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MJM BIOLABS

Caregivers' Experiences in Providing Home Care for Preterm Infants during the Initial Six Months Post-Discharge from the Neonatal Care Unit

Abiuty OMWENGA OMWERI*[1], MATTHEW LOFTUS[1], Pamela KIMETO[1]

[1] *School of Medicine & Health Science, Department of Family Medicine, Kabarak University, P.O BOX private bag 20157, Nakuru, Kenya.*

*Corresponding Author: aomwenga@kabarak.ac.ke

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ABSTRACT

Nearly 15 million preterm babies are born yearly, worldwide. Out of which 1 million succumb to the complications directly related to premature birth. In Kenyatta National Hospital the prevalence of preterm birth is 18.3% while the mortality rate of preterm babies under 5 years is about 7% per year countrywide. Many studies that highlight the experiences of caregivers of preterm babies have been conducted in neonatal care units and few outside the hospital setting. A majority of these studies have been done in developed countries. However, in Kenya, there is a scarcity of such studies exploring the experiences of caregivers of preterm babies not only in neonatal care unit (NCU) but also after they have been discharged. This study aimed to evaluate the experiences caregivers of preterm babies face at home in the first 6 months post-discharge. This was a phenomenological study. Sixteen preterm caregivers were purposively sampled from Litein Mission and Kapkatet County hospitals' outpatient clinics. Ethical approval was sought from KUREC and a Research Permit from NACOSTI. Interviews were conducted using a semi-structured interview guide at the participants' convenience. The interviews were audio-recorded, transcribed verbatim, and analysed thematically to identify sub-themes and key themes. Majority of the caregivers faced discrimination from the community; they were anxious and worried about the welfare of their babies as they were working throughout the day to keep them safe from harm. The caregivers face the following challenges: (a) stigmatization and fear of unknown (b) working round the clock (c) Support given to Caregivers. To overcome the above challenges, they received support from family members, peers, and church members. We conclude that caregivers may have a myriad of negative experiences at home. We recommend that healthcare givers be incorporated into community-oriented care to optimize and improve the well-being of the infants.

Keywords: Caregivers, Post-Discharge, Premature Birth, Preterm Babies

INTRODUCTION

Prematurity is defined as gestational age of less than 37 weeks. 60 per cent of these preterm births occur in Sub-Saharan Africa and Asia translating to almost the same number of parents with preterm babies in these regions. Of note is that these preterm babies die due to preventable causes of which neonatal sepsis, hypothermia, birth asphyxia, and respiratory distress remain on top of the list (Olack et al. 2021). Every year,

According to the World Health Organization [WHO] (2018), every year, 15 million premature babies are born. Additionally, 6.7% of these babies die due to complications directly related to prematurity. The mortality rate in less than five years old children in Sub-Saharan Africa and Asia is high compared to other regions in the world (WHO, 2018). The mortality rate in Kenya for preterm babies is about 7% of the 193,000 preterm births per year (Kenya Profile of Preterm and Low Birth Weight Prevention and Care, 2019).

There is a great need for professional support when transitioning preterm babies from hospital care to home care. This should be based on individual assessment of the caregiver's needs, like coping strategies, psycho-emotional state, stress levels, and social-economic status. This is essential so as to provide safe care and services post-discharge, which will be effective and efficient for both the parents and the preterm baby (Boykova, 2016). Mothers of extremely preterm infants suffer from anxiety, depression, and post-traumatic stress disorder (PTSD) for longer periods than those with term babies (Fowler et al., 2019). The PTSD would be as a result of the birth process itself, mother-child separation, the stress due to the procedures the babies have to undergo such as insertion of a nasogastric tube and intravenous access, long periods of being on oxygen supplement, and lack of enough sleep due to scheduled feeding overnight (Lasiuk et al., 2013; & Guillaume et al., 2013).

