Provision of psychosocial support for young people living with HIV: voices from the field

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Abstract

This review provides a synthesis of the experiences of organisations providing psychosocial support for young people living with HIV (YPLHIV) from throughout the world. Little research exists on psychosocial support for YPLHIV, with many providers uncertain about how to address their complex needs. Eighty-six organisations were sent a survey containing 15 semi-structured, open-ended questions. Sixty-eight organisations from the United States, Europe, Africa, Asia, Latin America and the Middle East responded. The survey asked what challenges the organisation's patient group face; what the organisational aims are; how, where and by whom psychosocial support is delivered; what types of psychosocial support have been effective and which have not; and what recommendations the organisation has for service provision and policy.

Data were stratified by age of population, region of the world and whether youth were infected at birth or in adolescence. The problems and needs across groups were more consistent than disparate. Adherence to medication, disclosure of HIV status, issues relating to sex and lack of support networks are problems faced by all YPLHIV. Most organisations use a multi-disciplinary team of individuals to meet these needs, with particular emphasis on individual and group therapy, educational support, and skills-building programmes.

The review stresses the importance of youth-centered and youth-led approaches that engage young people in the planning, implementation and evaluation of programmes. Organisations underlined the need for increased funding, capacity building and trained staff. They suggest that policy makers put more effort into understanding the distinctiveness of adolescence, particularly in the context of HIV, and challenge them to make longer-term commitments to funding and programme support. In order for organisations to provide better services, they need further evidence of effective solutions, programme guidance and support tools, and increased collaboration and communication with one another, and with policy-makers and donors.

Keywords: HIV/AIDS, youth, psychosocial, interventions.

Résumé

Cette revue présente une synthèse des expériences d'associations du monde entier fournissant un soutien psychosocial pour les jeunes vivant avec le VIH (JVVIH). Peu de recherches sur le soutien psychosocial pour les JVVIH ont été réalisées, et de nombreux prestataires ne savent pas vraiment comment répondre à leurs besoins complexes. Quatre-vingt-six associations ont reçu un questionnaire contenant 15 questions semi-structurées et ouvertes. Soixante-huit associations, des États-Unis, d'Europe, d'Afrique, d'Asie, d'Amérique latine et du Moyen-Orient, ont répondu. L'enquête a demandé quels sont les défis dans l'organisation de groupes de patients; quels sont les objectifs organisationnels; comment, où et par qui le soutien psychosocial est fourni; quels types de soutien psychosocial ont été efficaces et lesquels ne l'ont pas été; et quelles sont les recommandations de l'association concernant la mise à disposition et la nature de ce service.

Les données ont été stratifiées en fonction de l'âge de la population, de la région du monde et de la date de la contamination (à la naissance ou à l'adolescence). Les problèmes et les besoins des groupes étaient davantage cohérents que disparates. L'adhésion à la médication, la divulgation du statut VIH, les questions relatives au sexe et au manque de réseaux de soutien sont les problèmes rencontrés par tous les JVVIH. La plupart des associations utilisent une équipe multi-disciplinaire pour répondre à ces besoins, en mettant particulièrement l'accent sur la thérapie individuelle et de groupe, sur le soutien éducatif, et sur des programmes de renforcement des compétences.

La revue souligne l'importance des approches centrées sur les jeunes et menées par eux, qui les impliquent dans la planification, la mise en œuvre et l'évaluation des programmes. Les associations ont souligné la nécessité d'accroître le financement, les capacités d'accueil et le personnel qualifié. Ils suggèrent que les décideurs s'investissent davantage dans la compréhension de la spécificité de l'adolescence, en particulier dans le contexte du VIH; et les mettent aux défis de prendre des engagements à plus long terme pour le financement et le soutien du programme. Pour que les associations fournissent de meilleurs services, elles ont besoin de d'autres témoignages évoquant des solutions efficaces, d'outils d'orientation et de soutien du programme, et d'une plus grande collaboration et communication entre elles, ainsi qu'avec les décideurs et les donateurs.

Mots clés: VIH/SIDA, jeunesse, psychosocial, interventions.

