



What Support Systems do Women Caring for Preterm Infants at Home Require in Urban Ghana? A Qualitative Study

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Abstract

Introduction Caring for preterm infants and ensuring their survival beyond neonatal intensive care units remain a challenge in many low-income settings. While studies highlight the difficulties of caring for preterm infants at home, few have focused on the forms, sources, and accessibility to support systems. This study explored the forms of support systems women caring for preterm infants at home in urban Ghana require, and their accessibility to such support systems.

Methods An explorative cross-sectional qualitative study was conducted. A total of 19 women who were caring for preterm infants aged 2–6 months at home were purposively sampled. In-depth interviews were conducted and thematic content analysis used to analyse the data.

Results Women reported four main forms of support which they require: psychosocial support, practical support, material support and spiritual support. However, accessibility to these support systems was highly unequal, often depended on one's social status and the quality of one's family and interpersonal relationships prior to giving birth to a preterm infant.

Conclusion Women caring for preterm infants at home require a variety of support systems; but effective accessibility remains a challenge for many in urban settings. Interventions to strengthen community and home-based support for women caring for preterm infants at home, including use of social media-based peer support groups, are urgently needed.

Keywords Preterm birth, preterm infant · Newborn health · Support system · Accessibility · Ghana

Significance

What is already known on this subject? Studies show that adequate community support for parents experiencing preterm birth is critical to improved preterm birth outcomes outside health facility settings. The forms of support systems women require and accessibility to such support is however poorly understood in low-income settings.

What this study adds? Women require different forms of support, including psychosocial, practical, material and spiritual support to effectively care for their preterm infants at home. Accessibility to these support systems is however limited for some, including migrant and single women.

Interventions to support women with preterm infants both in NICU and at home should consider these differentiated support needs and access barriers.

Introduction

Infants born before 37 completed weeks of gestation are termed preterm births (Chawanpaiboon et al., 2019). Globally, approximately 15 million annual livebirths (approximately one in ten births) are preterm (Chawanpaiboon et al., 2019). About one million die soon following birth (Ashish et al., 2015; Patel et al., 2015). Preterm birth is the leading cause of under-5 child mortality, and an important cause of serious morbidity (Chawanpaiboon et al., 2019). Preterm birth survivors and their families can face adverse lifelong health consequences as well (Patel et al., 2015; Ashish et al., 2015; WHO 2018; Asiedu et al., 2019).

In Ghana, 128,000 preterm births occur annually (WHO 2018). Each year, approximately 29,000 newborn deaths occur in Ghana due to preterm birth complications (WHO

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2018). In some major health facilities in Ghana, the rate of premature birth is 20.3% among adolescent mothers and 12.2% among non-adolescent mothers (Abdulai et al., 2015; Anyikam et al., 2016).

Current evidence shows that parents often display a variety of emotions following a preterm birth, including shock, denial, anxiety, fear, sadness, anger, grief, and depression (Henderson et al., 2016; Lefkowitz et al., 2010). Mothers and parents of preterm infants therefore require a wide range of support (Akum 2018). Worldwide, Neonatal Intensive Care Unit (NICU) staff do an incredible job of caring for fragile, medically complicated preterm infants during periods of hospitalisation (Brett et al., 2011; Lawn et al., 2013). The challenge is when preterm infants leave health facility settings to be cared for at home. Parents of preterm infants may experience post-traumatic stress disorders partly because of lack of homebased support (Adama et al., 2017; Henderson et al., 2016). Studies show that emotional support, consolation, sympathy, and solidarity from family, peers and community members could help reduce stress and inspire confidence in women to enable them effectively care for their preterm infants at home (Arzani et al., 2015). While previous studies have highlighted the challenges of caring for preterm infants at home (Hall et al., 2015; Henderson et al., 2016), few focused on the forms of support systems women caring for preterm infants at home in urban contexts require (Akum, 2018). This knowledge gap could hamper efforts to effectively support them, and ultimately improve neonatal health outcomes. This study explored the forms of support systems women caring for preterm infants at home in urban Ghana require, and accessibility to such support systems.

Methods

Research Design

The data reported in this paper are part of a larger original study that was conducted to examine support systems for women caring for preterm infants at home, and their challenges and coping strategies in the Bolgatanga Municipality in the Upper East Region of Ghana. The design of the larger study was a cross-sectional quality study. The design, sample description, data collection, analysis, and reporting followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007).

Study Context

Empirical data were collected between 28th March and 29th June, 2018 in the Bolgatanga Municipality in the Upper East Region of Ghana. The Bolgatanga Municipality is the most

urbanised and cosmopolitan area in the region. In 2015, it had a total population of 131,550 with a fertility rate of 3.0 (Ghana Statistical Service, 2015).

