



African Palliative Care Association Guidelines for using the APCA African Children's Palliative Outcome Scale



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AFRICAN PALLIATIVE CARE ASSOCIATION

The African Palliative Care Association (APCA) is a non-profit making pan-African membership-based organisation which was provisionally established in November 2002 and formally established in Arusha, Tanzania, in June 2004. Acknowledging the genesis of modern palliative care within the United Kingdom, APCA strives to adapt it to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, in collaboration with its members and partners, APCA provides African solutions to African problems, articulating them with what is the recognised regional voice for palliative care.

APCA's vision is to ensure access to palliative care for all in need across Africa, whilst its mission is to ensure palliative care is widely understood, underpinned by evidence, and integrated into all health systems to reduce pain and suffering across Africa. APCA's broad objectives are to:

- Strengthen health systems through the development and implementation of an information strategy to enhance the understanding of palliative care among all stakeholders;
- Provide leadership and coordination for palliative care integration into health policies, education programmes and health services in Africa;
- Develop an evidence base for palliative care in Africa;
- Ensure good governance, efficient management practices and competent human resources to provide institutional sustainability;
- Position palliative care in the wider global health debate in order to access a wider array of stakeholders and to develop strategic collaborative partnerships, and;
- Diversify the financial resources base to meet APCA's current funding requirements and to ensure the organisation's future sustainability.

AIDSTAR-ONE

The AIDS Support and Technical Resources (AIDSTAR) mechanism is an indefinite quantity contract managed out of the Office of HIV/AIDS in USAID's Bureau for Global Health. AIDSTAR-One is a flexible mechanism available to US Government (USG) country teams, USAID/Washington operating units, Missions, and other USG agencies to access technical expertise and implementation support across a broad range of HIV/AIDS-related technical areas. AIDSTAR-One may be used for:

- Long- or short-term technical assistance and programme implementation support in specialised HIV/AIDS technical areas, including: behaviour change; clinical and community-based HIV/AIDS services; care for orphans and vulnerable children; monitoring and evaluation; and health systems strengthening specific to HIV/AIDS services.
- Long- or short-term in-country support for coordination and scale-up for HIV/AIDS activities in support of USG country strategies.
- Documenting and disseminating successful innovative approaches and sustainable models; evidence-based best practices and lessons learned; and new approaches, tools and methodologies in HIV/AIDS programming.

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FOREWORD

The World Health Organization defines paediatric palliative care for children as an active and total approach to care of the child's body, mind and spirit that begins from the time of diagnosis of a life-threatening, life-limiting or chronic condition requiring a multi-disciplinary approach to meet the physical (including management of pain and distressing symptoms), bereavement, emotional, social, spiritual, developmental and cultural needs of the child and their family.

Despite the significant need for children's palliative care in Africa, its development has been slow and only a few countries have established children palliative care programmes, with South Africa presently being the only country with a national network of services. In a continent where access to health care is often limited, and palliative care services for children are few, the most effective way to reach children is to integrate children's palliative care into existing services for children, hospitals, clinics and community organisations, and to build competence through integrating children's palliative care training into the undergraduate and post-graduate courses of all health care professionals. This integration, however, needs to ensure that there is recognition that children are not '*little adults*', and that they have specific developmental, psychological, spiritual and clinical needs that must be addressed.

Measuring quality of care for children is a complex issue and while validated tools exist to assess pain, there is an absence of culturally appropriate, relevant and rigorously validated measurement tools to assess the quality of care in children. These much needed instruments should be easy to use in resource-poor health and care settings where staff members are often overworked and patients are often very unwell.

In the absence of a such a measure, and building on the success of developing the APCA African Palliative Outcome Scale (POS) for adults, the African Palliative Care Association has developed the APCA African Children's POS. The tool has been validated across diseases, countries, settings and languages and used in both quality improvement and research studies. Moreover, feedback on the tool from doctors and nurses who have used it has been very supportive, with providers perceiving it as an easy-to-use instrument that helps them undertake holistic assessments that in part entail discussing difficult issues.

This booklet is a practical guide intended to help users employ the APCA African POS correctly. Following a discussion of the origins and background to the APCA African PPOS, the guide discusses the measurement of outcomes, the development of the tool and its use (including the analysis of collected data), before finishing with illustrative examples of the use of the questionnaire.

We hope that African health workers will find it useful in measuring and improving the standard of care they provide to children.

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CHAPTER I:

Introduction

This chapter is largely based upon Harding R, Sherr L, Albertyn R (2010)
The Status of Paediatric Care in Sub-Saharan Africa: An appraisal.
London: The Diana, Princess of Wales Memorial Fund.

Chapter 1: Introduction

As approximately two-fifths of Africa's population is under the age of 15 years (Parkin et al, 2008) (compared to 28% globally), and the infant / child mortality rate is extremely high (WHO, 2004), in the face of a significant disease burden (especially from HIV / AIDS and cancer), the humane and effective care of children affected by progressive, incurable and life-limiting disease in sub-Saharan Africa is a pressing public health matter.

1.1 HIV/AIDS

Of the 3.4 million children in the world living with HIV, approximately 90% (i.e. 3.06 million) live in sub-Saharan Africa (WHO / UNAIDS / UNICEF, 2011), while in 2010 (reporting prevalence estimates from the preceding year) the UNAIDS estimated that there were 14.8 million (of the global total of 16 million) AIDS-related orphans in the region (UNAIDS, 2010).

The significant number of HIV-positive orphans in sub-Saharan Africa with palliative care needs has presented practitioners with a set of complex management issues, and led to the establishment of AIDS hospices and orphanages for these children (Martin, 1998). The need for palliative care in achieving quality of life has been well described throughout the HIV disease trajectory from the point of diagnosis, through treatment initiation and adherence, into the chronic disease stage, alongside emerging co-morbidities, and into the end of life (Harding et al, 2005; Harding et al 2007, Harding et al, 2009). The evidence also shows inadequate access to HIV palliative care, particularly for children (Harding et al, 2005). Moreover, whilst the palliative care needs of adults with HIV disease (even among those accessing antiretroviral therapy [ART]) have been shown to be significant – with one study reporting that 50% of adult outpatients at a HIV clinic in Tanzania would benefit from palliative care (irrespective of treatment use) (Collins and Harding, 2007) – similar studies have not been conducted among children, although there is no reason to believe that their multidimensional problems (i.e. physical, social, psychological, spiritual) would be fewer.

1.2 Cancer

Additionally, each year approximately 166,000 children under the age of 15 are diagnosed with cancer worldwide (Cancer Research UK, 2003). By 2030, the developing world is expected to bear 70% of the global cancer burden (World Cancer Report, 2008). Poverty continues to be linked to cancer in the developing world (Economist Intelligence Unit, 2009), with cancers having already progressed to an incurable stage in 80% of patients by the time of detection and diagnosis (Kanavos, 2006). The available registry data in Tanzania has revealed that 11.5% of all malignant tumours recorded in the cancer registry were in children aged 0–14 years (Mgaya and Kitinya, 2000).

Around 36% of cancers in Africa are infection-related, twice the global average (Parkin, 2006). This reflects the challenge of infectious disease (particularly of HIV), and that many cancer patients have underlying HIV infection. A study of childhood cancers in Zambia found a significant rise in paediatric malignancies due to the HIV epidemic, with the authors reporting the most common presentations as lymphoma (36.9%), retinoblastoma (12.5%) and Kaposi's sarcoma (12.7%) (Chintu et al, 1995). Similar findings from Malawi in a retrospective audit identified increases for all cases due to the HIV epidemic, but particularly for Kaposi's sarcoma (with Burkett's Lymphoma being the most common childhood tumour in the country) (Sinfield, 2007). Burkett's Lymphoma is the most prevalent cancer among children across tropical Africa, and although usually treatable, evidence from Nigeria shows that children with a diagnosis of Burkett's Lymphoma will often need end-of-life care due to late presentation and their family's inability to afford curative options (Meremikwu, 2005). Moreover, a study of the impact of the costs of care on the family and patient found that the additional costs of transport to the care facility, food and the family carer's inability to work while attending the child in hospital, can lead to the abandonment of the child (Israels, 2008).

A lack of family-based, informal carers may place greater responsibility on palliative care teams to provide for the child's needs, both physical and emotional. A review of childhood cancer treatment in developing countries predicted that the high cure rates seen in developed countries will not be possible, due to a lack of resources and locally adapted treatment protocols, late presentation, and poor treatment compliance (Kruger, 2005).

1.3 Need for palliative care

There are no accurate figures on the number of children worldwide in need of palliative care services but estimates range from 7 million annually (Rushton, Caitlin, 2002) to 20 million (Scrimgeour et al, 2010). Quantification of the need is critical but complicated by various factors, such as uncertainty of population numbers and the unpredictability of disease trajectories.

Against the above sub-Saharan African epidemiological backdrop – notwithstanding the multiple other identified life-limiting diagnoses (Hain et al, 2010) – and in terms of the public health need for paediatric palliative care, attempts to extrapolate need have been made from available data in South Africa (Harding et al, 2010). Estimates of the need for palliative care in an area are traditionally based on mortality and morbidity statistics for chronic, incurable illnesses. In the Cape Town Metro area an estimated 2,951 children died in 2006 (Groenewald, 2008). The greatest number of childhood deaths in the Cape Town Metro area occurred in children aged 1–4 years (135/100,000). Of these deaths, 105,231 (44%) were from chronic communicable (HIV, tuberculosis [TB]) and non-communicable (e.g. cancers, organ failure, congenital conditions etc) illnesses. Mortality statistics only give an estimate of the need for improved end-of-life care (including bereavement) and do not reflect the whole spectrum of palliative care which ideally should begin with diagnosis. The estimated prevalence of chronic illness among children in South Africa (i.e. expected to last at least a year) is 20% (Robertson, 2006). Approximately one-fifth of these children will have a life-limiting or life-threatening condition requiring palliative care. An approximation of the number of children living with a chronic illness in the Western Cape based on the mid-year (2009) population census for the Western Cape is 397,580 (20% of the 1,987,900 children living there). Consequently, approximately 79,516 of these children (20%) would require palliative care.

Based upon such calculations, estimation of paediatric palliative care need is an area requiring further work.

1.4 Palliative care for children

While both adult and paediatric palliative care share common principles – taking a patient-focused and holistic approach, relying on a robust evidence base to make therapeutic decisions and balancing burden and benefit to ensure the patient's best interests are addressed – the axiom that 'a child is not simply a small adult' is especially pertinent in palliative care (Mellor, Hain, 2010).

1.4.1 Differences between children and adult palliative care

Although it is acknowledged there are similarities in the principles of palliative care for adults and children, it is crucial to emphasise the underlying differences. The unique concerns which should be taken into account in the planning of palliative care services demonstrate the need to develop children's issues separately:

- Causes of death in children are often different from those in adults, making adult palliative care guidelines inappropriate for children.
- A variety of childhood conditions are rare, and length of illness can vary greatly from days to years. The child may survive into early adulthood, extending palliative care over many years. Children with life-limiting conditions may require holistic and multidisciplinary services for long periods of time.

- Children continue to develop physically, emotionally and cognitively, which means their medical and social needs as well as understanding of disease and death is complex and changes with development and experience. Providing education to sick children is critical and a legal entitlement.
- Palliative care affects the whole family, with the burden of care falling upon parents or grandparents and siblings. Appropriate services are more likely to be home- rather than hospital-based. Additionally, more than one child may be affected in the family, and generic counselling may be necessary.
- It is shown that children receive more aggressive care compared to adults at the end of life, and may require specific symptom and pain management throughout the treatment course.
- Medications and dosages are more complex in children.
- Neonates have very unique palliative care needs.
- There is a higher emotional impact on families and health care workers.

1.4.2 Definitions of palliative care for children

Palliative care for children aims to relieve suffering and improve quality of life. The definition most commonly used worldwide is that developed by the World Health Organisation (2002):

'Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.'

Palliative care addresses the child's body, mind and spirit; therefore, it is important that all the components of holistic care are addressed (i.e. physical care, which includes effective pain assessment and management; spiritual care and psychosocial care). While physical care centres mainly on the child, spiritual and psychosocial care extends to children's families as well.

Categories of children requiring palliative care

There are two main categories covering life-limiting and life-threatening conditions:

(a) Life-limiting / life-shortening conditions: Life-limiting or life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

(b) Life-threatening conditions: Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

Four broad groups of life-limiting and life-threatening conditions can be delineated. Categorisation is not straight-forward and the illustrative examples used below are not exclusive. Diagnosis is only part of the process; the spectrum of disease, disease severity and subsequent complications, and the needs of, and the impact of the disease on, the child and family need to be considered.

- **Category 1**

Life-threatening conditions for which curative treatment may be feasible but can fail, and where access to palliative care services may be necessary when treatment fails. Children in long-term remission or following successful curative treatment are not included. Examples are: cancer, leukaemia, reversible organ failure of the heart, liver, or kidney; severe malnutrition; and multi-drug resistant TB.

- **Category 2**

Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples are: cystic fibrosis; HIV.

- **Category 3**

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples are: Batten disease, mucopolysaccharidoses, muscular dystrophy.