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Introduction

There are currently an estimated 5.4 million young people, ages 10 - 24, living with HIV worldwide (WHO/UNICEF, 2008). This group represents one of the most vulnerable, yet overlooked populations affected by the HIV/AIDS pandemic. Despite the increasing effectiveness and availability of highly active antiretroviral treatment (HAART) during the past decade, young people still make up 45% of new infections. Whether infected during the perinatal period or during adolescence, young people living with HIV (YPLHIV) have unique and pressing psychosocial needs, in addition to the daily challenges of adolescence. Health care providers and policy makers must be able to respond to the specific needs of YPLHIV, which differ in a number of ways from those of small children or adults.

The WHO and UNICEF initiated this study in 2008 to understand more fully the nature of existing interventions that provide psychosocial support for YPLHIV, with a view to develop guidance that can be adapted locally. The goals of the project were to: (*i*) conduct a literature review of published data on psychosocial support interventions for YPLHIV; (*ii*) develop a survey instrument to investigate what organisations are doing to provide psychosocial support for YPLHIV, the major problems faced by YPLHIV and the obstacles organisations must overcome to meet their needs, specific psychosocial outcomes that organisations are trying to achieve, what works and what does not, recommendations for service providers and policy makers, and research questions that remain unanswered; (*iii*) use a snow-ball sampling approach to identify organisations to participate in the study; (*iv*) conduct the survey and interpret responses using a grounded theory approach.

Since the early 1990s, a number of studies have been published on the psychosocial effects of HIV in children and adolescents. Far fewer, however, have explored the interventions designed to provide psychosocial support for YPLHIV, in order to help them manage issues such as treatment adherence, dealing with disclosure and stigma and preventing high-risk behaviours. Although little has been published, psychosocial support for YPLHIV is being provided by many organisations in many countries. Built within a constructivist framework, in which knowledge is generated from experiences, this review provides a first step in highlighting and synthesising some of the expertise and experiences of the people and organisations working with YPLHIV, with the aim to strengthen programme planning and advocacy efforts.

Methods

A semi-structured, self-administered survey of 15 open-ended questions was developed. The survey questions are detailed in Table 1. The questions derived from a 2006 WHO/UNICEF Global Consultation for YPLHIV in Blantyre, Malawi (WHO/ UNICEF, 2006), at which key questions about how to effectively provide psychosocial support for YPLHIV were documented for further review. The WHO defines 'young people' as 10 - 24 years old. Organisations were asked to respond to questions about their services that reach youth within this target age range. The research was conducted between April and August 2008, with organisations from around the world, through e-mail and telephone. Data were collected and analysed in Boston, Massachusetts and Geneva, Switzerland.

Organisations deemed eligible to participate in the survey included those that provide support for informing newly diagnosed adolescents of an HIV-positive test result, preparing for and assisting with disclosure of HIV status to others, assessing and assisting with adherence to medication, addressing feelings of isolation and emotional distress, and addressing needs associated with sexual health and emerging sexuality. Organisations exclusively providing medical and psychiatric treatment for disorders of an organic nature were not included.

A snow-ball sampling approach was used to identify eligible organisations to participate. To begin, contact was made with the organisations that participated in the 2006 Global Consultation in Malawi. (The Global Consultation brought together 49 YPLHIV, health and social care providers and directors of NGOs to discuss the priority challenges for YPLHIV to which the health sector should respond.)

They supplied names and contact details of other organisations providing psychosocial support for YPLHIV. An organisation in Boston gave the names of 30 health and social care providers working with YPLHIV or who conduct research with YPLHIV from across the United States. These organisations were then contacted and asked to participate, if eligible, and/or to provide contact details for others. During this initial phase, contact was made with 200 non-governmental organisations, international multilateral agencies, adolescent sexual health clinics, academia, and medicine. Every organisation meeting the eligibility criteria was sent a questionnaire by e-mail, notified about the general objectives of the study, and given three weeks to respond. The WHO Department of Child and Adolescent Health determined that human subjects review was not required to field this provider survey to develop a more comprehensive register of interventions and programmes focused on psychosocial support.

Data analysis

Responses in Spanish were translated by the PI and then cross-checked by a native speaker. Data were analysed using a grounded theory approach. In the initial phase, open coding was used to consider data in minute detail and to develop sub-codes. In the second phase, these codes were pooled and integrated into common themes (selective coding) and organised by core concepts. Table 1 provides a list of the questions asked and core concepts generated. Sub-codes are outlined in subsequent tables. The codes were analysed manually and measured for frequency and proportion. ANTHROPAC computer software was used to cross-check the data. Correlations were investigated based on three variables: geographical region of participating organisations, age of population served, and age at transmission of population served.

