PNG SUPPLEMENT

A pilot model of patient education and counselling for drug-resistant tuberculosis in Daru, Papua New Guinea

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Education and counselling for people with drug-resistant tuberculosis (DR-TB) is recommended by the World Health Organization, given the arduous treatment journey. A model of education and counselling involving counsellors and peer counsellors, standard sessions and novel education tools was piloted in the high DR-TB burden context of Daru, Papua New Guinea. The pilot contributed to high retention in care, highlighting the need for investment in scalable models. Future models will need to be adapted as better tolerated regimens are introduced. A focus on patient-centred care requires prioritisation in order to meet the End TB Strategy targets.

Papua New Guinea (PNG) is classified as a high-burden country for tuberculosis (TB) and drug-resistant TB (DR-TB).¹ A DR-TB response taskforce was established in PNG in September 2014,² in part to respond to an outbreak of DR-TB in Daru (2011 population 15 142),³ a small island in PNG's Western Province characterised by poor socio-economic conditions and overcrowding.⁴

ASPECT OF INTEREST

While new, better-tolerated regimens stand to revolutionise DR-TB treatment,⁵ until uptake increases, most people with DR-TB face an arduous treatment journey of up to 24 months. In Daru, this is exacerbated by extensive food, water and housing insecurity.⁴ Integrated, patient-centred care is a pillar of the World Health Organization's End TB Strategy,⁶ and support, education and counselling are recommended for all people with TB.⁷ Psycho-emotional and socio-economic support has been shown to improve TB treatment outcomes.⁸

In 2016, the Burnet Institute (Melbourne, VIC, Australia) partnered with the Western Province TB programme to pilot a patient education and counselling (PEC) model based on previously developed tools.⁹ The Daru PEC model was led by a social worker and implemented by a team of professional 'lead' counsellors and peer counsellors, termed 'TB-PALS' (People Affected by, Living with, or having Survived TB). All counsellors were remunerated and received extensive training in the areas of TB, counselling, motivational interviewing, gender-based violence, child protection, disability and self-care. PEC was fully integrated into

the community and a facility-based model of care (treatment is provided across five treatment sites, with only very ill patients hospitalised). There were three focus areas: emotional support, education and referral to external social services.

Patient education and counselling

The counsellors provided several types of PEC sessions, including:

Standard sessions: six standard counselling sessions (using flipcharts) were provided to all DR-TB patients based on a structured guide (Figure 1). These were timed to occur at critical stages of treatment (Figure 2). Visual aids and board games were used as educational tools for children and adolescents.

Preventive therapy sessions: the focus was on educating the guardians of children aged 0–5 years, who received three standard sessions. Counsellors also read TB storybooks to children and used cards showing images of different emotions, which encouraged them to discuss their feelings.

Special sessions: conducted at any time for self-administered treatment, diagnosis of extensively drug-resistant TB (XDR-TB), treatment interruption and palliative care (Figure 2). Special sessions on the initiation of new drugs (bedaquiline, delamanid), human immunodeficiency virus co-infection, families, couples and groups were also provided.

Adherence planning sessions: these helped patients identify reasons for completing treatment, potential barriers to adherence and actions to take if treatment was missed. A patient charter was provided to each patient, outlining their rights and responsibilities.

Referral pathways

Counsellors referred patients to clinicians, antenatal and family planning services, the police family and sexual violence unit, disability-focused organisations and the Department of Community Services.

Monitoring and evaluation

Both an electronic medical record (EMR) system (Bahmni™; ThoughtWorks, Chicago, IL, USA) and paper-based systems were used for patient management and for programme monitoring and evaluation (M&E). At the first session, a patient information form was completed, detailing household members and demographics. Session details were recorded in a hardcopy register and entered into Bahmni. Data were extracted from Bahmni for routine reporting and monitoring.

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Tools related to PEC used in the pilot can be found on the Burnet Institute website at https://www.burnet.edu.au/projects/283_rid_tb_patient_education_and_counselling.

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KEY WORDS

MDR-TB; outbreak; PEC; patient-centred care

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FIGURE 1 Summary of six standard counselling sessions for DR-TB. TB = tuberculosis; DR-TB = drug-resistant TB.

FIGURE 2 Timing of counselling and education sessions for drug-resistant tuberculosis patients. DST = drug-susceptible tuberculosis; XDR = extensively drug-resistant; SCR = short course regimen.

RESULTS

During the course of the pilot programme, three lead counsellors and 10 PALS were successfully trained; these provided PEC services to a cumulative total of 331 DR-TB patients registered from 2015 to 2017.¹⁰ PEC contributed to a reduced loss to follow-up, from 18% (2014 cohort) to 4% (2015 cohort).¹⁰

DISCUSSION

The PEC pilot programme was used to successfully train people affected by or living with TB as peer counsellors, empowering them to deliver a comprehensive PEC package. This has allowed for the task shifting of time-intensive DR-TB education and counselling from clinical staff. While successful, the Daru PEC model is resource-intensive due to the extensive peer counsellor training and mentoring required. The integrated nature of the pilot also meant that the PEC M&E could be incorporated into the EMR system introduced by the TB programme at the time; however, this required electricity, basic computer skills and adequate infrastructure. Another challenge was the reliance upon the (often limited) capacity and resources of external partners for the referral pathways component.

CONCLUSION

PEC has been an integral component of the successful model of TB care in Daru, highlighting the importance of increased investment in comprehensive psycho-emotional and social support in DR-TB 'hotspots' in PNG. Scalable models should be explored. Fu-

ture PEC models will need to adapt as better-tolerated regimens are introduced. PEC is a critical part of patient-centred care as outlined in the WHO's End TB Strategy,⁶ and requires prioritisation if we are to meet the End TB Strategy targets.

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L'éducation et le conseil aux personnes atteintes de tuberculose pharmacorésistante (DR-TB) sont recommandés par l'Organisation Mondiale de la Santé, étant donné les difficultés du parcours thérapeutique. Un modèle d'éducation et de conseil impliquant des conseillers et des pairs éducateurs, des sessions standard et de nouveaux outils d'éducation a été expérimenté dans le contexte de taux élevé de

DR-TB de Daru en Papouasie Nouvelle Guinée. Ce projet pilote a contribué à un taux élevé de maintien en soins et a mis en lumière le besoin d'investir dans des modèles évolutifs. Les modèles futurs devront s'adapter aux protocoles mieux tolérés qui seront introduits. Une concentration sur les soins centrés sur le patient requiert une priorisation afin d'atteindre les objectifs de la stratégie Mettre fin à la TB.

La Organización Mundial de la Salud recomienda actividades de educación y orientación dirigidas a las personas con diagnóstico de tuberculosis farmacorresistente (DR-TB), habida cuenta de la trayectoria ardua del tratamiento. En el contexto de Daru, donde la carga de morbilidad por DR-TB es alta, se ensayó un modelo de educación y orientación. El proyecto piloto comportó la participación de consejeros, la orientación entre pares, sesiones ordinarias y nuevas

herramientas pedagógicas. El proyecto contribuyó a lograr una alta retención en el servicio de atención y destacó la necesidad de inversión en modelos que se puedan ampliar. Será necesario adaptar los modelos futuros a medida que se introduzcan esquemas terapéuticos mejor tolerados. Un enfoque centrado en el paciente exige la definición de prioridades con miras a cumplir las metas de la Estrategia Fin a la Tuberculosis.