

A qualitative review of psychosocial support interventions for young people living with HIV



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Acronyms and abbreviations

AIDS	acquired immunodeficiency syndrome
GYCA	Global Youth Coalition on HIV/AIDS
HAART	highly active antiretroviral treatment
HIV	human immunodeficiency virus
NGO	nongovernmental organization
OVC	orphans and vulnerable children
UNICEF	United Nations Children's Fund
WHO	World Health Organization
YPLHIV	young people living with HIV

Executive summary

Adolescence being the difficult age that it is, the teenagers [living with HIV] encounter difficulties of a more personal nature such as self-awareness, defining their identity, building their peer group, making plans for the future, dealing with their sexuality. Generally, taking the step from childhood to adulthood is hard in more ways than one and generates inner conflicts materialized in confusion, identity crisis, stress, etc. From this point of view, they are not different from any other normal teenager. (Survey response from Romania)

The increasing effectiveness and availability of highly active antiretroviral treatment (HAART) during the past decade has resulted in the survival into adolescence of thousands of children born with human immunodeficiency virus (HIV) who would otherwise have died in childhood. At the same time, despite growing awareness about effective interventions to prevent HIV transmission among young people, they still make up 45% of new transmissions worldwide. Whether infected during the neonatal period or during adolescence, young people living with HIV (YPLHIV) have unique and pressing psychosocial needs on top of the daily challenges of being an adolescent. In the absence of empirical data, and confronted by a disease whose implications change constantly, this review explores the interventions that organizations are implementing around the world to provide psychosocial support for YPLHIV and synthesizes their recommendations for future interventions.

When comparing young people from different parts of the world, in different age groups and with different modes of acquisition, the results of the review indicate that there appears to be far more consistency than disparity in terms of their problems and needs. Adherence to medication, disclosure of HIV status, issues relating to sex and lack of support networks are problems faced by all YPLHIV. The majority of organizations use a multidisciplinary 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-centred and youth-led approaches that engage young people in the planning, implementation and evaluation of programmes. Respondents 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. Lastly, respondents argue that in order for their organizations 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 funders.

Background

Treat young people as young adults, not big children. (Survey response from the United Kingdom)

Young people aged 10–24 years make up one of the most vulnerable, yet overlooked, populations affected by the human immunodeficiency virus (HIV) pandemic. Forty-five per cent of new transmissions take place among this group (1), and there are currently an estimated 5.4 million young people living with HIV worldwide.¹ The continued spread of new infections, coupled with the increased accessibility to highly active antiretroviral treatment (HAART) and the subsequent longer survival of children infected during pregnancy, birth and the first year of life, means that the number of young people living with HIV is likely to significantly rise over the next 10 years. It is clear that health-care providers and policy-makers must be able to respond to the specific needs of this group of people living with HIV, needs that differ in a number of ways from those of small children or adults.

The Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV, sponsored by the World Health Organization (WHO) and the United Nations Children’s Fund (UNICEF) in Malawi in November 2006 acknowledged that “lack of psychosocial support” is one of the eight priority challenges for young people living with HIV (YPLHIV) to which the health sector should respond (1). The report from the consultation states: “The development of guidance to address the psychosocial needs of young people living with HIV is long overdue. Once this is developed, it can be adapted at the country-level as a training manual, in order to create or strengthen staff capacity to provide psychosocial support for young people through HIV care facilities” (1). This qualitative review is intended to highlight and synthesize some of the expertise and experiences of the people and organizations working with YPLHIV.

Literature review

Since the early 1990s, a number of studies have been published on the psychosocial implications of HIV in children and adolescents. Far fewer have analyzed the interventions designed to provide psychosocial support for YPLHIV in order to help them improve treatment adherence, strengthen their capacity to deal with disclosure and stigma, and prevent high-risk behaviours. A recent review of the literature concluded that little of the existing published research on interventions for psychosocial support focuses specifically on young people aged 10–24. Most cited interventions focus on children under the age of 10, family units, or the HIV-negative children of HIV-positive

¹ There are currently no good estimates or projections of the number of adolescents aged 10–14 years living with HIV.

parents. Of the seven journal articles found in the search of both published and gray literature,² only one commented specifically on youth, rather than young children.

