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ESTABLISHING A NEW SERVICE ROLE IN TUBERCULOSIS CARE: THE TUBERCULOSIS LINK WORKER

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Aim: This paper is a report of a study to develop a social outreach model of care, including the role of a link worker in developing collaborative care pathways, for marginalised groups with tuberculosis

Background: Social risk factors such as homelessness and substance misuse are associated with poor treatment outcomes. Models of interprofessional practice to address the health and social care of patients are needed to improve outcomes.

Methods: A process evaluation involving a prospective cohort study of 100 patients and interviews with eight agencies involved in their care was conducted in London between January 2003 and April 2005. Outcome measures included a profile of patient need to guide service development; referrals to care providers; goal attainment; social improvement and treatment outcomes; and, agencies' views on the benefits of link working.

Findings: The median age of the sample was 32.4 years and 62% were males. Reasons for referral to the link worker included housing need (56%); welfare benefits (42%); immigration (29%) and clinical management issues (28%). A third of patients were referred to other agencies. Goals, as agreed in the care plan, were attained totally or partially for 88% (59/67) of patients and 78% of patients successfully completed treatment. Barriers to attaining goals included service criteria which excluded some groups of patients and, in some cases, a patient's inability to follow a course of action.

Conclusion: Link workers can mitigate some of the social risk factors that complicate the treatment of tuberculosis by enabling integrated health and social care.

Key Words: tuberculosis link worker, public health nursing; multi-professional practice; process evaluation, interviews, treatment outcomes

SUMMARY STATEMENT

What is already known on the topic

- Tuberculosis in marginalised urban communities presents specific public health challenges globally
- Social risk factors are associated with treatment complications and poor health outcomes
- The development of models of care that address both the clinical and social needs of patients are recommended

What this paper adds

- There was a high level of social need in the cohort of tuberculosis patients and this provided the rationale for a coordinated multi-agency approach
- A link worker can mitigate some of the risk factors likely to complicate the treatment of tuberculosis through providing enhanced social support
- Strategies for tackling tuberculosis in marginalised groups need to go beyond health interventions, and partnerships with community organisations to promote inclusive health and social care are needed

INTRODUCTION

The risk of transmission of tuberculosis is greatest in cities and many cities worldwide have notification rates twice that of the rest of the country (Trebucq, 2007). Rates of tuberculosis have risen by 15% in the last two years in England (DH, 2007) and provisional data for 2006 suggest that London now accounts for 42% of reported cases with an incidence of 45.8 per 100,000 (Health Protection Agency, 2007). The fact that both disease prevalence and death rates have increased in Africa and parts of Europe between 1990 and 2005 (WHO, 2007) suggests that the control of tuberculosis presents a significant challenge in industrialised countries as well as those typically referred to as 'resource-constrained' with a high disease burden.

BACKGROUND

A number of social risk factors are associated with management complications and poor treatment outcomes (Story et al. 2007). Alcohol and substance misuse have been associated with extended treatment, prolonged hospital admissions and failure to attend appointments (Craig et al. 2007). Seventeen per cent of the London tuberculosis case load comprises patients with multiple needs likely to affect adherence (Story et al. 2007). From an epidemiological and social care perspective, the management of TB is likely to become more complex as the disease becomes increasingly concentrated in populations which experience poverty, exclusion and poor access to health and social services. The complexity of the case presentation, combined with the increasing trend in drug resistant tuberculosis involving longer treatment periods (18-24 months), has implications for workloads and the skill-mix of clinical teams (Craig and Hall, 2003).

Nurses and other healthcare practitioners therefore need to explore and develop more responsive models of service delivery to meet these new challenges in order to protect both the health of individuals and communities (Craig et al. 2007). International standards of care recommend assessments of social needs and non- adherence to treatments in addition to approaches which involve community based organisations in tuberculosis control (Tuberculosis Coalition for Technical Assistance, 2006).

This paper is a report of a three-year pilot project designed to develop and implement a model of tuberculosis care for patients with challenging health and social care needs, including a tuberculosis link worker (TBLW) whose role was to provide enhanced case management and strengthen alliances between the hospital and community services. The project, resourced by charities, funded a link worker based within the clinical team, a researcher-coordinator who developed and evaluated the model in conjunction with the TBLW and an administrator.

THE STUDY

Aim

The aim of the study was to develop a social outreach model of care, including the role of a link worker in developing collaborative care pathways, for marginalised groups with tuberculosis.

The research objectives were to :

- Define patient need in order to guide service development and define a caseload;
- Develop a risk tool to identify those who might benefit from link worker support;
- Identify organizations that could contribute to the care of patients with tuberculosis, develop collaborative care pathways and map resource utilisation;
- Identify barriers and enablers to achieving goals and outcomes;
- Assess whether the model was able to address need and mitigate some of the factors likely to complicate treatments.