Results

Of the initial contacts made, 86 organisations met the criteria for eligibility for inclusion in this study. Sixty-eight surveys were completed and returned (79% response rate). Two non-responding organisations indicated they did not have time to respond. Non-responding organisations were spread across all geographic regions equally, and the majority (72%) were hospital- or university-based. It is likely that other non-respondents were too busy to participate

Table 1. Questions and core concepts

Question	Core concepts elicited by question
Briefly describe the major problems facing adolescents living with HIV for which they require psycho-social support	Living with HIV Sexual health Managing stigma Being at-risk Mental health
What outcomes are you trying to achieve for adolescents living with HIV through your interventions?	Improved adherence Quality of life Prevention Disclosure Access to treatment Educating professionals
Briefly describe what your organisation is *doing* to provide psychosocial support for adolescents who are living with HIV	Therapeutic support Information/education Living with HIV Primary health care Collaboration/referrals
Please describe how you have involved young people living with HIV in the development and implementation of your activities	Programme development Advisory boards Peer counselling/support Community awareness Staff/volunteers
What programmes or elements of programmes supported by your organisation have been <u>most effective</u> in providing psychosocial support for adolescents living with HIV?	Therapeutic support Youth-centered Planning for the future Location/environment Community awareness
What programmes or elements of programmes supported by your organisation have been <u>least effective</u> in providing psychosocial support young people living with HIV?	Information-only Non youth-friendly/participatory Generic services Job training Unstable environment
How do you monitor and evaluate your programmes that provide psychosocial support for adolescents living with HIV?	Individual assessments Surveys Direct observation/site visits Periodic reports/reviews M&E framework Quantitative/process outcomes Dialogue/feedback
What do you think are the 3 most important things that need to be included in any guidance on psychosocial support that is developed for <u>service providers?</u>	Multidisciplinary Cultural competence Youth-involvement Development of guidance Mental health Skills training
What do you think are the 3 most important things that need to be included in any guidance on psychosocial support that is developed for <u>policy makers?</u>	Understanding/empathy Funding/sustainability Capacity building Stigma/discrimination SRH education Providing guidance

Table 1. Questions and core concepts — cont.

Question	Core concepts elicited by question
What do you think are the major obstacles to providing psychosocial support for adolescents living with HIV?	Youth involvement Stigma/prejudice Lack funds/resources Lack family/social support Lack adequate services
What 3 things would most help your organisation improve the quality and coverage of your psycho-social support interventions for adolescents living with HIV?	Qualified staff Funding Capacity building Programme support materials Mental health focus
What do you think are the most important research issues regarding interventions to provide psychosocial support for adolescents living with HIV?	Development of guidance Sexual health Mental health Planning for the future Stigma and rights Treatment effects

Table 2. Distribution of respondents and responding organisations

Geographic region	N	%*	Respondent's job title	N	%*
United States of America	24	35	Director/Executive Director	20	30
Eastern Europe (Romania only)	10	15	Program Officer/Coordinator	14	22
South America	9	13	Social Worker	11	16
Africa	8	12	Programme Director	8	12
Western Europe	8	12	Mental Health Professional	7	10
Asia	6	9	Primary Care Physician	5	7
Central America/Caribbean	2	3	Nurse	2	2
Middle East (Iran)	1	1.5	Physician's Assistant	1	1
Types of providers at site			**Age at transmission**		
Mental health professionals	37	54	At birth	21	31
Social workers	36	52	In adolescence	7	10
Nurses	32	47	Both	37	54
Physicians	26	38	Other	3	4
Counsellors	23	34			
Peers/volunteers	14	21			
Types of service sites			**Age of population served**		
Hospital/health clinic	17	25	10 - 14	9	13
Organisation office	11	16	10 - 19	12	18
Health clinic & community site	9	13	10 - 24	15	22
Office & community site	7	10	15 - 19	10	15
Community sites	6	9	15 - 24	15	22
Health clinic & office	5	7	20 - 24	7	10

* *N*=68, multiple responses allowed so per cents to do not add up to 100%.

in the survey. It is also possible that despite being identified as eligible, the providers in clinical and academic settings who received the survey do not themselves provide psychosocial support and failed to forward the survey onto those within their institutions that do.

