INTRODUCTION

Situated in the Soweto district of Johannesburg, South Africa, the Chris Hani Baragwanath Academic Hospital (CHBAH) is the third largest hospital in the world with about 3000 beds. It is a tertiary level referral hospital, although patients are often admitted directly from the community.

This paper describes and delineates The Baragwanath Palliative Care Programme, that is intended to mitigate and ameliorate the limited palliative care facilities available at and around CHBAH.

The goal of the Programme is:

To put into place palliative care measures that support patients with chronic end-stage renal failure, and their families, that ensure quality of life and dignity in death.

The Programme is supported by a Rotary Global Grant from the Rotary International Foundation Charity, which matches funds raised by Rotary Districts, which in turn match funds raised by Rotary Clubs.

This programme has been planned with Rotary International by Clubs in District 1260, (Herts, Beds and Bucks) in UK, led by the RC of Hatfield, and Clubs in District 9400 in SA, led by the Rosebank RC, all acting in conjunction with appropriate and expert Clinical and Administrative Staff from, or associated, with the Baragwanath Hospital and latterly The Witwatersrand Health Consortium in conjunction with the Gauteng Health Authority.

BACKGROUND

The Soweto region of Johannesburg covers an area of approximately 200 square kilometres divided into 29 suburbs with some 1.25 million inhabitants. Unemployment levels are extremely high. Mains power only reaches a small percentage of inhabitants and there are frequent power outages due to a lack of generating capacity.

There is one secondary level (district) hospital - Zola Jabulani (a level 1 – 2 hospital) which has recently opened and is still building capacity. There are 28 clinics in the region, as well as many private general practitioners and other specialists practicing in the Soweto area although the exact numbers are unknown.

There are two known Hospices and some home-based care organisations although these are experiencing difficulties due to decreased funding. Currently, palliative care is not part of the package of health care offered at the primary level facilities in Soweto.

The N'Doro Project, based at CHBAH, started operating in 2003. Since then this small project has been at the forefront of developing and piloting a model of palliative care, providing community outreach palliative care to HIV/AIDS and cancer patients in the Soweto area, and providing training and conducting original research.

The Gauteng Centre of Excellence for Palliative Care was established in 2007 at CHBAH and adopted by the Gauteng Province Department of Health.

The Wits Centre for Palliative Care was established in 2012, with a view to furthering academic excellence in palliative care. The Centre started to provide a paediatric palliative care service to CHBAH, funded by the Stephen Lewis Foundation, in 2013. Throughout, the limitation was that the entire Baragwanath hospital had only 6 battery powered Syringe Drivers.

The Palliative Care Team at CHBAH is a multidisciplinary team offering a nurse-led, doctor-supported, palliative care service to patients and their families. The team consists of qualified nurses, doctors, social worker and social auxiliary workers, volunteers and a pastoral carer on call. They are supported by a team of drivers, administration staff and general assistants.
The Team currently offers the following palliative care services:

- provide consultative services to support the doctors in the various adult and paediatric departments of CHBAH;
- provide home visits to registered patients within the Soweto area and a link between the patient and family at home and the hospital;
- provide telephonic and outpatient service to registered patients outside the Soweto area;
- provide a drop-in outpatient clinic to any registered patients or patients wishing to register with the service for the first time.

PALLIATIVE CARE

Palliative Care aims to improve the quality of life of patients and their families facing problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification, impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual. (WHO 2002)

Palliative care in principle:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates psychosocial and spiritual aspects of care;
- offers support systems 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 counseling, if indicated;
- enhances quality of life, and may also positively influence the course of illness.

End of Life Care and Terminal Care

The definition of these two concepts varies between organisations and countries, depending on viewpoint and core business. It is important to have a definition of each as these terms are often confused with palliative care in general and the three are seen as the same concept.

For the purposes of the CHBAH core business these terms are defined as follows:

- **End of Life Care**
  Care for a patient whose prognosis is measured in months (e.g. If the answer to the question: “Would I be surprised if my patient were to die in the next 6 months?” is no.)

