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Full Length Research Paper

Barriers to timely health seeking behaviour for children among care givers in an urban slum in Uganda

Nabukeera-Barungi Nicolette[1]* and Stefan Peterson[2]

[1]School of Medicine, Makerere University College of Health Sciences, Kampala, Uganda.
[2]School of Public Health, Makerere University College of Health Sciences, Kampala, Uganda.

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Current population trends show increasing rural-urban migration, with majority living in urban slums. Studies show higher disease burden and childhood mortality in the slums than rural areas. Late reporting to hospital is the main contributor to the reported 50 to 70% of hospital deaths in the first 24 h of admission in resource limited settings. Providing a free health unit within 5 km radius of every community is assumed to bridge the access gap. We set out to describe barriers to timely health seeking behaviour among caregivers of children under- 5 years in an urban slum community with geographical access free healthcare. This qualitative research used focus group discussions and key informant interviews. Subjects were caretakers of children under- 5 years living in Makerere Kivvulu slum. Their perceived risks of death during illness, options when children get sick, preferences, determinants of their choices and barriers to health care were assessed. Our study found that the caretakers could identify the signs of serious illness which needed hospitalization. The availability of money was the main determinant of their healthcare choices. They had several options for health care but they preferred Mulago Hospital, a free national referral hospital which also serves as their first level health unit. They appreciated the quality of services and the close proximity but are overwhelmed by barriers to its utilization. These barriers included long waiting hours, bribery in the waiting lines, rudeness of the health workers, lack of drugs in these free facilities among others. Although the community in this urban slum seem to have geographical access to free medical services, financial access still remains the main barrier to its utilization. For communities which depend on a daily income, a day spent in hospital translates into financial loss.

Key words: Urban slums, health seeking behaviour, free health services.

INTRODUCTION

Each year, 10 million children under 5 years of age die in the world from preventable causes: diarrhoea, pneumonia, measles, malaria, Human immunodeficiency virus infection / acquired immunodeficiency syndrome (HIV/AIDS), the underlying cause of undernutrition, and neonatal deaths (Black et al., 2003). Six countries account for 50% of worldwide deaths in children younger than 5 years, and 42 countries for 90% (Black et al., 2003). In Africa, an average of 1 in 6 children dies before the age of 5 years (World Health Reports, 1999). The Millennium Development Goal 4 (MDG 4) aims to reduce the global under-five mortality rate by two thirds between 1990 and 2015 (UNICEF, 2008). Reaching this target will require a reduction in the number of child deaths from 9.7 million in 2006 to around 4 million by 2015. In Uganda, under-5-mortality rate stands at approximately 137 children per 1000 live births. This means that one in every seven children do not survive to their fifth birthday (Uganda Bureau of Statistics, 2006). The Ministry of Health (MoH) under the Child Health Division set up by the Child Survival Strategy in order to accelerate the process of meeting the fourth MDG (The Ministry of Health, 2007).

According to a report from the United Nations Human

*Corresponding author. E-mail: nicbarungi@yahoo.com.

Settlements Program (2003), if current trends continue, within 30 years one in three people in the world will live in urban informal settlements – commonly known as slums – which are characterized by overcrowding, lack of basic infrastructure, inadequate public services, substandard sanitation, and widespread violence and insecurity (United Nations Human Settlements Program, 2003). For instance, Nairobi is experiencing an urban population boom, with more than 60% the city's population currently living in slum communities, which occupy only 5% of the residential land area (Matrix Development Consultants Report, 1993). In Uganda, the population is largely rural, with only 20% living in urban areas. However, the fast increasing rural to urban migration rates over the years has been; 1969, 1980, 1991, 2002, 2006 was 6.6, 6.7, 9.9, 12.3 and 20% respectively (Uganda Bureau of Statistics, 2006).

Disaggregated urban data shows that infant and under-5 mortality rates for the poorest slum residents are often higher than those found amongst similar groups in rural areas (United Nations Human Settlements Program, 2003). This is because of the big burden of disease in slums. In a study in an urban slum in Kampala, Uganda, 35% of children in slums had been ill within 2 weeks (Wallman et al., 1996). In another study, of 3015 under 5 year olds in a Nairobi slum, 999 (33.1%) children were reported to have been sick in the previous weeks (Negussie and Chepngeno, 2005).