Table 2 summarises the distribution of responding organisations across geographic region, job title of the survey respondent, age of the population they serve, age of the population at transmission, types of providers on-site, and the sites where services are provided. All of the survey respondents are professionals employed by their organisations. The large majority hold executive positions and/or professional degrees in primary or mental health care, indicating that their responses are evidence-based and trustworthy.

The majority of organisations work both with youth who were infected with HIV at birth and those infected during adolescence. Three organisations (all from Romania) work with young people who contracted HIV during infancy through blood transfusions in hospitals. All of the organisations surveyed use a multidisciplinary approach to provide psychosocial support for YPLHIV. Services are provided from a range of sites including hospitals, health clinics,

agency offices and community sites, with close to one-quarter of organisations providing services from a combination of sites.

Problems faced by YPLHIV

The four most frequent problems faced by YPLHIV were identified as: issues relating to adherence, sex and relationships, disclosure and coping with stigma and discrimination (Table 3). Adherence to medication was a key issue for organisations working with young people infected earlier in life, and who are more likely to require treatment during the adolescent period.

The general responses are similar across regions of the world; however, some regional differences were noted. Organisations in Africa work with youth who were orphaned at a young age and lack other adult support in their lives. These organisations identified that the responsibility for heading households is a serious problem for YPLHIV. In Eastern Europe, key problems include motivating young people to integrate socially and professionally, as well as to access health and support services. These organisations highlighted that youth are mobile, with little support structure at home and, therefore, have difficulty accessing services regularly.

Table 3. Core concepts and sub-codes for key questions

Problems faced by YPLHIV	N	%*	Organisational objectives	10-19	15-24	10-24
Adherence	27	40	Improved adherence	15	11	15
Issues relating to sex	27	40	Prevention	13	15	13
Relationships	16	24	Disclosure	7	4	6
Having sex	15	22	Coping with stigma	6	8	7
Sexuality	12	18	Achieving independence	5	15	14
Disclosure	26	38				
To friends/peers	9	13	**Effective programmes**	**N**	**%***	
To partners	9	13	Therapeutic support			
To family	4	6	Support groups	25	37	
Stigma/discrimination	31	46	Individual therapy	18	26	
In school	9	13	Multidisciplinary	18	26	
In the family	6	9	Youth-centered			
In the community	3	4	Culturally competent	18	28	
At work	4	6	Participatory	10	15	
In health care	2	3	Youth-friendly	6	9	
By peers	2	3	Achieving independence			
Lake of support	25	37	Adherence/disclosure	3	5	
Family support	9	13	Education support	3	5	
			Life-skills training	6	8	
Psychosocial support services			**Guidance for policy makers**			
Mental health	51	75	Understanding/empathy	30	45	
Individual therapy	44	64	Funding/sustainability	17	25	
Support groups	39	57	Access	14	20	
Family/partner counselling	15	22	Discrimination	9	13	
Peer support	14	21	Sex education	7	10	
Information/Education	15	22				
Referrals	13	19				
Education support	11	16				
Primary health care	11	16	**Evaluating programmes**			
			Individual assessment	26	38	
Youth involvement			Questionnaires	24	35	
Programme development	46	68	Observation	20	30	
Advisory boards	15	22	Periodic reports	13	19	
Peer counsellors	15	22	M&E framework	12	18	
Outreach to schools	9	13	Quantitative	20	30	
Volunteer staff	9	13	Dialogue/feedback	10	15	
Press/speaking	4	6	Pre/post surveys	2	3	
Improving quality & coverage			**Remaining research questions**			
Funding	53	78	Effectiveness	14	22	
Trained staff	30	45	Disclosure	10	16	
Materials/guidance	22	33	Stigma	10	16	
Motivating youth	15	24	Adherence	9	14	
Capacity-building	11	16	Behaviour change	9	14	

* *N*=68, multiple responses allowed so per cents do not add up to 100%.

In the United States, issues around school performance and school drop-out were discussed more frequently than in other regions.

Organisational objectives

As shown in Table 3, the outcomes organisations strive to achieve resonate with the problems they recognise as priority challenges for YPLHIV. Outcomes vary by the age of population served. Key outcomes include prevention, such as prevention with positives and prevention of risk-associated behaviour, disclosure, coping with stigma and discrimination and helping YPLHIV achieve financial and social independence. Improved adherence and prevention are organisational objectives for all age groups. However, those organisations working with 15 - 24-year-olds were more likely to respond that their main objectives are helping youth achieve independence and transition into adulthood.

