti o ni aisan abimo omo, kin ni kope ni inu aworan naa

.....

Aworan Sii:

1) Omo ti o pe 2) Omo ti o ni aisan abimo omo 3) Mi o mo

Ti o ba je ti omo ti o ni aisan abimo omo, kin ni kope ni inu aworan naa

.....

43. Nje won so fun yin pe won ye omo yin wo ni kete ti e bi? 1) Beeni 2) Beeko

44. Kin ni awon dokita tabi noosi so fun yin nipa ayewo ti won se fun omo yin ni kete ti e bi?

.....

.....

45. O to ojo melo leyin tie bi omo yin ti e fi ye ile iyagbe re wo? .....

46. Bawo ni e se se ayewo ile iyagbe re?

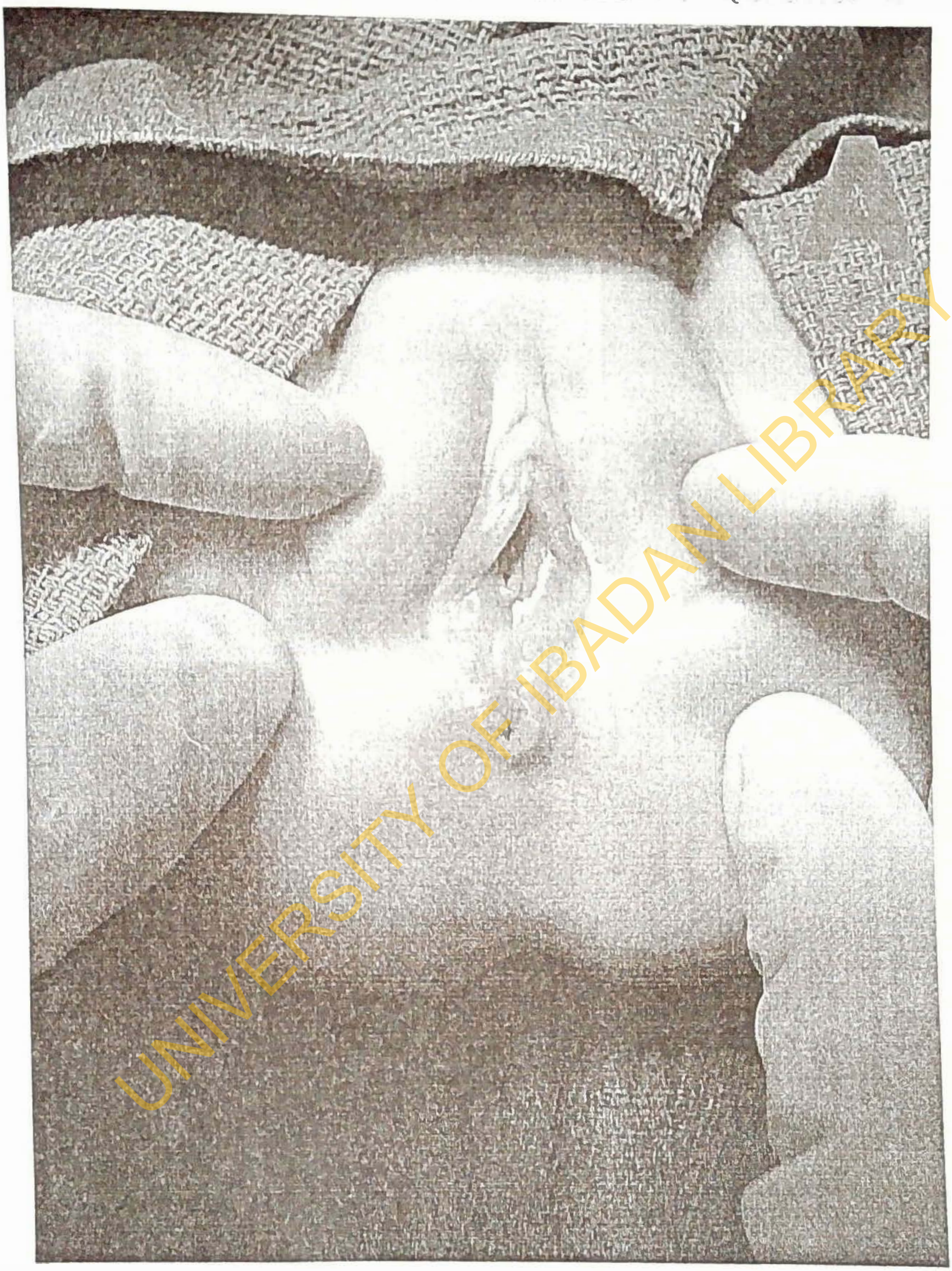
.....