The practice of appropriate health seeking has a great potential to reduce the occurrence of severe and life-threatening child illnesses. It would also reduce the 40 to 70% of hospital deaths in the first 24 h of admission mainly due to late reporting in developing countries (Wammanda and Ali, 2004; Menge et al., 1995; Rennie, 2003; African Population and Health Research Center, 2003). Seeking effective medical services is highly influential on whether the child survives or succumbs to acute respiratory infection (ARI) or diarrhea (African Population and Health Research Center, 2003). A study to assess the influence of socio-demographic, economic and disease related factors in health care seeking for child illnesses among slum dwellers of Nairobi, Kenya revealed the following: Of the 999 (33.1%) children who were reported to have been sick, medical care of some sort was sought for 604 (60.5%). Lack of finances (49.6%) and a perception that the illness was not serious (28.1%) were the main reasons given for failure to seek health care outside the home (Negussie and Chepngeno, 2005). Perception of illness severity was strongly associated with health care seeking. Household income was significantly associated with health care seeking up to certain threshold levels, above which its effects stabilized (Negussie and Chepngeno, 2005).

In the Uganda Demographic and Health Survey of 2006, 41% of children under five were reported to have had fever, a prominent symptom of both ARI and malaria, in the two weeks before the survey. Among children with fever, only 74.5% of rural and 76.8% of urban were taken to a health facility or provider for treatment (excluding drug shops, pharmacy or traditional practitioner) (Uganda Bureau of Statistics, 2006). Although 61.3% of children under five with fever are appropriately treated, only 28.9% received prompt treatment (Uganda Bureau of Statistics, 2006).

Study rationale

Having noted the big burden of disease in the slums and the need to improve child survival in this special group, it is important to identify their barriers to prompt health seeking behaviour. Interventions by the Ministry of Health to improve access to health services included removal of user fees and provision of a health unit within 5 km of every community. An eight month review of death records in Mulago hospital in the first 24 h of admission revealed that of those who lived within 5 km of the hospitals, 75 (20.8%) died from preventable causes like severe dehydration, severe anaemia and severe malaria in the first 24 h of admission. The population in Makerere Kivvulu slum have easy geographical access to free medical services. There is therefore a need to identify other barriers to timely health care apart from geographical access and medical bills. Addressing these gaps could directly have an impact on reducing morbidity and mortality in this population.

The overall goal of this study was to identify barriers to timely health seeking behaviour for under-5-year old children in Makerere Kivvulu slum in Kampala, a population with easy geographical access to free medical services.

METHODS

This was a cross-sectional qualitative community study using focus group discussions (FGD) as the data collection technique (Morgan, 1998). Mobilization was carried out by the local community leaders and meetings were carried out in the community. Four FGDs were carried out, each involving 8 to 10 participants, three of which were with women alone, and one for men alone. The discussion was in *Luganda*, the dominant language in that community. Study participants consecutively enrolled parents and guardians of children under 5 years living in Makerere Kivvulu slum for at least 2 months. The sessions were carried out using a FGD guide. There was a chairperson and a scribe who was taking notes in each session. Refreshments were served and each session took about one and a half hours. The sessions were tape recorded and transcribed, then translated to English. There were three key informant interviews with and opinion leaders in the village. These included 2 local leaders and 1 community nurse. Consent from

parents/guardians who were 18 years old and above and assent from parents below 18 years were sought. Those who were not able to communicate because of language barrier were excluded. Institutional consent was sought from the Research Committee of the Faculty of Medicine, Makerere University. Permission was sought from the local community leaders. Data was analyzed manually. It was grouped into theoretically pre-defined categories and transcripts were scrutinized repeatedly for building and adding of new categories. Two independent raters analyzed the data.

RESULTS

A total of 35 caregivers of under five year old children participated in the FGDs. Majority were females 27 (77%) and of these, 20 were mothers. Three key informant interviews were also carried out with one male and one female local leader and a nurse in the community. The following are the findings from the study.

Perceived risks of death during illness

The following signs show them that the children are so sick that they may need hospitalization; very weak, vomiting a lot, very hot, convulsing or if the eyes stare in the air. Sometimes just looking at their eyes shows them that they are very sick. Sometimes if they have treated them in nearby clinics or drug shop for three days without improvement, they decide that hospitalization is needed. Sometimes the health workers in the clinics or drug shops are the ones who refer them to the Hospital. However, they noted that they do not refer them if they can still get some money from them. "*The people in the clinics are the ones who tell you that your child needs to go to a big Hospital. However if they realize that you have money, they do not tell you."*

What is done when children get sick?

When children get sick, they first treat them at home. They do tepid sponging using a wet cloth when they are hot. They usually keep *Paracetamol* at home, which they use before seeking for medical help. A few of them use traditional medicine like *mululuza, bombo, bumba, kalitunsi* or fat of sheep. They however said it is hard to come by traditional medicine in their community.