In their studies of clinical opportunities for YPLHIV, Wright and Drainin (2) write that individual counselling is just one forum where young people can gain support. Youth-centred programmes offering a non-threatening atmosphere and opportunities for participation are crucial. They argue that when children feel more connected to an organization, they are more likely to seek peer and professional support. Increased confidence can then lead young people to become involved in a range of activities provided by the organization, including peer mentoring, community service and community outreach programmes. In addition, collaboration with other agencies can help relieve the isolation experienced by young people. The authors conclude that programmes must address a balance between the challenges adolescents face and the strengths they possess to increase resilience and live healthy lives.

The lack of robust, evaluated data reflects the complexity and sensitivity of working with adolescents and HIV, as well as the difficulty in conducting intervention research on this topic. Although very little has been published, it is clear from much anecdotal evidence that psychosocial support for YPLHIV *is* being provided by many organizations in many countries.

² See Appendix B for the full literature review.

Objectives

The Department of Child and Adolescent Health of WHO undertook, in collaboration with the Health and HIV departments of UNICEF in New York, a review of interventions for providing psychosocial support for YPLHIV. Drawing on information from key players and organizations around the world, the study investigated:

- what organizations are doing to provide psychosocial support for YPLHIV;
- the major problems faced by YPLHIV and the obstacles organizations must overcome to meet the needs of YPLHIV;
- specific outcomes that the organizations are trying to achieve;
- lessons learnt (what works and what does not);
- policy and programme recommendations;
- research questions that remain unanswered.

Eligibility

Psychosocial support is a complex term that means many things to many people. In our cover letter to respondents we asked them to report on programmes that provide support for:

- informing the newly diagnosed adolescent of an HIV-positive test result;
- preparing for and assisting with the disclosure of HIV status on the part of the adolescent to family members, peers and other people that the adolescent may feel a need to share this information with;
- assessing and assisting with maximizing adherence to medication and overall medical care in the adolescent patient;
- addressing feelings of isolation and other related emotional distress;
- addressing needs associated with emerging sexuality, including mechanisms for communicating HIV status to partners and avoiding high-risk behaviours.

For the purpose of the study, we excluded interventions that exclusively provide medical and psychiatric treatment for disorders of an organic nature but did include organizations that implement such activities as part of a broader package of psychosocial support.

Methods

Data collection

A questionnaire comprising 15 semi-structured, open-ended questions was developed and pilot-tested by colleagues at WHO, UNICEF and selected partner organizations. The questionnaire was translated into Spanish for organizations in Latin America. Using a snowball sampling approach, contact was made with a database of 200 nongovernmental organizations (NGOs), international multilateral agencies, adolescent sexual health clinics, academics, researchers, and primary health-care providers in order to identify eligible organizations to participate in the study. Every organization identified as being appropriate to take part in the review was e-mailed a questionnaire and given a deadline to respond. Additional contact was made with the organizations if they did not reply as requested, by e-mail and, where necessary, by telephone.

The majority of participants completed the questionnaire via e-mail. Two sent their responses by post, and four conducted phone interviews with the principal investigator. The responses that were received in Spanish from Latin America were translated by the principal investigator and then cross-checked by a native Spanish speaker.

Data analysis

Once all of the questionnaires had been collected, the responses were coded by specific themes. Five to six codes for broad themes and 10 to 25 subthemes were created for each question, to reflect the detail of the responses from the participating organizations. For example, the responses to the request “Briefly describe the major problems faced by young people living with HIV for which they require psychosocial support” were divided into five broad themes: (1) “living with HIV”, (2) “sexual health”, (3) “managing stigma and discrimination”, (4) “being at risk”, and (5) “mental health”. The category “living with HIV” was then further subdivided into “professional integration”, “social integration”, “coping”, “transitioning to adulthood and achieving independence”, “adherence to medication”, and “disclosure”.

In addition to analyzing the responses by hand, ANTHROPAC computer software, designed for analyzing anthropological data, was used to quantify the frequency with which each code appeared, the percentage of respondents mentioning that code, and each code’s salience, or frequency weighted by ranking. The data were also used to investigate correlations based on geographical region, mode of acquisition and age.

