Child PIP: Making mortality meaningful by using a structured mortality review process to improve the quality of care that children receive in the South African health system

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The Child Healthcare Problem Identification Programme (Child PIP) uses the mortality review process to assess the quality of care that children receive in the South African health system, and to suggest solutions for improvement. This paper describes the origins, growth and development of Child PIP over the last 5 years, and provides an overview of the findings and recommendations to date.

Background

In the mid 1990s, the transformation of the South African health system using the primary health care approach led many children's health workers to feel optimistic about the impending changes. However, in moving from academic and metropolitan facilities into regional and district hospitals, it quickly became evident that the quality of care received by children was suboptimal. The challenge was how to change this.

In 1996 the Perinatal Problem Identification Programme (PPIP),[1] and in 1997 the Confidential Enquiry into Maternal Deaths (CEMD),[2] were launched, with similar concerns about the quality of care received by babies (unborn and newborn) and pregnant women. Both PPIP and the CEMD pioneered the use of the mortality review process in South Africa for assessing and improving the quality of care received by these health populations.

Drawing on the philosophy and experience of these two programmes, Dr Angelika Krug piloted an Under 5 Healthcare Problem Identification Programme in the early 2000s in four sites in the Mafikeng region of North West province.[3] The programme was then field-tested in eight sites in 2004[4] giving rise to the first Saving Children report.[5] After field-testing, the programme was extended to be able to include all children (0 - 18 years) admitted to children's wards, the software platform was substantially updated and improved, and the package was renamed the Child Healthcare Problem Identification Programme or Child PIP.

Components of Child PIP

There are three main components of Child PIP:

1. The concept
2. The process
3. The findings.

The concept

There is a concern about the quality of care that children receive in the South African health system. This concern is made real by the following extracts from the clinical records of children who died in South African hospitals:

'Not seen on ward at all after admission; sats recorded as 66%; no oxygen given; sats never rechecked' (13-month-old Thando with ARI)

'LP considered, but not done. Diagnosis of meningitis delayed by 15 hours; antibiotic never started' (16-month-old Sanele with meningitis)

'Lift got stuck when intern called to patient. Patient already dead when she got there' (2-month-old Zweli, with no identifiable cause of death. Later in the day the intern slipped, running up the stairs, and broke her wrist)

'After initially improving, child appeared to drown in her own vomit' (8-year-old Samkelo with meningitis)

Health workers who care, reflect on what they do. When faced with the deaths of children such as these, the challenging question is: 'Is this the best I can do?' Individual experiences such as those described above may in themselves lead to change, but it makes more sense to answer this question in a formalised and structured way, so that the answers generate information that can make change for the better happen. Child PIP's central purpose, then, is to use the mortality review process to improve the quality of care that children receive in the South African health system.

The process

Child PIP provides a structure for assessing the quality of care children receive in the South African health system by:

- Ensuring all inpatient deaths are identified
- Assigning a cause to each death

- Determining the social, nutritional and HIV context of each child who dies
- Determining modifiable factors in the caring process for each child who dies.

Two main activities make up the Child PIP system, namely the mortality review process itself, and data management and analysis.

The **mortality review process** is outlined in a guideline available on the Child PIP website.[6] The mortality review process has four key steps:

1. The 24-hour review, where every death is carefully reviewed and summarised within 24 hours of its occurrence to ensure that all necessary information is captured.
2. The preparatory meeting, where the nurse and doctor in charge of a ward compile mortality statistics and analyse all deaths, selecting cases for presentation at the mortality meeting.
3. The mortality meeting, held weekly or monthly in a supportive and constructive way with opportunities for discussion, teaching and task allocation. One of the most important aspects of the review of deaths at the meeting is to identify modifiable factors in the process of caring for each child who died, i.e. instances of suboptimal care or missed opportunities. These are grouped by *where* they occurred (home, clinic, hospital) and by *who* was responsible (family/community, administrative manager, clinical personnel). This enables problem identification, prioritisation and planning.
4. Child PIP epidemiology and analysis, which enables broader problem identification with trend assessment and possible solutions or recommendations.

