Table 1 A list of the World Health Organization Clinical Stage 3 conditions found in patients beginning antiretroviral therapy (ART) in Malawi who had only one condition listed on their ART master card

Disease condition	*No.*	*(%)*
Unexplained severe weight loss >10% of presumed or measured body weight	808	20.8
Severe presumed bacterial infections (e.g. pneumonia, meningitis, etc.)	671	17.3
Unexplained fever (intermittent or constant for longer than one month)	588	15.2
Unexplained chronic diarrhoea for longer than one month	496	12.8
Oral candidiasis	447	11.5
Past history of pulmonary TB within the last two years	433	11.2
Active pulmonary TB	389	10.0
Vulvo-vaginal candidiasis (with systemic features)	35	0.9
Specific conditions in children	12	0.3
Oral hairy leukoplakia	1	
Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis	0	
Unexplained anaemia (haemoglobin <8 g/L), neutropenia (neutrophils <500/mm^3) or thrombocytopenia (platelets <50,000/mm^3)	0	
Total	3880	100

TB, tuberculosis

Discussion

This study shows that in patients starting ART in Malawi who are categorized as WHO Clinical Stage 3, the three most common conditions were symptomatic disease (unexplained weight loss, chronic /intermittent fever or chronic diarrhoea), TB and severe presumed bacterial infection. Together, these accounted for over 85% of the Stage 3 patients. None were started on ART due to anaemia, neutropenia or thrombocytopenia. The reasons for this are unclear, but may reflect either the generally poor laboratory infrastructure in Malawi (a situation that pervades much of sub-Saharan Africa[5]), or poor clinical assessments made by the staff who determine whether patients are eligible for ART.

This operational study has some limitations. Not all data were available as a small proportion of ART treatment master cards were poorly completed, and we cannot be certain that what was recorded accurately reflected the patient's clinical presentation. However, as a large number of patients were enrolled in this study and the routine data collection systems are subject every three months to validation and cross-checking,[6] the findings probably give a fairly accurate picture of the situation.

Almost half of the patients were started on ART because of unexplained weight loss, fever or chronic diarrhoea. The percentage was greater in government district hospitals than in the mission hospitals and health centers, which may be due to higher pressure of work in district hospitals leading to a more rapid and cursory assessment of patients. The findings are a source of concern. In sub-Saharan Africa, these features may be due to serious conditions such as TB, malignancy or low-grade septicaemia. The missed diagnosis of TB at the time of starting ART may either lead to TB manifesting within months of starting therapy[7] or may be one of the reasons for the high early mortality seen in African patients receiving ART.[8,9]

Three important points emerge from this study. First, the importance of performing haemoglobin and white cell counts in HIV-infected patients being assessed for ART must be emphasized to clinical staff, and laboratory services must be improved. Second, the medical and microbiological reasons for HIV-infected patients presenting with unexplained weight loss, fever or diarrhoea must be investigated and recorded – the possibility that the patient might have TB should always be borne in mind. Third, until the results of such studies are available clinicians should be more vigilant about screening ART patients for TB.

Acknowledgements

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Quality of life for families with spina bifida in Kenya

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SUMMARY Spina bifida (SB) affects children worldwide. Studies from developed nations have explored the impact of SB on the quality of life of children and their parents. However, there are no such studies available from developing countries. We have therefore undertaken to document the impact of the disability on the families of affected children in Kenya. A questionnaire was administered to 40 mothers and their children, who were receiving treatment for SB at our institution. The results of this study should indicate where community and governmental resources and educational efforts for the disabled should be directed.

Introduction

The International Classification of Functioning, Disability and Health (2001)[1] defines health in terms of impairment, activity limitations and participation restrictions. Children with spina bifida (SB) are affected in each domain. The neurological level influences mobility, continence and the risk of infections, while hydrocephalus causes cognitive impairments.[2] The chronic nature of SB can complicate parental resolution of grief and adaptation to the disability.[3] Multiple factors can lead to social isolation, school attendance problems, difficulty securing employment and, ultimately, can affect the quality of life (QOL) of the child and their family.

