A COST COMPARISON ANALYSIS OF PAEDIATRIC INTERMEDIATE CARE IN A TERTIARY HOSPITAL AND AN INTERMEDIATE, STEP-DOWN FACILITY

Submitted to the University of Cape Town in partial fulfilment of the requirements for the degree Master of Public Health in Health Economics

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DECLARATION

I, Kristal Catherine Duncan (student number DNCKRI001) hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abstract

Background: According to the National Cancer Registry of South Africa 600-700 new cases of paediatric cancers have been reported every year for the past 25 years. While in the year 2000 HIV/AIDS was responsible for 42 479 deaths in children under five. However support for and research in general for the paediatric intermediate care (encompasses palliative, sub-acute and respite care) needed by these children remains sparse. Costing studies are even rarer, with the few studies conducted in South Africa reporting a broad range of average costs per inpatient day.

Methods: A retrospective cost analysis for the period April 2014-March 2015 was undertaken from the provider perspective. Costs of paediatric intermediate care were estimated for an intermediate step-down facility and a tertiary hospital in Cape Town, South Africa. A step down costing approach was employed, and the costs were inflated to 2016 values and expressed in Rand and USD using an exchange rate of 1 USD = R14.87.

Results Cost per inpatient day was USD 713.09 at the hospital and USD 695.17 at the step-down facility. The cost for a paediatric patient who is HIV/TB co-infected was USD 7130.94 and USD 6951.67 at the hospital and step-down facility respectively, assuming an average length of stay (ALOS) of 10 days. For a patient who has a terminal brain carcinoma the cost was USD 19966.63 and USD 19464.69 at the hospital and step-down facility respectively, assuming an ALOS of 28 days. Personnel costs accounted for 60% of the total cost at the hospital, compared to only 17% of the total costs at the step-down facility. Overhead costs accounted for 12.33% at the step-down facility, almost 3 times that of the hospital (4.48%).

Conclusions The study highlights that the drivers of cost are not uniform across settings. Providing intermediate care at a step-down facility can be more cost-saving than providing this care at a hospital, there are however areas in which more savings could be realized. The costs presented in this study were considerably higher than those found in other studies, however, the paucity of cost data available in the area of paediatric intermediate care makes comparisons difficult.

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Table of Contents

List of tables

List of figures

List of abbreviations

ALOS – Average length of stay

ART - antiretroviral therapies

CBA - cost-benefit analyses

CEA - cost-effectiveness analysis

CUA - cost-utility analysis

DALYs - disability-adjusted life years

EOL - end-of-life

HBC – home-based care

HRQoL - health-related quality of life

ICU - Intensive Care Unit

IRIS - immune reconstitution inflammatory syndrome

LMICs - low- and middle income countries

LSPs - long stay patients

NCDs - non-communicable diseases

NGO’s - non-governmental organizations

NHLS - National Health Laboratory Services

NLUs - nurse-led units

PalY - Palliative Care Yardstick

PCCT - palliative care consultant team

PEPFAR - President's Emergency Plan for AIDS Relief

PICU - pediatric ICU

QALYs - quality-adjusted life years

RCWMCH - Red Cross War Memorial Children’s Hospital

SA - South Africa

SFCH - Sarah Fox Convalescent Home

TB - tuberculosis

UK - United Kingdom

US - United States

WHO - World Health Organization

YLL - years of life lost

Part A Protocol

Introduction

With the focus of the Western Cape government on the new policy of intermediate care, the formerly named sub-acute, respite and palliative care programs in place have to be re-evaluated in the context of this policy [1]. While palliative care has been provided by non-governmental organizations (NGO's) in Africa since the 1970's, there is very little information with regards to paediatric palliative care and more broadly paediatric intermediate care, and to the provision of this form of care in the public sector [2]. The Sarah Fox Convalescent Home is an intermediate care facility, providing care to children in the district of the City of Cape Town in the Western Cape and while it receives some money from the provincial department of health, it relies heavily on donor funding to continue its operations. The majority of their patients suffer with HIV/AIDS, TB and an array of terminal cancers. More specifically, the palliative care wing at Sarah Fox was established by a grant from The Children's Hospital Trust in July 2013 to address the shortage of facilities which provide this type of care to children. However this funding was only temporary and came to an end on 31 December 2014; as a result the district of the City of Cape Town is due to take over the funding of this wing of the facility at the end of February 2015 and thus the need for a costing study has never been more relevant. The belief is that these types of intermediate care facilities are far cheaper per patient than inpatient care at a tertiary hospital but no studies to show this have been done to date in paediatrics, in a South African setting. This study therefore aims to quantify the costs involved for caring for children with intermediate care needs and therefore enable government to budget effectively in order to provide this service.

Rationale and justification for the study

In 2000 HIV/AIDS was responsible for 42 479 deaths in children under five [3]. Additionally, according to the National Cancer Registry of South Africa 600-700 new cases of paediatric cancers have been reported every year for the past 25 years and due to under reporting that figure is most likely underestimating the true burden of disease [4]. It is therefore imperative that the responsibility for care of these children and their families should be that of the government's; however to date no cost analysis studies have been performed in South Africa to facilitate the budget planning required for this.

In 2009, a point prevalence study found that 20% of patients who had exceeded the expected length of stay at tertiary hospitals should have been discharged to an intermediate facility. This finding prompted the Western Cape government to release a document in 2012, in which the department detailed the policy on intermediate care which will encompass palliative care, respite and sub-acute care [1]. Additionally, the government also released a document in March 2014 entitled "*Healthcare 2030, the Road to Wellness*", which is a strategic framework for healthcare in the province and its direction for the next 15 years. Intermediate care forms a large part of this vision and is viewed as being critical to a more people-centred health system, which is the vision for healthcare held not only by local government but health agencies the world over. The health department of the province therefore proposes that this intermediate care be provided by intermediate care facilities (more commonly referred to as step-down facilities) and through home-based care as a means to make this vision a reality [5].

Given that home-based care (HBC) is not a feasible option for many households in the province due to low socio-economic status, an alternative and effective form of care must be available. A lack of facilities providing such care leaves the families of these children with no option other than to seek care from district or tertiary level hospitals, placing an extra burden on an already over-extended system. In the Western Cape currently only 2 institutes provide intermediate care for children, namely St Joseph's (with a bed capacity of 145) and Sarah Fox (with a bed capacity of 62). Both of these facilities serve communities which are severely impoverished and provide palliative, respite and sub-acute care, with the majority of the patients they serve having HIV/AIDS, TB and cancer.

Literature review

The term intermediate care is often used interchangeably with step down care and is defined differently in different areas of the world. In the context of policies in the Western Cape the term is relatively new and as a result no literature addressing all aspects of this care collectively is currently available. However, the three types of care which fall under intermediate care, namely sub-acute, respite and palliative care are well defined, standardized terms. Respite care refers to the care of a chronically ill or terminally ill patient, so as to provide respite for the caregivers of these individuals who may require time off from caring for these patients [6]. Sub-acute care was a term developed to describe the care needed by patients which was above the level provided at basic community health facilities, but less than the acute care provided at secondary and tertiary hospitals in the United States (US) in the 1980s [7]. Lastly, according to the World Health Organization (WHO) palliative care is defined as care which aims to improve the overall quality of life of a patient with a life-threatening illness, through the relief of suffering and treatment of all problems, namely physical, psychological and spiritual. WHO then goes on to elaborate that paediatric palliative care (defined as children 15 years and younger) differs from adult palliative care in that the care provided for adults must be provided for children as well as to their families in the paediatric setting (World Health Organization 2014).

Despite adult palliative care having been provided in Africa since the 1970s in Zimbabwe and South Africa (SA), data on costing remains sparse, with the majority of services still being provided by NGOs across the continent [2]. These NGOs provide this care through hospice settings, which usually encompass some respite care as well as palliative care for patients with life-threatening illnesses [7]. While in low and middle income countries (LMICs) HBC is encouraged as a form of palliative care service, the benefits of this are yet to be established. Additionally, many people needing palliative care do not live in homes suitable for home-based palliative care services due to overcrowding. The provision of end of life care also places a huge strain on informal caregivers and has been shown to decrease health-related quality of life years for these caregivers [9, 10]. HBC is a physical, emotional and financial burden on not only the caregivers but also on the other members of the family; with siblings perhaps feeling resentment with regards to the unequal distribution of resources to the in-need child. Furthermore, a study conducted in a rural area of SA has shown that caregivers often feel ill-equipped to deal with their patients effectively and feel there is a lack of guidance from hospital and clinic staff in the handover process at the time of discharge of the patient [11]. It is in light of this that one of the main functions of intermediate care facilities is to provide a bridge between tertiary and secondary hospitals and to facilitate the discharge of patients to a suitable home environment. Having these support structures in place improves the mental and emotional well-being of the patient and their family, as highlighted in a South African study in an urban setting [10].

The support and evidence of the benefit of palliative care is then clear but the benefits of intermediate care in its entirety still need to be established. ~~Two Cochrane reviews have attempted to establish the benefits and standard of care at nurse-led units (NLUs) in the United Kingdom (UK) and the effectiveness of rehabilitation services which provide sub-acute and respite care for elderly patients [12].~~ A Cochrane review revealed that NLUs had significant reductions in readmission rates of patients when compared to patients who had remained in hospitals and patients discharged from NLUs also had a significant improvement in functional status at discharge, compared to those patients discharged from hospital [12]. ~~However, despite the need for rehabilitation services for the elderly in the UK, the findings of the second Cochrane review highlight just how sparse the research is in this field. The need to alleviate strain on hospital beds by having these facilities has been identified, but the research to test the effectiveness and costs of such services remains sparse.~~

It is therefore clear that there is very little research into the area of intermediate care for adults and even fewer studies exist in the paediatric setting. Even in the developed world it is recognized that paediatric palliative care is a neglected set of expertise, with children accounting for only 0.4% of all hospice admissions in the US, despite the fact that the majority of infants and children die in hospitals (Reviewed in Himelstein et al. 2004) [14]. A retrospective study found that children with cancer were often said to suffer “a lot” and that it was often the parents and not the attending physician who reported these symptoms [15]. This is all indicative of the fact that children are often cared for in the home and not in a hospice setting. When you translate that into a developing world setting it becomes apparent that to achieve holistic paediatric care at home is an expensive undertaking and one which is far beyond the means of the average household in LMICs. The outcome of all of this is that many parents bring their sick and dying children into tertiary hospitals which places an undue strain on an already under-resourced service. Compared to developed countries, children in Sub-Saharan Africa are 15 times more likely to die before aged 5, with many of these deaths having been preventable if only they had access to adequate care by a trained health care provider [16].

While outcomes of successful palliative care provision are difficult to measure, it is even harder to measure in paediatric settings in the developing world. In contrast to developed countries, paediatric palliative care is a substantial portion of total palliative care needs in Africa with 80% of children globally living in LMICs and 60% of childhood cancers resulting in death in these countries [17, 18]. These statistics coupled with the high burden of childhood HIV and other communicable diseases such as malaria and tuberculosis, highlight the need for support of these children and their families in developing countries [19]. While two studies in SA have shown that various home-based palliative care projects are a cost-effective means of treating adult patients diagnosed with HIV and cancer, with cost savings being realized when compared to in-hospital care, as well as improved quality of life measures, no studies have been in done in this setting to analyse paediatric palliative care [10, 20].

Given the recent release of the policy framework for intermediate care by the Western Cape government and the need for funding for the palliative care wing at the Sarah Fox Convalescent Home, research into the area of intermediate care and more specifically the costs involved are required. It is for this reason that this current study is being undertaken so that by quantifying the cost of providing intermediate care in a tertiary hospital and comparing it to the cost of providing intermediate care in a step-down facility, policy makers will be motivated to increase infrastructure in the area of paediatric intermediate care.

Aim

To determine the difference in direct costs inpatient day for a paediatric patient requiring intermediate care at an intermediate facility versus the direct costs per inpatient day for a paediatric patient requiring intermediate care at a tertiary public hospital in the Western Cape.

Objectives

- To identify, quantify and value the resources required to provide intermediate care to paediatric patients at an intermediate, step-down facility.
- To identify, quantify and value the resources required to provide intermediate care to paediatric patients at a tertiary level hospital.
- To compare the costs inpatient day for a paediatric patient requiring intermediate care at a tertiary level government hospital compared to an intermediate, step-down facility.

