Mbekweni Community Hall
Paarl, Western Cape

13 November 2008

DISSEMINATION WORKSHOP
Tuberculosis: An Additional Tipping Stress on Poor Households in Mbekweni

Parts of South Africa are seriously affected by the dual epidemics of tuberculosis (TB) and HIV. While the government is attempting to integrate public TB and HIV services to reach co-infected people, there is little evidence on how the synergy of co-infection with TB and HIV plays out for affected families in the context of poverty and overstretched public services. An anthropological study carried out in 2006/7 documented the social and economic impact of TB, HIV, and food insecurity on poor households in peri-urban South Africa, namely Mbekweni Township, Paarl in the Western Cape.

Anthropological research was conducted by Busi Magazi from the University of Cape Town, based at the Desmond Tutu TB Centre (DTTC), in ten households affected by TB throughout the period of TB treatment, and in ten comparative non-affected households. A dissemination workshop was organised for this study on the 13th of November 2008 in Mbekweni Community Hall with the express intention of feeding back the results to community members including some of the families who participated in the study. Almost 100 community members attended with representatives from various organisations involved in the study including six TB patient and five comparative households.

The workshop was opened by Pastor Mntanga who acknowledged the support of ZAMBART in carrying out the research, the financial support of RENEWAL and the ongoing community work of the DTTC, reminding the workshop participants of the work of Desmond Tutu as an icon of South Africa. This notion was carried forward by Professor Nulda Beyers of the Centre who emphasized that the struggle led by Tutu for human rights continued in terms of focusing on the immense development challenges the country faced. She referred to the strength of a clenched fist when individual fingers came together to engage an issue; in this regard the work of DTTC, Stellenbosch University, Renewal, the Mbekweni Community, ZAMBART and the research teams from South Africa and Zambia.

Busi Magazi presented the research findings, which were translated from English into isiXhosa. She explained the importance of returning to the community with the research findings. This was noted by a representative of Mbekweni (Community Advisory Board) who emphasized that this was one of the first occasions that a research team had met their promise to return. To supplement the presentation, a flyer was distributed in both languages which provided a summary of the main findings with useful illustrations. Additional material was distributed with contact details for support organizations such as DTTC. The Community Hall was decorated in posters that communicated basic information about HIV, AIDS and TB.

Having clarified the background to the research including the comparative aspect between rural Zambia and peri-urban South Africa, Busi presented the main findings of the research under nine themes:

1. *The Physical Impact of TB*

- Many TB patients were extremely weak for the first three months of treatment during which time they were unable to work and move around, often frightened by their own frailty.
- Some of the patients had collapsed whilst at work and had to be brought home by their employers. Others had experienced a gradual deterioration. Terms used to explain this condition included "polluted", "thin like a rod", "felt like death" and "crippled".
- During the course of the study three TB patients died.

2. *Management and Care of TB Patients*

- The care of TB patients often fell to women in the family. Caregivers were often overstretched and ended up ill themselves. They indicated the difficulties of taking care of someone with TB.
- The diversion from household tasks was a major issue for many families.
- Four of the patients received support from local NGOs including the Caring Network and the Dutch Reformed Church. Support included food parcels, bedding, membership of support groups and treatment support.
- Eight out of ten patients received disability grants for the six months of TB treatment, which was an important source of income during illness. One male patient lost his identity document and the other male patient died while his application was in process. The payments were often made late (two or more months into treatment) and sometimes caused conflict within families about its allocation. Old Age Grants were a critical source of support before the Disability Grants arrived indicating the importance of such grants in supporting households.

3. *Food Security*

- Many respondents believed that TB drugs and ARV medication increased the hunger of TB patients. Many also believed that these medications should be taken with food ("to avoid an impact on the mind").
- TB patients placed additional demands on their families for "special" foods, high in protein and carbohydrates such as fish, chicken, eggs, fruit, red meat and soft drinks. All the families attempted to buy these foods although seven out of ten struggled with this burden. Four households indicated that they were short of food most of the time.
- "Special" foods were more affordable for some households when the heads of the household were in full employment.
- Some patients received milkshakes and porridge from the clinics.

4. *Economic Impact of TB*

- TB often resulted in a lost livelihood either because the patient died or because they were unable to return to work (only three out of ten resumed their previous employment).
- In many instances it took a long period (up to 10 months) for the TB to be diagnosed (families looked to different options before testing or were forced to wait for delays in the health care system) in which time families spent money on private doctors or other practitioners. All TB was diagnosed by government health services.
- During treatment some families spent money on traditional healers.
- In families where the patient died, considerable sums of money were spent on funerals, particularly in the Eastern Cape from whence they families came. Funeral costs were partly covered by the burial insurance payout.

5. Access to TB and ARV Medication

- All TB patients received medication from local clinics. Although they all completed their treatment course, three men and one woman remained unwell. One man was on retreatment.
- Patients who also had HIV received ARVs from Paarl East Hospital. Although they all received ARVs, some struggled to raise money for transport for routine examinations and to collect drugs.
- Three TB patients living with HIV interrupted their ARV treatment due to work hours and trips to the Eastern Cape.
- Local clinics began to provide ARVs in August 2007 as a result in Government reforms to its ART policy.

