Aspects of the management of children with cancer in Malawi
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“I just want my child to get better”
The story of Dalitso (6) and his mother

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April

Two days ago Dalitso, aged 6 years, was admitted to the pediatric oncology ward of the Queen Elizabeth Children’s Hospital in Blantyre, Malawi. He has been diagnosed with a Wilms tumor and is receiving treatment (chemotherapy). His mother, Mrs. Banda, is 26 years old. She has three sons; Yamikani aged 12 years old, Dalitso (6) and Chifundo, a baby boy of 6 months. She has never been to school.

Her husband died 2 months before Dalitso was admitted. She does not know why he died. He had had a fever, went to the hospital and died two days later. They had lived together in Limbe (a little town/neighborhood south from Blantyre) where he earned a little money as a tailor and selling soap. He managed to bring in 100 - 300 MK (US $ 0.80 - 2.25) per day.

After he died Mrs Banda moved back to her own village, near Mulanje, to live with her mother and she now has to rely on her mother’s salary of 2.200 MK per month (US $ 15.70) which she earns as a tea picker on a local tea estate. Her mother is the main decision maker as well as breadwinner of the household. Dalitso’s mother’s sisters live in the same village. They had been a family of twelve children but six have died and Mrs Banda is the oldest of the remaining six. Three of the aunts have a job, the others stay at home.

The grandmother’s house is made of mud sun dried bricks with a mud floor and a grass thatched roof. It was built by her in–laws though the land they live on is owned by the grandmother herself. They draw water from a bore hole and usually eat two meals of nsima (hardened maize porridge) with some relish a day. They do not have any domestic animals such as a goat or chickens, nor does the mother or grandmother own a bicycle or a radio.

At first Dalitso’s mother did not realize that the swelling in her son’s belly was a problem. But when it became bigger and when relatives and neighbors pressed her, she started seeking help. Her in–laws advised her to visit a traditional healer, but she could not afford them and did not go. When the lump kept growing she eventually went to Thyolo district hospital where she was told that the swelling needed special health care for which she was referred to Queen Elizabeth Central Hospital. It cost K100.00 (US $ 0.70) for a 1 hour 30 minutes journey to Blantyre. Her mother helped with this.
April

Dalitso’s mother left her home in her mother’s care. Grandmother is now looking after Yamikani, her first born son, who is in standard three at Mulanje Primary School. The baby is with his mother and Dalitso in the hospital. The mother’s other duties at home are cooking, washing, cleaning the house, cultivating the land (maize) and drawing water. As a subsistence farmer, she grows maize for her own family and she is not sure whether anyone is caring for the fields. She thinks not. Fortunately it is not the planting or harvesting season.

Sometimes, in Limbe, she could make a little money harvesting other people’s crops. But since the recent death of her husband life is still very difficult for her. While in hospital she worries a lot about her future because she is an unemployed widow with three children, and she is the eldest of her six siblings all of whom look to her for support.

She says she does not worry about Dalitso and his recovery as she has to leave this in the hands of God and the doctors.

Since admission to hospital, her mother and her niece (17), who lives in Blantyre, have visited her. They brought food in the form of nsima cooking flour (ufa), but no money. She also has no relish (vegetables) and has asked her in-laws who live in Blantyre to help her with this. With her mother she usually discussed Dalitso’s welfare. Her mother also brought the news that the grandmother is not well and that one of Dalitso’s mother’s older brothers has died while she and Dalitso have been in hospital.

Mrs. Banda does not know how long she will stay in hospital. She brought no money with her and food will have to come from home.

She has no problems with the injections (chemotherapy) that the sisters are giving to Dalitso, for she knows that the nurses are just helping him to get better. All she is waiting for is the removal of the tumour that will hopefully see her son healthy and well again.

May

The grandmother of Mrs Banda has died. She is the second relative who has passed away while she is still in the hospital and her main worry now is how is she going to survive? She finds it so hard in hospital with no relative to support her other than
her mother. At home she was able to do a little piecework (small ad-hoc ‘jobs’) and earn a little money but this is impossible in hospital. If it was not for her mother who has come to visit thrice and brought her some flour and with the last visit some money to buy relish, she does not know how she would survive. She has spent six weeks in hospital.

When she was told that her child had been diagnosed with a tumour (chotupa) in the stomach, she was ‘sad’. But she is now happy that the likelihood of recovery is promising. She has been told that during the next week he will undergo an operation, though she has not heard any details about what will happen and when.

Postoperatively

Dalitso was operated three days ago. Everything went well. The tumour was removed without any complication. Mother waited outside the theatre while they were operating upon him. Fortunately grandmother had come to visit again, because the mother was having a fever herself.

The mother is relieved that everything well, because during an operation ‘anything can happen’.

Dalitso is recovering quickly. He is already eating chiponde (locally made ‘peanut butter’) again.

Leaving the hospital, June

The main worry now is that the grandmother who was working at the tea estate has lost her job. When she visited during and after the time of Dalitso’s surgery both Dalitso and his mother were unwell and she had decided to stay longer than the leave granted by her employer. Upon returning home she found that she had been fired.

When Dalitso’s mother was asked what the most important things in her life are; she did not mention her children. She mentioned a source of income (any income generating activity) which can keep her going. This is also the main area in which she is missing her late husband. He had been very supportive.

When Dalitso was asked what he had enjoyed in hospital he said shyly that he had enjoyed the milk and chiponde which he used to receive. What he had hated most of all was getting a ‘drip’. Painful!
Home visit

People gathered in the village when they found out that Dalitso and his mother had come back from the hospital. Dalitso and his mother were very quiet. Dalitso’s grandfather is very happy and grateful that the swelling in Dalitso’s belly is gone. He had not been sure whether this child would survive. Fortunately the grandmother is not around. She got her job back as a tea picker. As mother expected, it later shows that her fields have not been taken care of. As her relatives say, one of the reasons why they have not taken care of her fields is that she has only recently rejoined the village.

Dalitso is expected to come back to QECH for his post operative chemotherapy in 5 weeks. Travel costs will be refunded.