Hypothesis

We hypothesise that the costs per inpatient day for a paediatric patient requiring intermediate care will be lower at an intermediate facility than at a tertiary hospital.

Methodology

A cost comparison study design will be used, using a step down costing approach. The economic evaluation will be undertaken from a provider perspective and will make use of retrospective costing data for each facility and thus no costs to the patient will be considered for the purposes of this study. In the case of the step-down facility- The Sarah Fox Convalescent Home (SFCH) has been providing intermediate care and respite care to paediatric patients since May 1965, however a 10 bed paediatric palliative care unit has been in operation since 01 July 2013 and the period of 1 April 2014- 31 March 2015 will be used for this study. The home can accommodate 62 patients in total, with two beds in the palliative care wing for parents of patients. The tertiary hospital to be used is Red Cross War Memorial Children's Hospital (RCWMCH), which is a public secondary and tertiary level hospital and the only specialist children's hospital in southern Africa. At this facility the financial year runs from 01 April of each year and we will therefore use financial records to ascertain the costs for the period 1 April 2014- 31 March 2015. The period of one year has been chosen to account for any seasonal variations which might occur and to account for the long average length of stay per patient in this scenario.

Cost measures will be the costs per inpatient day at each facility. However, the costing will be according to line item and all costs will be based on actual unit expenditure and not based on treatment guidelines as the level of care provided at both facilities is the same. Drug costs have not been included in this study because in accordance with the intermediate care policy, any patients admitted to SFCH have to be supplied with the drugs they require from RCWMCH, and as such the costs for drugs will be covered by RCWMCH, regardless of whether the patient is at SFCH or RCWMCH. In addition, the medication provided at SFCH is exactly the same as the medication that the patient would be given if they were at RCWMCH and as such the drug costs will be exactly the same for both facilities.

The costs to be included are listed below

Medical supplies: These will include items such as syringes, bandages and other wound dressing materials. For RCWMCH the costs will be determined using provincial government tender prices and for SFCH the costs will be determined by obtaining the market price of these items from the respective supplier.

Laboratory costs: Costs will be obtained from the National Health Laboratory Services (NHLS).

Consumables: These will include the costs of food, baby formula and disposable nappies and will be obtained from the financial records at SFCH and RCWMCH respectively and the average cost for these items per patient will be calculated.

Fuel: The cost of fuel per annum will be obtained from the financial records at SFCH and RCWMCH respectively and the average fuel cost per patient will be calculated.

Staff salaries: For nurses, doctors, pharmacists, occupational, speech, aroma and music therapists as well as a palliative care consultant. At SFCH some staff members are only there on certain days and as such salaries will be calculated proportionally to the time given to each facility by the employee.

Building costs: See details below.

Equipment and vehicle costs: The current useful life span of each asset will be determined and using this information the current replacement value of the asset will be determined.

Overhead costs: These are defined as additional costs, which are not directly related to the patient and have not been included elsewhere, namely water and electricity, and administrative, kitchen, cleaning and security staffing costs. These costs will be ascertained from the financial records at each institute and the relative cost per bed will be calculated.

To allow for the differential timing of capital costs (i.e. building, vehicle and equipment costs) these costs will be annuitized using a 10 year life span and a discounting rate of 3% will be used in accordance with international standards [21]. Once the costs per inpatient day per facility have been calculated, the costs per average length of stay will be compared between the two facilities. Two diseases will used as proxies for this average length of stay, namely patients with HIV/AIDS with a co-infection of tuberculosis and patients with terminal brain carcinoma, as these are the most common diseases been treated at SFCH.

All costs will be inflated to current 2016 values using an average inflation rate for 2016 of 6.2% [22]. All costs will be presented in both South African Rand and US dollars (the average exchange rate for 2016 of USD 1 = R14.87 will be applied).

Risks and benefits

As no human subjects will be involved in this research there are no perceived risks, while benefits from the study could possibly be an increase in the number of government paediatric intermediate care facilities if the hypothesis is proven to be true.

Privacy and confidentiality

The Western Cape Government's intermediate care policy framework and existing provider financial records will be used to estimate costs and no patient identifying characteristics will be used. All data obtained from these records will be maintained under a password protected laptop. Only myself and my supervisor, Edina Sinanovic will have access to these financial records and the data will be maintained for the period of one year following successful submission of the Masters in Public Health dissertation and submission of the study to a peer reviewed journal.

Time Frame

The proposed time frame for this research is given in Table 1

Table 1 Proposed time frame for research

Proposal development	February-March 2015
Departmental Review Committee submission	27 April 2015
Ethics submission	4 May 2015
Literature Review	May 2015
Data Collection	June 2015 – May 2016
Analysis of Results	June 2015 – August 2016
Write-up	September 2016 – October 2016
Thesis submission	December 2016

Budget

This study is self-funded, with no major costs being foreseen and forms part of a dissertation for a Master of Public Health in Health Economics.

Ethical considerations

Ethical approval will be obtained from the University of Cape Town’s Ethical Research Committee. No major ethical conflicts are anticipated as no human subjects will be used for the study.

Dissemination of study findings

The results of this study form part of the dissertation for submission for a Masters in Public Health in Health Economics and will be submitted for publication to a relevant peer-reviewed journal upon completion. It is hoped that the policy brief will be disseminated to the Western Cape Health Department.

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PART B: Structured Literature Review

Introduction

The purpose of this literature review is to define the term intermediate care and explain why this type of care is necessary given the burden of global mortality. This will be accomplished first by addressing the situation in developed countries and then by summarizing the situation in low and middle income countries (LMICs). Following this, the evidence in support of the health and economic benefits achieved by providing this care, both for the patient as well as the provider, will be presented. In conclusion previous economic evaluations performed in this field will be discussed and gaps in the literature identified, with specific reference to children in LMICs.

The literature search had to be kept broad due to the limited research available for this area of study and due to the term intermediate care being defined differently in different parts of the world. The literature reviewed was limited to articles published in English and various combinations of the following key words were used: “cost comparison”, “cost analysis”, “costing”, “paediatric /pediatric”, “tertiary care”, “palliative care”, “sub-acute care”, “respite care”, “intermediate care”, “step-down facilities”, “hospice”. The following databases were then searched using the key words above: Pubmed, CINAHL, Africa-Wide, NIPAD, Scopus, Web of Science. In this literature search it quickly became apparent that costing studies for paediatric intermediate care in general were limited and for this reason many studies from non-LMICs have been included in the review. In order to gain a complete literature review a snowball approach was used, where references from those publications found during the literature search were used to identify literature which was missed through the database search. Grey literature in the form of working papers and organizational reports were also included. The literature search was conducted between February 2015 and September 2016.

Defining intermediate care

While infectious diseases such as HIV and tuberculosis (TB) have been the leading causes of death in South Africa (SA), the trends of disease burden and mortality in the past few years highlight the need to also focus on non-communicable diseases (NCDs). In 2008, 4.8% of cancers occurred in children younger than 15 years of age on the African continent, in contrast to only 0.4% in Europe; this indicates that the burden of childhood cancers is approximately 12 times higher in Africa than in Europe. Additionally, in the same year cancer mortality in Africa stood at 69 deaths per million children, compared with only 31 deaths per million children in Europe, yet the field of paediatric palliative care remains a low priority [1]. Furthermore, a study in Uganda and SA indicates that almost a fifth of adult palliative care patients had an underlying

HIV diagnosis and the reported prevalence of symptoms in these patients was far higher than in other regions of the world [2]. Statistics SA's findings show that in 2010 NCDs overtook infectious diseases as a leading cause of death in SA and this trend continues with 53.1% of deaths being attributed to NCDs in 2013, compared to only 38.4% being attributed to infectious diseases. While in those aged 0-5 years, infectious diseases are still by far the leading cause of death, the picture begins to change for ages 5 through to 19, where the proportion of death as a result of NCDs and infectious diseases is equal at around 21% [3]. In spite of these convincing figures it is important to bear in mind the lack of cancer registries in LMICs, where most cancer registries are currently in urban areas, with none in rural areas, and as a result these numbers are more than likely an underestimate of the true burden of disease [1].

In SA, a quadruple burden of disease exists, namely maternal and child mortality, HIV/AIDS, chronic disease and mental health and lastly, violence and injury. The high burden of HIV/TB often results in a crowding out effect of other diseases in acute hospitals, giving even more support for the need for facilities which alleviate the burden on hospitals, such as intermediate care facilities. Furthermore, a series of articles recently published in The Lancet, highlight the need for intermediate care in this setting, namely, to address the needs of patients with chronic conditions and NCDs [4]. Specifically in the Western Cape in 2011, the leading cause of death and years of life lost (YLLs) was NCDs, which accounted for 60.9% of deaths, however HIV/AIDS and TB co-morbidity are still the leading cause of premature death. While the authors suspect that most deaths in under 5's are as a result of HIV complications, unreliability of the data make drawing a definitive conclusion impossible [5].

In SA the need to care for chronic diseases and NCDs is increasing substantially and, in recognising this, the Western Cape has recently released a new policy with regards to intermediate care in the province [5, 6]. According to this policy, intermediate care is a term used to integrate the previous terms of respite care, sub-acute care and palliative care under one new term - intermediate care [6]. Intermediate care is often used interchangeably with step-down care and this is in contrast to the United States of America (USA) which uses the term palliative care to cover this type of step-down care for life-limiting and life-threatening conditions [7, 8]. It is important to note that the term intermediate care is a relatively new term, which accounts for the lack of literature which encompasses all aspects of intermediate care. However, the three types of care which fall under intermediate care, namely sub-acute, respite and palliative care are well defined, standardized terms. Respite care refers to the care of the chronically ill or terminally ill patient, so as to provide respite for the caregivers of these individuals who may require time off from caring for these patients [9]. Sub-acute care was a term developed to describe the care needed by patients which was above the level provided at basic community health facilities, but less than the acute care provided at secondary and tertiary hospitals in the USA in the 1980s [10]. Lastly, according to the World Health Organization (WHO) palliative care is defined as care which aims to improve the overall quality of life of a patient with a life-threatening illness, through the relief of suffering and treatment of all problems, namely physical, psychological and spiritual. WHO then goes on to elaborate that paediatric palliative care (defined as children 15 years and younger) differs from adult palliative care in that the care provided for adults must be provided for children, as well as to their families in the paediatric setting (World Health Organization 2014). According to a 2011 report from WHO, diseases requiring palliative care, for both adults and children (defined as those under 15 years of age) were:

> "*Diseases requiring palliative care for adults:* Alzheimer's and other dementias, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, drug-resistant tuberculosis (TB).
> *Diseases requiring palliative care for children:* cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, kidney diseases, neurological disorders and neonatal conditions." (Worldwide Palliative Care Alliance and World Health Organization 2014, p.10)

Additionally palliative care is listed as part of the recommended package of services which LMICs should be implementing in order to meet the Sustainable Development Goals, one of which is to decrease premature deaths from NCDs [13, 14].

However before we can focus on LMICs it is necessary to briefly identify the burden of disease in the USA as the majority of the literature published in the field of paediatric intermediate care is from the region. According to a 2012 report on the 10 leading causes of death in the USA (which account for 74% of all deaths in the USA), heart disease and cancer ranked top, accounting for 46.7% of all deaths in the USA. Of the remaining 8 causes 3 were chronic conditions or NCDs. When excluding unintentional injuries from the leading causes of death in ages 1-4, 5-9 and 10-15, the top causes are congenital malformations and malignant neoplasms. Children with these types of conditions often require some medical assistance for an extended period but do not require medical care in a tertiary or secondary hospital, making them ideal candidates for an intermediate care facility [15]. Given the current trend in SA highlighted above, which shows an increase in mortality as a result of NCDs, we should look to countries like the USA to gain expertise in the field of intermediate care [3].

In light of the quadruple disease burden in SA it is important to acknowledge that while the focus of intermediate care has traditionally been in the area of NCDs such as cancer, the success of antiretroviral therapies (ART) has effectively resulted in people living with HIV requiring this type of care as well. In areas like the USA where HIV has largely become a chronic manageable disease, the need for intermediate care for these individuals has become more and more common. As SA moves toward greater coverage of ART under the new test and treat policy, the need for intermediate care for this group of patients will become just as necessary as for patients with other chronic conditions. This is even more true for children, who need greater support in order to manage the painful side effects of ART and to receive care for other complications such as infections [16]. A very common side effect in children on ART is immune reconstitution inflammatory syndrome (IRIS), which requires support in the form of intermediate care. This syndrome refers to the response of the immune system to a pre-existing infection, which surfaces as the patient's immune system begins to recover due to the ART. In SA in 2009 IRIS was found to affect 21% of children on ART, within a median of 16 days of initiation and children with IRIS would benefit greatly from intermediate care provision [17].