Pneumonia, septicemia, diarrhoea, asphyxia and tetanus are common health problems affecting newborns and infants in the municipality (Ghana Health Service, 2016). Health interventions that have been implemented in the municipality to improve newborn survival include an UNICEF-led Essential Newborn Care benefits package in 2012, and a Mother and Baby Friendly Health Facility Initiative (Ghana Health Service, 2016).

Within the municipality, participants were recruited from the NICU outpatient unit of the Bolgatanga Regional Hospital. This hospital is the main referral facility for all district hospitals in the region. The hospital's NICU sees the highest number of preterm births in the region. Between June 2016, and June 2018, 552 preterm infants were admitted and managed in the hospital's NICU.

Research Participants

Research participants comprised 19 women whose preterm infants were admitted into the NICU of the Bolgatanga Regional Hospital, and subsequently discharged to care for their infants at home. Participants were aged 18–41 years. Eleven participants had no formal education. Also, 15 participants were married. Most (11) were unemployed. The gestational age of the infants at birth ranged from 28 to 36 weeks, and the infants were aged between one and three months at the time of interviews.

Sampling and Recruitment

Participants were purposively sampled. Upon discharge from the NICU, women with preterm infants were approached by one trained research assistant. The women were individually told about the purpose of the study. A list containing the names and telephone numbers of all the women approached was then compiled. Each woman was given two weeks to decide on participation. The research assistant re-contacted each woman via telephone after the 2-week period. Out of 34 women approached, 19 expressed interest in the study. Individual interview dates were arranged, usually in the home of the woman.

Data Collection

In-depth interviews were conducted using either English or *Frafra* (local language). Interviews were conducted in a private space within the premises of the woman's home to ensure convenience, and privacy. Each interview was discontinued when saturation was achieved for all major discussion topics. Interviews lasted between 45 and 60 min. Interviews

were audio-recorded alongside handwritten field notes. An open-ended thematic topic guide was used to facilitate interviews. The guide focused on exploring two main questions: what forms of support systems the women require, and whether women have access to such support systems.

Data Analysis

Thematic content analysis was done. This involved several steps. An independent transcription specialist first transcribed all audio recorded interviews. All non-English transcripts were then translated into English. The first author performed back-to-back translation on selected transcripts to check translation quality. Transcripts were then read severally to gain general understanding. Thereafter, a codebook was developed using both the original and emergent research questions. All transcripts were then imported into QSR NVivo 11 software for coding. The coding process involved comprehensive review of each transcript, followed by coding into emerging themes. Finally, the themes were presented as narratives. Relevant quotations from the transcripts were used to support identified themes.

Quality Assurance and Analytical Rigour

The topic guide was pre-tested on three (3) women (not included in the actual study). This pretest allowed ambiguous or inappropriate questions to be reframed. During interviews, the researchers ended each interview by summarising the main issues each participant raised. This gave participants opportunity to confirm or repudiate what the researchers captured. The researchers also engaged in reflexivity by consistently reflecting on how their individual and collective biases could affect the data collection and analysis. This process of continuous reflexivity ensured that questions were appropriately asked and personal biases minimised.

Findings

Forms of Support Women Require

Participants were first asked about the kinds of support they require to effectively care for their preterm infants at home. Responses across interviews revealed four forms of support systems: psychosocial support, practical support, material support, and spiritual support. These forms of support could come from different sources depending on a woman's or her husband/partner's social status, and social connectedness. The different forms of support and their sources are explored below.

Psychosocial Support

Several participants mentioned psychosocial support as the most important form of support women caring for preterm infants at home in urban settings require. According to this account, the most difficult aspect of caring for a preterm infant at home is the anxiety and stress that women experience:

The most difficult part of caring for a preterm infant is the stress; you are always anxious about what will happen next.

Consequently, women talked about how psychosocial support could help strengthen them emotionally to better cope with the stress:

I will say emotional support is what I need most. My husband is my main source of emotional support; he always gives me words of encouragement whenever he sees that I am losing hope.

Another participant said:

There are times that I feel like running away... the emotional stress is too much to bear. But what keeps me going is the counselling, advice and encouragement that people give me. So, I will say I require constant emotional or psychological counselling and support.

In terms of the sources of psychosocial support, many participants mentioned their mothers, husbands/partners, and friends:

Sometimes the little praises my friends give me for taking good care of my baby serves as an encouragement. So, yes, my friends could provide emotional support.

