Alliance and compliance in tuberculosis treatment of older Pakeha people in Auckland, New Zealand

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SUMMARY

Setting: A community-based ethnography of tuberculosis (TB) treatment of ‘European’ New Zealanders in Auckland was completed in 2003.

Objective: To document and analyse the nature of the process of care in this population where the majority of patients are older with other health and social complications.

Design: Data collection included repeated semi-structured interviews with all patients who were willing and able to give consent, semi-structured interviews on health and TB with matched participants without TB, discussions with health care providers, participant observation with TB patients, readings of patient records and monitoring of TB in the media. Reiterative inductive analyses were made of transcripts, field notes and textual materials.

Results: Eight patients from 2003 (out of a possible nine) and one patient from 1997 participated. All were aged 47–75 years. They represent a wide socio-economic range. All completed treatment. The contribution of multidimensional care, from initial acceptance through exigencies of treatment to successful recovery, is evident in the participants’ narratives. The public health nurse is a key support and a lynchpin in the patients’ support network.

Conclusion: A model of care including alliances between patients and care givers as part of treatment is clearly successful in this population group. This study has implications for older cohorts in other low-incidence countries.

Key words: tuberculosis; patient centred care; patient compliance; New Zealand; delivery of health care

PAKEHA (‘European’ New Zealanders) enjoy the best health in New Zealand. Although they have the lowest rate of tuberculosis (TB) (1.5 per 100 000 population vs. 10.3/100 000 for all New Zealanders in 2002), because they constitute 80% of the population they contribute 10% of all TB cases (39/384 in 2002). The aim of the research was to construct an ethnography of the understandings and experience of TB and its treatment in this distinctive population, where the majority of those with TB are middle-aged to elderly (4.9/100 000 in those aged ≥70 years) and patients are drawn from across the socio-economic spectrum.

We analysed the process of care between Public Health Nurses (PHNs) and Pakeha people with TB using a theory of care drawn from Fox, which distinguishes between the ‘vigil of care’ and ‘care-as-gift’. As vigil, care stresses the disciplinary technology of surveillance that is part of directly observed treatment (DOT) or self-administered treatment (SAT), where patient compliance with the medical regimen is the goal. This notion builds on Foucault’s concept of biopower, which has been elaborated by medical anthropologists such as Scheper-Hughes and Lock. As gift, care alludes to notions of ‘love, trust and giving’, which create a reciprocal interpersonal alliance between patient and main care giver. This dimension stems from the work of Mauss, who examined the relationships created between people through the medium of gifts. We argue that both dimensions of care are implicated in successful treatment of this group of patients.

Design

All patients with TB disease in the Auckland region during the 2003 research period (February to October) who were identified as Pakeha/European and who were deemed able to give informed consent (n = 9) were invited to participate in the study by their PHN. Eight agreed and one patient from 1997 also volunteered to join the study (Table). The Auckland region has the nation’s highest rates (24.5/100 000) and numbers of TB notifications (90 cases in 2003). Each participant contributed two or three semi-structured interviews about their experience of TB disease and treatment. Eight of the nine participants consented to tape recording of interviews, which were based around Kleinman’s explanatory models of illness. The transcriptions and expanded interview notes were analysed for themes of

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the illness experience following the method of open coding, focused coding and integrative memo writing characteristic of the construction of ethnographic accounts. Selected themes relevant to this paper are presented in the Results section.

A further set of nine community interviews was conducted with people without TB, demographically matched to those with TB, to ascertain ideas and experience of health and illness and TB in the community. These interviews were contextualised by monitoring media items about TB (Lawrence J, Kearns R, Park J, Worth H. Discourses of disease: representations of TB in newspaper texts in NZ, 2002–2005. Article in submission).

Participant observation was incorporated through spending time with patients as they attended out-patient and other appointments. Participant observation provides opportunities for naturalistic observation of social interactions and daily routines, as well as for informal conversations, complementing interview methods.