Outside the home, they ask their neighbours about their experience with a certain disease and they do the same. Others go to buy medicine of their choice from a drug shop without taking the children for physical examination.

One participant said she gets medicine from a relative who works in a Government owned hospital. All participants denied "Doing nothing during a child's illness". Even with the minor illnesses, they always give some form of treatment.

Health Units options

Available options for health care were as follows; sometimes they go to Kampala City Council (KCC) Clinic in Kisenyi or Nkrumah road. These are located about 3 km away from them but they provide free medical care.

Many of them use *Mama Dora*'s private clinic located in Kisenyi, about 2 km away from their community. One male participant said,

"*But Mama Dora will take your little money and give you all the medical care you need, then she will ask you to pay the balance of money when you get it."*

Mulago Hospital, which is the national referral hospital located about 1.5 km from their community is also an option. Some said that they go straight to Mulago Hospital especially when they have no money. However, many only go there as a last resort. One participant reported; "*Mulago is a place of refuge when you have no money*"

They also have several clinics and drug shops within their community where they take their children when they have money. There are faith based facilities near them which they do not use because they are expensive.

Preferences

All the participants said that all things being equal, their preferred health facility would be Mulago Hospital. This is because the children are thoroughly examined, necessary tests are carried out and health personnel appropriately treat the ailment they have diagnosed. Some were satisfied with Mulago Hospital even when sometimes they do not get medicine from there.

"*When we buy the prescribed medicine from Mulago Hospital, our children always get cured*".

They especially appreciated Mulago Hospital when their children are very sick especially at night. They get treatment promptly and they recover. They suggested that they have so much faith in Mulago that if a doctor from there touches their children they are so comforted. If the child dies, they will accept the occurrence as God's decision.

One of the key informants also confirmed that they prefer Mulago Hospital because children are examined and treated well. She is informed that many drugs for children are available in the Hospital. A few caregivers said they prefer KCC clinics, which have shorter patient waiting lines than Mulago and also provides free medical

services including free blood tests.

Determinants of their choices

The main determinant of health facility choices when children were sick was money. When they have money, they go to the best private clinic. If not, they go where they can access health care services free. The baby's condition also determines their decision. If they are very sick, they act very quickly. Their choices are also influenced by testimonies of experiences from neighbors and friends about what medicine works and where to go for treatment.

Other determinants include the time of day. If the child is very sick at night, they wait for the morning because of fear of traveling at night. (Insecurity) "*If you have money to buy a tablet, you give it and wait till morning".*

They noted that work or job does not hinder them from seeking medical care if the child is very sick. As for who decides what to do and when, they responded that either the parents decide together or the one who has money decides. The female participants reported that the children's fathers do not hinder them from seeking medical care.

Barriers to timely healthcare

Lack of money was considered the main barrier at home even to free medical services because they reported bribery in Mulago Hospital. One participant said, "*Those who have money are seen early."* Ignorance is another barrier, regarding which one male participant reported "*You may think it is a simple illness yet it is more serious*". Children are left with young children or neighbors who either do not care or understand about sickness in children. The parents may take long to notice that the child is sick because they return home at night.

Self-medication is another barrier. Parents/guardians may give *Paracetamol* and if they see symptomatic improvement, they relax. If the sickness worsens, they buy more medicine of their choice until when the child is too sick then they remember to go to hospital. They freely decide on their own to buy drugs. One female participant said

"*Sometimes we ask for medicine we want ourselves. For example, we like Quinine syrup. We give it but we do not know what we are treating."* Another admitted, "*We use tablets so much. We do not seek for medical help immediately."*

One key informant said that parents and guardians are impatient. They do not want to wait in lines at health facilities. If they could wait, they would get proper health care.

The main barrier reported in the public health facilities was long lines and long waiting hours because of having many patients. They have to spend a whole day in the hospital. Bribes in the hospital were a big problem. One participant reported that the long lines would have been bearable if there was no corruption. "*It is difficult to see a doctor. Weekend coverage is poor. KCC clinics do not work on weekends".* They also believe it is hard to see a doctor in Mulago Hospital on a weekend and public holiday. They reported very poor customer care in the hospitals especially Mulago Hospital. All FGD participants agreed that medical workers do not show them care. They use abusive language and even shout at them. They expressed disgust at the abusive language especially when their children are very sick. One participant said, "*The nurses may tell you that they have seen many children dying."* This shows that they do not care. "*That is why we go to other places first. We go to Mulago as a last resort."* They perceived that medical workers are not committed to their work. Sometimes they see doctors conversing instead of seeing patients while they wait in the long lines. A female participant said, "*Doctors are slow in doing their work*." Another barrier is lack of medicine in the hospital. They feel frustrated if they brave the long lines and come out with no medicine especially when they have no money to buy it.

