Can community volunteers work to trace patients defaulting from scheduled psychiatric clinic appointments?

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To the Editor: Mental illness is set to become the second largest source of economic and social burden worldwide by 2020.[1] In many South African township communities, effective treatment is hampered because stretched professional staff are unable to follow up defaulting patients.[2] Defaulting can have disastrous consequences for patient health, including treatment breakdown, imprisonment, death by suicide, harm to others, homelessness, relapse and re-hospitalisation.[3]

Many countries have employed 'assertive outreach' workers to address the negative consequences of defaulting. These workers enable patients to remain in contact with services, resulting in enhanced treatment compliance, improved employment status and greater patient satisfaction.[4] In South Africa important public policy principles such as community involvement and the role played by volunteers in supporting family members and helping patients remain in treatment[5] must be incorporated into mental health assertive outreach systems, just as they have in key programmes such as directly observed treatment for tuberculosis and HIV/AIDS voluntary counselling and testing.

We report the results of a study assessing the feasibility of volunteers tracing patients who had defaulted from scheduled psychiatric clinic appointments. Volunteers were trained in the main features of mental health problems and equipped with the knowledge and skills to communicate effectively with people with mental health problems.[6] Training materials are available at **www.who.int/mental_health/policy/education/en**.

Psychiatric clinic nurses identified patients who had defaulted from scheduled appointments. Volunteers were responsible for tracing these patients and encouraging them to return to the clinic as soon as possible. Volunteers either accompanied patients to the clinic or recorded patients' decisions on a tracing slip – whether the patient agreed to return, was untraceable, had moved away, died, was in hospital or had another outcome. Nurses recorded when patients returned to the clinic.

Volunteers traced 178 (84%) of 211 defaulting patients, of whom 120 (57%) subsequently returned to the clinic. The remaining 58 traced patients included those who had died or relocated, were in hospital or prison, or were treated at home, or where contact was made with a relative or caregiver only (Table I). Volunteers contacted 98% of traceable patients within 3 days. A small number of patients were treated at home by clinic nurses who accompanied volunteers. Volunteers acted independently without professional support for 80% of visits. In 20% of cases volunteers assisted professional nurses to make contact with patients.

Table I. Outcomes of patients in tracing programme

Outcome	*N*	%
Returned to clinic	120	56.9
Relocated	22	10.4
Died	14	6.6
In hospital	12	5.7
In prison	2	0.9
Treatment given at home	6	2.8
Contact with caregiver/family only	2	0.9
Untraceable	33	15.7
Total	211	100.0

We have shown, therefore, that volunteers can make a major impact on defaulting rates in hard-pressed psychiatric clinics, through rapid tracing of patients who default from scheduled appointments. Most of the patients who did not return had died or moved away or were in institutions, valuable information previously unknown to the nurses running clinics. Nurses reported that they valued the assistance and feedback from volunteers, enabling them to provide effective and prompt attention to patients who would ordinarily be lost to their service. Volunteers mainly acted independently and reported gaining a significant sense of recognition and self-worth from their role. They also facilitated the nurses to work more effectively within the community, with nurses reporting feeling safer when visiting patients in the presence of a community volunteer.

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Nurses reported that they most valued the system when the feedback they received was prompt and consistent, and when volunteers worked regularly and were well known to the nurses. It would seem to be important, therefore, to embed a supervision, management and support system in a community-based organisation in order to ensure that volunteers continue to operate the system on a regular basis. This support could be offered by professionals and community volunteer co-ordinators working together.

It is now necessary to subject volunteer mental health outreach systems that integrate community volunteer health workers into mental health care systems to rigorous evaluation. Such studies should include assessment of patients' clinical outcomes, long-term retention in services, costs, community impact and the sustainable management of volunteer programmes.

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Dandy-Walker variant in an infant prenatally exposed to antiretroviral medication

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To the Editor: We report a case of Dandy-Walker variant (DWV) in the infant of a 35-year-old woman who received treatment for human immunodeficiency virus type 1 (HIV) and tuberculosis. She received stavudine (D4T), lamivudine (3TC), nevirapine and cotrimoxazole throughout pregnancy, and isoniazid, rifampicin, pyrazinamide and ethambutol from before pregnancy until 29 weeks' gestation, when DWV was detected on antenatal ultrasound. She had no history of genetic disorders, consanguinity, and alcohol or recreational drug use. Amniocentesis revealed a normal male karyotype. Serology for cytomegalovirus and toxoplasmosis did not indicate recent infection. The infant was full-term and appropriate for gestational age, with a normal head circumference, no dysmorphism, and no clinical features of HIV infection. Cranial ultrasound confirmed the presence of DWV and mild ventriculomegaly.