Design

Given that the TBLW was a new service role, the methodology adopted to inform the development and implementation of the model was a process evaluation framework (Power and Nozhkina 2002; Power, et al. 1991) and drew on a mixed methods

approach. Process evaluations focus on the effects of an intervention rather than establishing effectiveness per se (Peersman et al. 1998); they describe the process of both the planning and implementation phases and this can then be used to inform future programmes and evaluations (Sykes et al. 2003). Table 1 summarizes the aspects of the process evaluation and methods of data collection. The approach aimed to identify patient need and document link worker activities in meeting those needs including the potential for collaborative care with community care providers. Structured interviews were conducted with professionals involved in collaborative patient care.

Participants

Patients

A prospective cohort study was conducted with 100 consecutive patients presenting to the clinical services between January 2003 and April 2005. Inclusion criteria were adults with an active diagnosis of tuberculosis referred by means of a risk assessment at the start of their treatment.

Stakeholders

Eighteen agencies were sent a written invitation to participate in group discussions or interviews, either face-to-face or by telephone, about the role and value of the link worker post and collaborative practice. The agencies were representative of the type of referrals made by the TBLW and patients' presenting problems. Interviews were carried out at the end of tuberculosis treatment.

Developing the TBLW role

Service mapping

The first phase of the study involved a service mapping methodology, used to identify and map organisations in the community that can contribute to the care of tuberculosis patients (Gordon & Womersley, 1997, Luger et al. 2001). Agencies were identified through historical referral pathways, networks for staff working in the field of homelessness, and electronic and manual service directories. Agencies visited were categorised according to their function, for example housing or drug and alcohol services, and type of interprofessional working with the TBLW/tuberculosis services.

Implementing and evaluating collaborative care

Risk referral tool

The second phase involved the development of a risk referral tool designed to identify all patients with a diagnosis of active tuberculosis who might benefit from link worker support. The risk tool comprised items selected on the basis of their theoretical contribution to issues of tuberculosis treatment, support and adherence and is described in detail elsewhere (Craig et al. 2007) and was completed by the nurses in the outpatient clinic at the first patient contact .

Evaluation pro forma

The evaluation pro forma was designed to profile patients' needs and link worker activities in meeting those needs and in relation to the study objectives. The pro forma was developed iteratively in the first six months of the project through regular meetings between the researcher and TBLW based on a review of individualised patient case management. The data collected using the tool were: patient demographics; reasons for referral to the TBLW; patients' knowledge of and contact with community services (to assess levels of engagement with other agencies); referrals made by the TBLW; non-attendance at clinic appointments; whether the goals jointly agreed between the TBLW and patient in the care plan were attained and any associated barriers.

Ethical Considerations

The Local Research Ethics Committee, which approved the study, agreed that participant consent could be obtained orally because many of the questions in the risk assessment tool were asked routinely as part of the clinical history. However, patients were informed that they did not have to answer any questions if they did not wish to. Nurses explained that a new service was being offered, involving a link worker (who in this project was a social worker) who worked as part of the clinical team, and that the risk assessment formed part of the referral process, which was voluntary.

The TBLW obtained consent to share information with another agency from the patient in the form of a signed confidentiality agreement. Information was shared on a need-to-know basis. Oral or written consent, again agreed with the research ethics

committee, was obtained from the agencies to participate in an interview. Data were recorded using a unique patient identifier and all personal details were removed.

Data Analysis

Descriptive statistics were analysed using SPSS for Windows (version 13). Data from the structured interviews were entered into QSR NUDIST*Vivo 1.3 and analysed in relation to the questions in the interview schedule rather than thematically. The type and nature of contact with agencies were documented and coded on an Excel spreadsheet.

RESULTS

Participants

One hundred referrals were made to the TBLW and 85% of these were made using the risk referral tool. The majority of patients were male (62%) and the median age was 32.4 years. Continents of origin were: Europe, including the UK (33%), Africa (54%) and Asia (9%). In 4% of cases this information was not recorded. Eighteen per cent of patients needed interpreters for languages including Bengali, Somali, Turkish, Eritrean, Amharic, French Congolese, Afghani and Vietnamese.

Evidence of Implementation

Protocol deviations

Patients were referred on the basis of social need rather than diagnosis of active disease, including those receiving chemoprophylaxis for latent tuberculosis. They were also referred at any point during their treatment as problems emerged rather than at the beginning, as originally envisaged. Anyone requesting a referral was allowed to have one, regardless of their risk assessment, in order to guarantee equity in access to services.

Profiling patient need

Over half of referrals (56%) to the TBLW were housing-related. Just under a third (29%; 16/56) of these patients were homeless (defined as periods of sleeping on the

streets or relying on the charity of friends/relatives to share accommodation). Forty-two per cent of referrals related to claims for welfare benefits, with 16% of patients having no income at the point of referral. Fourteen per cent of referrals were made by nurses because of concerns about non-adherence to medication. Of the 14 patients referred to the TBLW for non-attendance at appointments, over half were also in housing need. A small number of referrals (7%) were because of alcohol/substance misuse and five of these patients had housing needs.

