

## ☀ WELCOME TO RHI ☀

The South African Academy of Family Practice's Rural Health Initiative (RHI) is proud to be able to bring you the following section of the journal, that will concentrate on issues pertaining to rural health in South Africa. We hope to provoke discussion on these issues and would encourage anyone interested in rural health to offer contributions to future issues.

In this issue we cover another of the problem areas in rural hospitals, an alternative to home-based care and introduce you to the Rural Health Initiative.

### ☀ RENDERING OF HOSPICE CARE IN RESOURCE-POOR SETTINGS ☀

As the number of people dying of AIDS grows, "home-based care" has become the much-touted solution to the overwhelming burden being placed on hospitals.

While an ardent supporter of home-based care (see my article in the previous issue), I have come to realize that there is a significant proportion of patients for whom home-based care is not a viable option.

I am a Family Physician working in Winterveldt, NW Province, based at a Government Health Centre. I also work with the Tumelong Home Care and Hospice Project, a church affiliated NGO. The story of a patient we have recently cared for will highlight the limits of home-based care.

Fernando Ndlovu (not his real name), is a 26yr old HIV+ man who was referred from the local community hospital to the government health centre in Winterveldt for TB treatment. Fernando is an "illegal" Mozambican refugee who was working as a labourer in Pretoria. At the time of referral he was living alone in a rented backyard room. He has no family in South Africa. On admission to TB treatment Fernando was very weak and obviously very ill. He had generalized lymphadenopathy, severe seborrhoeic dermatitis of the face and was emaciated. As he had previously had TB several years ago,

he was started on Regimen 2 – which meant he needed daily (weekdays) Streptomycin injections as well as oral treatment. It was obvious that he would not be able to come to the clinic for his daily injections – he lived ±5kms away, had lost his temporary job and had no money to pay for transport. It was arranged that the community health worker from Tumelong would visit him daily to give him his injection. His living conditions were squalid – a 2m x 2m single room, a blanket and mattress on the floor, a pile of clothes on a milk crate, a few plates and a primus stove were his only possessions. A week after commencing treatment he was in danger of being evicted by his landlord because of non-payment of his R50 monthly rent. We suggested that he return to Mozambique to stay with his family – but as the breadwinner he wanted to stay in South Africa, hoping that he would recover sufficiently to return to work. After negotiations with the landlord, Tumelong paid his rent, provided him with weekly food parcels and continued with his daily injection. After a few weeks however, Fernando developed severe diarrhoea. As he had no close friends and little contact with his neighbours, there was no one to provide basic care for him. He was admitted to the Tumelong Hospice, where with oral rehydration solution, Loperamide and Cotrimoxazole, his diarrhoea resolved after several days. He was still too ill to live alone, and at

time of writing is still in the hospice becoming progressively weaker.

How can residential hospice care be provided in resource poor settings?

Tumelong Hospice was opened in February 1999 and is affiliated to the Anglican Diocese of Pretoria. The need for a hospice had been felt for two years, after Tumelong had initially begun a home-based care programme in the Winterveldt area. As local hospitals refused to admit terminally ill patients, we found increasing numbers of people like Fernando for whom home-based care proved to be inadequate. A building in the rural community of Lekgema, previously used as a clinic was converted into a home with 4 bedrooms, kitchen, lounge, office and bathroom. This was done with money raised specifically for the purpose and was provided by a large mining house. The initial 7 beds has been extended to 11 beds with further funding and the erection of a big wooden room holding the extra 4 beds.

A team of 12 community health workers was selected after a laborious, transparent selection procedure (some had already been involved in community-based health projects, some were completely new). An 8-month, modified hospice care course (material provided by Hospice Assoc. of SA) was run by the Tumelong project manager (a professional nurse). 24-hour care in the hospice is provided by 3 community

health workers (one senior) during the day and 2 at night, with support from the professional nurse and myself. I visit the hospice twice per week to see all patients, and am on permanent call for any problems that arise. We provide good basic palliative care and management of opportunistic infections using EDL drugs. The senior community health worker is responsible for the day-to-day running of the project and a weekly meeting is held to discuss all aspects of the hospice care offered. A social worker on the staff is responsible for assisting with social issues, and visiting clergy and traditional healers provide spiritual support.

### Criteria for admission

Deciding who qualifies for hospice care has proved to be difficult. We face requests every week from family members and hospital professionals to admit people who are chronically ill (especially the elderly) and who essentially need a nursing home. After much discussion we have decided to take patients only if they:

- 1) have a confirmed terminal disease (not only AIDS)
- 2) have no adequate care-giver where they live and are too ill to take care of themselves i.e. are bedridden or very weak
- 3) to give the family respite (usually for a few days at a time)
- 4) to control symptoms e.g. diarrhoea / vomiting.