The history of intermediate and palliative care

Despite adult palliative care having been provided since the 1970s in African states such as Zimbabwe and SA, data on costing remains sparse, with the majority of services still being provided across the continent by non-governmental organizations (NGOs) [18]. These NGOs provide this care through hospice settings, which usually encompass some respite care as well as palliative care for patients with life-threatening illnesses [10]. However, it was only in 2006 that hospice and palliative care became recognized as a sub-specialty in the USA and as recently as 2003, Australia only had one training centre for physicians wanting to train in paediatric palliative care [7, 19]. Despite this late recognition of palliative care as an important sub-speciality, the literature is far more abundant for palliative care than for sub-acute care. We should therefore be focussing our efforts not only on palliative care (which in the USA encompasses respite care for chronic conditions and life-limiting and life-threatening conditions), but also on sub-acute care, one of the main functions of which is to provide a bridge between tertiary and secondary hospitals and to facilitate the discharge of patients to a suitable home environment. Having these support structures in place improves the mental and emotional well-being of the patient and their family, as highlighted in an urban setting in SA [7, 20].

Despite the fact that for every 1000 births in Africa an estimated 82 children under the age of 1 die every year, the care of these dying children has not been a priority for many governments [21–23]. Much of the literature is focussed on providing intermediate care for adults, however as mentioned above, when providing this care for children, certain additional considerations need to be taken into account (World Health Organization, 2014). Children suffering with life-limiting conditions often suffer from a very diverse range of illnesses, such as congenital malformations and neurodegenerative disorders, in addition to the usual life-threatening conditions such as cancer, typically found in adults. Due to this range of diseases, care provided may need to be end of life care, but will also include prolonged periods of therapy for children with chronic diseases. Additionally, often medications that have not been properly researched and trialled in children are necessary for pain management and doctors are therefore forced to use these drugs regardless of the lack of information on their use in children [19]. The WHO has approved the use of morphine in children as a means of pain management, but in LMICs access to these drugs, as well as adequately trained staff to administer them, results in limited and/or ineffective pain management [8, 13, 24]. Given these conditions it is important to distinguish between intermediate care provided to adults and that provided to children.

Built in 1981, in Oxford, Britain, Helen House was the first children's paediatric hospice. At the time the utilization of adult hospice care had been growing for some time and it was acknowledged that there was a need to provide similar hospice care to children suffering with chronic life-threatening and life-limiting illnesses. The first retrospective study of the institute indicated that families found great comfort in having the option of hospice care and this decreased levels of anxiety and undue stress on the families. In addition, the benefits of having respite care for their ill children was described as valuable by the parents [25]. In South Africa, the first hospice was opened in 1994, namely the Bloemfontein Children's Hospice, following which there has been a slow but steady increase in the number of paediatric palliative care facilities across the country [24]. An international report on palliative care service provision, issued in 2014 highlights how this progress has put SA ahead on the continent in terms of paediatric palliative care, having been given a ranking which states that hospice development is at a preliminary stage of integration into mainstream service provision in the country [12].

The progress of palliative care in SA is in direct contrast to the lack of progress in this field on the rest of the African continent. Between 2011 and 2013, 49 health professionals, from 38 hospitals, across 29 African countries, were examined to determine the extent of resources in this setting for paediatric palliative care for cancer patients. Findings indicate that there are no specialist nurses trained for paediatric palliative care and only 55% of hospitals had tumour registries, indicating a lack of sufficient data to estimate the need for these services [26]. Lastly, there was also great variation in survival rates across these centres, calling into question the quality of the care provided. The items most strongly requested from these facilities were more training and funds, followed by support from government [26]. This finding is supported by a review of the literature on childhood cancers in LMICs which highlighted the importance of improved infrastructure and skills training in these countries for improved outcomes in the case of childhood cancers [1]. However a systematic review of various levels of paediatric palliative care provision indicates that policies can be misleading and that the implementation of them should be looked at more closely to get a more accurate reflection of what is happening in practice. Furthermore this review once again highlights that for most of Africa (with the exception of SA) there is no data available to even begin to ascertain to what degree there is provision of paediatric palliative care [27]. Studies like these and the WHO report on palliative care highlight just how big the gap is between those in need of paediatric palliative care and those who actually receive it. The African region accounts for almost half the global need of palliative care (Figure 1) but despite this, human resources in the field and adequate training and research are scarce [12, 26]. Even in high income countries the need for paediatric palliative care far outweighs the availability, with examples like those from British Columbia, Canada where only 15% of children who had died from life-threatening conditions had received paediatric palliative care [28].

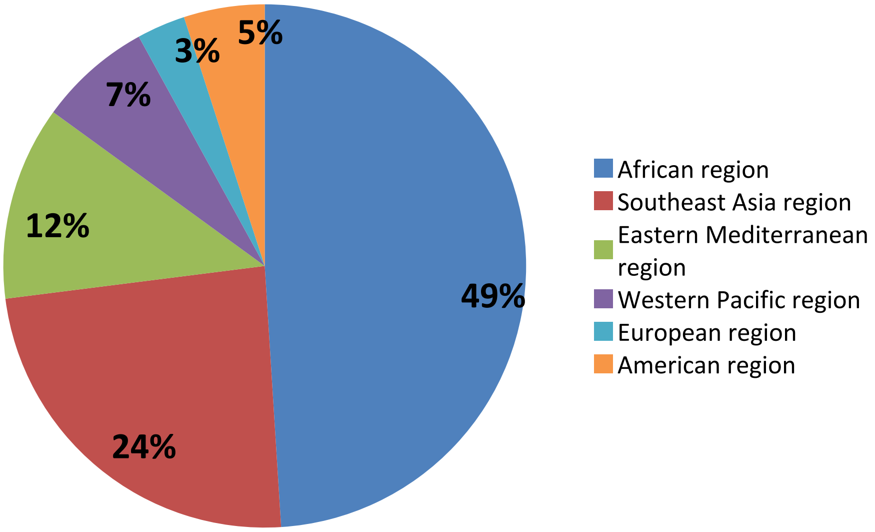

Figure 1 Distribution of children requiring palliative care at the end of life, by WHO regions *(Adapted from Worldwide Palliative Care Alliance and World Health Organization 2014)*[11]

Quantitative benefits of intermediate care

In Europe and the USA the benefits of palliative care have been highlighted in numerous studies and, as early as 1984 in the USA, it was shown that by transferring patients from inpatient hospital care to a hospice environment, the use of hospital days claimed from private health insurance decreased by 50% and the use of hospice care as opposed to inpatient hospital stays resulted in a relative cost reduction of 40% [29]. However the focus of palliative care has remained largely on adults and particularly the elderly. An example of which is the Catalonia World Health Organization (WHO) Palliative Care Demonstration Project which was started in 1990 as a collaboration between the Catalan Department of Health and the

Cancer Unit at the WHO (Geneva) [30]. The aims were to implement specialty palliative care services for all cancer and non-cancer patients throughout Catalonia and to serve as a model for other regions. An evaluation of the programme in 2005 indicated that palliative care services cover 95% of the population (bearing in mind that healthcare is completely free in Catalonia) and this increase in palliative care provision has led to an increase in the number of patients dying at home and a decrease in the use of emergency services and average length of stay in hospitals. This report also calculated that the savings realized for each cancer patient admitted to these specialized palliative care services was an average of 2250 Euros per visit [30].

The use of hospice care by Medicade (a form of health insurance administered by the federal government) patients in the USA has been well documented [31, 32]. In Florida it was found that of non-hospice users, 66% die in hospital, while 55% of hospice users died at home. This supports the argument that intermediate care facilities alleviates strain on hospitals and helps patients transition smoothly back into the home environment [31]. In a preliminary report of a pilot program for community-based paediatric palliative care which includes therapy, a nurse hotline, medical treatment and advice and respite care, a clear reduction in costs was observed. A 32% reduction in the average number of inpatient days per person per month enrolled in the program was observed, which translates into a 35% reduction in inpatient hospital costs per patient. In addition, average medical costs per enrolee were reduced by 11%; while an increase in pharmaceutical costs and outpatient costs was noted in patients enrolled in the programme, these costs are still far lower than inpatient hospital costs. The study consisted of 123 children aged 1-20, all suffering with life-threatening illnesses and the costs included were inpatients costs, outpatient costs and pharmacy costs. While the results of the study are promising, they should be interpreted with caution as this was merely a policy brief analysing the intervention and details of how the costing exercise was performed were not given [33].

With patients in the Intensive Care Unit (ICU) having the highest cost per bed per day in tertiary hospitals, it is of value to note the cost saving effect which intermediate care facilities can provide in relation to the utilization of the ICU, especially given the documented difficulty in providing this form of expensive medical care in under-resourced settings [34]. In the USA it has been shown that when a patient is admitted to a palliative care centre following ICU, there is a saving of USD 2000 per day, however this should be interpreted with caution because the study is from a private healthcare provider’s perspective, meaning that due to the extremely high cost of healthcare in the USA, this value is probably largely inflated compared to what it would be in other countries [35]. Furthermore, the use of a hospital-based palliative care consultant team (PCCT) has been linked to a decrease in the admittance of patients to the

ICU and if they were admitted they had significantly shorter stays than their counterparts who had not received care from the PCCT; in addition, total direct costs were significantly less for PCCT patients than non-PCCT patients [36]. Studies like these raise some other important issues, such as the transfer of patients out of ICU, which frees up beds in the ICU, an outcome which is desirable in a public health setting where resources are limited. Based on a review of the literature in the USA the authors concluded that there were fewer hospital admissions, fewer ICU admissions and lower costs when there was a palliative care programme in operation [35].

An aspect of providing intermediate care for children which can often be overlooked is the economic cost of having a carer for these children if they remain at home instead of in a healthcare facility. For example a study of sick children demonstrated that there are economic gains if parents/caregivers are supported in the home so that they can continue working. While the study is not recent, it shows that if a parent has to care for a child at home, it is costly in terms of lost wages and if they get a professional carer to give care at home it is even costlier. While the study only included ill children generally and not those with life-limiting or life-threatening conditions specifically, it is a good indication of the economic losses which parents incur as the result of having a chronically ill child [37]. This study highlights the high cost associated with caring for a sick child at home and while basic palliative care in patients' homes by community health workers in outreach teams may be a cheaper solution than hospice care , the patient's homes are often not suitable for this [8, 38–40]. Furthermore, their guardians cannot afford to stay at home to look after them or hire a caregiver to perform this task [37]. Additionally it is important to note that in cerebral palsy sufferers (one of the most common conditions treated at step down facilities in the Western Cape) the majority of deaths are due to respiratory issues; therefore if these issues can be properly managed at a facility the mortality rate for these children would be lower. Furthermore by providing intermediate care we may be able to address the issue of better preparing parents to care for a child with cerebral palsy and therefore improve the quality of life for both caregivers and patients [41].

One of the few studies which looked at actual inpatient costs, aimed to analyse the difference between inpatient costs and the cost of paediatric palliative care of high-cost paediatric patients by following 10% of the most high cost paediatric patients, for 2 years. This paediatric palliative care team is interdisciplinary and consists of inpatient and outpatient follow ups. A significant difference in cost was seen between inpatient costs of paediatric palliative care recipients and non- paediatric palliative care recipients in patients closest to death [42]. Other studies conducted in the USA support this finding that hospice use actually saves money in the final days of life, while over the period of the last year of life, cost savings seem to be limited [43]. The issue of the average length of stay (ALOS) is therefore clearly important;

however there is a wide range for the ALOS of patients in intermediate care facilities. In light of this a number of studies have tried to address which ALOS is therefore the most cost saving. It is obvious that very long hospice stays result in greater costs, but Taylor *et al.* add that the final hospitalization prior to hospice admission is a huge cost driver, while shorter stays which immediately precede death are cost saving [43]. A costing study which supports the findings of Taylor *et al.*, found that in a paediatric ICU, non-survivors had longer length of stays compared to survivors and accounted for 3 times the mean variable daily expenditure compared to survivors. While this study claimed to be a costing study, the costs accounted for only included medical costs (such as personnel and diagnostic tests) and not overheads and food costs. However their findings are in support of what is generally accepted, that personnel costs are the greatest cost drivers, with these costs accounting for 62.4% of total costs [44].

