

Caretakers' Experiences with Sick Children in Luapula Province: Implications for Child Survival Interventions in Zambia

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ABSTRACT

Objective: To gain a deep understanding of caretakers' perspectives about factors contributing to high under-five mortality in Luapula province of Zambia.

Methods: This report is a product of data that was collected using verbal autopsy for a study on Factors Associated with high Under Five Mortality in the Luapula province of Zambia. Verbal autopsies were used to collect information from three hundred and sixty (360) caretakers about illnesses that led to the death of their under-five children. The autopsies were analyzed using the Optimal Care-Seeking Framework (OCSF) to identify the factors associated with the high under-five mortality rate in Luapula province.

Results: The study identified that the under-five mortality rate in Luapula province is perpetuated by behavioral and health system factors that compromise the management of illnesses. Four obstacles to effective management of illness were identified and these include (i) poor recognition of signs of illness; (ii) delay in reaching a healthcare facility, (iii) delay in receiving definitive treatment, and (iv) poor compliance with recommended treatment and/or referrals.

Conclusion: Reduction of under-five mortality requires optimal management of illnesses through the removal of the four obstacles. This entails coming up with strategies not only to improve the healthcare

seeking behaviour of people but also streamline the healthcare system to enhance access to definitive healthcare.

INTRODUCTION

Under-five mortality (U5M), expressed as the number of under-five deaths per 1000 live births, is an important factor in designing and monitoring child survival policies and programs.³ Eleven million under-five children (U5s) die annually in the world, of which over ten million are in developing countries.⁴ Sub-Sahara Africa accounts for 45 % of child deaths and Zambia is one of the forty-five countries in the region being plagued by high U5M since 1990.⁵

Between 1960 and 1980, Zambia enjoyed an impressive and sustained decline in U5M from a rate of 220/1000 live births in 1960 to 165 /1000 live births in 1975. The decline was however halted during the 1980s and the rate rose to the level of 197 / 1000 live births in 1996.⁶ Since 1996 however, though still high, the U5M rate has been falling steadily and was recorded at 168/1000 live births in the year 2003.³ However, there are some regional variations in mortality levels with Luapula Province recording the highest U5M rate (248/1000 live births in 2001/2002) while North-Western province recorded the lowest (130/ 1000 live births) rate in the same year (Table 1).^{3,7}

Table 1: Under-five Mortality Rates by Province

Against this background of poor health indicators, in 2000, the United Nations adopted the Millennium Development Goals (MDGs). One of the goals is to reduce the U5M rate by two thirds between 2000 and 2015. For Zambia, this means reducing the 2001/ 2 U5M rate of 168 deaths/1000 live births to 64 deaths/1000 live births. Policy makers therefore need

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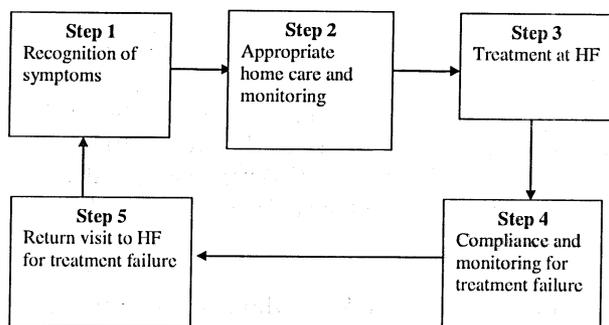
evidence to formulate policies and develop scientifically proven child survival interventions.

Many studies on U5M have been conducted in Zambia.^{3,6,7,8,9,10} However, most of them are quantitative in nature and some focus on disease. While these studies give the empirical configuration of mortality, understanding the complexity of etiology and death requires socio-anthropological methods of enquiry and precise knowledge of the health systems. This paper aims at building on our knowledge by providing a deep understanding of the interface between caretakers' care seeking behaviour and the healthcare system. It applies the Optimal Care Seeking Framework (OCSF) to explain the actual experiences of caretakers with sick children and their care seeking behaviour.

