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"Even God helps those who help themselves": Experiences of women who care for acutely ill young children in Nairobi's urban informal settlements

Summary of research findings by The CHAIN Network and KEMRI-Wellcome Trust

Introduction

Gender plays an important role in child health. In many African households, women are the main carers of young children but are less likely than men to be the primary resource providers or in control of available household resources (1–3). Studies have shown that women are often held responsible for the health of their children, but many household and community members can be involved in treatment-seeking decisions and actions (4–10).

Whether or not mothers make independent decisions regarding treatment of child illnesses is determined by a range of inter-related factors (3,6,11) including:

- the nature and perceived seriousness of the child's illness:
- who is perceived to 'own' the child;
- perceived cause of illness and;
- household roles and relations.

Whilst there is an extensive literature on gender relations and child treatment-seeking in rural Africa, this has been given less attention in the urban context.

Using a gender lens, this qualitative study aimed to explore treatment-seeking pathways for acutely ill young children living in the low-income settlements of Kibera and Mathare, in Nairobi County. This study was conducted within the CHAIN Network, which examined risks for childhood inpatient and post-discharge mortality. The CHAIN Network found that when children were admitted to hospital, almost half of the deaths that occurred happened after discharge. Hence, there was a need to better understand challenges and opportunities within the household. Twentytwo families of acutely ill children aged 2-23 months were followed up in their homes following a hospital admission. Each household was visited 3-5 times over the six-month period after hospital discharge. During these visits, discussions on the child's health, illness and related treatment-seeking were held with a range of family members including the child's primary carer.

This brief summarizes the key findings from the research. It also provides policy recommendations for

Key messages

- Gender plays a key role in child health, illness and related treatment seeking; and is an important consideration in developing interventions.
- In urban informal settlements of Nairobi, women were observed to be the primary decision-makers and engagers with the health system during child illness episodes.
- Men/fathers were involved predominantly as financial providers or to support with decisionmaking; but were largely absent in the day-today care of children.
- Other women in the mother's circle including female neighbours, played a very significant role in treatment action taken during a child's illness episode. They were also a source of social support for the child's mother.
- Women were disproportionately negatively affected by children's illness. This included loss of jobs and other income generating activities for mothers; as well as being blamed for their child's poor health.
- As the primary carers, women also bore the burden of dealing with the day-to-day challenges of interacting with the health system, which itself faced challenges in meeting the health care needs of their children.
- We recommend economic, community and health system initiatives to support vulnerable mothers and families during child illness.



Definition of Gender

The socially constructed roles, behaviors and resulting relationships that a given society considers appropriate for men and women.

addressing challenges experienced by women who care for acutely ill young children within Nairobi's urban informal settlements.

Key findings

1.Gendered responsibilities in child health and illness

In this study - as in other Kenyan settings - childcare and health was predominantly a female domain, with women being the main engagers with the health system. Women, primarily the mother and sometimes the child's grandmother or maternal aunts, were the main carers and decision-makers when it came to treatment seeking for child illnesses. This was the case even when the child illness was perceived as severe. Men were largely absent in the day-to-day care of the children other than as financial providers to obtain treatment. Mothers' independent ability to decide on child treatment was linked to their caring role. The children's fathers were usually informed to support with finances or with decision-making, rather than to seek permission. The latter was a key difference observed to previous studies conducted in rural Kenya by the same team (3,12). In the rural set up, although women were still the primary carers, they often had to seek permission from their husbands and/or other senior members of the household when it came to child treatment seeking, particularly where illnesses were perceived as serious.

"After around the fifth month [of illness], the father told me take this child to hospital. But I did not listen [because I did not think it was serious]. Instead...I would take him to the sister [chemist] nearby, depending on how I gauge his condition. [Initially] I did not think it was serious... [But when I saw it was] I immediately rushed the child to the [study] hospital. I didn't even call the father to tell him where I was going. I asked another woman [neighbour] to inform him that I had gone to the hospital". (Child's mother, Household 22, visit 1)

2.Mothers often consulted with other women, particularly where illnesses were prolonged or complex.