- **Category 4**

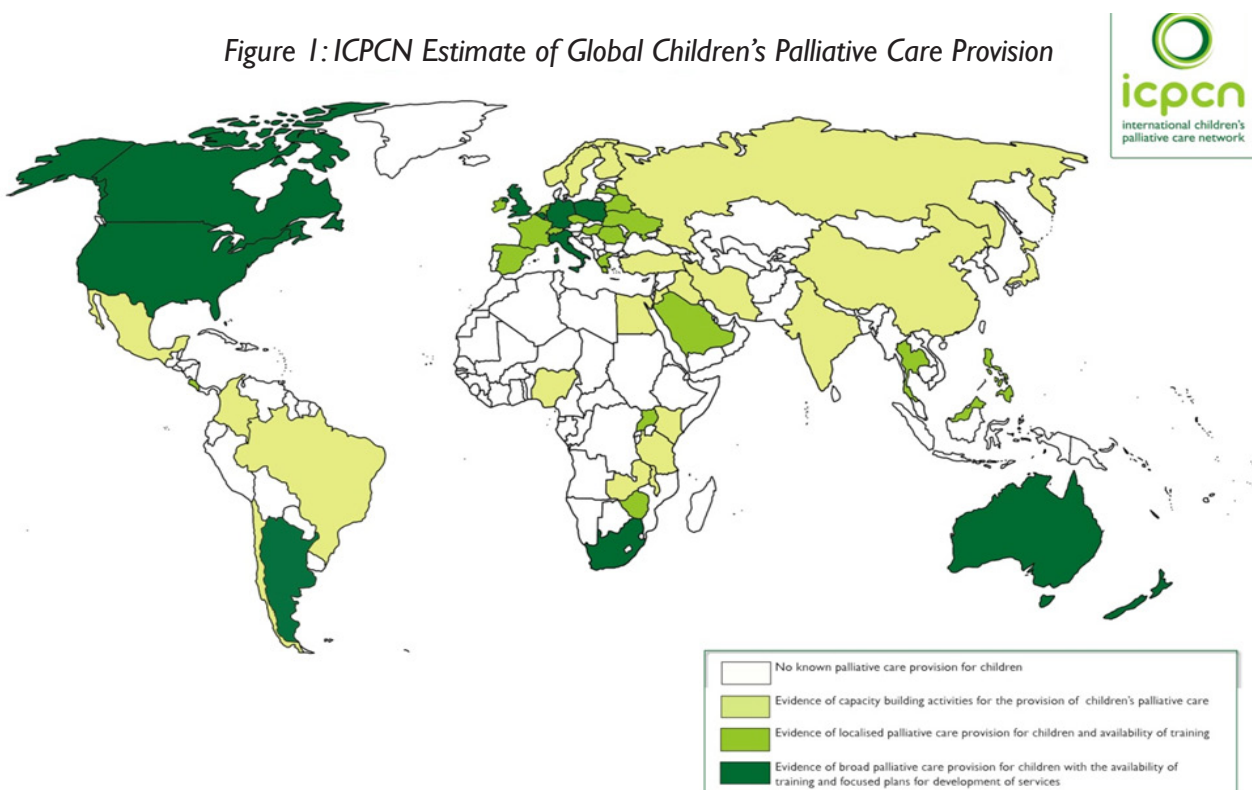
Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples are: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, and foetal alcohol syndrome.

In sub-Saharan Africa children facing loss and bereavement have been identified as a possible fifth category. Moreover, there is an ongoing international discussion over whether neonates should be located in a separate category.

1.5 Mapping of paediatric palliative care services

In a systematic review to map children's palliative care services worldwide, Knapp et al (2011) found there were 78 countries (65.6%) with no known activities, and only 5.7% had provision reaching mainstream providers (see Figure 1).

Figure 1: ICPCN Estimate of Global Children's Palliative Care Provision



Reprinted with permission from: International Children's Palliative Care Network

Of the 53 African countries, 81.1% were defined as level one, and only 1.9% at level four. Compared with the other regions in the world, Africa was second to Oceania in the highest percentage of countries at level one and the fifth lowest in the percent of countries at level four. Indeed, South Africa is presently the only country in the region with a paediatric portfolio within their national association, the Hospice Palliative Care Association of South Africa. This has led to the development of an extensive network of children's palliative care programmes in all provinces of the country.

1.6 Models of palliative care for children

Palliative care for children should be provided wherever the child is at any particular time, and along the whole continuum of care, from the home, through to the clinics or community services, children's residential homes, to hospitals and in-patient hospices, should be available from the time of diagnosis of a life-limiting condition, and provided by health care workers trained and competent in caring for children with palliative care needs. In practice in sub-Saharan Africa, palliative care for children tends to be provided within individual programmes, and dependent on an adequate referral system, and a willingness to refer, for the child to receive palliative care along the trajectory of the disease and continuum of care.

In sub-Saharan Africa, several models of service provision have been successfully implemented. There is no one perfect model except the model that best meets the needs of a particular community and the children in that community. Models can be a single programme or a combination of programmes; they can be exclusively focused on palliative care for children, part of a general palliative care programme, or part of a programme that provides care to vulnerable children.

Palliative care programmes for children can consist of one or more of the following elements:

- Home-based care;
- Day care with early childhood development;
- Community centres with after-school care and skills development;
- Anti-retroviral clinics;
- Hospital-based palliative care services;
- Bereavement services;
- Support for siblings;
- Family support, and;
- Family-centred care.

Most palliative care is provided at community and primary care levels in sub-Saharan Africa. There are a small number of programmes that have been established to provide palliative care exclusively for children, and an even smaller number of children's palliative care in-patient units. A growing number of organisations have recognised the importance of ensuring optimum stimulation and development for children, as well as the essential role of play, and the number of day care centres providing palliative care for pre-school children is growing.

While most children with a life-limiting condition will spend time in hospital, hospital-based palliative care for children is developing slowly, but with developed programmes in Malawi and South Africa. Moreover, paediatric palliative care training opportunities are few; consequently, the available pool of trained health care workers is also limited. A programme to develop Beacon centres for children's palliative care through the development of a multi-professional certificate course for palliative care for children has expanded training in Tanzania, Uganda and South Africa, and introductory courses have been presented in Malawi, Kenya and Zambia. The course has been developed to diploma level in Uganda and a diploma is available in South Africa. A project to present training through e-learning linked to clinical placements has also been initiated through the International Children's Palliative Care Network.

1.7 Current focus of paediatric services

A 2002 review of paediatric HIV care and support activities in Africa concluded that generally the aims and interventions focused on primary prevention among youth, prevention of mother-to-child transmission (PMTCT) and orphan support. Very few paediatric treatment guidelines were found at that point in time and training was rare, particularly in the field of pain and symptom control and palliative care (Woods-Francis, 2002).

Appropriate high-quality orphan care has been hypothesised to impact on primary HIV prevention, which may provide good health economic arguments for the care of AIDS orphans (Clifton, 2003). However, where orphan care services do exist, they have been found to focus on children's physical needs to the exclusion of their psychosocial needs (Ali, 1998). The social support and communication needs of HIV-infected and affected children have been demonstrated to be essential for children living long-term with HIV infection (Battles, Wiener, 2002). While there are examples of interventions for HIV-affected children (such as the 'Kids Express' programme, which aims to prevent psychological morbidity for children who are aware of their loved one's diagnosis) (Desiderio, Peabody, 2000), there are currently no such interventions described within the context of palliative care services.

1.8 Ensuring quality: Assessment and measurement to improve outcomes for children and their families

The palliative care research agenda for Africa has advanced significantly recently, and there is now a recognition of the central role of clinical and public health research to determine what constitutes appropriate and responsive palliative care, how to manage problems in progressive disease, and the importance of undertaking outcome evaluation to determine what works.

To date, however, the science has not progressed for children as it has for adult palliative care, and as a result the evidence base appears even smaller than it is in the growing field of adult palliative care. One of the challenges contributing to this lack of evidence is that the conduct of ethical, robust and rigorous research among children must address problems that are specific to the population. While some issues are common (Harding, 2010), specific research questions remain. These include the identification of the specific needs of children across diverse care settings, diagnoses and age groups, the ethical and valid collection of data, the design of appropriate measures, and the configuration and evaluation of paediatric interventions and services responsive to the various age groups.

Central to advancing this agenda is the important and immediate task of developing, validating and implementing tools to measure the multidimensional problems of children. The need for well designed and validated tools to measure children's problems is underlined by the Rose and Amery's statement that assessment is the most important aspect of delivering children's palliative care in Africa (Rose, 2009). Their research outlined some of the domains to be considered in the assessment of children: health, education, emotional and behavioural development, identity, family and social relationships, social presentation, family history and functioning, housing, employment and income, family's social integration, and community resources. These domains are indicative of the complexity and breadth of outcomes of interest.

Moreover, the assessment and measurement of pain and symptoms must be conducted using methods which recognise that children's experiences and expression of pain and symptoms will be mediated by age, experience, family and culture (Dussel, 2004). While systematic assessment underpins good palliative care, and self report is the most accurate source of information, the child may not be able to communicate well. Children should not be seen as 'little adults', and existing tools developed in adult populations may not be appropriate, either in terms of their domains / items and response methods, or because they are unvalidated in African populations. Furthermore, although the needs of family / carers are taken into account in palliative care in general, the needs of parents of dying children may be specific, and they may need assistance in accepting the diagnosis and prognosis of their child.

It has been noted that the assessment and management of symptoms and suffering in children are challenging, and that few reliable, valid and developmentally appropriate methods are available (Hurwitz, 2009). There are a small number of validated outcome tools for children, although to date none have been validated in Africa. These include the Memorial Symptom Assessment Scale (MSAS) paediatric version for children aged 7–12 years (Collins, 2002), and the faces pain scale, which is a well validated and used visual scale for children who may not be able to work well with verbal ratings (Bieri, 1990; Hicks, 2001).

There are other tools available for the assessment of pain in children (Ullrich and Wolfe, 2009), but none that are multidimensional (i.e. that address physical, psychological, social and spiritual domains) and validated for children in Africa. Moreover, as Harding et al (2010) concluded in their review of the status of paediatric palliative care in Sub-Saharan Africa, 'Despite a body of experts highly active in the field, the lack of time, resources, expertise and appropriate methods / measures has precluded good documentation of activity and outcomes' (p.50). Moreover, there is a growing consensus that not only should patient-reported outcome measures (PROMs) be developed for palliative and end-of-life care (Simon et al, 2012), but such PROMs should be short, multi-dimensional and easy to use (Downing et al, 2012), supported by guidance, training and resources (Daveson et al, 2011).

Consequently, the African Palliative Care Association (APCA) developed a paediatric patient-level outcome measure – the APCA African Children's Palliative Outcome Scale (POS) – for Africa and this guidance manual to help in its use.

CHAPTER 2:

Measurement of patient and family outcomes

Chapter 2: Measurement of patient and family outcomes

2.1 Measurement issues

Palliative care for babies, children and young people aims at improving quality of life, and reducing suffering. Measuring the outcomes of palliative care on the child and family can be complex and dependent on multiple factors. Children may be too young, too sick, or too disabled to answer questions regarding the outcome of palliative care interventions. Culture may also play a role in determining whether children are permitted to answer questions. Additionally, children may provide the answer they feel the interviewer or the parent / guardian wants to hear to please the adult, rather than expressing their actual life situation.

Where the child cannot answer questions due to illness, age, understanding or disability, the primary caregiver may be required to answer on behalf of the child, acting as a proxy respondent. In many cases in sub-Saharan Africa, the primary caregiver is also vulnerable and may be an elderly relative or a still-young sibling. Identifying the competence of the child or primary caregiver to answer questions correctly may be difficult for the interviewer. The correct use of assessment tools depends on the ability of the interviewer and the child or primary caregiver to understand these correctly, and to be competent to evaluate their pain, symptoms or emotions against a scale that may appear complex. For example, even adults can find difficulty in using a scale with more than 4 determinants (i.e. 0 – 3 points on a scale).

Quality of care is measured against defined standards for the provision of palliative care for children, and requires staff providing this care to be competent in its provision. Both the African Palliative Care Association (APCA) and the Hospice Palliative Care Association of South Africa (HPCA) have developed relevant standards, but in sub-Saharan Africa, where few countries have implemented education and training in palliative care for children, and where opportunities for supervised clinical placement are few, assessment of the quality of palliative care for children provided by untrained staff, may be difficult to measure.

Lastly, where non-governmental organisations are struggling to survive, with scarce human and financial resources, measuring the outcomes of care on the patient and family may not be seen as a priority. However, where resources are scarce, donors are increasingly asking to see the evidence of the impact of their funding and implementing this measurement may benefit the credibility and sustainability of an organisation.

2.2 Paediatric research ethics

All research with children must be carried out within a framework of children's rights, and must protect those rights at all times. Every organisation working in this field should have a child protection policy and should train their staff on implementing those rights.

Children are a vulnerable group in any population, and children with a life-limiting condition have an exacerbated vulnerability. All countries in Africa, with the exception of Somalia, have signed the UN Convention on the Rights of the Child, and all countries are signatories to the African Charter on the Rights and Welfare of the Child. Children's lives are often seen to be of more value than the lives of adults, but conversely, their rights are often not as well-respected as those of the latter.

