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Manuscript Title: 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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Keywords
PLHIV volunteer; co-provider; task-shifting; paediatric HIV; Thailand; Asia; health system strengthening
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.

Research highlights

1. As co-providers, volunteers constitute the interface between families, communities and clinics
2. Volunteer co-providers have multiple roles in HIV services and strengthen health systems in Asia
3. A shared identity and strong sense of purpose can foster commitment
4. A health systems approach can optimize volunteer contributions

Keywords

PLHIV volunteer; co-provider; task-shifting; paediatric HIV; Thailand; Asia; health system strengthening
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 [1,2]. The impact of task-shifting on health outcomes is well-documented, and its potential for strengthening the broader health system is now gaining attention [3,4]. 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 [5].

HIV services, like those for other chronic diseases, require provision by a multidisciplinary team. Antiretroviral treatment is highly effective, but is complex to manage [6]. Providers of HIV services need a broad range of skills covering clinical HIV management, monitoring procedures, supporting adherence, and ability to link to community social and economic support [7-10]. 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 [8,11-13]. 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 [3].

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 [14]. People with similar demographic characteristics can be effective communicators within their communities and are able to build trust
relationships to improve knowledge and influence behaviour [15,16]. The contribution of
peer volunteers has been shown to be invaluable in supporting paediatric HIV care in many
contexts [17,18]. 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 [6,19-22]. 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 [23]. 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.

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 [24-26]. 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 [27]. In the limited literature regarding the
contribution of these ‘co-providers’ they are highly praised and considered a vital element of
service provision [28,29].

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
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 [28,30,31]. 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 and in such a way that hospital staff often have limited time or capacity to do [24,28,32]. 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.

**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 [33,34]. 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 [35-37]. 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 [37,38]. 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 [4].

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.

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 [39]. 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-providers (total participants n=31),
individual interviews with ART service-users (n=35), and policy actors (n=20); and (Table 1).
Service-provider and service-user participants were recruited from a university, a provincial
and a district hospital in Khon Kaen Province, in Thailand’s poorest Northeast region (to
represent all levels of service provision). Data were collected May to December 2009. The
university hospital is a tertiary provider, whence most paediatric patients initiated treatment
before being referred back to the district hospital and provincial hospitals; it has close links
and an advisory role to HIV service providers across the region.

Table 1 Type and source of data collected

<table>
<thead>
<tr>
<th>Site</th>
<th>Service provider FGD</th>
<th>Service-user interviews</th>
<th>Policy actor interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type</td>
<td>1 District hospital (8 participants)</td>
<td>29 caregivers 6 adolescents</td>
<td>4 - NGOs 2 – International agencies 5 – Academic / Expert 9 - Government</td>
</tr>
<tr>
<td></td>
<td>1 Provincial hospital (11 participants)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 University hospital (12 participants)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3 (31)</td>
<td>35</td>
<td>20</td>
</tr>
</tbody>
</table>

FGDs with PLHIV co-providers and hospital service-providers

The three FGDs, held with 8-12 participants, took place at each hospital included in the
study and were chosen in order to observe and understand the team dynamic. All members
of the paediatric HIV team were invited, including the PLHIV volunteers, paediatricians,
nurses, pharmacists and social workers. In this paper ‘provider’ refers to formal hospital
employed health staff and ‘co-provider’ refers to PLHIV volunteers. Areas explored in the
FGDs included: (co-) provider and patient challenges in paediatric services, co-provider roles
in clinic and community, NGOs and support groups. FGDs were used so as to understand
how group norms and dynamics shaped experiences amongst the multidisciplinary HIV care
teams [40,41]. FGD groups were mixed as they reflected the structure of the HIV care team:
men and women, HIV positive and negative, varying professional status. Use of mixed FGDs
with a range of participants was considered carefully, but after observation of team
dynamics and consultation with staff this was considered acceptable and an enabling way
for the voices of all providers and co-providers to be heard. All but one of the PLHIV volunteers (n= 8) were female. They were conducted in Thai by experienced Thai facilitators and the lead author.