If the postpartum depression is not treated in time, the mother becomes less caring and worse still, insensitive to the preterm baby's needs (Slomian et al., 2019). A recent study has shown that mothers of preterm babies had an increased risk of developing ill-health and negative feelings towards their babies in the early months of their lives (Henderson et al., 2016), such as depression, which predisposes their children to inadequate breastfeeding, malnutrition, and eventually poor health (Dadi et al. 2020). In addition, due to lack of knowledge in the community about the care of preterm babies and their caregivers, mothers of preterm babies are discriminated, feel isolated, and eventually because of discrimination, they end up being psychologically traumatized and emotionally disturbed (Koenraads et al., 2017; Gondwe et al. 2014).

Several studies that have evaluated mothers experiences with taking care of preterm babies have been reported from developed countries such as from the United States of America and Europe (Purdy et al., 2015; Carson et al. 2015; Hoffenkamp et al. 2015; Lasiuk et al., 2013). A few studies on the same topic have been conducted in African countries such as Ghana and Malawi (Adama et al., 2021; Henderson et. al., 2016; Lydon et al., 2018; Godwe et al., 2014). Little is known about this topic in Kenya. Particularly, there is a paucity of knowledge on what goes on in the minds of caregivers of preterm babies on the day of discharge and their life at home with the community as they take care of their babies in the absence of a health professional worker.

The aim of this study was to assess the experiences caregivers of preterm babies have at home in the first 6 months post discharge form A.I.C Litein Mission and Kapkatet Sub-County Hospitals.

METHODOLOGY

A. *Study Design*

A phenomenological research design, following the guidelines of Creswell and Poth (2019), was implemented for this study conducted between May and July 2023. The research involved in-depth interviews and thematic analysis to explore and capture the lived experiences of caregivers in caring for preterm infants during the initial six months post-discharge from the Neonatal Care Unit.

B. *Study Location*

The research was conducted in Kericho County, specifically at A.I.C Litein Mission Hospital and Kapkatet Sub-County Hospital. Kapkatet Sub-County Hospital, located in Kapkatet town along the Kericho–Sotik highway, is a sizable government-managed facility. Presently, it functions as an accredited teaching and referral hospital. A.I.C Litein Mission Hospital, located in Buret Constituency, is categorized as a private faith-based Hospital.

C. *Study Population*

One hundred and twenty caregivers of preterm babies, who attended the out-patient clinics for follow-up in Kapkatet County Hospital and A.I.C Litein Mission Hospital and were discharged between August, 2021 and February, 2022 were targeted.

D. *Sample Population*

Inclusion criteria: All caregivers of preterm babies discharged home with their babies between August, 2022 and February, 2023 were included for the study. Exclusion criteria: All caregivers from other counties who could have liked the interviews to be conducted at their homes were excluded. Caregivers of preterm babies with gross congenital anomalies were also excluded.

E. *Sample Size Determination*

The sample size was arrived at once saturation had been reached, that is, once the information being given became repetitive of what had already been said. It was anticipated that saturation would be achieved after interviewing about 20-30 participants but it was reached after interviewing ten participants (Moser & Korstjens, 2018). However, six more caregivers were interviewed to be sure that no information was missed.

F. *Data Collection Procedure*

Caregivers of preterm infants were informed about the study during pediatric outpatient clinic days. Details about the study, its objectives, location, eligibility criteria, and the researchers involved were provided. Caregivers voluntarily participated, and those eligible (parents or caregivers of infants born before 37 completed weeks, discharged at least six months ago) were recruited with contact information collected for communication. Upon approval for data collection, participants were contacted via phone or face-to-face during clinic days, and specific interview dates and times were scheduled. In-depth interviews were conducted by the principal researcher, recorded, and lasted 20-45 minutes. Participants were assured of confidentiality, informed consent was obtained, and 75% of interviews were conducted at outpatient clinics, with the remainder at participants' homes. Selected locations ensured privacy. Recorded interviews underwent transcription and analysis. Two researchers employed open coding to identify sub-themes, which were then organized into overarching themes. Data integrity was maintained through triangulation methods, incorporating household interviews and key informant approaches. The document underwent further review by two experts for grammar, clarity, and coherence throughout the process.

