Appendix 1

Results of a survey of the inpatient population in the Adult Medicine wards of Kilimanjaro Christian Medical Centre.

Method

Researchers conducted paper questionnaires with all consenting inpatients who were present on the adult medical wards of KCMC on the day/s of the survey. Medical ward 2 (75 beds) was completed on the 12th Jan 2016, Medical ward 1 (44 beds) and Medical Intensive Care Unit (6 beds) were completed on the 15th Jan 2016, with all patients present on the wards on these days being eligible for inclusion.

Results

In total 117 patients were included in the survey. All were Tanzanian nationals. The mean age of patients included was 50.9 years, SD 18.6, range 14-90 years. This survey found that no inpatients had been seen previously by a palliative care team. No patient was prescribed oral morphine at the time of the survey.

Socio-demographic data of the inpatient population in the Adult Medicine Wards of KCMC.

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| --- | --- | --- |
|  |  | n=117 (%) |
| Sex | MalesFemales | 64 (51.2%)61 (48.8%) |
| Region | KilimanjaroArushaDar es SalaamOthers | 90 (75%)20 (16.6%)1 (0.8%)9 (7.5%) |
| Religion | ChristianMuslimTraditional AfricanOther not specified | 98 (83.7%)17 (14.5%)1 (0.8%)1 (0.8%) |
| Tribe | MchaggaMpareMmaasaiMarushaOthers (16 different tribes) | 64 (54.2%)14 (11.8%)9 (7.6%)5 (4.2%)26 (22.0%) |
| Marital status | SingleMarriedDivorcedWidowed | 34 (29.0%)54 (46.1%)6 (5.1%)23 (19.6%) |
| Occupation  | Professional (state sector)Business (private sector)Home makerStudentRetiredFarmer/ labourer Unemployed Other (driver, secretary, cook) | 10 (8.5%)29 (24.7%)3 (2.5%)3 (2.5%)11 (9.4%)41 (35.0%)13 (11.1%)7 (5.9%) |
| Level of education | NonePrimarySecondaryHigherCompleted university | 18 (15.3%)78 (66.6%)14 (11.9%)5 (4.2%)2 (1.7%) |
| Access to food | Food more than once daily Food once per day Struggles to find food | 109 (93.1%)6 (5.1%)2 (1.7%) |
| Water source | Piped waterCommon wellShared pump/tap Spring/river | 60 (51.2%)7 (5.9%)32 (27.3%)18 (15.3%) |

Appendix 2

**Focus group discussion/Semi-structured interview topic guide**

1. What is your understanding of the term ‘Palliative Care’?
2. How much teaching/training have you received in palliative care in your career so far?
3. Would you be willing to recommend a patient to receive palliative care? What type of patient?
4. Please describe your understanding of ‘active dying’ and ‘end-of-life’ care.
5. Describe your understanding of the availability of morphine in Tanzania. How willing are you to prescribe morphine (oral or other routes) to patients? Please explain your answer and give examples where possible.
6. Imagine you are diagnosed with a serious illness and have only one year of life left, what would your priorities be and your main concerns?
* Vignette A. You are looking after a Maasai lady who has breast cancer with suspected metastases to the brain diagnosed on CT scan 3 months earlier. She is a herdswoman with 15 children. She has come to hospital this time with focal seizures and slurred speech. She has a headache, drowsiness and nausea. An ultrasound abdomen shows multiple liver lesions. The working diagnosis is of progressive cancer. Her daughters want her to be discharged this morning because they see that her condition is deteriorating. They would like to take her to a church for an exorcism of evil spirits that they believe are causing these symptoms, and then to care for her at home. What are your thoughts and feelings about this case?
* What would you say to this patient’s relatives?
* How important is the place of care when a patient is seriously ill and dying?
* How important are people’s religious or spiritual beliefs about illness, death and dying?
* Can you think of any ways to manage this patient’s symptoms of headache, nausea and drowsiness?

Vignette B. You come across an 82 year old patient on the medical ward round who has metastatic lung cancer. He was admitted with a pathological fracture of the humerus and is not aware of his diagnosis. He appears elderly, frail and cachexic and complains of severe pain which stops him from sleeping.

* How would you approach this patient?
* How does looking after a patient like this make you feel?
* When would you consider starting analgesia? What would you prescribe?
* What are your worries or fears about managing this patient?
* In your opinion should the patient be told his diagnosis? Explain your opinion.

You review the patient two weeks later and he is very breathless. He is unable to lie flat and is too short of breath to walk to the toilet. He appears very low in mood and admits he has been “thinking too much”. He tells you he is worried about what will happen to his granddaughter (who is his carer) in the future, he is also very worried about his hospital bill. On examination he has a large right sided pleural effusion, his oxygen saturations drop to 80% when he talks.

* What can you suggest to help his social situation?
* What measures could you try to ease his breathlessness?
* What could you try in order to address his low mood and anxiety?

Vignette C. You are working on a medical ward and are called to see a 53 year old female patient who has presented with another collapse and sudden loss of consciousness. She fell down the day before yesterday and has not been able to respond to her daughter since then. Before this she had a weak right side after a stroke 3 years ago and only walked short distances with assistance. Her daughter is at the bedside and appears very concerned. On examination, the patient is comatose with a GCS of 3/15, the right pupil is fixed and dilated and her right plantar reflex is up going. Your working diagnosis is a recurrent stroke due to uncontrolled hypertension, and also likely aspiration pneumonia. Your plan is to pass an NG for feeding, give IV antibiotics and to treat her hypertension.

* What are your thoughts about the patient’s diagnosis and prognosis?
* What do you think of this management plan?
* Could anything have been done differently so far?

You are called to review her after several days on the ward as her condition has changed. The patient is gasping with a large amount of secretions. On examination her blood pressure and pulse is undetectable. You resuscitate her with IV adrenaline, hydrocortisone and suctioning. Despite your efforts she passes away. Her daughter has been at the bedside and starts to cry loudly. You confirm the death and leave the bedside to complete your documentation.

* What are your thoughts about this case?
* Do you think this patient could have been considered appropriate for palliative care?
* How could you support the family now?
* Can you think of any ways of managing the patient’s symptoms of secretions?
* How do you feel when reflecting on this history?
* Would you have done anything differently?

Paediatric case

A 5 year old boy who is seropositive attends the OPD clinic with his older sister, aged 16 years. He has been orphaned due to HIV/AIDS and the family are now struggling to feed themselves. His CD4 count is low, indicating therapeutic failure on second line antiretroviral medications. There are multiple Kaposi’s Sarcoma lesions on the child’s limbs, he appears malnourished and growth-stunted. He has been complaining of weakness and breathlessness and can no longer play.

* What issues here would you like to address?
* What challenges /difficulties do you face when trying to care for patients like this?