DWV is part of a continuum of rare developmental abnormalities of the posterior brain fossa. It includes cystic dilatation of the fourth ventricle and partial agenesis of the cerebellar vermis. Only in a minority of cases is there a known cause, such as a chromosome abnormality or other genetic syndrome, or teratogen – especially alcohol. The developmental mechanism is unknown but relates to abnormal hindbrain development at 7 - 8 weeks' gestation.[1] Its prognosis varies from normality to severe neurodevelopmental delay with hydrocephalus.[2]

The question arises as to whether the reported DWV represents a teratogenic effect of one or more of the maternal medications. We highlight deficiencies in the existing evidence.

The regulatory framework for assessing drug safety has not promoted optimal collection of information on teratogenicity. The most important authority regulating registration of new drugs is the United States Food and Drug Administration (FDA), from which other national registering agencies often take a lead. The FDA provides for assessment of drugs prior to approval for marketing and for post-marketing adverse event reporting. As pregnant women are not included in human clinical trials prior to FDA approval, assessment of

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teratogenicity relies heavily on animal studies (that cannot give definitive information regarding risk in humans) and post-marketing surveillance. The post-marketing surveillance system was recently strongly criticised,[3,4] particularly its over-reliance on passive surveillance and retrospective data, and poor enforcement.

Teratogenicity data for antiretrovirals (ARVs) is better than for most drugs because an Antiretroviral Pregnancy Registry[5] aims to obtain prospective information. Although aiming to collect data worldwide, the registry suffers from substantial under-reporting, containing only 15% of US exposures and, so far, only about 50 ARV-exposed pregnancies in South Africa. Ascertainment of birth defects is also not standardised, with varying use of diagnostic tests and level of expertise of reporting clinicians. A further problem in assessing teratogenicity data is the complexity of collecting information on drug combinations. Whether combination therapy increases the risk of birth defects is unclear, but one study has raised this possibility for the combination of ARVs and cotrimoxazole.[6] Teratogenicity data collected elsewhere may not hold true for South Africans. An example of this is the unusually high rates of fetal alcohol syndrome in South Africa. This is not easily explained by alcohol consumption patterns, and aggravating factors related to poor socio-economic status have been implicated.[7]

Regarding ARVs, most evidence for teratogenicity exists for efavirenz, which our patient did not receive. Efavirenz is an FDA category D drug, i.e. 'Evidence of human fetal risk exists, but benefits may outweigh risks in certain situations',[8] owing to concerns that it may cause birth defects of the central nervous system, based on animal data and four retrospective case reports, including one infant with Dandy-Walker syndrome.[9-12] The magnitude of risk with first-trimester exposure to efavirenz is unknown, and the four case reports may reflect background rates of birth defects. Prospective data, collected in the Antiretroviral Pregnancy Registry, indicates that the overall increased risk for birth defects among efavirenz-exposed infants is low: the rate of birth defects among infants with first-trimester efavirenz exposure was 2.4% (6 of 225 infants; 95% CI = 0.9 - 0.1%), compared with an expected rate of 3.1% (the background rate of congenital anomalies detectable at birth).[5]

Our case of DWV is an infant prenatally exposed to a drug combination including ARVs, but not efavirenz. We highlight the limited nature of information available to support the fears regarding the teratogenicity of efavirenz, and the converse lack of concern regarding other combinations of ARVs and other drugs used in HIV-infected individuals. Although we support current guidelines to avoid efavirenz in reproductive-age women not using contraception,[13] the evidence indicates a low risk to an inadvertently exposed fetus and does not justify pregnancy termination based on the possible risk of teratogenesis. A fetal anomaly ultrasound scan at 18 - 23 weeks' gestation is recommended, and genetic counselling is advisable for women who are anxious or want further information. In view of the limited available information and the large numbers of reproductive-age women initiating highly active ARV therapy, there is an opportunity and a need to systematically collect local data.

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