When involving children in research, every safeguard must be in place to protect the vulnerability of the child, and in Africa, the often vulnerable primary caregiver. Children aged over 5 could, in many cases, be involved in some ethical decision-making and the health care worker has an obligation to ensure good communication with both the child and their primary caregiver so that informed decisions are taken. As far as possible, communication should be in the first language of the primary caregiver and the child. Primary ethical principles in research ethics are:

- Beneficence – to do good;
- Non-maleficence – to do no harm;
- Autonomy;
- Justice;
- Informed consent, and;
- Truth telling.

Children over five have varying degrees of autonomy and competency to participate in ethical decision-making. They have different degrees of autonomy and may be able to provide assent where legal consent is not possible because of their low age and laws of a specific country. The children have a right to be informed of the truth in an age-appropriate language.

Three simple questions form the basis of ethics in children's palliative care and research ethics (Amery, 2009):

- What must be decided?
- Who decides?
- How do they decide?

Moreover, an autonomous person needs to:

- Understand the information given to them;
- Believe this information applies to themselves;
- Remember the information;
- Use the information to take decisions, and;
- Communicate the decision to others.

Some older children will be competent in all these areas. Others may not be fully competent but can still understand the issue and participate. A major challenge, however, is when the child could be considered autonomous but is not seen as legally competent according to the law, and where the decision of the child is at variance with the decision of the parent / guardian.

Another problematic issue in Africa is the identification of the proxy decision-maker when the child is orphaned and possibly living away from their family. Every effort must be made to ensure that decisions are taken by those legally authorised to take these decisions. A good collective rule could be to:

- Inform the child in an age-appropriate language;
- Involve the child in decision-making as far as he or she is competent;
- Listen to the wishes of the child;
- Ensure the decision is taken in the best interest of the child;
- Try to ensure a collaborative agreement where the guardian / parent and child are not in agreement;
- Where the child cannot give consent, try to get assent from the child, and;
- Respect the voice of the child.

2.3 Research methodology in children

Several methodologies are possible in conducting research with children, including the following:

- Interviews
- Participant observation
- Focus group discussions
- Randomised clinical trials

Given the nature of the APCA African Children's POS, this section discusses interviews only.

2.3.1 Interviews

One of several qualitative methodologies in paediatric research is interviewing, which allows for children to express individual opinions and experiences (Kortessluoma et al, 2003; Mack et al, 2005). Given the different developmental stages at which children can be, researchers should make efforts to tailor interviews to fit the individual developmental stages of their child interviewees.

Below are some generic (rather than specifically relating to the APCA African Children's POS) tips for conducting interviews with children (Kortessluoma et al, 2003):

- The beginning of an interview is typically the most important for setting the tone for the rest of the interview. Researchers should try to *establish rapport* with children and explain what will happen during the course of the interview. For younger children, playing with them first can help to build that rapport. Getting children to draw is another activity that can help researchers to build rapport with children at the beginning of interviews. Be open to accepting any answers children give in the beginning, keeping in mind to come back later to questions which need further response.
- Whereas adolescents might be more comfortable with abstract concepts, younger children might find abstraction difficult to comprehend. For younger children, using concrete examples in questions about abstract concepts can help children frame it in a context which is personally meaningful. An example is an 8-year-old girl who is asked to describe what headaches feel like, but also being asked about her own headaches allowed for more self-expression.
- Children should be assured that *there are no right or wrong answers*. Especially given the disproportionate power relations between children and adults, children might want to please adults with their responses. Using hypothetical situations in positive or neutral contexts can help to elicit answers from children. The following is an example from an interview with an 8-year-old boy who was asked to describe what pain is:

Interviewer: Now can you tell me what pain is?

Boy: It's like that something is painful or sore or a broken leg. That can hurt, too.

Interviewer: That's true.

Boy: And headache is pain.

Interviewer: Yes. If I didn't know at all what pain is like, how would you describe it to me so that even I would then understand what it is?

Boy: Well, I would say that if you, like, have a headache or something, that is pain.

Interviewer: How would I know that I have a headache if I never had one before?

Boy: You'd know it, because you'd feel sort of weird in the head.

Interviewer: It feels weird.

Boy: Yeah...

Interviewer: If your little sister didn't know what pain is, how would you make her understand what pain is?

Boy: Well, I would say that if I like hit you in the head with a bat, then that's pain ... and it's not pain if you are asleep in the morning and they can't wake you up and they throw cold water on you. That's not pain.

Interviewer: No, it isn't. What is it?

Boy: Coldering.

- Using *action-based questions*, such as 'what did / would you do?' can be helpful for children in answering questions. Action-related questions can also lead the way towards children expressing their feelings about a given topic.
- An '*I don't know*' response from a child can simply mean 'I don't know'. It could also mean that children do have answers to the question(s), but they do not know how to express those answers verbally. However, children are sometimes more likely to have an answer for every question in unfamiliar environments, whereas they might be more likely to say 'I don't know' in familiar environments where they are more comfortable.
- When children provide *answers which seem illogical*, try asking questions about the same topic in a different way and also keep the child's developmental stage in mind.
- The *interview should not be very long*, as children's attention spans are shorter than those of adults. The literature does not indicate what an ideal timeframe is for interviews with children, but since 1-2 hours is considered a reasonable length of time to interview adults, interviews with children should be shorter.

CHAPTER 3:

Development of the APCA African Children's POS

Chapter 3: Development of the APCA African Children's POS

3.1 Background

The APCA African Children's POS was developed in a consultative process that included a multi-disciplinary, multi-national group of experts in the field of children's palliative care in Africa. As a first stage in the process, a literature search was undertaken to review existing outcome measurements used among children that would enable the identification of available tools and measurement scales validated amongst this age group. It aimed to address the following questions:

- What are the important outcome domains when measuring paediatric palliative care?
- What outcome tools have been developed for paediatric palliative care?
- What are the methodological issues associated with collecting data from children and researching sensitive issues with children, including beyond palliative care?

The literature reviewed included systematic and academic reviews, tools, guidelines and manuals, pain and paediatric palliative care textbooks, original research journal articles, policy reports and papers, and studies. Several biomedical databases were searched, including PubMed, Cumulative Index to Nursing & Allied Health, EMBASE, Social Citation Index, Psychinfo/Lit, and BioMedCentral. More than 90 relevant websites were also visited. The literature review identified that:

- Among the main domain of paediatric palliative care, there is extensive literature about pain (within the physical care domain) but less information available about spiritual and psychosocial care. Effective pain management is a hallmark of effective palliative care, and from that point of view, therefore, it is beneficial for paediatric palliative care that there is an emphasis on pain assessment and pain management in the literature. However, paediatric palliative care is equally concerned about the spiritual and psychosocial wellbeing of children. The under-emphasis in the literature of spiritual and psychosocial care, and more generally holistic care, could risk a similar under-emphasis in clinical practice and in paediatric research. Consequently, it is important that any children's palliative outcome scale addresses the holistic nature of paediatric palliative care.
- Cancer forms the basis of a significant amount of literature on paediatric palliative care and pain in children. While cancer is one of the conditions facing children around the world, the global expansion of paediatric palliative care will encounter children with conditions that could be more locally prevalent than cancer. For instance, HIV/AIDS is a critical issue in Sub-Saharan Africa, and paediatric palliative care within the region will need to address HIV/AIDS and other locally prevalent conditions.
- There is a relative dearth of literature about paediatric palliative care in Sub-Saharan Africa. Most of the literature concerns non-African settings, and developed countries in particular. The paucity of Sub-Saharan African paediatric palliative care literature could be one reason why conditions such as paediatric HIV/AIDS are not as often addressed in paediatric palliative care literature as cancer, for example.

The literature review was followed by a workshop held in May 2009 in Kampala, Uganda, which brought together experts from across sub-Saharan Africa to review the feedback from the literature review, draft the initial children's outcome scale (including the domains to be measured, measuring tools to be used, target group to be included, and potential questions to be asked) for the first phase piloting.

The results of the literature review and the expert discussions found examples of good disease-specific tools for children, as well as those focusing on pain; however, it was found that there were fewer tools for measuring psychosocial and spiritual outcomes and the general quality of life of children. It was therefore agreed that there was a need for a multi-dimensional outcome scale for this age group. It was considered important that, as a multi-dimensional tool, the measure should address areas across the spectrum of palliative care, such as the psychosocial and spiritual domains and not just physical issues. Consequently, it was agreed that questions should be asked in the areas of: pain and symptom management; distress and anxiety; communication; comfort and spirituality; carer support and family involvement in care.

An initial draft version of the APCA African Children's POS was developed, with two versions of the tool: one for 'verbal' children and one for 'non-verbal children':

- APCA African Children's POS Version 1 for 'non-verbal' children: for children who are unable to communicate verbally, including those that are very young, have special needs or are developmentally delayed.
- APCA African Children's POS Version 2 for 'verbal' children: for children who are able to communicate verbally, possibly up to 16 years of age.

A first stage of piloting was conducted between September 2009 and February 2010 in four sites in three countries: Kenya, South Africa and Uganda. A meeting was held in Nairobi, Kenya, in March 2010 to review the findings following the first stage pilot and to revise the tool accordingly ready for second stage piloting. The **APCA African Children's POS** showed sensitivity to change over time in multiple domains among the target population. The expert panel made various recommendations for the ongoing development of the tool, including combining the two versions into one tool, given reported confusion on which version of the tool to use if, for example, a child was initially 'verbal' or 'non-verbal' in the course of a series of assessments but that status subsequently changed.

This tool was then subject to a second stage of piloting, which was undertaken in eight sites across five countries in diverse settings (e.g. hospital, homecare, hospice and outpatient, as well as in the rural and urban settings) and included a range of ages among the children.

The tool now had two sections: the first section (A) addressing questions about the children themselves, while the second section (B) addressing questions for the family / carers. Section A consisted of nine items, addressing physical and psychological symptoms, spiritual, and emotional concerns of the child. These questions were asked of the child themselves in the 'verbal' version of the tool and to the parent / carer in the 'non-verbal' version. Ideally, the questions in Section A were to be asked of the children themselves. However, as this was not always possible (i.e. the children may be too young or unable to express themselves due to illness, such as being in a coma, or brain impairment, or have other cognitive limitations), the questions could be asked of the parent or carer. On those occasions where there was no family member or carer present, this section would be completed by the nurse caring for that child. Section B consisted of five questions asked to the parent / carer.

The second phase pilot was conducted between July 2010 and September 2011 in eight sites in four countries: Kenya, South Africa, Uganda and Zimbabwe. Following the second phase piloting, the results were circulated to a group of experts from Kenya, South Africa, Uganda, the United Kingdom and Zimbabwe. Further modifications were made to the tool in preparation for its final validation.

The validation phase of the APCA African Children's POS's development was undertaken in three sites in three different countries: Kenya, South Africa and Uganda. The results from the validation exercise are to be reported in a separate publication.

3.2 Why use the APCA African Children's POS?

The APCA African Children's POS was developed as a children- and family-level tool to measure the outcomes of care being provided and to make recommendations on areas for improvement. The tool is a validated outcome scale for use in Africa. It can be used in multiple settings and by a variety of different stakeholders and for different purposes.

In clinical care, the tool can be used along with other routine clinical tools for assessing and monitoring the progress of children's illness and discovering whether the treatments given are effective. It can also be used in quality improvement to evaluate the impact of the services provided by a facility in order to inform decision-making, and in research for similar purposes and to provide the evidence base that can be used to inform policy formulation and advocacy work.

3.3 Who can use the APCA African Children's POS?

The APCA African children's POS can be used by health care workers, researchers, facility managers and other stakeholders who have been trained in its use.

Health care workers may decide to use the tool in routine clinical practice in different settings, so that they can see how they are managing different aspects of care. National palliative care associations can encourage their members to use the APCA African Children's POS on a regular basis for quality improvement purposes – it is important that palliative care providers develop a routine of auditing the care that they provide and address areas where improvement is needed. However, it is important that all those who use the APCA African Children's POS are trained effectively in its use. Consequently, training resources are found on the CD-ROM that accompanies these guidelines.

3.4 The APCA African Children's POS

As stated above, the APCA African Children's POS has two sections (see Figure 2): the first section addresses questions about the child themselves and the second section addresses questions for the carers. Ideally the questions in Section A should be asked of the child themselves, however this is not always possible as the child may be too young or is unable to express themselves due to illness, in which case the questions can be asked to the carer or nurse.

Within section A of the tool each question is phrased in two different ways: firstly, those to be asked to the child if they are able to respond to the questions themselves and, secondly, to be asked to the parent / carer. For the child to answer these questions they should have the cognitive ability to understand the question and know how to answer. As a thumb rule, generally this can be used for children aged six and older but there should be sensitivity to each child's cognitive and developmental abilities. Lastly, on occasions where there is no family member / carer present, this section may be completed by the nurse caring for that child.