.....

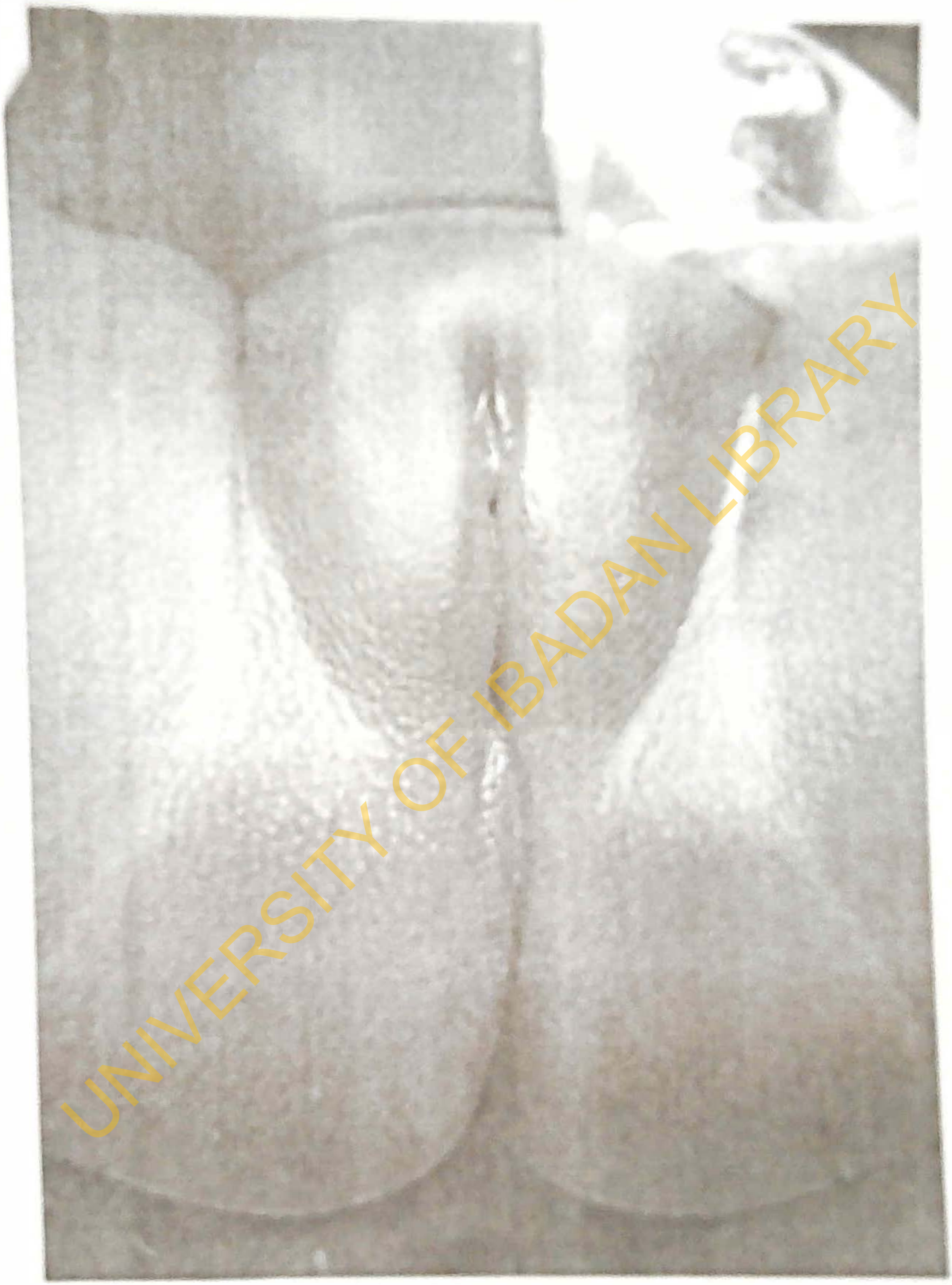
47. Ojo melo leyin ti e bi omo yin ni o ya igbe akoko? .....