G. *Data Analysis*

The collected data underwent thematic analysis following the approach recommended by Kiger and Varpio (2020). Verbatim data from audio recordings were transcribed into written hard copies, and a

line-by-line analysis was conducted. Open coding was employed, grouping common phrases into codes and subsequently organizing them. Research assistants compared narratives, reaching agreement on codes with an 85% similarity threshold. These codes were then categorized, leading to the identification of three themes: Stigmatization and fear of the unknown, working round the clock, and support given to the caregivers. To ensure confidentiality, the voice recorder and all data were securely stored and only accessible by the researcher. The voices were distorted, and identifiers were removed. Data will be retained for five years, after which it will be securely discarded through paper shredding and deletion of audio recordings.

H. *Ethical Considerations*

Participants were informed about the objectives and the purpose of the study on the same date of the interview by the researcher in charge of the study. The above information aided the participant to voluntarily decide to participate or decline. It was clearly explained that they will not get penalized if one declined to participate. They were assured that their decision to take part or not to participate in the study, will not in any way affect the services they get in the two institutions. The participants were also informed that the information given will be confidential and private since it will be only accessible by the researcher. They were allowed to ask any questions they had and clarification was given as it necessitated after which verbal consent was obtained from the participant and they did append their signature after they were satisfied with the information given. Ethical approval was sorted and given by Kabarak University institutional Scientific and Research Ethics Committee (KABU - ISERC - 010423) after which a research permit from National Commission for Science, Technology and Innovation (NACOSTI- License No: NACOSTI/P/23/25816) was issued. The participants signed a written consent form after reading and understanding it.

RESULTS

Sixteen caregivers aged 25 – 42 years were interviewed. Three (18.75%) were male while thirteen (81.25%) were female. Fourteen (87.5%) caregivers were married and lived with their spouses however; two (12.5%) of the participants were single mothers. Four (25%) had two children and twelve (75%) had at least three children exclusive of the preterm baby. Twelve (75%) of the caregivers said that it was their first time to have had a preterm baby while four (25%) had a preterm baby prior to the one they have. All of the caregivers had a formal education but only four (25%) were employed while the remaining majority were unemployed. Four (25%) of the participants had their preterm babies born before 28 weeks gestation (extremely preterm), eight (50%) born between 28 weeks and 32 weeks (very preterm), and four (25%) born between 32weeks and 37 weeks (moderate to late preterm) respectively. Their preterm babies' birth weight ranged from 900 grams to 1900 grams: less than 1000 grams (extremely low birth weight) one – 6.25%, more than 1000 grams but less than 1499 grams (very low birth weight) three – 18.75%, and more than 1500 grams but less than 2500 grams (low birth weight) twelve – 75%. Their hospital stay ranged between 7 days to 90days with an average of 30 days of admission in NCU(refer to Table 1).

Table 1:

Social-Demographic Characteristics of Caregivers

Characteristic	N(%)
Gender	
Male	3 (18.75)
Female	13(81.25)
Age	
25-34	4 (25)
35-44	12 (75)
Marital Status	
Married	14 (87.5)

Characteristic	N(%)
Single	2 (12.5)
Education Status	
Secondary	5 (31.25)
College	11 (68.75)
Employment Status	
Unemployed	12 (75)
Employed	4 (25)
Children	
1-2	4 (25)
3-4	12 (75)
Gestation (Weeks)	
Extremely preterm	4 (25)
Very preterm	8 (50)
Moderate to late preterm	4 (25)
Birth Weight (grams)	
1000-1499	4 (25)
1500-2500	12 (75)
Hospital stay (days)	
1-30	14 (87.5)
31-90	2 (12.5)

A. *Caregiver's Post Discharge Experiences*

Stigmatization and Fear of Unknown

All the caregivers faced stigmatization in the community due to lack of information about the care of preterm babies and their caregivers while at home. The preterm babies were called names such as 'small as a shoe' and 'the size of a rat'. Mothers were asked what kind of women they were to have given birth before the expected time of delivery. Consequently, some caregivers felt inadequate as women, mothers, and being wives since the community perceived them as failures. This led to low self-esteem and some were socially isolated from the community.