Conceptual Framework

Verbal autopsies were examined using the OCSF (Figure 1) which emphasizes that effective care management involves five steps; (1) recognition of signs and symptoms of illness, (2) appropriate home care and decision to go to a health facility (HF) when symptoms warrant, (3) correct diagnosis and treatment at a HF, (4) compliance with recommended treatment and referral, and (5) return visit to HF for follow-up care¹¹

Figure 1. The Model of Optimal Care Seeking



Source: Adopted from C. Baume and IMCI

METHODOLOGY

Study Sites

This paper is based on secondary data collected between January 2002 and January 2003 for a study on 'Factors Associated with high U5M in Luapula province in Zambia'.¹⁰ Luapula Province has the highest U5M rate of 248 U5 deaths/1000 live births.³ With a population of 775,353 and a poverty level of 81%, Luapula is one of the poorest provinces in Zambia and is predominantly rural. The major economic activities in the province include seasonal fishing and subsistence farming.¹

Sample Selection

Data were solicited from three hundred and sixty (360) caretakers who attended to the U5s captured in the sample during their last episode of illness. All U5 deaths that occurred three months prior to the study and during the study period were eligible for the study. Identification of deaths of U5s and respondents for the study was done through the use of key informants.

Data Collection and Analysis

Using a semi-structured questionnaire, three hundred and sixty (360) verbal autopsies were obtained from caretakers after obtaining their consent as well as ethical clearance. Each caretaker was asked about the illness that led to the death of her child, "what, in your opinion, was the course of the disease that led to the child's death?" The verbal autopsies obtained were then examined using the OCSF. Inherent in the methodology of this study is the limitation of using secondary data.

RESULTS

Characteristics of the Caretakers

Eighty-six percent (86.1%) [310] of the 360 caretakers in the study were aged 20 years and above, sixty-six percent (66.1%) [238] had only primary education while eighty-three percent (83.9%) [302] were married. Most caretakers (89.7%) [323] were Christian and the common sources of livelihood were farming (38.9%) [140] and trading (31.9%) (115) (Table 2).

Table 2: Socio-economic and demographic characteristics of caretakers in the sample

Table 2. Socio-Economic and Demographic Characteristics of the Caretakers in the Sample.

Characteristic	No.	(%)
Age (years)		
< 20	50	14
20-24	93	26
25-39	173	48
>40	44	12
Total	360	100
Education		
No formal Education	11	3
Primary	238	66
Secondary	64	18
College or higher (Post-Secondary)	47	13
Total	360	100
Marital Status		
Married	302	84
Single	58	16
Total	360	100
Religion		
Christian	323	90
Other	37	10
Total	360	100
Source of Livelihood		
Farming	140	39
Trading (Brewing beer, selling fish or farm produce)	115	32
Other (i.e. sewing)	105	29
Total	360	100
Relationship of caretaker to the child who died		
Mother	306	85
Other	54	15
Total	360	100

Perceived Causes of Childhood Illness

Under-five mortality in the study site is common with about half (49.4%) of the caretakers reporting that they had lost two or more U5s in their life time. Of the 360 U5s in the sample, 48.9% [176] died between 1-11 months while 45.0% (162) died between 12-59 months. Three common perceived causes of U5M were diarrhoea (25.7%) [88], malaria (16.7%) [57], and respiratory infections (13.7%) [47], all of which are preventable diseases (Table 3).

Table 3: Perceived Causes of Death among Under-Five Children

Table 2: Caretakers' Perceived Causes of Death among Under-Five Children (N=342)

Disease	No.	%
Diarrhea	88	26
Malaria/ Fever	57	17
Chest infections (i.e. cough, T.B, pneumonia, respiratory diseases)	47	14
Anemia	25	7
Protein energy malnutrition	21	6
Convulsions	13	4
Witchcraft	9	3
Don't Know	47	14
Others	35	10

* There were 18 non-response cases

Factors that Contribute to U5M

Two major factors are perceived to contribute to U5M (i) delay in seeking care, and (ii) poor case management and treatment outcomes.

Care-Seeking Behaviour

This study assessed whether the 360 caretakers sought care from a HF for the last episode of illness that led to the death of their child in the study sample, and for those who sought care, the study assessed whether care was sought promptly or not.

Twenty-one percent (20.8%) of the 360 caretakers did not seek care from a HF. Reasons for not seeking care were that the caretaker (i) thought the illness was not serious, (ii) was unable to go to the HF because of long distance, (iii) was using traditional medicine, (iv) and that the child died suddenly or on the way to the HF.