6. TB and HIV Stigma

- There was less stigma associated with TB with most respondents being open about their situation. However, some TB patients reported that their friends had begun to avoid them and many were scared of being stigmatized when they were physically weak.
- HIV stigma was more evident than that associated with TB. TB patients who also had HIV were scared of being labeled (LOTTO, which is the term used for the national lottery system) and some were reluctant to attend local support groups. In one case a father rejected his nine year old son who was HIV positive.

7. Coping with TB and Other Problems

- Families without TB were not noticeably better off than families with TB because they often experienced other health problems (high blood pressure, diabetes, arthritis, strokes, asthma) and because all families faced problems of crime, violence, unemployment, drug and alcohol abuse, gender inequality, food shortages and poor housing.

8. Key Conclusions

- In the first three months of TB treatment families were emotionally and economically drained by TB.

- Receiving disability grants, support from kin, government health services, employers and NGOs, improvement in the patients health, accessing ARVs (for those living with HIV) and returning to work, helped families recover from the impact of TB
- However, families remained threatened by loss of livelihood through death or loss of employment, transport costs when accessing ARVs, long-term food requirements of people living with HIV, and wider problems in the community.

9. Recommendations

- Prompt payment of disability grants necessary
- TB and HIV anti-stigma education
- Collaboration with alternative treatment options including private doctors and traditional healers necessary
- Prompt TB diagnosis
- Nutritional support for TB patients
- Family counselling in TB households
- Sustained HIV counselling by clinics

Having presented the main findings relating to Mbekweni, Dr Virgina Bond, principal investigator of the ZAMBART Study (Zambia AIDS Related TB Project), summarised some of the key findings emanating from the Zambia component of the overall research. These are presented briefly below:

- Many things resonated as being similar in terms of the impacts and experiences in Zambia.
- The major difference was the rural setting with significant distances between households and their nearest clinic (sometimes 60km). This made access to both TB drugs and ART more difficult. In many instances it took up to five visits to a clinic before a drug regime could begin. This meant that many patients died because they could not access the clinics as transport costs were beyond their means.
- The unavailability of a state run social protection system meant access to health care and support (food, livelihood support) remained elusive.
- Although NGOs operated in the area, there was little support available in terms of home-based care, food aid and support visits. As a result people relied more on themselves.
- As this was a rural area, many families used agriculture as a major livelihood strategy. The impact of a long illness on this type of livelihood was significant with resultant drops in production (and food security). Many households were forced to divert resources, including labour, to caring for the sick and buying medicines. Many were forced to borrow money to buy food, whereas food was usually secured through own production.
- TB treatment took eight months (as opposed to six) in Zambia with a longer period to build up debt. However, more patients recovered fully from the treatment (possibly because those that were very ill could not access the treatment). Those that died also had expensive funerals with the burden resting with the families as few burial societies existed.

Community Discussion

Thea Van Schoor of the University of Western Cape (previously of DTTC and leader of the Mbekweni Project) facilitated a community discussion around the main findings. Issues raised by the community included:

- Need to shorten periods for diagnosis and private doctors more skilled in working with TB (or referring to clinics). One suggestion was that everyone had a responsibility to demand better services from the State (around diagnostics). Politicians would respond if people mobilised around such issues.
- Parents were also responsible to recognise the potential of TB when their children were coughing for more than two weeks. Although intergenerational tensions were recognised as a major issue facing parents, many respondents felt that children should test for TB. Despite TB being a notifiable disease, many families did not act on the signs of infection. It was also suggested that support groups needed to be established to help parents engage their children.
- Thea Van Schoor and Nulda Beyers responded to a number of questions about diagnosis of TB and accessing healthcare, thus reinforcing the positive role that DTTC was playing in the community. Many elderly people attending the workshop seemed concerned about how the health care system operated. Referral was made to the DTTC Mbekweni Team who continually facilitate information and support sessions for the community on TB and HIV.

Closing Thoughts

The workshop ended as it had begun with a short prayer and thanks to the organising institutions. A group of community members undertook to set up a Health Forum in Mbekweni where such issues could be discussed more regularly with larger groups.

Clearly the research process had raised expectations within the community and through the study report, flyers, community workshop and ensuing discussion and debate has delivered on many of these. The results contributed to strengthening the work of DTTC and the ZAMBART Project in Mbekweni as well as developed potentially important information for local clinics and the Departments of Health and Social Development. As the research project is wound up it lies with RENEWAL, DTTC and ZAMBART to ensure that such opportunities are engaged and further opportunities sought.