Immigration status affects entitlement to welfare in the UK. Twenty-nine percent of referrals were because of asylum or immigration issues. Of these, 72% (21/29) also needed housing, including three who were sleeping on the streets and 13/29 who had no income. Other reasons for referral (15%) included assistance with discharge from hospital and ensuring that support was available in the community prior to discharge from hospital.

Forty-one per cent of patients presented with issues that developed following the initial risk assessment including homelessness and imprisonment. The data suggest that the treatment journey is neither linear nor straightforward, and this points to the need for regular assessment and review.

Patient contact with other service providers

Prior to referral to the TBLW, nearly three-quarters (74.2;69/93) of patients had some form of contact with service providers. Two-thirds (67.8%; 63/93) had contact with between 1 and 3 agencies, and these ranged from informal drop-in centres to more formal care providers. Patients' knowledge of services, how to access them and their levels of engagement with services were rated by the TBLW using a 5-point Likert scale ranging from 1 (good knowledge, access and engagement(to 5 (poor knowledge, access and level of engagement). Ratings were based on a sample of patients with care plans (n=51) and for whom the TBLW had in-depth knowledge of their care.

Patients' knowledge of available services was rated as better (mean 2.92; SD 2.9, n=51) than their knowledge of how to access those services (mean 3.06; SD 1.05) and their overall level of engagement with agencies (mean 3.35; SD 0.96).

TBLW caseload

Link worker activities were recorded and the level and intensity of support each patient required was graded as low, medium or high. This was done on the basis of the presenting problems and reviewed at the end of treatment. In 30% of cases the TBLW provided high intensity support requiring regular contact throughout treatment. These patients usually had difficult-to-resolve housing issues, either because of a history of debt or arson or because of complex immigration issues which excluded them from receiving services. Twenty-one percent of patients required a medium level of support. These patients were often already linked into services but required additional assistance or liaison with other care providers. In 49% of cases patients needed a minimum level of support or time limited assistance such as information, advice or provision of a supporting letter.

Non-attendance at appointments

A third of patients were failing to attend between 5 and 17 appointments. The median number of missed appointments for those referred to the TBLW was 6 (range 2-15; IQR 4) compared with those referred on other grounds (median 2; range 0-17;IQR 5).

Evidence of Impact

Referrals to other services

The TBLW referred a third of patients (34%; 34/100) to between one and three agencies. The majority of referrals (41%; 21/51) were to agencies which specialised in asylum and immigration. Over a quarter of referrals (27.5%; 14/51) involved statutory housing services. A number of additional links (50 referrals) were made for 31% (29/94) of patients by the agencies receiving referrals from the TBLW.

Attaining goals and outcomes

Seventy-eight percent of patients (70/90) completed their treatment and 7% were still on treatment due to drug resistance at the time when the project ended. In the remaining cases the various outcomes were: treatment stopped (3.3%); found not to have tuberculosis (4.4%); lost-to-follow up (2.2%); treatment transferred to another

service (3.3%); and one patient died. The median length of treatment for patients referred to the TBLW was 209 days (IQR:170.25; range 168-694, n=70), which compares with the recommended regimen of six months (approximately 168 days).

Goals were jointly agreed with 67 patients, and both goals and outcomes were defined in relation to the presenting problems. Goals were totally achieved for 57% (38/67) of patients and partially achieved for 31% (21/67). Three refused assistance from the TBLW and in 12% of cases goals were not achieved because:

- Patients did not contact the community services (5/12)
- Patients were not considered eligible to receive the service (4/12)
- Patients refused the housing offered to them (2/12)
- There were no vacancies at the hostel (1/12)

Table 2 describes the range of social improvement outcomes achieved through link working and interprofessional practice. Ninety-seven outcomes were achieved for 67 patients. The remaining 37 patients received information and advice. In line with the presenting problems, 36% of outcomes (35/97) addressed housing need, including provision of accommodation in the short or medium term. Measures to prevent homelessness included supporting patients through disputes with other tenants, preventing eviction and ensuring that accommodation was available following discharge from hospital or prison. Thirty-four per cent of outcomes were income/benefits-related and included travel passes for transport to the clinic, and providing evidence to obtain financial assistance for those left destitute. Many of these outcomes were achieved jointly with a community refugee agency. Outcomes for alcohol/drug use included referrals to programmes for rehabilitation. Other interventions were aimed at preventing unplanned discharge from prison without appropriate community support in place.

Evidence of reach of project: interprofessional working and partnerships

The role of the TBLW was one of enhancing existing links with community service providers through improved communication and networking. In addition, 57 links were made with community-based organisations: Over a third of these involved

referrals (37%; 21/57) and two thirds (66.7% ;38/57) involved collaborative care. In 16% (9/57) of cases the contact involved an information exchange about respective roles and tuberculosis education. Table 3 gives a summary of the different modes of interprofessional working.

