African Palliative Care Association

Guidelines for Use of the APCA African Palliative Outcome Scale

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 U.S. 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.

Contents

Acknowledgements

Foreword

The scaling up of palliative care across the African continent demands not only a quantitative increase in the number of service providers, but equally a demonstrable improvement in both the quality of care provided to patients with progressive disease and their families, and their health outcomes.

However, showing 'demonstrable improvements' in Africa is premised upon culturally appropriate, relevant and rigorously validated measurement tools. Moreover, these 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 measure, the African Palliative Care Association (APCA), in collaboration with multiple partners, developed such a tool: the APCA African Palliative Outcome Scale (POS), based in part upon the original POS that originated at the Department of Palliative Care, Policy and Rehabilitation, at King's College London, England, and focuses on the World Health Organization's definition of palliative care, capturing physical, psychological, social and spiritual problems.

The APCA African POS has since 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 that is intended to help users employ the APCA African POS correctly. Following a discussion of the origins and background to the APCA African POS, 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, and answering some frequently asked questions.

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

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Chapter 1: Introduction

The Guidelines for the Use of the APCA African Palliative Outcome Scale (POS) has been developed by the APCA, in collaboration with stakeholders, to help appropriately trained health practitioners and researchers across the region to utilise the APCA African POS in their work place (Powell et al, 2007; Warria et al, 2007). Not only do the guidelines provide a clear rationale for measuring palliative care outcomes, but they also outline practical information on how to use the tool to collect data and analyse its results.

So why is there a need for these guidelines? Palliative care as a concept and discipline is not well understood across Africa, and its development is still embryonic in many countries. While there are many obstacles that hinder palliative care development on the continent, a key challenge is the lack of accurate information about the palliative care being provided and its outcomes. The APCA African POS is a useful tool to help us measure these outcomes and, given that measuring palliative care outcomes remains a relatively new concept, it is important to guide people on how to use the tool.

Of course, these guidelines are not intended to address everything related to the measurement of palliative care outcomes; they contain only essential information for providers. More detailed information on the use of outcome tools, and in particular within the research setting, can be gained from contacting relevantly trained professionals.

1.1 Background

The need for effective palliative care service provision across Africa has never had such a high priority. By 2009, an estimated 22.5 million people living with HIV/AIDS originated from sub-Saharan Africa, 67 per cent of the global disease burden (Joint United Nations Programme on HIV/AIDS, 2010), and in 2007 there were an estimated 700,000 new cancer cases and nearly 600,000 cancer-related deaths on the continent (Garcia et al, 2007). For the overwhelming majority of Africans who currently endure these and other progressive, life-threatening illnesses, access to culturally appropriate holistic palliative care (that includes effective pain management) is at best limited, and at worst non-existent (Harding and Higginson, 2004).

In addition to extending the coverage of palliative care services across the continent, the APCA was established to ensure those services attain an optimal level of quality. Progress achieved in the quality of care provided as part of a continuous improvement strategy must, however, be embedded in, and inform, routine service-level daily practice to be sustainable. Despite the reported need (Harding et al., 2003), measuring progress in the quality of palliative care provided by services across Africa has been problematic in the absence of rigorously validated outcome instruments (Harding and Higginson, 2005). Consequently, a simple and brief multi-dimensional outcome measure for palliative care (called the APCA African Palliative Outcome Scale) using patient- and family-level indicators that could be used in routine clinical practice, was developed and validated. The APCA African POS is one of a group of palliative care outcomes scales that are being used in different contexts and settings throughout the world.

1.2 The aim of the APCA African POS

The APCA African POS was developed as a patient- and family-level tool to measure the outcomes of care being provided and to make recommendations on areas for improvement. It can be used within routine clinical care to enhance individual patient management, but also as a quality improvement tool and in research, and can help inform policy formation and best practices within palliative care.

The World Health Organization (WHO) defines palliative care as:

'An approach which improves the quality of life of patients and families facing the problem of life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual. It will enhance quality of life, and may also positively influence the course of illness. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, or antiretroviral / opportunistic infection (OI) therapy and includes those investigations needed to better understand and manage distressing clinical complications' (World Health Organization, 2002).

Based upon this definition, the APCA African POS addresses five key domains of palliative care: pain and symptom relief; access to drugs; emotional / spiritual support and grief counselling; support for family carers; and family-based advanced care planning. It is aimed at measuring the care outcomes of patients with life-threatening illnesses and their families in both specialist and non-specialist settings.

1.3 Why use the APCA African POS?

The APCA African POS is a validated outcome scale for use in Africa (Harding et al, 2009). It can be used in multiple settings and by a variety of different stakeholders. Its questions are short and easy to administer, which is important within the palliative care setting.

The tool can help determine whether a method of treatment or a particular intervention package is working. It can also be used to clarify which interventions or packages of care work best for patients with particular sets of problems associated with palliative care.

1.4 Who can use the APCA African POS?

The APCA African 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. Feedback from staff has shown that the APCA African POS facilitates a structured engagement with patients that not only addresses the needs of both patients and their caregivers, but also ensures that staff address life domains that are pertinent to a patient but which, for various reasons, can be neglected (Powell et al, 2007). National palliative care associations can encourage their members to use the APCA African 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. The APCA African POS has also been used as an

outcome tool in a variety of different research projects and has shown to be a valuable tool in demonstrating change in outcomes (Simms et al, 2010; Harding et al, 2010). However, it is important that all those who use the APCA African POS are trained in its use. Consequently, training resources are found on the CD-ROM that accompanies these guidelines.

1.5 When to use the APCA African POS?

The APCA African POS can be used for clinical care, quality improvement or research. In clinical care the tool can be used along with other routine clinical tools for assessing and monitoring the progress of patients 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. It is used in research when one is seeking to measure change over a period of time for patients with life-threatening illnesses, the outcomes of the care given to patients and identifying the key areas of patient care. The tool can also be used in teaching about palliative care measurement and planning for care.

Chapter 2: Measurement of patient and family outcomes

Measuring the quality of care that is provided helps both practitioners and policy makers to determine how they are performing and how services can be improved. However, it is important to identify what we mean by 'quality care' – and in this case, quality palliative care – before we can look at measuring the outcomes of care. For example, it is important to agree on what we mean by 'palliative care' and what we think are the outcomes that would demonstrate quality care. Once agreement has been reached, it is possible to develop a tool to measure those outcomes.

Measuring the outcomes of palliative care is an important mechanism for developing and maintaining high quality health care systems worldwide (Pasman et al, 2009). Health care professionals are required to embrace quality control, base clinical practice on evidence and set out clear protocols and standards for clinical practice. Most importantly, financial resources are increasingly being directed to those services that can demonstrate efficiency and effectiveness. Indeed, in some countries the commissioning of health care services is dependent upon patient-reported outcome measurement evidence (Bausewein et al., in press). Consequently, in the drive towards improving service quality, monitoring intervention practice and provision is becoming an increasingly integral part of the health care system (Hanks, 1993).

Palliative care aims to meet the physical, psychological, social and spiritual needs of individuals with life-threatening illnesses. The WHO defines palliative care as:

'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;

- Affirms life and regards dying as a normal process;

- Intends neither to hasten or postpone death;

- Integrates the psychological and spiritual aspects of patient care;

- Offers a support system to help patients live as actively as possible until death;

- Offers a support system to help the family cope during the patient's illness and in their own bereavement;

- Uses a team approach to address the needs of patients and their families, including bereavement counsellors if indicated;

- Will enhance quality of life, and may also positively influence the course of illness;

- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications' (World Health Organization, 2002).

Therefore, this includes the needs of patients, their family and friends. The holistic nature of palliative care requires that services be provided by a range of organisations, and by staff working in multi-disciplinary teams. Assessment and measurement of palliative care services must therefore reflect the issues that surround patient care, the services provided to family, friends and other people close to the patient, and the complex relationship between different service providers (Aspinal et al, 2002).

