LEVEL OF KNOWLEDGE OF NEONATAL DANGER SIGNS AND FACTORS THAT INFLUENCE KNOWLEDGE AMONG MOTHERS AT JUBA TEACHING HOSPITAL AND AL SABBAH CHILDREN'S HOSPITAL IN JUBA, SOUTH SUDAN – A HOSPITAL-BASED DESCRIPTIVE CROSS SECTIONAL STUDY

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DECLARATION

I certify that this dissertation is my original work and has not been presented for the award of a degree in any other university.

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ABBREVIATIONS

ANC	Antenatal Care
AOR	Adjusted Odds Ratio
CES	Central Equatoria State
COR	Crude Odds Ratio
GOSS	Government of South Sudan
IMNCI	Integrated Management of Neonatal and Childhood Illness
JTR	Juba Teaching Hospital
МСН	Maternal and Child Health
МоН	Ministry of Health
NBU	Newborn Unit
NDS	Neonatal Danger Signs
NMR	Neonatal mortality rate
OPD	Outpatient department
OR	Odds Ratio
РНСС	Primary Health Care Centre
PNC	Postnatal Care
SDG	Sustainable Development Goals
SSA	Sub-Saharan Africa
UN	United Nations
USD	United States Dollar
WHO	World Health Organization
YICSSG	Young Infant Clinical Signs Study Group

OPERATIONAL DEFINITIONS

Knowledge: information, understanding or skills gained through education or experience; awareness of or familiarity with a subject or practice gained through experience or observation

Neonatal danger signs: signs of illness in the newborn that could be associated with increased risk of mortality (1). These include:

- stopped feeding well/difficulty feeding
- history of convulsions or fits
- fast breathing (breathing rate of ≥ 60 breaths per minute)
- severe chest in-drawing
- no spontaneous movement
- fever (temperature $\geq 37.5^{\circ}$ C)
- low body temperature (temperature <35.5°C)
- jaundice in first 24 hours of life, or yellow palms and soles at any age
- signs of local infection: umbilicus red or draining pus, skin boils, or eyes draining pus

Mother: the female parent of a child. For the purposes of this study, a mother will be defined as a woman who has given birth to the child and has the primary responsibility for the physical and emotional care for the child.

Practice: the customary, habitual or expected procedure or way of doing something. For this study, it will be care seeking if or when signs of illness are detected.

Delayed care seeking: seeking medical attention more than 24 hours after recognizing signs of illness (2).

Unstable neonate: for the purposes of this study, an unstable neonate will be defined as a baby with conditions requiring lifesaving intervention such as cardiopulmonary resuscitation or treatment for hypoglycemia, convulsions, hypothermia, shock, and severe respiratory distress.

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ABSTRACT

Background: The Neonatal Mortality Rate (NMR) in South Sudan is high at 38.6 deaths per 1000 live births. Early detection and timely care seeking for sick neonates are critical steps in improving neonatal survival. Poor knowledge of neonatal danger signs (NDSs) results in poor care seeking practices. This study aimed to determine the level of knowledge of NDSs among mothers in Juba and their care seeking practices once illness is recognized.

Objectives: The primary objective was to assess the level of knowledge of NDSs among mothers at two public health facilities in Juba, South Sudan. The secondary objectives were to assesses care seeking practices of mothers of sick neonates and to determine the factors that influence this knowledge and care seeking practices.

Method: A hospital based descriptive cross-sectional study of mothers of neonates seeking services at JTH and Al Sabbah Children's Hospital. An interviewer administered questionnaire was used to capture sociodemographic data as well as knowledge of NDS and care seeking practice. Knowledge on NDSs and care seeking practice was presented as percentages with 95% confidence intervals (CI). Logistic regression models were used to find associations between variables, with statistical significance set at p<0.05,

Results: A total of 274 mothers were recruited. Only 36%(95%CI:30.1%-41.8%), were found to have good knowledge on NDS. Internet access AOR =2.77, 95%CI:1.34–5.73, p =0.006, prior knowledge on NDS AOR =2.93, 95%CI:1.58–5.45, p =0.001 and NBU admission OR =4.00, 95%CI:1.4–10.90, p =0.009 were factors associated with good knowledge. Only 55% of mothers of sick neonates sought medical care withing 24 hours. Factors associated with good care seeking practice included neonatal age \leq 7 days OR =2.01, 95%CI:1.12–3.83, p =0.022, and maternal possession of a smart phone, OR =1.90, 95%CI:1.10–3.61, p =0.035.

Conclusion: Maternal knowledge on NDSs and care seeking practice for neonatal illness were poor. Effective education programs on NDSs and appropriate health seeking practise for neonatal illness are needed.

CHAPTER ONE: INTRODUCTION

1.1. BACKGROUND

Despite concerted efforts by governments worldwide to reduce Neonatal Mortality Rate (NMR) to less than 12 deaths per 1000 live births, the rate of decrease in newborn mortality has been slow. The global average yearly rate of decline of NMR was 2.6% from 1990 to 2018 compared to 3.6% among children between 1-59 months of age (3,4). As a result, the estimated 2.5 million deaths that occur within the first month of life account for approximately 47% of all deaths in children under the age of five years. Globally, NMR range from 1 death per 1000 live births to 42 deaths per 1000 live births.

Three conditions contribute to seventy-five percent of the neonatal deaths. They include preterm delivery (35%), intrapartum related complications (24%), and infections (23%) (4,5). These are preventable conditions and for which affordable evidenced-based treatment exists.



Figure 1: Global distribution of causes of neonatal mortality (6)

Thirty percent of newborn mortalities occur within 24 hours of birth, and 75% occur by the first week(6,7). Many newborns die at home due to early hospital discharge, barriers to access of health facilities and delays in seeking care for sick and small newborns (8). Thadeus and Maine designed

a model that described three main stumbling blocks to access to high quality maternal care (9): 1) delay in recognizing sickness and delay in making the decision to seek medical help; 2) delay in finding and getting to a health facility; and 3) delayed access to prompt and appropriate care. Other researchers have since used this approach to determine what factors play a role in why neonates die in their settings. Waiswa et al used this model to examine data on 64 deaths in eastern Uganda. They discovered that caregiver delays in noticing a problem and deciding to seek medical help were the major causes of neonatal deaths. (10). Similar studies done in India and Sudan found that of the neonatal mortalities that were credited to delay is seeking care, inability of mothers to recognise a sick child was a major contributing factor (11,12).

1.2. NEONATAL MORTALITY IN SOUTH SUDAN

Neonatal mortality rate in South Sudan remains high at 38.6 deaths per 1000 live birth (13). This places South Sudan among the top 10 countries with the highest NMRs in the world. Neonatal mortality accounts for 42% of all under 5 mortality (U5M) and 65% of all infant deaths in the country.

Some of the factors contributing to this high NMR include civil war and conflict, high prevalence of non-use of Maternal and Child Health (MCH) services, weak health care system, poverty, maternal illiteracy, negative perceptions and limited access to high-quality health-care services (14).

Longstanding war and continued political instability since independence in 2011 has severely affected the country's socioeconomic development. According to estimates, over 50% of the population lives on less than \$1 a day, 63% is illiterate, and 75% does not have access to health care services (15). It has been found that the chance of a child dying before their fifth birthday was 80 times higher in war-torn nations than in non-affected nations (16,17). According to estimations from the World Bank, nine of the twenty nations with the highest U5MR in the world—including South Sudan—were war-torn (17).

The high prevalence of women not making use of Maternal, Neonatal and Child Health (MNCH) services is a significant contributor to the high NMR in South Sudan (18,19). Only 18% of pregnant women attend at least 4 ANC visits, and 58% of them skip ANC altogether (18). A Skilled Birth

Attendant (SBA) attends only 19% of births (20,21). Although nationwide statistics on facility based deliveries are currently unavailable, a study by Tongun *et al* found that only 25% of deliveries in Jubek state took place in a health facility (22). There are no statistics available on how frequently postnatal services are used. This high prevalence of non-utilization of MCH services means that most pregnant and postpartum women do not get the opportunity for education on appropriate newborn care and their children also miss out on essential newborn care.

1.3. NEONATAL DANGER SIGNS

Because clinical signs and symptoms of most newborn illnesses are not always specific, the Integrated Management of Neonatal and Childhood illness (IMNCI) model has endeavored to provide a standardized criteria of several neonatal illnesses founded on key clinical signs that may indicate severe disease in young infants(1) – these collectively are known as Neonatal Danger Signs (NDS). They include poor feeding, convulsions or fits, severe lower chest indrawing, fast breathing (respiratory rate >60breaths/minute), no spontaneous movement, hypothermia (temperature <35.5°C), fever (temperature > 37.5°C), jaundice in the first day of life or yellow palms hands and soles of feet at any age, local infection (umbilical redness or drainage of pus, skin pustules/boils or purulent eye discharge) (1).

These specific signs and symptoms were chosen based on results from a large World Health Organization (WHO) multicenter (South Africa, Ghana, Bolivia, Pakistan, India, and Bangladesh) study on the clinical predictors of severe illness in young infants (1). It enrolled 3177 neonates aged 0-6 days and 5712 infants aged 7-59 days who had been brought to health centers with acute illnesses. Thirty-one signs and symptoms were documented, after which each case was evaluated separately, by a qualified paediatrician, for serious disease requiring hospitalization. The researchers then looked at the specificity, sensitivity, and odds ratio for each sign separately, and in algorithms, to see how well they could predict serious illness. The finding revealed that for neonates aged 0-6 days, the occurrence of any one of following twelve signs/symptoms predicted severe disease (sensitivity 87% and specificity 74%): difficulty feeding, lack of spontaneous movements, convulsions, lethargy, respiratory rate of 60 breaths per minute or more, grunting, severe chest indrawing, temperature below $35 \cdot 5^{\circ}$ C or $37 \cdot 5^{\circ}$ C and above, cyanosis, stiff limbs and

prolonged capillary refill. The algorithm was later condensed to just seven signs (difficulty feeding, lack of spontaneous movement, convulsions, respiratory rate equal or more than 60 breaths per minute, temperature of 37.5°C or more or below 35.5°C and severe chest indrawing), with sensitivity of 85 percent and specificity of 75 percent remaining relatively unchanged. Sensitivity and specificity for infants 7-59 days of age were 74% and 79% respectively.

Other studies have shown similar results (23–26). Opiyo *et al* conducted a comprehensive evaluation of the data from observational studies on the clinical markers of critical illnesses in infants 0–59 days of age, particularly those that tried to establish a minimum set of signs and symptoms that predicted the need for hospital level care (27). The review concluded that overall, the evidence suggested that severe illness in young infants was best predicted by eight clinical signs. These included: convulsions, reduced level of activity, feeding difficulty, fast breathing/respiratory rate \geq 60 breaths per minute, grunting, severe chest indrawing, cyanosis and axillary temperature \geq 37.5°C or <35.5°C. These signs were chosen based on the ease with which they could be recognized, prevalence in the study population and their degree of associations with severe illness.

Although jaundice was not excluded in the Young Infant Clinical Signs Study Group (YICSSG) study, it is included among the WHO neonatal danger signs because jaundice in the first 24 hours of life (pathological jaundice) and jaundice to the soles of the feet (indicating hyperbilirubinemia) increases the risk of bilirubin-induced mortality or long-term neurodevelopmental impairment (28).

These signs are used by health care workers during assessment of the newborn and should be taught to all pregnant women and postpartum mothers at every point of contact to raise awareness and to enhance early detection of illness in the newborn. Raising awareness on danger signs in the neonate among caregivers and communities and encouraging prompt medical attendance from trained personnel can go a long way in improving newborn outcomes (29). Concerning caregivers' care-seeking behaviors after recognizing danger signs, studies have revealed that prompt and appropriate care-seeking does not always followed recognition of these symptoms (9,30,31). It is, therefore, important that equal emphasis be placed on caregivers' education on NDSs and appropriate care seeking practice.