Figure 2: The APCA African Children’s POS

Children Reference Number:		Date:				Visit 1						
						Visit 2						
						Visit 3						
						Visit 4						
QUESTIONS TO BE ASKED TO THE CHILD		Visit 1	Visit 2	Visit 3	Visit 4	QUESTIONS TO BE ASKED TO THE CARER OR NURSE IF THE CHILD IS UNABLE TO RESPOND		Visit 1	Visit 2	Visit 3	Visit 4	
Question	POSSIBLE RESPONSES					Question	POSSIBLE RESPONSES					
SECTION A: ABOUT THE CHILD												
Q1	Can you tell me how much pain you have had since yesterday?	0 (No pain) – 5 (The worst pain you can imagine)					Can you tell me how much pain your child has had since yesterday?	0 (No pain) – 5 (The worst pain you can imagine)				
Q2	How much have other problems with your body been troubling you since yesterday? (Prompt only if needed: e.g. being sick, going to the toilet a lot)?	0 (No other problems with my body have been troubling me) – 5 (Other problems with my body have been troubling me very much)					How much have other problems with their body been troubling your child since yesterday (Prompt only if needed: e.g. vomiting, diarrhoea, skin problems etc)	0 (No other problems with their body have been troubling my child) – 5 (Other problems with their body have been troubling my child very much)				
Q3	Can you tell me how much you have been feeding since yesterday?	0 (Feeding enough) – 5 (Not feeding at all)					Since yesterday, how much has your child been feeding?	0 (Feeding enough) – 5 (Not feeding at all)				
Q4	Can you tell me how much you have cried since yesterday?	0 (Not cried at all) – 5 (Cried all the time)					Since yesterday, how much has your child cried?	0 (Not cried at all) – 5 (Cried all the time)				
Q5	Can you tell me how often you have felt happy since yesterday?	0 Happy all the time) – 5 (Not happy at all)					Since yesterday, how much has your child felt happy?	0 (Happy all the time) – 5 (Not happy at all)				
Q6	How much have you felt like playing since yesterday?	0 (Felt like playing all the time)– 5 (Have not felt like playing at all)					Since yesterday, how much has your child felt like playing?	0 (Felt like playing all the time) – 5 (Have not felt like playing at all)				
Q7	How much have your questions about your sickness been answered since yesterday?	0 (As much as I wanted) – 5 (Have not been answered at all)					How much have your questions about your child’s sickness been answered since yesterday?	0 (As much as wanted) – 5 (Have not been answered at all)				

SECTION B. QUESTIONS ABOUT FAMILY / CARER (Note: The time period is <i>since yesterday</i>)					
Q8	How much have you been feeling worried about your child's illness?	0 (Worried all of the time) – 5 (Not at all worried)			
Q9	Have you been able to share how you are feeling about your child's illness with others when you have wanted to?	0 (Not at all) – 5 (Talked freely)			
Q10	How much information have you and your family been given about your child's illness?	0 (None) – 5 (As much as wanted)			
Q11	Have you had enough help and advice for your family to plan for the future with regards to your child's illness?	0 (None) – 5 (As much as wanted)			
Q12	How confident does the family feel caring for the child?	0 (Not at all) – 5 (Very confident)			

CHAPTER 4:

Using the APCA African Children's POS

Chapter 4: Using the APCA African Children's POS

To ensure that the APCA African Children's POS is used correctly and consistently, and to ensure its reliable implementation and analysis, instructions have been developed to accompany the APCA African Children's POS (see Appendix 1). These instructions need to be read and understood before a person conducts any interviews with children/ family carers or seek to address a number of key issues that need to be considered when using the tool:

- Training
- Adaption
- Assessment
- Analysis

Use of the APCA African Children's POS is free of charge; however, in order to use it you need to complete the permission form (found in Appendix 2) and submit it to the APCA.

4.1 Training

Like other clinical and quality improvement / research tools, using the APCA African Children's POS is most effective when it is fully accepted by the clinical team. Importantly, the team must recognise its utility in the clinical setting if they are to avoid perceiving the instrument as a burdensome paper exercise that is in addition to, rather than an integral part of, their daily work commitments.

Consequently, and prior to any orientating training programme, informing and consulting staff on the introduction of the tool to ensure staff buy-in is an important first step. Not only is the rationale and need for the use of the tool explained, but staff are given an opportunity to input into the decision-making process so they own that process and are not sidelined from it.

Subsequent to the consultation process, it is essential that the tool is leveraged into everyday use by a supportive training programme, which could be supplemented by supervisory interventions. Such a programme should enable staff to:

- Appreciate the underlying rationale and purpose of the APCA African Children's POS ;
- Feel informed and assured about using it;
- Feel confident in analysing the resulting data, and;
- Understand the ways in which results can be used to improve care for children and overall service delivery.

While Appendix 3 outlines instructions that can be used to inform such a training programme, multiple editable PowerPoint presentations that can be used to deliver that programme are located in the enclosed CD-ROM.

In order to sustain staff commitment to using the APCA African Children's POS, it is important that those responsible for data analysis share their results and conclusions with all team members. This will help ensure that children, staff and the service as a whole benefit from the feedback. Additionally, a culture of individual blame must be avoided; the team will need to see solutions and provide recommendations to identified problems. Equally, staff need to be equipped with the skills and knowledge to enable them to act upon any questions or problems that arise from the tool. For example, should a child score a rating of five (i.e. most severe) on the question on pain question, it is critical that staff know how to fully respond.

Equally, practitioners should be aware that use of the APCA African Children's POS may extend the time of each child contact by enhancing the therapeutic experience. More specifically, given the structured nature of the tool, questions may be asked that might otherwise not have been raised by staff members with the children. This should be perceived in a positive light as a valuable opportunity to gather data on multiple aspects of the children's life and experiences.

Ultimately, the APCA African Children's POS should be regarded as an integral component of routine clinical care. However, for this to occur, and for its implementation to be effected reliably, requires ongoing, periodic training.

4.2 Adapting

Clinical tools have immense value in identifying children's concerns and guiding the appropriate care, as well as in evaluating treatments and interventions. Ensuring such tools are appropriate for the target audience often requires linguistic or cultural translation to ensure their validity.

4.2.1 Translating the APCA African Children's POS

Translating tools can help bridge the language gap that is often a barrier to establishing effective communication between the care provider and children. Moreover, by translating tools, health professionals can begin to identify and meet the health care needs of children from diverse groups.

However, the translation process is not a straightforward one; to ensure methodological rigour, there is a standardised process that needs to be followed. In this respect, the majority of published studies involving translation of clinical tools use very similar translation procedures (Brislin, 1986; Cull et al, 2002; Goh et al, 1996), which can broadly be summarised as:

- Step 1: Forward translation;
- Step 2: Back translation;
- Step 3: Reconciliation of differences;
- Step 4: Pre-testing, and;
- Step 5: Piloting.

In the forward translation process (for which it is often advisable to use an experienced translation company), the tool is translated from its original English into whatever language is desired. The resulting translations are then back translated into English by a different translator to that which undertook the forward translation. Discrepancies between the original and back-translated English versions are then discussed by the translation team (this is the reconciliation of differences stage) to decide on the most appropriate wording. The translated APCA African Children's POS is then pre-tested among a representative sample of the target population in order to ascertain their opinions of the translation's acceptability, comprehensibility, suitability and cultural relevance. Extensive piloting would then be needed to assess the validity and reliability of the translated APCA African Children's POS.

4.2.2 Adapting the APCA African Children's POS

In some clinical settings it might be appropriate to not only translate the APCA African Children's POS, but actually adapt its questions to better reflect particular clinical environments and children's needs. For example, some questions may not apply to particular child groups and more relevant information could be elicited when questions are adapted.

Questionnaire adaptation is one important implementation consideration for users of the APCA African Children's POS. It is important to remember, however, that extensive testing will be required to ensure that the adapted questionnaire has cultural applicability to the target audience (i.e. that the questions asked have cultural relevancy and meaning) and will produce accurate results.

4.3 Assessment

The frequency of administering the APCA African Children's POS can be influenced by a number of factors, including the organisational setting, child group and clinical need. For example, in an in-patient unit one may use the tool twice in a week to inform ward round discussions, providing a summary of children's conditions and to assess clinical interventions.

However, when children's conditions become critical, or particular symptoms become acute, the tool can be administered more frequently to help assess rapidly changing conditions and the appropriateness of clinical interventions. The frequency of assessments can be decided during the implementation phase, although it must be made clear what decision has been reached about its frequency before use of the APCA African Children's POS starts.

Regarding the period between assessments, the APCA African Children's POS asks for assessments based on the preceding one day. However, whilst children receiving in-patient care might be assessed every two-three days, children receiving outpatient or home-based care might be assessed at every contact, which could be once per week. In practice, users of the APCA African Children's POS may adopt a flexible approach to assessment frequency to closely reflect their own service.

Whereas it is not necessary that the tool is used concurrently with children and their main carers (e.g. some may not have an identified carer), the complementary perspectives that they produce can provide valuable information about children's' needs over time.

4.3.1 Signs of an incorrect assessment

Illustrative examples of occasions when the tool may have been administered incorrectly include:

The majority of scores are either '0' or '5', with few scores in between these extremes.

The tool is being completed by family members who cannot communicate verbally.

Questions are being missed (this can especially be the case with questions considered more sensitive by the person administering the tool).

The same score is recorded for all (or the overwhelming majority) of questions.

4.4 Analysis

4.4.1 Storing

APCA African Children's POS scores can be stored in a number of ways, including within children's clinical notes or in a computerised database. From the outset, it is important to recognise that methods of storing potentially sensitive APCA African Children's POS data should conform to the national legal requirements for the ethical protection of confidential data. Consult with your national ethics body on what these are for your country.

4.4.2 Scoring

The physical, psychological, spiritual, practical, emotional and psychosocial domains represented in the APCA African Children's POS are scored using a 6-point (i.e. 0-5) Likert-type scale, with numerical and descriptive labels at the extreme scores (i.e. 0 and 5). Children are asked to provide the answer that best represents their condition.

The APCA African Children's POS enables two types of scores to be generated:

- First: scores can relate to individual question items. Individual item scores can enable staff to monitor change over time amongst individual children and allow a focus on particular items (e.g. anxiety), as pertinent to particular children. Such procedures allow staff to assess and measure change in children's conditions against interventions adopted. Importantly, scores for individual children should not be reversed for analysis purposes.

- Second: scores can be summarised. The summary score is generated by the production of a rating against a potential range of scores from 0-35 for children and totalling scores from each question, and 0-25 for family members / carers questions. Importantly, to ensure that all scores are correctly directed (i.e. for the child's questions, the lower the score the better the outcome against an item the higher the score, the more severe the outcome), question 3 in child's section and the family questions – i.e. questions 8-12 – in section B of the tool, should be reversed²

4.4.3 Analysing³

As a starting point, it is good practice to check the data set that has been produced to ensure that none of the values from each item fall outside the legitimate value range (e.g. a score of 6 when the valid scores range from 0-5) by checking the minimum and maximum values. In this respect, frequency distributions can be used; this involves counting the number of observations in each category (e.g. the frequency distribution for the pain score is the number of children and carers who selected a pain score at a specified time point). Missing values (which are relatively common in palliative care, especially in studies conducted over time) should be noted.

²When using the tool in conjunction with other tools, however, the data analyst may wish to reverse the scores so they are consistent across the research instruments (e.g. all high scores indicate a positive outcome, low scores negative etc).

³This section is aimed primarily at practitioners with minimal experience of data analysis. It is always advisable, however, to secure assistance from recognised statisticians to avoid potential errors in analysis.

Some useful statistics that can be used to summarise the data that is gathered include:

- Mean: the average, calculated by summing all scores and dividing them by the number of items.
- Median: the value of the middle observation when all observations are listed in order from lowest to highest.
- Standard deviation: a measure of the dispersal of observations around the mean score.

To help grasp the meaning of a series of numbers visually, graphs can be used for the individual variables. The frequencies can be illustrated by a bar chart, with the bars drawn proportional to the frequencies or percentages in each category (see Figure 3 as an example). Usually the scores are listed on the horizontal scale, with their frequency along the vertical scale. Such graphs can be constructed using simple Microsoft Excel spread sheets.

However, graphs (which can be misleading depending upon how they are constructed) should be regarded as visual aids only and not as evidence of association or trends. Such evidence should only be drawn from statistical tests.