Figure 1: The quality improvement cycle

Set standards and goals

Review and make changes if neccessary

Monitor and observe practice
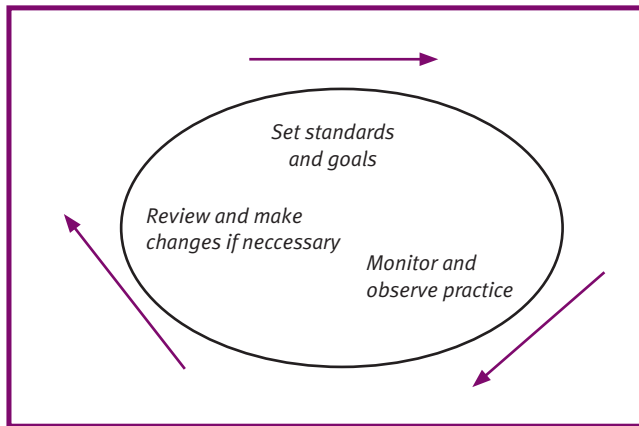
Outcomes measures, and in particular the APCA African POS, can be used in a variety of ways in clinical practice, quality improvement and research. In clinical practice they can be used in routine care, administered at the start of a patient assessment, as a quick means of identifying and prioritising need (e.g. pain management). The completed measures can be retained in the patient's medical record and can help the clinician to see a change in their outcomes over time.

Clinical audit is a method of reviewing existing clinical practice against agreed standards of care to identify areas for improvement in the quality of care provided. It provides a framework within which health care providers can analyse what is presently being undertaken in terms of the clinical care offered, learning from it, and subsequently changing work practices (Powell and Downing, 2007). Therefore, audit is an important part of quality improvement – the benefits to patients and carers being improved care and support and better quality of life, with the benefits to staff including improved teamwork, the ability to provide better care, evidence of the worth and effectiveness of their work and better funding prospects for the service. Importantly, audit should be undertaken in a non-threatening way; the aim of audit is not

to be critical or negative, but to help improve provider practice and service provision.

An example of when the APCA African POS has been used successfully in a quality improvement process was during the ENCOMPASS project (Ensuring Core Outcomes and Measuring Palliation in Sub-Saharan Africa) when the audit cycle (see Figure 1) was used in five palliative care services, four in South Africa and one in Uganda. The audit cycle involved:

• Measuring some patients' outcomes using the APCA African POS.

• Looking at the data: what do the services do really well? What could the services work to improve?

• Going back and measuring outcomes in new patients again using the APCA African POS.

• Looking at whether the services have improved those things that they had wanted to?

Outcome measures are also a valid tool for research – for example, when trying to identify whether there has been a change in the outcomes of care over time following a specific intervention. Examples of how the APCA African POS has been used in research include the President's Emergency Plan for AIDS Relief (PEPFAR) evaluation of palliative care undertaken in Kenya and Uganda (Harding et al, 2010; Simms et al, 2010;), an evaluation of a pilot programme for palliative care in Namibia (Downing et al, 2009), a study investigating the added value of palliative care in the era of ART in Uganda (Powell et al, 2008), along with other studies which are currently ongoing across the region.

Chapter 3: Development of the APCA African POS

APCA is committed to the development of palliative care across Africa both through extending coverage of palliative care services and through ensuring the quality of the services provided (African Palliative Care Association, 2007). However, despite the reported need among care providers (Harding et al., 2003), measuring progress in the quality of palliative care provided by services has been problematic in the absence of a locally developed tool for outcome measurement, validated using robust scientific methods (Harding and Higginson, 2005; Harding et al, 2008). Therefore, APCA set out to develop a brief multi-dimensional African outcome measure for palliative care in accordance with acceptable international standards for tool development, and using patient-level indicators that can be used in routine clinical practice.

The APCA African POS was developed by a multi-disciplinary team of palliative care experts from across the region, including Kenya, South Africa, Malawi, Tanzania, Uganda, Zambia and Zimbabwe, along with support from King's College London, UK, and the National Hospice and Palliative Care Organization in the USA (Powell et al, 2007). It has been rigorously developed and tested by a panel of experts across different settings and countries in Africa.

This process began in 2005, when the expert panel first met and reviewed the WHO definition of palliative care (World Health Organization, 2002). Consequently, five key domains of palliative care were identified for measurement: pain and symptom relief; access to drugs; emotional / spiritual support and grief counselling; support for family carers; and family-based advanced care planning. These domains were reduced to an initial set of 12 patient-level outcome indicators which were informed by, but significantly adapted from, the original POS (Hearn and Higginson, 1999).

Initial piloting was undertaken in four palliative care sites across three countries to address issues such as: utility and feasibility in application; acceptability to patients and its comprehension; applicability in diverse settings; sensitivity to change; and some preliminary steps towards validity. Following the initial pilot, the expert group met again to review the tool, which was further adapted and piloted in eleven services in eight countries, prior to finalisation for further validation studies (Powell et al, 2007).

The validation phase of the tool development was undertaken by King's College London, in conjunction with four sites in South Africa, one in Uganda and the APCA (Harding et al, 2010). This validation process tested whether the measure could:

a) Yield information of clinical relevance to palliative care;

b) Cover those domains considered to be important to this type of care and nothing more, and;

c) Achieve a consensus among specialists that (a) and (b) had been met.

The validation study (Harding et al, 2010) used a 3-phase design that entailed:

- Face validity (i.e. the appropriateness and acceptability of the measure to the target population);

- Construct validity (i.e. comparison of the tool with a different measure of the same construct that has previously been validated in the same population, in order to determine convergence or divergence [NB: the only palliative care scale previously validated in a similar population was the MVQoLI {Missoula Vitas Quality of Life Index}, Namisango et al, 2007]).

- Internal consistency (i.e. how consistently individuals respond to the items within a

scale), and test / re-test reliability (i.e. the stability of the tool over a short time period in order to determine whether a measure is sensitive to change but not so sensitive as to report clinically insignificant changes).

The validation sites selected represented a variety of models of care, including homecare, day care and inpatient care, as well as rural, peri-urban and urban settings. Two of the sites provide care from the point of diagnosis through to the end of life, while the remaining three focussed primarily on advanced disease.

The development process for the APCA African POS has shown several important things (Powell et al, 2007; Harding et al, 2010):

1. It can be used as a rigorously tested monitoring and evaluation (M&E) quality improvement instrument that can facilitate continuous quality improvement in palliative care service provision.

2. It has potential utility in being more than just a research instrument administered to passive respondents.

3. It is a valid and reliable instrument which has met the accepted standards for tool validation (Terwee et al, 2007; Higginson, 2007).

4. It can be added to the family of POS instruments that have been developed internationally.

5. There is a need to develop a tool specifically for children as this is still an area with unmet need – consequently, the APCA African Children's POS is currently (2011) being developed.

3.1 The APCA African POS

The APCA African POS (see Figure 2) contains 10 items, addressing the components of palliative care as per the WHO definition (i.e. physical, psychological, social and spiritual concerns) (World Health Organization, 2002), and includes the needs of both the patient and their family. The tool is in two parts, with the first seven questions being asked to the patient and the final three questions being asked to a family member.

The answers to all questions are scored using Likert scales from 0 to 5, with numerical and descriptive labels available if needed. On such a scale, the numbers 0 and 5 represent opposites, with numbers in-between both (e.g. when measuring pain, 0 represents 'no pain' and 5 represents the 'worst possible pain that you can imagine'). There is also a 'not applicable' option for use in the questions aimed at the family when the patient does not have an informal carer. The tool is staff administered and respondents indicate their answers either verbally or using a hand scale (0=closed fist, 5=all fingers open). The responses use a combination of high score=best status and low score=best status as a mechanism to avoid response bias where people provide the same answer without thinking about individual questions (Harding et al, 2010).

When the APCA African POS is used for quality improvement purposes, it is necessary to collect additional demographic information in order that meaningful comparisons can be made between groups. Key demographic characteristics that should be included are the patients':

• Gender

• Age

• Diagnosis

• Occupation

• Marital status

• Living arrangements, and

• Ethnic origin.

Other important information could include, for example:

• Place of care

• Place of death

• Date of death

• ECOG score [Eastern Cooperative Oncology Group] (Oken et al, 1982).

ECOG	Grade
Fully active: able to carry on all activities without restriction	0
Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature	1
Ambulatory and capable of self-care but unable to carry out any work activities. Up and about more that 50% of waking hours	2
Capable of only limited self-care: confined to bed or chair 50% or more of waking hours	3
Completely disabled: cannot carry on any self-care: totally confined to bed or chair	4
Dead	5

Information about drugs and treatments used will also enable the comparison of outcomes from different treatments. A sample tool for collecting the demographic data can be found in Appendix 1.