1.4. ABILITY OF CAREGIVERS TO RECOGNIZE DANGER SIGNS

Signs of disease in newborns are often subtle and difficult to distinguish, and if left untreated, infections can rapidly progress to become life-threatening. Early recognition of a sick child and prompt attention from qualified health professionals are therefore essential for survival and/or prevention of long term disability (26). Numerous studies have shown that the delay in seeking medical attention for small and sick newborns is significantly influenced by caregivers' ignorance of the early symptoms of neonatal illness, which, in turn, results in poor neonatal outcomes (10–12).

CHAPTER TWO: LITERATURE REVIEW

2.1. MATERNAL KNOWLEDGE OF NEONATAL DANGER SIGNS

According to studies, mothers' health-seeking behavior is influenced by their understanding/awareness of NDS. Neonatal mortality is significantly impacted by the mother's lack of knowledge of NDSs and her delay in seeking care (8–10,12).

The level of awareness of mothers and other caregivers on NDSs has been the subject of numerous research in Sub-Saharan Africa (SSA) and other developing nations (33–38). Most results show that a paucity of knowledge on NDSs exists among most caregivers. Poor knowledge is, in turn, linked with delay in seeking medical help (10,39). This is represented as delay number one in the three-delay model which was originally created by Thaddeus and Maine to understand maternal death (9).

Kibaru EG *et al* carried out a cross sectional descriptive study on the knowledge of NDSs among mothers attending immunization in Nakuru, Kenya (37). Of the 414 mothers who were interviewed, a majority, 350 (84.5%), could not identify more than 3 NDSs. Among others, factors such as education level, postnatal care (PNC) accompanied by spouse, explanation of the Maternal and Child Health (MCH) book by medical workers during antenatal care and education provided on NDSs resulted in better understanding of NDSs.

A community based cross sectional study conducted by Nigatu SG *et al* in Northwest Ethiopia looked at the level of mothers' knowledge about NDSs and its associated factors (33). Six hundred and three mothers were interviewed, and the results revealed that only 18.2% of all mothers had knowledge on three or more NDS. Factors positively associated with improved knowledge included maternal and paternal education status, antenatal and postnatal care attendance, and access to a television-probably indicating better socioeconomic status. These positive associations were attributed to possible increased exposure to education on NDS.

Similarly, Ekwochi U *et al.* carried out a community-based descriptive and analytical study in Enugu state, Southeast Nigeria, to evaluate the perception and knowledge of mothers and care givers of danger signs in newborns and found that knowledge of NDSs was poor (36). Three

hundred and seventy-six participants from four communities in four of the 17 local government areas were recruited and interviewed. Only 0.3-30.3% of mothers recruited from the four communities could name more than 3 WHO recognized NDSs. They recommended that more effort be put into the education of all pregnant women on NDSs and the right measures to take once danger signs were recognized.

Results from similar studies conducted in other developing countries echo those found in SSA (9,38). A cross sectional survey conducted by Abu-Shaheen A *et al* in Saudi Arabia on knowledge and experience of mothers and caregivers of NDS found that of the 1428 women interviewed, only 37% could identify three or more NDSs. Even though most mothers had attended the required minimum of four ANC, there was surprisingly poor knowledge of NDS (38). Similar results were reported in Uganda from a community survey of 765 postpartum mothers that assessed their knowledge on NDSs (40). These findings raised concerns on the quality of education and counselling given during ANC as earlier studies done in Malawi and Laos indicated that education on NDSs given during the ANC period improved the knowledge of danger signs throughout and after pregnancy (10,41).

Table 2 below summarizes studies done caregivers' knowledge on neonatal danger signs. These studies demonstrated that knowledge on NDSs among caregivers is generally poor.

Author and Title	Study design and	Results
Kibaru E <i>et al</i> 2016 Knowledge of neonatal danger signs among mothers attending well baby clinic in Nakuru Central District, Kenya(37).	E et al 2016Cross sectional descriptive study84.5% identified lessIge of neonatal danger iong mothers attending by clinic in Nakuru District, Kenya(37).Cross sectional descriptive study 414 mothers84.5% identified less Education level, PNC by husband, danger si information to mother positively associated improved knowledge	
Nigatu S <i>et al</i> 2015 Level of mothers' knowledge about neonatal danger signs and associated factors in Northwest Ethiopia(33).	A community- based study 603 mothers	18.2% had knowledge of 3 or more NDSs.Level of education, ANC and PNC attendance and access to television were associated with good knowledge.
Ekwochi U <i>et al</i> 2015 Knowledge of danger signs in newborns and health seeking practices of mothers and caregivers in Enugu State, South- East Nigeria(36).	A community based descriptive and analytical study 376 mothers and caregivers	Knowledge of 3 or more WHO recognized NDSs was poor (0.0- 30.3%). Knowledge of at least 1 NDSs significantly determined health care seeking behaviour.
Abu-Shaheen A <i>et al</i> 2019 Mothers' and caregivers' knowledge and experience of neonatal danger signs(38).	A cross sectional survey in Saudi Arabia 1428 women	37% could identify 3 or more neonatal danger signs.Level of knowledge was low despite most women having attended the recommended 4 or more ANC visits.
Sandberg S <i>et al</i> 2014 Inadequate knowledge of neonatal danger signs among recently delivered women in Southwestern rural Uganda(40).	A community Survey 765 women	Overall, respondents had poor knowledge. 58.2% could identify 1 sign. 14.8% could identify 2 signs. No association was found between attending recommended ANC visits with knowledge of NDSs.

Table 1: Literature review on factors that influence maternal and caregiver knowledge of NDSs

2.2. NEONATAL DANGER SIGNS AND CARE SEEKING PRACTICE

Care seeking practices of mothers and/or caregivers has a significant impact on the outcome of neonatal illness. The timing and type of care sought when neonatal illness is recognized often determines whether the infant lives or dies (10,42). Studies carried out in various low-resource settings show that care seeking practice by mothers and/or care givers for neonatal illness is universally poor (9,31,34,42,43).

Bulto GA *et al.* conducted a study among mothers at government facilities in Ambo town, Ethiopia, where they tried to find out what knowledge mothers had on NDSs and what steps they took when they suspected illness in the neonate (30). They found that both knowledge and appropriate care seeking practices were poor. Only 20.3% of mothers could name at least three WHO-recognized NDSs. Sixty percent of mothers whose newborns showed danger signs sought immediate treatment from medical facilities, 20.9% waited for symptoms to resolve and 8.9% only sought medical attention when the infant's condition deteriorated.

Another study conducted in Sarlahi district, Nepal by Lama TP *et al* found that even though danger signs and symptoms were often noticed early, the severity of the sickness was not recognized until later. This hampered timely seeking of health care for both women and newborns (9). Most sick mothers and neonates were initially attended to by non-medical health practitioners such as village doctors, traditional healers and traditional birth attendants before facility-based care was sought. Sick neonates were taken to hospitals only when management by unofficial providers failed or upon referral. Respondents believed that public hospitals provided poor quality care for newborns, hence private facilities were preferable.

According to a quantitative study conducted in Pakistan, Bangladesh and Nepal, routine care seeking, particularly in the post-natal period, was found to be inadequate (43). This was attributed to local customs, a lack of understanding of the need for immediate medical help when danger signs are detected, and a perception of substandard health-care quality. Because of tradition/spiritual philosophies, economic constraints, and limited access to medical centers, families who sought help preferred traditional healers over trained health workers.

Table 2 below summarizes studies done across the globe on care seeking behaviour among mothers and care givers of sick neonates. The results demonstrate a worrying trend of delay in seeking care, with failure to recognise signs of illness being a predominant reason.

Author and title	Study design and population	Results
Bulto G <i>et al</i> 2019 Knowledge on Neonatal danger signs, care seeking practice and associated factors among postpartum mothers at public health facilities in Ambo town, Central Ethiopia(34).	Institutional based descriptive cross-sectional study 404 women	 20.3% had good knowledge on NDSs. 60.5% of mothers whose babies developed NDSs sought treatment immediately. 20.9% waited for improvement and 18.9% sought treatment when condition worsened.
Lama T <i>et al</i> 2017 Illness recognition, decision making and care seeking for maternal and newborn complications in Sarlahi District, Nepal (9).	A qualitative study 36 cases	Delayed care seeking due to delay in perceiving severity of illness. Care was often sought from informal health providers
Syed U <i>et al</i> 2008 Care seeking practice in South Asia: using formative research to design program intervention to save newborn lives (43).	A qualitative study in Bangladesh, Nepal, and Pakistan	Routine care seeking in postnatal period was poor. This was attributed to local traditions, poor knowledge on importance of care seeking and recognition of danger signs, and perceived poor-quality care in health facilities

Table 2: Literature on care seeking behaviour of mothers and caregivers

2.3. CONCEPTUAL FRAMEWORK

Knowledge on NDSs influences care seeking practices of mothers and caregivers (11,12). Using the three-delay model, Waiswa et al demonstrated that caretaker delay in illness recognition and care seeking was an important contributor to neonatal death (10). This finding has been corroborated by other studies carried out in SSA and abroad that consistently showed that inadequate knowledge on NDSs leads to late care seeking for sick and small newborns (9,31,43). Meanwhile, the impact of maternal knowledge on NDS on care seeking practice can be enhanced or jeopardized by various sociodemographic characteristics of mothers and family dynamics (9,30,31,42,43). Furthermore, studies that assessed maternal knowledge on neonatal danger signs showed that certain socioeconomic characteristics of mothers and caregivers were also directly associated with good or poor knowledge (33,37,40,44). These relationships and associations between the variables as well as potential moderating factors are demonstrated in the conceptual framework below.



Figure 2: Conceptual framework depicting the relationship and associations between dependent and independent variables and potential moderating variables.

Blue box: independent variables. Black box: dependent variables. Orange box: moderating variables

2.4. STUDY JUSTIFICATION

Despite the many strategies designed and employed by governments and international organizations worldwide to improve newborn outcomes, NMR remain high in SSA and Southern Asia. With a NMR of 38.6 deaths per 1000 live births, South Sudan is among the 60 nations the WHO projects will not be able to achieve Sustainable Development Goal (SDG) 3 of lowering NMR to 12 deaths per 1000 live births or less by the year 2030 (4).

Neonatal infections account for approximately 28% of all neonatal deaths in South Sudan (13,45). Early detection of illness and early appropriate medical intervention is an important step toward improving newborn survival. This can only be achieved if mothers, who are the primary neonatal care givers in most households, are knowledgeable on the symptoms of neonatal illness, and appreciate the need for timely seeking of medical care for the sick neonate.

With a high prevalence of mothers not using MCH service (18,19) – important avenues for maternal education- together with poorly staffed and equipped health facilities (46,47), many newborns are at risk of preventable deaths due to inadequate education. No studies had been done in South Sudan assessing maternal knowledge of NDSs and where mothers sought help once illness was detected; particularly, of the mothers who utilize MCH services. Although many studies estimate just the cause of mortality among newborns, understanding the care-seeking processes and therapeutic interventions taken before each death is equally significant for designing effective health programming (48).

In a country with poor health care systems and a population that is ravaged by extreme poverty and who has poor access to high-quality medical services (19), focus on early recognition of important signs of a sick neonate and early care seeking should be encouraged. This will prevent progression to severe illness that require advance skills in management, that are often lacking in South Sudanese health facilities.

Maternal health education has proved to be an effective and sustainable means of improving knowledge on newborn care (41). However, to design effective education programs and other preventative strategies, data on the current gaps in knowledge and health seeking practices is required.