According to the mothers, very harsh words were used against them, for instance:

'*My friends asked me, what kind of a woman are you giving birth to a very small baby? He is too small even my shoe is big; his size is that of a rat' Caregiver C (Mother).*

Another caregiver said:

'*I didn't have the courage to carry our baby to the clinic since I feared what our neighbours would say about the size of our child. Sometimes I could hear them say; how is she going to carry that small thing called a baby! It can slip out of the blankets without her noticing...*' Caregiver G (Mother).

One mother had this to say:

'*Waoo! What an experience to even talk about!! People see you as a failure... It is not easy, you always ask yourself, why is she so tinny? Why is she so different from others? What did I do wrong?*' Caregiver A (Mother).

Another mother narrated;

'I used to lock myself inside because other women (mothers) used to say that this child is too small. I felt bad. Furthermore, I could not attend meetings because my baby was too little' Caregiver F (mother).

Every one of the participants was concerned about the safety of their preterm babies. Some feared that something bad could happen to their babies, others were afraid their babies might be injured or die, and as a result of these insecure feelings, they could not trust anyone to take care of their babies

as they could do themselves. This anxiety started right on the day of discharge since majority of the caregivers were not prepared either due to lack of information or the fear of unknown for their baby outside the hospital setting.

Caregiver A, who is a mother said;

'I was not ready to go home because you see, I will be alone.. no nurses or doctors for support.. I was scared' Caregiver A (Mother).

One caregiver (mother) elaborately said this:

'You need more time, you are forced stop every other chore because you don't know what will happen to him; you cover him well but then he covers himself including the head, he can die. Sometimes he vomits through the nose.....this scares me a lot. I wonder whether he will speak, walk or he will be disabled... '(tears), Caregiver D (Mother).

Due to the feelings of insecurity of her baby, one mother resigned from her job in order to protect her preterm baby. She said:

'Wherever I went, I took her along with me since I could not trust anyone that could take care of her as I do... I actually quit my job in the second month so that I could take care of her and protect her from any trauma' Caregiver C (Mother).

A father said:

'I could sneak from work so as to keep checking if he is okay and sometimes carry her for 30 minutes before i sneak back to work' Caregiver B (Father).

Care Around the Clock

Majority of the caregivers said that their babies needed more time to take care of them compared to term babies. They felt fatigued and exhausted because they barely had enough time to rest. Sometimes some could fall asleep while seated. They were unable to attend to other chores because of the preterm baby's demands.

One mother said:

'This child probably needed 15 to 20 hours a day for proper care.. My hubby could sometimes close his business so as to take care of us' Caregiver A (Mother).

Another caregiver (mother) added:

'Feeding as required was a challenge leave alone waking at night every 2-3 hours... was an uphill task that needed sacrifice and dedication. I could feel fatigued and so tired that during the day I could fall asleep while seated.. anyhow' (laughter) Caregiver D (Mother).

Mother E crowned it all when she said;

'*Having a premature baby takes all your energy and time compared to a normal baby. The one who has been born maturely has no much work real... it's like a walk-over kind of...'* Caregiver E (Mother)

Support Given to Caregivers

All caregivers expressed their gratitude for the support they received from the spouses, relatives, and the community at large. Of note, all women (mothers) appreciated the psychosocial support their husbands gave them that included finances, doing house chores like cleaning the house, utensils and laundry work. The mothers' in-law and in-laws played a great role in the support of caregivers of preterm babies.

Family members:

A woman was proud of her hubby as she expressed it in her statement:

'...He was not only my husband but my counsellors and everything in this world' Caregiver H (Mother).

Another woman said:

'*My husband would wake up early, do all the cleaning in the house, cook breakfast, prepare the other children for school and escort them to school. He used to make sure he has cooked my lunch and packed it well for me...*' Caregiver K (Mother).

A father said:

'My sisters took turns to do the cooking, cleaning of the house, washing the dishes, washing and dressing our preterm baby, fetching water from the river and even escorting our son to and from school every day' Caregiver I (Father).

A mother applauded her mother in-law:

'... My mother in-law used to cook, wash all the clothes, mob the floor and any other thing that needed to be done; she could go to school to pick our son...' Caregiver K (Mother).