Figure 2: The APCA African POS

PATIENT NO. _____	POSSIBLE RESPONSES	Visit 1 DATE _____	Visit 2 DATE _____	Visit 3 DATE _____	Visit 4 DATE _____
ASK THE PATIENT					
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (no pain) - 5 (worst/overwhelming pain)				
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all) - 5 (overwhelmingly)				
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all) - 5 (overwhelming worry)				
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) - 5 (yes, I've talked freely)				
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all) - 5 (Yes, all the time)				
Q6. Over the past 3 days, have you felt at peace?	0 (no, not at all) - 5 (Yes, all the time)				
Q7. Have you had enough help and advice for your family to plan for the future?	0 (not at all) - 5 (as much as wanted)				
ASK THE FAMILY CARER					
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A				
Q9. How confident does the family feel caring for _____?	0 (not at all) - 5 (very confident) N/A				
Q10. Has the family been feeling worried about the patient over the last 3 days?	0 (not at all) - 5 (severe worry) N/A				

1 A different time frame instead of the past 3 days could be used if appropriate (e.g. if only visited once a week).

The time taken to complete a tool is important when assessing its appropriateness for a patient group and use in clinical practice, particularly in patient populations at the end of life. Throughout the development of the APCA African POS, the time taken to complete the tool has depended on its use. When used in a research or quality improvement context, the average time for completing the APCA African POS was low (i.e. a mean of 8-9 minutes and a median of 5-7 minutes), thus indicating that it is brief to use and may be easily incorporated into routine clinical assessment. However, health care workers who have integrated the APCA African POS into their clinical practice, and who are using it to aid the assessment of the patient, have indicated times as long as 30 minutes to complete it, although this recognises the wide variety of other questions that are being asked alongside the tool (e.g. if the patient says that they have pain, further pain assessment is undertaken whilst using the APCA African POS).

The validation studies have provided rigorous evidence that the APCA African POS has sound psychometric properties and it also appears to have high levels of acceptability and utility in the African clinical setting (Harding et al, 2010).

3.2 What languages is the APCA African POS available in?

The APCA African POS was developed and validated in English. However, it was acknowledged right from its development that often health care workers will be translating it as they administer it. In the original pilot study for the development of the tool, it was translated verbally into 14 languages, including Afrikaans, Kiswahili, Luganda, Somali and Zulu. Since its validation in English, the APCA African POS has been translated into several different languages:

- Afrikaans
- Kiswahili
- Luganda
- Oshiwambo
- Runyankole
- Runyoro
- Sotho
- Xhoso
- Zulu

When translating a tool such as the APCA African POS, it is important that this is done in a standardised manner and that the translated tools undergo a process of re-validation in order to ensure that they have retained their meaning (see section 4.2.1).[2]

2 Copies of these translations can be obtained from APCA.

Chapter 4: Using the APCA African POS

To ensure that the APCA African POS is used correctly and consistently, and to ensure its reliable implementation and analysis, instructions have been developed to accompany the APCA African POS (see Appendix 2). These instructions, to be read and understood before a person conducts any interviews with patients or family carers, 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 POS is free of charge; however, in order to use it you need to complete the permission form (found in Appendix 3) and submit it to the APCA.

4.1 Training

Like other clinical and quality improvement / research tools, using the APCA African 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 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 patients and overall service delivery.

While Appendix 4 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 POS, it is important that those responsible for data analysis share their results and conclusions with all team members. This will help ensure that patients, staff and the service as a whole benefit from patient 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 patient score a rating of five (i.e. most severe) on a particular question, it is critical that staff know how to fully respond.

Equally, practitioners should be aware that use of the APCA African POS may extend the time of each patient 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 their patients. This should be perceived in a positive light as a valuable opportunity to gather data on multiple aspects of the patient's life and experiences.

Ultimately, the APCA African 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 patient 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 POS

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

However, the translation process is not a straight-forward 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 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 POS.

4.2.2 Adapting the POS

In some clinical settings it might be appropriate to not only translate the APCA African POS, but actually adapt its questions to better reflect particular clinical environments and patients' needs. For example, some questions may not apply to particular patient 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 POS. For example, some of the descriptive labels attached to questions might be altered in some organisations to better reflect local needs. 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 administrating the APCA African POS can be influenced by a number of factors, including the organisational setting, patient group and clinical need. For example, an in-patient unit may use the tool once per week to inform ward round discussions, providing a summary of patient conditions and to assess clinical interventions.

However, when patients' conditions become critical, or particular symptoms become acute, the tool can be administered more frequently to help assess rapidly changing patient 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 POS starts.

Regarding the time frame between assessments, the APCA African POS asks for assessments based on the preceding three days. Clearly, to avoid overlap between the time reference points, it is important to have a minimum of three days between assessments. However, whilst patients receiving in-patient care might be assessed every three days, patients 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 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 patients and their main carers (e.g. some may not have an identified carer), the complementary perspectives that they produce can provide valuable information about patients' 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 patients and / or 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.
- The tool is used retrospectively rather than prospectively.

4.4 Analysis

4.4.1 Storing

APCA African POS scores can be stored in a number of ways, including within patients' clinical notes or in a computerised database. From the outset, it is important to recognise that methods of storing potentially sensitive APCA African 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 POS are scored using a 6-point (i.e. 0-5) Likert-type scale, with numerical and descriptive labels. Patients are asked to provide the answer that best represents their condition.

The APCA African 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 patients and allow a focus on particular items (e.g. anxiety), as pertinent to particular patients. Such procedures allow staff to assess and measure change in patients' conditions against interventions adopted. Importantly, scores for individual patients should not be reversed for analysis purposes.

- Second: 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 0-15 for family members / 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 4-9 (i.e. if the patient gives them a score of 5, you reverse that to a score of 0).[3]

4.4.3 Analysing[4]

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 patients 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.

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3 When 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).

4 This 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.

Figure 3: Baselines score for pain on a sample of 67 patients
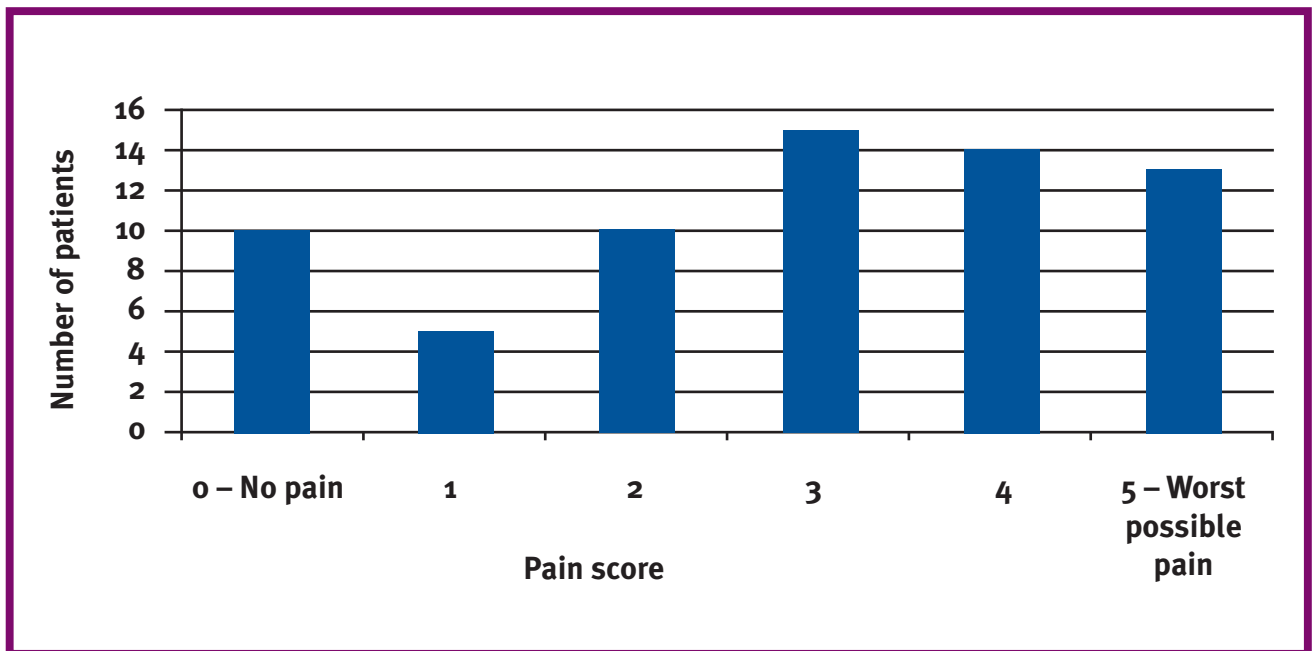
Some useful statistics that can be used to summarise the data that is gathered include:

