



Policy Brief:

The Social Impact of a Specialist Pediatric Surgical Service in Rwanda

WHAT IS THE ISSUE?

The Lancet Commission have firmly put the need to increase surgical provision in low- and middle-income countries (LMICs) on the agenda, arguing that it is an essential element of a functional, responsive and resilient health care system and that such provision should be affordable, timely and safe. Sustainable Development Goal Targets for 2030 requiring a reduction of a third in deaths from non-communicable diseases, many of which are treatable by surgical intervention, reinforce the need for increased surgical provision if the burden of disease is to be reduced. It is estimated that approximately 85% of children in LMICs will have had a surgically treatable condition by the age of 15 years. However, there has been little focus on childhood surgical conditions; the spotlight falls mostly on infectious diseases and obstetric care. In trying to address this in recent years, attention has focused on increasing the paediatric workforce to meet children's unique needs, and little consideration has been given to the social impact of caring for children with complex surgical conditions pre- and post-operatively, the burden of which falls mainly on their families. Rwanda appointed its first and, to date, only accredited paediatric surgeon in 2016,

based at the University Teaching Hospital (CHUK) in Kigali, the only referral centre in Rwanda for children with health problems that require complex surgical intervention. A Cancer Centre of Excellence was opened in Butaro Hospital in 2012 to which children are referred when they require chemotherapy before and/or following surgery. The validity of notion that the provision of a specialist paediatric surgical service will improve the wellbeing of children who have complex health problems that need surgical intervention is self-evident. The provision of the specialist service is to be welcomed. However, little is known about the impact in low-income settings on the families of children with complex health problems needing surgical interventions. A pilot study carried out in Uganda on the impact on families caring for a child with a surgically created stoma found that families were socially excluded by their communities, that over half the fathers abandoned their families shortly after the children were discharged from hospital, that children tended to be socially isolated within their extended families and the communities more generally and that meeting the costs of care had driven many of the families into extreme poverty, with mothers having to give up employment and families having to sell assets.

METHODS

Sampling

We sampled 20 families, each with a child with one of four moderately prevalent conditions that need complex surgery and require the family to provide post-operative care for their

child. Care was taken to ensure that the sample included both urban and rural families and both girls and boys. The families of children with other conditions that are referred to CHUK for surgical treatment are likely to share the experiences of families with children with these four conditions.

Condition	Description
Nephroblastoma (Wilms' tumour)	A paediatric renal tumour that is fatal if not removed surgically. Children normally undergo a course of chemotherapy before surgery. Prognosis following surgery is much lower in middle- and low-income countries than in high-income ones
Ano-rectal Malformation	A birth defect where the anus and rectum do not develop properly. If left untreated it is fatal. Corrective surgery usually requires an operation creating a stoma followed by further surgery to connect the rectum to the anus and close the stoma.
Hirschsprung's Disease	A birth defect in which the nerves in part of colon are missing, preventing normal defecation. It is fatal if not treated surgically. The unhealthy part of the large intestine is removed and a stoma created. A second operation is performed, usually after about a year, to connect the large intestine to the bowel
Hypospadias	A common birth defect in which the penis does not work well because the urethra opens on the underside of the penile shaft and looks abnormal. There can be concerns about gender identity.

Data Collection, Management and Analysis

The carer(s) of the children were interviewed by trained researchers using an agenda that was developed to capture the experience of caring for their child from the point at which they suspected that something was wrong to the date of the interview, which in all cases was post-operative. The interviews were recorded with the agreement of the carer(s) and contemporaneous notes taken by one researcher while the other interviewed the carer(s). The agenda was designed to enable the carer(s) to describe their experiences of caring for their child. The interviews were in Kinyarwanda. All recordings and notes were transcribed and translated into English. The transcripts were analysed thematically. Transcripts were anonymised and stored on password-protected computers. Linking data was stored in a separate secure location accessible only to the lead fieldwork researcher.

Ethics

The project was given ethical approval by the Rwanda National Ethics Committee at its meeting of 12 October 2018, approval number 390/RNEC/2018. Carers for children who met the inclusion criterion - successful surgery for one of the four selected conditions - were

asked by staff at the hospital if they would be willing to be interviewed for the project. When parents agreed their details were passed to the lead researcher, who contacted the parents and agreed a date for interview. All parents were given a participant information sheet and asked to sign an informed consent form. All data have been stored in such a way as to ensure the confidentiality of the families. The names of all children recorded on the transcripts are pseudonyms.

