What motivates lay volunteers in high burden but resource-limited tuberculosis control programmes? Perceptions from the Northern Cape province, South Africa

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SUMMARY

SETTING: The Northern Cape province, Republic of South Africa.

OBJECTIVES: To explore factors that motivate lay volunteers to join tuberculosis (TB) control programmes in high burden but resource-limited settings.

DESIGN: A qualitative study consisting of three focus group discussions and a documentary review of the records of 347 lay volunteers involved in the tuberculosis programme in the Northern Cape province of South Africa. Additional data were also collected in a cross-sectional study that involved questionnaire interviews with 135 lay volunteers.

SUBJECTS: Lay volunteers in the TB programme. One focus group discussion was also carried out with youth not involved in the TB programme.

RESULTS: Volunteers do not receive any monetary incentives in the TB programme in the Northern Cape province, but due to the high level of unemployment in this setting, hope for eventual remuneration was found to be the strongest factor motivating youth to join the programme. The study found attrition rates among volunteers to be high (22% had dropped out of the programme within one year of joining); 75% of the drop-outs gave loss of interest and a desire for paid work as the reasons for leaving the TB programme. Other motivating factors identified included altruism, a need to find something to do with one's spare time, gaining work experience, and the novelty of the community-based TB programme.

CONCLUSION: In the absence of monetary incentives, attrition rates of lay volunteers may be high and this can threaten the effectiveness of community-based TB programmes. In resource-limited settings, it is important to identify and implement appropriate alternative incentives that could motivate lay persons in order to sustain community participation in high TB burden areas.

KEY WORDS: tuberculosis, community participation, volunteers

TUBERCULOSIS (TB) is a great burden in the developing countries, where 95% of people infected with the disease live and 98% of the estimated mortality from the disease occurs.1–4 Nine of the ten countries with the highest incidence of tuberculosis in the world are found in sub-Saharan Africa.5 In most of these countries, treatment completion rates are generally low,6 which poses a serious risk not only to the individual patient, but also to the community.

Combating tuberculosis in such high burden but resource-limited countries remains a challenge, and health care managers have had to seek innovative and effective ways of delivering treatment to the large number of patients diagnosed annually.

Over the years, many workers have noted that poor adherence is one of the principle causes of unsatisfactory treatment outcomes in both developing and industrialised countries.7–12 In light of this, several specific strategies have been employed in an attempt to improve adherence to anti-tuberculosis treatment.13,14 One such strategy entails the actual direct supervision of pill-taking by a health worker or some other designated person, a practice that is referred to as directly observed treatment (DOT).15,16

Innovations with DOT have resulted in the development of community-based tuberculosis treatment delivery whereby patients are offered ambulatory treatment and are supervised by lay persons whilst taking their medication from home.

Lay persons, acting as community health workers, have shown that they can effect major changes in mortality and other indices of health status; in some communities they can satisfy health needs that cannot realistically be met by other means.17,18 While lay health workers have been incorporated into many TB control programmes in different parts of the world,19–21 little is
known about the motivation of those who choose to volunteer to supervise TB patients within community-based programmes.22

The aim of this study was to explore the perceptions of lay volunteers on what motivated them to join one such community-based TB programme in the Northern Cape province of South Africa.

MATERIALS AND METHODS

This study was ethically approved by the Department of Health, Northern Cape province, South Africa.

Setting and population

South Africa remains one of the 22 countries with the highest burden of tuberculosis in the world.23 In 2000, the country contributed an estimated 15% of the total tuberculosis caseload for Africa, yet it accounts for only 7% of the continent’s total population.24

The present study was conducted in the Northern Cape province of South Africa. The Northern Cape is the largest province in South Africa but has the smallest population, which is currently estimated at 850 000 persons.25 The climate is semi-arid, and most of the people live in and around small towns. The main economic activities within the Northern Cape province involve mining and quarrying, as well as social and personal services. There is very little manufacturing activity, and unemployment levels in the province are high. Almost one-third of the eligible work force was found to be unemployed in the 1996 October household survey.25

TB services

In 1997, the Northern Cape province reported 4432 patients with tuberculosis, which translated into an incidence rate of 521 cases per 100 000 population.26 In 1997, the TB programme in the Northern Cape province adopted the guidelines of the DOTS (directly observed treatment, short course) strategy recommended by the World Health Organization (WHO).27 Treatment for uncomplicated pulmonary tuberculosis is ambulatory, and is given through the primary health care clinics. TB patients are given the choice of either reporting to the clinic 5 days per week to receive DOT from clinic staff, or being supervised at home by lay community members.