**Service-user interviews**

Thirty-five paediatric ART clinic service-users (caregivers: grandparents, parents, other relatives; and older children) participated in qualitative interviews using a semi-structured guide designed to elicit detail. Information was asked about family and socio-economic needs, HIV support structures, PLHIV volunteers, HIV education, perceptions about services, challenges related to HIV. The interviews were carried out in Thai or local Northeastern dialect by a female PLHIV researcher and lead author. Participants were selected purposively by the HIV care teams on clinic days to represent a range of different experiences including: adolescence; orphanhood; a range of income levels; adherence issues; experienced social exclusion, stigma or abuse; psychosocial difficulties or isolation; HIV disclosure issues. Registered patients who had not experienced any of these HIV related difficulties were rare; effort was made to ensure positive and negative experiences were elicited. Child participants were required to be 12 years or older.

**Interviews with policy actors**

Policy actors (n=20) were purposively sampled following discussion with Ministry of Public Health and academic advisors; additional respondents were recruited through snowball sampling (Table 1). Inclusion criteria were based on current or recent contribution and experience of HIV policy processes. Interviewees were sought from all sectors contributing to paediatric HIV policy. NGO staff were considered as policy actors given the long-standing and important contribution they have made to HIV policy. Interviews were conducted by
Analysis

All qualitative data were recorded, transcribed and translated to English then analysed using a thematic framework in QSR Nvivo (v8) software. Emerging themes were grouped and coded by the lead author, the entirety of transcripts were coded to minimize risk of selectivity of data. Codes were refined, shared and discussed in the light of the Yaya-Bocoum framework [4] with two members of the research team. In addition, preliminary themes and analyses were presented to co-/providers in the two one-day workshops. These workshops were run by two facilitators and the lead author. Most participants had been present at the initial FGDs, the aim was to check for validity, minimize possible bias in the analytic process, and obtain feedback which was used to structure the final coding frame from which final queries were run in the software. The workshops served as a data collection method and a means of analytic triangulation and so were also recorded, coded and analysed. Provider participants were this time divided according to cadre: provider and co-provider because the focus was on problem-solving and generating ideas, for which this group dynamic was appropriate.

Trustworthiness and validity of the data were strengthened through methodological triangulation of the results between FGDs, interviews and workshops and between types of respondents. These triangulation techniques were used to enhance reliability through a reflective, multi-dimensional interpretation of the data and resolution of contradictions [42]. Results obtained from the different methods were intuitively related to each other and checked for convergence and divergence [43].
The research protocol received ethical approval by the Liverpool School of Tropical Medicine (Protocol No.07.57), the Thai MOPH (Protocol No.150/2551), Khon Kaen University (for Srinagarind Hospital) and Khon Kaen Provincial Hospital (also covering the district level hospital). Written consent was obtained directly from participants, including young participants. Young participants who attended clinic unaccompanied did not require additional consent from a caregiver, written consent was obtained from a caregiver for those who were accompanied.

The findings in this paper present combined triangulated results from all participants, organized using both adapted demand and supply side effects extracted from the Yaya-Bocoum et al framework [4]. Where appropriate, feedback and suggestions from the workshops are also included in the findings section. Illustrative quotations are used and annotated with the type of method, participant information and the following abbreviations: SU=Service-user; CP=Co-provider; P=Provider; Pol=Policy actor; Gov=Government employee; NGO=non-Government organization staff.

**FINDINGS**

We present the findings according to the demand and supply side effects of co-providers. They are then ordered as the major themes that emerged in the data. Each theme incorporates data from various respondent types to show where views differ or confer.

**DEMAND SIDE EFFECTS**

*Contribution of co-providers to service quality*

The co-providers were recognized by service-users, providers and to some extent policy actors (particularly NGOs) for conducting multiple tasks both in and out of clinic setting. Table 2 summarizes the range of contributions cited by respondents. Not all co-provider
volunteers performed all roles but their contributions were considered an important part of enabling a more holistic care package in which co-provider volunteers created a link between service-users and hospital providers, one NGO activist explained that:

“It is important to have PLHIV support in every hospital, they can help, though they don’t always have sufficient experience. Without this help the hospitals can’t cope.”