- **Terminal Care**
  Care for a patient whose prognosis is measured in hours to days.

Palliative Care for Renal Failure

The Renal Unit at CHBAH sees approximately 500 patients a month, with just under 90 patients on haemo-dialysis. These patients are potential candidates for renal transplant, however there are usually only 2 transplants a year: donor kidneys are limited by a general tribal belief that on death a person must be buried as a complete body. A further 30 patients are on peritoneal dialysis.

There are 4 haemodialysis units which are utilised for acute situations where renal failure is usually caused by an acute insult such as malaria and patients are expected to recover renal function within 6 weeks. Patients on haemodialysis usually need to come in to the unit 4 times a week for a period of approximately 4 hours.
Patients on peritoneal dialysis have the diasylate delivered to their homes and need to dialyse themselves about 4 times a day. Consequently, these patients need to meet certain economic requirements such as having a home with a spare room to store the diasylate, running water and electricity; often these patients cannot have formal employment due to the regular 6 hourly need for dialysis.

Whether on haemo-dialysis or peritoneal dialysis, patients need to be very committed and motivated to stay on the program and they need a source of income to finance this. Many are assisted with disability grants; the Renal Unit has a multi-disciplinary team to support patients on dialysis.

Unfortunately the need for dialysis is much greater than the capacity and patients who do not fit the criteria for renal transplant are managed conservatively. Many patients who do fit the criteria are on a waiting list for dialysis. Because of the few transplants, and the effectiveness of dialysis in maintaining renal function, the waiting list is long: patients often have a deterioration in renal function and eventually are no longer fit for transplant and are removed from the list, or die before receiving dialysis.

For patients who are not receiving dialysis, there is no further care beyond monthly check ups for blood tests: they are left without hope and no means to manage the illness. There is no preparation for the inevitable deterioration and death and families and patients are left to cope the best they can: this often means repeated admissions to hospital and eventually a messy death in hospital.

While end-stage renal failure is usually not a very painful condition, it does have other difficult symptoms that need to be controlled for quality of life. No access to life-saving procedures or to be removed from a life-saving program for any reason, is very distressing to families. It can also be very disturbing to staff who develop a relationship with the patients. There is certainly a lot more that could be done for patients for whom ‘there is nothing more we can do’.

Such patients would benefit from palliative care so that they and their families are supported, know what is happening and can anticipate the deterioration in function, plan for the future and, with support, avoid the numerous unnecessary hospital admissions and hopefully experience a more dignified death at home or in a hospice. This would help the families financially and emotionally and do the same for the Hospital and the staff working in the Renal Unit.

CONCLUSION

The above description of the palliative care facilities available at the CH Baragwanath Academic Hospital suggested that a programme of appropriate and substantial improvements to its provision was needed and possible.

The sequel outlines the ROTARY INTERNATIONAL GLOBAL GRANT PROJECT to introduce just such a Programme.

FT/RW 15 May 2016
1. PROJECT GOAL

Establish a Programme of Palliative Care at Home measures at the Chris Hani Bargwanath Academic Hospital (CHBAH) in South Africa to support patients with chronic end stage renal failure and their families. Give quality of life and dignity in death to terminally ill patients.

2. PROJECT OBJECTIVES

- Improve the quality of life of patients and their families faced with life threatening illness, by focussing on immobile patients who can best be treated at home;
- Reduce the need for and costs of hospital visits and prolonged hospital stays, and the related costs and pressure on overworked hospitals.

3. SCOPE OF THE PROJECT

- Patients who are eligible for inclusion in the project will be identified at the Renal Clinic and in the wards at CHBAH.
- Patients who reside in Soweto will be visited at home weekly, bi-weekly or monthly as required.
- Patients residing out of Soweto will be seen at the Palliative Care Out–Patients Department.
- As part of ensuring sustainability, the Jabulani Hospital and the clinics in Soweto will be introduced to the Programme and be given training in Renal Palliative Care as required.