Results

Respondents

Of the 200 initial contacts made, 86 organizations were identified as being eligible for participation in the review, and 69 of the 86 questionnaires sent to these eligible organizations were completed and returned. One was rejected because it did not comply with the eligibility criteria, leaving 68 of 86 questionnaires (79%) completed and returned.

Responses by region

The majority of questionnaires (24, 35%) were from organizations in the United States of America. Ten (15%) were from Romania, the only country in eastern Europe from which organizations returned the questionnaire. Nine (13%) were returned from South America, eight (12%) from both Africa and western Europe, and six (9%) from Asia. Two of the questionnaires were from organizations working in Central America and the Caribbean, and there was one from Iran, representing the Middle East region.

Mode of acquisition

Twenty-one (31%) of the organizations work exclusively with young people who contracted HIV at birth, and seven (10%) work exclusively with young people who were infected during adolescence. The majority (28, 41%) of respondents work with both groups, while 6 (9%) indicated that they work mostly with those infected perinatally, 3 (4%) work mostly with YPLHIV infected during adolescence, and 3 (4%) were identified as “other” (all three organizations in this final group are in Romania and work with young people who contracted HIV during infancy through blood transfusions in hospitals).

Service providers

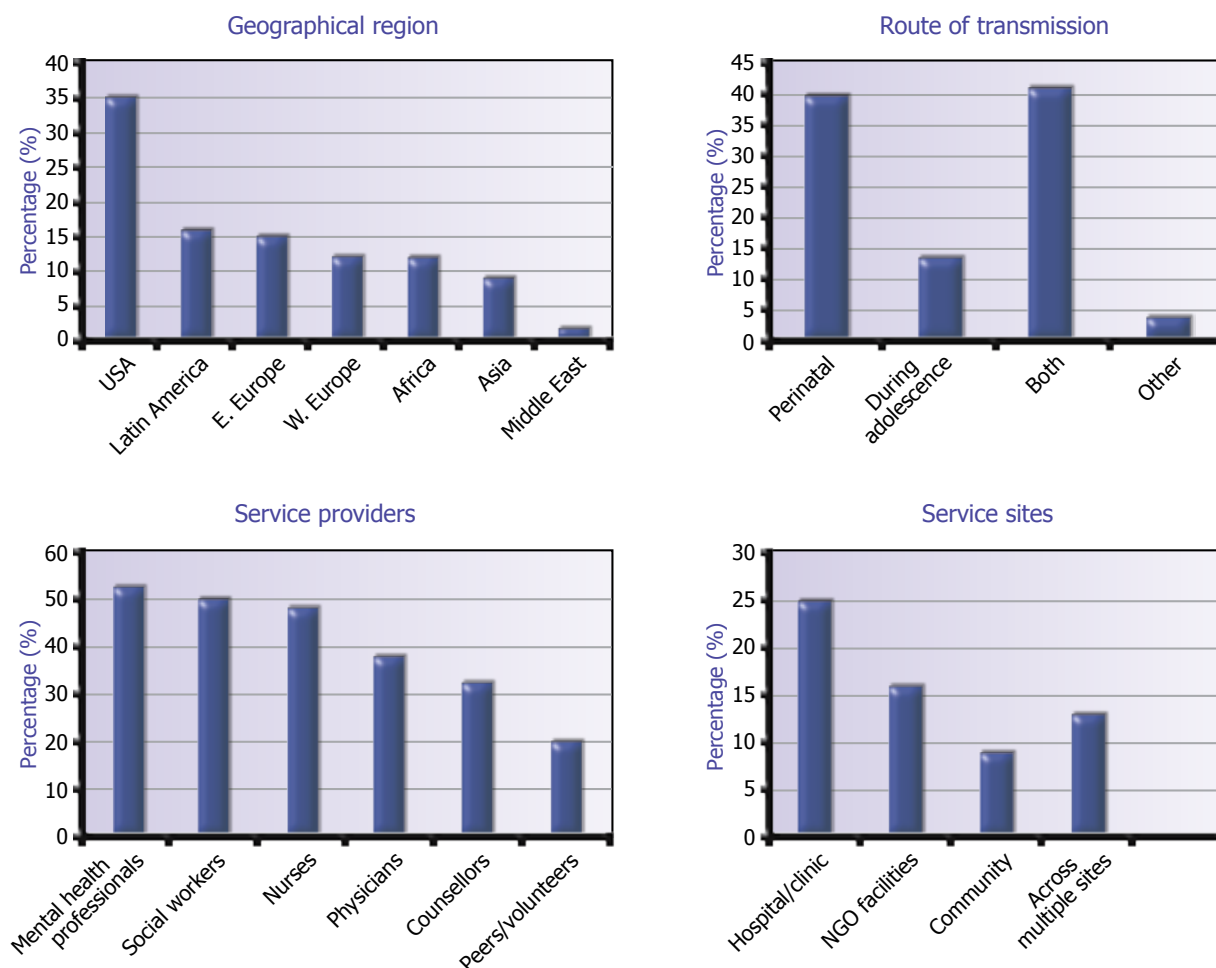
All of the organizations surveyed use a multidisciplinary approach to providing psychosocial support for adolescents living with HIV. The majority employ social workers (52%) and mental health professionals (54%) in addition to nurses (47%), physicians (38%), counsellors (34%), and peers or volunteers (21%).