One mode of interprofessional practice was developed specifically in response to patients with asylum and immigration issues and involved a refugee organisation which played an instrumental role in attaining shared outcomes and was an example of a care pathway involving the TB services, voluntary sector and refugee community. In addition to immigration casework and general advocacy, the agency provided social support, hot meals, activities and workshops.

Feedback on collaborative care: Stakeholder interviews

Eight semi-structured and one group interview with professionals from eight care providers (response rate 44%) with experience of collaborative working were conducted, either face-to-face or by telephone. Table 4 summarises the benefits of the TBLW identified in these data. Agencies reported that a major advantage of the post was the additional time, intensive support that the TBLW was able to offer patients, sharing of information and raising awareness of the disease. The ability to advise on any potential difficulties a patient was experiencing which could impact on treatment plans, including early warning signs that someone might disengage from services, was valued. An appreciation of the support needs of patients undergoing treatment for tuberculosis was also mentioned:

Once the client was diagnosed with TB he was quite unmotivated, missing appointments, and we worked jointly to help him re-motivate himself with the understanding he would feel weak, have a temperature and he wasn't just being lazy. Now we understand the symptoms and can be flexible around that (Key worker, Homeless hostel worker).

Effective linkages between the patient, health and community services was also reported:

The TBLW's done what the job implies: Link the community, person and health service with a consistency of service you wouldn't otherwise get. With limited resources it's helped us to make appropriate criteria links, by accessing the medical to those most in need (Social Worker, Asylum and Refugee Team)

Greater awareness of tuberculosis and how to access services was mentioned, including the preventative aspect of the role:

It's been good for frontline staff to understand where TB links in, and get support accessing services. (Homeless Forum)

Other advantages of having a link worker were the emotional and practical support offered to patients and the opportunity for establishing a level of trust. Homeless people often experience difficulties in sustaining relationships outside their homeless peer groups and have little or no contact or support from families (Crane et al, 2006). Professional support may go some way toward ameliorating this, particularly in the case of failed asylum seekers, who often have unmet needs but limited opportunities for support due to the very strict eligibility criteria operated by services which can exclude this group:

The TBLW knew more about the client and we could share experiences. There was extra support for the client which I wasn't able to give. (British Red Cross worker, Refugee Unit)

There were also benefits for the statutory housing services in terms of improved assessment of the need for housing and support, based on the information provided by the TBLW:

Referrals are very comprehensive, which is good for us. We are not experts on the medical condition and they've been good at letting us know how long people are taking their medication, what the risks are, make sure we don't expose anyone to TB, reassure hostels that there is a support worker involved. (Statutory housing officer)

The importance of demonstrating that support for patients was in place before the housing services would accommodate certain groups was also mentioned:

It's been really valuable when trying to put forward a case to get housing. The TBLW provided good evidence of the availability of support post [hospital] discharge, which helps to secure accommodation. The housing [services] want to see the support set in place (Caseworker 1, Homeless healthcare agency)

Improved communication with doctors on the hospital wards, particularly in relation to hospital discharge, was stressed. The status of the TBLW as a public health representative was credited as having an impact on decisions about patient discharges. The ability to forge better links between the hospital ward and TB clinic was seen to improve continuity of care and, hence, adherence to treatment. Provision of a 'one-stop-shop' was reported as an additional incentive for patients to engage with the services:

They will have loads of other issues apart from their health and are more likely to turn up to the services if other issues can be addressed. It's like a day centre - get tea, see nurses, get help with housing and other issues (Caseworker 2, Homeless healthcare agency)

An additional advantage reported was the provision of 'evidence' of need within very tight deadlines. Delays in producing the necessary information could result in vulnerable young people left homeless on the streets, and at risk of sexual assault in the case of one female refugee.

DISCUSSION

Study limitations

In this paper we have described the process of implementing a model of care and have drawn on a process evaluation to demonstrate the role and value of a TBLW. It was not the aim of the study to establish a causal connection between the TBLW and treatment outcomes, but to demonstrate social need and ways in which a link worker alleviates social risks which can complicate outcomes. Indeed, outcomes were achieved as a result of multiple interventions, including inputs from various service providers.

The catchment area of the clinic where the project was based was characterised by both high levels of homelessness and a concentration of agencies working with this group. Patient and community needs were met through those agencies being able to deliver services that addressed housing needs; offered proactive interventions to maximise entitlements to welfare and prevent debt; provided advocacy and support to those seeking asylum, including an expertise in immigration law; delivered substance/alcohol misuse and harm-reduction interventions and those that specialised

in mental health for diverse communities. Other localities may have fewer resources, which may be a factor when considering the generalisability of our work to other contexts.