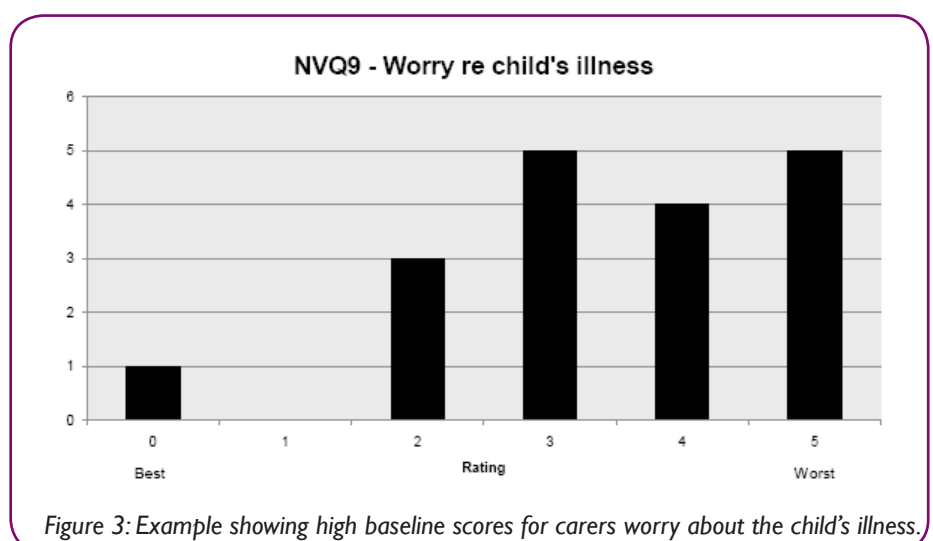
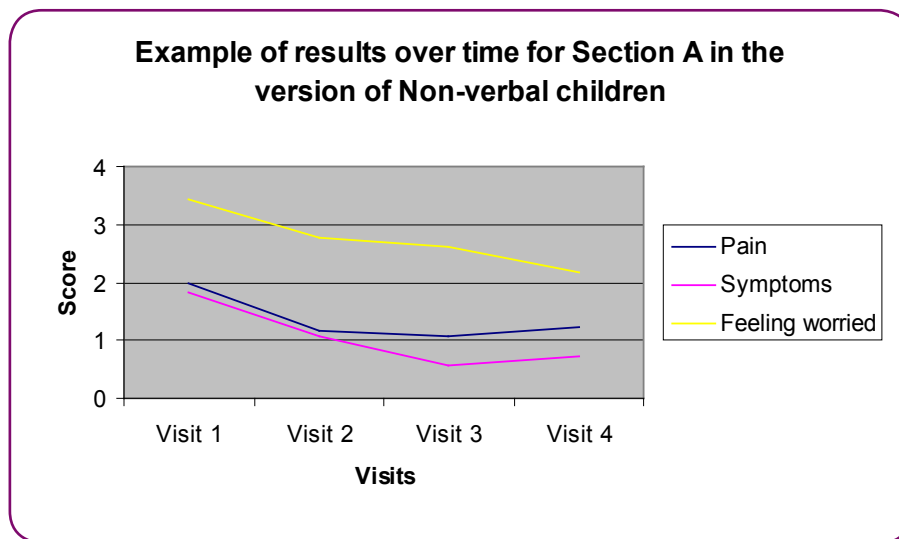


Figure 3: Example showing high baseline scores for carers worry about the child's illness.



Critical to the analysis stage is the detection of changes in scores over time (see Figure 4).

Each variable (e.g. pain) should be examined individually to this end. Graphs can also be used in this instance to depict changes, with the time variable on the horizontal axis, and the APCA African Children's POS scores listed on the vertical axis. In this way, mean scores can be compared over time to establish a trend. Importantly, it is easier to detect change when the means at different time points are compared with the mean at baseline (i.e. the first time point that an assessment was made).⁴ Depending upon local needs, it can also be helpful to investigate what happens to those with worst scores only (e.g. 4 and 5 scores) as a special need category to establish whether the care provided is making a difference.

When looking at change over time, you need to look at whether the results are statistically significant or not (i.e. whether the improvement seen can be put down to chance or whether the difference between the two groups is due to some systematic influence – e.g. the care given), and cannot be attributed to chance.

⁴It must be noted that whilst comparing T1 with subsequent time points is valid, caution should be exercised in interpreting the results. For example, the statistical test may indicate a significant change in pain scores between T1 and T2. However, another test comparing T1 and T3 would also include a measurement of the change from T1 and T2 (when children's presenting problems tend to be addressed by services before the children stabilizes, which means that differences between subsequent time points may not achieve statistical significance). Consequently, another analysis approach would be to compare the first time point to the last (i.e. T1 with T4), with the conclusion that over the time period under care, children scores improved / deteriorated, even if most of it occurs within the first assessment period. However, researchers need also to be aware of the Bonferroni's Principle; essentially that you will 'find' something if you look hard enough, in terms of conducting multiple statistical tests as part of what has been called a data mining approach to analysis. Again, discussions with statisticians in this respect are also critical.

P value

There are a series of statistical tests that can help you to decide whether the changes seen are significant or not. The main thing that you are looking for is the significance level (i.e. the probability that what you observe is due to the care that you give rather than due to chance). You are looking for what is called a 'p' value. If you see that $p < 0.05$, it means that there is a 1 chance in 20 that any differences found were due to chance. Hence the smaller the p value, the greater the significance of your results (i.e. the more likely that the results are not due to chance, but due to your intervention).

Further information on which statistical tests to use and how to use them can be seen in Appendix 4, where an example of some data from the APCA African Children's POS is given and you are shown how to calculate the mean, the median, the total APCA African Children's POS scores, and the significance of any change over time. More detailed information on how to analyse the APCA African Children's POS can be found through looking on line at different websites, for example:

- www.fon.hum.uva.nl/Service/Statistics/Signed_Rank_Test.html
- <http://udel.edu/~mcdonald/statsignedrank.html>

Both of these sites also have the facility for you to enter your data from which it will calculate the p value for you using the Wilcoxon signed rank test, along with giving information about different statistical packages you can use.

When socio-demographic data have also been collected for children, summary statistics and graphs could be used to profile the particular characteristics of the children group. Such data would also enable analysis that compared, for example, APCA African Children's POS scores by age group, clinical diagnosis, or the setting in which palliative care is being given. Moreover, variation over time could be seen.

4.4.4 Interpreting

Once children have completed the tool, there are many possible interpretations. These interpretations will be guided by clinical experience and the children's general condition. When analysed on an individual basis, the APCA African Children's POS scores enable a determination of an individual child's and family's needs within each domain over time, with interventions adjusted accordingly. Differences in scores between children and their main carers can help highlight specific issues for practitioners that need to be addressed.

More generally, differences in scores for particular items can help to identify areas for practice development, staff education and training.

CHAPTER 5:

The APCA African Children's POS in practice

Chapter 5: The APCA African Children's POS in practice

When using the APCA African Children's POS you will occasionally need to be flexible given there are some times when children and / or family needs are given priority. For instance, you may not ask all the questions during the first visit (e.g. if the child is in severe pain you may need to get their pain under control before they are able to respond to the remaining questions).

The APCA African Children's POS may be used in different ways (e.g. routine clinical practice, quality improvement, research etc). The exact process of how you administer the tool may vary slightly depending on the reason for its use (e.g. in routine clinical practice you do not need signed consent, whereas in research you do). For example, when using the APCA African Children's POS for research, it can be divided into four simple steps:

1. Opening the discussion
 - a. If possible make sure the interview is done in a relaxed environment where there are no interruptions or distractions.
 - b. Greet the child and carer and introduce yourself. Ensure both do not feel intimidated by you, as this may lead to bias.
 - c. Administer the information sheet and the consent form. Explain to the child (and family member / carer) why the interview is being done, how it will help the child, what it will involve, how much time it will take, and how the feedback of the interview will be used to benefit the child.
 - d. Answer any questions from the child and / or family member / carer.
2. During the administration of the APCA African Children's POS
 - a. Make sure you have a *thorough knowledge* of the questionnaire and scales and how to complete them.
 - b. Build and establish a good rapport and interview environment.
 - c. Avoid making any judgment, forming stereotypes or assumptions about the child and / or family member / carer as this may affect the relationship during the interview and lead to biased responses by the child.
 - d. Ask the questions in exactly the way they are worded and in the order in which they appear on the questionnaire. Never decide that a question is inappropriate; let the respondent decide if it is inappropriate or not.
 - e. Take note of non-verbal cues (e.g. gestures, body language, and facial expression). Apply the distress protocol when necessary (see Appendix 5).
 - f. Encourage the child to answer the question by being interested (i.e. nodding, focussing attention on the children, not interrupting). Probe if the child or the carer is unsure what the question means: reread the question, repeat the explanation of the responses to be chosen from, use visual signs and record the response. Remember, there is no right or wrong answer, hence be sensitive to your reaction to the child's answers even if you do not agree with them.
 - g. Remember to remain professional throughout the interview, showing empathy as appropriate.

3. Ending the interview

- a. Allow the interview to wind down so that the child and family member / carer feels they have said all they want to say.
- b. Never rush the child or family member / carer.
- c. Alert the child that the interview is coming to an end.
- d. Reassure the carer that the information given will be treated as confidential and used only for the purpose of improving the child's care.
- e. Discuss and agree with the child and carer about the next appointment. If it is the last interview, inform them so.
- f. Give the child and family member / carer time to ask question or give comments.
- g. Thank the child and or carer for their time.
- h. Release the child and family member / carer and advise on the next step (i.e. what to do next).

4. After the interview

- a. Look through the questionnaire and make sure all the questions are responded to (if the interview was not completed, state why not).
- b. Keep the questionnaire in a safe confidential place as governed by the facility (i.e. locker, children file, folder).
- c. Enter the data into the computer as appropriate.

Distress protocol

Any respondent who appears to be in distress during the administration of the APCA African Children's POS should be offered the opportunity to cease the interview (with the reassurance that to do so will not affect their care and treatment) and to either abandon or restart (with a rescheduled appointment time and date) when they are comfortable.

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APPENDICES

Appendix I: User guidelines for using the APCA African Children's POS

The African Palliative Care Association has developed the following user guidelines to assist with the correct and consistent use of the APCA African Children's POS. The guidelines have been developed to accompany the APCA African Children's POS Permission Form to Reproduce / Use form.

At first glance, this document may seem rather long. However, as you will see, there are only 12 questions in the tool itself and these guidelines are intended to clarify what we mean by each question. ***It is important to read and understand the guidelines before you conduct any interviews with children or family carers.***

Instructions for completing Section A of the tool

Within section A of the tool each question is phrased in two different ways. The questions on the left-hand side of the table should be asked to the child themselves if they are able to respond to the questions. In order for the child to answer these questions they should have the cognitive ability to understand the question and how to answer; generally this can be used for children aged six and older. The questions on the right-hand side of the table are those to be asked to the parent / carer. On occasions a child may be able to respond on one visit but too unwell to respond on another. For the sake of consistency, however, the same respondent should answer the questions over time. Lastly, Section A should always be completed by the family / carer and, if the child is able to, then it should be completed by the child as well. On occasions where there is no family member / carer present, this section may be completed by the nurse caring for that child.

Questions for the child

Questions in the first section of the tool will be asked to the child themselves, where possible. In introducing this questionnaire to the child, you could say something like:

'I would like to ask you some questions to help me understand how we can look after you in the best way that we can. I will need to ask you the same questions today and then during my next three visits. The questions are not difficult and you can take your time answering. If you are not sure what any of the questions mean, I can explain and if you don't want to answer any of the questions then that is OK; just tell me that you do not want to answer it at the moment.'

You will ask the child to respond to each question by using either the hand or verbal scale:



If possible, ask the questions to the child without the carer present so it does not influence the carers' responses to the questions they will be asked. If this is not possible, then it may be better to ask the carer the questions in Section A before asking the child. Please note that the verbal descriptors are only at the extreme items, and the children and carers should place themselves somewhere in between the anchor points of possible answers (i.e. the top and bottom scores, such as worst and best for 0 and 5).

Question 1: Can you tell me how much pain you have had since yesterday?

- Remind the child that we are talking about *any* pain he / she feels today or has felt since yesterday.
- **Before** asking this question, discuss with the child what pain could include (i.e. anything that hurts, interferes with daily activities – such as sleep, dressing, walking, eating, washing, work including household chores). Remember, pain is whatever the child says it is and is not only physical.
- Explain the rating scale 0 and 5. Choose which of the rating scales would be the best way of assessing **this** child's pain :
 - 0 = No pain
 - 5 = The worst pain you can imagine.
- Check that the child understands the question (e.g. 'Does this question make sense to you?').
- Allow them time to decide on his / her response to the question.
- Record the child's response on the response sheet.

Question 2: How much have other problems with your body been troubling you since yesterday? (Prompt only if needed: e.g. being sick, going to the toilet a lot)?

- This question is addressing the issue of other symptoms – we are specifically looking at physical symptoms here – you may need to explain this further to the child.
- Allow them time to decide on his / her response to the question.
- Explain the rating scale 0 and 5.
 - 0 = No other problems with my body have been troubling me
 - 5 = Other problems with my body have been troubling me very much
- Record the child's response on the response sheet.

Question 3: Can you tell me how much you have been feeding since yesterday?

- This question deals with issues around nutrition and feeding. It is looking at whether the child has felt like eating – it is trying to assess their appetite.
- Do not rush this question. Allow the child enough time to think about it.
- Explain the rating scale 0 and 5.
 - 0 = Not feeding at all
 - 5 = Feeding enough
- Please **NOTE** that this scale is **REVERSED**, with **0** being the most negative and **5** being the most positive response.
- NB: If the child is being fed artificially then choose option 5 for 'eating enough.'
- Record the child's response on the response sheet.

Question 4: Can you tell me how much you have cried since yesterday?

- Crying is another way that a child can communicate – not crying could be due to depression or a lack of interest in what is going on, whilst a lot of crying could be due to pain or anxiety etc.
- Do not rush this question. Allow the child enough time to think about it.
- Explain the rating scale 0 and 5.
 - 0 = Not cried at all
 - 5 = Cried all the time
- Record the child's response on the response sheet.

Question 5: Can you tell me how often you have felt happy since yesterday?