Secondly, **data** need to be systematically **managed** and **analysed.** Child PIP has paper tools for data tracking and gathering, with monthly admission data being collected on monthly tally sheets, as well as detailed data on each death. Once gathered the data are entered onto a dedicated software programme, where analysis is automatically generated. There is also an option for self-generated analyses (see http://www.childpip.org.za/).

The findings

Both the purpose and structure of Child PIP make changes possible within an institution from the inception of its use. There is usually an immediate improvement in record keeping, result checking, and basic clinical assessment and management.

Once analysis of Child PIP data begins, information is provided that describes:

1. The children who die, particularly their health context and profile; and
2. The quality of health care provided in the health system.

This information is used locally at ward or hospital level within an audit cycle to address local problems. Data are also exported to a national database which amalgamates data from all participating sites to begin to provide a country picture. This information has been published in two reports to date, Saving Children 2004 and 2005.[7]

The growth and structure of Child PIP

From the four sites that participated in the pilot study in 2002, and the eight that field-tested the programme in 2004, there are now over 50 hospitals participating in the process (Table I).

TABLE I. CHILD PIP PROVINCES AND SITES 2004 - 2008

	2004	2005	2006	2007	2008
Provinces	6	9	9	9	9
Sites	14	21	31	51	57

The 57 participating hospitals are from all levels within the district health system (Table II). Percentages show coverage for the different facility levels.

TABLE II. CHILD PIP DISTRIBUTION AND COVERAGE 2008

District	Regional	Tertiary	Central
30/257 (12%)	22/65 (34%)	3/6 (50%)	2/9 (22%)

To date, 39 of these hospitals have submitted data to the national database. The software platform change in 2005 was substantial, and the current database therefore only contains data from 2005.

Child PIP as an organisation currently has a co-ordinator in each province (a health worker employed at a hospital with full clinical responsibilities) who provides support and oversight of the hospitals/sites using Child PIP in that province. The provincial co-ordinators, as well as some additional experts, form the Child PIP Technical Task Team which drives the organisation. A National Executive Committee manages the finances and takes final responsibility for the growth and sustainability of the programme.

New sites are provided with a start-up package (a folder, manual and the software). A comprehensive training programme was developed in 2007 for use by individual sites or at national and provincial workshops.

Results

Core data

To illustrate the power of Child PIP, data for 2005 - 2007 are provided. The core data are shown in Table III. Child PIP data currently arises from over 100 000 admissions and over 6 000 deaths. The total for deaths from monthly tally data usually does not equate with the total for audited deaths because tally sheet data rely on ward admissions registers, which are often poorly administered. In addition, where possible, hospitals audit children who are dead on arrival or who die in casualty or outpatients, and these deaths do not contribute to monthly tally data. Almost 7 000 deaths have been audited in detail.

The in-hospital mortality rate varied considerably from site to site with annual rates ranging from 3 to 15 deaths per 100 admissions. For every death there were on average two modifiable factors.

TABLE III. CORE DATA 2005 - 2007

Total admissions*	105 637
Total monthly tally deaths*	6 279
In-hospital child mortality rate*	5.9
Audited deaths†	6 839
Total modifiable factors (MFs)†	15 229
MF rate (per death)†	2.2

*From monthly tally sheets.
†Individual audited deaths.

Information about the children who died

Child PIP gathers considerable information about the children who died, including:

- Age and gender
- Referral patterns
- Length of hospital stay and time of death
- Caregiver information
- Nutritional profile
- HIV experience (laboratory and clinical classification, PMTCT and ART exposure), and
- Cause of death.

A selection of these parameters will be described in more detail.

Age distribution (Table IV)

Almost 90% of the deaths occurred in children under 5 years of age, with 64% being under one year. Child PIP includes neonates, who made up 9% of the total audited deaths.

Nutritional profile (Table V)

Sixty-four per cent of the children who died were underweight, and over half of them were severely malnourished. The data have indicated an improvement in the number of children with recorded weights. Whereas in 2005, 17% of deaths were never weighed, in 2006 this had decreased to 8%.

HIV laboratory classification (Table VI)

Almost two-thirds of children were tested for HIV, and of these nearly half were HIV infected. A further third were HIV exposed, thus over 80% of those tested were either HIV infected or exposed.