Referrals come from families, hospitals, other NGO's, clinics, The Cancer Association of SA and the Sungardens Hospice in Pretoria East.

### Statistics

During the first 8 months of this year we cared for 263 patients. 201 "out-patients" 85 of whom have died 62 "in-patients" 51 of whom have died

### Challenges

*Financial constraints:* Running a hospice is obviously a relatively high expenditure per patient. However, with changing attitudes, provincial governments and large NGO donors seem to be more willing to help fund hospice projects.

*Referral system:* The fragmentation of care of terminally ill patients between clinics, community and tertiary hospitals, makes an efficient referral system difficult to implement. Patients are often discharged from hospital without being referred to home-based care or the hospice, leaving desperate family members to sort out referrals. Ongoing education of medical and nursing staff attempts to correct this.

*Misperceptions:* Family members and patients are often unsure what a hospice offers. People often assume it is a small hospital until it is carefully explained by the CHW's what palliative care entails. Some cannot accept that

their loved one is terminally ill and feel that we have "given up". Generally however, family members and patients appreciate the care offered.

*Destitute families:* We have patients who do not belong to a burial society and have had to arrange and pay for several funerals since the hospice was opened. On several occasions we have had to arrange transport for patients or family members to Mozambique, Zimbabwe and other South African Provinces. On two previous occasions we have had to transport bodies to their family homes in other Provinces.

*Orphans:* We have 134 orphans in the Tumelong Orphans Register to date. Children who have lost their parents – mostly through AIDS and have been absorbed by neighbours, grandmothers, other extended family members or become part of child-headed families – many of these care-givers are themselves destitute. Tumelong has initiated a non-residential haven for orphans in response to this challenge.

### Conclusion

In my view, residential hospice care is an essential back-up to an effective home-based care system. NGO's (especially the church) are probably best placed to run hospices. However, they need government support (financial – a partnership and payment for services rendered) and the involvement of district health services for efficient referral of patients from hospitals and clinics. There is no reason why a rural hospital cannot have a "hospice ward" attached, run by community health workers and 1 or 2 nurses. Unless we develop more creative ways of caring for people for whom home-based care is not feasible, we are in danger of abandoning them to a frightening, painful and lonely death.

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### Cost of running a hospice.

#### Salaries

x 12 CHW's @ R2 200 / month x 13	= R 343 200
x 1 driver @ R2 200 x 13	= R 28 600
x 1 Social Worker @ R5 500 x 13	= R 71 500
Transport @ +- R1 500 / month (including servicing, insurance)	= R 18 000

#### Operating Costs

(food, electricity, stationery, etc) @ R1 800 / month (we receive donations of food, blankets etc from churches as well)	= R 21 600
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<b>Medicines and other medical supplies</b> @ +- R2000 / month (most patients have access to medication from the local government hospital)	= R 24 000
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<b>TOTAL</b>	= R 506 900
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## ☼ RURAL HOSPITAL FOCUS - DEBATING POINTS ☼

This is the second in the series on the 3 major problems encountered in almost every rural hospital. Please feel free to send in your comments.

### "No Transport, No Primary Health Care"<sup>[1]</sup>

In the first article in this series, I stated that in my experience there are three problems common to most rural hospitals, viz. staffing, transport and accommodation. I went on to discuss issues related to staffing. This time, I will focusing on the issue of transport which I believe to be essential for effective functioning of rural hospitals.

In the COHSASA Accreditation Programme for hospitals, transport does not warrant even a mention. How can this be? It is a matter of focus. I think if one focuses very narrowly on the hospital, and what goes on within its walls, as health planners tend to do, then it is easy to see why transport is not seen as an issue - especially if one comes from an urban centre. However, if one begins to look outside the walls, even through a window, the issue of transport becomes critical.

Knowing you, the reader, already to be amongst the converted (otherwise you would not be reading this), I will nevertheless risk preaching to you, in that I will try to explain why I believe transport is key to effective rural hospital functioning.

Firstly, we can consider how our patients get to us. Usually they are scattered far from the hospital, wherever it may be located in the district. Often there are not the established transport routes and services that exist in more developed areas. Thus the patient who needs to go to hospital - because s/he is referred, or has a relative admitted, or requires special treatment, etc. - is faced with the obstacle of getting there in the first place. It is not unusual for patients to walk for up to a day (and even two days!) to reach the hospital. (Heaven help you

if you are a disabled patient on top of it all). In the past, hospital transport services would often assist those patients referred from clinics, but bureaucrats have increasingly insisted this be reserved for emergency cases only, and in a situation of limited resources it is difficult to argue against that. Of course, getting home after the hospital visit is no less problematic.

The next difficulty occurs if the rural hospital cannot sort out the patient's problem and refers her on to a regional or tertiary hospital. Few rural patients can afford the expense of such a trip, and it becomes incumbent on the rural hospital to organise transport for such referrals. If this is not done, patients inevitably do not go - the core district health system principles of access and equity are violated.