Practical Support

Participants also talked about practical support. Practical support meant day-to-day support in caring for their preterm infants, including assistance with domestic chores:

I think the support I require now is the day-to-day help in getting things done...like if I have to wash cloths or go to market, somebody has to be there to look after my baby. Otherwise, hunger will kill me because my baby needs full attention all the time.

Another participant said:

For me the form of support I require the most now is help in doing things around the house. Because of her situation [referring to baby], I cannot do anything. So,

I mostly rely on friends and my mother to get basic things like cooking and washing done.

One participant also said:

One of the problems with caring for a preterm infant is that you always have to be with the infant all the time. So, it is always difficult to do anything. I require support from extended family to do things around the house.

As regards the sources of practical support, several participants mentioned their mothers and extended family members as potential sources of practical support.

Material Support

Nearly all participants mentioned that material support from family and friends was important in the care of a preterm infant at home. According to this account, the high financial, time and material resource costs involved in caring for a preterm infant mean that many parents are unable to effectively care for their preterm infant without greater empathy and material support from friends and family. Monetary donations and gifts in the form of soap, baby cloths, diapers, food, meat, millet flour, shea butter and *dawadawa* (local food spice) were mentioned as examples of material support.

I will say money and other material things are my biggest support needs in caring for my preterm infant at home. I have received some gifts... soap, millet flour, groundnuts, baby clothes, shea butter and dawadawa. In this our community, people generally give gifts when their friends or family members have new infants. But when your baby is preterm, you always require a lot of resources.

Many single women in this study particularly talked about how they would not have been able to care for their preterm infant but for material support they received from friends, family and church members.

For me as a single mother, I can say that if not for the gifts of soap and baby cloths my church members gave me, I would not be able to care for my baby at home.

Church members, friends and family members were identified as the main sources of material support.

Spiritual Support

Many women also talked about their reliance on spiritual support in caring for their preterm infants. This group of participants were mostly Charismatic and Pentecostal Christians who believed that God's healing power is greater than anything else:

As I believe, I am convinced that God gave me this baby to teach me something greater. So, I believe God will heal my baby. Even though it is difficult, my faith in God gives me strength and hope.

Another participant said:

For me, Jehovah [God] is my biggest support in caring for this baby. I console myself with prayers...and I need prayers.

Indeed, few participants linked the birth of their preterm infant to evil spirits, and suggested spiritual interventions including fasting and prayers as forms of support to deal with the situation. In this regard, being a member of a Charismatic or Pentecostal church was critical:

One thing I also want to mention is faith...I mean the spiritual aspect. We need it. Some of my church members do come and pray for me and the baby. It is very important, and I value this spiritual support. I believe that is the reason my baby and I are still alive today.

Accessibility to Support Systems

While many participants reported the different forms of support they require, accessibility to such support systems varied. In many interviews, it was mentioned that whether one received adequate support in caring for a preterm infant at home often depended on one's social status and the quality of one's interpersonal relationships with others prior to a preterm birth.

I will say that whether people empathise and support you depend on your relationship with them. There are people, including my family members, that I have good relationship with so they provided support when they heard that my baby was preterm. But there are others too that I do not currently have good relationship with; such people have not asked how I am doing. So, I can say that it all depends on relationships.

In relation to family support, it was reported that while support is often available in contexts where there is a functional extended family system, accessibility is often a challenge for those living far from their natal or matrimonial home towns, including women living in detached urban apartments with limited space to accommodate extended family members:

It is difficult to get support from family because we do not stay with anyone here. I was staying with my younger sister but a week after birth she left for our home town leaving my husband and I alone.

Participants also talked about limitations in accessing community support:

I did not get any support from community members. It is only my husband who assists me in taking care of my child.

Inaccessibility to family and community support was particularly common among migrant women. One woman who recently migrated from a neighbouring region noted how she did not receive any material support from family, friends and community members:

...Oooh, I did not actually get anything from anywhere apart from what my husband and I had...because I do not know many people here; I came to settle here not too long ago.

Also, while NICU staff were highly praised for providing professional support and coaching during their NICU admission, many reported that upon discharge from hospital, it was difficult to access regular professional support at home.

At the hospital, the nurses used to teach us about Kangaroo Mother Care. We the mothers shared knowledge on Kangaroo Mother Care; the newly admitted mothers were educated by those already on the ward.

While several women recounted how helpful supportive sharing of experiences with their peers was, many lamented the absence of peer support systems for women caring for preterm infants in their communities. This situation was concerning because the nature of urban living made it difficult to regularly interact with other women:

At the hospital, the mother-to-mother support group was there for us to share ideas, experiences and ask questions concerning how to take proper care of our babies. But since I got home, there is no such support group ...and because of how people keep to themselves in this town, it is not easy to find women with experiences similar to yours.