Service sites

Twenty-five per cent of the organizations surveyed provide services from hospitals or health clinics, 16% provide services from the organization’s own office or site, and 7% provide services from both

a clinic and an office setting. Close to 9% of organizations provide their services from community sites such as community centres, churches and outdoor spaces. Thirteen per cent of the organizations provide services from both a clinic and a community site, and 10% provide services in community sites, clinics and home-based settings.

Figure 1. Breakdown of responding organizations



Responses to key questions

Question: What are the problems facing young people living with HIV for which they require psychosocial support?

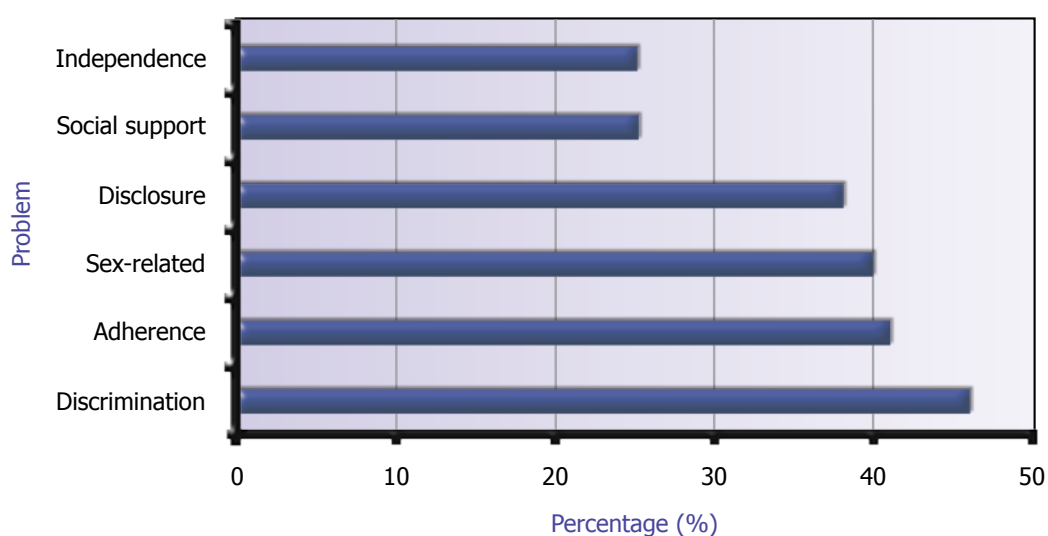
The shock of becoming HIV-positive is difficult to deal with for anyone, let alone an adolescent who is already experiencing developmental challenges of adolescence and young adulthood. (Survey response from the United States of America)

Overall, adherence to medication; disclosure of HIV status; issues relating to sex, stigma and discrimination; and lack of support networks were the problems most often described by respondents. Adherence was listed in 41% of the responses and also carries a salience of 41%. Responses coded as

“adherence” also included difficulty with pill swallowing, readiness to take medication for the newly diagnosed, taking medication in front of people, ambivalence about medication, and treatment failure.