There has been an effort to encourage community participation in the TB programme, and up to one-third of the TB patients receive their treatment from lay volunteers.28 Community-based DOT is carried out by unpaid lay volunteers who receive 4 days of training and are taught to dispense anti-tuberculosis medications to patients 5 days per week for the full duration of treatment. Additionally, these lay volunteers record each intake of pills they observe, follow-up absent TB patients when they skip a consultation, remind patients about clinic appointments, and refer those TB patients with other problems to the relevant services.

In the Northern Cape province, TB treatment for new patients lasts for 6 months, while that for retreatment patients lasts 8 months.

Data collection

This study was part of a larger study carried out on community-based tuberculosis treatment in the Northern Cape province during the period between October 1999 and October 2000. For the study described in this paper, qualitative interviews were the main research method employed, as the field of research was relatively unexplored and the research question was open-ended.29 The background characteristics of lay volunteers in the Northern Cape province were, however, collected in a cross-sectional study involving 135 volunteers attached to 30 randomly selected clinics in the province (Table). The cross-sectional study involved the administration of a largely pre-coded interviewer-administered questionnaire to the respondents. Initial drafts of the questionnaire were piloted in clinics that did not participate in the study, in order to determine the most appropriate wording and structuring. The question-

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residence of lay volunteer</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>32 (23.7)</td>
</tr>
<tr>
<td>Urban</td>
<td>103 (76.3)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>10 (7.4)</td>
</tr>
<tr>
<td>Female</td>
<td>125 (92.6)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>44 (32.6)</td>
</tr>
<tr>
<td>Coloured</td>
<td>90 (66.7)</td>
</tr>
<tr>
<td>White</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td>Age category (years)</td>
<td></td>
</tr>
<tr>
<td>15–29</td>
<td>45 (33.3)</td>
</tr>
<tr>
<td>30–44</td>
<td>59 (43.7)</td>
</tr>
<tr>
<td>45–59</td>
<td>23 (17.0)</td>
</tr>
<tr>
<td>≥60</td>
<td>8 (6.0)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4 (3.0)</td>
</tr>
<tr>
<td>Primary</td>
<td>40 (29.6)</td>
</tr>
<tr>
<td>Secondary</td>
<td>80 (59.3)</td>
</tr>
<tr>
<td>Higher</td>
<td>11 (8.1)</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>23 (17.0)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>101 (74.8)</td>
</tr>
<tr>
<td>Retired</td>
<td>10 (7.4)</td>
</tr>
<tr>
<td>Student</td>
<td>1 (0.8)</td>
</tr>
<tr>
<td>Place of DOT</td>
<td></td>
</tr>
<tr>
<td>Volunteer’s home</td>
<td>94 (69.6)</td>
</tr>
<tr>
<td>Patient’s home</td>
<td>28 (20.8)</td>
</tr>
<tr>
<td>Clinic</td>
<td>13 (9.6)</td>
</tr>
<tr>
<td>Need for further recognition</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>122 (90.4)</td>
</tr>
<tr>
<td>No</td>
<td>13 (9.6)</td>
</tr>
</tbody>
</table>

DOT = directly observed treatment.
naire was administered by a trained interviewer, either in Afrikaans or English, depending on the preference of the respondent. Informed consent was sought before each interview; none of the lay volunteers approached declined to participate in the study.

Initial questions on the questionnaire sought to verify the identity of the respondent and to collect basic demographic information. Questions that were relevant to this study included: perceptions on what motivated respondents to join the TB programme; whether respondents felt a need for further recognition for the activities they performed; and the suggestion of some non-monetary ways in which respondents felt they could be compensated for duties done.

Two focus group discussions were carried out with the lay volunteers and a third was conducted with young people from a similar socio-economic background as the lay volunteers, but who had not volunteered for the TB programme. Participants in the lay volunteer focus group discussions were recruited from those who participated in the one-to-one interviews.