Scott Drimie, RENEWAL Regional Coordinator

Registration from for Mbekweni Dissemination Meeting – 14 November 2008

No.	NAME	ORGANISATION NAME	COMMUNITY MEMBER (YES/NO)
01	Oscarina Williams	C152	Mbekweni
02	Nombuyiselo Madikane	V38	Mbekweni
03	Mr Ncethezo	A 34	" "
04	S N Ngikoshe	K72	" "
05	E N Majola	K62	" "
06	N Ntamehlo	T 1822	" "
07	M M Lonzi	A 15	" "
08	N M Lindi	A 47	" "
09	L Njunze	B 85	" "
10	R Mkamana	E 13	" "
11	J Sijaji	H 65	" "
12	B Soko	D 210	" "
13	I K Johnson	D 1392	" "
14	Babalwa Kwimi	N 210	" "
15	Phumla Mketsu	D 238	" "
16	Nomoti Magwa	2867 P/P	" "
17	Andiswa Bangwe	Caring Network	" "
18	Honjiswa Dondolo	" "	" "
19	Siyanda Kapa	3596	" "
20	Nokuzola Kepe	(CHMT) Siyayinqoba- Beat It	" "
21	Mzimasi Nqokomashe	TAC/CAB	" "
22	Thelma Zungula	Hope	" "
23	Thelma Qolo	The Caring Network	" "
24	Eunice Soko	" "	" "
25	Nolundi Xuza	D 190	" "
26	L Nyanga	33	" "
27	Thapelo Maahloli	DTTC	" "
28	B 79	" "	
29	Zithulele	V 61	" "
30	Pastor Mtanga	2500 Monte Christo Ministries	
31	F Manquma	DTTC	0720670160
32	N Sigugu	B 85	Mbekweni
33	A Mjobo	A 35	" "
34	Patti Manuels	7626	" "
35	Mea van Huyssteen	TC Newman Hospital - paarl	Cnr Rosary& Brdway
36	Vuyokazi Godu	193 White city	Mbekweni
37	Andiswa Gonza	3655 Project II	" "
38	Nomfusi Tofile	3475 Langabuya	" "
39	Cecilia Dakuse	3559 Project II	" "

No.	NAME	ORGANISATION NAME	COMMUNITY MEMBER (YES/NO)
40	Annie Barker	Desmond Tutu TB Centre	" "
41	Dalene Gallant	" "	" "
42	Xolani Mvula	Mbekweni Comm. Health Centre	" "
43	Luleka Myezu	" "	" "
44	Nulda Beyers	Desmond Tutu TB Centre	Stellenbosch
45	Amanda Kruger	" "	Kenilworth
46	Nophelo Mlalwa	" "	Mbekweni
47	Dastile Nomawetu	13364 Pola park	" "
48	Nontembiso Tom	J 48	''2''
49	Nondumiso Dywili	270 B White city	" "
50	Scott Drimie	RENEWAL	Johannesburg (0832903620)
51	Elsabe Botha	DTTC	Tygerberg
52	Elzeth Van Schoor	Cooper 21 Durbanville	Durbanville
53	Thea van Schoor	University of .Western .Cape	Durbanville
54	Virginia Bond	ZAMBART Project, Zambia	Lusaka
55	Birgitta Johnsson	Sweden project	Sweden and Mbekweni
56	Charisse Pedro	DTTC, Tygerberg	Mbekweni
57	Chris & Vicky Hinrichsin	Thembacare	Grabouw
58	Zuzeka Magqwazima	T3b White city	Mbekweni
59	Louis Van Zyl	DTTC	
60	Levy Chilikwela	Box 50697, Lusaka	Zambia
61	Suan Mulewa	Box 80697, Lusaka	Zambia
62	Sipho Kwaza	1680, Silvertown	Mbekweni
63	Nhose Abongile	1553, Silvertown	" "
64	Isaac Skiti	3529, Bukanani str,	" "
65	Zizipho Nqoshela	M-122, UmuyaMA STR	" "
66	Neliswa Mzuzwana	Mbekweni Comm. Health Centre	" "
67	Nomnikelo Tshiwila	1886 Themb. sq	" "
68	Nobuhle Masunda	568 Phokeng str.	" "
69	Wendy Rolihlahla	2130, Chris-Hani	" "
70	Nomvuyo Simone	B111 Bhagoto Str.	" "
71	N Feliti	B10	" "
72	Adam Braaf	DTTC	
73	I Jacioni	2639, Polo Park	Mbekweni
74	Wesley Veldsman	DTTC	
75	Mxolisi Ntanyana	Thembani 2 132	Mbekweni
76	Zimasa Tungata	Old Beer Hall	" "
77	Nomtile Dangala	" "	" "
78	Andiswa Bobe	DTTC	" "
79	Simphiwe Gidiso	02 35	Mbekweni
80	N Feliti	B 10	" "
81	Evelyn Somngqeza	V 153 Mkhonto str.	" "

82	Thelma Zono	5026, Langabuya	" "
83	Victor Mangindama	2364,, Hola park	" "
84	Nancy Cowie	Monte Christo Ministries	Wellington
85	Dr Nelius Grobelaar	Paarl East Hospital/Be Part	Paarl
86	Boniswa Kobi	DTTC	Tygerberg
87	Linda Khohlakala	DTTC	Mbekweni