This study, therefore, aimed to assess the level of knowledge of mothers on neonatal danger signs and their care seeking practices once they suspect illness in the neonate. It explored the sociodemographic characteristics of mothers that had association with good knowledge of these signs and their health seeking behaviours. Selection of the two largest public health facilities in the country ensured that the study participants were drawn from a cohort that is representative of the larger population. This helped in overcoming the financial and time constraint that a community survey would have presented. The two hospitals are accessible to many of the residents of Juba and for most part, provides neonatal services that are unavailable in other public health facilities. The data that has been generated will be used to audit the current MCH services in terms of education of pregnant and postpartum mothers on newborn care. It will also be used for advocacy to prompt the Ministry of Health (MoH), Government of South Sudan (GOSS) to put more emphasis and resources in maternal education in health facilities and community non-health facilities as strategy to reduce neonatal mortality.

2.5. STUDY QUESTION

What is the level of knowledge of neonatal danger signs among mothers seeking any health services (both curative and preventative services) for neonates at Al Sabbah Children's Hospital and Juba Teaching Hospital, Juba, South Sudan?

2.6. OBJECTIVES

2.6.1. Primary Objective

 To assess the level of knowledge of neonatal danger signs among mothers of neonates aged 0-28 days in Al Sabbah Children's Hospital and Juba Teaching Hospital in Juba, South Sudan.

2.6.2. Secondary Objective

 To assess factors that influence knowledge of WHO recognized neonatal danger signs among mothers seeking care for sick neonates aged 0-28 days in Al Sabbah Children's Hospital and Juba Teaching Hospital in Juba, South Sudan.

- 2. To assess care seeking practice (signs and symptoms that prompt care seeking, duration between recognition of sick neonate and seeking care, who makes decision to seek care and where care is first sought) among mothers of sick neonates aged 0-28 days in Al Sabbah Children's Hospital and Juba Teaching Hospital in Juba, South Sudan.
- To assess the factors that influence care seeking practice among mothers of sick neonates aged 0-28 days in Al Sabbah Children's Hospital and Juba Teaching Hospital in Juba, South Sudan.

CHAPTER THREE: METHODOLOGY

3.1. STUDY DESIGN

This was a hospital-based descriptive cross-sectional study.

3.2. STUDY SITE

This study was conducted in two public hospitals in Juba, South Sudan. Juba is the largest city in South Sudan and serves as the country's capital as well as the state capital of Central Equatoria State. It lies on the banks of the White Nile River. As of 2021, the city's population was estimated to be approximately 421 000, with a 4.47% yearly growth rate (49). Longstanding war and continued political instability since independence from Sudan in 2011 has severely affected the country's socioeconomic development. Sixty-three percent of the population is reported to be illiterate and over fifty percent live on less than a dollar a day (15).

Juba Teaching Hospital (JTH), the only tertiary care referral hospital in the country, is located within Juba city. It has a 580-bed capacity and not only serves the people of Juba, but the entire population of South Sudan. It is funded by the MoH, GOSS together with support from Real Medicine foundation, Medical Missions International, United Nations (UN) agencies and other non-governmental organizations. As of 2018, paediatric services for infants and children beyond the neonatal period were fully transferred from JTH to Al Sabbah Children's Hospital. The patients in the paediatric age group served at JTH are stable newborns with their mothers in the postnatal ward, and small and sick neonates admitted in the Newborn Unit (NBU). The NBU has a 20-bed capacity and admits sick and preterm in-born neonates, and out-born (particularly preterm) neonates. On average, the hospital conducts about 400 deliveries monthly and approximately 100 neonates are admitted to the NBU per month (source: 2021 Hospital database). Mothers in the labour and postnatal wards are under the care of maternity nurses, registered medical officers and medical officer interns under the supervision of a consultant obstetrician. Newly born babies are usually reviewed by the attending medical officer/medical officer intern, and most are not reviewed by a paediatrician prior to discharge. Barring any complications, most mothers who have

had vaginal deliveries, are discharged home within 24 hours of delivery. Mothers of newborns who are delivered through caesarean delivery are discharged within 48 to 72 hours of delivery.

Al Sabbah Children's Hospital, also located in Juba, was built by King Sabbah of Kuwait in 1983 as a donation to the then Southern region of the Republic of Sudan. Since 2008, the hospital has been under the administrative charge of the Central Equatorial State (CES) Ministry of Health, which also provides most of the funding for the hospital. Supplementary funding is provided by the national MoH and Health Pool Fund (HPF), an initiative that is funded by multiple donors that aims, in partnership with GOSS, to strengthen health systems and provision of vital services in the country. The hospital provides preventative, curative, and rehabilitative services to children within Juba County and beyond. Up to 200 children per day are attended to in the outpatient department (OPD); approximately 50% of whom are neonates. The hospital has a designated neonatal ward where all sick neonates requiring hospital admission are treated. On average, the total number of neonates seen in the various departments are as follows: OPD 750 neonates, neonatal inpatient ward 350 neonates, well baby/immunization clinic 400 neonates (sources: 2021 Hospital database). Care is provided by paediatric nurses, clinical officers, and medical officers and interns, all of whom are under the supervision of consultant paediatricians.

ANC services are available at four public facilities within Juba County, namely JTH, Kator Primary Health Care Centre (PHCC), Malakia PHCC and St Kizito PHCC. All pregnant women are provided with a MCH booklet during their first ANC visit and are encouraged to attend at least 8 clinics during the pregnancy. Reviews are done by trained nurses or clinical officers and expectant mothers are referred to an obstetrician should a complication arise.

All services provided at public health facilities are free of charge, except for laboratory tests for which patients/clients pay a subsidized rate to support reagent supply.

3.3. STUDY POPULATION

The population of interest were mothers of neonates aged 0 - 28 days admitted in the paediatric and postnatal wards and those attending the well-baby and casualty paediatric outpatient clinics at Juba Teaching Hospital and Al Sabbah Children's Hospital in Juba, South Sudan.

3.3.1. Inclusion Criteria

- Mothers of neonates aged 0-28 days seeking curative and preventative services in the selected hospitals during the study period and who gave consent.

- Mothers of neonates with underlying medical conditions that require routine follow-up who had come to hospital on a non-scheduled visit.

3.3.2. Exclusion Criteria

- Caregivers other than the mother of the infant.

- Neonates with scheduled appointment for illnesses/medical conditions that require follow-up other than routine neonate care. The decision to bring these infants to hospital is usually not inspired by recognition, by the mothers, of signs of illness but rather because they have been instructed to bring the babies to hospital at specified intervals. Additionally, these mothers would have had more contact with health care workers than the average mother and as such, may have had more opportunity for education on NDSs, thereby, introducing bias.

- Mothers of neonates aged 0 to 28 days who were unable to communicate owing to significant sickness or mental retardation.

3.4. SAMPLE SIZE DETERMINATION

The total sample size of the study was determined using single population proportion formula by assuming 5% level of significance, 5% margin of error, and taking 29% proportion of good maternal knowledge on neonatal danger signs based on similar studies in Ethiopia(33).

The Cochran formula for calculating sample size was used.

$$n_0 = \frac{z^2 p q}{e^2}$$

Where:

- n_0 = is the sample size
- z = is the selected critical value of desired confidence level
- p = is the estimated proportion of an attribute that is present in the population

-
$$q = 1 - p$$

- e = is the desired level of precision

Therefore:

 $n_0 = \frac{(1.96)^2(0.29)(0.71)}{(0.05)^2}$

 $n_0 = 274$

The calculated sample size (n_0) is 274

3.5. SAMPLING METHOD

Proportionate allocation of study participants based on the number attended to at each clinic or ward was done. Eligible participants in the various departments, wards and clinics at JTH and Al Sabbah Children's hospital were consecutively sampled until the desired sample size was reached. The research eligibility criteria were used to screen all mothers of newborns seeking medical attention at the institutions. Those satisfying the criteria were approached by the interviewer and requested to participate in the study. Potential study participants in the clinics (outpatient and immunization clinics) were selected from the queue as they awaited registration or attendance by the clinicians or nurses. All mothers admitted in the postnatal ward or mothers of babies admitted to the NBU in JTH or the neonatal ward at Al Sabbah Children's hospital were considered potential candidates, if they gave consent to participate. New admissions were identified through the admission records.

Proportionate allocation of study subjects based on the number of neonates seen per hospital per month was done. The total number of study participants recruited from each hospital and then each clinic or ward in the relevant hospitals depended on the patient/client flow per clinic/ward per month. According to the respective hospital records, approximately 2000 neonates are seen across the two hospitals on a monthly basis (source: 2021 Hospital database). Table 3 below summarizes the distribution of neonates seen across both hospitals monthly.

Juba Teaching Hospital		Al Sabah Children's Hospital		
Department	Number of patients attended to per month	Department	Number of patients attended to per month	
Postnatal Ward	400	Outpatient department	750	
NBU admissions	100	Neonatal inpatient ward	350	
Immunization clinic	100	Immunization clinic	300	
Total	600		1400	

Table 3: Distribution of neonates across both hospitals monthly

Based on these numbers, the distribution of study subjects was as follows: 30% from JTH and 70% from Al Sabbah Children's hospital. At JTH, 20% of mothers were selected from the NBU, 60% were selected from the postnatal ward and 20% from the immunization clinic. Distribution of study participants from Al Sabbah was as follows: 55% from OPD, 23% from neonatal inpatient wards and 22% from the immunization clinic. This distribution of participants reflected on average how each department contributes to the total number of paediatric patients seen across both hospitals and within each department. This manner of distribution also ensured that more than 50% of participants were mothers seeking curative services for sick neonates, thereby ensuring recruitment of adequate numbers for the assessment of health seeking practices.

3.6. STUDY PROCEDURE

The sampling procedure was followed, and potential candidates were identified using the eligibility criteria. The interviewer began by outlining the study's objectives, methods, advantages, and risks. Participants were told that their participation was entirely voluntary, and the highest level of confidentiality would be maintained. The interviewer also briefly explained the contents of the consent form and questionnaire and described the interview process. Mothers who agreed to take part in the study were then provided with the consent form to read and sign. For those who were illiterate, the interviewer gave them a more detailed explanation of the contents of the consent form and the questionnaire. Illiterate mothers who consented to participate indicated agreement by placing their thumb print on the consent form. Each mother was only recruited once, included mothers of multiples i.e. twins, triplets, etc.

Once study participants had signed the consent form or indicated consent by placing their thumb print, the interviewer proceeded to fill in their sociodemographic data and answers given to the questions pertaining to knowledge on NDS and care seeking practice. As this was an interviewer administered questionnaire, the interviewer asked the questions and tick/fill out unprompted responses on the questionnaire. Mothers with stable neonates were interviewed prior to review by the clinician/doctor while mothers of unstable neonates requiring emergency treatment, were interviewed once the baby has been stabilized.

The study was conducted over a three-month period between September 2022 and November 2022.

3.7. STUDY TOOLS

Study questionnaire: the study utilized a structured interviewer administered questionnaire that captured the sociodemographic characteristics of the study subjects, together with their knowledge on NDSs and care seeking practices, and the neonates' biodata. The questionnaire was adapted from review of literature on similar studies (26,27,30). It was first be written in English (Appendix 4), before being translated into the local Arabic dialect (Juba Arabic) (Appendix 5) and then back to English by a language expert. Prior to the study starting, it was tested for ambiguity. The piloting

test was carried out in two facilities, namely Nyakuron PHCC and Malakia PHCC. Consent was first sought from the Director of Primary Health Care in the state Ministry of Health and then from the administrators of the two facilities. Once granted, 10 mothers from each facility who met the eligibility requirements were chosen at random to take part in the piloting test. The study's objectives, methods, advantages, and risks were fully disclosed to the mothers. The interviewer went through the consent form and answered all questions regarding the same. Consenting mothers were asked to read and sign or place their thumb print on the consent form. The interviewer then administered the questionnaire. Following completion, the interviewer debriefed respondents to get feedback and reactions to the questions, the survey design and process. Each question was reviewed and discussed individually with the respondents. They were asked to remark on what they believed they were being asked and if they found anything confusing or misleading about the questions. They were then asked whether the information provided in the consent form was clearly understood. The researcher also addressed reasons for any skipped or unanswered questions. Local terminologies and interpretation of danger signs were identified during the piloting exercise and categorized according to the WHO-recognized NDSs. Information gathered from this exercise was used to make changes to questionnaire to remove ambiguity and ensure that the questions that were eventually asked produced responses that would meet the goals of the study. Piloting of the tool also provided an opportunity for the training of the research assistant officers. The records filled during the piloting of the study were not included in the analysis of this study.