A ten year retrospective study, which also weighed in on the debate of ALOS, used multivariate analyses to compare hospital resource utilization of 425 paediatric patients before and after enrolment in a paediatric palliative care programme. Cases were divided into cancer and non-cancer diagnoses, and ALOS, hospital admissions and total hospital charges for the group were analysed. A significant drop in ALOS of almost two weeks was observed in the pre- versus post-enrolment period, but this was more significant for non-cancer patients than for cancer patients. Non-cancer patients who received at least six months of paediatric palliative care showed a significant decrease in total billed charges, with an average decrease from pre- to post-program admission of nearly USD 275,000. Whilst the study has some shortcomings, such as no control group was included for patients who were not admitted to paediatric palliative care and the analysis did not include professional fees in the inpatient costs. As a result these costs are likely underestimated and highlight the complex nature of providing intermediate care to paediatric patients with different life-threatening diseases. It suggests that certain cases benefit more in terms of decreased costs, ALOS and hospital admissions to tertiary hospital care, than other cases [45].

The effects of ALOS on costs can be seen in an investigation of the cost of long stay patients (LSPs) in a pediatric ICU (PICU). The usage of these patients of PICU, found that LSPs account for only 4.5% of the population but 36.1% of PICU bed days were used for them alone. LSPs were defined as more than 12 consecutive days in PICU and the purpose of the paper was to develop an algorithm so that LSPs could be identified prospectively so as to minimize costs by improving management of these patients. Given that in this study intermediate care facility referrals were a risk factor for increased likelihood of admittance, these facilities could possibly aid in the management of these patients to decrease costs to secondary and tertiary hospitals. By providing support services such as counselling for the parents and the patient, these facilities could alleviate the financial burden on hospitals, thereby allowing for these facilities to be used for those with acute diseases [46].

One way to reduce ALOS is through home-based outreach services, as home visits can significantly reduce inpatient days and ALOS. Both in SA and internationally providing intermediate care through outreach services has been shown to reduce ALOS for patients [20, 45]. Despite indicating that home-based palliative care is cheaper than inpatient admissions, the authors highlight that in the South African setting, homes are often not suitable for this type of care due to overcrowding and poor infrastructure. However the authors also recognize that providing care for these patients outside of hospitals frees up beds for more critical cases and it is therefore worthwhile to provide care outside of district hospitals, whether through intermediate care facilities or home-based care. The costs per hospital outreach visit and in-hospital visits were USD 71 and USD 80, respectively, when using a step-down approach to cost the visits. The cost per outreach visit was 50% less than the average cost of a patient day equivalent for district hospitals of USD 142, when capital costs were excluded, indicating a significant saving when providing care outside of the hospital environment [20].

While the findings of the research conducted in the USA and other developed countries should be interpreted with caution when applying it to a South Africa setting, one thing which is common is the large portion of costs which are attributable to personnel costs. A costing study of generalized inpatient stays of 5 district hospitals, across 4 provinces, in 2002, in SA found that personnel costs were by far the greatest proportion of inpatient unit costs, ranging between 73-82% of total costs, more specifically paediatric wards had personnel costs of between 77-83% [47]. While this only accounted for inpatient unit costs, a study analysing different palliative care models in an urban area in South Africa cited personnel costs as accounting for 63% of the total cost of the programme [20]. The unit costs per inpatient day ranged between USD 38.04 and USD 103.68 in South Africa and this large range of costs is due to the wide variety of diseases being treated, which makes calculating an accurate cost difficult, as it is just a generalized cost per patient [44, 47]. However in the only costing study performed in SA, when the costs of just paediatric patients receiving palliative care was quantified, the cost per patient per day at a district hospital was slightly higher than USD 142 [20].

A study performed in the Western Cape, of an outpatient palliative care program (consisting of group clinics with families and patients and a multidisciplinary team) for adults with advanced organ failure, found the cost to be USD 130 per patient per bed day (direct and indirect costs). This is not substantially lower than the USD 142 inpatient costs in the study by Hongoro *et al.* but the mean admission costs for patients on the programme, compared to patients in the control group for the period of the study was R4977 lower, which is a substantial saving [20, 48]. However this was not a full economic costing and data was collected over a very short period of only 2.5 months but, due to the lack of costing studies in the field of intermediate care in the Western Cape, the results are useful. A substantial difference in inpatient days was observed between the intervention and the control group, where the intervention group had an average of 4.52 inpatient days, compared to 9.3 in the control group, which translates into the substantial savings in admission costs indicated above [48].

A review of paediatric cancer in LMIC highlights the need for improved access to care and specifically palliative care for children in LMICs to improve outcomes and possibly decrease childhood cancer mortality [1]. The findings of a study in the USA indicate that the out of pocket payment associated with hospital care for the families is substantially less in hospice care cases than if patients are treated at hospitals [29]. An interesting argument made by the authors is that saving children from childhood death is much more cost-effective as they still have their entire productive lives ahead of them to contribute to the growth of the economy [1]. It is also worthwhile to note that the issue of access is not one simply for LIMICs, but is also an issue in the USA, where it has been shown that out of over 1500 paediatric patients, only 11% had used hospice care in their final year of life. Furthermore, there was a significant difference in use of hospice care between white and non-white children (Hispanic and black), suggesting that minority groups are less likely to access hospice care, even with the same level of Medicaid coverage, possibly due to discrimination by care workers [31]. The issue of the cost of intermediate care being a barrier to access, has even been raised as a concern in the USA where it was demonstrated that if caregivers feel that children are covered (through the Medicaid health insurance scheme or through free services) they are more likely to seek care sooner, in an outpatient facility, before it escalates to inpatient stays which are more costly [49]. Therefore as SA embarks on expanding its intermediate care provision, it is important to understand the issues of access (financial barriers as well as the attitudes of staff at facilities) surrounding the use of this type of care [32].

The focus of intermediate care is a more holistic approach than that which is usually taken to treat acute cases of disease and a summary of the benefits of intermediate care can be seen in Table 2. Often when caring for children with life threatening and life limiting conditions, there is a need to value the outcomes qualitatively, in addition to the quantitative outcomes. One well investigated topic of qualitative outcomes in the literature is the effect of end-of-life (EOL) conversations on the outcomes for patients and their families [50–53]. EOL discussions refer to the health professional, usually the physician, disclosing the life-threatening nature of the patient’s illness to them. One such study conducted in the USA with adults diagnosed with terminal cancer, indicated that EOL discussions are associated with fewer aggressive interventions (which come at a high cost) in the final week of life. Conversely, these aggressive interventions are associated with a significant decrease in quality of life in the final week of life for the patient and poorer bereavement coping mechanisms for caregivers [51]. These EOL discussions are only given if health professionals are trained in palliative care and therefore this highlights the benefit of having a specialized team to deal with palliative care [51, 54]. Recent findings from SA indicate that patients as well as health care professionals themselves benefit from being adequately trained in palliative care and in having access to a palliative care team, as this decreases the emotional anxiety health care providers face when having EOL discussions [55]. In an attempt to address the issues surrounding this debate, a study using only adult participants in the USA, translated these EOL discussions into monetary value, using cost estimates based on national hospital averages and excluding outpatient costs. Their findings are in agreement with those of Wright *et al.*, that patients who had had EOL conversations were less likely to be admitted to hospital, had longer stays in hospice and reported less physical distress in the final week of life [50, 51]. Costs of care in those who had had EOL conversations, while not statistically significant, were 35.7% lower. Higher medical costs in the final week of life are also associated with a greater level of physical distress for the patient and from this it could be implied that they had more life sustaining measures taken, which increased the cost. It is important to note that despite this increase in hospital expenditure at the end of life, there was no difference in survival rates. The authors therefore conclude that improved communications between patients and doctors could lead to improved outcomes at the end of life, as well as cost savings because if more patients had EOL discussions, they would opt for less life-sustaining measures which in turn results in reduced costs at the end of life [50].

Table 2 Benefits of intermediate care for patients, care givers and providers

Benefits of intermediate care for patients	Benefits of intermediate care for care givers	Benefits of intermediate care for providers
Support for patients on long-tern chronic medication, such as ART, benefit from medical support to deal with often painful side-effects. [16, 17].	In cases where the diagnosis is terminal caregivers take comfort in the support team provided at intermediate care facilities [25].	A reduction in the number of inpatient days, ICU days and a decrease in ALOS for patients enrolled in an intermediate care programme results in cost saving for providers [33, 45].
Improved mental and emotional well-being for the patient [20, 7].	Improved mental and emotional well-being for the patient s family [20, 7].	A reduction in the number of inpatient days and ICU days for patients enrolled in an intermediate care programme results in free beds being available for those who need acute care [33, 45].
The well-documented positive effect of the effect of end-of-life conversations on the outcomes for patients and their families [50–53].	The provision of intermediate care allows caregivers to still have employment, thereby saving them from losing their wages [37, 56].	The cost of providing intermediate care at an intermediate care facility is assumed to be cheaper than providing it at a tertiary level hospital, mostly due to the staffing mix at each facility.
	Parents benefit by having more time with trained staff to learn how to care for the child with a life-limiting disease at home [41].	

The role of home-based care in intermediate care provision

In the late 1990’s there was a move towards home-based care (HBC) models in the USA, due to the literature at the time highlighting the disadvantages of institutionalized care and the advantages of HBC with a hospice philosophy. In high income countries home-based respite care as well as home-based palliative care are associated with reduced days of hospitalization and a reduction in negative mental and physical side effects for caregivers [57–59]. More specifically a pilot of a home-based palliative care service in the USA showed that children enrolled in the program had a nearly 50% reduction in average inpatient days per month, which translated into a cost saving of USD3331 per enrolee per month, when comparing mean costs before and after enrolment [59]. However, while the benefits of HBC have been clearly demonstrated, there are a number of practicalities to consider. For example, a pilot study in Canada of families with children requiring a ventilator highlights the need for support from trained professionals in order for HBC to be effective [60]. This need for caregivers and families to be properly trained in order to provide quality care at home has been supported by other studies in respite care centres and hospices [61, 62]. Many caregivers in the home stated that the regimens of care prescribed by different medical professionals were often conflicting and not practical in their home environment. Furthermore, there was no real emotional support when at home for parents and caregivers, who were constantly dealing with the ever present fear of death [60]. More specifically, a study conducted in a rural area of SA has shown that care givers often feel ill-equipped to deal with their patients effectively and feel there is a lack of guidance from hospital and clinic staff in the handover process at the time of discharge of the patient [63].

In order to address the issue of support for families caring for sick children at home, there have been a number of projects which send out nurses or physicians to the home at regular intervals to provide care [59]. However in under resourced settings this is not an option as health care facilities are already short staffed and, to have health care professionals go out into communities is not possible in many instances. In an attempt to address this issue there have been many home-based palliative care interventions using community health workers to provide very basic care in LMICs [8, 38–40]. However, in these settings many people needing specialized medical palliative care interventions do not live in homes suitable for home-based palliative care services due to overcrowding and poor infrastructure [20]. The provision of end of life care also places a huge strain on the informal caregivers and has been shown to decrease health-related quality of life years for these caregivers [20, 64]. Home-based care is a physical, emotional and financial burden on not only the caregivers but also on the other members of the family; with siblings perhaps feeling resentment with regards to the unequal distribution of resources to the child in-need , and adversely the child in-need feeling like a burden on the household [60].

The issue of cost to the family is another important concern to consider in LMICs, because it has been shown that those families able to financially support their child's needs were more stable than those who struggled to make ends meet. As caring for a child at home often requires one parent to give up employment to stay at home and look after their child, this HBC approach will often result in lost income in the form of lost wages [56]. Furthermore homes need to be modified to accommodate wheelchairs and other medical devices and these modifications also come at a cost and are not possible for many families in LMICs [60]. Even in the USA the view that there is increased financial burden on families of chronically ill children is supported. An assessment of over 500 children with malignant cancers indicated that all nonmedical costs as a result of illness are borne by the family and family out of pocket payments accounted for 50% of the total cost of disease-related care [56].