Out of the 285 caretakers who sought care from a HF, one hundred and fifty-four (54.2%) delayed in seeking care for their child for a day or two. Three major reasons for delay in seeking healthcare were identified as (i) long distance to HFs, (ii) reliance on traditional remedies and (iii) ineffective referral systems. Other reasons include home treatment, and failure to recognize danger signs and symptoms of childhood illness.

(i) Long Distance to Health Facilities

One hundred and fifty-four (54.2%) of the 285 caretakers who sought care from a HF delayed in seeking care. Of these, thirty-nine (25.4%) attributed the delay to long distance to HFs. And of the seventy-five (20.8%) caretakers that did not seek care from a HF, six (8%) sighted distance to the HF as the major obstacle and seven (25.9%) of them did not comply with referral recommendations due to lack of transport. One caretaker had this to say:

"I noticed that my child was purging blood and vomiting at 16.00 hours but I was not able to take the child to the Health Centre (HC) at that very time because the HC is very far away... Instead, I used traditional medicine from a friend. The next morning, around 07.00 hours as I was preparing to go to the HC, the child died".

Long distance to HFs is also compounded by economic activities of caretakers. Seasonal migration to crop fields and fishing camps in particular posed transport problems and delay in care-seeking for sick children as caretakers narrate:

"When the child fell sick we were travelling to sell building poles... we travelled for five days... on the sixth day I took the child to the hospital. By then the child was tired and had sunken eyes. The child was admitted, given medicine and put on a drip. The following day around 13.30 hours the child died".

"When the child fell sick I was at a fishing camp. It takes days to get back from the fishing camp; as a result I delayed in taking the child to the HC for four days. I continued to take him to the clinic for two days but he died".

(ii) Use of Traditional Treatment

Forty-four (12.2%) of the 360 caretakers reported having consulted traditional practitioners either before or after seeking modern healthcare as some caretakers narrated:

"The child had fever and convulsions...she then became yellowish and the colour of the nails turned white. We first used traditional medicine for convulsions but it did not help... then we went to the HC where they referred

us to the hospital because they said the child had no blood...on the way to the hospital the child died".

"...at the HC the child was given quinine and the convulsions stopped...and he was discharged on fansidar. We stayed only one day at home and convulsions recurred...we then took the child to the traditional healer but convulsions continued. I then took him to the hospital where he died after two days".

(iii) Referral Systems

This study recorded forty-two (14.7%) referral cases; twenty-seven (64.3%) were referred by healthcare providers while fifteen [35.7%] were self referrals. Of the twenty-seven (27) U5s referred to the next level of care, four (4) died on the way to the referral facility while seven (7) did not go to the referral facility because they had no transport money. Voices of the mothers highlight the transport factor:

"... When my daughter started purging I took her to the HC where I was told that she had no blood and that I should take her to the big hospital for further treatment. I could not take her to the hospital because I had no transport money. Consequently, my child lost her life".

"...We were referred to a hospital, but before we could find transport, the child collapsed and died".

Fifteen (15) cases of self referral were mainly due to dissatisfaction with the healthcare provided at HFs and/or poor treatment outcomes as revealed by caretakers:

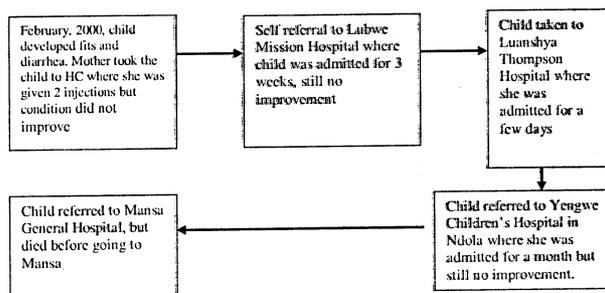
"The child developed fever and diarrhoea and was taken to the HC where he was treated as an outpatient case. Three days passed without an improvement in the condition...so we took him to another HC where he was admitted... five injections were given but the fever persisted until he died".

"My daughter had fever, diarrhoea, a cough and worm infestation. I took her to the HC on a Monday and I went back on Thursday but she was not given anything except a packet of Oral Rehydration Solution (ORS)... so on Friday, I just went straight to the hospital.

An injection and a drip were given at the hospital but the child died before the drip could finish”.

Results of this study further show that sometimes sick children are referred to several health facilities for the same illness without improvement in the condition (Figure II).