Data collection was performed by the principle investigator as well as three clinical officers and a medical officer intern selected from both hospitals who received two days of training on the purpose of the study, WHO-recognized NDSs, how to get informed consent, and how to correctly administer and fill out the questionnaire. The interviewers were proficient in English, Arabic and Juba Arabic.

Consent form: The consent form included a summary of the study, its goals, the required procedures, and the benefits and risks of participating in the study. Additionally, it included details on protecting participant privacy and dissemination of study results. (Appendix 2 and Appendix 3).

3.8. STUDY VARIABLES

3.8.1. Dependent variable

The dependent variables were the knowledge of mothers on neonatal danger signs and the care seeking practices of mothers of neonates who exhibited signs of illness.

3.8.2. Independent variables

The independent variables included age of the mother, age of the neonate, marital status, parity, level of education, employment status, household income, ANC attendance and whether the mother/family owned various media sources including television, radio, smart phone and access to the internet.

Maternal knowledge on NDSs: Mothers were asked whether they had ever received any education on signs of illness in a neonate. Responses were recorded as "yes" or "no". They were then asked to list, without prompting, what they consider to be signs of serious illness that could endanger a neonate's life.

Spontaneous responses by mothers were compiled and organized into WHO-recognized danger signs and their perception of danger signs. Using WHO definitions, the "WHO-recognized dangers signs" were grouped as follows: i) Poor feeding or refusal to breastfeed; ii) Only moves when stimulated or not at all (included weakness or sleeping excessively); iii) Convulsion (included the local term for convulsions of 'teshunajat'); iv) Temperature of \geq 37.5 degree centigrade (included hotness of body or fever); v) Temperature \leq 35.5 degree centigrade (hypothermia or coldness); vi)Severe chest indrawing (included difficulty in breathing); vii) Respiratory rate of 60 or more (fast breathing); viii) Yellow palms/soles (sign of jaundice); ix) Umbilicus redness or draining pus, skin boils, or eyes draining pus (sign of local infection). Based on the responses, mothers were further categorized as "good knowledge" or "poor knowledge" accordingly by applying a 3-point cut-off based on their knowledge of the listed WHO-recognized signs. There currently exists no universally accepted standard for the measurement of knowledge of NDSs. Most studies that have assessed maternal knowledge of NDSs have defined good knowledge as awareness of three or more NDSs (33,34,36–38). This is what was used in this study to inform the choice for the cut-off for the primary outcome. Each NDS carried 1 point; satisfactorily knowledgeable mothers were

those who could identify at least three of those NDS as recognized by the WHO. Responses that did not fit into one of these categories were labeled as "others" and carried no points. They, therefore, were not included in assessing adequacy of knowledge on NDS.

i) Mothers were also asked if their infants had ever experienced any of the danger signs that they had mentioned and responses were categorized as "yes" or "no", and ii) Those who answer 'yes' were further asked to list the signs of illness ever experienced by their baby. Responses were again grouped into WHO-recognized NDSs and whatever the study subjects perceive to be NDSs; iii) the actions resorted to upon the baby manifesting NDSs were grouped into "did nothing", "home remedy", "traditional/faith healer", "local chemist", "clinic/hospital"; iv) the participants were further asked to recall the time taken between noticing the earliest signs of illness and seeking care. The waiting duration was recorded in hours. For those who waited for more than 24 hours, time in hours was grouped as "24-48 hours", "48-72 hours", and ">72hours"; v) reasons for delay in seeking care were recorded using mothers' response to the direct question "what was the reason for waiting for more than 24 hours" and answers were categorized as follows: "Did not think illness was serious", "waited for baby to improve or worsen", "distance to health facility", "waited for permission from husband/other family members and did not have money for treatment". Responses that did not fit any of these categories were categorized as "other" but later analyzed combinedly upon the completion of data collection and cleaning.

Sociodemographic data: i) Age of mother in years ii) age of the baby in days. This was later be categorized into "< 7" days and "7-28 days"; iii) Marital status: was grouped into "single", "married", and "separated/divorced"; iv) Level of education: was evaluated using the mother's highest level of educational attainment and was categorized into "primary or lower" and "secondary or higher"; v) Employment status was grouped as follows: "employed", "self-employed" and "unemployed"; vi) monthly household income (wealth index) was captured in South Sudanese Pound and then converted into US dollars. These were then later categorized as "lower class", "middle class", or "upper class" based on Barnajee and Duflo's definition of incomes of the middle class in low income countries (50). They defined the lower class as those whose monthly incomes fall below USD 60, the middle class as monthly income between USD 60 and USD 300, and upper class as monthly income above USD 300; vii) Parity: this was assessed as the total number of children born to the mother, whether alive and deceased.

Antenatal related variables: i) antenatal clinic attendance was assessed using the number of visits throughout pregnancy. These were categorized into "<4 visits" and ">4 visits".

3.8.3. Moderating variables

Potential moderating variables, for the purposes of this study, were factors which were thought to affect the relationship between maternal knowledge of NDSs and care seeking practices. The study investigated whether factors such as whether distance to the hospital, cost of treatment and decision maker for seeking care had any effect on the care seeking practice of mothers. While assessing the causes for delay in seeking care once illness is identified, some of the categorized answers to the question "what was the reason for waiting more than 24 hours" were "distance to hospital" and "did not have money for treatment". Mothers were asked about who made the decision to seek care and answers were grouped into (i) mother, (ii) father, (iii) both parents, (iv) friends/relatives. Responses that did not fit any of these categories were categorized as "other".

3.9. SAFETY MEASURES

Considering the COVID 19 pandemic, steps were taken to prevent virus transmission. A minimum distance of 1.5 meters was maintained between individuals where possible. Masks were encouraged, as was hand washing with water and soap, and/or the use of an alcohol hand sanitizer. Compliance with Covid regulations at the two hospitals were strictly adhered to as per hospital policies.

3.10. DATA MANAGEMENT AND ANALYSIS

Data were collected using questionnaires then transcribed and saved in a Microsoft Excel version 2019 workbook that was password-protected. These were then cleaned and analyzed using IBM[™] SPSS version 25 (51). Back-ups of all generated data sets were made in the cloud and on a password-protected hard disk.

Primary objective

For the mothers' understanding of neonatal danger signs, percentages and frequencies (95% CI) were computed.

Mothers were judged to have good knowledge if they properly mentioned three or more NDSs, while those who named fewer than three NDSs were deemed to have poor knowledge. These definitions are based on similar studies that used the same criteria to define good knowledge on NDSs(33,34,36–38).

Secondary objectives

a) The strength of relationship between independent and dependent factors was determined using binomial logistic regression analysis. Statistical significance was set at p-value 0.05.

b) Percentages and frequencies were used to present care seeking practices. Mothers were deemed to have good care-seeking behavior if they had brought their newborns to a hospital or health facility within 24 hours of noticing symptoms of illness in the baby (2).

3.10.1. Study results dissemination plan

As part of the Masters Program requirements, the study results will be submitted in both hard and soft copies to the University of Nairobi's Department of Paediatric and Child Health. The study's hard copies will be submitted to the University of Nairobi's repository for storage. The findings will be shared with the Ministry of Health, the GOSS, and the two hospitals. The findings will also be submitted to peer-reviewed scientific journals for publication.

3.11. ETHICAL CONSIDERATIONS

1. Permission to conduct the study was sought from the UoN-KNH ERC, Research, Ethics and Review Board (MoH, GOSS) and the relevant authorities at Juba Teaching Hospital and Al Sabbah Children's Hospital.
- 2. A written informed consent explaining the details, procedures and protocols of the study was obtained from the study participants before enrollment.
- 3. Only consenting mothers were enrolled in the study.
- 4. Participants were informed that participation was entirely voluntary, and they were able to withdraw at any point without incurring any consequences.
- 5. To ensure confidentiality, no personal identifiers were used, and participants were issued unique identification codes. The questionnaires and data were accessible only to the lead investigator and authorized research assistants, or any other individuals of interest to the study upon authorization by the principal investigator.

CHAPTER FOUR: RESULTS

4.1. RECRUITMENT PROCEDURE AND DISTRIBUTION OF PATIENTS IN THE VARIOUS STUDY SITES

The study investigated the level of knowledge of neonatal danger signs among mothers of neonates aged 0 -28 days in Al Sabbah Children's Hospital and Juba Teaching Hospital in Juba, South Sudan. A total of 274 mothers of neonates were recruited into the study representing a 100% response rate. Table 4 below shows the distribution of study participants across the wards and clinics in the study sites.

Table 4: Distribution of study participants across	various departments,	clinics and	wards in JTH
and Al Sabbah Children's Hospital (N=274)			

Juba Teaching Hospi	tal	Al Sabbah Children's Hospital			
Place of recruitment	Number of participants recruited	Place of recruitment	Number of participants recruited		
Postnatal Ward	52	Outpatient department	103		
NBU admissions	18	Inpatient neonatal ward	42		
Immunization clinic	17	Immunization clinic	42		
Total	87		187		

Figure 3 below illustrates the procedures that were used to recruit mothers into the study and how the participants were distributed across the two hospitals.



Figure 3: Study procedure and distribution of study participants across the two hospitals and the various departments

4.2. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Mothers' socio-demographic characteristics: The average age of the study participants was $25.6(SD\pm5.2)$ years with 133(48.5%) aged between 25 and 34 years. Further analysis revealed that 249(90.9%) of the respondents were married and 248(90.5%) were Christians. A minority 90 (32.8%) were first time mothers and 177(64.6%) reported that they had attended ≥ 4 ANC. More than half 162(59.1%) had primary or lower level of education and 197(71.9%) of the respondents had an average monthly household income of between \$60 - \$300. Less than half of the mothers had a radio 122(44.2%) or smartphone 113(41.2%). The demographic characteristics of the mothers are outlined in table 5 below.

Characteristic	Frequency(n)	Percent(%)	
Age of the mother (Mean, SD)	25.6(SD±5.2)		
≤18 years	23	8.4	
19 - 24 years	102	37.2	
25 - 34 years	138	50.4	
>35 years	11	4.0	
Marital status			
Single	17	6.2	
Married	249	90.9	
Separated/divorced	8	2.9	
Religion			
Christian	248	90.5	
Muslim	18	6.6	
Areligious	8	2.9	

Table 5: Sociodemographic characteristics of the study participants recruited into the study from JTH and Al Sabbah Children's Hospital (N=274)

Characteristic	Frequency(n)	Percent(%)
Education level		
Primary or lower	162	59.1
Secondary or higher	112	40.9
Employment status		
Unemployed	197	71.9
Self employed	48	17.5
Employed	29	10.6
A verage income		
Lower (<\$60)	16	16.8
Middle (\$60, 200)	107	71.0
$V_{1} = (\$00 - 500)$	21	11.9
Opper (>\$300)	51	11.5
Parity		
Primiparous	90	32.8
Multiparous	184	67.2
ANC attendance		
<4 visits	97	35.4
>=4 visits	177	64.6
Ourmonship of modio gourso		
	00	20.2
Television	80	29.2
Radio	122	44.5
Smartphone	113	41.2
Internet	81	29.6

Neonates' demographic characteristics: the mothers recruited into the study collectively had 279 babies aged 0-28 days, 10 of whom were twins. Most of the neonates 178 (63.8%) were aged \leq 7 days.