Thirdly, there are the patients needing emergency transfer to a higher level. Whether the hospital has its own ambulances or relies on provincial ambulance services, this is a major problem. One transfer from a rural hospital to the city can use up a vehicle for up to a whole day. Anyone who has worked in a rural hospital will have experienced the dilemma of deciding when to send an emergency patient because doing so - if it is indeed possible in the first place - may mean there is little chance of being able to transfer any other emergency patient for a number of hours. This can create a terrifying situation for any doctor in an isolated rural hospital, and has certainly been the cause of many deaths. It is significant that the report on the Confidential Inquiry into Maternal Deaths, "Saving Mothers" (National Department of Health), mentions this issue.

Fourthly, transport is required for outreach to, and support of, district services. A host of hospital-based health workers at the primary care level need to reach out into the community, from rehabilitation teams to social workers, to psychiatric teams, to dental services, etc. Also there is a need for visiting doctors, dentists and other staff to reach clinics and to give regular support to clinic-based staff. Where this does not happen the quality of services deteriorates, the range of access to services is reduced and staff morale decreases. Once again, patients furthest from the hospital suffer.

Another aspect of support is keeping the clinics supplied - with drugs, stationery, equipment, linen, etc. Along with this there is the need for equipment to be repaired, buildings to be maintained, etc. While in theory this is the function of the district or sub-district office, the district hospital inevitably is involved, through the resources it has - or would be involved where there is transport.

Finally, staff in district hospitals need to go to meetings, workshops, courses, etc. In the city this is fairly easily achieved and often staff will go directly with their own, or public, transport. In rural hospitals, meetings are often held hundreds of kilometres away from the base - because that is where district, regional or provincial offices are located. Often there is more than one meeting on the same day in different places, putting extra strain on transport resources.

What complicates this all is that very often rural hospitals are located in areas with bad roads which increase the inevitable wear and tear that always occur when vehicles are used by many people.

Vehicles are expensive, as is maintaining them. However, there are ways to reduce these costs - proper management of vehicle fleets (e.g. allocating vehicles to specific drivers or sections or tasks, vehicle monitoring systems, etc.), or subsidised vehicles, or paying

staff for use of their private vehicles.

Despite the expense, money must be budgeted for and spent on acquiring, replacing and maintaining vehicles if the rural district hospital is to achieve anything with respect to primary health care.

1. Title of publication by Initiative for Sub-District Support (Health Systems trust), March 2000.

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## ❁ RURAL HEALTH INITIATIVE ❁

The Academy's Rural Health Initiative is a programme that Professor Bruce Sparks began in 1997, during his tenure as the Chairman of the South African Academy of Family Practice / Primary Care. Its prime objective is the educational support of South African rural doctors in an effort to improve the health care of the rural communities they serve.

This new section of SA Family Practice is our latest project. It is becoming increasingly clear in South Africa that rural medical practitioners and the issues that they face require the earnest attention of all people concerned about the sustainability of the South African health care system. One of the mechanisms for publicising (? and getting those in the know to address) these issues may be the publication of this rural section. We intend doing this for six months and then reviewing your feelings on whether or not it is providing a valuable service to rural doctors.

With this project, we are trying to:

1. attempt to guarantee a credible journal forum for rural issues,
2. circulate information regarding the Rural Health Initiative to a wider audience,
3. provide a focused Continuing Professional Development programme for South African rural doctors.

In an attempt to encourage rural doctors to contribute to this journal we will be offering two prizes, which will be awarded at the WONCA 2001 congress in May 2001 in Durban (see

notices for this congress elsewhere in this issue):

- Prize for the best contribution by a rural doctor: RI 000
- Prize for the best original article by a rural doctor: RI 000


We hope that this will provide some incentive to those of you who may be a little hesitant to put pen to paper (or fingers to keyboard).

Another project that RHI started this year was a site at Ellisras Hospital in the Northern Province. Dr. Ayo Medaiyese ably started this, but the leadership of the project has now passed to Dr. Nicci Pannell. Amongst other things, this hospital has played an important role in community AIDS awareness projects and in bringing accessible accredited CPD activities to this far-flung community. The following photographs show some of the

activities that have taken place, including school education programmes, CPD activities and community projects.

The Rural Health Initiative would be happy to consider starting any other new sites at rural hospitals around the country. If anyone is interested in making enquiries, they can phone Penny Bryce on (011) 807 6605, or Dr. Julia Blitz (Director) on 082 452 7849.

Last, but not least, we also launched a distance-based course in medical ethics, which has been designed by a South African Family Physician - Dr. Keymanthri Moodley, specifically for South African conditions. We would urge you to seriously consider gaining your obligatory ethics CPD points through participating in this course (see advert below).



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**ACCREDITATION: 20 CPD POINTS**