Psychosocial support services

Three-quarters of the organisations provide some form of individual or group mental health support. Individual therapy includes psychotherapy, cognitive behavioural therapy and individual counselling. Organisations providing substance abuse counselling and partner counselling primarily serve adolescents who contracted HIV behaviourally.

Information and education interventions mostly encompass topics such as sexual and reproductive health, positive prevention, nutrition, HIV knowledge and developing life-skills. Organisations making referrals typically collaborate with agencies providing primary and mental health care services, legal advocacy, immigration services and vocational rehabilitation. Those providing educational support have tutoring programmes, scholarship opportunities for continuing education, course offerings at local schools and training centres, and education reintegration interventions. Primary health care services include the distribution of HAART, physiotherapy, occupational therapy and sexual and reproductive health services.

When looking at service provision across age groups, the data change only slightly, and the changes reflect accurately the different needs of younger and older YPLHIV. For example, most of the organisations working solely with 10 - 14-year-olds work closely with the adolescents' families through family interventions, family therapy and support groups for parents and caregivers. For the most part, these organisations serve youth who were born with HIV. This means that the youth and their family members, some of whom are also likely to be infected with HIV, have been involved with the health care system for many years. None of the organisations working with young adults aged 20 - 24 offer family interventions (data not shown). Equally, while recreational activities such as summer camps, social outings, dance, yoga, arts and crafts are provided for groups between the ages of 10 and 19, none of the organisations providing support solely for 20 - 24-year-olds provides such activities. These organisations provide partner therapy, employment support, instrumental support such as housing, education support, case management and substance abuse counselling (data not shown).

Programme effectiveness

All of the participating organisations monitor and evaluate their programmes. Based on their records, observations and experiences, they were asked to comment on which of their programmes were most effective in reaching their organisational goals, and which were least effective. Overall, the activities and strategies that organisations said were most effective fall into three broad themes: (*i*) therapeutic support, (*ii*) youth-centered approaches and (*iii*) achieving independence (Table 3). Organisations stressed the importance of utilising a multidisciplinary team, including primary and mental health care professionals, social workers, and peer advocates. Engaging professionals from diverse cultural backgrounds, creating strong networks of professionals both within organisations and with outside agencies, and establishing clear and robust communication pathways are crucial in providing comprehensive care. Youth leadership and the participation of young people in the planning, implementation and evaluation of programmes were stressed as crucial to ensuring that programmes adequately meet the community's needs. This includes conducting needs assessments with the population, incorporating models of peer leadership and support, and creating accessible feedback platforms so that young people can safely and effectively contribute toward the evaluation of programmes. In addition, participants stressed that effective programmes are led by service providers who are empathetic, non-judgmental and culturally competent. In order to help youth achieve independence, effective programmes support youth with adherence and disclosure, and provide educational support and life-skills training. Twenty-two per cent of organisations said that information-only services are not effective (data not shown). These include interventions that do not address attitude and behaviour change, and which are not complemented by interactive learning, individual and group support or life-skills education.

Organisations working specifically with perinatally infected youth stressed the importance of social worker involvement, while those working with young people infected during adolescence identified educational support and case management as most effective. Service providers based in health clinics recommend individual psychological assessments and professional mental health support, collaboration with services outside the clinic and strong referral networks. Service providers based in community sites instead stressed the importance of providing and exchanging up-to-date and accurate information with one another and with young people, as well as being flexible, culturally competent and empathetic toward the population with whom they are working.

Guidance for policy makers

Close to half of the organisations said that policy makers need better understanding of adolescent development in the context of HIV. This includes the recognition that adolescents' needs differ from those of children and understanding the developmental impact of HIV on young people. It includes knowing the facts about HIV, understanding the impact of existing guidelines and regulations on young people's ability to access services, and understanding how their social environments influence their ability to cope and live with the virus. Organisations stressed that a better understanding

of these issues will help policy makers foster a deeper appreciation of psychosocial support as a *necessity* to caring for YPLHIV, rather than a luxury.

A further 25% of organisations responded that funding and sustainability are crucial for public policy. This includes long-term commitments to funding, understanding that psychosocial health is not a short-term outcome for anyone living with HIV. Organisations need time if they are to produce significant results. Organisations also highlighted the need for policy surrounding improved access to treatment and health services, including psychosocial support services. For example, many US-based organisations lamented that cuts in health spending at the state level nearly always result in the elimination of psychosocial support services first. This breaks down institutions' abilities to provide a holistic package of support. In addition, organisations noted that fair policies surrounding sex education in schools, and more specifically how HIV/AIDS is taught, are paramount to overall education of young people and breaking down social stigma. Stigma in health care and the workplace was identified as a problem that policy makers can help tackle by creating and enforcing legislation that protects people from discrimination.