(Female Pol interview, NGO)

Table 2 – PLHIV contribution to ART services (demand-side)

<table>
<thead>
<tr>
<th>Co-provider role</th>
<th>Community</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health advice and information</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Moral support and preparing for disclosure of status</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Advice on financial matters</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Adolescent specific advice</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Telephone advice</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Home visits</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Community education events</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Life skills and youth camps</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Tackling stigma</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Attending pre-clinic case conferences</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Admin support and measuring/recording weight and blood pressure</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Linking with provincial health office/ local administrative organizations</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Pill counting</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Adherence checking</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

In addition to the interaction service-users had with co-provider volunteers in clinic and at home, many children and their caregivers regularly attended several different support groups; attendance was reported at the following types of activities: 1) group activities on HIV-clinic days: organized by hospital staff and supported by co-provider volunteers; 2) community peer-support groups: organised at district or sub-district level by the PLHIV network (often with a financial or meal incentive); 3) child and adolescent camps: organised by volunteer groups or hospitals.
The PLHIV support which existed in each of the three hospitals in this study were perceived by most co-/providers to have an essential role in improving the quality of the service that patients received. As HIV-positive individuals, co-providers knew that they were well-placed to understand the circumstances of the service-users:

“Our job doesn’t stop in the hospital, we wouldn’t be able to analyse people properly; we need to be able to visit them at home, see the condition of the child at home, how they fit in to the community, observe their environment, it isn’t enough just to ask at clinic.” (Female District Co-P, workshop).

“The volunteers are very important, usually children are living with elderly caregivers and some of them are excluded from school and there is just no one that they can talk to...the regular hospital staff don’t have much time beyond the clinical side of treatment.” (Female Pol NGO, interview)

Patient satisfaction: Sharing identities, developing rapport

Appreciation of the central role played by co-providers was a strong theme; both HIV positive adolescents and the caregivers of younger children expressed the importance of this:

“[We get] Knowledge and interaction with people who know about things that I don’t know... Things like taking medication, or every day life skills... The volunteers are good, they don’t interfere too much but if I have a problem I know I can talk to them and they won’t tell anyone, else they help.” (Female adolescent SU, age 17)

“The volunteers help explain the medicines, but [at the group activities] I like the games we do with friends, and drawing pictures... [they say] that we don’t need to worry about living with others, sharing with others, eating together, it is fine, there is
no need to think about it, HIV isn’t that easy to catch.” (Female adolescent SU, age 14.)

The co-providers were viewed as integral to services but also as outsiders from the hospital team, giving them an in-between or link status. A unique attribute that was recognised was their ability to communicate with service-users, partly due to their shared language (Iesan dialect) and experiences:

“We help on many levels in the hospital...one role is, when patients come for treatment, they come to the volunteers first; what I mean is that they trust us... and talk about things in a way they couldn’t say to the doctor.” (Female University Co-P, workshop).

They (volunteers) can help improve relations, and there is plenty of potential for building their capacity too.” (Female University P, FGD)

Service-users and co-providers developed trusting relationships that sometimes functioned on an emotional and practical level and covered a range of issues:

“I trust the volunteers the most because they give good advice, we are close.”

Grandmother SU, interview)

“There is one volunteer I have known since the start, she has given me helpful information, she said she is also infected and [explained] that I didn’t need to be disgusted by my nephew, she helped me to understand... It is such a shame that when my sister was alive they didn’t have these support groups, people you can talk to.” (Aunt SU, interview).

Not all interviewees had attended PLHIV group activities, but those who had attended found they were generally helpful, and only a minority did not wish to attend. Groups had multiple
and over-lapping functions as sources of HIV-related knowledge (on treatment, disclosure, care and transmission), a forum for advice for discussing financial-support solutions and sharing experiences with other HIV-infected and affected people:

“I like it [at the groups], the children can have fun drawing, but for me it is nice to have people massage me, they do exercises with us too, as well as giving us information about health and treatment. I can now also help other people...

They [volunteers] help, like suggesting ways to make an income and they say that if I need help then I should ask them.” (Grandmother SU, interview).