- Do not rush this question. Allow the child enough time to think about it.
- Explain the rating scale 0 and 5.
 - 0 = Happy all the time
 - 5 = Not happy at all
- Record the child's response on the response sheet.

Question 6: How much have you felt like playing since yesterday?

- Children like to play – for each child play may take on a different form, particularly if that child has special needs or is developmentally delayed. It is not, therefore, the amount or type of playing that we are interested in here but whether the pattern of their play has changed, for example not wanting to play at all.
- Do not rush this question. Allow the child enough time to think about it.
- Explain the rating scale 0 and 5.
 - 0 = Felt like playing all the time
 - 5 = Have not felt like playing at all
- Record the child's response on the response sheet.

Question 7: How much have your questions about your sickness been answered since yesterday?

- Children have questions, they want to know what is happening to them, and they want to feel that their questions, however difficult, have been answered or addressed.
- Do not rush this question. Allow the child enough time to think about what might be sources of worry or questions.
- The child will then need to decide on the intensity of the worry
- Explain the rating scale 0 and 5.
 - 0 = As much as I wanted / had no questions
 - 5 = Have not been answered at all
- Record the child's response on the response sheet.

Questions for the family / carer

Having asked the child the questions in Section 1, you also need to ask the carer the questions from that section – they have been rephrased and can be found on the right hand side of the table – as well as the questions in Section 2. In the rare occasion where there are no carers available, then the health professional themselves can complete Section 1. However, if this is the case then they should do it before asking the child. In introducing this questionnaire to the parent / carer, you could say something like:

‘I would like to ask you 12 questions to help me understand how we can provide the best care for yourself and your child. I will need to ask you the same questions today and during my next three visits. The questions are not difficult and you can take your time answering. If you are not sure what any of the questions mean, I will be happy to explain. If any of these questions make you feel uncomfortable, just say ‘I don’t want to answer that at the moment’.

‘The information that you share with me may be used to help other people, but your name will not be written on the questionnaire.

‘Before we start, is there anything you need to do or to ask?’ (e.g. they may want a drink of water, have a change in position etc.).

‘You will be asked to respond to each question with an answer on a 0-5 scale using either the hand scale or verbal rating scale:



Section A: About the child

Question 1: Can you tell me how much pain your child has had since yesterday?

- Remind the parent / carer that we are talking about any signs of pain he / she has seen in their child over the last one day.
- Remember, pain is whatever the children says it is and is not only physical.
- Explain the rating scale 0 and 5. Choose which of the following scales would be the best way of them assessing signs of pain in their child.

Verbal rating scale:

0 = No signs of pain at all

5 = Signs of overwhelming pain / the worst pain that you can imagine

Hand scale:

0 = Thumb up = No signs of pain at all

5 = All five fingers = Signs of overwhelming pain / the worst pain that you can imagine

- Check that the parent / carer understands the question (e.g. ‘Does this question make sense to you?’).
- Allow them time to decide on his / her response to the question.
- Record their response on the response sheet.

Question 2: How much have other problems with their body been troubling your child since yesterday (Prompt only if needed: e.g. vomiting, diarrhoea etc)

- Before asking this question, make sure that the parent / carer understands what the word 'symptom' means. If they are not familiar with the word, explain that it refers to any unpleasant sensation or feeling.
- Allow them time to decide on his / her response to the question.
- Explain the rating scale 0 and 5.
0 = Not at all
5 = Overwhelmingly
- Record their response on the response sheet.

Question 3: Since yesterday, how much has your child been feeding?

- This question deals with issues around nutrition and feeding. It is looking at whether there have been any changes in their feeding pattern. This may mean eating more than usual or less than usual; however, what is important is that they are having enough to eat.
- Do not rush this question. Allow the parent / carer enough time to think about it.
- Explain the rating scale 0 and 5.
0 = Not feeding at all
5 = Feeding enough / the child is unconscious / being fed artificially
- Please **NOTE** that this scale is **REVERSED**, with **0** being the most negative and **5** being the most positive response.
- Record their response on the response sheet.

Question 4: Since yesterday, how much has your child been crying?

- Crying is another way that a non-verbal child can communicate – less crying than usual could be due to depression or a lack of interest in what is going on, whilst more crying than usual could be due to pain or anxiety etc. Therefore we are looking at any changes in their crying pattern that might reflect something deeper that is going on.
- Do not rush this question. Allow the parent / carer enough time to think about it.
- Explain the rating scale 0 and 5.
0 = Not crying at all / the child is unconscious
5 = Crying constantly
- Record their response on the response sheet.

Question 5: Since yesterday, how much has your child felt happy?

- Happiness is an outward sign of something deeper – if a child is happy then they are more likely to be 'at peace'. However, it is a subjective term and may not be easy for the parent / carer to understand – helpful terms could include comfortable, satisfied, at ease, content.
- Do not rush this question. Allow the parent / carer enough time to think about it.
- Explain the rating scale 0 and 5.
0 = Happy all the time
5 = Not happy at all
- Record their response on the response sheet.

Question 6: Since yesterday, how much has your child felt like playing?

- Children like to play – for each child play may take on a different form, particularly if that child has special needs or is developmentally delayed.
- Do not rush this question. Allow the parent / carer enough time to think about it.
- Explain the rating scale 0 and 5.
 - 0 = Felt like playing very well
 - 5 = Not felt like playing at all / the child is unconscious
- Record their response on the response sheet.

Question 7: How much have the child's questions about his / her sickness been answered since yesterday?

- Children have questions, they want to know what is happening to them, and they want to feel that their questions, however difficult, have been answered or addressed.
- Do not rush this question. Allow the parent / carer enough time to think about what might be sources of worry.
- The carer will then need to decide on the extent to which their questions have been addressed:
 - 0 = As much as I wanted / child had no questions
 - 5 = Have not been answered at all
- Record their response on the response sheet.

Section B: About the family / carer

NB: Please note that like the child questions, the period for all questions is since yesterday.

Question 8: Since yesterday, how much have you been feeling worried about your child's illness?

- This question deals with any concerns the parent / carer might have about his / her child's illness (e.g. the impact on their role as breadwinner or mother, increasing dependency, becoming a burden to the family, inability to cope with daily living activities, financial concerns, coping with symptoms etc. Note: These are only examples for you and are not intended as prompts for the parent / carer).
- Do not rush this question. Allow the parent / carer enough time to think about what might be sources of worry.
- The carer will then need to decide on the intensity of the worry:
 - 0 = Not at all worried
 - 5 = Worried all of the time
- Record their response on the response sheet.

Question 9: Since yesterday, have you been able to share how you are feeling about your child's illness with others when you have wanted to?

- It is important to consider that some people may find it risky or culturally inappropriate to discuss their feelings with family members or friends. Please take this into account when you ask the question.

- Do not rush this question. Allow the parent / carer enough time to think about it.
- Explain the rating scale 0 and 5.
0 = Not at all
5 = Talked freely
- Please **NOTE** that this scale is **REVERSED**, with **0** being the most negative and **5** being the most positive response.
- Record their response on the response sheet.

Question 10: Since yesterday, how much information have you and your family been given about your child's illness?

- We are trying to find out whether the family feels that they are part of the care team and whether they feel that they have had their questions answered.
- Do not rush this question. Allow the parent / carer enough time to think about it.
- Explain the rating scale 0 – 5.
0 = None
5 = As much as wanted
- Please **NOTE** that this scale is **REVERSED**, with **0** being the most negative and **5** being the most positive response.
- Record their response on the response sheet.

Question 11: Have you had enough help and advice for your family to plan for the future with regards to your child's illness?

- Planning for the future could mean short term (e.g. the next few days, or long term, such as the next few months). It could include making arrangements for completing a memory box, deciding where and how you would like the child to be cared for etc.
- The concept of planning for the future could be a problem issue for some children's and some cultures. You will need to use your own judgement as to how far you can explore this issue with the parent / carer.
- Do not rush this question. Allow the parent/ carer enough time to think about it.
- Explain the rating scale 0 – 5.
0 = None
5 = As much as wanted
- Please **NOTE** that this scale is **REVERSED**, with **0** being the most negative and **5** being the most positive response
- Record their response on the response sheet.

Question 12: How confident does the family feel caring for ----- (Note: name of the child here)?

- This question is aimed at finding out whether giving family carers information and showing them how to care for the children at home makes them feel more confident about providing care.
- You might need to discuss what confidence means by asking what the person / family felt they couldn't, or were afraid to do before and whether they feel that they can do these things for the children now.
- Do not rush this question. Allow the parent / carer enough time to think about it.
- Explain the rating scale 0 – 5.
0 = Not at all
5 = Very confident
- Please **NOTE** that this scale is **REVERSED**, with **0** being the most negative and **5** being the most positive response.
- Record their response on the response sheet.

How to deal with possible responses

- It is important that you respond to any needs that are identified during the administration of the tool. For example, if the child indicates severe or overwhelming pain, then you will need to stop asking questions and deal with this.
- Both the child and their carer may have questions for you in response to the questions that you are asking – use this as an opportunity to answer their questions and provide any information that they might need.
- At all times the well-being of the child is your concern.
- Please refer to the distress protocol if either the carer or the child gets distressed during the administration of the questionnaire.

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Date: April 2012

Appendix 2: APCA African Children's Palliative Outcome Scale: Permission to reproduce / use

Please complete either section A or B, and your contact details in Section C, and email a scanned version to info@africanpalliativecare.org or fax it to +256 (0)414 266 217 or complete the online form that can be found at the APCA website www.africanpalliativecare.org.

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Appendix 3:

Training programme for using the APCA African Children's POS

Like other clinical and quality improvement / research tools, using the APCA African Children's POS is most effective when it is fully accepted by the clinical team, and therefore it may be important to conduct some training for the team. Power Points have been developed to help with this and they can be downloaded from the APCA website or from the CD that accompanies these guidelines.

There are six different presentations focusing on:

1. APCA
2. The APCA African Children's POS
3. Data collection (i) – General
4. Data collection (ii) – Specific
5. Data entry and storage
6. Analysis

These can be used together or separately, as you feel appropriate.

Appendix 4:

Example of analysing the APCA African Children's POS

The analysis of the APCA African Children's POS is an area in which people feel nervous. This section is aimed to take you through a step-by-step process for analysis the APCA African Children's POS. Below follows an example of some data from the APCA African Children's POS from a palliative care organisation. In this example, the APCA African Children's POS has been used on 10 different children over 4 time points (please note that this is only an example and ideally the number of patients potentially should be significantly higher to conduct statistical analysis).

APCA African Children’s POS scores on child’s section for verbal child

Questions	Patient 1				Patient 2				Patient 3				Patient 4				Patient 5			
	Assessment Number				Assessment Number				Assessment Number				Assessment Number				Assessment Number			
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Q1. Can you tell me how much pain you have had since yesterday?	5	5	3	2	3	1	1	1	5	3	3	1	4	3	2	2	5	2	2	1
Q2. How much have other problems with your body been troubling you since yesterday? <i>(Prompt only if needed: e.g. being sick, going to the toilet a lot)?</i>	1	1	3	4	4	3	3	1	1	5	4	1	4	3	2	2	4	4	2	1
Q3. Can you tell me how much you have been feeding since yesterday?	1	1	1	1	3	3	1	1	4	3	2	1	5	5	2	2	4	4	2	2
Q4. Can you tell me how much you have cried since yesterday?	4	4	2	2	3	3	3	3	1	1	3	4	2	2	4	4	0	0	2	3
Q5. Can you tell me how often you have felt happy since yesterday?	2	2	3	2	0	0	2	2	1	2	3	4	3	3	1	1	2	2	2	2
Q6. How much have you felt like playing since yesterday?	2	2	3	3	1	1	3	4	0	1	3	3	1	1	1	1	2	2	3	3
Q7. How much have your questions about your sickness been answered since yesterday?	2	2	2	2	3	3	5	5	2	2	3	3	4	4	3	3	3	3	4	4
Family questions																				
Q8. How much have you been feeling worried about your child’s illness?	0	1	3	3	1	3	3	4	2	2	3	3	2	4	4	3	1	1	3	3
Q9. Have you been able to share how you are feeling about your child’s illness with others when you have wanted to?	0	1	2	3	1	2	2	3	1	2	3	3	2	2	2	3	2	2	3	4
Q10. How much information have you and your family been given about your child’s illness?	2	4	3	1	5	4	4	2	5	3	1	1	5	3	1	2	4	2	2	1
Q11. Have you had enough help and advice for your family to plan for the future with regards to your child’s illness?	0	1	3	3	1	3	3	4	2	2	3	3	2	4	4	3	1	1	3	3
Q12. How confident does the family feel caring for the child?	0	1	2	3	1	2	2	3	1	2	3	3	2	2	2	3	2	2	3	4

Questions	Patient 6				Patient 7				Patient 8				Patient 9				Patient 10			
	Assessment Number				Assessment Number				Assessment Number				Assessment Number				Assessment Number			
	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Q1. Can you tell me how much pain you have had since yesterday?	0	1	3	1	5	4	4	2	5	3	1	1	4	3	1	2	2	2	2	1
Q2. How much have other problems with your body been troubling you since yesterday? <i>(Prompt only if needed: e.g. being sick, going to the toilet a lot)?</i>	5	2	2	2	4	4	2	1	5	3	2	2	2	4	2	1	3	3	1	1
Q3. Can you tell me how much you have been feeding since yesterday?	1	1	0	0	1	4	2	1	5	3	1	1	3	3	2	2	3	1	1	1
Q4. Can you tell me how much you have cried since yesterday?	1	1	3	3	3	1	1	1	0	2	2	3	2	2	2	2	2	2	3	4
Q5. Can you tell me how often you have felt happy since yesterday?	2	2	3	3	1	1	3	4	0	1	3	3	1	1	1	1	2	2	3	3
Q6. How much have you felt like playing since yesterday?	2	2	3	2	0	0	2	2	1	2	3	4	3	3	1	1	2	2	2	2
Q7. How much have your questions about your sickness been answered since yesterday?	2	2	3	3	1	1	1	1	0	1	3	3	1	1	3	4	2	2	3	3
Family questions																				
Q8. How much have you been feeling worried about your child's illness?	3	3	3	3	1	2	4	4	2	4	4	5	2	2	2	1	1	4	4	4
Q9. Have you been able to share how you are feeling about your child's illness with others when you have wanted to?	3	3	3	3	3	3	4	4	2	1	3	4	1	1	2	2	0	2	3	4
Q10. How much information have you and your family been given about your child's illness?	5	2	2	1	5	5	3	2	5	3	3	1	1	1	1	5	2	3	3	2
Q11. Have you had enough help and advice for your family to plan for the future with regards to your child's illness?	3	3	3	3	1	2	4	4	2	4	4	5	2	2	2	1	1	4	4	4
Q12. How confident does the family feel caring for the child?	3	3	3	3	3	3	4	4	2	1	3	4	1	1	2	2	0	2	3	4

I. Calculating the average

The **mean** is the average and is calculated by summing all scores and dividing them by the number of items. Therefore, if you wanted to know the mean score at each time point for pain you would add up all of the scores for each patient for question 1 for time point 1, and then time point 2, and then time point 3 and then time point 4 and divide each of them by the number of patients, as below.