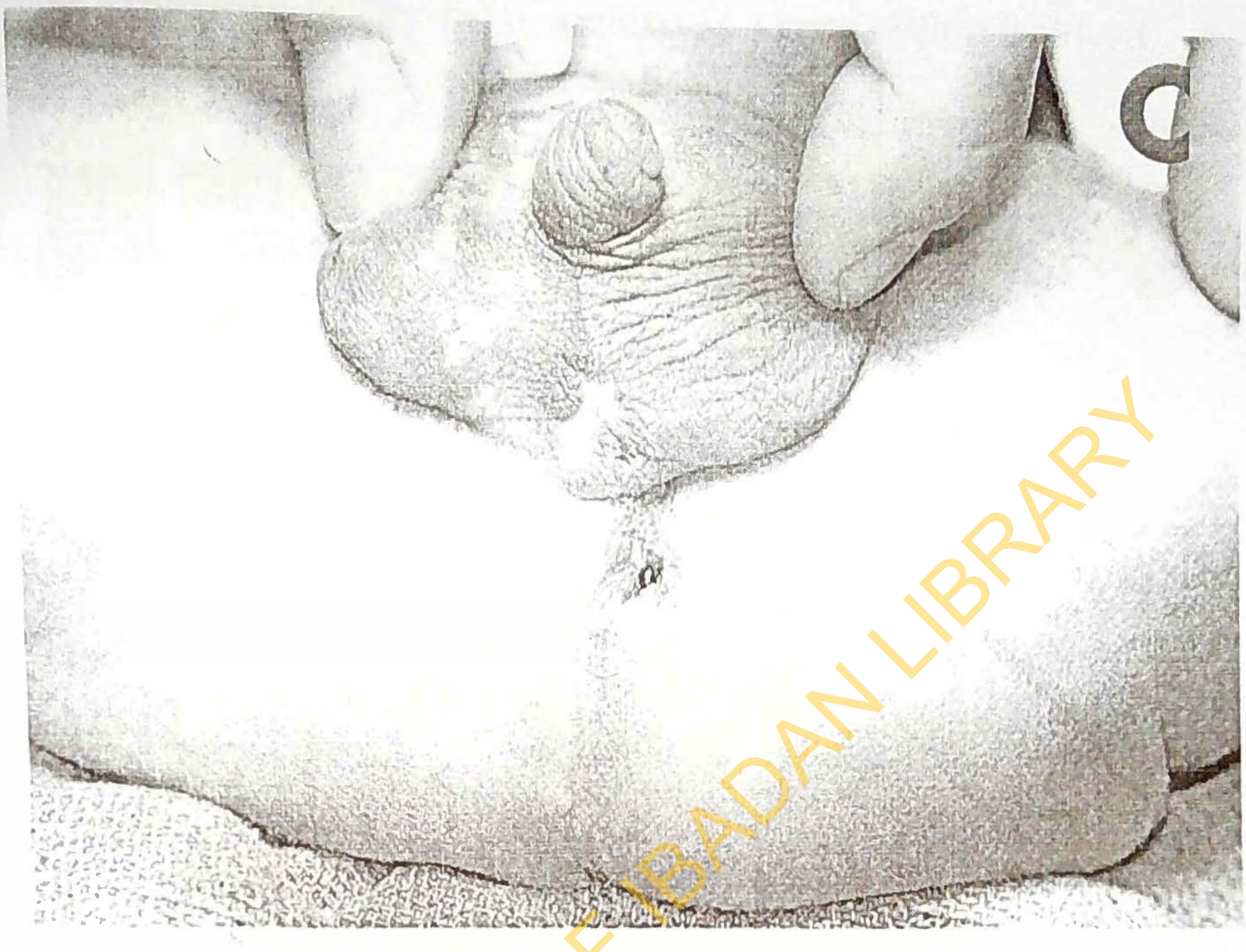
E se pupo

APPENDIX IB – PICTURES TO BE USED FOR QUESTION 42

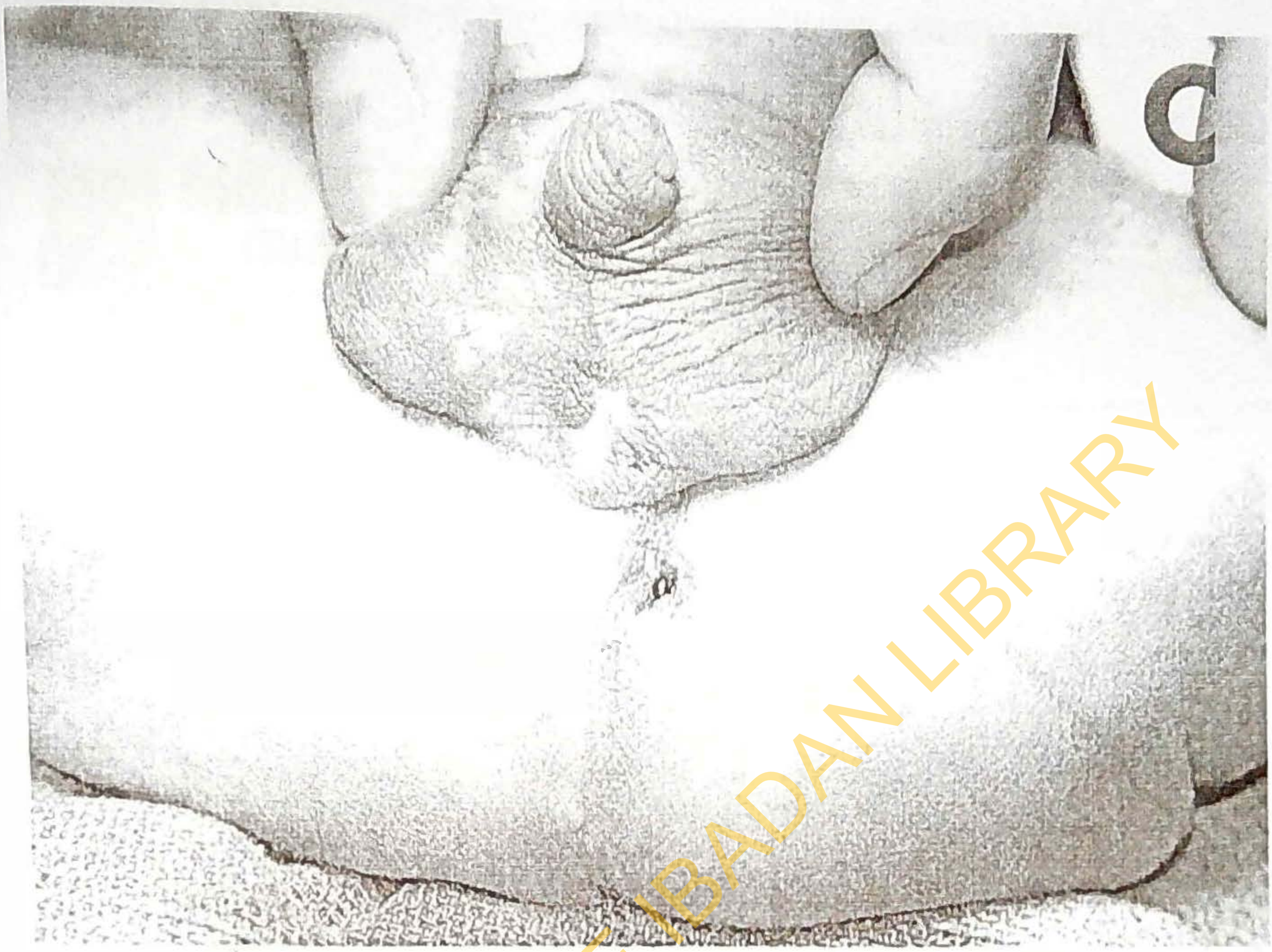


Newborn female with anorectal malformation and recto-perineal fistula





Male newborn with anorectal malformation and recto-perineal fistula



Male newborn with anorectal malformation and recto-perineal fistula

APPENDIX II – ETHICAL APPROVAL FROM UI/UCH ETHICAL COMMITTEE

INSTITUTE FOR ADVANCED MEDICAL RESEARCH AND TRAINING (IAMRAT)
COLLEGE OF MEDICINE, UNIVERSITY OF IBADAN. IBADAN, NIGERIA.
Director: Prof. A. Ogunniyi, B.Sc(Hons), MBChB, FMCP, FWACP, FRCP (Edin), FRCP (Lond)
Tel: 08023038583, 08038094173
E-mail: aogunniyi@comul.edu.ng

UI/UCH EC Registration Number: **NHREC/05/01/2008a**

NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW

Re: Maternal Perspectives about Birth Defects and Anorectal Malformations in Ibadan, Nigeria

UI/UCH Ethics Committee assigned number: UI/EC/12/0026

Name of Principal Investigator:	**Dr. T. A. Lawal**
Address of Principal Investigator:	Department of EMSEH, College of Medicine, University of Ibadan, Ibadan.
Date of receipt of valid application:	24/02/2012