- 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 4: Graph showing change over time in a sample for the question 3 about worry
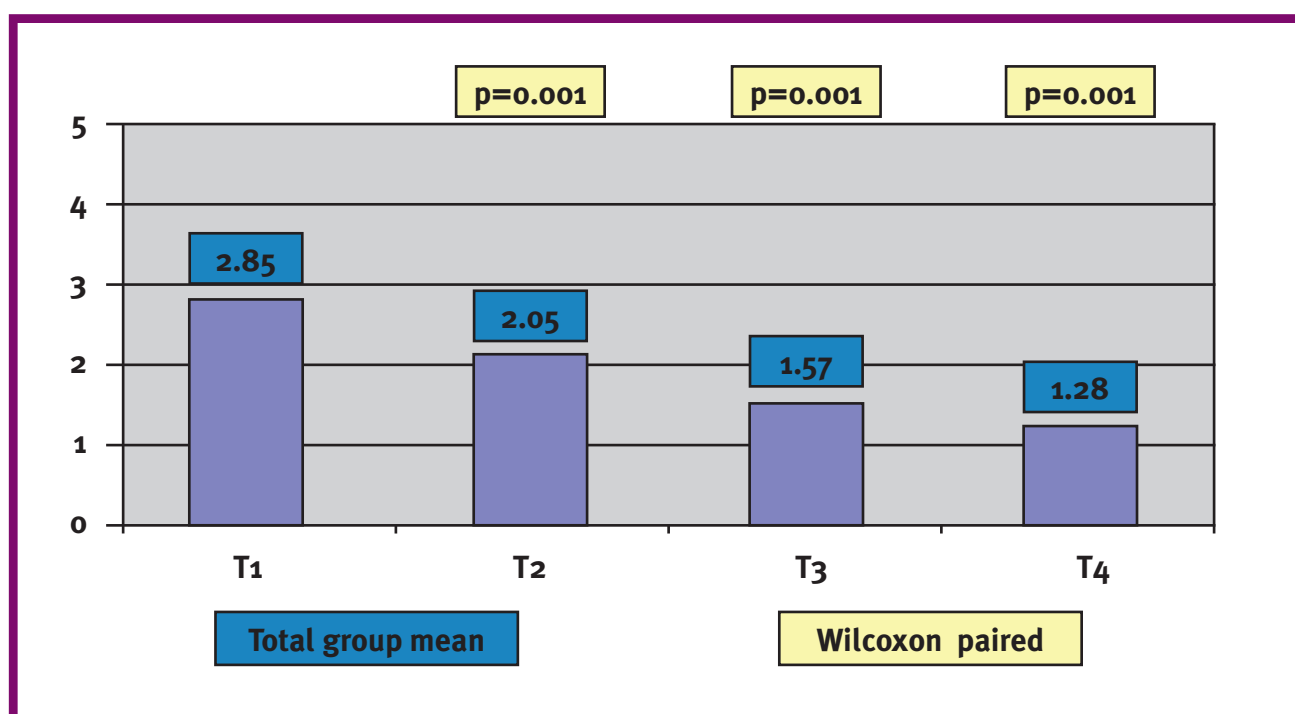
Critical to the analysis stage is the detection of changes in scores over time (see Figure 4). Each variable (e.g. anxiety) should be examined individually to this end. Graphs can also be used in this instance to depict changes, with the time variable on the horizontal axis, and the APCA African POS 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).[5] 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

5 It 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 patients' presenting problems tend to be addressed by services before the patient 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, patient scores improved / deteriorated, even if most of it occurs within the first assessment period.

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 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 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 5, where an example of some data from the APCA African POS is given and you are shown how to calculate the mean, the median, the total APCA African POS scores, and the significance of any change over time. More detailed information on how to analyse the APCA African POS can be found through referring to the APCA website or 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 patients, summary statistics and graphs could be used to profile the particular characteristics of the patient group. Such data would also enable analysis that compared, for example, APCA African 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 patients have completed the tool, there are many possible interpretations. These interpretations will be guided by clinical experience and the patients' general condition. For example, if a patient describes themselves as slightly affected by pain, it may suggest that pain limits some activities but does not impair them enough to affect their everyday living and associated quality of life. This prevents the patient from describing their pain as moderate.

When analysed on an individual basis, the APCA African POS scores enable a determination of individual patients' needs within each domain over time, with interventions adjusted accordingly. Differences in scores between patients 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 POS in practice

When using the APCA African POS you will occasionally need to be flexible given there are some times when patient and / or family needs are given priority. For instance, you may not ask all the questions during the first visit (e.g. if the patient 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 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 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 patient and introduce yourself. Ensure the patient does not feel intimidated by you, as this may lead to bias.

    c) Administer the information sheet and the consent form. Explain to the patient (and family member / carer) why the interview is being done, how it will help the patient, what it will involve, how much time it will take, how the feedback of the interview will be used to benefit the patient.

    d) Answer any questions from the patient and / or family member / carer.

2. During the administration of the APCA African 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 patient and / or family member / carer as this may affect the relationship during the interview and lead to biased responses by the patient.

    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, facial expression). Apply the distress protocol when necessary (see Appendix 6).

    f) Encourage the patient to answer the question by being interested (i.e. nodding, focussing attention on the patient, not interrupting). Probe if the patient is unsure what the question means: reread the question, repeat the explanation of the responses to be chosen from, and record the response. Remember, there is no right or wrong answer, hence be sensitive to your reaction to the patients 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 patient feels they have said all they want to say.

   b) Never rush the patient or family member / carer.

   c) Alert the patient that the interview is coming to an end.

   d) Reassure the patient that the information given will be treated as confidential and used only for the purpose of improving the patient's care.

   e) Discuss and agree with the patient about the next appointment. If it is the last interview, inform the patient so.

   f) Give the patient / family member / carer time to ask question or give comments.

   g) Thank the patient and / or carer for their time.

   h) Release the patient / 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, patient 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 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.

Example of the use of the APCA African POS for quality improvement at Hospice Africa Uganda

After the development of the APCA Africa POS, the tool was validated through the ENCOMPASS project (Harding et al, 2010), a multi-centred study involving 5 centres, 4 in South Africa and one in Uganda. Following validation, the sites piloted the use of the APCA African POS as a quality improvement tool. A clinical audit was undertaken in each site in two phases: Phase 1 between January to June 2007 and Phase 2 between September 2007 to February 2008.

Patients were enrolled at Hospice Africa Uganda (HAU) according to set inclusion criteria (i.e. adults over 18 years who receive services from the facility and were either new patients or old patients who had developed new symptoms). The tool was administered during routine care when the nurse was visiting the patient. Patients were enrolled across all care settings (e.g. home, hospital, hospice clinic and day care).

During phase 1, data was collected weekly for 6 weeks, producing 6 data points, within a range of 5 to 11 days. Most patients were able to be followed up within one week and 100 patients were enrolled. The results were analysed and the findings reported. It was discovered that there was good pain and symptom control as these problems kept decreasing steadily and significant differences were seen across the time period. This was attributed to the effective use of oral morphine and the palliative care approach. However, the results were not so good for the non-physical problems and this was the same across all the sites. The data was analysed and the team met to identify strategies on how to handle psychosocial issues. The strategies implemented included:

- Training and supporting staff on how to handle psychosocial issues;
- Improving assessment methods and reviewing criteria for support, and;
- Improving the system for securing funds for clients.

Since clinical audit is a process, phase 2 was an integral part of the process. Thus data collection was repeated amongst different patients of the same services to see if the implemented strategies from phase 1 of the audit had made a difference. The results showed that there had been some improvement with the implemented strategies. However, there was still a need for further improvement. The strategies regarding the systems and funds remained a challenge as it was difficult to secure funds to socio-economically support and accommodate the cancer patients.

The process of clinical audit helped HAU to be able to identify areas of strength and weaknesses in their provision of care and improve on them as necessary. The hospice will continue to use the tool during other audit cycles and include it in the periodic M&E system.

Example of the use of the APCA African POS at the Hospice and Palliative Care Association of South Africa

Since its validation as a quality improvement tool, the APCA African POS has been used quite extensively by South African hospices. It has been found to be particularly valuable in terms of identifying areas requiring quality improvement activities. Examples of the type of quality improvement activities undertaken by various hospices as a result of APCA African POS findings have included:

- Restructuring programmes and changing the job descriptions of professional nurses to ensure that these scarce professional resources are optimally utilized with regard to the co-ordination of pain and symptom control in very sick patients;
- Creating additional psycho-social posts in order to address the level of worry identified in patients and families, and;
- Conducting clinical audits to develop better protocols to manage pain and other distressing symptoms.