Main Characteristics of the Achieved Sample

The age of the children at diagnosis was between birth and just over seven years, and age at the time of interview varied between just under one year and eleven years. The older children tended to have Nephroblastoma or Hypospadias but three children with bowel conditions were not diagnosed until they were over six months and one was not seen at a hospital until 27 months. Before the child was diagnosed, most of the families were managing reasonably well financially, with most in Participatory Poverty Category Three. At the time of the diagnosis all the children except two lived with both their parents; the fathers of two children had never recognised them as theirs. Fourteen of the children had one or more siblings living at home.

RESEARCH FINDINGS

Pathways to Treatment

The pathways to treatment differed by condition. Ano-rectal Malformation was usually diagnosed shortly after birth. The parents were generally told by the health centre to go to the district hospital, and the district hospital then referred them to CHUK. At CHUK a diagnosis was made very quickly and the children operated on within a few days. Diagnosis was delayed longer for babies with Hirschsprung's Disease. Parents generally took the baby to the health centre when their stomachs swelled up and they seemed to be in pain. The health centre then generally referred them to the district hospital. The doctor at the district hospital generally diagnosed constipation, told the parents that they were not giving their children enough food and prescribed medicine. It was only when the medicine failed to bring about any improvement that the children were referred to CHUK, a correct diagnosis was made and arrangement made to operate on them. Parents did not generally recognise that their sons with Hypospadias had a medical problem and it was only when they took them for circumcision at around two years that they found out that their sons needed surgery. They were generally referred to CHUK by the hospital to which they had taken their sons for circumcision, the diagnosis was confirmed there and arrangements were made for an operation. Unlike the first three conditions, Nephroblastoma is not a birth defect but a cancer that is diagnosed in older children. Parents realised that their child had a problem when one side of their belly became swollen. Health centres referred them to district hospitals, where the doctor arranged for an Xray. The doctors in the district hospitals did not make a diagnosis and referred the parents to CHUK, where they underwent further tests

and a diagnosis was made. They were then sent to Butaro hospital for a course of chemotherapy before returning to CHUK for the surgical removal of the affected kidney. On discharge after surgery they were referred back to Butaro for a further course of chemotherapy. Parents found it difficult to understand what was happening during the referral process and did not understand what was wrong with their children. They tended not to find the health care workers in the health centres and district hospitals very helpful and found waiting times to see a doctor long. They were generally more complementary about CHUK and found the doctors helpful, and having appointments meant they did not have to wait for a long time. The parents generally came to have a reasonable understanding of the treatment their children were undergoing, the surgical procedures to correct the problem and how to look after their child but not of the condition itself. At the time we interviewed the parents all but one of the children with Ano-rectal Malformation or Hirschsprung's Disease had completed their treatment and had their stomas reversed and the parents understanding was that they would now be able to lead a normal life. All the children with Nephroblastoma had completed their treatment but their parents reported having been given little information about the prognosis and some feared that their child would get another tumour. The boys with Hypospadias still had to undergo more corrective surgery. Their parents were concerned that they might not be able to have a normal sex life when they grew up but they did not seem to have been given any information about this by the medical staff whom they had seen. to have a normal sex life when they grew up but they did not seem to have been given any information about this by the medical staff whom they had seen.

Travelling for Surgery

All the carers found travelling to get health care for their sick child a challenge. In all but one case it was the mother that travelled with the children, sometimes accompanied by the father or another relative, and who stayed with the children while they were in hospital. Most walked to the local health centre, which took then anything from 15 minutes to two hours. Some also walked to the district hospital but others took a moto or bus and journey times even by bus could be longer than an hour. However, what the parents found most challenging was travelling to CHUK and Butaro. All but one family did this by bus with journey times of anything between one and five hours. In Kigali they often had to walk from Nyabugogo bus station because the motos refused to let them travel carrying a child and they could not afford a taxi. It was difficult for the parents to remember the number of bus journeys they had made to CHUK (and to Butaro in the case of those whose children had Nephroblastoma), but

Caring for the Child

In all cases except two the mother was the main carer, and in some but not all cases fathers and/or other relatives provided some help. The father was the main carer for one child, as he had a back problem and cannot work and his wife works 14 hours a day, 7 days a week to provide for the family. The grandmother and aunt shared the care of another child while his mother works in Kigali to support the family. The carers of children with Ano-rectal Malformation and Hirschsprung's Disease had to provide full-time care for their children post-operatively, and some even found it difficult to find time to collect wood and water. The carers of children with Nephroblastoma also said that they had to care for them full time apart from one of the older ones whose carer said she was able to leave her on her own. The carer of the other older one said she had to stay with her all the time as she was suicidal. They also needed to take their child for chemotherapy post-operatively and for check-ups. The carers of children with Hypospadias said that they did not need to provide any care beyond what was required by other young children. Most of the carers said that it was necessary for them to give up work in order to care for their child both while they were having treatment and post-operatively, and they were caring for them full time. In some cases, the father also gave up work while the child was undergoing medical treatment. They also found the cost of special diets and materials to clean the stoma difficult to afford. Most use towels in place of the recommended materials (which cost 600 RWF a day).