Working toward adherence to different treatments is our principle objective but we know that in order to achieve it, we cannot focus on treatment alone. Rather, emotional containment, social inclusion and the development of life projects are pillars in improving the biopsychosocial health of these children and adolescents affected by HIV. (Survey response from Argentina)

Figure 2. The problems facing YPLHIV for which they require psychosocial support



Stratification by mode of acquisition

Of the 24 organizations working with young people who were infected perinatally or in early childhood, 18 (75%) listed adherence as one of the most important problems, often listing it first. Only two of the organizations working with young people infected during adolescence (29%) listed adherence to medication as a major problem. These numbers probably reflect the number of young people currently on medication, as it is more likely that young people who are perinatally infected are taking medication than those infected during adolescence, many of whom are likely to require treatment only later in life as their disease progresses.

Not surprisingly, 89% of the organizations listing adherence as a major problem faced by YPLHIV also listed “improved adherence” as an outcome that they are trying to achieve through their psychosocial interventions. Seventy-five per cent of those organizations provide their services from a hospital or clinic.

Disclosure was mentioned by 26 organizations overall (38%), with 9 organizations listing disclosure to friends, 9 listing disclosure to partners, 4 listing disclosure to family members and 1 listing a general fear of disclosure. One organization specifically mentions the difficulties faced by young people as they themselves learn about their HIV status, and one organization speaks to the difficulties faced by young people when first “coming out”.

The adolescents suffer anxiety on what the future holds for them. They often question “Will I ever have a lasting and meaningful relationship (sexual)? How will I initiate such a relationship? Will my partner still love me despite my HIV status? Will I be able to have children of my own?” (Survey response from Kenya)

Forty per cent of the respondents listed various issues that relate to sex. Sixteen organizations (24%, 16%)³ described problems with relationships, and 15 (22%, 11%) mentioned issues relating to having sex. Twelve respondents (18%, 14%) listed concerns around sexuality, and two (3%, 1%) mentioned issues concerning condom use. Forty-six per cent of organizations listed stigma and discrimination as major problems faced by YPLHIV. Respondents additionally specified where discrimination most commonly takes place: 9 (13%, 13%) listed discrimination in school, 6 (9%, 8%) listed discrimination in the family, 3 (4%, 3%) listed discrimination in the community, 4 (6%, 2%) listed discrimination at work, 2 (3%, 1%) listed discrimination in health-care settings, and 2 (3%, 1%) listed discrimination by peers.

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. (Survey response from India)

Twenty-five organizations (37%) said that the lack of support networks is one of the major problems for YPLHIV. Of these, nine (13%, 7%) specified the lack of family support.

In addition to these five priority areas, the challenges of achieving independence and mental health problems were frequently identified as being important areas for action. Achieving independence is a broad theme that encompasses social integration (25%), professional integration (21%), coping (18%), and transitioning to adulthood and adult health care (6%). Mental health problems were also listed as major problems faced by YPLHIV, most notably depression and anxiety (25%), followed by bereavement and fear of dying (15%), and poor cognitive development (10%).

Problems across the regions

When looking at the responses to these questions across geographical regions, there are many similarities and only a few differences. For example, all of the regions are working with problems such as stigma and discrimination, lack of support networks, problems with disclosure, managing relationships, and anxiety about having children. YPLHIV are struggling in almost all of the regions with coping skills, issues relating to sex, bereavement and isolation.