As part of a project funded by the Canadian International Development Agency, the Hospice Palliative Care Association (HPCA) also used the APCA African POS to assess what collective difference fifty home-based care programmes were making to the lives of the patients and families they serve. To this end, 336 questionnaires were analysed at the University of Cape Town and the following statistically significant examples of results, reflecting improved physical, psychosocial and spiritual aspects of care, were documented. Each question had a response rate ranging from 0–5.

- Pain scores dropped from an average of 4 on visit 1 to an average of 1 on visit 6 (p=<0.001).

- Scores for level of worry identified by the patient dropped from 4 to 1 (p=<0.001).

- Scores reflecting the family's confidence in caring for the patient increased from 3 to 5 (p=<0.001).

These results are a clear indication of the success of the holistic palliative care provided by hospices to patients and families throughout the country. It is hoped that having objective evidence of the value of palliative care programmes will be successfully used to lever much-needed funding for hospice programmes.

The APCA African POS was also used to assess patient and family perceptions of care in a recent pilot project during which professional nursing supervision was provided to non-professional caregivers working in non-hospice home care programmes. The encouraging findings have contributed to the decision to explore the expansion of this project.

In order to encourage the ongoing assessment of care on patient and family outcomes, one of the criteria in the service element of quality management and improvement in the second edition of the Hospice Palliative Care Standards (Hospice Palliative Care Association, 2009) refers to using a validated quality improvement tool to improve the quality of service delivery. We believe that the APCA African POS can play an important role in the realisation of HPCA's vision of 'Quality palliative care for all' and will provide an important barometer to assess the success of mentorship to organisations who do not fall under the jurisdiction of the HPCA by member hospices.

Chapter 6: Frequently asked questions

1.   Why should I use the APCA African POS in addition to the regular clinical assessment sheet?

The APCA African POS is a validated tool for measuring palliative care outcome for patients in the African setting. It has been found useful in measuring change over time, hence a good indicator of the impact of your care on the patient and for quality improvement of existing programmes.

2.   How do I interpret the APCA African POS?

The scores can be rated in relation to individual items, to one individual or summarised to a group of individuals depending on the purpose. For instance, you can interpret changes in pain for one patient by examining the subsequent scores or you can add up the scores for the patient and compare with subsequent scores to find out the progress. You can also compare the scores of several patients to find out the progressive trend of patients receiving palliative care in a care setting, or to compare programmes' impact by patients' socio-demographic characteristics (e.g. age, gender).

3.   Do I need permission to be able to use the APCA African POS?

In order to use the APCA African POS you need to complete the permission form (Appendix 3) and submit it to APCA. You can download the permission form from the APCA website and it can be found on the CD that accompanies these guidelines. If you publish any material from a project where you have used the APCA African POS, then the tool should be referenced accordingly.

4.   Do I need special training in order to use the POS

These guidelines have been developed to help you use the APCA African POS and training materials can either be downloaded from the APCA website or found on the CD-ROM that accompanies these guidelines. However, it is important to have some background or experience in palliative care in order to meaningfully use the APCA African POS.

5.   If I get stuck or need some advice where can I get help?

If you get stuck or you need some advice with regards to how to use the APCA African POS or to analyse it, then please contact APCA at info@africanpalliativecare.org or via the APCA website.

References

African Palliative Care Association (2007) *Strategic Plan 2007-10 for the African Palliative Care Association*. Kampala: APCA

Aspinal F, Hughes R, Higginson I, Chidgey J, Drescher U, Thompson M (2002) *A User's Guide to the Palliative Care Outcome Scale.* London: King's College London

Bausewein C, Simon ST, Benalia H, Downing J, Mwangi-Powell FN, Daveson BA, Harding R, Higginson IJ and On behalf of Prisma (2011) Implementing patient reported outcome measures (PROMs) in palliative care: Users' cry for help. *Health and Quality of Life Outcomes*, 9: 27

Brislin, RW (1986) Wording and translation of research instruments. In: Lonner WJ, Berry JW (Eds.) *Field Methods in Cross-Cultural Research.* London: Sage Publication

Cull A, Sprangers M, Bjordal K, Aaronson N, West K, Bottomley A, on behalf of the EORTC Quality of Life Group (2002) *EORTC Quality of Life Group Translation Procedure.* Second Edition. Brussels: EORTIC

Downing J, Tymon J, Mwangi-Powell F, Powell RA, Kaye R (2009) *Implementing a comprehensive public health approach to palliative care development in Namibia.* Committed to People. 11th Congress of the European Association of Palliative Care, 7-10 May. Vienna, Austria. Oral presentation

Garcia M, Jemal A, Ward EM, Center MM, Hao Y, Siegel RL, Thun MJ (2007) *Global Cancer: Facts and Figures 2007.* Atlanta, GA: American Cancer Society

Goh CR, Lee KS, Tan TC, Wang TL, Tan CH, Wong J, Ang PT, Chan ME, Clinch J, Olweny CLM, Schipper H (1996) Measuring quality of life in different cultures: Translation of the FLIC into Chinese and Malay in Singapore. *Annals Academy of Medicine Singapore,* 25: 323-34

Hanks GW (1993) Foreword. In: Higginson I (Ed.) *Clinical Audit in Palliative Care.* Oxford: Radcliffe Medical Press

Harding R, Higginson I, Stewart K, Marconi K, O'Neill JF (2003) Current HIV/AIDS end-of-life care in sub-Saharan Africa: A survey of models, services, challenges and priorities. *BMC Public Health* 3: 33

Harding R, Higginson IJ (2004) *Palliative Care in Sub-Saharan Africa: An Appraisal.* London: The Diana, Princess of Wales Memorial Fund

Harding R, Higginson IJ (2005) Palliative care in Sub-Saharan Africa. *The Lancet,* 365: 1971-77

Harding R, Powell RA, Downing J, Connor SR, Mwangi-Powell F, Defilippi K, Cameron S, Garanganga E, Kikule E, Alexander C (2008) Generating an African palliative care evidence base: The context, needs, challenges and strategies. *Journal of Pain and Symptom Management,* 36: 304-309

Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, Mashao T, Mmoledi K, Moll T, Mpanga Sebuyira L, Panjatovic B, Higginson IJ (2009) Validation of a core outcome measure for palliative care in Africa: The APCA African Palliative Outcome Scale. *Health and Quality of Life Outcomes,* 8: 10

Harding R, Simms V, Penfold S, Namisango E, Downing J, Powell RA, Mwangi-Powell F, Atieno M, Gikarra N, Munene G, Ali Z, Moreland S, Higginson IJ (2010) *PEPFAR Public Health Evaluation Care and Support. Phase 2 Kenya.* London: King's College London and MEASURE Evaluation

Hearn J, Higginson IJ (1999) Development and validation of a core outcome measure for palliative care: The palliative care outcome scale. *Quality in Health Care,* 8: 219-227

Higginson IJ (2007) Quality criteria valuable with slight modification. *Journal of Clinical Epidemiology,* 60: 1315

Hospice Palliative Care Association (2009) *Hospice Palliative Care Standards.* South Africa: Hospice Palliative Care Association

Joint United Nations Programme on HIV/AIDS (2010) *Report on the Global AIDS Epidemic.* Geneva: UNAIDS

Namisango E, Katabira E, Karamagi C, Baguma P (2007) Validation of the Missoula-Vitas Quality-of-Life Index among patients with advanced AIDS in urban Kampala, Uganda. *Journal of Pain and Symptom Management,* 33: 189-202

Oken MM, Creech RH, Tormey DC, Horton J, Davis, TE, McFadden ET, Carbone PP (1982) Toxicity and response criteria of The Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology,* 5:649-55

Pasman RW, Brandt HE, Deliens L, Francke AL (2009) Quality indicators for palliative care: A systematic review. *Journal of Pain and Symptom Management,* 38: 145-156

Powell RA, Downing J (Eds.) (2007) *Mentoring for Success: A Manual for Palliative Care Professionals, Organisations and Associations.* Kampala: APCA

Powell RA, Downing J, Harding R, Mwangi-Powell F, Connor S (2007) Development of the APCA African Palliative Outcome Scale. *Journal of Pain and Symptom Management,* 32: 229-232

Powell RA, Downing J, Mwangi-Powell F (2008) *Protocol for the Study Investigating the Added Value of Palliative Care in the Era of ART in Uganda.* Kampala: APCA

