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What can volunteer co-providers contribute to health systems? The role of people living with HIV in the Thai paediatric HIV programme

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ABSTRACT

In Thailand people living with HIV (PLHIV) have played a major role in shaping policy and practice. They have acted as volunteer co-providers, although their potential in terms of paediatric service provision has seldom been explored from a health systems perspective. We describe the Thai paediatric HIV care system and use both demand- and supply-side perspectives to explore the impact, opportunities and challenges of PLHIV acting as volunteer co-providers.

We employed qualitative methods to assess experiences and perceptions and triangulate stakeholder perspectives. Data were collected in Khon Kaen province, in the poorest Northeastern region of Thailand: three focus group discussions and two workshops (total participants $n = 31$) with co-providers and hospital staff; interviews with ART service-users ($n = 35$). Nationally, key informant interviews were conducted with policy actors ($n = 20$).

Volunteer co-providers were found to be ideally placed to broker the link between clinic and communities for HIV infected children and played an important part in the vital psychosocial support component of HIV care. As co-providers they were recognized as having multiple roles linking and delivering services in clinics and communities. Clear emerging needs include strengthened coordination and training as well as strategies to support funding.

Using motivated volunteers with a shared HIV status as co-providers for specific clinical services can contribute to strengthening health systems in Asia; they are critical players in delivering care (supply side) and being responsive to service-users needs (demand side). Co-providers blur the boundaries between these two spheres. Sustaining and optimising co-providers' contribution to health systems strengthening requires a health systems approach. Our findings help to guide policy makers and service providers on how to balance clinical priorities with psycho-social responsiveness and on how best to integrate the views and experience of volunteers into a holistic model of care.

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1. Introduction

Task-shifting is a widely used mechanism for dealing with constraints in human resources for health. It is the delegation of tasks to cadres of less qualified health-workers, intended to reduce costs yet ensure deployment of capable personnel (World Health Organization, 2008; Philips et al., 2008). The impact of task-shifting on health outcomes is well-documented, and its potential

for strengthening the broader health system is now gaining attention (Van Damme et al., 2008; Yaya Bocoum et al., 2013). Volunteers working as peer supporters are one such cadre whose contribution to task-shifting is expanding. Peer support volunteers share key personal characteristics, circumstances, or experiences with patients, this is thought to add value to how they provide services; peer volunteers do not generally complete short-term, competency-based training (Simoni et al., 2011).

HIV services, like those for other chronic diseases, require provision by a multidisciplinary team. Antiretroviral treatment is highly effective, but is complex to manage (Wouters et al., 2009). Providers of HIV services need a broad range of skills covering

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clinical HIV management, monitoring procedures, supporting adherence, and ability to link to community social and economic support (Boyd and Cooper, 2007; Callens et al., 2008; Harries et al., 2010; Webel et al., 2013). Paediatric HIV care has further complications and providers should be equipped with additional capacity in paediatric medicine, caregiver assessment, providing a service guided by children's cognitive development, offering age appropriate emotional and psychosocial support and adolescent targeted services (Callens et al., 2008; Giannattasio et al., 2011; Smith Fawzi et al., 2012; Bosteels and Goetghebuer, 2008). People living with HIV (PLHIV) are well integrated into task-shifting initiatives as peer-supporters in many settings but the relating evidence is skewed towards Africa (Van Damme et al., 2008).

The familiarity of PLHIV with a given social setting and personal experiences of HIV infection and treatment make them 'expert patients' who can move between the public-health system and communities (Kielmann and Cataldo, 2010). People with similar demographic characteristics can be effective communicators within their communities and are able to build trusting relationships to improve knowledge and influence behaviour (Medley et al., 2009; Go et al., 2013). The contribution of peer volunteers has been shown to be invaluable in supporting paediatric HIV care in many contexts (Maddison and Schlech Iii, 2010; Assefa et al., 2010). They may be active in antiretroviral treatment (ART) clinics and in the community. Evidence exists that they can be important in supporting monitoring, HIV status disclosure, adherence, quality of life indicators, greater equity in access to services, increased paediatric testing, shortened waiting times, reduced stigma and better overall ART outcomes including association with lower patient mortality (Wouters et al., 2009; Zachariah et al., 2007; Van Wingham et al., 2008; Kabore et al., 2010; Orne-Gliemann et al., 2008). Task shifting to volunteer PLHIV may have an important potential contribution to the comprehensive provision not only of psychosocial support but also clinical support services to ensure that children affected by HIV receive the same standards of social acceptance, personal development and quality of life as others (Sirinirund, 2010). There is however scant evidence of the potential of PLHIV volunteers to be integrated as formal co-providers for paediatric HIV services, despite the additional needs of this population.