Impact on Carers' Wellbeing

Most of the mothers reported feeling stressed and upset

the trips were numerous: in some cases, the number was well over 30. They found travelling by bus difficult, especially with a sick child as they could not usually carry the child on their backs and sometimes had to stand for the whole trip. They also found it difficult to find money to cover the cost of travel. Carers' estimates of how much they spent on travel varied from a low of 58,000 RWF to a high of 600,000 RWF. 58,000 RWF to a high of 600,000 RWF. Parents generally had to stay in Kigali and Butaro when their child was receiving inpatient treatment. One family rented a house in Butaro while their child was undergoing chemotherapy but most could not afford to pay for accommodation or even food. About half of the parents were able to stay with relatives or friends in Kigali who did not ask for any payment and provided them with food. The rest slept in the grounds of the hospital; while a few bought meals in the hospital canteen others had to rely on philanthropists who came in the evening to the hospital and gave them food.

because of their child's illness. In some cases, the symptoms suggest that they may be suffering from clinical depression and in others that they worry about what will happen to their child in the future and are finding it difficult to cope. One mother cried throughout the interview, had lost weight and could not sleep, some reported not being able to eat or eat properly, others reported not having any energy and one had attempted suicide. Two fathers were also said to be displaying signs of depression; one had had to take time off work and the other had closed in on himself.

Impact on the Economic Security of Families

All the families became financially insecure as a result of having to pay for transport, staying with the child while he or she was in hospital and other additional costs of caring for their sick child. They all found it a struggle to cover these costs. Most of the mothers and some of the fathers had to give up employment because of the demands of caring for the sick child, taking the child to medical appointments, staying with him or her in hospital and looking after other children at the same time. Any savings that they had were used up. Those that had land and/or farm animals had been forced to sell in order to cover the costs of caring for their child. A number had loans from relatives that they are unable to pay back. All the families' economic circumstances had become more precarious and only three seem able to cover their daily living costs – but they have had to change their lifestyle to get by. In a few cases older siblings at secondary boarding schools had had to leave school because the parents could no longer cover the costs.

Policy recommendations

The Sustainable Development Goals have moved the agenda from a focus on communicable diseases in LMICs to investing in non-communicable diseases, including surgical conditions. There is an unmet need for paediatric surgical services in Rwanda as in many other LMICs - not just for paediatric surgeons but for other qualified paediatric health workers as

well. To date attention has focused on the need to recruit qualified staff and provide appropriate services. In this policy brief we have focused on the impact on families of having a child who has been successfully treated by complex surgery. The results suggest: -

1. The training of more paediatric surgeons and other paediatric health care workers may reduce the cost and care

burden on families if they are employed in hospitals outside Kigali - but this will take time to put in place;

2. The availability of chemotherapy at more hospitals would reduce the financial burden on families whose children are being treated for cancer;

3. Ensuring that all babies have a post-natal check-up shortly after birth and a follow up at one month to enable early diagnosis of congenital conditions;

4. The development of a sustainable local system for stool management to reduce the burden of care for families whose children have a stoma with the cost covered by the community health insurance;

5. More education for parents on the conditions from which their children are suffering, making certain that they understand

and, if possible, providing them with written material that they can understand;

6. Consideration of how the community health insurance can be extended so that in complex cases it covers the costs of diagnosis, all treatment, medicines, and materials;

7. Considering the provision of hostel accommodation with cooking facilities for parents while their children are in hospital;

8. Covering some of the costs of travelling to Kigali and Butaro for medical appointments for at least the poorest families

9. Considering providing psychosocial support for parents, especially the main carer;

10. Considering how community health workers can provide some advice for carers when they first realise that there is something wrong with their child.

Professor Pamela Abbott, January 2020

Acknowledgements.

This research was funded by the University of Aberdeen Trust Fund. The views expressed in this report are those of the author alone. Professor George Youngson conceived of the idea of doing the research and obtained the funding for it. Ill health forced him to withdraw from actively participating in the research in December 2018. Without his original contributions to the conception of the research it would not have been possible to carry it out.

Roger Mugisha and Edmond Ntaganda were involved in the conception of the research and the obtaining of ethical approval. Roger Mugisha was responsible for organising the fieldwork and carried out the field work with the support of nurse Theophilla Kayitesi.

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v Hirschsprung's Disease occurs in about 1 in 5000 live births, Hypospadias occurs in about 1 in 200 boys, Ano-rectal malformation in about 1 in 1,500 live births and Nephroblastoma is the most common extracranial tumour of infancy, occurring in about 1 in 100,000 children.