Doctors encouraged group attendance and service-users at the university hospital were unable to avoid the hospital-based group as they were obliged to collect their prescriptions from the group-activities room. For some people the groups were a rare opportunity to talk openly about HIV:

“The doctor suggested I go to the group; they give us advice about the medicines. It is good to be a member; you meet and talk to other people about this, it is comforting. I know the volunteers are infected too; there is no discrimination between people.” (Grandmother SU, interview).

Recognition that co-provider contribution to improved patient satisfaction was not universal however, for example, occasionally service-users did not want the extra support or to discuss HIV related issues, fear of disclosure and inability to talk openly about HIV acted as a deterrent for some to talk to co-providers or attend group activities in the community:

“I don’t want to talk to anyone about it. I don’t know what the result [of going to the volunteer activities] would be; what do they do? I’m already busy looking after the children.” (Father SU, interview).

Better access to services close to home and promoting equity
The current paediatric HIV service delivery model expects volunteers to provide a degree of follow-up in the community even though some service-users chose to attend clinic at distant hospitals. This had demand side benefits that were noted by some respondents. Home visits by co-providers were seen as useful, to give health advice, informal support to the family (such as encouraging other at-risk family members to have HIV testing), and so that they could get a sense of underlying problems such as poor HIV knowledge or discrimination in the community or at school. The visits also sometimes provided an opportunity to be advised on health problems at home between clinic visits:

“If there is any problem they’ll come and visit us at home, they’re good, they have plenty of time for us.” (Grandmother SU, interview).

“Volunteers from here visited home, they gave [HIV related] information to the neighbours. We lived in a rented compound, so people had complained.” (Father SU, interview).

“We organized training in a school which improved (HIV) understanding.” (Female District Co-P, FGD)

In the community, support extended beyond medical help to general advice such as coordinating financial support:

“We can help families make the application for money from the local administration... they can apply for funds for raising cows, farming fish, or growing vegetables.” (Female District Co-P, workshop).

It was noted by some policy makers and (co-)providers that the distribution of support from volunteers was not even across the province or the country as a whole, and that access to support at home or in the community was irregular. For example families living in areas of low prevalence were less likely to have a strong volunteer presence, while other districts simply lacking enthusiastic or skilled PLHIV and so were neglected:
“It varies, some areas have many PLHIV groups and some have very few.” (Female Pol Gov, interview)

“There are some places where children are not accessed by volunteers, they are very important as often otherwise they have no support at all. It is only a very small number of children we come across who are close enough to their caregiver or to their teacher and can get the advice they need from them.” (Female Pol NGO, interview)

It was suggested that simple mapping of child residence and regular review of all cases in clinic would indicate oversights in community support mechanisms.

**SUPPLY-SIDE EFFECTS**

**Tackling team challenges: Staff turnover and confidence**

Co-providers were seen to have an impact on issues where hospital teams had difficulties.

Two of the three hospitals had staffing problems, either shortages or high turnover, many of the members of the hospital paediatric HIV teams at the provincial and district levels were relatively new to their posts and staff confidence was quite low in these sites:

“The hospital administration knows there is a shortage of staff for every position.” (Male District P, FGD).

Some respondents therefore felt that volunteers were an important aspect of long-term continuity in service provision in an environment of high staff turnover and it was noted that some volunteers had long-standing relationships with service-users:

“...the group can help a lot because there are not enough staff here, particularly in things like contact with patients, because sometimes we are already acquainted.” (Female Provincial Co-P, FGD).

Staff confidence in their ability to do their work well and deal with complex issues like disclosure counselling were also seen as hindrances to delivering good quality services:
“We feel we aren’t that good, we need to improve ourselves. Well, we need to receive more training and have a clearer system; we need to build a system, and to improve our confidence for things like counselling.” (Male Provincial P, FGD).