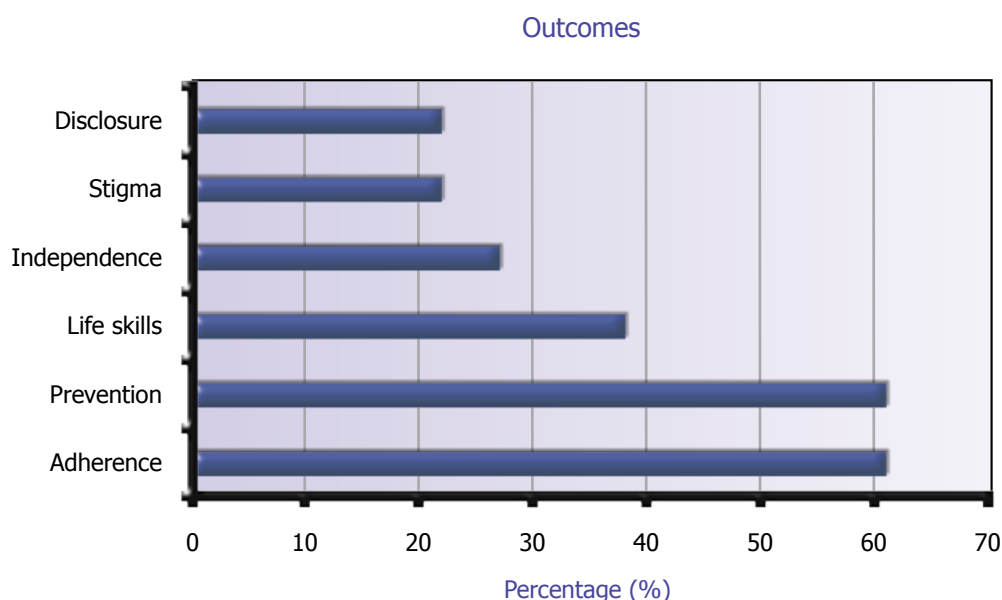
³ Where two percentages appear together in parentheses, the first is proportion and the second is salience.

There are, however, a few key differences that should be highlighted. For example, organizations in Africa were the only respondents who indicated that heading households is a serious problem for YPLHIV. In eastern Europe, the overwhelming response is that motivating YPLHIV to integrate socially and professionally within society and to access health and support services is the largest problem that they face. In the United States of America, issues around school performance and dropping out of school are listed far more frequently than in other regions, and only in the United States of America are issues of neurocognitive development and learning delays listed as major problems.

Question: What outcomes are you trying to achieve for young people living with HIV through your interventions?

Sixty-one per cent of respondents said that improved adherence is the major outcome that they are trying to achieve. Adherence had a salience of 50% in answer to this question. The same proportion of respondents also said that prevention is a key outcome of their interventions. In the analysis, the theme of “prevention” included responses mentioning positive prevention, sexual health and preventing high-risk behaviours. Thirty-eight per cent listed coping and life skills, while a further 27% listed achieving independence. Twenty-two per cent of organizations said that disclosure is a key outcome, while another 22% mentioned coping with stigma and discrimination.

Figure 3. Targeted outcomes for YPLHIV



Outcomes stratified by age

When broken down by age, adherence was mentioned by 15 organizations (37%) working with the 10–19 age group, 11 organizations (27%) focusing primarily on 15–24 year olds, and 15 organizations (37%) working across all ages. Positive prevention was listed by 14 organizations (34%) working with the 10–19 age group, 15 organizations (37%) working with the 15–24 age group, and 14 organizations (34%) working with both age groups.

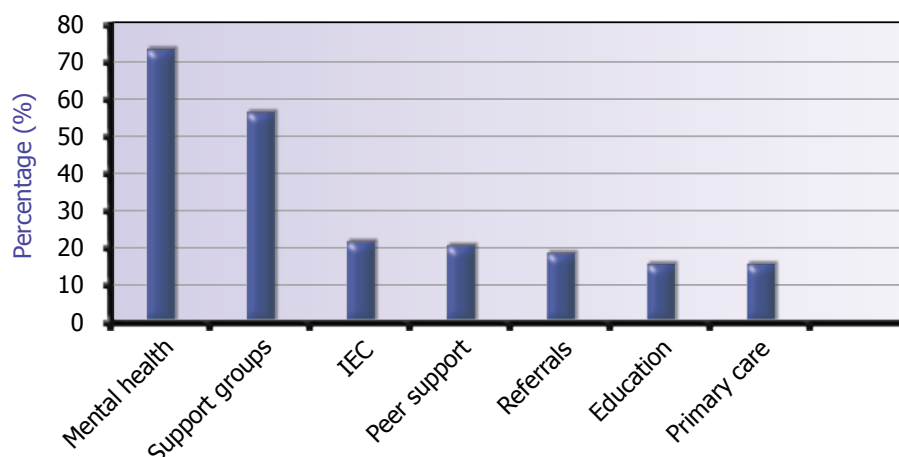
Achieving independence was highlighted as a key outcome by 5 organizations working with the 10–19 age group (28%), 15 of those working with the 15–24 age group (83%), and 14 working with all age groups (78%). Seven organizations from the 10–19 age group (47%), 4 organizations from the 15–24 age group (27%), and 6 organizations working with all ages (40%) listed disclosure support as a key outcome of their work. Lastly, 6 organizations working with 10–19 year olds (40%), 8 organizations working with 15–24 year olds (53%), and 7 organizations working across all ages (46%) focus on helping young people cope with stigma and discrimination.