Simms V, Harding R, Penfold S, Namisango E, Downing J, Powell RA, Mwangi-Powell F, Nkurunziza GB, Nsubuga C, Kwebiiha CN, Kataike J, Moreland S, Higginson IJ (2010) *PEPFAR Public Health Evaluation Care and Support. Phase 2 Uganda.* London: King's College London and MEASURE Evaluation

Terwee CB, Bot SDM, de Boer MR, van der Windt DA, Knol DL, Dekker J, Bouter LM, de Vet HC (2007) Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology,* 60: 34-42

Warria C, Ogwethe V, O'Keeffe C, Harding R (2007) *Piloting the APCA African POS among HIV patients in Kenya.* APCA Palliative Care Conference, Nairobi, Kenya

World Health Organization (2002) Palliative care. Available from: www.who.int/hiv/topics/palliative/PalliativeCare/en/

Appendix 1: Example of a demographic data form

	Patient 1 Ref No:	Patient 2 Ref No:	Patient 3 Ref No:	Patient 4 Ref No:	Patient 5 Ref No:	Patient 6 Ref No:
Age Years/ month						
Relationship of Primary carer						
Is the primary caregiver with the patient?						
First language						
Setting						
Inpatient /home care/ other (SPECIFY)						
Diagnosis i.e. HIV Cancer Other						
Gender						
Reason for referral						
Functional status						
Household family size						

Appendix 2: User Guidelines for using the APCA African POS

The African Palliative Care Association (APCA) has developed the following user guidelines to assist with the correct and consistent use of the APCA African Palliative Outcome Scale (POS).

The guidelines have been developed to accompany the APCA African POS Permission Form to Reproduce / Use form.

Introduction

At first glance, this document may seem rather long. However, as you will see, there are only 10 questions in the APCA African POS tool (i.e. seven for patients and three for their family members / informal carers) 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 patients or family carers.

Select patients who are new to your service or who present with new symptoms. Unless there is a specific population being targeted by, for example, a research study, please do not select a special group of patients but administer the questionnaire to the new patients who are routinely assigned to you.

This tool is not intended to disrupt your normal routine of patient visits. Please do not arrange special visits but use the questionnaire during the patient visits that you would normally schedule.

Preparation for the interview with the patient

Before using the tool, it is advisable to direct the patient to a confidential, private place for its administration. Introducing this questionnaire to the patient, you could say something like:

'I would like to ask you 7 questions to help me understand how we can provide the best care for you. 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.

Note: At this point you should discuss the patient consent form and obtain the relevant signatures.

Before we start, is there anything you need to do or to ask?' (e.g. the patient may want a drink of water, have a change in position, empty their bladder or call a relative, etc.).

Conducting the interview with the patient

Question 1

Please rate your pain from 0 = no pain to 5 = worst/overwhelming pain during the last three days.

- Remind the patient that we are talking about any pain he/she feels today or has felt over the last three days.

- Before asking this question, discuss with the patient 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 patient says it is and is not only physical.

- Explain the rating scale 0 – 5. Choose which of the following scales would be the best way of assessing this patient's pain.

Verbal rating scale:

0 = No pain at all

1 = Slight pain

2 = Moderate pain

3 = Severe pain
(interferes with activities of daily life)

4 = Very severe pain

5 = Overwhelming.
The worst pain you can imagine.

Hand scale:

0 = Thumb up = No pain at all

1 = Small finger = Slight pain

2 = Ring finger = Moderate pain

3 = Middle finger = Severe pain

4 = Index finger = Very severe pain

5 = All five fingers = Overwhelming

Faces scale:
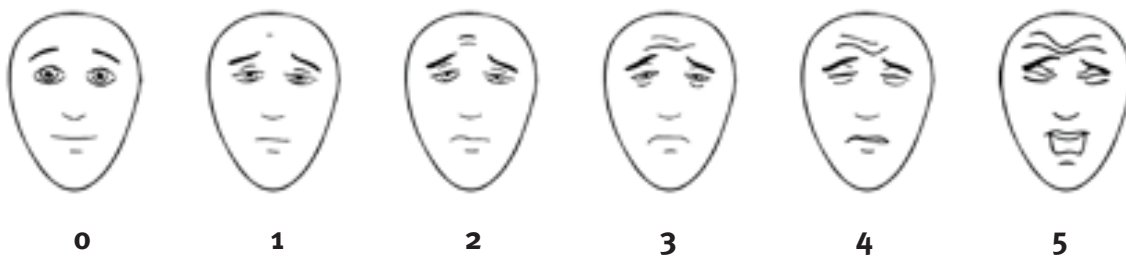
- Check that the patient understands the question (e.g. 'Does this question make sense to you?').
- Allow the patient time to decide on his/her response to the question.
- Record the patient's response on the response sheet.

How to deal with possible patient responses

- If the patient indicates that he/she has no pain but you sense that this might not be an accurate response, you could ask about specific body parts and whether there is any discomfort in any area.
- If the patient indicates slight or moderate pain, ask whether you can continue with the interview or whether the pain needs to be treated first.
- If the patient indicates severe or overwhelming pain, you will need to stop the interview and deal with this.

Question 2

Have any other symptoms e.g. nausea, coughing or constipation been affecting how you feel in the last 3 days.

- Before asking this question, make sure that the patient understands what the word 'symptom' means. If the patient is not familiar with the word, explain that it refers to any unpleasant sensation or feeling.

- Allow the patient time to decide on his/her response to the question.

- Rate the symptoms using the same scale as for Question 1 i.e.:

- 0 = No symptoms at all
  1 = Slight symptoms
  2 = Moderate symptoms
  3 = Severe symptoms
      (interferes with activities of daily life)
  4 = Very severe symptoms
  5 = Overwhelming. The worst
      symptoms you can imagine.

- Record the patient's response on the response sheet.

How to deal with possible patient responses

- If a symptom is causing severe distress, stop the interview and deal with the symptom before continuing.

- Reassure the patient that the questionnaire can be completed at another time.

Question 3

Have you been feeling worried about your illness in the past 3 days.

- This question deals with any concerns the patient might have about his/her 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 patient).

- Do not rush this question. Allow the patient enough time to think about what might be sources of worry.

- The patient will then need to decide on the intensity of the worry:

  0 = Not at all worried
  1 = Worried very occasionally
  2 = Worried some of time
  3 = Worried a lot of the time
  4 = Worried most of the time
  5 = Worried all of the time

- Record the patient's response on the response sheet.

How to deal with possible patient responses

- If the patient's score is 4 or 5, you might need to stop the interview to explore the issues the patient has raised.

- Before deciding how to respond, ask the patient if he/she has talked to anyone else about these concerns.

- Discuss possible approaches to address worries with the patient.

- Make a referral if necessary.

You will notice that for the first 3 questions, it is hoped that the scores indicated by the patient will decrease over the next few visits (i.e. that the pain score would come down). In the following 4 questions it is hoped that the values will increase over the next few visits (i.e. a higher score would indicate that the patient is feeling more at peace)

Question 4

Over the past 3 days have you been able to share how you are feeling with your family or friends.

- It is important to consider that some patients 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.

    0 = Not at all
    1 = Only once
    2 = Occasionally
    3 = Fairly frequently
    4 = Often
    5 = Yes, I've talked freely

- Allow the patient time to decide on his/her response to the question.

- Record the patient's response on the response sheet.

- How to deal with possible patient responses

- If the score is low, you could explore with the patient whether he/she would find it helpful to share feelings and whether you could be of help.

- If the patient feels that sharing feelings is not something they would like to do, you will need to respect this.

Question 5

Over the past 3 days have you felt that life was worthwhile?

- Discuss with the patient what the word 'worthwhile' could mean. Worthwhile is similar to feeling that one's life has meaning or is satisfying.

    0 = Not at all
    1 = Not very often
    2 = Occasionally
    3 = Some of the time
    4 = Most of the time
    5 = Yes, all the time

- Allow the patient time to decide on his/her response to the question.

- Record the patient's response on the response sheet.

How to deal with possible patient responses

- If the patient's score is low, you will need to ask how long the patient has been feeling this way, whether he/she has spoken to anyone, whether he she feels depressed (or the appropriate language equivalent).

- Consider making a referral for this patient to a spiritual advisor.

Question 6

Over the past 3 days have you felt at peace?

- Discuss with the patient what feeling at peace could mean. Feeling at peace could include feeling safe, feeling that there is a higher being providing comfort and protection, not having any worries/anxieties.