Co-providers had potential to mitigate some of these problems, but despite expressing pride in their skills and potential, some also experienced problems with low confidence. They made suggestions about how their knowledge could be improved:

“It would be good to be trained in communication with children, but also for child development and appropriate activities. Sometimes I lack confidence in talking to children on these issues.” (Female District co-P, FGD)

Cost and sustainability

Co-provider attendance at clinic depended on the commitment of the local PLHIV networks to provide training and financial support. Activities were often reliant on short-term funds from local institutions, although some funding was also available from central government. The FGDs revealed that PLHIV groups found it increasingly difficult to secure government funds and future funding for training was uncertain:

“The provincial health office provides training for the [PLHIV] group leader of each district, that is 26 districts. The regional Disease Control Office used to give us money to organize activities and home visits, but their budget is small now.” (Female District P, FGD)

Co-/provider and policy respondents talked about the changes to PLHIV groups’ subsidy. In 2009 financing of the ARV programme was taken over by the National Health Security Office. When the new Office was set up there was no longer a comprehensive volunteer funding
mechanism and volunteer expenses could not be guaranteed, even though the policy-level
interviewees concurred that PLHIV groups have long been accepted as a valuable resource.
The official stance is that groups could receive funding (allocated from central to local
government) but that they would now need to actively demonstrate their value. Co-
providers explained that they lacked the skills (for example, grant and proposal writing) to
do so.

“Groups are not guaranteed funding and must undergo formal registration to compete
for shrinking funds.” (Male Pol Gov, Interview).

Sustainability of co-providers and insufficient budgets to cover costs were a recurrent
concern across all sites voiced by co-/providers. For example, despite the integral role the
seven co-providers at the district hospital were playing at the time of this study, they
received no financial support at all because the hospital did not have a budget for such
activities, local sources of funding had been exhausted and central government funding had
not been allocated to them.

Coordination and training needs

Some co-providers felt that their informal position meant that good leadership in the PLHIV
network was crucial and poor provincial leadership would have an impact on the functioning
of all the groups within that province. The national network for PLHIV was recognized as
having strength in co-ordination needs and facilitated good quality peer support by
providing training and tools, distributing new information, co-ordinating funds and activities
and liaising with the formal health sector:

“It continues to operate a hierarchically structured network ranging from policy-
advocates at national level to offices in every region and province, to support-
volunteers in villages, who work to educate communities, tackle discrimination and
provide peer-support.” (Male Pol Gov, Interview).
Government level action would however have been welcomed by several respondents:

“The national PLHIV network is good, but there should be greater central government cooperation and support of the network groups... if you have a problem with a child in the community ... you can go to local authority but they have limitations, the network representatives can go in and encourage them to act, but they don’t have power without central government support.” (Female Provincial P, Workshop).

Co-providers’ clinic activities were shaped by the current needs of the staff and patients in each setting. Co-providers explained they received a basic qualification about ART from their local PLHIV network and in addition received a variety of further ad hoc trainings in opportunistic infections, drug resistance, self-care, leadership, counselling and disclosure. These were offered by the provincial health office, hospitals and other organizations. The successful running of the HIV clinic days was largely deemed to depend on cohesion in the team, efficiency and communication between team members, both providers and co-providers:

“The clinic co-ordination is mostly good, people help each other, but I think it could develop more.” (Male District P, FGD).

“We are on the HIV committee which is active in each department.” (Female District Co-P, FGD)

Some co-providers felt the need for greater recognition of their contribution, one approach suggested for this would be to give those who had acquired a certain level of accredited training a formally certified role in the ART clinic:

“We have the ability, but don’t have the confidence to speak out.” (Female Provincial Co-P, Workshop)
**Performance Gaps**

ART guidelines – where they had been issued to HIV clinics – were thought to be effective and were used frequently in order to check dosing, side effects and all medical issues likely to be encountered in the HIV clinic. However providers felt there were deficiencies in psychosocial guidance, adolescent issues, communications and disclosure,

“We have hardly any tools for this [communication with patients] at all, really very few... We don’t see anything new like for example, how to deal with teenagers” (Female District P, FGD)

In contrast, some co-providers, noted they had received valuable additional guidelines from other sources, this district hospital respondent felt this contributed to the performance of the team overall:

“We receive them [guidelines] from the network; we have guidance in communication with HIV-infected children, how we should talk to them, care for them, what we should ask them, stigma, problems at school and so on”

(Female District Co-P, FGD).