Church members

The church members did visit the caregivers of preterm babies and prayed for their babies providing encouragement and hope to them.

One mother said:

'My church members visited me, prayed for the good health of my son and protection from evil.. they stood by my side wherever I needed them' Caregiver J (Mother).

Another mother satisfactorily said:

'..... they (church members) *were my pillar when my faith was weak'* Caregiver H (Mother).

Peers' support

Over two thirds of the caregivers said that they were so much encouraged by other mothers who had preterm babies within their locality. They were visited and even shown healthy and energetic teenagers who were born prematurely. One mother shared her encouragement by saying;

'*She told me not to fear, her child was even smaller than mine but now he is a grown man like any other man*.... He will be a man. '*This encouraged me'* Caregiver H (Mother).

DISCUSSION

Pregnancy for most women is a happy moment for them and they look forward to delivering a healthy baby at term however, this is not always the case. Some babies are born before their expected time of delivery and these are categorized into extremely preterm, (< 28 weeks), very preterm (28 to 32 weeks), and moderate to late preterm (32 to 37 weeks) babies (Quinn et al., 2016). In this study, the caregivers stated that they did not expect to have a preterm baby and due to that, they faced a range of challenges such stigmatization, fear of unknown and working around the clock, in taking care of their preterm babies the first months after discharge in agreement with Lasiuk et al., (2013); Koenraads et al., (2017); Gondwe et al., (2014); Nabiwemba et al., (2014).

Stigmatization and Fear of Unknown

Stigma was one of the key themes identified in our study. First, stigma was linked to the size of the baby. In a study conducted in Malawi by (Koenraads et al., 2017), stigma was highlighted as one of the major contributors to psychological trauma of the caregivers. For instance, some caregivers in this study lamented that their babies were called names for instance, 'small as a rat' and 'smaller than a shoe'. More than half of the mothers in this study were traumatized psychologically because of the size of their babies unlike those mothers in Lasiuk et al., (2013) whose main concerns were those of uncertainties of their babies. However, Hoffenkamp et al. (2015) from Netherlands did conclude that the caregivers' psychological disturbances were not related to the size of the baby and prematurity per se but the negative perspectives and characteristics of the parents of the preterm babies. The perceived insults and stigma led to most women having a sense of inadequacy as women and mothers. As a result of stigmatization, majority of the mothers spent most of their time indoors to avoid what other women would say about them and their babies (Gondwe et al., 2014; Fowler et al., 2019). The above differences could be due to the cultural believes of where the studies were conducted. In the African context, especially where this study was conducted, it is believed that the mother of a premature baby must have committed some offence or her family must have done something wrong in the past and that is why she gave birth before the expected date of delivery.

Some caregivers bitterly lamented that no one came for a cup of tea in their houses as it is a custom in the community to celebrate a new-born and this clearly highlighted the degree of discrimination. Consequently, the mothers felt socially isolated, psychologically disturbed, and emotionally drained leading to low self-esteem unlike the fathers who the society esteemed to be blameless in this matter. This discrimination was linked to what Koenraads and colleagues (2017) in Malawi reported about lack of sensitization and inadequate knowledge among community members on the care of premature babies and their caregivers. This was also exhibited in this study that was done in a poor resource setting unlike those in developed countries like Netherlands and Sweden that have well established systems with knowledgeable communities. Apart from the stigma and discrimination they experienced, they were filled with uncertainties.

Fear of unknown was a major topic in the discussions with the caregivers. Many of the caregivers clearly indicated that they were not ready to go home because of the uncertainties their preterm babies could face at home in the absence of a nurse or doctor for their help or support. In fact, majority of the caregivers expressed their anxiety whether they were at home or away. This was in agreement with Fowler et al., (2019) who clearly pointed out the emotional stress parents of preterm babies undergo while in NCU and after discharge. The caregivers in this study constantly feared that something wrong could happen to their babies whether they were at work or at home. At the same time, the caregivers were worried if their preterm babies would ever walk, speak, or grow to adulthood making them psychologically and emotionally disturbed. These same findings were also illustrated in Henderson et al., (2016); Carson et al., (2015) studies done in developed countries like United Kingdom [UK].