  0 = Not at all
  1 = Not very often
  2 = Occasionally
  3 = Some of the time
  4 = Most of the time
  5 = Yes, all the time

- Use the same rating scale as before.

- Allow the patient time to decide on his/her response to the question.

- Record the patient's response on the response sheet.

How to deal with possible patient responses

- If the patient's score is low, you will need to explore why the patient feels a lack of peace and whether there are any particular areas causing anxiety.

- It could be helpful to explore the patient's belief system or to refer to an appropriate spiritual counsellor who could do this.

Question 7

Have you had enough help and advice to plan for the future?

- 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 the care of children, making a will, deciding where and how you would like to be cared for.

- The concept of planning for the future could be a problem issue for some patients and some cultures. You will need to use your own judgement as to how far you can explore this issue with the patient.

  0 = None
  1 = Very little
  2 = For a few things
  3 = For several things
  4 = For most things
  5 = As much as wanted

- Use the same rating scale as before.

- Allow the patient time to decide on his/her response to the question.

- Record the patient's response on the response sheet.

How to deal with possible patient responses

- If the patient's score is low, this could be because he/she is feeling too overwhelmed to make decisions. You could clarify the issues and help to prioritise what the patient feels is important.

- If you feel it is an area the patient does not want to explore, you will need to respect this.

Note: Please remember to thank the patient for his/her willingness to answer the questions.

Conducting the interview with the family carer

Introducing this questionnaire to the family carer, you could say something like:

'I would like to ask you 3 questions to help me understand how we can support you in caring for ………… (Note: name of patient here). 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 families, but your name will not be written on the questionnaire.

Note: At this point you should discuss the family carer consent form and obtain the relevant signatures.

Before we start, is there anything you need to do or to ask?'

Question 8

How much information have you and your family been given?

- 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.

- Explain the rating scale 0 – 5. Choose which of the following scales would be most appropriate for this person:
  - Verbal
  - Hands
  - Faces

- Check that the person understands the question (e.g. 'Does this question make sense to you?').

  0 = None
  1 = Very little
  2 = Some
  3 = Quite a lot
  4 = A great deal
  5 = As much as wanted

- Allow the person time to decide on his/her response to the question.

- Record the response on the response sheet.

How to deal with possible responses

- If the score is low, you will need to find out what further information the person feels he/she/the family need.

- Provide the information if you can. If not, consult with other members of the care team.

Question 9

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

- This question is aimed at finding out whether giving family carers information and showing them how to care for the patient 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 patient now.

  0 = Not at all
  1 = Not confident about many things
  2 = Confident about a few things
  3 = Confident about some things
  4 = Confident about most things
  5 = Very confident

- Allow the person time to decide on his/her response to the question.

- Record the response on the response sheet.

How to deal with possible responses

- If the score is low, you will need to find out what further information or help the person feels he/she/the family need in caring for the patient.

- Provide this if you can. If not, consult with other members of the care team to address the areas where they don't feel confident.

Question 10

Has the family been feeling worried about the patient over the last 3 days?

- This question deals with any concerns the family might have about the patient (e.g. patient's pain, loss of appetite, anxiety, worsening condition, coping with the dying process. Note: These are only examples for you and are not intended as prompts for the person).

- The person will then need to decide on the intensity of the worry:

  0 = Not at all worried
  1 = Worried very occasionally
  2 = Worried some of time
  3 = Worried a lot of the time
  4 = Worried most of the time
  5 = Worried all of the time

- Do not rush this question. Allow the person enough time to think about what might be sources of worry.

- Record the response on the response sheet.

How to deal with possible responses

- If the score is high, you will need to explore the particular issues the person identifies as causes of worry.

- Ask whether the person/family has talked to anyone else about their concerns and how they thought these could be handled.

- Discuss possible interventions.

- Make a referral for further help if necessary.

Note: Please remember to thank the person for his/her willingness to answer the questions.

Appendix 3: APCA African Palliative Care Outcome Scale: Permission form 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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2. Make no changes (be that additions or deletions) to the tool.

3. Permission shall only apply to the work specified above. A new application must be made for any additional works.

4. The development article to be cited is: Powell RA, Downing J, Harding R, Mwangi-Powell F & Connor S on behalf of the APCA M&E Group (2007) Development of the APCA African Palliative Outcome Scale. Journal of Pain and Symptom Management, 33: 229-232.

5. The validation article to be cited is: Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, Mashao T, Mmoledi K, Moll T, Mpanga Sebuyira L, Panjatovic B and Higginson IJ; (2009); Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. Health and Quality of Life Outcomes, 8 (10)

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Name of funding agency:

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C. Contact details

Name of lead author / Principal Investigator (PI):

Full work address of lead author / PI:

Country:

Tel:

Fax:

Permission is granted on the above terms:

By: African Palliative Care Association, PO Box 72518, Kampala, Uganda
Tel: +256 (0)414 266 251
Fax: +256 (0)414 266 217

Name of APCA representative:

Signature:

Date:

Appendix 4: Training programme for using the APCA African POS

Like other clinical and quality improvement / research tools, using the APCA African 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. PowerPoints 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 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 5: Example of analysing the APCA African POS

The analysis of the APCA African 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 POS. Below follows an example of some data from the APCA African POS from a palliative care organisation. In this example the APCA African POS has been used on 10 different patients 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 POS Scores

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. Please rate your pain during the last 3 days	5	5	3	2	3	1	1	1	5	3	3	1	4	3	2	2	5	2	2	1
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	1	1	3	4	4	3	3	1	1	5	4	1	4	3	2	2	4	4	2	1
Q3. Have you been feeling worried about your illness in the past 3 days?	1	1	1	1	3	3	1	1	4	3	2	1	5	5	2	2	4	4	2	2
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	4	4	2	2	3	3	3	3	1	1	3	4	2	2	4	4	0	0	2	3
Q5. Over the past 3 days have you felt that life was worthwhile?	2	2	3	2	0	0	2	2	1	2	3	4	3	3	1	1	2	2	2	2
Q6. Over the past 3 days, have you felt at peace?	2	2	3	3	1	1	3	4	0	1	3	3	1	1	1	1	2	2	3	3
Q7. Have you had enough help and advice for your family to plan for the future?	2	2	2	2	3	3	5	5	2	2	3	3	4	4	3	3	3	3	4	4
Q8. How much information have you and your family been given?	0	1	3	3	1	3	3	4	2	2	3	3	2	4	4	3	1	1	3	3
Q9. How confident does the family feel caring for ____?	0	1	2	3	1	2	2	3	1	2	3	3	2	2	2	3	2	2	3	4
Q10. Has the family been feeling worried about the patient over the last 3 days?	2	4	3	1	5	4	4	2	5	3	1	1	5	3	1	2	4	2	2	1

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. Please rate your pain during the last 3 days	0	1	3	1	5	4	4	2	5	3	1	1	4	3	1	2	2	2	2	1
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	5	2	2	2	4	4	2	1	5	3	2	2	2	4	2	1	3	3	1	1
Q3. Have you been feeling worried about your illness in the past 3 days?	1	1	0	0	1	4	2	1	5	3	1	1	3	3	2	2	3	1	1	1
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	1	1	3	3	3	1	1	1	0	2	2	3	2	2	2	2	2	2	3	4
Q5. Over the past 3 days have you felt that life was worthwhile?	2	2	3	3	1	1	3	4	0	1	3	3	1	1	1	1	2	2	3	3
Q6. Over the past 3 days, have you felt at peace?	2	2	3	2	0	0	2	2	1	2	3	4	3	3	1	1	2	2	2	2
Q7. Have you had enough help and advice for your family to plan for the future?	2	2	3	3	1	1	1	1	0	1	3	3	1	1	3	4	2	2	3	3
Q8. How much information have you and your family been given?	3	3	3	3	1	2	4	4	2	4	4	5	2	2	2	1	1	4	4	4
Q9. How confident does the family feel caring for ____?	3	3	3	3	3	3	4	4	2	1	3	4	1	1	2	2	0	2	3	4
Q10. Has the family been feeling worried about the patient over the last 3 days?	5	2	2	1	5	5	3	2	5	3	3	1	1	1	1	5	2	3	3	2

1. 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. Please rate your pain during the last 3 days		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. Please rate your pain during the last 3 days		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. Please rate your pain during the last 3 days		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. Please rate your pain during the last 3 days		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 5 5 5 (i.e. the average between 4 and 5 so the median is 4.5)

The median for time point 2 is:
1 1 2 2 3 3 3 3 4 5 (i.e. the median is 3)

The median for time point 3 is:
1 1 1 2 2 2 3 3 3 4 (i.e. the median is 2)

The median for time point 4 is:
1 1 1 1 1 1 2 2 2 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:

$$S = \sqrt{\frac{\sum\left(x - \overline{x}\right)^2}{N-1}}$$

Where:

S   is the standard deviation

Σ   is sigma, which tells you to find the sum of what follows

X   is each individual score

$\overline{X}$ 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):

a) 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.

b) Compute the mean of the group – we have already done this and it is 3.8.

c) Subtract the mean from each score, as below.