With the participants' permission, their medical and nursing records were consulted to provide an additional perspective on their illness and treatment. Informal and formal interviews with PHNs completed the data set. All names used are pseudonyms and the project has ethics approval from the Auckland Ethics Committee.*

Multiple data sources, a variety of fieldwork methods, repeated interviews with good rapport and a systematic, iterative mode of analysis which employed both inductive and deductive methods have enhanced the trustworthiness of this study.

### RESULTS

All participants were referred by general practitioners (GPs) to the publicly funded health service when TB was suspected or confirmed. Patients with pulmonary tuberculosis (PTB) disease were hospitalised until the initial treatment rendered their TB non-infectious. Prior to patient discharge, the PHN visited the ward to meet the new client and discuss personal and treatment needs before home visits began. A decision regarding the most suitable method of treatment delivery was made by medical and nursing staff, as revealed in patient notes and interviews with nurses. This decision was based on the staff’s holistic assessment of the patient’s circumstances.

In the public imagination, as ascertained from the community interviews and media monitoring, TB is perceived as either a disease of the past or of ‘others’ and not of Pakeha, with the result that Pakeha TB is invisible and unexpected. This fact is implicated in diagnostic delay and creates a distinctive stigma for Pakeha people. Despite this, all participants successfully completed their treatment. Patients attributed this positive outcome to the kind of interpersonal care and support that they received from PHNs. We outline the components of this care below.

### Facilitating patients’ self-acceptance

Several nurses and patients regarded patients’ acceptance of the illness and its consequences as a prerequisite to treatment success. Patients revealed lengthy struggles towards acceptance. Frank (aged 47 years) recalled his emotions in the early stages of treatment and the effects of supportive contact with a nurse when he began to confront the restrictions of his illness and the long treatment.

The whole thing hit me when they sat down and spoke to me about the medication, nine months of medication, you can’t do this and you can’t have a drink. I suddenly realised and I felt quite depressed. All the things I couldn’t do. The nurse was absolutely wonderful, I recall going outside and sitting with her in the sun, having a chat and she gave me some very positive thoughts and the encouragement.

His need for an informed, compassionate listener was met, leading him to an acceptance he encapsulated many times as ‘you can’t fight your body’. Frank acknowledged that acceptance was a challenging process, as:

### Table: Characteristics of participants, identified by pseudonym

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Sex</th>
<th>TB Complications</th>
<th>Treatment</th>
<th>Income</th>
<th>Living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rose</td>
<td>75</td>
<td>F</td>
<td>Reactivation (PTB)</td>
<td>DOT</td>
<td>Retired</td>
<td>Alone</td>
</tr>
<tr>
<td>Dick</td>
<td>50</td>
<td>M</td>
<td>Primary (PTB)</td>
<td>DOT</td>
<td>Unemployed</td>
<td>Boarding house</td>
</tr>
<tr>
<td>David</td>
<td>47</td>
<td>M</td>
<td>Primary (PTB)</td>
<td>—</td>
<td>Self employed</td>
<td>Alone</td>
</tr>
<tr>
<td>Diane</td>
<td>73</td>
<td>F</td>
<td>Reactivation (PTB)</td>
<td>DOT/SAT</td>
<td>Retired</td>
<td>Alone</td>
</tr>
<tr>
<td>Dennis</td>
<td>75</td>
<td>M</td>
<td>Reactivation (EPTB)</td>
<td>SAT</td>
<td>Retired</td>
<td>Partner</td>
</tr>
<tr>
<td>Danny</td>
<td>75</td>
<td>M</td>
<td>Reactivation (PTB)</td>
<td>SAT</td>
<td>Retired</td>
<td>Partner</td>
</tr>
<tr>
<td>Debbie</td>
<td>60</td>
<td>F</td>
<td>Primary (EPTB)</td>
<td>SAT</td>
<td>Employed</td>
<td>Family</td>
</tr>
<tr>
<td>Dale</td>
<td>57</td>
<td>M</td>
<td>Primary (PTB)</td>
<td>DOT</td>
<td>Unemployed</td>
<td>Alone</td>
</tr>
<tr>
<td>Frank</td>
<td>47</td>
<td>M</td>
<td>Primary (EPTB)</td>
<td>SAT</td>
<td>Employed</td>
<td>Alone</td>
</tr>
</tbody>
</table>

TB = tuberculosis; F = female; PTB = pulmonary tuberculosis; DOT = direct observation of treatment; M = male; SAT = self-administered treatment; EPTB = extra-pulmonary tuberculosis.