Table 6: Demographic characteristics of the neonates of the study participants recruited into the study from JTH and Al Sabbah Children's Hospital (N=274)

Characteristic	Frequency(n)	Percent(%)
Twins/singleton		
Singletons	269	96.4
Twins	10	3.6
Age of neonate		
≤7 days	178	63.8
>7 days	101	36.2

4.3. ASSESSMENT OF THE LEVEL OF KNOWLEDGE OF NDS

The findings revealed that 35.8% (95%CI: 30.1%–41.8%), of the mothers had good knowledge on NDSs, as shown in Figure 4. Mothers who were able to name three or more WHO-recognized NDSs were considered to have good knowledge (30,33,36–38).



Figure 4: Maternal level of knowledge of NDSs

4.3.1 Knowledge of WHO recognized neonatal danger signs among mother in the study group

Mothers were asked to freely list or name as many signs of neonatal illness as they could. The most identified signs include fever 260(94.9%), poor feeding/refusal to breastfeed 139(50.7%) and fast breathing 70(25.5%). Low body temperature 8(2.9%) and jaundice in the first 24 hours of life/up to palms/soles 9(3.3) were the signs least identified as signs of severe illness in a neonate. Table 7 below summarises the findings on assessment of maternal knowledge of neonatal danger signs.

Table 7: Results from assessment of knowledge of NDSs among study participants recruited from JTH and Al Sabbah Children's Hospital (N=274)

Knowledge of neonatal danger signs	Frequency(n)	Percent(%)
The signs of illness in the newborn*		
Fever	260	94.9
Poor feeding/refusal to breastfeed	139	50.7
Fast breathing	70	25.5
Convulsions/fits	54	19.7
Local infection: umbilical redness or purulent drainage; purulent rash; purulent eye discharge	38	13.9
Only moves when stimulated or not at all	31	11.3
Inward movement of the lower chest wall during breathing	18	6.6
Low body temperature/coldness	8	2.9
Jaundice in the first 24 hours of life or up to palms/soles	9	3.3
Level of knowledge		
Good	98	35.8
Poor	176	64.2

*Unprompted, multiple responses

4.3.2. Mothers who had been educated on NDSs and the sources of information on NDSs among mothers in the study group

As shown in figure 5, 168(61.3%) of the participants had received some form of education on NDSs.



Figure 5: Distribution of study participants who had received prior education on NDSs

Among these participants, 119(70.8%) had received information through antenatal/postnatal/clinic, 56(33.3%) had received education through radio, 27(16.1%) had received education through social media while 16(9.5%) had received information through community awareness programs. The sources of education on NDSs are summarised in table 8.

Sources of education*	Frequency(n)	Percent(%)
TV	3	1.8
Radio	27	16.1
Social media	16	9.5
Family/friends	56	33.3
Antenatal/postnatal clinic	119	70.8
Community awareness programs	16	9.5

Table 8: Sources of education on NDSs for mothers recruited from JTH and Al Sabah Children's Hospital (N=168)

*Multiple responses

4.4. FACTORS ASSOCIATED WITH KNOWLEDGE OF NDSs

4.4.1. Association between mothers' sociodemographic characteristics and knowledge of NDSs

Binary logistic analysis: this was carried out to determine the factors associated with knowledge of WHO recognized NDSs, as shown in Table 9. The findings revealed that mothers who had previously been educated on NDSs were 3.5 times more likely to have good knowledge compared to mothers who had not, crude odds ratio (COR)=3.43, 95%CI:1.95-6.03, p<0.001. Having a television set, COR =2.35, 95%CI:1.37 - 4.01, p =0.002, or a radio, COR = 2.37, 95%CI:1.43 - 3.93, p =0.001, was significantly associated with good knowledge. Owning a smartphone and having internet access increased the odds of having good knowledge on NDS by more than three times COR =3.42, 95%CI:2.04 - 5.73, p<0.001 and more than 4 times COR =4.16, 95%CI:2.41 - 7.20, p<0.001 respectively. No significant association was found between the age or parity of the mother and knowledge of NDSs.

Table 9: Binary logistic analysis to determine participants' characteristics associated with good knowledge of NDSs

	Knowledge			
Variables	Good n(%)	Poor n(%)	COR (95%CI)	P-value
Age of mother				
≤ 18 years	2(2.0)	21(11.9)	6.0(0.90 - 40.14)	0.0065
19 - 24 years	37(37.8)	65(36.9)	1.0(0.28 - 3.66)	0.995
25 - 34 years	55(56.1)	83(47.2)	0.86(0.24 - 3.08)	0.82
>=35 years	4(4.1)	7(4.0)	Ref	

	Knowledge			
Variables	Good n(%)	Poor n(%)	COR (95%CI)	P-value
Age of child				
<=7 days	66(67.3)	109(61.9)	1.27(0.75 - 2.13)	0.432
>7 days	32(32.7)	67(38.1)	Ref	
Marital status				
Single	4(4.1)	13(7.4)	Ref	
Married	89(90.8)	160(90.9)	3.00(0.70 - 12.83)	0.139
Separated/divorced	5(5.1)	3(1.7)	5.42(0.88 - 33.36)	0.069
Religion				
Christian	84(85.7)	164(93.2)	1.17(0.27 - 5.02)	0.831
Muslim	11(11.2)	7(4.0)	0.38(0.07 - 2.13)	0.272
Areligious	3(3.1)	5(2.8)	Ref	
Education level				
Primary or lower	57(58.2)	105(59.7)	0.94(0.57 - 1.55)	0.898
Secondary or higher	41(41.8)	71(40.3)	Ref	
Employment status				
Unemployed	62(63.3)	135(76.7)	1.33(0.59 - 2.99)	0.488
Self employed	25(25.5)	23(13.1)	0.56(0.22 - 1.44)	0.23
Employed	11(11.2)	18(10.2)	Ref	

	Knowledge			
Variables	Good n(%)	Poor n(%)	COR (95%CI)	P-value
Average monthly				
Income				
Lower (<\$60)	15(15.3)	31(17.6)	0.72(0.26 - 1.98)	0.523
Middle (\$60 - 300)	75(76.5)	122(69.3)	0.57(0.24 - 1.33)	0.191
Upper (>\$300)	8(8.2)	23(13.1)	Ref	
Parity				
Primiparous	29(29.6)	61(34.7)	0.72(0.47 - 1.35)	0.423
Multiparous	69(70.4)	115(65.3)	Ref	
ANC attendance				
<4 visits	36(36.7)	61(34.7)	1.10(0.65 - 1.83)	0.415
>=4 visits	62(63.3)	115(65.3)	Ref	
Ownership of media				
source				
Television	40(40.8)	40(22.7)	2.35(1.37 - 4.01)	0.002
Radio	57(58.2)	65(36.9)	2.37(1.43 - 3.93)	0.001
Smartphone	59(60.2)	54(30.7)	3.42(2.04 - 5.73)	<0.001
Internet access	48(49.0)	33(18.8)	4.16(2.41 - 7.20)	<0.001
Education on NDSs				
Received education on	77(78.6)	91(51.7)		
danger signs			3.43(1.95 - 6.03)	<0.001

			Knowledge			
Variables			Good n(%)	Poor n(%)	COR (95%CI)	P-value
Experience	of illne	SS				
Experience	signs	of	63(64.3)	107(60.8)		
illness					1.61(0.70 - 1.94)	0.605

Multivariate analysis: Variables that had p<0.05 on bivariate analysis were subjected to a multivariate model using logistic regression to obtain the factors that were independently associated with good maternal knowledge of NDSs. Mothers who had internet connection were 2.8 times likely to have good knowledge compared to those without internet connection, adjusted odds ratio (AOR) =2.77, 95%CI:1.34 – 5.73, p =0.006. Those who had been educated on danger signs were 2.9 times more likely to have good knowledge on NDSs compared to those who had not received any prior education on NDSs, AOR =2.93, 95%CI: 1.58 – 5.45, p =0.001. These findings are summarised in the table below.

	Knowledge			
Variable	Good n(%)	Poor n(%)	AOR(95%CI)	P-value
Ownership of media source				
Television	40(40.8)	40(22.7)	1.33(0.72-2.44)	0.363
Radio	57(58.2)	65(36.9)	1.52(0.86 - 2.66)	0.147
Smartphone	59(60.2)	54(30.7)	1.57(0.79 - 3.09)	0.197
Internet access	48(49.0)	33(18.8)	2.77(1.34 - 5.73)	0.006
Education on NDSs				
Received education on danger	77(78.6)	91(51.7)		
signs			2.93(1.58 - 5.45)	0.001

Table 10: Participants' characteristics independently associated with good knowledge of NDSs

4.4.2. Association between the ward/clinic where neonates were attended to and maternal knowledge of NDSs

Mothers of neonates who were admitted in the NBU at JTH were four times more likely to have good knowledge on NDSs compared to those who were not admitted in the NBU, odds ratio (OR) =4.00, 95%CI: 1.44 - 10.90, p =0.009. Those who were admitted in the postnatal ward were 3 times likely to have good knowledge on NDSs compared to those who were not admitted in postnatal ward, OR =3.42, 95%CI:1.83 - 6.37, p<0.001. However, mothers who had brought their neonates to the immunisation clinic were 74% less likely to have good knowledge on NDSs, OR = 0.26, 95%CI: 0.12 - 0.55, p<0.001. Interestingly, being admitted to neonatal ward or seeking care in the OPD at Al Sabbah Children's Hospital did not significantly affect knowledge.

Place of	Knowledge			
recruitment	Good n(%)	Poor n(%)	OR (95%CI)	P-value
NBU				
Yes	12(12.2)	6(3.4)	4.00(1.44 - 10.90)	0.009
No	86(87.8)	170(96.6)	Ref	
Postnatal				
Yes	31(31.6)	21(11.9)	3.42(1.83 - 6.37)	<0.001
No	67(68.4)	155(88.1)	Ref	
Immunization				
Yes	9(9.2)	50(28.4)	0.26(0.12 - 0.55)	<0.001
No	89(90.8)	126(71.6)	Ref	
OPD				
Yes	33(33.7)	70(39.8)	0.77(0.46 - 1.29)	0.363
No	65(66.3)	106(60.2)	Ref	
Neonatal ward				
Yes	13(13.3)	29(16.5)	0.78(0.38 - 1.37)	0.600
No	85(86.7)	147(83.5)	Ref	

Table 11: Association between the ward/clinic where neonates were attended to and maternal knowledge of NDSs

4.5. CARE SEEKING PRACTICE OF PARTICIPANTS

4.5.1. Signs of illness experienced by the babies of study participants

The results showed that 170(62%) of participants asserted that their neonates had ever experienced signs of illness. Among mothers whose babies developed signs of illness (n=170), 55.3% (95%CI:47.5%-62.9%) had good practice of seeking care within 24 hours of first recognising these signs (2).



Figure 6: Proportion of mothers whose neonates had ever experienced signs of illness



Figure 7: Care seeking practice of mothers of neonates who had ever experienced signs of illness

4.5.2. Signs and symptoms experienced by the babies of study participants that prompted care seeking

Among participants who stated that their neonates experienced signs of illness, 126(74.1%) identified fever as the most common symptom experienced. Other signs identified include poor feeding/ refusal to breastfeed 49(28.8%), fast breathing 28(16.5%), local infection: umbilical redness or purulent drainage; purulent rash; purulent eye discharge 17(10%) as shown in Figure 8. Irritability and flu-like symptoms were the most common signs outside of the WHO recognised NDSs that were reported to have been experienced. Mothers were asked to name all the signs their baby had experienced, and as such, could mention more than one sign.