The idea behind the focus group discussion method was to further explore and clarify some of the views of the lay volunteers that the investigators thought had not been adequately explored in the one-to-one interviews. It has been reported that the ‘safety in numbers’ factor may encourage participation of those who are wary of individual interviews or who are anxious about talking.31

Each of the focus groups consisted of six to eight members who, due to logistical problems, were chosen from within the same locality. There was a preponderance of females in the lay volunteer focus groups, due to the fact that the majority of DOT providers in the TB programme in the Northern Cape are females.

The youth focus group was chosen in such a way that it had a majority of males, as the investigators felt that it was necessary to explore the reasons why men did not participate in the TB programme as much as women did.

Focus group discussions were conducted over the weekends when the participants were free to attend, and refreshments were provided during the discussion. Each focus group had a moderator—a local person who explained the aim of the focus group and encouraged discussion among the members. A note-taker who observed and recorded the group dynamics as well as other subtle reactions and interactions that might be of interest to the analysis was also present. The proceedings of the focus group discussions were audio-taped after obtaining permission from the participants. The discussions usually lasted between 1–2 hours.

Finally, a documentary review was undertaken of 347 lay volunteers who were trained in the Lower Orange region of the Northern Cape province during the second half of 1998. The aim of this review was to determine the attrition rate of lay volunteers and establish reasons given for leaving the programme.

Analysis
Audio-taped interviews were transcribed verbatim. Textual data were then explored using content analysis.32 Codes were developed and assigned to relevant segments of data independently by the two investigators who then met to discuss any disparities. In such instances, code assignment was agreed upon through consensus.

All relevant data in each category were identified and examined using the process of constant comparison, in which each item was checked or compared with the rest of the data in order to establish analytical categories. Informed by the analytical and theoretical ideas developed during the research process, the categories developed were further refined by grouping them together until the key categories were identified. NUD*IST 4 software (Qualitative Solutions and Research) was used to aid this process.

Quantitative data was entered into SPSS version 9.0 (SPSS Inc, Chicago, IL) for analysis.

RESULTS
The characteristics of lay volunteers who were interviewed in the cross-sectional study are presented in the Table. From the Table, it can be seen that almost 93% of lay volunteers were female, 70% were aged under 45 years and 75% did not have any formal employment. Ninety per cent of the respondents in the one-to-one interviews expressed a need for further recognition from the health services. This issue was explored further in the qualitative interviews.

Motivation of lay volunteers
The themes that emerged from the data collected as to what motivates community members to volunteer for the TB programme were altruism, having spare time, a need to gain work experience and the novelty of the community-based programme. These themes are further discussed below.

Altruism
The desire to work for the good of others was commonly expressed as a reason for volunteering for the TB programme. Many respondents acknowledged that they knew the scale of the TB problem in the Northern Cape province and wanted to assist and fight the disease. This view was further strengthened by empathic feelings towards the patients by those who had either been patients themselves or whose close relatives or friends had been afflicted by the disease:

I personally was on TB treatment in 1981. I happened to be admitted at the hospital and I know what happens when you are diagnosed with TB. When I was cured, my desire was always to help TB patients. Someone asked me if I would like to do voluntary work at the hospital, I declined and said I would rather be involved with TB in the community.

Female volunteer in her 40s
Altruistic feelings were more commonly expressed by the older female volunteers who had previously worked in the health services or had been engaged in some sort of community work:

As a former community worker, when I heard of DOTS supporters, I volunteered to go and work for my community . . . I supported the clinic by working for my community.

Female volunteer in her 40s

Filling in spare time

The majority of lay volunteers (75%) in the cross-sectional study were found to be unemployed. Hence many felt the need to find something to do with their time. This was found to be a strong motivating factor to join the TB programme among the younger volunteers who had finished their high school education and had been frustrated by a futile search for jobs.

Long periods at home without doing anything worthwhile exacerbated the boredom that these young people felt and may have led them to search for alternatives to paid jobs:

I knew about the TB problems in [Galashewe] and as I had finished Matric [High School] in 1997 and was at home still looking for a job, I decided to come and work as a TB supporter!