The missionary facilities were reportedly to be too expensive for them. They have an SDA missionary hospital in their community, which they do not use at all because they said it is too expensive for them. At the gate of Mulago Hospital, some reported that gatekeepers want a bribe while others did not agree with them.

Barriers in the private facilities (clinics/ drug shops): Participants reported that they run to the clinics because they are near them and they can get treated on credit. However, they are not satisfied with the service, for instance, one participant said, "*They only check babies with a thermometer but in Mulago they check very well.*" A key informant was very concerned about the qualifications of the people running these facilities as many are not trained at all. The qualified persons who own the units work in other hospitals and only see them very late in the evening. They help in the simple illnesses but many get cured only by chance.

They reported that the clinics are after money and therefore they can give wrong drugs, half doses and even expired drugs.

Respondents suggested the following solutions; At home, self medication should stop and instead seek medical health early. Training the community on feeding, hygiene and childhood diseases would be helpful in disease prevention.

In the Health units, they suggested that the medical workers in Mulago Hospital should learn to show love and care to patients. They should be sensitized about the need to show hospitality. The government needs to take serious measures about corruption in Health Units.

It should also increase the number of medical workers, check the quality of health care service given in the private facilities so that clinics should not retain children with complicated ailments and delay their going to hospital.

DISCUSSION

This study found out that although this urban slum community is located near free good quality medical services, they only use the free facilities as a last resort when they have no money or when the children are very sick or when other treatments have failed. Several studies have found that removal of user fees led to increased hospital utilization (WHO, 2005; Valéry et al., 2012; Burnham et al., 2004). However, in rural Eastern Uganda, it is the category of the poorest who reported more utilization of the public free health services (Bakeera et al., 2009). This is similar to what we found that they use the free services when they do not have money. This community depends on a daily income and spending a day in hospital results in financial loss and yet they have several cheaper options in their community. Although they do not like private clinics in their community because of not having qualified medical workers who only examine with a thermometer, they tend to run to them because they save time, they get treatments no matter how little money they have and some even treat them on credit.

When asked about their preference if they had all the money, most of them reported that it was Mulago Hospital. They prefer it to other services because they get quality medical care from trusted medical workers who do tests to make a diagnosis and treat what they know. However the barriers of time wastage in long lines with corruption and rudeness hinder them from its utilization. Rudeness and informal fees have been reported in Uganda as a hindrance to free services (Bakeera et al., 2009; Kiwanuka et al., 2008). Their most popular private health facility "*Mama Dora's"* is not even located in their community. They like it because the customer care is good and they get treatment on credit. Improving health worker attitude could therefore improve utilization.

A systematic review of access to health care among the poor in Uganda showed that perceived quality of care and availability of drugs are key determinants of utilisation. Other barriers which were also present in our study were late referrals, health worker attitude, costs of care and lack of knowledge (Bakeera et al., 2009). It is therefore not surprising that faith- based facilities in their community were not utilized because they were perceived to be expensive.

Determinants of their choices are mainly availability of money and severity of the child's illness. The women do not depend on the men on what to do because most of them are working. They take their own decisions or they are in agreement with the men. This is a different finding from rural settings where most women depend on men since they have no source of income (Uganda Bureau of Statistics, 2006).

This study found that parents always did something about children's illness unlike the Nairobi slum study where 40% of children with fever did not receive any treatment (Negussie and Chepngeno, 2005).

The strength of this study is that it was a community study where data was obtained from 35 caregivers of young children, including both men and women in separate groups where they were free to express their views. We were able to generate a lot of data in the discussions compared to what one would get in a coded individual interview tool. The weakness is that it lacked a quantitative element. This data can be generalized to other urban slums in Kampala because they are all exposed to similar choices. They all have free government-based medical services and paying private units. It cannot however be generalized to the whole country because many of the women in slums near Kampala are working and are therefore empowered to take their own healthcare related decisions while many in slums in other parts of the country are not working.

The government made the service free of charge and with easy geographical access but the main barrier to timely health seeking behaviour is still money. Some of the possible solutions which can be addressed by the hospital include stopping bribery in the health units and sensitising staff on proper patient care attitudes. The Ministry of Health and Public Service should increase medical staff numbers in order to reduce the long waiting hours. Another strategy could target the private practitioners in the clinics and drug shops. Since they are widely used by the community, they should be trained to provide a good service to these people.

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