Figure 8: Signs and symptoms reported to have been experienced by babies of participants

4.5.3. Courses of action taken and duration to seeking medical care for sick neonates

The study investigated the immediate course of action that mothers took after realizing that their neonates were ill, as shown in Table 12. The results showed that of the mothers who recognised signs of illness in their neonates (n=170), 59(34.7%) took their neonates to clinic/hospital, 51(30%) did nothing, 41(24.1%) resorted to home remedy while 11(6.5%) sought help from local chemists/pharmacy. Only 94/170(55.3%) of the mothers sought medical care within the first 24 hours.

Variable	Frequency(n)	Percent(%)
Course of action (n =170)		
Home remedy	41	24.1
Traditional/ faith healer	3	1.8
Local chemist	11	6.5
Clinic/hospital	59	34.7
Did nothing	51	30.0
Admitted directly from delivery room	5	2.9
Duration before seeking medical care (n=170)		
≤24 hours	94	55.3
>24 hours	76	44.7

Table 12: Course of action and duration to seeking care for sick neonates aged 0-28 day in JTH and Al Sabbah Children's Hospital

4.5.4. Reasons for delay in seeking medical care and the decision makers for seeking medical care for sick neonates

Among mothers who took more than 24 hours to seek medical care (n=76), the commonest reasons cited for delay include "did not think illness was serious" 35(46.1%), "waited baby to improve or worsen" 23(30.3%) while 18(23.7%) stated that the distance from health facility prevented them from seeking prompt medical care. Slightly more than half of the participants, 90/170 (52.9%) stated that the mother of the neonate made the decision to seek medical care, while 36/170(21.2%)

stated that their partners made the decision to medical seek care. These findings are summarised in table 13 below.

Variable	E roquonov(n)	Domoont(0/)
variable	Frequency(II)	Percent(%)

Frequency(n)	Percent(%)
35	46.1
23	30.3
18	23.7
11	14.5
7	9.2
8	10.5
90	52.9
36	21.2
11	6.5
22	12.9
11	6.5
	35 23 18 11 7 8 90 36 11 22 11

* Multiple responses

** Other: mother was ill, baby fell ill at night, fears about security at night, bad weather

4.5.5. Participants' characteristics associated with good care seeking practice

Logistic regression was conducted to determine the factors associated with care seeking practices among mothers of sick neonates as shown in Table 14. Mothers of neonates aged \leq 7 days had higher odds of having good practice compared to those who had neonates aged more than 7 days, OR =2.01, 95%CI:1.12 – 3.83, p =0.022. Furthermore, mothers who owned smartphones were 1.9 times more likely to have good practice compared to those who did not own a smartphone, OR =1.90, 95%CI: 1.10 – 3.61, p =0.035. No association was found between decision maker for seeking care and care seeking practice.

	Practice			
Variable	Good n(%)	Poor n(%)	OR(95%CI)	P-value
Age of the mother				
≤24 years	47(50.0)	31(40.8)	Ref	
25 - 34 years	44(46.8)	39(51.3)	0.33(0.08 - 1.42)	0.136
≥35 years	3(3.2)	6(7.9)	0.44(0.10 - 1.89)	0.272
Age of the child				
\leq 7 days	54(57.4)	30(39.5)	2.01(1.12 - 3.83)	0.022
>7 days	40(42.6)	46(60.5)	Ref	
Marital status				
Single	7(7.4)	3(3.9)	0.43(0.04 - 4.64)	0.486
Married	85(90.4)	71(93.4)	0.84(0.12 0 6.08)	0.859
Separated/divorced	2(2.1)	2(2.6)	Ref	
Religion				
Christian	82(87.2)	68(89.5)	3.32(0.36 - 30.38)	
Muslim	8(8.5)	7(9.2)	3.50(0.31 - 39.15)	
Areligious	4(4.3)	1(1.3)	Ref	
Education level				
Primary or lower	51(54.3)	52(68.4)	0.55(0.29 - 1.03)	0.082
Secondary or higher	43(45.7)	24(31.6)	Ref	

Table 14: Participants' characteristics associated with good care seeking practice

	Practice			
Variable	Good n(%)	Poor n(%)	OR(95%CI)	P-value
Employment status				
Unemployed	71(75.5)	55(72.4)	1.22(0.44 - 3.35)	0.703
Self employed	12(12.8)	14(8.4)	1.83(0.54 - 6.22)	0.331
Employed	11(11.7)	7(9.2)	Ref	
Average monthly income				
Lower (<\$60)	19(20.2)	13(17.1)	0.76(0.24 - 2.39)	
Middle (\$60 - 300)	65(69.1)	54(71.1)	0.92(0.35 - 24.44)	
Upper (>\$300)	10(10.6)	9(11.8)	Ref	
Parity				
Primiparous	36(38.3)	20(26.3)	0.58(0.30 - 1.11)	0.100
Multiparous	58(61.7)	56(73.7)	Ref	
ANC attendance				
<4 visits	31(33.0)	27(35.5)	0.89(0.47 - 1.61)	0.747
>=4 visits	63(67.0)	49(64.5)	Ref	
Ownership of media source				
TV ownership	29(30.9)	22(28.9)	1.10(0.57 - 2.12)	0.867
Radio ownership	40(42.6)	32(42.1)	1.02(0.55 - 1.88)	0.539
Smartphone ownership	41(43.6)	22(28.9)	1.90(1.10 - 3.61)	0.035
Internet ownership	24(25.5)	17(22.4)	1.19(0.58 - 2.42)	0.719
Education on NDSs				
Received education on danger signs	62(66.0)	42(55.3)	1.56(0.84 - 2.92)	0.205

	Practice			
Variable	Good n(%)	Poor n(%)	OR(95%CI)	P-value
Knowledge of danger signs				
Good	34(36.2)	29(38.2)	0.92(0.49 - 1.72)	0.457
Poor	60(63.8)	47(61.8)	Ref	
Decision makers to seek care				
Mother of the child	46(56.1)	43(56.6)	0.56(0.21 - 1.65)	0.111
Father of the child	21(25.6)	15(19.7)	0.51(0.11 - 1.61)	0.223
In-laws	5(6.1)	7(9.2)	0.27(0.09 - 1.14)	0.141
Friends and relatives	7(8.5)	3(3.9)	0.53(0.09 - 3.03)	0.472
Both mother and father of the child	3(3.7)	8(10.5)	0.16(0.02 - 1.07)	0.059
Healthcare providers			Ref	

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1. DISCUSSION

This study aimed to assess the level of knowledge of mothers on WHO-recognized neonatal danger signs and care seeking practices of mothers of sick neonates seeking care at Juba Teaching Hospital and Al Sabah Children's Hospital in Juba, South Sudan. It also sought to determine the factors that were associated with good knowledge and good care seeking practices among these mothers. The findings revealed that 36% (95%CI: 30.1%–41.8%), of the 274 mothers interviewed were able to name three or more NDSs. Factors such as prior education on NDSs and having access to an internet connection were significantly associated with good knowledge. Mothers of neonates admitted to the Newborn Unit and postnatal wards in JTH were also found to have higher odds of naming three or more NDSs. Out of the 170 mothers who reported that their babies had ever experienced signs of illness, only 55.3% (95%CI:47.5%-62.9%), had good practice of seeking medical care within the first 24 hours of recognizing that their baby was ill. Mothers of babies aged less than 7 days and those who owned a smartphone had higher odds of having good practice.

5.1.1. Level of Knowledge

According to this study, only 36% (95%CI: 30.1% - 41.8%) of mothers could recognize three or more NDSs, indicating an overall low level of knowledge of these signs. This is in keeping with studies done in Ethiopia (37.2%) and Saudi Arabia (37%) (38,52). The mothers in this study performed better than those from studies conducted in Ghana (28.3%) and Kenya (15.5%) (37,53). A similar study done in Iraq found that 81% of mothers could name 3 or more neonatal danger signs (54). These discrepancies in knowledge may result from differences in study populations and study sites. Our study population consisted of mothers seeking preventative and curative services at two major public health facilities in an urban setting, with a significant proportion of the participants being mothers seeking curative services. Other studies done in hospital settings yielded results that showed better knowledge compared to studies that were

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community based (33,55,56). In addition, variation in sample size and sociodemographic factors may also have contributed to the differences seen across the different studies. Better maternal knowledge on NDSs was found in studies where mothers had attained secondary level and above education, had attended 4 or more ANCs and those who had received postnatal counselling on NDSs (55,56).

Fever (94.9%), refusal/difficulty breast feeding (50.7%) and fast breathing (25.5%) were the signs/symptoms most commonly known, in keeping with results from studies conducted in other SSA countries (33,34,37,56). These other studies showed that between 39%-81% of mothers/caregivers mentioned fever as a sign of illness. Although neonatal sepsis is the commonest cause of fever in the neonatal period, the higher awareness of fever in our study sample may be due to the endemicity of malaria in the region (26,57). Knowledge on low body temperature (2.9%) and jaundice (3.3%) as danger signs was the poorest, similar to Ekwochi *et al* finding in Nigeria(44). Previous studies show that knowledge on hypothermia and jaundice as danger signs ranged from 0.3 - 13% and 2.9 - 64% respectively (37,40,52,55,56). The differences in disease spectra between different countries and regions, as well as the differing emphasis on health education given to mothers, may help to explain these variations in findings.

5.1.2. Factors associated with good knowledge

After adjusting for other independent variables, having had prior education on NDS was significantly associated with good knowledge. Mothers who had been educated on NDS were almost 3 times more likely to have good knowledge than those who had not been educated. These results are similar to studies done in Kenya and Ethiopia which showed that a higher proportion of mothers who had been given health information on neonatal care and illness had better knowledge on NDSs (37,56).

Owning a radio, television, smart phone and having access to the internet was significantly associated with good knowledge. This outcome is congruent with research conducted in Ethiopia. (33,56,58). Having access to various media sources improves knowledge due exposure to programs that teach the community on various maternal and child health issues. Quattrin *et al* found that mass media campaigns on health-related matters had significant positive impact on

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societal knowledge, attitude and behaviour (59). Repeated exposure improves memory retention of newly acquired knowledge (60). Internet access can be an indicator of better socio-economic status (61,62), which as been associated with better maternal knowledge of NDSs (30,33,37,56).

Surprisingly, ANC attendance was not significantly associated with good knowledge. This is incongruent with results obtained by Kibaru and Adem but similar to results obtained by Sandberg in Uganda(37,40,56). This raises concern about the effectiveness of the education strategies currently being employed in the ANCs in South Sudan.

Mothers of infants admitted to the NBU were four times more likely to have good knowledge compared to those who were not. This may be attributed, in part, to the fact that experience of illness results in better health knowledge (30).

Maternal level of education and monthly household income was not significantly associated with better knowledge of NDSs. This may be due to the low level of education of women in South Sudanese communities and that overall knowledge or understanding of newborn health is very poor, such that even educated women do not have much of an advantage over uneducated mothers.

5.1.3. Care seeking practice

Sixty two percent of participants reported that their infants had experienced signs of illness, with 55% (95%CI:47.5%-62.9%), reporting that they sought medical treatment within 24 hours of recognizing signs of illness in their babies. These findings were better than those obtained by Abu Shaheen *et al* in Saudi Arabia and Molla *et al* in Ethiopia (38,63). Abdulrida, however, found that 61.2% of mother who recognized signs of illness in their neonates, sought treatment from a health facility within 24 hours (55). These variations in health seeking behaviour could be related to study sites differences (community vs hospital-based studies) and the study population (urban vs rural). Differences in the level of maternal knowledge on NDSs, societal perception of neonatal illnesses and cultural differences in newborn care may also account for the variation in care seeking practice. Although this study did not assess maternal perception of neonatal illness, many studies have demonstrated that perceived severity of neonatal illness as well as traditional

beliefs about supernatural causes and traditional treatment of neonatal illness serve as barriers seeking medical care (9,31,42,43,54,55). Some cultural practices, such the postpartum confinement of mother and newborn to the home, also influence care seeking practice (9,43).