Individual score	Mean	(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-$\overline{X}$)	(X-$\overline{X}$)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 1.69 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. Please rate your pain during the last 3 days		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

Figure 5: number of patients who had pain on baseline assessment
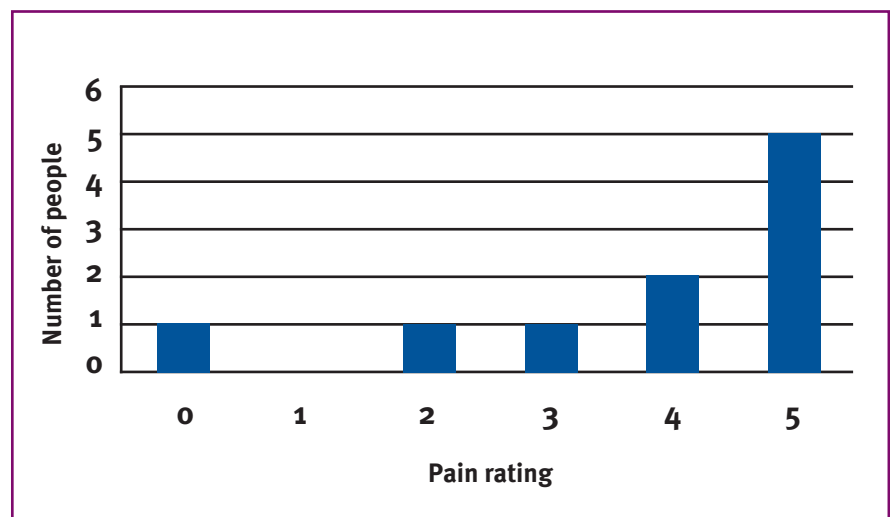
Once you have this information for all of the questions you can look at the graphs and identify which were the worst problems at the time of the baseline assessment – for example, you can tell from the chart above that many of the patients (70%) had a score of 4 or 5 for pain, showing that there was 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 6).

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.

Figure 6: chart showing showing change over time for Q1 on pain
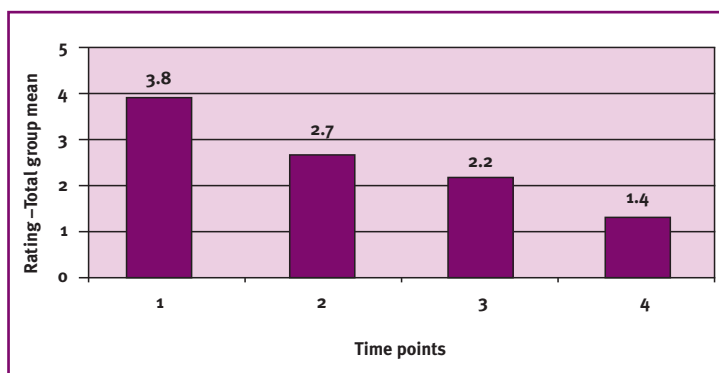

However, it is not always this clear, and if you are conducting an audit of your services or trying to use the APCA African POS for a research study then you will need to look at whether the results are statistically significant (i.e. whether the improvement seen can be put down to chance or whether 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 POS. Important is the extent to which the data is distributed 'normally' in a bell-shape, as shown in Figure 7.

Figure 7: The normal distribution of data

Scater Graph	Frequency Distribution Histogram	Frequency Distribution Histogram
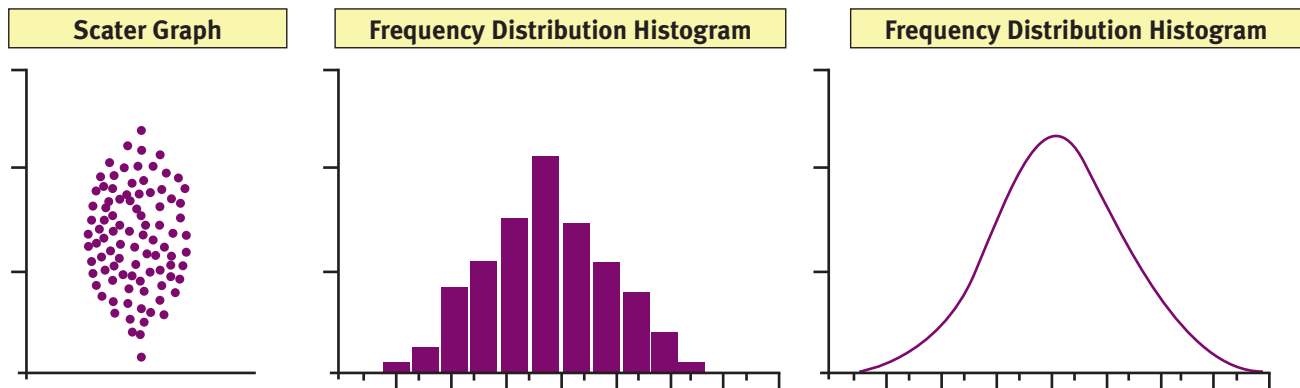
Reproduced from: www.microbiologybytes.com/maths/spss2.html

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	$(X - \overline{X})$
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). It is our experience at APCA when using the APCA African 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.

Examples of parametric tests	Examples of non-parametric tests
• Paired t-test • ANOVA (one way) • Independent t-test • Person product moment correlation	• Wilcoxon signed rank test • Kruskal Wallis • Chi square • Mann-Whitney U test • Spearman's rank order correlation

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 1 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

Time point 1 and time point 4 – p<0.01 (see Figure 8)

Figure 8: chart showing change over time for Q1 on pain
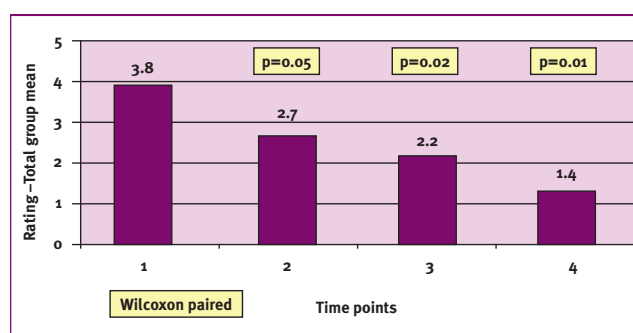
4. Total APCA African POS scores

The APCA African 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 0-15 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 4-9 (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 4-9 and then total them up.

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

Questions	Patient 1				Scores with questions 4-9 reversed			
	1	2	3	4	1	2	3	4
Q1. Please rate your pain during the last 3 days	5	5	3	2	5	5	3	2
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	1	1	3	4	1	1	3	4
Q3. Have you been feeling worried about your illness in the past 3 days?	1	1	1	1	1	1	1	1
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	4	4	2	2	1	1	3	3
Q5. Over the past 3 days have you felt that life was worthwhile?	2	2	3	2	3	3	2	3
Q6. Over the past 3 days, have you felt at peace?	2	2	3	3	3	3	2	2
Q7. Have you had enough help and advice for your family to plan for the future?	2	2	2	2	3	3	3	3
Total POS Score Patient					17	17	17	18
Q8. How much information have you and your family been given?	0	1	3	3	5	4	2	2
Q9. How confident does the family feel caring for ____?	0	1	2	3	5	4	3	2
Q10. Has the family been feeling worried about the patient over the last 3 days?	2	4	3	1	2	4	3	1
Total POS Score Carer					12	12	8	5

So what does this tell us? We may use this to try and derive a picture of the overall status of the patient and their carers. In this instance, the total APCA African 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 1 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 6: Example of a distress protocol

The health professionals administering the tool is expected to be compassionate, patient and respectful at all times during the administration of the tool. If during the administration of either of the tools the patient 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 patient'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 patient 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 if you want you 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 patient distressed. You would need to ask them whether they would like a counsellor or someone else to talk to the patient.

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) 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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