Co-providers suggested (and demonstrated) that, as a result of the involvement of national PLHIV network members in HIV-policy formulation, they received up-to-date guidelines and information about HIV policies. Their knowledge sometimes preceded and/or exceeded that of the hospital staff; for example, they were aware of the right to annual-viral load testing before some hospital employees. They regarded this knowledge as potentially helpful particularly in hospitals where staff turnover was high and clinical staff might struggle to keep up with developments across the health sector. Such contributions were generally well-accepted by hospital staff at all sites.
Paediatric-specific issues were an area where performance of providers and co-providers was uneven and some policy makers felt that paediatric HIV support lagged behind adult support services.

“Work with children has not yet reached the results that we want to see. For example, working on attitudes... Frequently people [providers and charities] simply don’t know what to do with such children, so they just ‘release’ them” (Female Pol NGO, interview)

One reason suggested for this was that co-providers were initially based in adult ART clinics and support for children only emerged gradually as the need was recognized. Some co-providers, and indeed hospital staff, expressed limited experiences with paediatric-HIV issues; co-providers themselves did not necessarily have HIV-positive children of their own or any direct experience of them beyond their volunteer duties. They suggested their existing skills could be usefully developed and productivity improved by expanding knowledge on specific areas relating to nutrition, children’s rights, clinical management of paediatric ART, sex education, communicating with adolescents and special psychosocial support for individual vulnerable children such as orphans and those with elderly caregivers.

It was suggested that acquisition of these and other paediatric skills would counter the sense that they (sometimes) feel exploited or under-used due to the perceived tendency of clinic staff to allocate menial tasks to them.

**DISCUSSION**

Within the context of northeastern Thailand our study shows that as paediatric HIV service co-providers, volunteers constitute a critical interface between community, family and clinic. Using the framework developed by Yaya-Bocoum et al [4] as a basis for this analysis we observed both the effects and the potential that co-providers have for health systems within the supply and demand spheres: although the distinction between these two spheres was
sometimes blurred due to overlapping contributions. Co-providers were seen to have an important linking role: clinics and communities; patients and hospital staff. Their work frequently made the difference between merely adequate provision of care and a holistic provision of care.

On the demand side there was a high level of appreciation of the added value co-providers bring by taking services to the community; it created accessible and equitable provision of services on a range of health and support issues. On the supply side co-providers were seen as a valuable human resource that helped mitigate staff retention and turn-over problems, improved team performance and efficiency and filled gaps in service provision and through bringing additional skills to the team. Services were threatened due to the reduction of government and other funding sources.

Our data did not map exactly on to Yaya-Bocoum’s framework of twenty health-systems effects. The effects that we identified were broader and more interlinking and lacked many of the potentially negative effects on the health system shown in their framework. For example, tension about roles, responsibilities and hierarchies; professional protectionism; frustration due to increased demand in services; and low motivation were not pronounced in our study. Documented challenges and limitations to task-shifting include investment for training, support and remuneration for staff and volunteers, integration of new members into health-care teams and the supervisory time load [44]. The issue of investment was indeed a problem in the Thai scenario; co-providers do have some costs and a long term funding commitment is essential to ensure both sustainable and effective services. There is a clear need to improve the funding mechanism. Financing PLHIV hospital activities was believed to be a sustainable and cost-effective measure by a World Bank review (in 2004) given the perceived benefits [29].
The findings reported here broadly corroborate limited existing evidence from Thailand relating to PLHIV interventions which cite their benefits such as sharing experiences, meeting people, a sense of solidarity, receiving information, learning about coping mechanisms, emotional support and feeling less isolated and more positive \([45,46]\) and their impact on reducing the workload of hospital staff \([47]\). There is no published evidence from Thailand reporting the negative impact of PLHIV co-providers and contrary to the health-systems effects framework, in our study the effect of volunteer co-providers was largely positive. One reason for this may be that task–shifting in the context of Thai HIV services is long-established, the PLHIV network has been involved in HIV policy and service provision since the earliest days of the epidemic and has always had government backing as co-providers of HIV care.