Male volunteer in his 20s

The volunteerism shown by this group of respondents was therefore not entirely for altruistic purposes. Many respondents felt that in the absence of anything better to do, offering to help in the TB programme was a more attractive option than simply sitting at home. Furthermore, some harboured hopes of eventually securing employment in the formal health sector when job openings became available.

Those who had this view took volunteerism as displaying a show of interest in nursing, which might improve their chances of attaining further education within the health services:

May be they should give us bursaries or scholarships to the college to study nursing because they can see that we are interested in nursing but we just don’t have the money to go to college.

Female volunteer in her 20s

Gaining work experience

Some of the volunteers thought that working for the TB programme would help them get good recommendations and valuable contacts that would assist them in looking for paid jobs. Respondents felt that a history of having performed voluntary service within one’s community was an attribute that would be appealing to prospective employers.

They felt that this could provide a competitive advantage in a situation where so many unemployed youths were vying for the very few paid jobs that were available:

So if you help out at the clinic, at least you are doing some work. So if you are looking for another job, at least those people will know that you were not just sitting at home or going to the Shebeen [local pub].

Male volunteer in his 20s

This stance can explain the insistence on being given certificates as well as the desire to have formal graduation ceremonies at the end of training, expressed by many of the respondents when asked what non-monetary incentives they would prefer to be given.

The novelty factor

The fact that community participation in the TB programme in the Northern Cape province was relatively new may have motivated some people to become involved. Respondents noted that they had been told about the DOTS programme by the clinic nurses or that they had heard about it from radio announcements and had decided to follow it up. This was particularly appealing to unemployed people who thought this may be a potential job opportunity:

. . . I heard an announcement over Radio Teemaneng informing people about TB and how to become a DOTS supporter. I decided to be one of the people helping because I was doing nothing for the past 3 years!

Female volunteer in her 30s

There was hope that the government had now realised the seriousness of the TB problem and was keen to involve community members to fight the disease. Some of the respondents thought that adequate funds would be released to the TB programme and jobs would be created in the process.

When this did not happen, volunteers started to leave as soon as the novelty wore off and they realised that they had to support patients for long periods of time without pay. Documentary review of the records of 347 lay volunteers trained in the second half of 1998, in the Lower Orange region of the Northern Cape province, revealed that 77 (22%) of these volunteers had dropped out of the programme within one year of joining.

Of the dropouts, over 75% had lost interest in the work, got better jobs or relocated to other areas in search of paid work. The reasons for dropping out are given in the Figure.

The fact that volunteers were not paid for their work appeared to be a crucial factor in determining whether people decided to volunteer at all. Discussions with youth who had not volunteered for the TB programme revealed that many of them felt that they could not do unpaid work. Some looked down on those who had decided to work for free. This deprecation was felt by some of the lay volunteers:

When I fetch treatment for my patients, people on the street will ask me: “Are you people receiving payment for what you are doing?” When I tell them that it is a
voluntary service, people will laugh and think that we are mad—can we really work for nothing?

Female volunteer in her 20s

Furthermore, males felt more inclined to look for paid work than the females. There was a feeling that since many of the females had young children, they had an obligation to stay home and could therefore carry out supervision in the community, whereas the males were expected to go out and look for some work.

The following excerpt from one of the focus group discussions succinctly explains why 93% of the lay volunteers interviewed were female:

**Interviewer**: Let me ask this: my experience in the Northern Cape so far has been that there are fewer male volunteers than female. Why do you think this is so?

**Male volunteer d1**: Yes, I also notice that there are more women than men who help TB patients. I think this is because very few of us men would want to work for free. The women may not mind, they can help without getting anything. But for us, we want something man! We need to do a lot of things . . . support our families, build homes . . . you cannot finish Matric and tell people that you are working!

**Female volunteer in her 30s**

The fact that they were not paid was also suggested as a reason why there were not a lot of young people volunteering for the TB programme:

**Female volunteer in her 20s**

**DISCUSSION**

This study explored the relatively under-studied area of the motivation for community participation in TB programmes in high burden but poorly resourced settings. Our choice of focus group discussions as the main method of data collection for this study can be justified by the relative lack of literature on the subject area. We employed triangulation in order to increase the reliability of the data collected.