Few studies exploring QOL in children or families affected by disability have been published from developing nations.

Patients and methods

Patients were recruited from two neighbouring institutions dedicated to the medical, surgical and spiritual needs of children with disabilities – Bethany Crippled Children's Centre of Kenya (BCCCK) and BethanyKids at Kijabe Hospital (BKKH). BCCCK/BKKH have always practiced a policy of non-selective surgical intervention for children with SB. Care included the management of neurogenic bowel and bladder, orthotics and developmental interventions.

The questionnaire included demographics, the presence of hydrocephalus, the need for clean intermittent catheterization (CIC) and QOL questions deemed appropriate for age and for the Kenyan setting. The neurological levels were obtained from the hospital charts.

Results

The sexes were evenly represented; mean age was four years (range 11 days–22 years). Hydrocephalus was present in 23 children, 18 of whom had a shunt. Recorded motor levels were 21% thoracic, 46% lumbar and 33% sacral. Of 19 children over 18 months of age, eight (42%) had urinary incontinence. CIC was practiced by 40% of the mothers. Half of mothers reported a great financial impact of the child's disability. Most were married, with variable impact of the child on their marriage. Three marriages had broken down as a result of the child's condition. Urinary incontinence had a negative impact on marriage (4.4/5 score for incontinent children versus 3.9 for continent, 5 being the worst). The use of CIC had a positive impact on the marriage (3.3/5 with CIC versus 4.2 without); neither of these differences reached statistical significance.

Only 17 of the mothers were taking folic acid provided free by our institutions – despite the majority knowing of its importance during pregnancy for the prevention of neural tube defects.

Only six found their community very helpful, while 15 had received no assistance at all. Seven reported being shunned; nine felt that they or their other children were cursed because of the birth of the disabled child. Seventeen reported that their spiritual life had been impacted by the child, in most cases positively. Thirty had been befriended by someone from their local church, but eight had received no support. Half the mothers knew of other families in their community with a disabled child.

Discussion

QOL may be determined more by a combination of functional loss and dependency than by the type of disability.[4] Western studies have documented the social disadvantages associated with the loss of power and mobility, impaired bowel and bladder control and hydrocephalus – including a decreased opportunity for peer relationships, prolonged dependency on parents and decreased community acceptance.[5,6] They suggest that QOL could be increased if mobility and bladder impairment were addressed; yet in Kenya, SB children are typically still carried as braces and wheelchairs are expensive, not easily available, or unusable due to the rough terrain.[6] Low cost aids to improve activities of daily living (ADLs) may result in an improved QOL for both children and parents.

Incontinence appears to be one of the most stressful aspects of SB, even more than impaired motor function.[7] Bladder problems may act as a focus of strain on family relationships, but CIC itself was well tolerated.[8] Our data supports the evidence that incontinence has a negative impact on marriage, while CIC appeared to positively impact social life.

The social acceptance of people with visible disabilities remains an issue in Kenya. One well-educated mother said: '*Many family members, even the grandparents, have not seen the baby because they are afraid of a curse*'. The curse idea, with a resulting lack of support received from the extended family, was also prominent in a Nigerian study of SB and hydrocephalus – the early treatment of the baby's deformities was, in fact, sought in order to allow the baby to look 'normal' before being seen by the community.[9]

This study documents the pervasive social, financial, emotional and spiritual impact that SB has on the QOL of the family in a developing country. Family resources, such as hope and instrumental support, are predictors of QOL in children with SB.[5] In our study, mothers who received help from their community or church found it very beneficial. Support groups for parents of children with disabilities are relatively new in Kenya but are growing rapidly, mainly due to the introduction of public education. Indeed, education is essential for the prevention of social isolation and for providing support. Medical providers, faith and other communities and empowered parents can all be agents for the education of the public and advocates for change.