Youth involvement and evaluating programmes

All of the participating organisations involve young people in various areas of programme development, implementation, evaluation and outreach. This includes needs assessments, focus groups, advisory boards, awareness raising and public speaking (Table 3).

All of the organisations have some monitoring and evaluation mechanisms in place, with the majority using multiple approaches. Individual assessments such as one-on-one interviews, checklists and home visits are used alongside quality-of-life and patient satisfaction questionnaires, and the generation of periodic reports.

Organisations also measure quantitative data, including school attendance records, exam scores, grade completion, number of referrals made, CD4 count, viral load and chart reviews. Others use informal dialogue, suggestion boxes and focus groups to provide feedback on interventions. Two organisations monitor their health workers through pre- and post-training surveys.

Improving quality and coverage

Organisations face major gaps in funding, staff training, and programme support materials, all of which would help them to improve the services they provide. They emphasised that the lack of trained staff results in less time spent with young people, staff burnout, the unavailability of trainers to train others, and the lack of good professionals that want to work with adolescents, as well as want to work with HIV. Maintaining youth involvement is a major challenge, especially as there is evidence suggesting that youth participation is a must for effective service provision. Organisations find great difficulty in keeping young people motivated to attend health services and support groups, stay in school, or seek jobs. They stress that young people are often complicated and have a range of problems that are difficult to manage and resolve. They require long-term support but frequently move or disappear.

Organisations in Latin America particularly stressed the need to overcome myths and taboos associated with HIV in the health care and workplace settings, as well as wider society. In the US, particular attention was paid to the lack of caregiver support at home as a major obstacle to providing high-quality psychosocial support for YPLHIV.

Remaining research questions

Providers would like further research on the effectiveness of psychosocial interventions for YPLHIV, in order to develop tools and resources. They also want research about disclosure, including barriers to disclosure. Other areas of research they recommend are treatment adherence, to help understand the link between age and adherence, and stigma and discrimination, including reducing workplace stigma. Lastly, respondents noted a need for research on behaviour change and positive prevention, including health-seeking and sexual health behaviour.

Discussion

HIV is now a chronic illness among adolescents and this study highlights key issues surrounding provision of psychosocial support as youth grow into adulthood. Overall, there is broad consistency regarding priority problems, effective approaches, challenges to service provision, and recommendations for policy and programming across organisations, geographic regions and groups of YPLHIV (i.e. age groups and age at transmission). It is clear from the data that the key challenges, goals and focus for organisations providing psychosocial support for YPLHIV are those that help this group of young people achieve:

- good health, including physical health achieved through adherence to medication, sexual health achieved through positive prevention and disclosure to partners, and mental health individual and group therapy
- independence, including school and/or employment integration through educational support, life-skills training, scholarship opportunities and career counseling.
- social integration through coping and life skills, leadership opportunities, peer mentorship, strengthening capacity and social networks.

While the experiences of a perinatally infected 13-year-old in Africa can differ greatly from those of a behaviourally infected 22-year-old in the USA, this study found that despite socio-environmental differences, the pillars on which psychosocial support interventions should be built are the same. Youth-centered, peer-led and purpose-built programmes that harness the creativity and energy of young people, coupled with the support of a diverse professional team that is empathetic and outcomes-focused, will result in improved access to care and improved overall health for YPLHIV. 'The philosophy of health-care delivery should evolve from an "acute and fix" model towards a coordinated comprehensive system of care' (Michaud, Suris & Viner, 2007).

For any chronically ill young person growing up through the health care system, a multidisciplinary team approach that combines continuity of primary health care with preventive intervention and confidential counselling is crucial for establishing long-term and trusting relationships with providers (Michaud, Suris & Viner, 2007, Hampson *et al.*, 2001). Organisations should look for ways

to collaborate further with professionals across the primary care, mental health, social services and legal sectors, as well as with peer groups, in order to strengthen their capacity to provide psychosocial support for YPLHIV.