Due to the fear of unknown, the caregivers took all the measures they thought could guarantee their babies' safety and good health. These safety measures included covering the preterm baby with more than one blanket to prevent the baby from getting pneumonia; taking turns to check on the baby during the night since the baby may cover her face and suffocate or vomit through the nose and would be chocked by the vomitus and lastly, other caregivers could not allow the other siblings to take care of the preterm baby because they thought that they could hurt the preterm baby. On the other hand, some caregivers could sneak from work to check on the well-being of their babies since they did not have a place at work where they could breast their babies like it is in Finland. Eventually, some had to resign from their employment so as to take care of their premature babies. These fears led to psychologically trauma of the caregivers and as a result some caregivers were so much affected to an extent that they could not produce enough milk for their babies. The emotional and psychological stress of parents of preterm babies was summed up in a study conducted by Carson et al., (2015) in UK which pointed out that the risk of developing postpartum depression among mothers and depression among fathers of preterm babies was doubled compared to that of mothers and fathers of term babies. It is good to note that more than 90% of the caregivers had no prior experience of taking care of a preterm baby and this contributed to their anxiety and fear of unknown. These caregivers ended up working round the clock to ensure the babies are safe.

Working Round the Clock

Findings from this study reveal a clear challenge of taking care of preterm babies at home. Caregivers pointed out the challenges they experienced upon their discharge from hospital such as a need for more time in taking care of the premature baby compared to a baby born at term. More time was associated with roles such as breastfeeding, nursing, keeping the baby warm which made caregivers work around the clock. Majority of the mothers in this study needed at least 15 hours to carter for the babies' daily needs making it difficult to attend to other chores like doing business as identified by Gondwe et al., (2014); Amorim et al., (2018). Some babies especially those born with extremely low birth weight needed round the clock care affirming the findings of Amorim et al., (2018) who stated that care of the very preterm baby needed 24 hours. The study of Amorim and colleagues (2018) also observed that the caregivers of extremely preterm babies were negatively impacted in terms of their quality of life because they had no time to attend social gatherings, to do business, do farming, or even have time to rest and for self-care. The babies' needs were given the first priority neglecting other duties.

Many of the caregivers in this study like those of Nabiwemba et al., (2014) said that their needs ranged from 2 hourly feeding, keeping the environment clean and safe, and keeping the baby warm. The study of Nabiwemba et al., (2014) was conducted in the neighbouring country of Uganda which has got almost the same psychosocial economic and healthcare system challenges as Kenya. Meanwhile, due to lack of enough sleep, Henderson et al., (2016) observed that the caregivers felt fatigued, tired,

and sometimes disoriented during the day and these would lead to negative feelings like anger and resentment towards their preterm babies. This in return affected the health of their babies. In order to overcome the above challenges, the caregivers received support from their spouses, relatives, peers and the church as discussed below.

Support Given to Caregivers

This study showed that the caregivers had a wide range of bad experiences when they were in hospital and the community but on the other hand, some had good experiences both in hospital and at home. These positive experiences constituted the physical, psychological, and even emotional support they received from their relatives, spouses, peers, and the church members. For example, Fowler et al., (2019) pointed out the need to support mothers of extremely preterm babies mentally and socially for their psychosocial stability and this could in return have a positive impact in the care of the preterm baby. This care or support starts right in the NCU and should extend all the way to the community. Of note is that, once the caregivers were out of the hospital with their preterm babies, the family members shouldered the responsibility of giving the required support as vividly expressed by majority of the caregivers. The caregivers expressed the need for well outlined follow up procedures before leaving the hospital and the continuity of care to be extended to the community level as suggested by Bockli et al. (2014) and García Reymundo et al. (2019).

