

Environmental disaster: Linking partners to tuberculosis prevention around the Aral Sea

The Aral Sea has shrunk to just one third of its original size over the past three decades, creating a humanitarian disaster for millions of people who live around its shores. Soviet-era irrigation canals have siphoned off the waters of the Syr-Darya and Amu-Darya rivers which used to feed the Aral Sea, leaving behind a wasteland of white sand. Salt levels have tripled, devastating the fishing industry and leaving large tracts of farmland infertile. Farmers compensated by using more pesticides and fertilizers, but poisoned their soils and left the region's water undrinkable for animals or humans alike. Summers have become hotter and winters colder, since the sea's moderating influence on the regional climate has declined. As ecological and economic stability have crumbled, thirst, malnutrition and disease have followed. More than 20 million people across the Aral region suffer poor health as a result. Female anaemia is as high as 97 per cent. Kidney failure, immunodeficiency and tuberculosis have soared, as well as a host of other diseases attributable to malnutrition. Tuberculosis (TB) infection rates are estimated at between 250-370 cases per 100,000 people – a major epidemic. Hospitals lack the resources to cope. Many of the region's people are resistant to the drugs used to combat TB. Perhaps worst of all, TB sufferers are stigmatised. In Uzbek culture, TB is associated with poverty. TB sufferers are traditionally excluded from employment. Girls from infected families may suffer poor marriage prospects. TB is also known to be a leading killer of those suffering from HIV/AIDS. Hence, many families go to great lengths to hide the fact that family members may suffer from TB.

The intervention

Drugs are not the only weapon in the war on TB – good nutrition is also essential. Since 1998, the Red Crescent Society of Uzbekistan (RCSU), supported by the American Red Cross (ARC) and the International Federation of Red Cross and Red Crescent Societies (Federation), has carried out an extensive programme of humanitarian food aid in order to reduce the negative impacts of TB among those living in the Aral Sea zone.

- The programme was based on the findings of detailed sociological research, conducted by the RCSU, in collaboration with the Federation and the Uzbekistan government's Public Centre for Social Ideas in four regions around the Aral Sea (the Autonomous Republic of Karakalpakstan, and the provinces of Khorezm, Navoi and Bukhara). The research analysed



the vulnerability of the populations living around the Aral Sea and recommended a programme focused on increasing their capacity to cope with the disaster's consequences. In particular, the study found that nutritional assistance would be the intervention most likely to reduce vulnerability.

- The ARC, with support from the US government, responded by donating approximately 5,500 tonnes of basic food aid (oil, rice, beans, high protein corn soy blend, and flour) to the RCSU annually. The RCSU organized around 60 distribution sites and trained their personnel to deliver the relief aid to vulnerable populations both in their homes and in selected institutions.
- Early 2000, an evaluation indicated that the programme's focus should be sharpened to optimize its effectiveness: TB victims became the principal beneficiaries. To date, 70,000 TB sufferers have benefited from the Red Cross's nutritional assistance.
- An educational component was introduced in 2002. Knowledge of proper nutrition and hygiene can help prevent people from contracting TB – as well as helping them to recover. Accordingly, the RCSU formed nutrition education teams (NETs), staffed by qualified medical or educational experts and aimed at helping those suffering from TB and their carers. The NETs have implemented training modules specifically developed for the language and culture of the regions in which they operate. They have also trained community leaders (training of trainers) in order to reach the widest possible audience. To date, nearly 9,000 people have benefited from the Red Crescent's health education.



RCSU food distribution and NET volunteers in action in Khorezm province

- To mark the occasion of World TB Day, over 60 volunteers from Red Crescent youth clubs in the cities of Urgench and Kiva organised a week-long series of theatre productions to promote healthier lifestyles. The actors performed in schools across the country, using popular youth themes to encourage behavioural change – such as the importance of proper hygiene and nutrition in preventing and curing TB. They were enthusiastically received.

Positive impacts

- According to Uzbek doctors, deaths from TB have fallen in Khorezm province over the past five years, pointing to the programme's success in improving recovery rates of TB patients.
- There has been a considerable increase in the number of newly registered TB patients. This indicates that the programme has encouraged individuals to come forward and seek treatment voluntarily. The earlier patients present themselves with the disease, the easier it is to treat.
- The positive publicity which the programme has attracted, along with the programme's strong advocacy of the needs of TB victims, has lessened the social stigma associated with the disease.
- The four successive programmes to tackle TB since 1998 have greatly increased the capacity of the RCSU to manage the operational complexities of a large humanitarian relief effort, including the detailed customs clearance, transport, physical accountability and central storage of relief commodities in four regions of the country. This reinforces the RCSU's disaster preparedness to respond to future disasters requiring emergency relief operations.

Links with government, NGOs and civil society

- The Uzbek government supported the relief programme by providing free transport and storage at distribution sites, and facilitated duty-free customs clearance.
- The combination of supplemental nutrition and education targeting TB sufferers has complemented drug therapy programmes provided by Médecins Sans Frontières and Uzbekistan's TB institutions.
- Youth volunteers have helped organize communities to fight TB through educating primary school children, producing relevant literature and creating theatre productions focused on building awareness of TB and changing risky behaviour.

Lessons learned

- After four years of donating food aid, refining beneficiary lists and eliminating those no longer eligible, there is some evidence of relief dependency.
- The addition of an educational component to reinforce the impact of free food donations has helped to promote positive behavioral change among many of those affected by TB.
- Programmes of supplemental nutrition and education could also be implemented to reduce the risks posed by other diseases prevalent in the region (e.g. anaemia, iodine deficiency).
- Vulnerable people will not retain the educational messages relevant to TB prevention and recovery without ongoing training and outreach by RCSU staff.
- The costs of the health education component of the programme amount to around US\$ 20,000 per year. Ongoing donor funding is needed to sustain this initiative.

Conclusion and recommendations

- Better nutrition and health education have helped to save lives and improve livelihoods among TB sufferers.
- Collaboration between the Red Cross Red Crescent, researchers, local government, volunteers, school children and NGOs is crucial to ensure the programme is integrated into the lives of ordinary Uzbeks.
- Extending this two-pronged approach to tackle other diseases in the region would improve lives further.

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