Economic evaluations of intermediate care

A review of economic evaluations performed for the treatment of cancer in children highlights just how sparse the data is for paediatric intermediate care; with the focus largely on acute lymphocytic leukaemia (ALL) and few other cancer variants, and all in a developed world setting with access to the newest therapies [65]. While calls are being made to increase research activity, to support evidence based policies in Africa, with a specific ask for costing research in palliative care in Africa, what is currently available is very limited. Reviews of the literature support the fact that more monitoring and evaluation is needed in palliative care to truly assess outcomes, quality of care and the benefits, in order to complete cost-effectiveness studies and provide care which is appropriate and acceptable to people on the African continent [66]. Therefore while we can gain some insight from these studies, these evaluations are out of context in South Africa and more work in LMICs in this area is needed. The greatest issue with conducting these evaluations is the difficulty experienced when measuring outcomes. As children present with a variety of symptoms and diseases which are treated through intermediate care, this makes the use of a generic tool to quantify outcomes difficult [67, 68]. As mentioned above, ALOS has an obvious impact on costs. In the US a study of 1252 children with life-threatening conditions who died in hospital in the last year of life show just how varied length of stay can be for children with life-threatening complex conditions, with total hospital costs in the last year of life costs ranging from USD 109 000– 504 000, depending on disease type [69]. In addition to the general difficulty of measuring health-related outcomes in children, it is even more difficult in paediatric intermediate care specifically as admittance to this care is voluntary which introduces a selection bias into the data. Furthermore in children with life-threatening and life-limiting diseases their health-related quality of life (HRQoL) is dependent on when in the progression of their disease they seek intermediate care, as the earlier they obtain this care the better their HRQoL will be. By 2010 only 130 studies had used HRQoL in children as different tools need to be tailored for each age category, making statistically significant sample sizes difficult [67]. While quality-adjusted life years (QALYs) are usually used as outcome measures in economic evaluations, this is difficult in the case of intermediate care as the outcome measure needs to be able to account for changes occurring in relatively short periods of time as, for example some patients stay for two weeks, while others stay for 2 months [67, 70]. It is necessary therefore to evaluate service packages as opposed to individual services as these are difficult to standardize across patients with differing palliative care needs and with different diseases [67]. Due to the complexity of the care provided and outcomes achieved as a result of intermediate care a different outcomes tool has been suggested. This alternative tool, the Palliative Care Yardstick (PalY), would use the basic framework of a QALY and then would have added in measurements which are not sufficiently covered by a QALY [68].

Given that it is established that the treatment of childhood cancers is very different to that of adulthood cancer and approaches to it from a health systems' perspective need to be different, the lack of data for paediatric care is a cause for concern. One of the few studies to even address this issue in LMICs is for ALL and Burkitt's Lymphoma in Brazil and Malawi. These diseases were chosen because of the substantial health gains possible if treated and due to their large contribution to the burden of disease in these countries. In order to address the assumption that treating childhood cancers is not cost-effective in LMICs, disability-adjusted life years (DALYs) and the WHO-CHOICE CEA framework (cost required to avert 1 DALY), were used to quantify the outcomes. The authors found that the greatest gains in DALYs averted are due to a decrease in years of life lost (YLL), however only one study from each country was used and only the per incident fixed costs were accounted for and not the variable costs. They concluded that it is cost effective to treat childhood cancers in LMICs based on threshold analysis, but ultimately this threshold is arbitrary and is not always relevant in settings with very few resources [71, 72].

The role of economic evaluations in public health

The study of economics is derived from the fact that there are a finite number of resources, i.e. that resources are scarce and therefore how to allocate and make use of these resources is of utmost importance. In health systems the role of economic evaluations has become more and more appreciated in recent years, as scarce resources are needed by a growing population. Issues such as how best to allocate staff to various departments or what course of treatment for a specific disease is best, can be addressed through proper economic evaluations (Creese & Parker 1994; Drummond 2005). According to Drummond *et al.* "economic evaluations can be defined as the comparative analysis of alternative courses of action in terms of both their costs and consequences" (Drummond 2005a, p.9). Two important questions need to be answered before proceeding with an economic evaluation; namely are two outcomes being compared and secondly, are both inputs (costs) and outputs (consequences) being considered. It is important to note that the choice between doing something and doing nothing is still a choice between two alternatives. The current study being performed here is therefore only a partial economic evaluation as consequences have not been considered; it is the hope of the author that this initial study will therefore form the basis for a more complete economic evaluation at a later stage, as costing analysis is the basis and starting point of any cost effectiveness analysis (Drummond 2005).

Table 3 Explanations for the four different economic evaluations

Type of Study	Measurement of costs	Identification of consequences	Measurement/valuation of consequences

Cost analysis	Monetary units	None	None
Cost-effectiveness analysis	Monetary units	Single effect of interest, common to both alternatives, but achieved to different degrees.	Natural units (e.g. life-years gained, disability-days saved etc).
Cost-utility analysis	Monetary units	Single or multiple effects, not necessarily common to both alternatives.	Healthy years (most commonly measured as quality-adjusted life-years).
Cost-benefit analysis	Monetary units	Single or multiple effects, not necessarily common to both alternatives.	Monetary units

Source Drummond *et al.*- [76]

In order to give context to this type of study, a brief explanation of the various costing study approaches is necessary as the terms cost comparison, cost-effectiveness and cost-benefit analysis are often used interchangeably when referring to economic evaluations, however the methodologies employed in each of these studies is different. In order to understand how economic evaluations add value to decision making in health systems, it is important to understand the various forms of evaluation and how they differ. The four main types of costing studies are cost-effectiveness analysis (CEA), cost-benefit analyses (CBA) and cost-utility analysis (CUA) and these approaches are summarized in Table 3.

For the purposes of this study the cost comparison methodology will be employed due to time constraints and the difficulty in the measurement of end of life care outcomes, as highlighted previously [68].

Costing for economic evaluations

Costing as part of an economic evaluation refers to more than just financial costs, which would simply be the monetary value of goods and services which have been purchased [77]. When performing economic evaluations we are interested in the economic costs of these items and more specifically the opportunity costs associated with them, which accounts for the cost of having forgone the alternative in order to purchase this good or service. Economic costs differ from financial costs in that they take into account the costs of donated items and services and that they account for the preference of individuals to make use of a good or service now rather than later. Additionally, economic costs account for the cost of an item when the financial cost does not reflect the cost of using the item productively elsewhere [73]. It is crucial to think of costs in the true economic sense and not merely in the financial sense as mentioned previously. Many items not holding a budget line need to be considered to do a robust cost analysis, for example a volunteer nurse at an organization does not hold a place on a budget line but the opportunity cost of her time needs to be considered for an economic evaluation because were she not there this service would have had to have been paid for [78].

Any intervention has two types of costs, namely direct and indirect costs [78]. Overhead costs fall into the category of indirect costs and need to be evaluated in the context of utilization of these overhead costs by the specific intervention being costed. Economic costs can further be broken down into fixed (these are input costs which are fixed and do not vary with the scale of outputs) and variable costs (these are input costs which change, as the scale of outputs varies), and capital and recurrent costs and each of these has to be dealt with differently in the evaluation (M. Drummond et al. 2005). Capital costs refer to costs which last for longer than one year and have a monetary value of greater than USD 100, while recurrent costs refer to costs associated with goods or services whose use lasts for less than a year [73]. Total costs are then comprised of both recurrent and capital, and fixed and variable costs, and these types of costs can further be broken down into direct, indirect and intangible costs.

Discounting and annuitization

Goods which fall into the capital costs category are often purchased once off and therefore the equivalent economic cost of this item needs to be accounted for appropriately for all the years for which it is used. It is not enough to simply use the replacement value of the item as the cost, as there is depreciation of the asset over time and by having spent the money on this item in a particular year, we have foregone having invested that money and gaining interest on our investment. By using the practice of discounting, researchers are able to account for an individual's time preference for purchasing goods later, but wanting to reap the benefits now. While through the use of annuitization researchers are able to assign an economic cost to a capital item for a given year, by taking into account its depreciation over time and the lost interest from the investment foregone in order to purchase this item [79]. What rate should be used for discounting has always been a contentious issue, however the recommendation which is generally accepted is 3-5%, as long as attention is paid to the standard rate previously used in the particular field being studied [76]. In this case , very few costing studies have been performed in the area of paediatric intermediate care and thus the international standard of a discounting rate of 3% and an annuitization period of 10 years have been chosen (Gold et al. 1996; M. Drummond et al. 2005; Walker & Kumaranayake 2002).

Costing approaches

For the purposes of this study we will considering direct costs, as well as indirect costs in the form of overhead costs, as this is most appropriate when undertaking a cost comparison study from a provider perspective. The provider perspective has been chosen, as the aim of the study is to indicate that intermediate care facilities provide the same level of care as tertiary hospitals for the purpose of paediatric intermediate care, but at a lower cost. The study will therefore only need to account for direct costs and not mortality, morbidity or other intangible costs associated with the patient and society at large. In addition to selecting a costing perspective and defining the research question which the study needs to answer, the outputs of the study (e.g. costs per inpatient day) also need to be defined. The calculation costs for a specific programme or treatment option can be employed through one of two approaches: ingredients-based or step-down costing. Ingredients based costing refers to simply taking each item used in the specific programme and multiplying the unit costs by the quantity used, while step-down costing is usually utilized for overhead costs, where there is a bulk payment made, and the proportion of that good or service (used by a particular programme) needs to be calculated. Overhead costs refer to all costs which are shared by different programmes and departments and, as a result, their contribution to the running costs of a specific programme or department need to be accounted for [76].

Conclusion

While there is an abundance of literature on the benefits of palliative care generally, the area of paediatric palliative care has received far less attention. Delays in the recognition of paediatric palliative care as a type of care which is distinct from adult palliative care, has resulted in far less research having been conducted in the field, even in places like the USA. Furthermore, if we are to look at intermediate care as a whole, literature on sub-acute care in children is extremely sparse, with no true economic evaluations having been conducted in the field. Economic evaluations of intermediate care generally are in their infancy in the field, which is not surprising given the many gaps in the literature. Economic evaluations for intermediate care are made more complex by the difficulty associated with measuring health-related benefits and quality of life for children receiving intermediate care, who are a very heterogeneous group [67–69]. As cost comparison studies are the basis of all economic evaluations, more of these studies are required in varying contexts, as a basis for very necessary cost-effectiveness and cost-benefit analyses the field of intermediate care.

In a country where 44% of health care expenditure supports only 16% of the population, economic evaluations are a critical part of ensuring that the remaining 56% of health care expenditure is used efficiently and effectively to serve the majority of the population [80]. With specific reference to intermediate care, the majority of this care is currently provided by hospices, with most of these services still being provided by NGOs, as stated previously [18]. This reliance on donor funding is not sustainable in South Africa and is far from ideal. This fact has become a very real problem recently with the *President's Emergency Plan for AIDS Relief* (PEPFAR) withdrawing its direct support of various HIV/AIDS programmes across South Africa [81]. As a direct result of PEPFAR slowly decreasing its donor funding to SA the Hospice Palliative Care Association of South Africa claimed in early 2013 that they were being forced to retrench staff and decrease the number of patients they could admit to hospice care across the country, due to insufficient funds [82]. It is therefore far more sustainable to have intermediate care provided in the public sector by the government, rather than NGOs and this also allows for more standardization of the quality of care across institutions, if they are all funded by the ministry of health. It is within this context that the Western Cape government released the policy framework for intermediate care and within which the funding for the palliative care wing at the Sarah Fox Convalescent Home must be found [6]. In light of this new policy, facilities which are already in existence should be strengthened and supported. In South Africa we are at an advantage compared to the rest of the continent in that we do have some knowledge and expertise in the field of palliative care, which can be built on for the purpose of providing intermediate care [12]. If SA is to survive the shift in funding which is currently occurring, the country is going to have to provide intermediate care through its public health systems and in order to do this efficiently, costing studies in the field will be central to this process. It is for this reason that this current study is being undertaken, so that by quantifying the cost of care in a tertiary hospital and comparing it to the cost of care in an intermediate facility, policy makers will have the tools necessary to support and build on existing infrastructure already in place. The benefits of and need for intermediate care have been well established and this cost comparison study is the first step towards conducting the necessary economic evaluations of this type of care in a South African setting.

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PART C: Journal Article

A cost comparison analysis of paediatric intermediate care in a tertiary hospital and an intermediate, step-down facility in the Western Cape, South Africa

Abstract

Background: According to the National Cancer Registry of South Africa 600-700 new cases of paediatric cancers have been reported every year for the past 25 years. While in the year 2000 HIV/AIDS was responsible for 42 479 deaths in children under five. However support for and research in general for the paediatric intermediate care (encompasses palliative, sub-acute and respite care) needed by these children remains sparse. . However support for and research in general for paediatric intermediate care (encompasses palliative, sub-acute and respite care) remains sparse. Costing studies are even rarer, with the few studies conducted in South Africa reporting a broad range of average costs per inpatient day.