To begin with, almost all caregivers said that they received much help from their relatives especially the in-laws. For instance, mother in-laws used to cook, wash all the clothes, and mop the floor after which they could proceed to school to pick up other siblings as they are released home. On the other hand, sisters' in-law played a big role in supporting the caregivers of preterm babies by cooking, mopping the floor, dropping and picking other children from school, and lastly, they could baby-sit the preterm baby as the mother took a nap. With the help above, caregivers could have humble time for bonding with their preterm babies and this helped them to feel loved and cared for. At the same time they were at peace mentally, psychologically, and even physically same as the parents in the studies of Jerntorp et al. (2021) and Baldoni et al. (2021). These stability and peace could eventually help to overcome the negative feelings like hatred the parents more so mothers, could harbour towards their preterm babies as identified in the study of Henderson et al. (2016). These findings are similar to those in other countries like Ghana and Uganda, however; it is a cultural norm in the locality where this study was conducted for the in-laws to take care of mothers the first few months after delivery.

Apart from the in-laws, peers whose babies were born prematurely but now are grown-ups, encouraged the caregivers especially first-time mothers by teaching them how to handle their little ones in order to avoid at all costs, any trauma be it be physically or psychologically. The peers also taught them how to feed and keep their preterm babies warm as needs identified in the study of Nabiwemba et al. (2014). The mothers shared their gratitude for the psychosocial support they received from those who had preterm babies within their locality. Some participants (mothers) cheerfully narrated that their peers' children were too small than theirs but now they are grown, young, and energetic men and women, so even their baby boys will be grown men soon. This encouraged the caregivers so much and made them to have a positive attitude towards their children.

On the other hand, men (fathers) were applauded for their financial, psychological, and physical support they provided to their spouses (wives) as needs identified in a study done by Adama et al., (2021) unlike the findings of Gondwe et al., (2014) where men were accused of extramarital sex. For instance, more than half of the mothers interviewed testified that their husbands would not only accompany them to the hospital during their clinic visits for the preterm babies but they would also carry the babies themselves. Their presence meant emotional stability and physical support in agreement with the studies of Baldoni et al., (2021); Jerntorp et al., (2021) which brought out the important role of a father in the care of a preterm baby. This was a unique finding in this study because it is perceived that in the African contest, it is the work of women to look after the children, cook, take them to school, and to attend clinic follow ups.

Lastly, despite all the support described above, at some point in the lives of the caregivers, they felt like their faith in keeping with the uncertainties was getting weak and they needed some spiritual power to

give them hope amidst the uncertainties of life. Religion was said to be a key coping mechanism as it provided a source of hope for the hopeless. Some caregivers were visited by their church members and had them pray for their loss of faith and the preterm baby. This was important for their psychological stability in agreement with Lydon et al., (2018) who brought out the role of religious leaders together with health caregivers in supporting the caregivers of preterm babies in the community both socially and emotionally. The participants especially mothers, were so much grateful for the visitation of their church members, the prayers offered for the good health of their preterm babies and their protection from the powers of darkness. In every one of these supportive systems in the community like the peers' support, support from in-laws and spouses, the church became a unifying factor for them all by rejuvenating the caregivers' hope as they were taking care of their preterm babies at home.

CONCLUSION

Preterm babies are not only a blessing to the family but they can also be a challenge to the family. Caregivers of preterm babies experience both good and bad experiences not only while in the hospital but also at home after discharge. The good experiences majorly include the financial, psychological, physical and emotional support given to the caregivers by the relatives, peers, and the church. Fathers (men) played a key role in supporting their families (wives and children) in all aspects of life. The bad experiences were as follows; working round the clock, having fear of unknown, and stigmatization. These affected every caregiver as they were taking care of their preterm babies at home.

RECOMMENDATIONS

The patient-oriented care given at the hospital level to be in-cooperated with community-oriented care for efficient, effective, and wholesome care of preterm babies and their caregivers in and outside the hospital.

In order to reduce stigmatization of the caregivers of preterm babies, there is need to create awareness in the community concerning the care of preterm babies and their caregivers.

The hospitals to collaborate with the communities to create support groups for the caregivers of preterm babies in the community.

Family and the community members' support, especially the in-laws to be encouraged as they play a major role that results in the outcome of the family and the preterm baby.

Men (Fathers) be supported in the care of their preterm babies by making policies that define their role and support

There is a need for a country wide study to be conducted for the findings to be generalizable.

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Conflict of Interest:

All authors declare no conflict of interest.

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