Criteria for inclusion in the Programme:

- Chronic Kidney Disease stage 5;
- Answer is 'no' to the Surprise Question: 'Would I be surprised if this patient died in the next 6 months?'

4. METHODOLOGY

- Training of clinic staff and hospital staff. Recruit and train project nurses, social workers and a driver to deliver care in patients' homes.
- Identify patients in the hospital and clinic who fit the criteria for referral;
- Enrol patients into the program;
- Support group sessions to give education and support for coping with renal failure;
- Visit patients at home to track progress and to offer support with deterioration;
- Maintain symptom control within the home with support for the families;
- Liaise with Soweto Hospice for home care and for admission to the in-patient unit if required.
- A SPIRITUAL CARE Co-Ordinator has been recruited. Training of spiritual leaders to provide care for families has taken place.
- Supervision and debriefing for the team has happened.
- Writing up the model for publication has been done.
5. TIMING OF PROJECT

The following timetable is now planned and started:

- Select/employ additional people and train them – March – end April 2016
- Acquire equipment, prepare manuals – February – April 2016
- Train project staff April / May 2016
- Operate for a full financial year – April 2016 – March 2017

6. COSTING and ACCOUNTING STRUCTURE

- The existing costing structures of CHBAH and WITS will be used. This will include office space, furniture, telephones, stationery and similar costs;
- Additional equipment required in the form of vehicles, cell-phones & computers have been purchased.
- Further operating costs will be incurred in the vehicle running costs, cell-phone usage costs, printing of manuals, outsourced training and possibly other costs;
- The draft budget outline is the best estimate of the costs of the project.

Funding advances:

- Funds have been advanced in mid March 2016 for the next 4 months;
- Thereafter funds will be advanced for the following 3 month period after receipt of a financial report for the previous 3 months;

Accounting and reporting:

- WITS will keep a separate set of books from Rosebank Rotary Club.
- The shape and frequency of reporting to Rotary on progress have been defined.
- Financial reports will be required every 3 months from the start within 14 days of the end of the period.

7. SERVICE STRUCTURE

- House visits via a vehicle with driver, supported by a nurse and social auxiliary worker;
- Team makes 5-10 home visits per day, Monday to Thursday (Friday for administration);
- The number of visits per patient per month will depend on medical conditions. An average of 2-4 visits per month per patient has been estimated.
- Medical files are maintained for each patient and reports made on each visit.
- The Nurse supervisor will co-ordinate the programme, review patient reports and handle upward reporting as needed;

Further additional employment needs are:

- a Driver;
- a Nurse Co-ordinator;
- a Social Auxiliary.
8. EXPECTED OUTCOMES

Improved Quality of Care

- Better understanding of the disease process;
- More appropriate care at the right time and place;
- Adequate psychosocial support;
- Well-managed symptom control at end of life;
- Family and patient prepared for the end stages and for death with advance care plans.

Cost savings

- Patients are not admitted unnecessarily;
- Fewer admissions to hospital;
- Home or hospice deaths rather than hospital deaths.

9. MEASURES OF SUCCESS

- Reduction in hospital admissions;
- Reduction in hospital deaths;
- Improved quality of life as evaluated using the APCA POS;
- Improved patient and family satisfaction by survey.

10. FUTURE EXPANSION

- . . . to Zola Jabulani hospital;
- . . . to clinics in the region;
- . . . to other district hospitals feeding into CHBAH;
- . . . to include all chronic end stage diseases.

11. SUSTAINABILITY

Sustainability of the Project is assured by:

- the success of the Abundant Life Project at Victoria Hospital in Western Cape;
- the expertise and staffing of the existing palliative care team at CHBAH;
- the existing funded multidisciplinary team at the Renal Unit;
- An MoU with the Academic part of CHBAH, The University of Witswatersrand is to manage the project.
- Gauteng Department of Health has committed to a palliative care policy and will continue the employment of project staff at project completion.
- CaSIPO project to assist with palliative care policy, implementation, training and research;
- WHO Resolution 67.19 urges governments to include palliative care in their health systems.