During a child's illness, particularly where the illness was prolonged or complex, there were other - predominantly female - individuals, who influenced the decision-making process. These included the child's grandmother, other relatives such as the mothers' sisters and aunts, female neighbors and friends, and traditional and religious healers. The influence ranged from giving their 'diagnosis' of the perceived cause of illness to advice on the management of the child's condition, which the mothers often adhered to. Female neighbours in particular, were observed to be very influential throughout the child's illness trajectory. They were sometimes the first point of contact when a mother was unsure about their child's symptoms.

The two illustrative quotes below show the influence of other women, in particular senior women such as grandmothers as well as (female) neighbours and peers. "...when the child started getting sick, [neighbours] told me it's mambo ya ukoo (family issues) they started telling me that maybe the [father's] family went to a witchdoctor so that I can give them the baby.... So, they said I should take a cold shower with the baby, and when the droplets of water splash on her, [the evil spirit] will leave the child's body..."

(Child's mother, Household 1, visit 1)

"...I don't know which drugs they gave him [the child] at the herbalist's...Because I already tried all kinds of medicine. It's mum [child's grandmother] who advised that we stop giving him the medicines [and instead use herbal treatment] since they made him weak...It's at that point when they gave him the herbs..."
(Child's mother, Household 9, visit 1)

3.Other women as a social support system

Beyond being significant influencers in 'diagnosing' and management of child illnesses, women were often a strong support system for mothers with ailing children. For example, while mothers were admitted to hospital with their sick children, (female) neighbours, friends and other relatives took up the responsibility of caring for other children left at home. This included cooking for them, ensuring they got to/from school safely, washing their clothes and so on. This support was especially important where the other children left at home were younger.

"I used to come back in the evenings and care for the twin. During the day, I used to make her porridge in the morning and leave her with my (female) cousin, then go to the hospital and come back at six in the evening...My sister is the one who used to spend the night at the hospital. I used to sleep at home, because of the twin sister since I did not want her to stop breastfeeding and also start disturbing me [also fall sick]."

(Child's mother, Household 5, visit 1)

Older women on the other hand were viewed as a community resource. They would guide and help younger parents both routinely, as well as during crisis such as when a child was acutely ill. This was because senior women were regarded as knowledgeable, trustworthy and wise; and able to offer appropriate advice when children were sick.

"There are these mothers...older mothers, those that understand these things, you know when you are young, you have to ask those older than you how things are done. So, when they come with their suggestions you will have to listen... you must listen, if they advise you, you will have to listen. So that's how we do it." (Child's father, Household 20, visit 2)

4. Child illness and associated treatmentseeking had gendered socio-economic consequences for households

In this study, we observed that the economic consequences of children's illness episodes disproportionately impacted women compared to men. Mothers sometimes had to leave employment (voluntarily or dismissed), reduce working hours, or close their businesses to care for their sick children. This was especially the case where illness was prolonged, or where - due to the child's dire condition - the mothers wanted to be present after discharge from hospital to ensure the child fully recovered. This in turn resulted in reduced income for both the mother and the household more broadly. It also increased mothers' financial reliance on others such as their husbands or their own mothers.

"I closed the shop because I wanted to care for the baby. You see when the child was admitted, I couldn't continue running the shop...and the child wasn't getting better, so I saw there was no point...I saw if I keep the shop open, with this child's condition, I will suffer. The way I put in so much effort to care for this child? You know even God helps those who help themselves. You can't leave the child here [at home] or take the child to day care and go to work [yet the child is sick]." (Child's mother, Household 12, visit 2)

"When the child fell sick the restaurant owner [where I was working], told me to stop working. I did not go to work for a long time because we were admitted at the hospital. So, he said I should stop going to work."

(Child's mother, Household 9, visit 1)

Another gendered impact of child illness was blame towards the mother either by other family members or health workers. Mothers described sometimes being held responsible for their child's poor health as they were the primary carers. There was an implicit expectation that women should pay attention to, and take good care of, their children including taking necessary precautions to ensure that they do not fall sick. As such, when a child became ill, it was sometimes perceived as indicating sub-optimal care from the mother. This would also sometimes result in marital tension within the home.