* AKX/03/01/003.
a fit young person (47 years) you know, materially comfortable, nothing to worry about, good family, strong family, all the support I want from family and friends . . . bang, this happens! You have got to adjust your life, it takes a while to realise that.

Continuing moral support

Acceptance is a beginning but many patients needed support through the long haul that is community-based treatment. Those on the SAT regimen found support from the nurse visits:

I think the practice nurse came once a month just to have a chat and see how I was and give a bit of a pep talk and make sure I was taking my medicine, but it was really all of a social visit and a cup of tea quite frankly. She was a lovely lady and I quite enjoyed chatting to her. (Frank, 47)

In the light of these comments one might suppose that the visits were superfluous; however, Frank talked of how distraught he felt about the prolonged treatment that:

felt like it would go on forever . . . I recall once toward the end of treatment actually pouring the orange tablets on my bed and I lined them up . . . I diaried the numbers backwards like 30 through to one, so that every day was one less day of this damn medication because I was so sick of it that I just couldn’t wait . . .

Despite short-course therapy, the day-to-day reality of taking drugs for up to 12 months is hard for patients to sustain, even with good support and the high standard of living that this participant benefited from. For those with side effects, such as debilitating gout or general malaise, this continuing support was crucial to recovery.

Participants were not passive recipients of support: they crafted their relationships with their nurses to maintain privacy, continue employment, avoid stigmatisation and to make life changes. Debbie (aged 60 years) was concerned about the stigma of TB and was materialistic and to make life changes. Debbie (aged 60 years) was concerned about the stigma of TB and was relieved that PHNs were sensitive to this and when medication because I was so sick of it that I just couldn’t wait . . .

Participants who enjoyed a high alcohol intake found the abstinence required during TB therapy hard to bear. The results of experiments were self-limiting: ‘. . . one glass of beer or anything I’d just feel violently ill . . . it would be like a minor food poisoning attack’ (Dale, aged 57 years). As an alternative to alcohol, one participant experimented with oral recreational drugs. He remorsefully explained this in a phone call to his nurse, concerned that he had undermined his treatment and needing to ‘confess’ and obtain reassurance about his relationship of trust with his nurse. This incident also exemplifies the long-term requirement for support as patients struggle with the acceptance of the quotidian implications of TB.

Nursing care as a lynchpin of social structural support

The nurses were sometimes able to ease structural constraints that can be strong impediments to patients’ ability to complete treatment by organising interagency referrals. For example, Rose (aged 75 years) now lives alone in a pensioner flat after initially spending time with her daughter. The PHN housing referral was part of a resolution of conflict between Rose and her daughter that was observed and discussed in the regular DOT visits. Another participant who was without support was offered ‘Meals on wheels’ and food supplement drinks because of his PHN’s concern about his nutrition, and yet another, a phone connection. Nurses may take food with them when administering DOT to minimise side effects if they believe the household is needy.

Transport across the city to clinic was difficult for many participants, and some clients were barely capable of managing the walking that public transport involved. Patients are monitored at the clinic for about a year after treatment ends, so repeated visits are required, drawing heavily on family resources, if they exist. At times, the PHNs acted as a safety net for transport to ensure medical clinic supervision of treatment took place. These journeys provided opportunities for conversation between the nurses and their patients. The extra resources are provided from a range of sources: the Lung Health Association, Auckland District Health Board, and, at times, business and community organisations.