TABLE IV. AGE DISTRIBUTION

Age	No.	%
0 - 1 month	615	9.0
1 month - 1 year	3 662	53.5
1 year - 5 years	1 810	26.5
5 years - 13 years	711	10.4
13 years - 18 years	24	0.4
Unknown	17	0.2
Total	6 839	100

TABLE V. NUTRITIONAL PROFILE

Nutritional category	No.	%
Overweight for age	67	1.0
Normal	1 728	25.3
Underweight for age	1 997	29.2
Marasmus	1 742	25.5
Kwashiorkor	342	5.0
MK (marasmus-kwashiorkor)	283	4.1
Unknown	680	9.9
Total	6 839	100

TABLE VI. HIV LABORATORY CATEGORY

Laboratory category	No.	%
Negative	715	10.5
Exposed	1 559	22.8
Infected	2 065	30.2
Not tested (but indicated)	700	10.2
Not tested (not indicated)	283	4.1
Unknown	1 517	22.2
Total	6 839	100

Child PIP has shown that the quality of HIV categorisation of a child serves as a valuable proxy for the quality of care that the child received. It is striking that for over one-third of children dying in South African hospitals the HIV status was unknown.

Cause of death

When looking at cause of death, the most accurate assessment of disease burden and significance is provided by looking at all diagnoses made, as children often die with many diagnoses. Illnesses occurring most frequently in children who died are illustrated in Fig. 1, which shows acute respiratory infections (ARI) and gastroenteritis as the most common, followed by sepsis, tuberculosis and PCP. All of these are preventable conditions.

Child PIP categorises all children who die by HIV laboratory status and clinical stage, thus it does not use HIV as a cause of death. However, almost half the children died with HIV disease, being HIV stage III or IV.

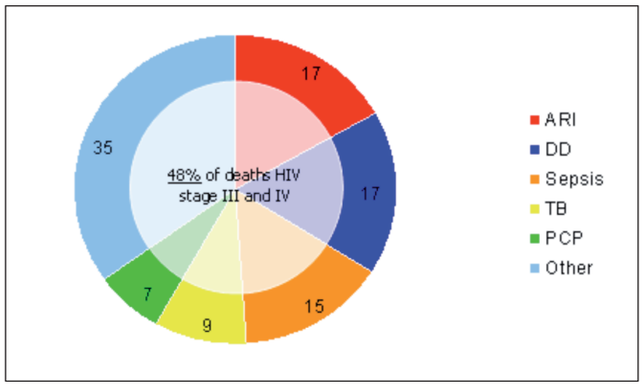


Fig. 1. Cause of death (all diagnoses).

Information about the quality of health care

Quality of care information is given in Child PIP through the assessment of the quality of the health records, as well as the identification of modifiable factors (MFs) in the overall processes of care.

Table VII shows the **place** where modifiable factors occurred as well as the **person** responsible. Many modifiable factors occurred in the home, a reflection of the challenges faced by caregivers who form an essential part of the health system. However, the highest rates were recorded in hospitals, which is further emphasised when looking at the MF rate by person responsible, with there being just over one MF related to clinical personnel for every child death that occurred.

TABLE VII. MODIFIABLE FACTORS

Where they occur	No.	Proportion of MFs (%)
Home	4 695	30.8
Clinic/ambulatory	2 063	13.5
Admission & emergency care	3 277	21.5
Ward	4 260	28
Other	934	6.1
Total	15 229	100
Who is responsible	**No.**	**Rate (per death)**
Caregiver	5 058	0.7
Administrator	2 993	0.2
Clinical personnel	7 178	1.1
Total	15 229	2.2

Recommendations

The strength of Child PIP is to generate information that can lead to improved quality of care. In making recommendations for improvement, Child PIP follows two main principles:

1. Recommendations must arise out of Child PIP information
2. Recommendations must be clear in their formulation with regard both to their level for action (policy, administration, clinical care, and education) and to who is responsible (policy makers, managers, clinical personnel and educators – especially medical schools and nursing colleges).

Saving Children 2005 described five recommendations which addressed the prevention and treatment of HIV, the proper management of nutrition in clinics and hospitals, the importance of having and implementing good standards of clinical care for children, essential norms (for staffing, equipment and transport) and the vital role of monitoring quality of care (Fig. 2).