"It happens [the blame] ... sometimes we used to disagree since the father always claims that I do not cook proper food for the child [and that is why she fell sick], but the problem is when I cook the child doesn't eat [i.e. child is a reported poor feeder]. At times I ask him to feed the baby himself [so he can see], he will try and claim that he does not know how to feed the child, so it is my responsibility to feed her."

(Child's mother, Household 21, visit 2)

5.Experience of the health system

As the primary engagers with the health system, women were the ones who dealt with the day-to-day challenges of interacting with the health system, which itself faced challenges in meeting the health care needs of their children. This manifested in different ways including:

- challenging interactions between mothers and healthcare workers or hospital support staff;
- long waiting times even when children were in dire condition and mothers had been referred upward from other facilities;
- sharing beds with other mothers and their children while admitted in hospital, which also raised concerns around cross-infection;
- poor and inadequate hospital facilities, including power and water shortages at the admitting hospital which sometimes increased their overall indirect expenses as illustrated in the quote

"...There was a water shortage [while we were admitted at hospital]. One could not even get a place to relieve themselves...I had to go and pay for a toilet outside... because the toilets were full of waste, you couldn't use them ...[when] there is no water it becomes a real problem." (Child's mother, Household 12, visit 2)

Specifically, in relation to difficult interactions with hospital staff, mothers cited inappropriate or poor communication as being most challenging for them. This in turn had adverse consequences on children's recovery, as mothers would sometimes discontinue recommended care (or not attend follow up appointments after hospital discharge). The quotes below illustrate some of these challenges that were directly related to challenging interactions with health workers.

"You call her [the ward nurse] to come and check on the child but she is not concerned. She just sits there at her desk. You go back thrice. You wait for her she still doesn't come, so you go and call her again and she tells you if you are in a hurry, you can treat the child yourself. Now you wonder how you should start treating the child yourself for the illness that made you take the child there [to hospital] in the first place?" (Child's mother, Household 12, visit 3)

"I decided to remove the child [from the nutrition programme] because the child was always sick...when the child falls sick they [nurses] would reprimand me whenever I'd go to collect the food supplements... they would say that I am selling the flour...and I don't give the child the porridge...so I decided to stop going..."

(Child's mother, Household 11, visit 2)



Conclusion

Acute child illness episodes have adverse impacts on households more broadly. This study used a gender lens to explore whether these impacts were gendered. Unsurprisingly, and as is common to the Kenyan context, the study found that childcare and health was predominantly in the female domain. Nonetheless, the study highlights other gendered issues that are important for policy makers and programme implementers to consider when designing responsive policies and actionable interventions. In particular, the influence of other women in the mother's circle emerged very strongly in our findings. These findings suggest that beyond targeting mothers of young children in health interventions, a more holistic approach that considers the role of other significant influencers needs to be employed. The disproportionate economic impact of child illness on mothers is also noteworthy. Below we offer some more specific recommendations for consideration.

Recommendations

Based on the findings we recommend:

- 1. Targeted economic strategies such as cash transfers, to safeguard the most vulnerable women and households. As a longer-term measure, there is a need for more robust labour policies that ensure more family friendly work policies, and which specifically protect women from unfair dismissal for example for taking extended time off to care for ailing children.
- 2. Deliberate engagement of men in child health to counteract the dominant perception of child health and care as a female-domain. This could be encouraged through community-led strategies for example using (male) 'champions' to raise awareness and encourage participation, and framing child health as 'everyone's business'. In addition, primary healthcare facilities that are predominantly accessed by women and children and might be perceived as unfriendly towards men, should be organized in a manner that promotes and encourages male participation particularly as regards child health.
- 3. There is also a need to implement strategies at the health system level to improve interactions between health workers and the community members. Such strategies could include participatory and on-the-job training on communication skills and emotional awareness. In addition to this, it is important to ensure an adequately staffed and well-paid health workforce. This in turn avoids overworked and over-stretched health workers, as this potentially also contributes to the less-than-optimal interactions with community members.

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