Methods: A retrospective cost analysis for the period April 2014-March 2015 was undertaken from the provider perspective in the public sector. Costs of paediatric intermediate care were estimated for an intermediate care facility (where the majority of disease burden is for HIV/AIDS, TB and cancer) and a tertiary hospital in Cape Town, South Africa. A step down costing approach was employed, and the costs were inflated to 2016 values and expressed in Rand and USD using an exchange rate of 1 USD = R14.87.

Results Cost per inpatient day was USD 713.09 at the hospital and USD 695.17 at the step-down facility. The cost for a paediatric patient who is HIV/TB co-infected was USD 7130.94 and USD 6951.67 at the hospital and step-down facility respectively, assuming an average length of stay (ALOS) of 10 days. For a patient who has a terminal brain carcinoma the cost was USD 19966.63 and USD 19464.69 at the hospital and step-down facility respectively, assuming an ALOS of 28 days. Personnel costs accounted for 60% of the total cost at the hospital, compared to only 17% of the total costs at the step-down facility. Overhead costs accounted for 12.33% at the step-down facility, almost 3 times that of the hospital (4.48%).

Conclusions The study highlights that the drivers of cost are not uniform across settings. Providing intermediate care at a step-down facility can be more cost-saving than providing this care at a hospital, there are however areas in which more savings could be realized. The costs presented in this study were considerably higher than those found in other studies, however, the paucity of cost data available in the area of paediatric intermediate care makes comparisons difficult.

Keywords

Paediatric, cost comparison, intermediate care, palliative

Background

In 2000 HIV/AIDS was responsible for 42 479 deaths in children under five and in areas such as the Western Cape, this burden of diseas is compounded by tuberculosis (TB) [1, 2]. Additionally, according to the National Cancer Registry of South Africa 600-700 new cases of paediatric cancers have been reported every year for the past 25 years and this is likely an underestimation due to poor reporting [3, 4]. In light of these figures and given that the high burden of HIV/TB often results in a crowding out effect of other diseases in acute hospitals, the need for facilities which care for children with these and other life-limiting and life-threatening diseases is clear [5].

A point prevalence study conducted in the Western Cape in 2009 aimed to identify the need for intermediate care (encompasses palliative, sub-acute and respite care) for different disease types and indicated that 20% of patients who had exceeded the expected length of stay at tertiary hospitals should have been discharged to an intermediate facility [6]. Prompted by these findings the Western Cape government released a document in 2012, detailing a policy on intermediate care [6]. However to date no cost analysis studies have been performed in SA to facilitate the budget planning required for this type of care.

Intermediate care can be provided via a home-based care (HBC) system or be based at facilities, preferably situated in the communities which need it. Given that HBC is not a feasible option for many households in the Western Cape due to overcrowding and poor infrastructure in homes, there is a need for facility based care [7, 8]. In the Western Cape, which has a population of 6,2 million, there are only nine institutions that provide intermediate facility-based care for adults and only two which provide this care for children [9]. Both of these facilities serve communities which are severely impoverished and provide palliative, respite and sub-acute care for patients suffering from HIV/AIDS, TB, malnutrition, cerebral palsy and cancer.

A 2014 WHO report indicates that African region accounts for almost half of the global need for palliative care , however access to this care for children in low- and middle income countries (LMICs) remains scarce and there is a paucity of research on cost estimates for paediatric intermediate care [4, 10, 11]. In one of the few costing studies conducted in SA, personnel costs were shown to account for the greatest proportion of inpatient unit costs at a district hospital, accounting for between 73-82% of total costs, and more specifically paediatric wards had personnel costs accounting for between 77-83% [12]. The generalized unit costs per inpatient day at a hospital ranged between USD 38.04 and USD 103.68 and this large range of costs is due to the wide variety of diseases being treated, which makes calculating an accurate cost difficult [13, 12]. An analysis of a programme combining outreach services and in-hospital stays for providing intermediate care in Gauteng found that personnel costs accounted for 63% of the total cost of the programme [7]. Interestingly, in-hospital intermediate care had a cost of USD 142.00 per inpatient day, which is more than the previous study's estimate of USD 103.68 and possibly indicates that intermediate care is only cheaper if provided outside of a hospital setting [6].

This broad range of per inpatient day costs indicates the need for costing studies in the context in which the intermediate care facilities are to be built, which will facilitate the budget allocation for these facilities. This study aims to estimate and compare the cost of providing the standard of care to children with life-limiting or life-threatening illnesses in a tertiary hospital and compare it to the cost of providing the standard of care to children with life-limiting or life-threatening illnesses in a step-down facility.

Methods

Study setting

A cost comparison study, undertaken from the provider perspective in the public sector, was performed using a step down costing approach. Two models which are located in Cape Town were selected for comparison - a tertiary children's hospital and an intermediate step-down facility. The tertiary hospital is a public tertiary level hospital, and the only specialist children's hospital in Southern Africa. The intermediate facility has been providing sub-acute care and respite care to paediatric patients since 1965. A 10 bed paediatric palliative care unit has been in operation since 2013. The home is a non-profit facility and receives some money from the district department of health, with a large reliance on private donors. The home can accommodate 62 patients in total, with two beds in the palliative care wing for parents. The majority of patients at this intermediate care facility suffer with HIV/AIDS, TB and cancer.

Data collection

The cost data were retrospectively collected for the period April 2014- March 2015. The period of one year has been chosen to account for any seasonal variations which might occur, and to account for the long average length of stay of patients in intermediate care facilities.

Data analysis

Costing was calculated as per the details given in table 4 and the total costs divided by the unit cost, namely inpatient days for the total year. All costs were apportioned based on number of inpatient days at both facilities, due to the fact that intermediate care patients suffer with a range of illnesses and as such are spread out across the tertiary hospital. Cost categories include: capital (equipment, computer, furniture; building costs and staff training and) and, recurrent (personnel; consumables; transport; laboratory costs; medical supplies and building operating & maintenance). Drug costs were not included in this study. In accordance with the intermediate care policy, any patients admitted to a step-down facility have to be supplied with the drugs they require from the hospital and as such the costs for drugs will be covered by the hospital, regardless of whether the patient is at the step-down facility or the hospital [6]. The step-down facility receives donations of disposable diapers and food, which were valued according to their replacement value and included in the total costs appropriately.

The cost per inpatient day for each facility was estimated, and then inflated to the 2016 values using an average annual inflation rate of 6.1% [14]. The costs per inpatient day were compared between the two facilities and all costs are presented in both South African Rand and US dollars (the average exchange rate for 2016 of USD 1 = R14.87 was applied).

Utilization & Annuitization

Utilization rates at both facilities were comparable at approximately 83%. The inpatient days for the step down facility were calculated using the monthly bed occupancy rate provided by the facility for the period of 1 April 2014- 31 March 2015. The number of inpatient days at the hospital for this same period were provided by the hospital’s financial management unit.

To allow for the differential timing of capital costs (i.e. building, vehicle and equipment costs) these costs were annuitized using a discounting rate of 3% in accordance with international standards[15].

Table 4 Intermediate care costs included in a cost comparison analysis of a hospital and a step-down facility in Cape Town, South Africa

Type of cost	Categories	Costing method	Valuation method
Recurrent costs			
Personnel	Clinical staff (doctors, nurses, physiotherapists), and support staff (cleaning, cooking) and administration and management.	Percentage of time spent at each facility.	Total remuneration package costs, including professional membership fees and resettlement expenditure.
Medical supplies	Includes items such as syringes, bandages and other wound dressing materials.	Actual quantity consumed.	For the hospital the costs are based on provincial government tender prices. For the step-down facility costs are based on market price of these items from the respective supplier.
Laboratory costs	Diagnostic tests conducted.	Actual number of tests conducted.	Costs were obtained from the financial records at both facilities.
Consumables	Includes the costs of food, cleaning products, baby formula and disposable nappies.	Actual quantity consumed.	Costs were obtained from the financial records at both facilities.
Transport	Transport running costs- fuel and shuttle service fees.	Number of kilometres travelled.	At the hospital fuels costs and vehicle maintenance costs were obtained from financial records. At the step-down facility costs are based on invoices from the shuttle service provider.
Building operating & maintenance	Water, electricity and contracted services.	Actual quantity attributable to each facility.	Costs were obtained from the financial records at both facilities.
Capitals costs			
Building costs	The facility structures and all attached offices.	The building cost per m^2 was set at R40000, which includes inside finishes, and this value was supplied as a standard by the provincial department of health.	The area of the step-down facility was calculated using Google Earth Pro [16]. The area for the hospital was supplied by the facility.
Equipment	Medical and non-medical		The current useful life span of each asset was

	equipment, furniture, staff uniforms and linen		determined and the current replacement value of the asset calculated.
Training	Expenditure on training of staff at each facility.	Actual expenditure on staff training, at each facility.	Costs were obtained from the financial records at both facilities.

Average length of stay for proxy cases

Due to the wide array of diseases requiring intermediate care, two diseases were used as proxies for the average length of stay, namely patients with HIV/AIDS with a co-infection of tuberculosis (TB) and patients with terminal brain carcinoma. These are the most common diseases being treated at SFCH, and are among the top four diseases requiring intermediate care, according to the Western Cape Department of Health [6, 13, 12]. The only value that RCMWCH could provide was a general ALOS for the entire hospital, which was 3.9 days for the period of analysis. At SFCH the length of stay for patients with HIV/TB co-infection ranged from 6-644 days and for terminal brain carcinoma the length of stay ranged from 407-604. Given this extremely varied length of stay the ALOS was determined using what was available in the literature. International literature indicates an ALOS of 8- 11 inpatient days for children receiving care for HIV-related admissions, with a South African study finding a mean of 12.7 inpatient days [17–19]. Therefore an ALOS of 10 days will be used for the proxy case of a child who is HIV positive and co-infected with TB. Only one study has been published on the ALOS for terminal brain carcinoma in children, indicating an ALOS was 28.9 days [20]. Given this, a period of 28 days will be used for the proxy case of a child who has a terminal brain carcinoma.

Sensitivity analysis

A one way sensitivity analysis was performed, testing one parameter at a time. The first parameter tested was the ALOS due to the diversity of ALOS in the literature. The lowest ALOS was 3.9 days (general ALOS at the hospital according to records), while the highest was 498 days, as determined through a review of patient files at the step-down facility. Thus for scenario one the lower bound value of 3.9 days and the upper bound value of 498 days was used for ALOS. The second parameter tested was the discount rate. A discount rate of 6% was used to test the assumption of using a discount rate of 3%.

Ethics

Ethical approval for this study was obtained from the University of Cape Town's Human Research Ethics Committee (HREC REF 249/2015). In addition, institutional approval was obtained from the Board of Trustees at the step-down facility and from the manager of medical services at the hospital.

Results

Per inpatient day costs

Cost per inpatient day was USD 713.09 at the hospital and USD 695.17 at the step-down facility. The difference in the cost per inpatient day between these two facilities was minimal at USD 17.93 (Table 5). The cost for a paediatric patient who is HIV/TB co-infected was USD 7,130.94 and USD 6,951.67 at the hospital and step-down facility respectively, assuming an average length of stay

(ALOS) of 10 days. For a patient who has a terminal brain carcinoma the cost was USD 19,966.63 and USD 19,464.69 at the hospital and step-down facility, respectively, assuming an ALOS of 28 days.