Date of meeting when final determination on ethical approval was made: **24/05/2012**

This is to inform you that the research described in the submitted protocol, the consent forms, and other participant information materials have been reviewed and *given full approval by the UI/UCH Ethics Committee*

This approval dates from 24/05/2012 to 23/05/2013. If there is delay in starting the research, please inform the UI/UCH Ethics Committee so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside of these dates. *All informed consent forms used in this study must carry the* UI/UCH EC *assigned number and duration of* UI/UCH EC *approval of the study*. It is expected that you submit your annual report as well as an annual request for the project renewal to the UI/UCH EC early in order to obtain renewal of your approval to avoid disruption of your research.

The National Code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations and with the tenets of the Code including ensuring that all adverse events are reported promptly to the UI/UCH EC. *No changes are permitted in the research without prior approval by the* UI/UCH EC *except in circumstances outlined in the Code. The* UI/UCH EC *reserves the right to conduct compliance visit to your research site without previous notification*

UI/UCH EC
APPROVED
COLLEGE OF MEDICINE

Prof. A. Ogunniyi
Director, IAMRAT
Chairman, UI/UCH Ethics Committee
E-mail: uiuchirec@yahoo.com

APPENDIX III – INFORMED CONSENT FORM

I am Dr. Taiwo Akeem LAWAL, a Lecturer/Consultant in the Department of Surgery, University College Hospital, Ibadan and a student in the M.Sc Programme of the Department of Epidemiology and Medical Statistics. I am conducting a study on the perception of mothers about birth defects and anorectal malformations. I am interviewing mothers attending immunisation clinics in UCH/AMH, Ibadan of which you are one of those selected. I will need to ask you some questions regarding awareness and knowledge of these birth defects. Please note that your answers will be kept strictly confidential. Your name and that of your child will not be written down on the forms and will not be used in connection with any information that you provide. The information that I obtain from you concerning birth defects will be used by surgeons and paediatricians to help improve upon the care of children in Nigeria, especially those delivered with birth defects. You are free to refuse to participate in this study and you have a right to withdraw at any stage without giving a reason for doing so. I appreciate your assistance in participating in the study.

Consent: Now that the study has been well explained to me and I fully understand the content of the study process, I am willing to take part in the study.

....

Signature/Thumbprint of Participant/Date Signature of Interviewer/Date

.....

Signature/Thumbprint of Witness/Date (if required)

TRANSLATED INFORMED CONSENT FORM

GBIGBA ASE LATI KO PA NINU IWAADI

Oruko mi ni Dokita Taiwo Lawal. Mo je oluko ni eka ti ati n se ise abe bee si ni mo je akeko agba ni ogba nla faasiti ilu Ibadan. Emi ati awon elegbe mi yi o maa se ayewo nipati ibeere lowo awon mama wa ti o da lori aisan abimo omo ati ki omo ma ni ile iyagbe nigbati aba bi. Mo ma se ayewo yi ni ile igbabere ajesara ni ile iwosan ogba nla ti Ontamefa ati ti Adeoyo ni Yemetu, Ibadan, eyi ti o je pe e wa lara awon eniyan ti a yan lati kopa ninu iwaadi yii. N o beere ibeere lowo yin lehin naa ni n o se ayewo rupe fun awon omo yin. Eyi o si je ki a mo bi imo se gbile si nipa aisan abimo omo ati ki omo ma ni ile iyagbe ti aba bi.

Mo fe fi daa yin loju wipe gbogbo idahun si ibeere mi ko ni han si elomiran ati wipe oruko yin ati ti omo yin ko ni si ni ori iwe ibeere yii. Kikopa yin ati awon eniyan yooku ti a yan fun iwaadi yii yoo gbe eto ilera laruge ni orilede yii, paapaa ni eka ti itoju olomode. E ni eto lati maa kopa ati lati so pe eko ni kopa ninu iwaadi yii mo ni igba ku gba ti o ba wu yin. Aikopa ko ni fa idiwo si gbigba itoju ni ile iwosan yii.

Adupe lowo yin fun kiko bi ara si ati lati kopa ninu iwaadi yii.

Gbigba ase

Nigba ti won ti se alaye fun mi lekun rere ni pa iwadi yii, mo setan lati ko pa

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Fifi owo si ni ofiri eka olukopa/oju **Fifi owo si iwe olu beere/oju**

_____

Fifi owo si iwe/titi eka elerii/oju