The study found that in the Northern Cape province, the majority of the volunteers for the TB programme were young, reasonably educated but unemployed. This threatened the sustainability of the community-based programme in that the volunteerism of this group seemed to have been directed more towards looking for work rather than for altruistic purposes. This was evidenced by the high dropout rate of volunteers in one of the regions where this study was done.

We sought to identify factors that motivated individuals to volunteer for community-based TB programmes and found that the major motivating factor was the hope of remuneration. This expectation of payment for any kind of work performed is a reflection of the economic reality in the Northern Cape province, where unemployment and poverty are high. Similar expectations would probably be found elsewhere in poorly resourced developing countries, and in such areas this could have an impact on the extent of community participation in TB control programmes.

However, it was interesting to note that despite the desire to be paid, many of the respondents recognised the limitations the government had in giving them a regular salary. Nonetheless, there was talk of the need...
for at least an occasional ‘token’ of appreciation to be given. This is worth considering, as in the literature many of the successful TB community-based programmes described had community volunteers who received a monetary incentive for their work.21,34,35

Some of the non-monetary incentives identified in this study, such as T-shirts and badges, were regarded by many of the volunteers as being ‘enablers’ rather than ‘incentives’. Other volunteers viewed certificates obtained after the completion of training as evidence of added qualifications that would be useful while looking for better jobs.

These issues need to be carefully considered by health care planners who want to attract and maintain community participation such as TB treatment delivery in programmes. While local research needs to be performed in order to establish the kind of incentives that would be most suitable for particular contexts, it is arguable that in many developing countries the motivating factors for volunteers that have been identified in this study would also apply.

Finally, we suggest that TB control programmes in high burden settings should explore the option of providing monetary incentives to volunteers as a way of reducing attrition rates. This may be hard to achieve in resource-limited settings, but it will become of even greater importance if integration of TB/HIV programmes for management of dually infected patients at community level—as recommended by the WHO—is achieved, and the workload of volunteers providing this home-based care increases.

Acknowledgements

We would like to thank all the volunteers who participated in this study. This study was funded through grants from the Sir Halley Stewart Trust and the Department for International Development, United Kingdom.

References


OBJECTIFS : Explorer les facteurs qui motivent les volontaires non professionnels à participer aux programmes de lutte antituberculeuse dans les contextes à haute prévalence et à ressources limitées.

SCHEMA : Étude qualitative comportant trois discussions focalisées de groupe et une revue documentaire des dossiers de 347 volontaires non professionnels impliqués dans le programme antituberculeux de la Province du Cap Nord en Afrique du Sud. Des données complémentaires ont été recueillies dans une étude transversale impliquant des interviews par questionnaire chez 135 volontaires non professionnels.

SUJETS : Volontaires non professionnels dans le programme antituberculeux. Une discussion focalisée de groupe a été également menée avec des jeunes non impliqués dans le programme antituberculeux.

RÉSULTATS : Les volontaires ne bénéficient d’aucun incitant financier dans le programme antituberculeux de la Province du Cap Nord, mais en raison du degré élevé de chômage dans ce contexte, l’espoir d’une rémunération éventuelle s’est avéré le facteur le plus puissant motivant la jeunesse à se joindre au programme. L’étude a démontré que les taux d’abandon parmi les volontaires étaient élevés (22% d’entre eux avaient quitté le programme dans l’année où ils y étaient entrés) ; 75% des défaillants ont donné comme raison d’abandon du programme antituberculeux la perte d’intérêt et le désir d’un travail rémunéré. D’autres facteurs de motivation identifiés ont comporté l’altruisme, le besoin de trouver quelque chose à faire pendant les loisirs, l’acquisition d’une expérience de travail et la nouveauté d’un programme antituberculeux basé sur la collectivité.

CONCLUSION : En l’absence d’incitants monétaires, les taux d’abandon des volontaires non professionnels peuvent être élevés, et ceci peut mettre en danger l’efficience des programmes antituberculeux basés sur la collectivité. Dans les contextes à ressources limitées, il est important d’identifier et de mettre en œuvre des incitants alternatifs appropriés qui pourraient motiver des personnes non professionnelles de façon à maintenir la participation de la collectivité dans les zones à haute prévalence de tuberculose.