Table 5 Summary of unit costs for the hospital and step-down facility

	Tertiary hospital			Step-down facility		
Type of cost	**Cost per inpatient day (ZAR)**	**Cost per inpatient day (USD)**	**Percentage of total cost**	**Cost per inpatient day (ZAR)**	**Cost per inpatient day (USD)**	**Percentage of total cost**
Capital costs	**2,103.52**	**141.46**	**19.8%**	**6,174.88**	**415.26**	**59.7%**
Equipment, computer, furniture	498.042	33.49	4.7%	476.06	32.01	4.6%
Building costs	1,598.54	107.50	15.1%	5,543.15	372.77	53.6%
Staff Training	6.94	0.47	0.1%	155.67	10.47	1.5%
Recurrent costs	**8,500.19**	**571.63**	**80.2%**	**4,162.61**	**279.93**	**40.3%**
Personnel	6,309.84	424.33	59.5%	1,615.50	108.64	15.6%
Consumables	652.67	43.89	6.2%	681.85	45.85	6.6%
Transport	0.94	0.06	0.0%	342.87	23.06	3.3%
Laboratory costs	318.11	21.39	3.0%	4.96	0.34	0.0%
Medical supplies	569.36	38.29	5.4%	6.43	0.43	0.1%
Building operating & maintenance	649.26	43.66	6.1%	1,510.99	101.61	14.6%
TOTAL	**10,603.71**	**713.09**		**10,337.48**	**695.19**	

Largest cost drivers of overall cost

Analysis of each of the cost types highlights the different cost drivers at the two facilities. At the hospital, recurrent costs account for around 80% of total costs, while at the step-down facility capital costs are the biggest cost drivers, accounting for nearly 60% of total costs (Table 5). A detailed analysis of capital costs indicates that equipment costs accounts for nearly a quarter of the total capital costs at the hospital, compared to the step-down facility, where less than a tenth of the capital cost is attributable to equipment (Figure 2). For both facilities building costs account for the largest proportion of capital costs, 76% and 90% at the hospital and the step-down facility respectively (Figure 2).

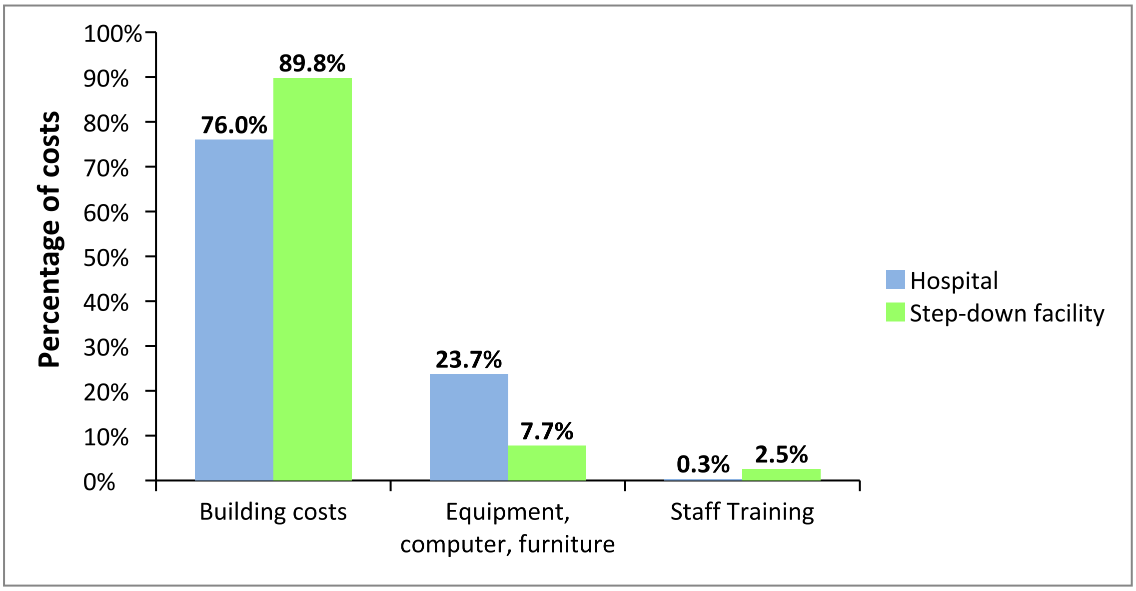


Figure 2 Breakdown of capital costs for the hospital and step-down facility

Personnel costs are the largest contributors to recurrent costs at both facilities, accounting for nearly 75% of all recurrent costs at the hospital, compared to only 39% at the step-down facility (Figure 3). Building operating and maintenance costs are also a large contributor at the step-down facility (36.3%), but are only a marginal fraction of recurrent costs at the hospital (7.6%) (Figure 3).

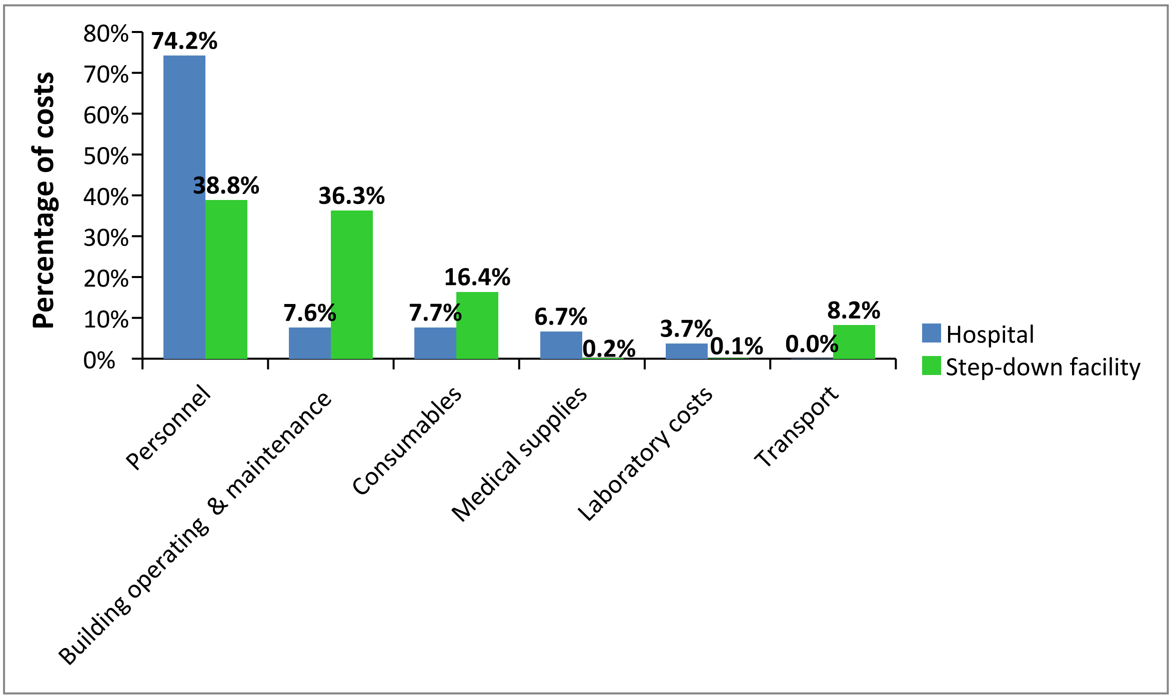
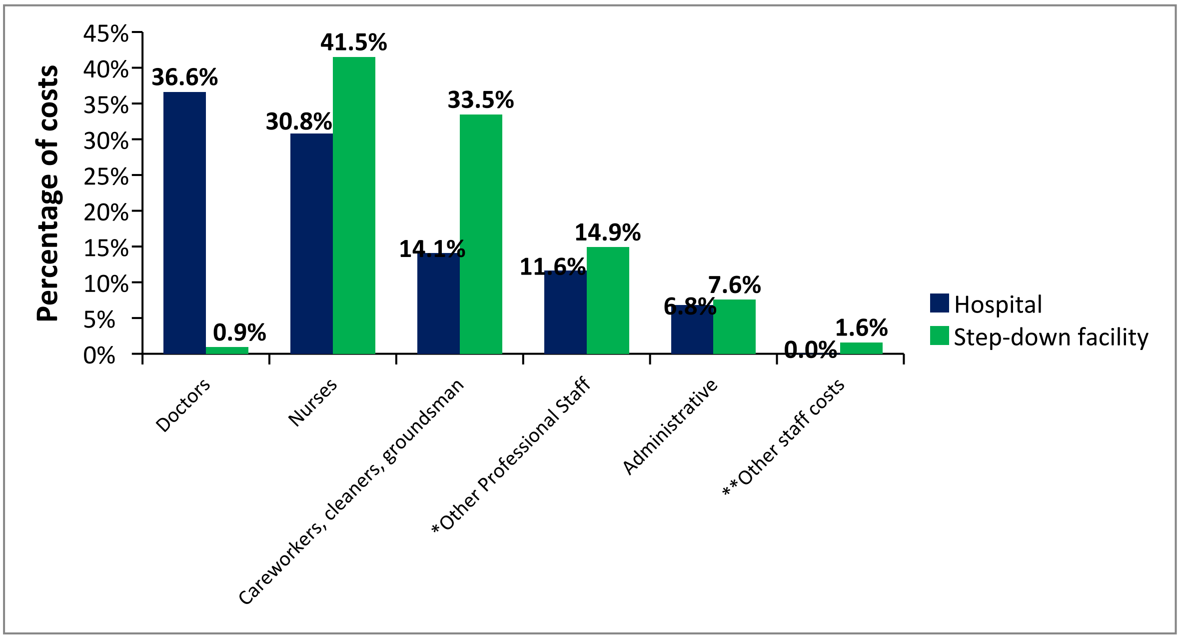


Figure 3 Breakdown of recurrent costs for the hospital and step-down facility

Given the large contribution of personnel costs to the total recurrent costs, a more in-depth analysis is necessary. Administrative staff, nurses and other professional staff (dieticians, physiotherapists and laboratory technicians) have comparable contributions to the total personnel costs at each facility. Noticeable differences can be seen for doctors, who contribute 37% of personnel costs at the hospital compared to only 1% at the step-down facility (Figure 4).



**Other Professional staff includes dieticians, physiotherapists and laboratory technicians **Other staff costs include labour settlement, resettlement fees and membership fees*

Figure 4 In-depth analysis of personnel costs for the hospital and step-down facility

Sensitivity analysis

Under all of the scenarios the original outcome that per inpatient day costs at the step-down facility are cheaper than at the hospital, holds true (Table 6). Under the first scenario, the lower bound ALOS of 3.9 days results in a saving of USD 4,240.51 and USD 4,349.87 per inpatient day at the step-down facility and hospital respectively. While the upper bound ALOS of 498 days results in an increase in unit cost of USD 326,728.68 and USD 335,154.17 at the step-down facility and hospital respectively. A discount rate of 6% instead of 3% results in the unit cost being USD 71.70 higher at the hospital than the step-down facility; a difference which is 4 times greater than that calculated in the baseline scenario.

Table 6 Effect on unit cost by differing assumptions of the baseline case

		Step-down facility		Tertiary hospital	
Baseline		Unit cost (ZAR)	Unit cost (USD)	Unit cost (ZAR)	Unit cost (USD)
	Total per inpatient day cost	10,337.14	695.17	10,603.71	713.09
	Cost for TB/HIV co-infected patient	103,371.39	6,951.67	106,037.08	7,130.94
	Cost for terminal brain carcinoma patient	289,439.90	19,464.69	296,903.81	19,966.63
Scenario 1	Total per inpatient day cost	10,337.14	695.17	10,603.71	713.09
	Cost for ALOS of 3.9 days	40,314.84	2,711.16	41,354.46	2,781.07
	Cost for ALOS of 498 days	5,147,895.44	346,193.37	5,280,646.34	355,120.80
Scenario 2	Total per inpatient day cost	19,400.02	1,304.64	20,732.72	1,394.26
	Cost for TB/HIV co-infected patient	194,000.24	13,046.42	207,327.20	13,942.65
	Cost for terminal brain carcinoma patient	543,200.66	36,529.97	580,516.16	39,039.41

Discussion

The total costs identified in this study are considerably higher than the costs in other South African hospital costing analyses. Previous studies in district hospitals put the cost per inpatient day between USD 37.23 and USD 212.09, for various programmes within a district hospital setting [7, 12]. The unit cost here is therefore almost four times the highest inpatient costs cited in hospitals in SA previously, however the hospital investigated here is a tertiary hospital, not a district hospital, but no studies of tertiary paediatric hospitals have been conducted in SA [7, 12]. Another possible explanation for this discrepancy could be that the broad scope of the current study which is to assess care provided to patients with a range of diseases, whilst previous studies have focussed on only one department or programme, and not an entire facility. The proportion of costs attributed to the various cost centres within a hospital setting is in line with previous literature, where in district hospitals in SA personnel costs were found to account for between 63% - 82% of the total costs [7, 12]. It is difficult to make comparisons with the findings here for intermediate care facilities, as no such studies have been done in SA or LMICs previously. However overhead costs are a large driver of cost at the step-down facility, which is contrary to what would be expected, given that this facility is far smaller than the hospital. This finding highlights the need for further investigation into these costs and possible ways in which they could be reduced. If the step-down facility had been fully funded by the Western Cape Department of Health for 2016, the cost would have been 0.02% of the total budget for the province [21]. Given that this is a large percentage of the total provincial budget for a 62 bed facility, more detailed economic evaluations are needed to determine whether this type of care in its current format is cost-effective.