The timing of the stakeholder interviews, at the end of tuberculosis treatment, may have influenced response rates due to staff turnover, which can be high in the social care sectors (Henwood, 2001). Staff retention also has implications for how partnerships are maintained and institutionalised within organisations. It is also likely that those who participated in the interviews were those with a positive experience of interprofessional practice, as evidenced by their comments. Future evaluations might explore the use of a partnership tool to assess the strength and merits of collaborative working (Hardy et al. 2003) pre- and post -intervention.

In this project the researcher offered strategic direction and enacted a developmental role in addition to her role as evaluator. She was therefore a 'stakeholder' in the project: a model which is replicated in other health sciences (clinical research, health promotion, action research) (Rootman et al. 2001)
This contrasts with positivist models of research where the researcher is viewed as detached and separate from the object of enquiry. She did not, however, have direct responsibility for patient care.

DISCUSSION

Research findings have emphasised the importance of social context, including financial support and stable housing, in enabling patients to adhere to tuberculosis treatment (Noyes and Popay 2007; Balabanova et al. 2006; Sumartojo, 1993). This study has highlighted the level of social need in a cohort of patients with tuberculosis referred to a link worker, and attests to the added value of the post in addressing social risks through effective interprofessional alliances and collaborative practice. The link worker intervention also addressed the social inclusion agenda by prioritising both clinical and social need (Story et al. 2006). Previous research has also reported on the beneficial effects of referral facilitators in improving access to the voluntary sector for patients with psychosocial problems (Grant et al. 2000).

Recent guidelines on the commissioning of TB services in England recommend partnership working between the health, social and non-profit sectors (DH, 2007) and international care standards suggest community-based organisations have an important role to play in improving patient adherence (Tuberculosis Coalition for Technical Assistance, 2006). Since the 1970s the WHO has encouraged community involvement in the management of tuberculosis (Kironde and Neil, 2004), and models of community participation exist in high disease-burden settings (Villanueva et al. 2006; Chowdhury et al. 1997). The role of the voluntary sector in the UK, however, remains relatively undeveloped.

We found that a number of patients were already linked into community services and that their knowledge of service provision was better than how actually to access services, which also gives some evidence of the need for a link worker. However, the number of contacts with services does not necessarily equate with good care, and nor does it provide evidence of effective use of resources. Future evaluations would need to focus on these aspects to ensure that link-working models are resource-efficient. Moreover, some patients were reluctant to disclose information about other agencies involved in their care or refused permission to share information, in some cases due to the stigma of the disease; this limited opportunities for collaborative working.

Interprofessional practice appeared to work best where there was strategic commitment and support (Cameron and Lart, 2003), for example, the attainment of joint targets (see London Borough of Camden, 2004) or a willingness to innovate practice and push boundaries, as evidenced by individual workers in some of the voluntary organisations. The personal skills of individuals (eg friendliness, accessibility and flexibility) also played a role. The success of link worker posts are therefore likely to depend on local resourcing contexts, policy and practice, as well as the personalities of individuals (Camden and Lart, 2003).

With respect to appointment failures, a number of patients were not referred to the TBLW, suggesting the need to systematise referrals. For example, missed appointments in high risk groups should trigger automatic referral to the TBLW for early outreach prevention and re-assessment of risk and need.

Although nurses referred patients to the TBLW because of substance/alcohol misuse, patients did not always perceive these issues as their main priority in the face of more immediate concerns. Drug and alcohol issues, therefore, were raised by the TBLW, depending on individual circumstance. Where a patient was already linked into services, the link worker liaised with those agencies. Where it was apparent that a patient was not attending a treatment programme this was discussed with the patient, and where drug/ alcohol use was affecting treatment (i.e. not attending appointments, or attending intoxicated) the TBLW addressed this. The TBLW therefore used a non-directive approach, including raising awareness of alcohol/drug use, and directing patients to appropriate services. The clinical services are ideally placed to contribute to targets to increase the participation of alcohol and drug users in treatment programmes (DH, 2006). The apparent disjuncture between patient and public health constructions of 'risk' supports the need to understand risk behaviours in their social context (Rhodes et al. 2006; Swigart and Kolb, 2004; Popay and Williams 1996).

The high profile of the project in the community also created a demand for TB education which outstripped the capacity of the TBLW and clinical team. Need was met through a cascaded training programme delivered by nurses initially, followed by housing trainers, to 179 housing staff in a series of eight workshops organised over four months (see Craig et al. 2006). Future initiatives will need to identify resources and models of community education to support link workers where nurses are unable to perform educational roles.

Implementation issues

The caseload

The TBLW was responsible for a small caseload of patients and enacted a gamut of roles requiring a range of skills on a needs-led basis, made referrals as appropriate and offered reassurance, encouragement and support to patients throughout treatment. Maintaining and improving communication with external agencies was a crucial element of the post. The recommended caseload for nurses is currently one nurse per 40 active cases of TB (CDSC 2002). Latent or other forms of tuberculosis are not

included in this figure, although these also form part of nurses' caseloads. However, defining the caseload for a link worker is more complex as, ethically, it could be argued that this should be based on social need rather than type of disease. In the link project the TBLW carried an active caseload of between 14-18 cases, graded medium to high involvement, in recognition of the intensity of support needed, which can vary throughout treatment.