Continuity of care: the glue in the system

Participant observation demonstrated that continuity of medical care is unusual in the hospital chest clinic. Patients unknown to the doctor, short consultation times and no preparatory time to read notes often saw doctors politely trying to familiarise themselves with the patients’ situation during the consultation. Consultations generally focused on the latest chest X-ray (CXR) and laboratory results on the computer screen. Technical aspects of chemotherapy were attended to, the next laboratory test arranged and participants left for home, often saving their questions
for their PHN. Interviews with nurses indicated that PHNs not only provided occasional transport but sometimes attended the clinic appointments to ensure that their clients managed to raise certain issues with the doctor and to remain abreast of their client’s treatment plan. In these ways PHNs acted as bridges between clients and hospital medical personnel to ensure their patients’ needs were met.

**Treatment success**

Successful treatment is far more complex than the patient ‘doing the right thing’ even when a publicly funded health infrastructure exists. Numerous other actors are involved. For example, even in this small study there were instances of delay, particularly with regard to a timely diagnosis. Although all participants sought medical help promptly, several returned to their GPs many times before TB was suspected either by them or their doctor. Several participants had health issues that compounded their TB illness (stroke, heart disease), while some were marginalised in other ways with addictions or social isolation. This group was particularly affected by lack of transport, a perennial issue, especially when a no-show at clinic is deemed an act of non-compliance. Such problems did not necessarily correlate with socio-economic status, age or sex in this small sample.

**Study limitations**

The study (being limited by both the time and resources available) is small, although it represents most of the Pakeha TB patients in Auckland in 2003. Given the lack of obvious correlations between difficulties with treatment and socio-economic status, age or sex, a much larger group would be necessary to explore potential linkages. This would have to be of several years’ duration and New Zealand-wide, given both the relatively small numbers involved and their health status and age. On the other hand, use of multiple methods and data sources provided rich and trustworthy data about the experiences of those involved. Related studies of other patient groups in Auckland are currently being completed and will provide further points of comparison.

**DISCUSSION**

Human relations are a key theme in the international literature on successful treatment completion, whether through the support mechanisms of a close-knit family or an accompagnateur in conditions of poverty, where the treatment experience is shared with a community advocate who is willing to ‘walk with the patient’ and take on the ‘role of the wise’, that of an ally who possesses knowledge and sensitivity to the patient’s experience and ‘before whom the individual need feel no shame’. Once accepted, ‘the wise’ become courtesy members of a stigmatised category, allowing them to engage in social interaction that provides a sense of normalcy and reduces isolation so that the fear of disclosure is removed and a trustworthy relationship can develop. To act as a buffer between the patient and the outside world, ‘the wise’ require resources of empathy, time and knowledge to fulfil their role.

In this study, this role was usually filled by a professional carer, a PHN, who is resourced to deliver a patient-centred model of care tailored to fit the lifestyle and needs of the person under treatment. PHNs have the resources to co-ordinate other services when the need arises. Supervision encompasses more than just ‘watching the medicine go down’. Frequent visits by PHNs as a guest in the home for treatment supervision brought about sustained contact that led to an understanding of the patients’ social environment and general health and personal concerns. The PHNs strive to be available for their clients, and this offers constancy in the midst of changing medical personnel and technology.

The success of the patient-centred care that nurses strive to deliver is contingent on continuity of care over the long treatment period and an emphasis on the process, irrespective of whether DOT or SAT is prescribed. A socially supportive relationship is only possible with adequate, stable staffing. PHNs in Auckland worked in assigned geographical areas, and in this case they were all mature Pakeha women, meaning that they possibly shared similar world views with these clients. An enduring relationship that promoted trust between patients and nurses was complemented by the comprehensive nature of care made possible through links the PHNs were able to make with other welfare agencies and health providers.