It should be noted that since conclusion of this research the palliative care wing at the step-down facility was shut down due to a lack of funding and the patients who were in the wing were integrated into the general ward until an alternative arrangement could be made. It is therefore clear that the issue of providing intermediate care is a complex one, compounded by the fact that this type of care is provided across a range of diseases. For this reason it is imperative that more research in this area is conducted in order to equip policy makers with the necessary evidence base with which to implement policies effectively. Despite the fact that the findings of this study indicate that cost of care at a step-down facility is not significantly cheaper than at a hospital, the benefit which families obtain from being supported by health care providers who are trained in palliative, sub-acute and respite care specifically is clear from the literature [22–26].

Prior to the commencement of the study it was clear that facility management assumed that step-down facilities are cheaper largely due to the fact that they are staffed by nurses, while doctors only work on a part-time basis. The findings here indicate that personnel costs are indeed far lower in these facilities than in a tertiary hospital, with doctors accounting for a very small amount of personnel costs overall at the step-down facility. Another area which is cost-saving is evident upon closer analysis of capital costs. Equipment costs at the hospital account for just under a quarter of the total capital costs, compared to only 7% at the step-down facility. It is therefore clear that in certain cost categories the step-down facility is the cost-saving option. However, policies should give guidance on possible ways to reduce overhead costs as these were found to be a large driver of costs at the step-down facility, and these costs should be minimized if these facilities are to become truly cost-saving. Given that the building costs both in terms of capital cost and recurrent costs (in the form of maintenance) are large cost drivers, it may be cost-saving if the step-down facility was located on hospital property. This is one way in which the cost-savings seen in personnel and equipment costs could be maximized.

Lastly, while the current study illustrates the high cost of care from a provider perspective for children with life-threatening and life-limiting diseases, it did not include costs from the patient's perspective. While it is probable that some cost-sharing does occur even in the public sector, given that the population served by the step-down facility has a relatively low socio-economic status, it is reasonable to omit the patient's perspective for this current study. However future work should address this issue. Nonetheless other research suggests that these costs, which include transport costs and lost wages, are high and future research should aim to quantify these costs in LMICs [27]. Given the challenges with assessing the quality of care and outcomes associated with care at the two facilities under comparison here, it is clear that a more in-depth, full cost-effectiveness assessment of intermediate care compared to care at a tertiary hospital is needed. However this study is a first step towards addressing the numerous calls for increased research activity, to support evidence based policies in Africa, with a specific focus costing research in palliative care in Africa [16]. Given that a systematic review highlights that for most of Africa (with the exception of SA) there is no data available to even begin to ascertain to what degree there is provision of paediatric palliative care, studies such as these across the continent are necessary to begin to understand what is needed and how much it will cost [17]. Furthermore while the difficulty with estimating health outcomes in children is well-documented, future studies should investigate the cost-effectiveness of providing intermediate care at a step-down facility, versus providing the same care at a hospital [21, 77, 78]. The next step for research in this area of paediatric palliative care in SA should attempt to understand differences in the ALOS and the outcomes of the care received for the wide variety of patients who receive intermediate care at both step-down facilities and tertiary hospitals.

Limitations

The limitations of the study are that the ALOS used for the calculation is based on very limited available data, especially in the case of paediatric terminal brain carcinoma. The first scenario in the sensitivity analysis has addressed this limitation by testing a range of ALOS periods for both proxy cases, however further research is needed to estimate more accurately the ALOS of the many different types of patients who require intermediate care. Another limitation of this study is the lack of data available to be able to separate out intermediate care patients from other patients at the tertiary hospital. Future work should look at following a small sample of patients admitted to this tertiary hospital who require intermediate care.

Conclusions

Intermediate care provided at a step-down facility is cheaper than providing this type of care at a hospital, however there is the possibility for further cost reductions, especially with regards to overhead costs. It is clear that economic evaluations in the area of paediatric intermediate care are lacking generally and even more so in SA and other LMICs. Much more research in this field is needed if ministries of health are to provide interventions which are cost-effective and meet patient needs, and devise policies which are feasible given budgetary constraints in the health sector.

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PART D: Policy Brief

Providing intermediate care to children with life-threatening and life-limiting diseases

Is it cheaper for the Western Cape Department of Health to provide care at a tertiary hospital or a step-down facility?

Key messages

- The Western Cape Department of Health released a document in 2012, detailing a policy on intermediate care which will encompass palliative care, respite and sub-acute care. Economic evaluations are needed to assess the feasibility of this policy.
- A cost comparison revealed that a paediatric step-down facility was cheaper at a cost per inpatient day of USD 695.17, compared to the cost of USD 713.09 at a paediatric tertiary hospital.
- Building and operating costs at the step-down facility are considerably higher than would be expected and should be cut-down in order to make step-down facilities a good investment.
- More research is needed in this field in order to guide policy on cost-saving mechanisms is needed in order to reduce the costs of providing intermediate care.

Introduction

While palliative care has been provided by non-governmental organizations (NGO's) in Africa since the 1970's, there is very little information with regards to paediatric palliative care and more broadly paediatric intermediate care [1]. A 2009 study conducted in the Western Cape found that 20% of patients who had exceeded the expected length of stay at tertiary hospitals should have been discharged to an intermediate facility. This finding prompted the Western Cape government to release a document in 2012, in which the department detailed the policy on intermediate care which will encompass palliative care, respite and sub-acute care [2].

In the Western Cape, only two institutions provide intermediate care for children, namely St Joseph's and Sarah Fox. Both of these facilities serve communities which are severely impoverished and provide palliative, respite and sub-acute care, with the majority of the patients they serve having HIV/AIDS, TB and cancer. The palliative care wing at Sarah Fox was established by a grant from The Children's Hospital Trust in July 2013 to address the shortage of facilities which provide this type of care to children. However this funding was only temporary and came to an end on 31 December 2014 and as a result the palliative care wing has since been closed at SFCH and the patients integrated into the general ward. The belief is that these types of intermediate care facilities are far cheaper per patient than inpatient care at a tertiary hospital but no studies to show this have been conducted to date in paediatrics, in South Africa.

Objectives

The present study identified, quantified and valued the resources required to provide intermediate care to paediatric patients at an intermediate, step-down facility, as well as at a tertiary level government hospital.

The aim was to determine the difference in direct costs, between these two facilities, per inpatient day for a paediatric patient requiring intermediate care in order to enable local government to budget effectively for the provision of this service.

Methods

A cost comparison study, undertaken from the provider perspective, was performed using a step down costing approach. The two facilities used for comparison are a tertiary children's hospital and an intermediate step-down facility in Cape Town. The cost data were retrospectively collected for the period April 2014- March 2015 and all costs are based on actual unit expenditure. Lastly, the unit cost is expressed as the cost per inpatient day for each facility and costs were inflated to 2016 values. The costs per average length of stay were then compared between the two facilities for two proxy cases, namely a patient with HIV/AIDS with a co-infection of tuberculosis (TB) and a patient with terminal brain carcinoma. All costs are presented in both South African Rand and US dollars (the average exchange rate for 2016 of USD 1 = R14.87 was applied). An ALOS of 10 days was used for the proxy case of a child who is HIV positive and co-infected with TB [3–5]. While a period of 28 days was chosen for the proxy case of a child with a terminal brain carcinoma [6].

Main findings

- Overall it was found that the cost per inpatient day at a step-down facility is indeed cheaper than the cost of an inpatient day at a tertiary hospital, however this difference was minimal at USD 17.93. Cost per inpatient day was USD 713.09 at the hospital and USD 695.17 at the step-down facility. The cost for a paediatric patient who is HIV/TB co-infected was USD 7,130.94 and USD 6,951.67 at the hospital and step-down facility respectively. For a paediatric patient who has a terminal brain carcinoma the cost was USD 19,966.63 and USD 19,464.69 at the hospital and step-down facility respectively.
- The current policy on intermediate care recommends a stay of 6 weeks, which would be USD 752.92 cheaper per 6-week stay at the step-down facility than at the hospital.

- At the hospital, recurrent costs account for around 80% of total costs, while at the step-down facility capital costs are the biggest cost drivers, accounting for nearly 60% of total costs.
- The proportion of capital costs contributed by equipment at the hospital (23.7%) is approximately three times the proportion attributed by equipment costs at the step-down facility (7.7%).
- Closer analysis of recurrent costs indicate that at the hospital personnel costs are the greatest drivers, accounting for 74% of these costs, compared to 39% at the step-down facility. While at the step-down facility building operating and maintenance costs account for 36% of recurrent costs, which is approximately than 5 times the proportion of the contribution of these costs at the hospital (7.6%).

Policy implications

The findings presented here should be interpreted with caution given the time constraints of the study, small sample size and the lack of data available with regards to outcomes at each facility. However these preliminary findings do indicate that personnel costs at the step-down facility are far cheaper than the hospital in terms of providing intermediate care. However building operating and maintenance costs were found to be a large driver of cost at the step-down facility, which is contrary to what would be expected, given that this facility is far smaller than the hospital. Therefore considering the large contribution of building operating and maintenance costs and of building costs for the step-down facility, the space occupied by a step-down facility should be utilized in its entirety. Any cost savings which can be realized using step-down facilities will only be achievable if all the beds are made available and the bed occupancy rate is kept at around 85% [7].

Despite the fact that the findings of this study indicate that the cost of providing intermediate care at a step-down facility is not significantly cheaper than providing this care at a hospital, if we compare the difference in cost per 6-week stay (USD 752.92) the difference is more significant. While the benefits of intermediate care are well documented, the cost implications of this type of care still needs further analysis in South Africa [8–12].

While the current study illustrates the high cost of care from a provider perspective for children with life-threatening and life-limiting diseases, the findings do indicate that care at a step-down facility is cheaper and that building operating and maintenance costs are an area in which more cost savings could be realized. Though the current policy on intermediate care gives guidance on the average length of stay, which is one approach to reducing costs, it makes no reference to any other cost implications of this type of care. Further policy guidance is therefore needed on possible ways to reduce building operating and maintenance costs and achieve optimal bed occupancy rates at step-down facilities in order to make this type of care more affordable to health care providers.

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PART E: Appendices

Appendix A

Appendix B

Appendix C

BMC Health Services Research

Research article author guidelines

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

present a title that includes, if appropriate, the study design e.g.:

"A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"

or for non-clinical or non-research studies a description of what the article reports

list the full names, institutional addresses and email addresses for all authors

if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the “Acknowledgements” section in accordance with the instructions below

indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

Background: the context and purpose of the study

Methods: how the study was performed and statistical tests used

Results: the main findings

Conclusions: brief summary and potential implications

Trial registration: If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be in stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

the aim, design and setting of the study

the characteristics of participants or description of materials

a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses

the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

Ethics approval and consent to participate

Consent for publication

Availability of data and material

Competing interests

Funding

Authors' contributions

Acknowledgements

Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

include a statement on ethics approval and consent (even where the need for approval was waived)

include the name of the ethics committee that approved the study and the committee’s reference number if appropriate

Studies involving animals must include a statement on ethics approval.

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If your manuscript does not report on or involve the use of any animal or human data or tissue, please state “Not applicable” in this section.

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If your manuscript contains any individual person’s data in any form (including individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

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If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

All data generated or analysed during this study are included in this published article [and its supplementary information files].

The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].

Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available here.

BioMed Central also requires that authors cite any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare. 2014. http://dx.doi.org/10.6084/m9.figshare.853801

With the corresponding text in the Availability of data and materials statement:

The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].[Reference number]

Competing interests

All financial and non-financial competing interests must be declared in this section.

See our editorial policies for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

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Funding

All sources of funding for the research reported should be declared. The role of the funding body in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript should be declared.

Authors' contributions

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Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

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Endnotes

Endnotes should be designated within the text using a superscript lowercase letter and all notes (along with their corresponding letter) should be included in the Endnotes section. Please format this section in a paragraph rather than a list.

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All references, including URLs, must be numbered consecutively, in square brackets, in the order in which they are cited in the text, followed by any in tables or legends. The reference numbers must be finalized and the reference list fully formatted before submission.

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Smith JJ. The world of science. Am J Sci. 1999;36:234-5.

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