Given that link working requires a range of different approaches, a degree of flexibility is required for the post to be effective. Indeed, the success of development work, such as partnership-building, depends on the ability to separate this aspect from day-to-day clinical work. The language support required for non-English speakers was also resource-intensive. Our experience suggests that a small, active caseload allows link workers to give an appropriate level of support to patients while carring out other aspects of the post.

Disseminating the model

We recommend the implementation of an interprofessional model with an emphasis on prevention, maintenance and support (see Keene, 2001 for example) through collaborative care planning and the assessment of risk and need (see figure 1), and agencies may wish to explore the use of common assessment procedures that may contribute to a sense of shared ownership amongst the various providers in achieving outcomes. Lessons may be learned from good practice in the substance misuse field, which uses patient-centred care plans 'based on achievable goals' in the short-, medium- and long-term (Randall and Drugscope, 2002). Systems for monitoring and reviewing care plans and models of communication, including protocols for sharing information, between patients, the clinical services and community care providers need to be explored. Models of integrated governance, guidelines and standards for quality improvement in the context of mixed economies of care will also be needed.

Our experience suggests that link worker posts may be drawn from a range of health and social care backgrounds. Flexibility to work across service boundaries is an important aspect of the post. Effective management and support are therefore essential to the success of the posts (Cameron and Lart, 2003), and there may be a

case for a joint management structure involving an operational manager for the day-to-day work, but a separate line manager for the overall strategic direction of the post, particularly in relation to policy and partnerships. This will have implications for nurse education in terms of overseeing new roles in increasingly complex environments (Craig et al. 2007).

CONCLUSION

In this project, the TBLW role was highly acceptable to the local nursing team, which re-configured a nursing post in order to finance the continuation of the link worker post as part of the statutory services. A number of similar posts have developed in other tuberculosis services across London with different roles, remits, grading and funding streams. In presenting our findings here, we aimed to inform the future direction of these posts and their integration into clinical teams. They are also of relevance to international contexts, particularly in relation to initiatives that link hospital and community services.

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References

Cameron A and Lart, R (2003) Factors promoting and obstacles hindering joint working: A systematic review of the research evidence. Journal of Integrated Care. 11(2)9-17.

Chowdhury, A M. Chowdhury, S.,Islam, M N. Islam, A., and Vaughan, J P. (1997), Control of tuberculosis by community health workers in Bangladesh. Lancet. 350 (9072): 169-172.

Craig G, Booth H, Story A, Hayward A, Hall J, Goodburn A, Zumla A. (2007) The impact of social factors on tuberculosis management. Journal of Advanced Nursing. 58 (5): 418-424.

Craig G, Booth H, Hall J, Story A, Hayward A, Goodburn A, Zumla A (2006). The TB Link Project: Developing a social outreach model for disadvantaged groups. London: University College London.

Craig G, Hall J. (2003) The missing link. Health Service Journal. 113(5880):34-35.

Crane, M., Warnes, A. M., & Fu, R. (2006). Developing homelessness prevention practice: combining research evidence and professional knowledge. Health and Social Care in the Community 14(2):156-166.

Department of Health (2007), Tuberculosis prevention and treatment: a toolkit for planning, commissioning and delivering high-quality services in England. London: Department of Health

Department of Health (2006) The NHS in England:The Operating Framework for 2007/2008. London: Department of Health.

Gordon, A. and Womersley, J. (1997), The use of mapping in public health and planning health services. Journal of Public Health Medicine. 19(2):139-147.

Grant, C., Goodenough, T., Harvey, I., Hine, C. (2000) A randomised controlled trial and economic evaluation of a referrals facilitator between primary care and the voluntary sector. British Medical Journal. 320 (7232) 419-423

Hardy, B. Hudson, B. and Waddington, E. (2003) Assessing Strategic Partnership: The partnership assessment tool. London: Office of Deputy Prime Minister

Health Protection Agency (2006) Focus on Tuberculosis:Annual surveillance report 2006 - England, Wales and Northern Ireland. London: Health Protection Agency Centre For Infections.

Health Protection Agency (2007). Cases of Tuberculosis continue to rise during 2006. (Press statement. 22 March 2007). Retrieved from http://www.hpa.org.uk/hpa/news/articles/press_releases/2007/070322_tb.htm on 16 July 2007

Henwood M (2001) Future Imperfect? Report of the King's Fund Care and Support Enquiry. London, Kings Fund

Keene, J (2001). Clients with complex needs:Interprofessional practice. London:Blackwell.

Kironde, S. and Neil, S. (2004), Indigenous NGO involvement in TB treatment programmes in high-burden settings: experiences from the Northern Cape province, South Africa. International Journal of Tuberculosis and Lung Disease. 8(4):504-508.