Time point 1

Questions	Patient	1	2	3	4	5	6	7	8	9	10	Sum of all of the scores	Mean (i.e. sum divided by 10)
	Visit	1	1	1	1	1	1	1	1	1	1		
Q1. Can you tell me how much pain you have had since yesterday?		5	3	5	4	5	0	5	5	4	2	38	3.8

Time point 2

Questions	Patient	1	2	3	4	5	6	7	8	9	10	Sum of all of the scores	Mean (i.e. sum divided by 10)
	Visit	2	2	2	2	2	2	2	2	2	2		
Q1. Can you tell me how much pain you have had since yesterday?		5	1	3	3	2	1	4	3	3	2	27	2.7

Time point 3

Questions	Patient	1	2	3	4	5	6	7	8	9	10	Sum of all of the scores	Mean (i.e. sum divided by 10)
	Visit	3	3	3	3	3	3	3	3	3	3		
Q1. Can you tell me how much pain you have had since yesterday?		3	1	3	2	2	3	4	1	1	2	22	2.2

Time point 4

Questions	Patient	1	2	3	4	5	6	7	8	9	10	Sum of all of the scores	Mean (i.e. sum divided by 10)
	Visit	4	4	4	4	4	4	4	4	4	4		
Q1. Can you tell me how much pain you have had since yesterday?		2	1	1	2	1	1	2	1	2	1	14	1.4

The **median** is the value of the middle observation when all observations are listed in order from lowest to highest. If there is an even number the median is simply the average between the middle two values. So:

- The median for time point 1 is: 0 2 3 4 4 5 5 (i.e. the average between 4 and 5 so the median is 4)
- The median for time point 2 is: 1 1 2 2 3 3 3 (i.e. the median is 2)
- The median for time point 3 is: 1 1 1 2 2 2 3 (i.e. the median is 2)
- The median for time point 4 is: 1 1 1 1 1 1 2 (i.e. the median is 1)

The **standard deviation** is a measure of the dispersal of observations around the mean score (i.e. in practical terms, it is the average distance from the mean and is the most frequently used measure of variability). There is a formula for calculating the standard deviation which looks more complicated than it is:

$$s = \sqrt{\frac{\sum (x - \bar{x})^2}{n - 1}}$$

Where:

- S is the standard deviation
 \sum is sigma, which tells you to find the sum of what follows
 X is each individual score
 \bar{x} is the arithmetic mean of all the scores
 n is the sample size

A simple way to calculate the standard deviation is as follows (we will use the data from Question 1 time point 1):

- List each score – it does not matter whether the scores are in any particular order, i.e. 5 3 5 4 5 0 5 5 4 2.
- Compute the mean of the group – we have already done this and it is 3.8.
- Subtract the mean from each score, as below.

Individual score	Mean	(X- \bar{X})
5	3.8	1.2
3	3.8	-0.8
5	3.8	1.2
4	3.8	0.2
5	3.8	1.2
0	3.8	-3.8
5	3.8	1.2
5	3.8	1.2
4	3.8	0.2
2	3.8	-1.8

d. Square each individual difference, as below.

Individual score	$(x-\bar{x})$	$(x-\bar{x})^2$
5	1.2	1.44
3	-0.8	0.64
5	1.2	1.44
4	0.2	0.04
5	1.2	1.44
0	-3.8	14.44
5	1.2	1.44
5	1.2	1.44
4	0.2	0.04
2	-1.8	3.24
Total	0	25.6

- e. Sum all of the squared deviations about the mean – as you can see above the total is 25.6.
- f. Divide the sum by n-1 (i.e. 10-1 = 9, so that is 25.6/9 =2.84).
- g. Compute the square root of 2.84, which is 1.69.

Therefore the standard deviation for this set of scores is 1.69 – i.e. that each score for this question differs from the mean by an average of 1.76 points. So what does this mean? The larger the standard deviation, the more spread out the values are, and the more deviant they are from one another. If the standard deviation is 0 this means that they are all identical in value and rarely happens.

2. Calculating frequencies

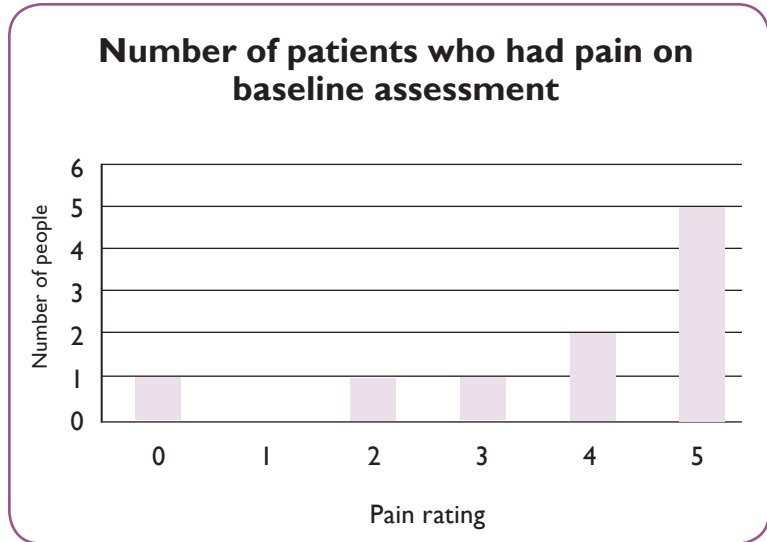
Frequencies can be illustrated by a bar chart, with the bars drawn proportional to the frequencies or percentages in each category (see Figure 5 for an example). Usually the scores are listed on the horizontal scale, with their frequency along the vertical scale. So if you take this set of data as an example and you want to see the number of patients who had pain on baseline assessment you would look at the following information:

Questions	Patient	1	2	3	4	5	6	7	8	9	10
	Visit	1	1	1	1	1	1	1	1	1	1
Q1. Can you tell me how much pain you have had since yesterday?		5	3	5	4	5	0	5	5	4	2

If the data is entered into an Excel sheet you could then produce a table and a graph such as:

Rating	Number of Patients
0	1
1	0
2	1
3	1
4	2
5	5

6



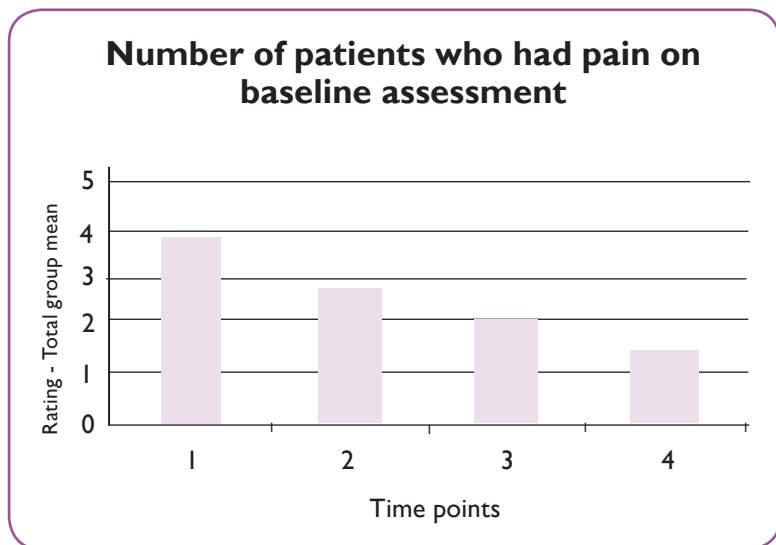
Once you have this information for all of the questions you can look at the graphs and identify which were the worst problems at the time of the baseline assessment – for example, you can tell from the chart above that many of the patients (70%) had a score of 4 or 5 for pain, showing that there was a high level of pain at the baseline assessment. This will help you get a feel of the problems that you patients are experiencing and also when looking at change in scores over time you know the key problems that you need to look at.

3. Detection of change in scores over time

The detection of changes in scores over time is important to the analysis stage and will show you whether you are making a difference in that particular area (i.e. has there been a change in score over the 4 visits). This can be done in two different stages – firstly, you can look at the mean scores at each stage and compare this, and secondly you can look at whether these are statistically significant or not.

If we continue to use the first question as an example, we can clearly see that there has been a change in scores over time by looking at the means at each time point, as below (see Figure 5).

Time point	Mean Score
1	3.8
2	2.7
3	2.2
4	1.4

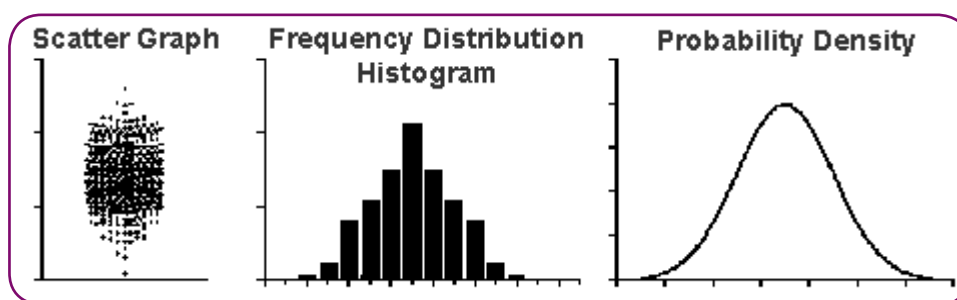


In this example, it is easy to see that change has occurred over time as the differences between the means are quite large. On many occasions in the clinical setting this is the main thing that you are looking for – so from looking at this example you could say that generally the patient's pain is being managed by the site and is improving over time.

However, it is not always this clear, and if you are conducting an audit of your services or trying to use the APCA African Children's POS for a research study then you will need to look at whether the results are statistically significant (i.e. whether the improvement seen can be put down to chance or whether the difference between the two groups is due to some systematic influence; e.g. the care given, and cannot be attributed to chance). There are a series of statistical tests that can help you to decide whether the changes seen are significant. The main thing that you are looking for is the significance level (i.e. the probability that what you observe is due to the care that you give rather than due to chance). You are looking for what is called a 'p' value. If you see that $p < 0.05$ it means that there is a 1 chance in 20 that any differences found were due to chance. Hence the smaller the p value, the greater the significance of your results.

The distribution of the data in your dataset will in part (the other factor being the numbers of cases entailed) determine the nature of the appropriate statistical tests to be used with the APCA African Children's POS. Important is the extent to which the data is distributed 'normally' in a bell-shape, as shown in Figure 6.

Figure 6: The normal distribution of data



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A normal distribution forms the basis for many statistical tests. Determining if your data is distributed in this way can be done in several ways – the two simplest ways to do this are by:

- a. Checking if the mean and median are equal (this is a perfect normal frequency distribution), with the data continuous and symmetrically distributed around the central point. As can be seen from our example above, the mean and median are not equal for question 1.