Although all participants were part of the numerically and socially dominant Pakeha group, they experienced stigma from a general population who feared a disease they had little knowledge of and evinced a wide range of psychological and social needs, in keeping with Rajeswari et al.’s recent findings in South India. Ultimately, in the delivery of treatment, ‘care-as-gift’ is a necessity because even in a relatively privileged population, people with TB are rendered vulnerable by the disease itself, its treatment and side effects and the social stigmatisation that often accompanies it. PHNs address these complex factors through a philosophy that emphasises alliance, while maintaining their vigil of care. It is this approach that overcomes the tensions inherent in the two dimensions of care. The disciplinary aspect of DOT as surveillance was generally overlooked or normalised by participants in this study. Instead, notions of reciprocity created by the gift of non-judgmental care are stressed. As one patient put it:

You’re grateful, you play the game, you’ve a sense of loyalty. I’d be dead now without the treatment. [My PHN] made it easy, she didn’t judge me, she understood.

(Dale, aged 57 years)
CONCLUSION
This study analysed patient care received during treatment delivery (by DOT or SAT) in a relatively resource-rich setting in a low-incidence country. The patients in this case were middle-aged to elderly, and several had other health complications. The issues identified show how the interactive processes of a community-based, patient-centred care strategy engendered trust and provided support through a long period of chemotherapy.

As cohorts who were exposed to a high incidence of TB in their youth become elderly and experience other stress factors, the TB disease rates will increase even in low-incidence countries, yet such groups are rarely studied. This small study therefore has a wider relevance.20,21

Care and support during TB illness and recovery are integral to successful therapy despite the modern short-course drug treatment that has effectively eliminated long periods of hospitalisation. Following Porter and Ogden,22 we believe a return to a focus on the process of treatment delivery to meet patient’s health needs is appropriate, to critique a biomedical discourse of compliance or adherence.23

To the stigma that TB already attracts, the labeling of some patients as non-compliant further blames the victim, an imputation of other ‘imperfections on the basis of the original one’.16 The World Health Organization (WHO) has moved toward advocating a comprehensive support strategy for all.24 A patient-provider relationship that is based on alliance is more likely to create a collaborative process toward good treatment outcomes.25 It refuses a construction of the patient as a passive ‘complier’ and instead imputes agency to both patient and health care provider as they construct an alliance that encompasses both the vigil and the gift of care.4

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References
11 Park J, Littleton J. Ethnography plus in tuberculosis research. SITES, in press.
CONTExTE: On a achevé en 2003 une étude ethnographique dans la collectivité au sujet du traitement de la tuberculose (TB) des Néo-zélandais «européens» à Auckland.

OBJECTIF: Documenter et analyser la nature des processus de soins dans cette population où la majorité des patients sont plus âgés et atteints d’autres complications sociales et sanitaires.

SCHEMA: Le recueil des données a comporté des interviews semi-structurées, répétées, avec tous les patients qui acceptaient et étaient capables de donner leur consentement ainsi que des interviews semi-structurées sur la santé et la TB avec des participants non-tuberculeux appariés, des discussions avec les travailleurs de soins de santé, l’observation des participants avec les patients TB, la lecture des dossiers des patients et le suivi de la TB dans les médias. Des analyses inductives réitératives ont été conduites sur les transcriptions, les notes de terrain et les textes.

RÉSULTATS: La participation a comporté huit patients de 2003 (parmi les neuf possibles) et un patient de 1997. Tous étaient âgés de 47 à 75 ans. Ils couvrent un éventail socio-économique très large. Tous ont achevé le traitement. La contribution des soins multidimensionnels, depuis l’acceptation initiale et les exigences du traitement jusqu’à une guérison couronnée de succès est évidente dans les récits des participants. L’infirmière de santé publique constitue un soutien-clé et est la pierre angulaire dans le réseau de soutien aux patients.

CONCLUSION: Dans ce groupe de population, un modèle de soins incluant comme élément du traitement une collaboration entre les patients et les pourvoyeurs de soins est clairement couronné de succès. Cette étude a des implications pour les cohortes âgées dans d’autres pays à faible incidence.