Luger, L., Carrier, J., & Power, R. (2001) Mapping as a method for analysing policy response in the management of health services. Health Services Management Research. 14(4): 220-228.

National Institute for Health and Clinical Excellence (2006) Tuberculosis: clinical diagnosis and management of tuberculosis, and measures for its prevention and control. London, National Institute for Health and Clinical Excellence. (Quick reference guide)

Noyes, J. and Popay, J. (2007), Directly observed therapy and tuberculosis: how can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis, Journal of Advanced Nursing. 57(3):227-243.

Peersman, G., Harden, A., & Oliver, S. (1998) Effectiveness of health promotion interventions in the workplace:A review. London: Health Education Authority,

Popay, J. & Williams, G. (1996) Public health research and lay knowledge. Social Science and Medicine. 42(5):759-768.

Power R, Nozhkina N. (2002). The value of process evaluation in sustaining HIV harm reduction in the Russian Federation. AIDS. 16(2):303-304.

Power R, Dale A, Jones S. (1991) Towards a process evaluation model for community-based initiatives aimed at preventing the spread of HIV amongst injecting drug users. AIDS Care. 3(2):123-135.

Randall G and Drugscope (2002). Drug Services for homeless people: a good practice handbook. London:Office of Deputy Prime Minister

Rhodes, T. Stoneman, A. Hope, V. Hunt, N. Martin A. Judd, A (2006).

Groin injecting in the context of crack cocaine and homelessness: From 'risk boundary' to 'acceptable risk'? International Journal of Drug Policy. 17(3):164-170

Rootman, I., Goodstadt, M., Potvin, L., & Springett, J. (2001). A framework for health promotion evaluation. In I. Rootman & M. Goodstadt & B. Hyndman & D. V. McQueen & L. Potvin & J. Springett & E. Ziglio (Eds.), *Evaluation in Health Promotion: Principles and Perspectives* (pp. 7-38). Denmark: World Health Organization.

Sumartojo, E. (1993) When tuberculosis treatment fails. A social behavioral account of patient adherence, American Review of Respiratory Diseases. 147(5): 1311-1320.

Story, A., Murad, S., Verheyen, M., Roberts, W., & Hayward, A. C. (2007) Tuberculosis in London - the importance of homelessness, problem drug use and prison, *Thorax*. [online] thorax.bmj.com (10.1136/thx.2006.065409). [Accessed 13-02-07]

Story, A., van, H. R., & Hayward, A. (2006), Tuberculosis and social exclusion. British Medical Journal. 333(7558): 57-58.

Swigart, V. and Kolb, R. (2004). Homeless persons' decisions to accept or reject public health disease-detection services. Public Health Nursing 21(2):162-170.

Sykes M, Theobold S and Squire B (2003) Qualitative methods for process evaluation. Liverpool: Liverpool School of Tropical Medicine.

The London Borough of Camden (2004) Homeless Strategy 2003-2008. London:London Borough of Camden

Trebucq, A (2007). Tuberculosis and big cities. International Journal of Tuberculosis and Lung Disease. 11(7):709

Tuberculosis Coalition for Technical Assistance (2006). International Standards for Tuberculosis Care (ISTC). The Hague:Tuberculosis Coalition for Technical Assistance.

Villanueva, M. Vianzon, R G. Merilles, OEA. Magno, M. (2006) Finding and Curing TB cases: Establishing community groups to enhance case finding and case holding-a part of the global Fund TB projects in the Philippines. The International Journal of Tuberculosis and Lung Disease. 10 (11) supplement 1 [Abstract]

WHO (2007). Global tuberculosis control: surveillance, planning, financing. WHO report 2007. Geneva, World Health Organization (WHO/HTM/TB/2007.376)