Figure 2. Referral Cycle of one Under-five Child who died from Convulsions and Diarrhoea (Case 84)



(iv) Home Treatment

In this study, twenty-one (5.8%) of the caretakers reported having treated their children at home. Generally, anti-malarial drugs, pain killers and traditional medicine were administered to children at home as the statements from caretakers reveal:

“On 4th March, 2002 in the morning, my child developed fever. We gave her Cafino tablets but she remained feverish. On 6th March the fever persisted. She stopped breast feeding at 04.00 hours and we took her to the hospital. She was admitted and given Chloroquine tablets, folic acid and two injections, but she collapsed and died around 15 hours”.

“...soon after we arrived from the fishing camp, the child developed abdominal pains, I prepared warm water which I applied as first aid, but did not work. I gave her some herbs but also did not work. I did not know what the child was suffering from and she died after two days”.

(v) Recognition of Danger Signs and Symptoms of Childhood Illnesses

In thirteen [3.6%] of the cases reviewed, caretakers did not recognize danger signs and

symptoms of illness as caretakers’ statements highlight:

“When the child became sick, we were at home thinking that the condition would improve but the illness persisted until on the fourth day, that is when I took the child to the HC...the child stayed there only one day and died”.

“Two weeks after birth, the baby’s body and eyes became yellowish. Since it was my first child I did not notice any danger. Later the child had malaria...after two days I took the child to the HC where she was given some medicines...I continued giving the child the same medicine until the day she died”.

Case Management and Treatment Outcome

One hundred and twenty-four caretakers (43.5%) reported that the treatment that they received at the HC did not help their child:

“...the child was sick for two weeks...treatment was given at the hospital...but there was no improvement until the child died”.

“...the child had suffered from diarrhoea for more than two weeks and could not recover even after treatment from the HC as well as the hospital...”.

Forty-four (15.4%) of the children in the sample were not managed according to Integrated Management of Childhood Illness (IMCI) National Guidelines. Some children with malaria for example were given third line drugs (quinine) followed by second line drugs (fansidar). Other children were repeatedly given chloroquine though they were not responding to the drug. In addition, some children with danger signs such as convulsions were not referred to the next level of care as caretakers’ narrate:

“The child’s body became very hot and I took him to the HC where he was given chloroquine and panadol... On our way home the child had convulsions and I took him back to the HC...we found a Classified Daily Employee (CDE) on duty who administered some drugs, but convulsions continued, so he was admitted...when the clinical Officer came, the child was given quinine and the convulsions

stopped...and was discharged on fansidar. The convulsions resumed after a day and I went to a traditional healer to get some medicine but the convulsions could not stop...I took the child back to the hospital where he died on the third day of his admission”.

“...I took the child to the HC where she was given chloroquine injection ...she completed the course, but her condition did not improve. I took her back to the HC...she was put on chloroquine injection again and her condition improved., but around 04:00 hours the condition changed. Her eyes started rolling and she was given another injection... they tried to put a drip but they could not find the vein...so we were referred to the hospital ...my daughter died on the way to the Hospital”.

Shortage of drugs at Rural Health Centres was reported by eighteen (6.3%) caretakers. Two of the caretakers had this to say:

“The child developed diarrhea and was vomiting. When we took her to the HC, there was no medicine and we went back home. The following day we went to another HC where she was admitted... later referred to a hospital where she was admitted again... But the condition changed at night and she died”.

“The child developed fever and cough at night. In the morning, the child was taken to the HC where he was given panadol as there was no chloroquine and anti cough drugs. Around 04:00 hours the child died”.

DISCUSSION

Failure to seek and/or delay in seeking healthcare contributes to the high levels of U5M in Luapula. Of the 360 caretakers sampled, 20.8% did not seek care while 54.2% delayed in doing so. A study in Ethiopia revealed that delayed healthcare seeking or not seeking care at all were the main factors influencing U5M.¹² And the ‘three delays model’ used in emergency obstetric care shows that delay in arriving at HF is a major contributing factor to maternal mortality which is closely related to neonatal mortality.¹³

In this study delay in seeking care can be attributed to both healthcare system and behavioural factors. The system factors include distance to HF, ineffective referral system and perceived ineffective treatment. Like in most rural parts of Zambia, 50% of the population in Luapula live more than 5 kilometres from the nearest HF.¹⁴ A study in Congo DR indicates that a distance of more than 5 kilometres to the nearest HF is associated with increased conditional odds for U5M especially in communities where public transport is not readily available.¹⁵ People’s economic activities, seasonal migration to fishing and farming camps, also caused delay in healthcare seeking. In case of illness, people have to travel long distances back to HF either by canoe or on foot. In Kenya and Cameroon^{16,17} it is documented that delay in seeking medical attention was associated with subsistence farming.