There is an increasing focus on care and support for HIV at community level in line with task-shifting approaches and initiatives to foster community peer support. There is little knowledge about what types of peer intervention work best, and why, except that success seems usually to be dependent on building upon existing relationships between peers and the target group \([48]\). The shared identity and experience of peer supporters is likely to support the motivation and commitment of co-providers some of whom are long-standing activists for HIV patients’ rights and all of whom are part of a strong national network. They are able contribute as co-providers by drawing on their own personal experiences and unique position to support service-users as ‘expert patients’ who can move between the public-health system and individuals \([14]\). The needs of children are broader and more complex than those of adult patients \([8,11-13]\); our data show that the contribution of co-providers is valued in supporting these additional needs. Paediatric care involves a complex triangle of children, adults and caregivers; it also involves giving information and advice
appropriate to developmental stage and supporting the transition of childhood into adolescence. The potential to respond to these needs give co-providers in the Thai context a multi-dimensional role across policy, service provision and communities and an ideal task-shifting position for strengthening the health system across those spheres. Our data demonstrate the strong potential of a formal role of volunteers integrated as co-providers in paediatric HIV service provision that link and support HIV positive children, communities and clinics.

There are limitations to the capacity of the co-providers in this study and it is likely that intervention will be needed to maintain the motivation, skills and retention of this vital cadre. Our study highlighted the need for recognition and more formal integration of PLHIV volunteers (such as certification and accreditation of training). Capacity would inevitably be strengthened by their participation in formal HIV team training and meetings that are organized through the Ministry of Public Health.

Our findings suggest a systems-thinking approach is a logical one which, at policy level, involves standing back from individual components and keeping the strengthening of the whole system in mind when designing and evaluating innovations [49]. It is likely that the contributions of co-providers in the Thai HIV programme are not actually perceived by most policy actors as task-shifting per se, nor as having a role in health systems strengthening and this oversight may ultimately limit their potential. While the conditions described in this paper may appear unique to the Thai context, there is evidence of scope for transferability. The PLHIV model and training curriculum has been adapted and exported to other countries in the region: Vietnam, Cambodia, Laos, Nepal, Burma and Yunnan in Southern China [28]. This demonstrates willingness from other Asian nations to learn from the Thai experience and to enhance HIV service provision through task-shifting to this cadre. Distribution of
some child and adolescent specific tools enhanced the quality of services but it was felt more focus on paediatric skills for co-providers was needed.

Our study has several limitations. Service-user respondents were selected by health care workers, interviewed at health facilities and were recruited from a cultural group previously documented as averse to expressing criticism [50,51]. There was indeed a general reluctance from service-users to criticize providers, and adolescents in particular were reticent to express themselves fully although efforts were made to mitigate this by use of a trained and experienced PLHIV social worker interviewer. It was possible to recruit few adolescents for interview, therefore the service-user perspective is largely one of adults used as proxy respondents. There was unease among policy actors to discuss financing issues possibly as a result of the restructuring of the recent financing of the health sector. Data on health outcomes effects (part of the evaluation framework) were beyond the scope of this study, our findings suggest a further larger study with focus on health-systems strengthening would be beneficial. Existing evaluations of task-shifting have not tended to focus on their impact on health-systems [4]. Qualitative techniques have enabled recognition of the value of PHLIVs as co-providers, but future evaluation would benefit from the development of additional measurable indicators.

CONCLUSION

Motivated PLHIV volunteers constitute a critical interface between families and health services in paediatric HIV care in Thailand. Using volunteers as co-providers for specific clinical services, can contribute to strengthening health systems in Asia both from the demand side (patient and the caregiver) perspectives and from the supply-side (human resources). Our findings can help to inform policy makers and service providers on how to balance clinical priorities with psycho-socio responsiveness and on how best to integrate the
views and experience of volunteers into a holistic and equitable model of care. In order to optimise and sustain the vital contribution of volunteer co-providers an approach that embeds them within the health systems is required. They, as any other human resource require support, training, coordination and motivation from the health system alongside the recognition and appreciation from service-users, communities and individual health care workers.

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