Table 1 Evaluation of the tuberculosis link worker (TBLW) model

ASPECT	METHOD
EVIDENCE OF IMPLEMENTATION	
Number of risk referral tools completed by nurses on first patient contact, copied to the TBLW and placed in patients' notes	• Continuous weekly monitoring and feedback between nursing and research team. Forms checked against each new patient on electronic patient records and nursing notes (quantitative data).
Protocol deviations	• Discussed at regular research steering group meetings attended by research team and nurse representative.
Profiling patient need: reasons for referral to TBLW	• Recorded on risk referral form by nurses and evaluation pro forma by TBLW in consultation with patient. Problems documented using coding scheme devised by researcher based on patient throughput in the first six months. Problems evolving during course of treatment documented.
Profiling patient need: contact with other service providers	• Recorded in evaluation pro forma by TBLW in consultation with patient (quantitative data)
Link worker activity	• Recorded in evaluation pro forma as information, advice or referral (quantitative data)
Defining a caseload	• Based on intensity of support required using a coding scheme developed by the researcher in collaboration with the TBLW (Quantitative data).
Non-attendance at clinic appointments	• Data collected from the electronic patient record and recorded on the evaluation pro forma by the TBLW (quantitative data)
EVIDENCE OF IMPACT OF TBLW	
Referrals to other agencies	• Documented in evaluation pro forma. Coded by researcher (quantitative data)
Attaining goals	• Goals agreed between the patient and TBLW were documented in the evaluation pro forma and coded as totally, partially or not achieved by researcher in consultation with TBLW (quantitative)
Treatment outcomes	• Quantitative data collected from London TB register.
Evidence of reach of project	• Number and type of contacts with community providers. Mapping and coding of organisations according to function and type of interprofessional working by researcher and TBLW (quantitative data)
Evidence of partnership and increased involvement	• Changes in the density of networks, partnerships and policy and working practices (recorded in research diary and case studies as presented in research report).
Feedback on collaborative care	• Review meetings with community providers involving nurses, research team and TBLW. Recorded in minutes and research diary.
END OF PROGRAMME	
Feedback on collaborative care	• Structured interviews with stakeholders (qualitative data)
Mainstreaming of TBLW	• Based on experience of added value of TBLW, advocacy of nursing team, support from TB network manager and use of research findings (used throughout project).

Table 2 Outcomes

Outcomes	N=97 outcomes for 67 patients
Housing/Homelessness	36%
Found housing:	
Temporary	12
Permanent	3
Other housing	8
Other measure to assist with finding accommodation	8
Prevent homelessness	4
Income/benefits	34%
Income secured through benefits/vouchers/national asylum-seeker services or community care assessment by social services	24
Travel passes (free travel)	2
Hardship grant £100	2
Pension backdated	1
Reconnection of services (gas/electricity) following fuel debt	1
Exemption certificate obtained (free medication)	1
Sickness certificate issued	1
Supporting medical evidence to claim welfare	1
Immigration	7%
Indefinite leave to remain (confers entitlement to welfare benefits)	4
Maintain welfare support from national asylum-seeker services	1
Allocated solicitor for immigration application to Home Office	2
Appointments/treatment completion	8%
Patient attended appointment	5
Patient attended 3 month follow-up appointment	2
Completed treatment with additional support	1
Drugs and alcohol	3%
Re-referral to a drugs methadone programme	1
Placed on methadone programme	1
Placed on the waiting list for community care assessment for rehabilitation (alcohol)	1
Criminal justice	3%
Court case adjourned (preventing risk of unplanned discharge from prison)	2
Provide information to probation officer to prevent imprisonment	1
DOT	3%
Arrange DOT at drug unit to be taken with methadone	1
Assist health care assistant to set up DOT	2
Miscellaneous	5%
Assist with obtaining personal identification (eg birth certificate in order to access services)	1
Register with a general practitioner	1
Advise on professional case conference (later set up)	1
Assist with registration at employment agency	1
Medical services examination relocated to local venue	1

Table 3 Examples of interprofessional working

- Contact visits with agencies and information exchanges to learn about services and professional roles and remits
- Seeking advice from agencies about appropriate referrals and patient management issues
- Seeking input from agencies into the development of assessment tools
- Sharing information with agencies to achieve patient-centred goals
- Joint visits to other agencies
- Sharing assessment tools and methods of assessment
- Collaborative care planning
- Attend/convene professionals' meetings with those involved in patient care
- Develop policy and procedures
- Joint training initiatives
- Evaluation of inter professional working and training (informal and formal).

Table 4 Summary of the benefits of link working: stakeholder perspectives

Benefits of tuberculosis link worker (TBLW) for stakeholders

- Share information and concerns about patients
- Share tasks
- Effective targeting of resources because of TBLW's knowledge and assessment of patients' needs
- Greater awareness of TB and its impact on patients health and motivation
- Effective linkages between the patient, hospital and community services
- Greater awareness of patients' social circumstances
- Better understanding of what patients are capable of and the impact of TB on their activities and daily living
- Assist both clinical and frontline staff to understand the support needs of patients
- Greater awareness of how to access the TB services
- Frontline staff more likely to prioritise the mobile X-ray because of the raised awareness of TB attributed to the TBLW
- Better assessment of the housing needs of patients
- Patients more likely to be allocated housing if additional support guaranteed by the TBLW
- Better communication between patient and care providers
- More holistic approach to care
- Better case retention through effective linkages between the hospital wards and TB clinic
- The provision of evidence/supporting information in housing, asylum and immigration cases
- Tuberculosis prevention initiative through increased awareness of the disease

Benefits of TBLW for patients

- Able to discuss strategies for overcoming difficulties with taking medication
- Enable clients to understand how health and social care services work and explain the process
- Provides an opportunity for establishing a level of trust for those most socially excluded
- Assist secure housing/accommodation
- Impact on patient's quality of life by obtaining economic resources (eg. facilitate entitlements to housing and benefits)
- Impact on the psycho-social aspects of the disease through enhanced social support

Figure 1 Inter-professional practice: tuberculosis care