Fever (74%) was the most frequently experienced sign of illness that was recognized and that prompted care seeking from a medical facility, similar to finding from studies done in Nigeria and Iraq (44,55). This perhaps reflects the fact that fever is usually easily detectable and is universally acknowledged to be a sign of illness (64).

5.1.4. Courses of action taken

Only 34% of mothers who recognized signs of illness in their infants reported seeking care from a health facility as their immediate or initial course of action. Thirty percent reported that they did nothing and 24% resorted to home remedies to relieve the symptoms. This is in keeping with a study done in Bangladesh which found that only 27.5% of neonates were taken to a medical facility upon falling ill and in 47% of the cases, no care was ever sought outside of the home (31). Our study also found that of those who eventually sought medical care but waited more than 24 hours. The most frequently cited reason for the delay was that 43% of the mothers did not think that the baby was seriously ill and 28% waited to see how the illness would progress. This may reflect poor maternal knowledge and/or understanding of neonatal illness. Although not explored in our study, maternal perception of neonatal illness may have played a role in delay in seeking care once illness was recognized.

Less than 2% of mothers sought care from traditional/faith healers. This is in contrast to studies from rural India and South Asia which found that most mothers initially sought care from traditional faith healers before qualified health professionals were consulted (9,43,54). This difference in care seeking practice may be due to differences in the cultural and religious beliefs of our study population as well as the study setting (i.e. urban vs rural setting where traditional healers may be more available and accessible compared to medical facilities).

The distance to the hospital (22.2%) and the cost of treatment in medical facilities (13.6%) were also reported as barriers to seeking prompt and appropriate treatment; a common problem in many LMIC (9,31,42,43,63).

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In 53% of the cases, the mother of the infant made the decision to seek medical help. This is in contrast to results from the study done by Sharma were it was found that the father of the child often made decisions on when and where care was sought for neonatal illness(31).

5.1.5. Factors associated with care seeking practice

Mothers of neonates aged 7 days or less were two times more likely to seek medical treatment within 24 hours of recognizing illness than mothers of older neonates. This is consistent with studies conducted in Burkino Faso and SSA which found that younger age of a sick child resulted in better care seeking behaviour(65,66). This, perhaps, reflects the greater attention given to the health of younger infants due to perceived vulnerability to severe illness.

The mother being the decision maker for seeking care was not significantly associated with better care seeking practice. This is in contrast to a Nepalese study which showed that maternal decision making had positive correlation with better use of a range of health services (67). Furthermore, according to Molla *et al*, an important predictor of positive health seeking behavior was mothers' improved decision-making power when it came to their newborn's health (63). An Ethiopian study found that mother's age more than 35 years, higher monthly income and adequate knowledge on neonatal danger signs positively influenced maternal decision-making autonomy (68). The fact that most of the mothers in our study were below the age of 35, unemployed and had poor knowledge on NDS may explain why maternal decision-making autonomy was not associated with good care seeking practice.

Good knowledge on neonatal danger signs was not significantly associated with good care seeking practice. In contrast, Abdulrida *et al*'s study revealed a positive correlation between awareness of NDS and good care-seeking behavior (55). Our findings can be explained by the fact that making the decision to seek care for a sick neonate is influenced by more than just having adequate knowledge. Some of the factors cited as reasons for delay in seeking care may perhaps explain why some mothers did not seek care despite recognizing that their child was ill. The decision maker being the father or other family members did not have an effect on care seeking practice, in contrast to a South Asian study that showed that family level decision making was an important determinant of when and where treatment was sought for sick neonates(43).

5.2 STUDY STRENGTHS AND LIMITATIONS

The major limitation to my study, like other studies that have looked at caregivers' knowledge on NDSs and care seeking practice for sick neonates, was the possibility of recall bias. Most studies recruited mothers and caregivers of infants who were no longer within the neonatal period. Caregivers recruited had infants that ranged in age from 6 weeks to 2.5 years These long recollection periods may have resulted in recall bias in genuine knowledge of mothers and time to seeking medical attention for sick neonates. Sandberg *et al* noted that participants that had given birth within thirty days of the study had stronger recollection than mothers with older infants (30). This study will, therefore, attempted to mitigate the limitation of recall bias by restricting study participants to mothers of infants less than 28 days of age.

Secondly, the decision to recruit mothers of living infants and who were already in hospital may have introduced selection and survival bias. These mothers may have been the ones with better health seeking behavior than the general population. However, due to security, financial and time constraints, we could not conduct a community survey to get mothers in their homes. This study does, however, provide some data on community care seeking practices as it has explored some of the causes for delay in getting treatment and the factors that influence decision on when and where care is sought. Additionally, selection of the two largest hospital in Juba where comprehensive MCH services are provided ensured that our study sample was drawn from a population that well represented the general population.

In addition, some mothers may have been tempted to give answers that they believe to be best practice as opposed to what was practiced. The principal investigator and research assistance continually assured and re-assured study participants of confidentiality and privacy and requested them to be as truthful as possible.

5.3. CONCLUSION

Knowledge of three or more NDS was poor among mothers of neonates at Al Sabah Children's hospital and Juba Teaching hospital. The sign most frequently names as a sign of neonatal illness was fever followed by poor breastfeeding. Having received prior education on NDSs and having internet access was associated with good knowledge. Mothers of neonates admitted to the NBU also had better knowledge. A majority of the mother's reported that their neonates had ever experienced a sign of illness and over half sought treatment at a medical facility within 24 hours. Mothers were more than three times more likely to seek care for their babies if they were less than seven days old or if they owned smart phones.

5.4. RECOMMENDATIONS

1. There is need to enhance education of women on NDSs as the study found that prior education on NDSs was associated with better knowledge.

2. The content and effectiveness of existing education programs in the ANCs and PNCs should be evaluated and possibly revised so that adequate emphasis is placed on improving mothers' knowledge on what NDS are, how to recognise them and what actions to take once they realize that their babies are sick.

3. Relevant stakeholders (the national and state ministries of health, NGOs, health care workers and community awareness groups) should be encouraged to adopt mass media campaigns through radio, television, and social media as important and effective tools for educating mothers on newborn health.

4. A community-based study later will be required to obtain a better picture of maternal knowledge on NDSs and care seeking practices in the community.

5. More research is required to examine the impact of maternal and community perceptions of newborn sickness on care-seeking behavior as well as some of the contributing factors to care-seeking delays despite understanding of the symptoms of neonatal illness.

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CHAPTER SIX: APPENDICES

6.1. APPENDIX 1: REFERENCES

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6.2. APENDIX 2: CONSENT FORM FOR PARTICIPATION IN THE STUDY

Study title: THE LEVEL OF KNOWLEDGE ON NEONATAL DANGER SIGNS AND CARE SEEKING PRACTICE OF MOTHERS AT JUBA TEACHING HOSPITAL AND AL SABAH CHILDREN'S HOSPITAL.

Investigator: Dr Ann Hiri Kumba

I am a medical doctor currently undertaking a Master of Medicine degree in Paediatric and Child Health at the University of Nairobi, Kenya.

I am conducting a study on the level of knowledge of neonatal danger signs and care seeking practices of mothers at Juba Teaching Hospital and Al Sabah Children's Hospital. The purpose of this consent form is to give you information that will help you decide whether you wish to participate in the study.

The aim of the study is to learn how much mothers of young infants know about signs of illness in the newborn and what steps are taken once illness is recognized. This is important because knowledge of neonatal danger signs often determine when and where care is sought for the sick neonate. This in turn has an impact on newborn survival. Data from this study will help us as health care workers understand some of the gaps that exist in maternal knowledge on neonatal danger signs and care seeking practices. This will help us develop strategies including, but not limited to, education programs to improve education on newborn care.

The study involves getting information from mothers of neonates aged 0 - 28 days old about their level of knowledge on the signs of illness in a neonate. We will also gather information on when and where treatment is sought once a neonate is recognized to be sick, as well some of the factors that informed the decision to seek care. A few personal data such as age, marital status, monthly income, employment status and number of children will also be collected. Information will be gathered using an interviewer administered questionnaire. The interviewer will ask a question and record unprompted answers. You have the right to refuse the interview or to answer any question asked during the interview.

Please understand that:

Participation is voluntary and no remuneration or compensation will be offered to the participants of the study.

Confidentiality shall be maintained at all times. Your name will not appear in any record in our study and a number assigned to your questionnaire will be used instead. Only staff involved in the study will have access to the data. When we report results of the study, we shall not use your name or the child's name.

You are free to decline or withdraw participation in the study at any time without injustice or loss of benefits. Refusal of any participation in the study will not attract any penalties or place your child at any disadvantage.

Risks: There are minimal risks in participating in this study. It does not involve any physical pain inflicted on you or your child.

Benefits: The study and its results will not provide any direct benefit to you or your child. Your community will, however, benefit because the results of the study will help us develop strategies for better education of women and reduction of neonatal mortality. This may in turn reduce the number of young infants dying in the community

If you have further questions or require further clarification about your participating in this study, please call or send a text message to the principal investigator, Dr. Ann Kumba, on +211 925380416/+254723091538 or the lead supervisor, Dr Osano on +254722646720.

For more information, you can also contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethic and Research Committee on 2726300 Ext. 44102, email <u>uonknh_erc@uonbi.ac.ke</u> or Ministry of Health Research, Ethics and Review Board on +211926595329.

Kindly answer all questions with utmost honesty.

Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I, ______ consent voluntarily to participate in this research.

Name of Participant: _____

Signature/thumb stamp of participant: _____

Date: _____

Researcher's name: Dr. Ann H. Kumba

Researcher's signature:	
-------------------------	--

Date: _____

Role in the study: _____

6.3 APENDIX 3: CONSENT FORM FOR PARTICIPATION IN THE STUDY TRANSLATED TO JUBA ARABIC

FOM TA MWAFAGAH

MUSTAWA AL MAARIFA AN ARAD TA MARAD LE JENA AL WELEDU JEDID MA DOURIA FI MUSHESFA AN UMAHAT FI MUSHESHFA JUBA MA MUSHESFA TA IYAL TA AL SABAH.

Isim ta Bahith: Dr. Ann H. Kumba

Ana diktor al gi agara Masters al Afya ta iyal fi University of Nairobi, Kenya

Ana gi amulu dirasa an mustawa al maarifa an arad ta marad le jena al weledu jedid ma douria fi mushesfa an umahat fi musheshfa juba ma mushesfa ta iyal ta al sabah. Sabab ta fom ta muwafaga de ashan be wodi le ita mouluma ashan ita bi fekir kan ita der wele ita ma der shakir fi dirasa de.

Sabab ta dirasa de anina der arif kan umahat arif arad ta marad le jena al weledu jedid ma amulu shunu kan kalas arufu fi ayan. De muhim ashan maaluma ta arad ta marad fi jena al weledu jedid gi saidu ashan bi arufu bi shilu jena de miten ma mahal al bi ilaju jena de de gi saidu ashan bi afya jena de.

Fi dirasa de, bi asalu ita su'alat yala bi katifu juwab fi waraga. Ita indak hak ashan aba shariku wele juwabu iya su'al.

Kede ita fahim gali:

Mushraka taki fi dirasa de min niya taki ma mabi gurus albi wodi le intum fi dirasa de.

Sir: Iya haja bi kun sir. Isim taki bi talau min iya haja fi deresa de yala ragam yau bi istamilu fi fom taki. Wu su'alat de bikun ma zol al shakal ma anina bes. Anina ma bi istamil isim taki wele ta jena taki fi dirasa de.

Musharaka taki de min niya taki. Ita indak hak ashan aba kun fi dirasa de. Mafi ukum le ita wele jena taki. Kan ita rudu ashan kun fi dirasa de, indik hak ashan wegif fi iya zaman.

Kuturat: Fi kuturat shweiya kan ita shariku fi dirasa de. Mafi iya waja le ita wele jena taki.