1.1. PLHIV as co-providers of HIV care in Thailand

HIV policy and agenda setting in Thailand has historically unfolded through multi-stakeholder consultation with clinicians, academics, civil society representatives, non-government organizations (NGOs) and providers (Tantivess and Walt, 2008; United Nations Development Programme, 2004; UNDP, 2004). Thai PLHIVs have been recognized as a valuable resource since the 1990s and are trained to support patients and delivery processes in clinics and communities (Phoolcharoen et al., 1998). In the limited literature regarding the contribution of these 'co-providers' they are highly praised and considered a vital element of service provision (Ford et al., 2009; Revenga et al., 2006).

Since the early 2000s the Ministry of Public Health has encouraged the provision of ART through a multidisciplinary team, which includes PLHIV volunteer workers organized through a national network. The model requires that the PLHIV volunteer group must have at least two trained core members, be able to work regularly, have transparent financial management and a clear work-plan (Kumphitak et al., 2004). The volunteers are coordinated in groups at provincial and district level through the national network who develop curricula and train the volunteers, developing their capacity to work with hospital ART teams (Ford et al., 2009; Kumphitak et al., 2004; World Health Organization, 2007). The PLHIV role is to provide administrative and general support in

ART clinics and psychosocial support to patients in clinics and communities; PLHIV are able to support and care for patients in such a way that hospital staff often have limited time or capacity to do (Tantivess and Walt, 2008; Ford et al., 2009; PLHIV TNo, 2009). This is particularly important with children's services; HIV infection impacts on a wide range of aspects of their health and well-being and their support needs are more prominent.

1.2. Thai paediatric ART services

Children's HIV services in Thailand are provided free of charge through a holistic model, incorporating clinical and psychosocial aspects with volunteer PLHIV an integral part of service delivery. Services are increasingly provided as a 'one-stop' clinic aiming to maximize convenience while offering a range of services. This includes consultations with a nurse, paediatrician, pharmacist and social worker; clinical monitoring and volunteer-group activities. Clinics are sometimes linked to off-site services provided by volunteers (and occasionally hospital staff). In 2006 the 'Children's ART Network' was introduced and has been gradually scaled-up; this decentralized system aims to reduce the burden on provincial hospitals and improve adherence (Bureau of AIDS TB and STIs, 2008; Bureau of AIDS TB and STIs, 2007). Through this network, children diagnosed with HIV-infection initiate ART at tertiary hospitals and are referred back to a district hospital when their health becomes stable (Department of Disease Control, 2010; TUC; Hansudewechakul et al., 2006). At district level the programme again assumes the integration of the volunteers and aims to mobilise the PLHIV and communities to give psychosocial and adherence support, and strengthen capacity for long-term clinic follow-up and home-visits (Hansudewechakul et al., 2006, 2012). The findings in this paper relate to services provided through the decentralized model described.

The objective of this paper is to analyse the impact, opportunities and challenges of PLHIV acting as volunteer co-providers of paediatric HIV care in Thailand. We describe the role of PLHIV volunteers in reference to the Thai paediatric HIV programme and report findings from a qualitative study in order to assess the potential contribution of volunteers to strengthening health systems in an Asian context. We draw on a framework developed by Yaya Bocoum et al. that conceptualises the wider range of effects of task shifting through a 'systems-thinking' lens (Yaya Bocoum et al., 2013).

The framework presents 20 possible effects of task shifting on the system as a whole, many of which are not only positive, but are unintentional. The negative effects in their study were found to be unrelated to task-shifting *per se*, but reflections of weaknesses in the underlying health-system. They are broadly divided into supply and demand side effects and health outcomes effects; the supply side incorporating human resources issues such as workload, motivation, staff retention and confidence, while the demand side incorporates the social impact, patient satisfaction, access and equity issues. We use this framework as a basis for analysing and describing the contributions of the co-providers.

2. Methods

Qualitative methods in HIV research are valued for bringing in-depth understanding to the patient experience and recognition of the important influence of contextual factors that occur at intra- and interpersonal, community, social, cultural, and economic levels (Sankar et al., 2006). We used multiple qualitative methods to assess and triangulate a range of perspectives on the role PLHIV volunteers in paediatric HIV services. We conducted three focus group discussions with service providers and volunteer co-

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