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An audit of obstetric fistulae in a teaching hospital in South Africa

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SUMMARY Obstetric fistulae are still common in the rural areas of South Africa. This study describes the demographic and clinical characteristics of 41 women with obstetric urinary fistulae. All were from poor socioeconomic backgrounds and had limited or no access to antenatal care.

Introduction

Most cases of obstetric urinary fistula (OUF) result from neglected labour and are a significant cause of physical and psychological disability.[1] Data on OUF in KwaZulu-Natal (KZN), South Africa, a province of nine million people, who mainly live in rural undeveloped areas, is lacking. The aim of this study was to evaluate the 'patient profile' of women presenting with OUF at the King Edward VIII Hospital.

Methods

The clinical data of women admitted with a diagnosis of vesico-vaginal fistulae (VVF) from 1999 to 2003 was documented. Demographic and obstetric information was obtained utilizing a structured data sheet.

For descriptive purposes, OUF were categorized into simple VVF, complicated VVF and vesico-uterine fistulae. Successful repair was defined as total continence.

Results

Forty-one women were evaluated. The clinical data is shown in Table 1. Fourteen were <18 years of age at the time of fistula occurrence.

Table 1 Clinical data ($n = 41$)

Age (years)	Mean 29 (range 15–51)
Parity	Mean 3 (range 0–8)
Marital status	$n = 1$
Height (cm)	Mean 144.6 (range 118–168)
Weight (kg)	Mean 48.2 (range 38–80)

Social data

Forty were unemployed and lived with their families. The majority (35/41) had primary school education; five had no formal education and one had secondary education. Public transport was extremely poor, particularly at night. Forty women cited lack of transport as a major factor of delay in seeking emergency medical care.

Twenty-two (53%) were aware of community health-care centres and eight (20%) were aware of district hospitals. Only 11 (27%) received antenatal care at health facilities.

Twenty-one (51%) were primigravida; six were parity 2; 10 were parity 3 and the rest parity ≥5. Nineteen (46%) delivered at home, 17 (41%) at a district hospital, three (7%) at a regional and two (4%) at a tertiary hospital. Three women had hysterectomies following obstructed labour, complicated by postpartum haemorrhage in two and a ruptured uterus in the other.

The obstetric outcome is shown in Table 2. The second stage of labour was prolonged in the majority of cases (40/41).

The timing of diagnosis was variable ranging from intrapartum to four months post delivery; two cases of ruptured uteri had bladder involvement and following hysterectomy and bladder repair, were found to have OUF. In another two in whom total abdominal hysterectomy was done for puerperal sepsis, urinary leakage was noted postoperatively. Of six who underwent forceps delivery, urinary leakage was noticed in four immediately postinstrumentation. The majority of the fistulae (32/41) were diagnosed within the first week following delivery. Three of four women with vesico-uterine fistulae and one with ureteral-uterine fistula noticed urinary incontinence six weeks following caesarean section.

The level of the fistula was variable and included the bladder neck, trigone and urethra. Eleven had previously failed surgery; five were repaired at rural district hospitals and six at regional hospitals. The route of repair was abdominal in 26 patients, vaginal in 13 and two had a combined approach. At the time of discharge, 33/41 were continent. Of the remaining eight, five had urethral incontinence and three had true surgical failures (all three had simple VVF). Sixty-six percent defaulted or were lost to follow-up, six months after the surgery.

Discussion

With an annual delivery rate of approximately 100,000 in KZN, the frequency of OUF from the present survey is low compared to that reported from other countries in Africa such as Nigeria (reported fistula rate is 350 cases per 100,000 deliveries).[2] This low incidence is tertiary hospital based and does not reflect the true incidence, as many fistulae

Table 2 Obstetric outcome ($n = 41$)

Forceps	6 (15%)
Ventouse	2 (5%)
Caesarean section	14 (34%)
Symphysiotomy	2 (5%)
Vaginal delivery	17 (41%)
Live births	5 (12%)
Neonatal deaths	2 (5%)
Stillbirths	36 (87%)