Time point	Mean Score	Median Score
1	3.8	4.5
2	2.7	3.0
3	2.2	2.0
4	1.4	1.0

- b. Checking if, for a perfect normal frequency distribution:
 - 68% of samples fall between ± 1 standard deviations from the mean
 - 95% of samples fall between ± 2 standard deviations from the mean
 - 99.7% of samples fall between ± 3 standard deviations from the mean

If we look at our sample again from question 1 and time point 1, we see that:

- 3 out of 10 (30%) of scores fall between ± 1 standard deviations from the mean
- 9 out of 10 (90%) of scores fall between ± 2 standard deviations from the mean
- 9 out of 10 (90%) of scores fall between ± 3 standard deviations from the mean

Individual score	Mean	(X-X)
5	3.8	1.2
3	3.8	-0.8
5	3.8	1.2
4	3.8	0.2
5	3.8	1.2
0	3.8	-3.8
5	3.8	1.2
5	3.8	1.2
4	3.8	0.2
2	3.8	-1.8

Therefore it can be seen from these two very simple tests that the distribution of the data is not a normal distribution.

This is important in helping us to decide which test we should use to determine the significance of the results that we have. If the distribution of data is normal (i.e. bell-shaped), parametric tests can be used (i.e. those that take into account *all* collected scores, and are therefore affected by the 'parameters' of the data sets); if it is not, as in our example, then non-parametric scores can be used (i.e. those that are not affected by the distribution of the data).

Examples of <i>parametric</i> tests	Examples of <i>non-parametric</i> tests
<ul style="list-style-type: none"> • Paired t-test • ANOVA (one way) • Independent t-test • Person product moment correlation 	<ul style="list-style-type: none"> • Wilcoxon signed rank test • Kruskal Wallis • Chi square • Mann-Whitney U test • Spearman's rank order correlation

It is our experience at APCA when using the APCA African Children's POS that we rarely achieve a normal distribution for the data and so we tend to use a non-parametric test to check for significance called the Wilcoxon signed-rank test. This test is based on the difference between scores at the two times you are comparing (i.e. between time point 1 and time point 2). It examines whether the median difference between pairs of observations from the two groups is equal to zero. Whilst the test appears quite complicated, the example below will take you through it step by step to help you calculate whether the difference is significant or not.

- a. If we look at our example again with regards to the question on pain, and want to compare time points 1 and time points 2. The difference between them is:

Time point 1	Time point 2	Difference
5	5	0
3	1	2
5	3	2
4	3	1
5	2	3
0	1	-1
5	4	1
5	3	2
4	3	1
2	2	0

- b. As the difference is 0 for two of them, these are excluded from the ranking, hence the remaining differences are ranked, assigning a different rank for each difference, and assigning the difference (i.e. the positive or negative) to the rank itself. The absolute value of the differences between observations are ranked from smallest to largest, with the smallest difference getting a rank of 1, then next larger difference getting a rank of 2, etc. i.e.:

Time Point 1	Time point 2	Difference	Sign of Difference	Absolute Difference	Rank
3	1	2	+	2	7
5	3	2	+	2	6
4	3	1	+	1	4
5	2	3	+	3	8
0	1	-1	-	1	3
5	4	1	+	1	2
5	3	2	+	2	5
4	3	1	+	1	1

- c. The remaining differences are then ranked in ascending order of magnitude, as below.

Time Point 1	Time point 2	Difference	Sign of Difference	Absolute Difference	Rank
4	3	1	+	1	1
5	4	1	+	1	2
0	1	-1	-	1	3
4	3	1	+	1	4
5	3	2	+	2	5
5	3	2	+	2	6
3	1	2	+	2	7
5	2	3	+	3	8

- d. If any differences are equal, then average their ranks – so, in our example, there are 4 that have a difference of 1, so you add up their ranks (1+2+3+4 and divide by 4) = 2.5. The same with the 2s (5+6+7 and divide by 3) = 6. So you are left with:

Time Point 1	Time point 2	Difference	Sign of Difference	Absolute Difference	Rank	Absolute Rank	Signed Rank
4	3	1	+	1	1	2.5	2.5
5	4	1	+	1	2	2.5	2.5
0	1	-1	-	1	3	2.5	-2.5
4	3	1	+	1	4	2.5	2.5
5	3	2	+	2	5	6	6
5	3	2	+	2	6	6	6
3	1	2	+	2	7	6	6
5	2	3	+	3	8	8	8

- e. You then count up the ranks of positive differences and of the negative differences and denote the sums by T+ and T- respectively. i.e.:

$$T+ = (2.5*4) + (6*3) + 8 = 33.5$$

$$T- = 2.5$$

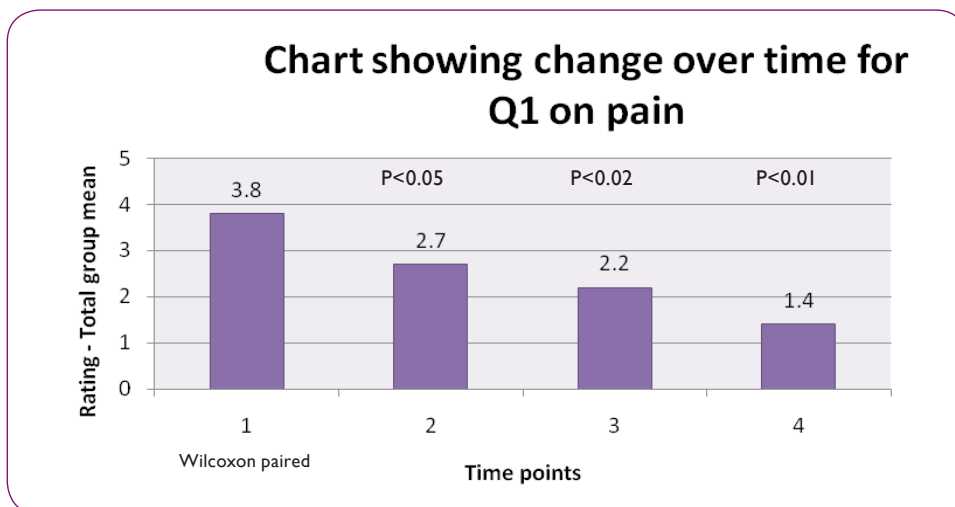
- f. If there are no differences, then the sums T+ and T- would be similar. If there are differences then one sum would be much smaller and one sum would be much larger than expected. Denote the smaller sum by T. So in this example, T = 2.5
- g. The Wilcoxon signed rank is based on assessing whether T is smaller than would be expected by chance. The p value is therefore derived from the sampling distribution of T. Note that the appropriate sample size (n) is the number of differences that were ranked rather than the total number of differences and therefore does not include the zero differences (n is the number of non-zero differences). The smaller the p value the greater the significance. The p value can be found by comparing the value of T with values for p=0.1, p=0.05, p=0.02, and p=0.01 given in table I below. In the table:

N = the number of non-zero differences
 T = the smaller of T+ and T-
 It is significant if T < the critical value

So in our example, to get the p value look at the table down the first column (marked N) until you get to number 8 (i.e. the number of non-zero-differences that we had in part a). We know that T is 2.5, which falls between the numbers for 0.05 and 0.02 so that means that p < 0.05, which means that it is likely that any change is not due to chance but due to the care provided.

If we calculate the significance value (p value) for each of the time points we begin to get a picture of the significance of the changes associated with the question on pain, i.e. between:

- Time point 1 and time point 3 – p < 0.02
- h. Time point 1 and time point 4 – p < 0.01 (see Figure 7)



4. Total APCA African Children’s POS scores

Original	Reversed
0	5
1	4
2	3
3	2
4	1
5	0

The APCA African Children’s POS scores can be summarised. The summary score is generated by totalling scores from each question, and the production of a rating against a potential range of scores from 0-35 for patients and 0-25 for carers. Importantly, to ensure that all scores are correctly directed (i.e. the lower the score the better the outcome against an item, the higher the score, the more severe the outcome), those who are responsible for data analysis must reverse the scores for questions 3, 8-12 (i.e. if the patient gives them a score of 5, you reverse that to a score of 0). Therefore, using our example above, if we look at patient 1 – we need to look at their scores at each time point, reverse scores for questions 3, 8-12 and then total them up.

Questions	Patient 1				Scores with questions 3, 8-12 reversed			
	1	2	3	4	1	2	3	4
Q1. Can you tell me how much pain you have had since yesterday?	5	5	3	2	5	5	3	2
Q2. How much have other problems with your body been troubling you since yesterday? (Prompt only if needed: e.g. being sick, going to the toilet a lot)?	1	1	3	4	1	1	3	4
Q3. Can you tell me how much you have been feeding since yesterday?	1	1	1	1	4	4	4	4
Q4. Can you tell me how much you have cried since yesterday?	4	4	2	2	4	4	2	2
Q5. Can you tell me how often you have felt happy since yesterday?	2	2	3	2	2	2	3	2
Q6. How much have you felt like playing since yesterday?	2	2	3	3	2	3	3	3
Q7 How much have your questions about your sickness been answered since yesterday?	2	2	2	2	2	2	2	2
Total APCA African Children's POS Score: Child					24	20	20	22
Q8. How much have you been feeling worried about your child's illness?	0	1	3	3	5	4	2	2
Q9. Have you been able to share how you are feeling about your child's illness with others when you have wanted to?	2	3	2	5	3	2	3	0
Q10. How much information have you and your family been given about your child's illness?	2	1	2	3	3	4	3	2
Q11. Have you had enough help and advice for your family to plan for the future with regards to your child's illness?	0	1	2	3	5	4	3	2
Q12. How confident does the family feel caring for the child?	2	4	3	1	3	1	2	4
Total POS Score: Carer					19	15	13	10

So what does this tell us? We may use this to try and derive a picture of the overall status of the child and their carers. In this instance, the total APCA African Children’s POS score for the patient has not changed much over time. However, if we look at the individual questions we will see that, whilst their pain has improved, their symptoms have got worse so their overall feeling of wellbeing has stayed the same. If we look at the carers experience, we can see that they are feeling more confident and less worried about caring for the patient than they were previously.

It would then be possible to look at the significance of any of these results using the statistical analysis discussed above.

Table I Critical values for the Wilcoxon matched pairs signed rank test

N	0.1	0.05	0.02	0.01	N	0.1	0.05	0.02	0.01
5	1				28	130	117	102	92
6	2	1			29	141	127	111	100
7	4	2	0		30	152	137	120	109
8	6	4	2	0	31	163	148	130	118
9	8	6	3	2	32	175	159	141	128
10	11	8	5	3	33	188	171	151	138
11	14	11	7	5	34	201	183	162	149
12	17	14	10	7	35	214	195	174	160
13	21	17	13	10	36	228	208	186	171
14	26	21	16	13	37	242	222	198	183
15	30	25	20	16	38	256	235	211	195
16	36	30	24	19	39	271	250	224	208
17	41	35	28	23	40	287	264	238	221
18	47	40	33	28	41	303	279	252	234
19	54	46	38	32	42	319	295	267	248
20	60	52	43	37	43	336	311	281	262
21	68	59	49	43	44	353	327	297	277
22	75	66	56	49	45	371	344	313	292
23	83	73	62	55	46	389	361	329	307
24	92	81	69	61	47	408	397	345	323
25	101	90	77	68	48	427	397	362	339
26	110	98	85	76	49	446	415	380	356
27	120	107	93	84	50	466	434	398	373

If you have a sample where >50, you can refer to the information at <http://udel.edu/~mcdonald/statsignedrank.html>

Appendix 5: Example of a distress protocol

The health professionals administering the tool is expected to be compassionate to children and respectful at all times during its administration. If during the administration of either of the tools the child or carer becomes distressed (e.g. they show strong emotions or start to cry), then the health professional will stop the administration of the tool and will use the following distress protocol, as appropriate.

- a) If the family member / carer shows distress (e.g. if they show strong emotions or start to cry) then the health professional will say the following:

I understand that what we are discussing is emotionally difficult for you.

[wait and if the participant is still in distress proceed to following sentence; otherwise carry on with asking the questions]

We can stop asking you questions if you wish. To do so will not affect your / the child's care and treatment.

[wait and if the participant says he / she wishes to stop proceed to following sentence; otherwise carry on with asking the questions]

If it helps, I have a contact number of a counsellor [NAME OF COUNSELLING SERVICE], which you may call to talk through any of the issues or else you may talk through them with me if that would help *[TELEPHONE NUMBER - provide if the participant requests]*

You are free to withdraw the information you have given me up to this point, would you like to do this?

[wait and record answer]

If this research has harmed you in any way, I do apologise and you can contact [NAME OF A CONTACT PERSON] on [TELEPHONE NUMBER] for further advice and information.

Thank you very much for your time and effort.

- b) If the child shows distress (e.g. if they show strong emotions or start to cry), then the health professional will say the following:

I understand that what we are discussing is emotionally difficult for you.

[wait and if the participant is still in distress proceed to following sentence; otherwise carry on with asking the questions]

We can stop asking you questions if you wish. To do so will not affect your care and treatment.

[wait and if the participant says he / she wishes to stop proceed to following sentence; otherwise carry on with asking the questions]

If it helps, you may want to talk through these issues with your parents (or carer etc) or else can talk to me.

Would you like us to stop asking you questions at the moment?

[wait and record answer]

You may then need to ask similar questions as above to the family member / carer as they may be distressed at seeing the child distressed. You would need to ask them whether they would like a counsellor or someone else to talk to the child.

IMPORTANT: If the health workers have a high level of concern about a participant (e.g. if they suspect a participant is very depressed and possibly suicidal for older children), they must discuss this as a matter of urgency with their manager to proceed with appropriate action to further assist and aid the participant in question, if this is felt appropriate.

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