Discussion

Studies have shown that adequate family and community support for parents experiencing preterm birth is critical to the survival of preterm infants outside health facility settings (Lawn et al., 2013). This study explored the forms of support systems women require, and their accessibility to such support systems in an urban setting in northeastern Ghana. Findings revealed four main forms of support systems that women valued: psychosocial, practical, material and spiritual support. These support systems come from multiple sources: husbands/partners, mothers-in-law, extended family members, friends and church members. Nevertheless, accessibility to these support systems is highly unequal, often

contingent on one's social status and the quality of interpersonal relationships.

Some aspects of our findings have parallels in previous studies. In Iran, women sought prayers and spiritual support from religious heads when disturbed about their preterm infant's condition (Schenk & Kelley, 2010). Similarly, Arzani et al. (2015) found that women required emotional support from partners, family members, and relatives to address stress associated with caring for their preterm infant at home. One qualitative study in Ghana also reported that mothers of preterm babies received practical support from their mothers-in-law, including help with house chores, including fetching water, and washing the infant's clothes (Akum, 2018).

Other aspects of our findings are however new, at least in the context of Ghana. For instance, although all women required some form of support, access to such supportive systems was limited for some. Migrant and single women were more likely to have inadequate psychosocial, practical, material and spiritual support in caring for their preterm infant at home. Migration and the concomitant detachment from one's extended natal or matrimonial family ties accounted for this differentiated access. Another factor is the individualistic nature of urban living, which, as some participants noted, often makes it harder to interact with others. Interventions to support mothers caring for preterm infants should therefore target and address the unique needs and challenges of disadvantaged women like single mothers and poor migrant mothers.

Another aspect of our results that demands further reflection relates to inaccessibility to community-based practical and psychosocial support from peers. Many women indicated that the experiences they shared in the NICU were very beneficial, especially when peers whose infants are doing well are used as references. This finding is consistent with Ardal, Sulman and Fulle-Thomson's (2011) study in Canada, where peer support groups helped to normalise the experience of new NICU parents and helped them accept the condition of their preterm infant by modeling positive attitudes. Providing NICU staff regular training and resourcing them adequately could therefore empower them to properly coach, support and prepare women with preterm infants for home care (Gallegos-Maetinez et al., 2013; Lawn et al., 2013).

At home however, many women reported that they did not benefit from mother-to-mother peer support. Policy makers in Ghana, including Ghana Health Services, should take steps to encourage formation of peer support groups beyond the NICU settings. Different models could be used. In-person support, telephone support and internet-based communication (e.g. zoom) support are some of the ways (Brett et al., 2011; Hall et al., 2015). Social media technology and platforms, including WhatsApp and Facebook,

could be used to encourage and facilitate easy peer-to-peer communication outside health facility settings. NICU staff could even be part of such platforms, serving as sources of appropriate information and advice. This form of support could be essential for women from low-income backgrounds who may not have well-functioning social support networks. Peer support provided through social media rather than in-person has several advantages for women who may not have time to meet with their peers. Social class, gender and age differences that often interfere with effective face-to-face interaction could also be minimised. Other benefits of internet-based support include accessibility to support anytime and anywhere. However, low literacy among women as exemplified in this study, poverty and poor internet connectivity are possible limitations.

This study has limitations. The use of a relatively small sample of urban women allowed in-depth exploration of support systems they require and accessibility to these support systems. However, the limitations of generalising the results beyond the context of the study is acknowledged. Also, some interviews were conducted in *Frafra* and later transcribed and translated into English. It is possible that some meaning may have been lost in the processes.

Conclusion

This study provides new evidence on support systems women caring for preterm infants at home in an urban context require. It shows that women require different forms of support, including psychosocial, practical, material and spiritual supports to effectively care for their preterm baby at home. However, accessibility to these support systems is highly unequal. Therefore, interventions to support women caring for preterm infants both in the NICU and at home should consider these differentiated support needs and access barriers. Social media and internet-based peer support groups could be used to help address the support needs and access bottlenecks among relatively disadvantaged women such as single mothers and poor migrant mothers.

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Declarations

Conflict of interest The authors declare that they have no conflict of interests.

Ethical Approval The study was reviewed and approved by the Ghana Health Service Ethical Review Committee (GHS-ERC: 061/01/18), and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. Informed written consent was obtained (signature or thumb print) from all participants prior to their inclusion in the study. All

interviews were conducted in venues that ensured privacy and confidentiality of all participants. Neither participants' names/addresses nor any voice identifiers were used to identify individual participants in interview transcripts.

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