To illustrate the formulation of the recommendations, an extract from the HIV recommendation in Saving Children 2005 appears alongside.[8]

Responses to Child PIP

Child PIP has been funded by the United States Centers for Disease Control (CDC) since its inception to the present.

There has also been both international and national interest shown in the programme with Child PIP being invited by the

Identifying and treating children infected with HIV

What Child PIP says

A laboratory assessment of the HIV status of 46% of children who died was not done. Of those tested, 15% were negative, 37% were HIV exposed and 48% HIV infected. In terms of clinical staging of HIV, 17% of infected or exposed children were not clinically staged. Fifty per cent of all the deaths were assessed as stage III or IV and thus eligible for ART, yet only 3% of deaths were documented as having received ART. Only 1% of mothers were documented as being on ART but information was lacking in 77%.

Recommendation

Provide ready and universal access to ART for children and their parents

Action

Increase capacity to improve ART services.

Implementation

POLICY

- All children should have an HIV PCR test done at 6 weeks of age at their first vaccination visit, so that infected children are identified early.
  Responsibility: National and provincial Departments of Health.
- Admissions to hospital should be seen as opportunities for accessing ART. All children admitted to hospital who have no documented HIV test, must be tested on an opt-out basis for HIV infection (PCR under 18 months, rapid serology over 18 months). Eligibility for ART must be established through CD4 testing and/or clinical staging.
  Responsibility: District, institutional (hospitals and clinics) and unit managers.

ADMINISTRATION

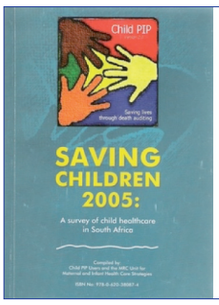
- Laboratory systems must be developed to be able to meet children's need for universal PCR testing at six weeks of age.
  Responsibility: National Laboratory Service.
- Paediatric ART services need additional staff to treat the rapidly increasing number of patients.
  Responsibility: District, institutional and unit managers.

CLINICAL PRACTICE

- Labelling children 'Known RVD' or 'RVD +', a common occurrence in the audited deaths, negates the possibility for an holistic and appropriate HIV care plan. Doctors looking after hospitalised children must categorise all children's HIV status using, as an example, the classification system in Child PIP (laboratory status and clinical stage), which is in line with the teaching of paediatric HIV experts. Testing children should follow the opt-out approach. Barriers to testing should be seen as barriers to accessing ART for the child.
  Responsibility: Heads of paediatric departments and medical staff in children's wards.

EDUCATION

- Medical schools should ensure that graduates know how to classify children in relation to HIV and AIDS, and realise that HIV testing and staging improves quality of care, rather than reduces it.
- Child PIP data relating to HIV and AIDS can be used in training and education to highlight the poor assessment of children in the South African health system.
  Responsibility: Heads of paediatric departments at South African medical schools.



- HIV/AIDS
  - Prevention & Treatment
- Nutrition
  - Clinic & Hospital
- Gold Standards for Care
  - Clinic & Hospital
- Norms
  - Staffing, Equipment & Transport
- Improving Quality of Care

Fig. 2. Recommendations in Saving Children 2005.

World Health Organization (WHO) to participate in a workshop on hospital care for children in the developing world,[9] as well as by the South African Human Rights Commission to make representations for child health in South Africa.

Partnerships between Child PIP, PPIP and the CEMD have been strengthened with the publication of Every Death Counts in March 2008,[10] which received significant media coverage. This publication seeks to integrate the recommendations arising out of the three programmes and it is the first time that something of this nature has been done anywhere in the world.

There has also been growing interest in and considerable support for Child PIP from both the national and provincial Departments of Health, with the hope that the programme will be able to contribute to immediate improvements in child health care and to future health system planning.

Conclusion

The Child PIP audit provides information about the health profile of a paediatric population ravaged by HIV and poverty, and dying of preventable conditions. It also describes the quality of paediatric health care they received in the SA health system and goes on to suggest how this could be improved. It is now the responsibility of health workers and managers to respond to the challenges posed, and to implement solutions. It is hoped that Child PIP and the Saving Children reports will continue to contribute positively to this process.

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