Forty-three percent of the caretakers reported that the treatment their child received at the HF was not effective. This could be explained by the fact that children arrived at HF too late to benefit from available interventions. The major question arising from this is whether caretakers are able to relate their care-seeking behaviour to child survival. Other factors include shortage of drugs and skilled staff observed at HF. Caretakers’ reported ineffectiveness of treatment should be treated with caution as they may not have adequate knowledge and skills and may be laden with emotions to objectively evaluate treatment prescribed by healthcare providers. Nevertheless, perceptions about treatment outcomes are important because they determine caretakers’ seeking behaviour and confidence in a healthcare system as caretakers can only seek care when it is judged that available interventions at the HF can cure the particular illness.¹⁸

The referral system in Luapula acts as a deterrent and source of delay for children to receive definitive treatment. Out of 27 referrals, 26% did not comply due to lack of transport. This reveals that the referral system is not effective in ensuring that sick U5s get definitive treatment.¹⁹

Behavioural factors that delayed healthcare seeking are reliance on traditional medicine, home/self treatment and failure to recognize symptoms of childhood illnesses. Consistent with earlier studies,^{20,21} this study underscores that community beliefs in the efficacy of traditional medicine for

specific illnesses such as convulsions and witchcraft-related conditions delays healthcare seeking and undermines compliance with follow-up medical care. In Cameroon, one study²⁰ observed that the use of traditional medicine significantly delays care-seeking for modern healthcare in communities with strong traditional culture. In Luapula, the use of traditional medicine is also driven by loss of confidence in the modern healthcare system.

In Zambia, home/self treatment is common in treating various illnesses.^{22,3, 11} Six percent of caretakers in Luapula administered anti-malarial drugs, pain killers and traditional medicines before taking their child to a HF. While home treatment is a recognized strategy for management of fever,¹⁹ it has its own limitations as caretakers may not have adequate knowledge/skill to make the correct diagnosis. This may result in wrong treatment and dosage. Further, home/self treatment is associated with under-dosing and the emergence of resistant strains of disease.^{23, 11} and in this study, it contributed to delayed in care seeking.

Failure to recognize signs and symptoms of childhood illness is another factor that prevented or delayed care-seeking. Although only 3.6% of caretakers reported that they did not perceive the child's condition to be serious even among those who did not seek care or delayed in doing so could have failed to recognize the danger signs timely. The OCSF¹¹, states that early recognition of illness symptoms is a prerequisite to appropriate and timely management of childhood illnesses because in young children illnesses such as malaria, diarrhea, and pneumonia if not promptly treated can, progress from mild to severe in a few hours. Further, the Health Belief Model¹⁸ states that when symptoms are perceived as a threat to life, individuals will take action i.e. seeks care.

CONCLUSION

Actual experiences of caretakers with childhood illnesses in Luapula reveal four major obstacles to optimal care seeking (i) poor recognition of danger signs (R), (ii) delay in arriving at a HF and or not seeking care at all due to lack of transport, (D), (iii) delay in receiving definitive or correct treatment due to inadequate supplies and human resource at the HF (D), and (iv) poor compliance with recommended treatment and/or referral mainly due to loss of

confidence in the health care system and/or lack of transport (C).

The four obstacles – which we refer to as the RDDC – represent gaps in the healthcare seeking behaviour and the healthcare system in Luapula. The first three RDDC obstacles are consistent with the OCSF and the “three delays model”.¹³ Further, it is worth noting that the fifth step of the OCSF does not apply to care seeking in Luapula because children in the sample arrived at HFs too late to benefit from the available child survival interventions – rather, children arrived at HFs just to die.

The RDDC should therefore form the basis for strategies to prevent U5M. For maximum benefit, the four RDDC obstacles should be addressed concurrently so that the benefits of removing one obstacle are not compromised by the presence of the other obstacles.

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