> *As long as HIV is targeted alone, or in a disease prevention framework, we will not consistently engage young people, get broad uptake of HIV testing, or high programme adherence.* (USA)

Programme support materials such as training manuals, programme curricula, guidebooks and checklists should be designed for use by people with a range of professional backgrounds and shared across the health sector so that they can be adapted for programmes in different countries and settings. WHO, UNICEF and partner organisations should continue to develop programme and capacity-building support tools along the lines of those that have already been developed (for example the adolescent module for inclusion in the IMAI-IMIC [Integrated Management of Adolescent and Adult Illness; Integrated Management of Childhood Illness] Basic HIV Care with ART and Prevention training course), in order to improve staff capacity and strengthen the quality of programmes.

However, such approaches need to be tailored to the reality of different settings and may be particularly challenging in resource-poor settings. For instance, organisations in non-industrialised countries do not have the human or technological capacity to test and treat neurocognitive delays. Organisations in the US were the only ones to identify neurocognitive development and learning delays as problems they address through their service provision, but are also the only organisations in the study population who said they were testing for neurocognitive ability. Involving youth in programme planning and implementation will help organisations take the resources that are developed and adapt them for the specific needs of the population they serve.

While YPLHIV can benefit from successful interventions for youth with other chronic illnesses, particularly those that incorporate peer support and youth-led approaches (Michaud, Suris & Viner, 2007), the differences in how an HIV diagnosis affects the health and well-being of a young person, versus any other chronic disease diagnosis, cannot be overlooked. The pervasive stigma and discrimination that YPLHIV face, or at least perceive, leads them to isolate themselves and often develop high-risk behavior, including non-disclosure to partners.

> *Stigma associated with the disease is the major obstacle. In our society HIV is generally associated with unsafe sex practices and sex before marriage is considered a taboo. Due to this, the adolescents do not disclose their status nor come forward to access services, making the situation much worse.* (India)

Youth therefore have to be provided with safe and supportive environments that are youth-friendly, confidential and allow them to help determine how their treatment, care and support are delivered. This includes creating a positive image of the health-care system and making services look attractive to young people. In addition, having drop-in centres, short waiting times, easy registration processes and the active participation of young

people in designing the support environment are useful tools for engaging youth and retaining them in services. When young people feel more connected to an agency, they are more likely to seek peer and professional support. Increased confidence then leads young people into leadership opportunities provided by the agency (Wright & Draiman, 2000). Programmes must address a balance between the challenges adolescents face and the strengths they possess to increase resilience and live healthy lives.

Organisations should use the evidence from this review, in combination with their own data and research, to strengthen advocacy for YPLHIV, to raise awareness, generate political commitment, ensure that there are supportive policies in place and generate the funds necessary to help YPLHIV reach their full potential. Further efforts should be made to engage YPLHIV in meetings and conferences that give them a forum to gain peer support and tools for communicating their messages about living with HIV, as well as a voice that is often under-represented among health and policy experts.

Last, it is clear from the responses that many organisations working with YPLHIV feel relatively isolated. There is a need for better information exchange among them, particularly around sharing best practices and collaborating on projects.

> *Researchers need to focus on codifying 'best practice' rather than looking for rigorous outcomes in an area that is unlikely to yield definitive findings. The landscape is so complex, it is more fruitful to engage in qualitative inquiry and rigorous description with an eye to making 'best practice' strategies adaptable to other cultures.* (USA)

This review is the first step in providing a synthesis of the work that is being done and the development of a working collaboration of organisations involved in providing psychosocial support for YPLHIV.

Strengths and limitations

The generalisability of this study's findings is enhanced by the high response rate. The consistency of themes and key points for action across different types of organisations and different groups of YPLHIV forms a potential consensus for developing model practices. Finally, the diversity of geographic and organisational responses enhances the richness of the data.

There are also limitations to the research. First, it includes only a sample of organisations working with YPLHIV and it is not a census. Using a snowball approach to identify organisations inevitably left some out. Details about the types of organisations that responded (e.g. government, non-government, religious, etc.) were not collected. Second, it was not possible to stratify the responses to reflect gender differences, differences in sexual orientation, or routes of transmission for those infected during adolescence. Third, the review reflects the opinions of organisations working with YPLHIV, rather than of the young people themselves. No statistical significance was tested because the numbers were too small. Last, with the survey tool used, respondents could interpret questions differently from investigators and the investigators could interpret the responses differently from what was intended. We made every

effort to reflect the voices of the responding organisations as accurately and comprehensively as possible.

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