Faida: Dirasa de ma netija to ma bi kun ma faida towali le ita wele jena taki. Lakin bi saidu jama kulu fi Junub ashan netiga de bi saidu anina fetisu teriga al bi alimu nasawin ma nagis wozin ta iyal al gi mutu bedri.

Kan indak ziada su'al an musharik taki fi dirasa de, ita bi agder dugu telefun le Diktor Ann Kumba +211925380416/+254723091538.

Le ziada moulumat, ita badger wonusu ma mudir ta lejna ta ayinu uslub fi Musheshfa ta Kenyatta – Jama ta Nairobi fi 2726300 Ext. 44102, email to <u>uonknh_erc@uonbi.ac.ke</u> fi wizara saha ragam tomon +211926595329.

Juwabu iya su'al ma amana.

Kilima ta tawfik

Ana agara moulumat de wa/au zol tani agara le ana. Ana kan indu sajah ashan asalu au wadi zaman ashan asalu suhalat. Iya suhalat al ana asalu kan juwabu kweis.

Ana, ______wafik ashan sharik fi dirasa de.

Isim	ta	musharik:	

Imda musharik:	

Yom: _____

Isim ta Bahith: Dr. Ann H. Kumba

Imda ta Bahith: _____

Yom: _____
6.4. APPENDIX 4: QUESTIONNAIRE

THE LEVEL OF KNOWLEDGE OF NEONATAL DANGER SIGNS AND CARE SEEKING PRACTICE OF MOTHER'S AT AL SABAH CHILDREN'S HOSPITAL AND JUBA TEACHING HOSPITAL IN JUBA, SOUTH SUDAN

Investigator: Dr Ann Hiri Kumba

1. Participants No:
2. Date:
3. Name of Facility:
4. Ward/Clinic:
Part 1: Sociodemographic data
5. Age of mother in years
6. Age of baby in days
7. Marital status
i) Married () iii) Single () iii) separated/divorced () iv) widowed ()
8. Religion
i) Christianity ii) Islam iii) Areligious iv) other
9. Level of education completed
i) No formal education () (ii) Primary () iii) Secondary () iv) Tertiary ()
10. Employment Status
i)unemployed () ii) Self-employed () iii) Casual () iv) formal employment ()
11. Monthly household income in South Sudanese Pounds
12. Number of children
i) Alive ii) Dead
13. Number of ANC clinic attendance

14. Do you own any of the following (tick all that apply)

i) TV () ii) Radio () iii) Smart phone () iv) internet

Part 2: Knowledge of Neonatal Danger Signs

15. Have you ever received any education on neonatal danger signs?

i) Yes () ii) No ()

16. If yes, what was your source of information? (*tick as many as apply*)
i) TV()
ii) Radio ()
iii) Social Media ()
iv) Family/friends ()

v) antenatal/postnatal clinic () vi) community awareness programs () vii) other _____

17. According to you, what are the signs of illness in the newborn? (*Free listing without prompting - Tick all that apply*)

i) Poor feeding/refusal to breastfeed ()

ii) Only moves when stimulated or not at all ()

iii) Convulsions/fits ()

iv) inward movement of the lower chest wall during breathing ()

v) Fever ()

vi) Low body temperature/coldness ()

vii) Fast breathing ()

viii) Jaundice/yellowness in the first 24 hours of life or up to palms/soles ()

ix) Local infection: umbilical redness or purulent drainage; purulent rash; purulent eye discharge ()

x) Others:

18. Has your baby ever experienced any of these signs you have mentioned?

Yes () No ()

If yes, proceed to part 3

Part 3: Care seeking Practice

19. Which sign(s)/symptom(s) did your baby experienced? (tick as many as apply)

i) Poor feeding/refusal to breastfeed ()

ii) Only moves when stimulated or not at all ()

iii) Convulsions/fits ()

iv) inward movement of the lower chest during breathing ()

v) Fever ()

vi) Low body temperature/coldness ()

vii) Fast breathing ()

viii) Jaundice/yellowness in the first 24 hours of life or up to palms/soles ()

ix) Local infection: umbilical redness or purulent drainage; purulent rash; purulent eye

discharge ()

x) Others:

20. When your baby showed the signs of illness, what did you first do?

i) Home remedy () ii) Traditional/Faith Healer () iii)Local chemist ()

iv) Clinic/Hospital () v) Did nothing ()

21. How many hours did it take to seek care?_____

22. If more than 24hrs, was it

i) 24-48 hours () ii) 48-72 hours () iii) >72hours

If more than 24 hours, proceed to number 23

23. What was the reason for waiting > 24 hrs?

i) Did not think illness was serious ()
ii) Waited for baby to improve or worsen ()
iii) Distance to health facility ()
iv) Did not have money for treatment ()
v) Waited for permission from husband/other family members ()
vi) Other:

24. Who made the decision that the baby should be brought to hospital?

6.5. APPENDIX 5: QUESTIONNAIRE TRANSLATED TO JUBA ARABIC

MUSTAWA AL MAARIFA AN ARAD TA MARAD LE JENA AL WELEDU JEDID MA DOURIA FI MUSHESFA AN UMAHAT FI MUSHESHFA JUBA MA MUSHESFA TA IYAL TA AL SABAH.

Isim ta Bahith: Dr. Ann H. Kumba

1. Nimira ta musharik	
-----------------------	--

2. Tarikh _____

3.	Isim	ta	musteshfa_	

4. Ambar/Eyada_____

Part 1: Beyanat al-ijtimaiya al-dimographia

5. Omur be sinin	
6. Omur ta jana be ayam	

7. Hala al-ijtimaiya:

i) Muzowij () ii) Ma muzowij () iii)Ferteku ()

iv) Mara ta morhum ()

8. Din:

i) Mesihi ii) Muslim iii) Kafir iv) Tani _____

9. Marhala ta ta'alim:

i) Assas/Ibtidaiya () ii) Sanawi () iii) Fok al-Sanawi () iv) Ma agara ()

10. Hala ta Shukhul:

i) Shukhul resmi () ii) Shukhul Khas () iii) Shukhul ma resmi ()

iv) Ma shakhal ($\)$

11. Dakhil ta bet (gurush) fi shahar be Dollar_____

12) Adad ta iyal:

15. Ita ligo eya no min ta'alim an arad ta Khutura ta weleda? i) Ayi () ii) La ()

16. Kan ijaba to ayi, ita ligo ta'alim de min wen? (sahu kulu kan mumkin)

17. Benisba le ita, arad ta marad le jana al-lisa weledu shunu? (Wori kulu kan mumkin)

i) Huma ()ii) Inkhifad to dereja to harara to jism (ta Jena) ()

iii) Tashonujat ()

iv) Mafi Haraka ta jena barau ()

v) Nefes guamguam ()

vi) Indifa'a shedid fi dus (sadr) ()

vii) Ma gi akulu kwes/gi aba rada (uma ta tu) ()

viii) (Ayan) ta Jondis fi awal 24 saa ta haya lahadi batna ta ida wa nufus fi eya omur ()

ix) Iltihab Mahali: Surra al-ahmar au Tesrif Sedidi, hubbub wa moyo ena ()

x) Zidu tannin kan fi_____

18. Hal Jena taki ligo arad tany to ayan/Marad?

i) Ai/na'am () ii) La () Kan ijaba taki ayi, rua fi juzu nimra 3

Part 3: Mumarasa al-gitalabu ra'aya

19. Yatu min arad al-Jena taki ligo? (Wori kulu)

- i) Huma ()
- ii) Inkhifad to dereja to harara to jism (ta Jena) ()
- iii) Tashonujat ()
- iv) Mafi Haraka ta jena barau ()
- v) Nefes guamguam ()
- vi) Indifa'a shedid fi dus (sadr) ()
- vii) Ma gi akulu kwes/gi aba rada (uma ta tu) ()

viii) (Ayan) ta Jondis fi awal 24 saa ta haya lahadi batna ta ida wa nufus fi eya omur ()

ix) Iltihab Mahali: Surra al-ahmar au Tesrif Sedidi, hubbub wa moyo ena ()

x) Zidu tannin kan fi_____

20. Zaman al-jena taki to woru arad to ayan/marad, ita amulu shunu awal?

i) Ilaj ta bet ()
ii) Kujur/salawat ta shifa ()
iii) Mu'alij be al-ashab ()
iv) Iyada/Musteshfa ()
v)Ma amulu eya haja ()

21. Shilu ita kam sa'a ashan ita bi ligo enaya/dictor ?_____

22. Lou kan aktar min 24 sa'a, kan:

i) 24-48 sa'a () ii) 48-72 sa'a () iii) Aktar min 72 sa'a ()

kan aktar min 24 sa'a, rua fi nimra 23

- 23. Sabab shunu it stena le aktar min 24 sa'a?
 - i) Ma fekir gali ayan/marad de sa'ab ()
 - ii) Ana gi stena kan jena bikun kwes au ayan/marad bizudu ()
 - iii) Masafa le musteshfa ()
 - iv) Mafi gurush le ilaj ()
 - v) Geni istane ta'alimat min rajil au ahal tanin ()
 - vi) Zidu tani kan fi_____

24. Munu yau wedi karar ta shilu jena le musteshfa?

6.6. APPENDIX 6: STUDY WORK PLAN AND BUDGET

6.6.1. Study timelines

	Feb 2022	Mar-	Sep	Oct	Nov	Dec	Jan 2023	Feb	Mar	Apr	May	Jun
Finalize research	2022	Aug					2023					
proposal and submit												
for clearance from	v											
FRC and Directorate	л											
of Research and												
planning (MoH												
COSS)												
After obtaining												
clearance inform												
and got consent and			v									
and get consent and			л									
the relevant												
authorities from the												
two hospitals												
Two nospitais												
repare research												
tools including			х									
printing of												
questionnaires												
Identify, recruit and												
train research			х									
assistants												
Pilot and finalize			х									
Study tool												
Collect data			X	Х	X							
Data editing, coding												
and entry into the					х							
Computer												
Data analysis					X	X						
Report writing						X						
Disseminate and												
discuss research												
findings and							х					
recommendations												
with administration												
and department												
Decrease final second												
Prepare final report												
and submit to								х				
institutions												
Institutions												
Disseminate and												
discuss research												
indings with												
hands/mars.rative									х			
neaus/managers and												
I DONCY makers	1	1	1	1	1	I	1	1	I	I		I

Draft preliminary							
plan of action					х		
Discuss						х	
implementation plan							
with policy makers							
and managers							
Follow up on							
implementation							х
action plan							

6.6.2. Budget

Personnel/Item	Rate (Ksh)	Total (Ksh)
Research assistant 1	10 000	
Research assistant 2	10 000	35 000
Research assistant 3	15 000	
Statistician	55 000	55 000
Air fare trip 1 (piloting)	55 000	
Air fare trip 2 (data collection)	55 000	110 000
Transport/fuel	15 000	15 000
Stationary (printing,	20 000	20 000
photocopies, etc)		
Miscellaneous	10000	10 000
Contigency	50 000	50 000
Grand total		295 000

6.7. APENDIX 7: APPROVALS

6.7.1. KNH-UON Ethics and Research Committee approval letter



Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) <u>https://research-portal.nacosti.go.ke</u> and also obtain other clearances needed.

Yours sincerely,

DR. BEATRICE K.M. AMUGUNE SECRETARY, KNH-UON ERC

c.c. The Dean, Faculty of Health Sciences, UoN The Senior Director, CS, KNH The Assistant Director, Health Information Dept., KNH The Chairperson, KNH- UoN ERC The Chair, Dept. of Paediatrics and Child Health, UoN Supervisors: Dr. Boniface O. Osano, Dept. of Paediatrics and Child Health, UoN Prof. Grace Irimu, Dept. of Paediatrics and Child Health, UoN

Protect to discover

6.7.2. Research and Ethics Review Board-Ministry of Health approval letter