Question: Please describe what your organization is doing to provide psychosocial support for young people who are living with HIV.

A large proportion of organizations (75%) provide mental health support for YPLHIV. This includes 43 (64%, 35%) providing individual therapy and another 15 organizations providing family and partner counselling. Individual therapy was coded broadly to include psychotherapy, cognitive behavioural therapy, and counselling, including substance abuse counselling. Thirty-eight organizations (57%) provide support groups for YPLHIV and another 14 (21%, 10%) listed peer support as part of their service provision. Peer support was kept as a separate theme because it could relate to either or both individual and group support.

Fifteen organizations (22%) provide information and education workshops on topics such as: sexual and reproductive health, positive prevention, psychoeducation, nutrition, HIV knowledge and life skills. Thirteen organizations (19%) collaborate with and provide referrals to other social service agencies such as mental health workers and primary care providers, as well as link with legal advocacy services, immigration services and vocational rehabilitation. Eleven respondents (16%) provide education support through tutoring, scholarship programmes for continuing education, opportunities to take classes at local schools and training centres, and education reintegration interventions. Another 11 organizations provide primary health-care services including the distribution of HAART, physiotherapy, occupational therapy, and sexual and reproductive health services.

Figure 4. Psychosocial support provided for YPLHIV



Service provision across age groups

When looking at service provision across age groups, the data changes only slightly, and the changes reflect accurately the different needs of younger and older YPLHIV. For example, most of the organizations 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. None of the organizations working with young adults, aged 20–24, list family interventions in their service provision.

Equally, while recreational activities such as summer camps, social outings, dance, yoga, and arts and crafts are provided for groups between the ages of 10 and 19, none of the organizations providing support solely for 20–24 year olds provides such activities. These organizations provide, rather, partner therapy, employment support, instrumental support such as housing, education support, case management, and substance abuse counselling – services that are not usually provided by organizations working with 10–14 year olds.

Question: What programmes or elements of programmes supported by your organization have been most effective in providing psychosocial support for adolescents living with HIV?

The respondents’ perceptions of the most effective interventions and strategies fall into three broad themes: (1) therapeutic support, (3) youth-centred approaches and (3) achieving independence.

Within therapeutic support, support groups are mentioned by 25 organizations (38%), and individual therapy and support is mentioned by 18 organizations (27%). In terms of group approaches, there is no complete consensus on effective group size. One organization has found that larger groups are most effective, while another organization says that smaller groups are better. Utilizing a multidisciplinary team approach is listed by eight organizations (12%). These organizations stress that the various types of support need to complement one another in order to

provide an effective service, and that it is important to use a team of people from diverse professions and cultural backgrounds. This approach includes creating strong networks of professionals both within organizations and with outside agencies and health services, as well as establishing clear and robust communication pathways in order to provide comprehensive care.

In the context of youth-centred service provision, 10 organizations (15%) say that services must be participatory and 6 (9%) stress that they must be youth-friendly. Some organizations mention PhotoVoice and art therapy, while others emphasize youth involvement in programme planning, implementation and evaluation.

Achieving independence includes adherence and disclosure support (5%), educational support (5%), life skills training (8%) and prevention (3%).

Effectiveness stratified by mode of acquisition

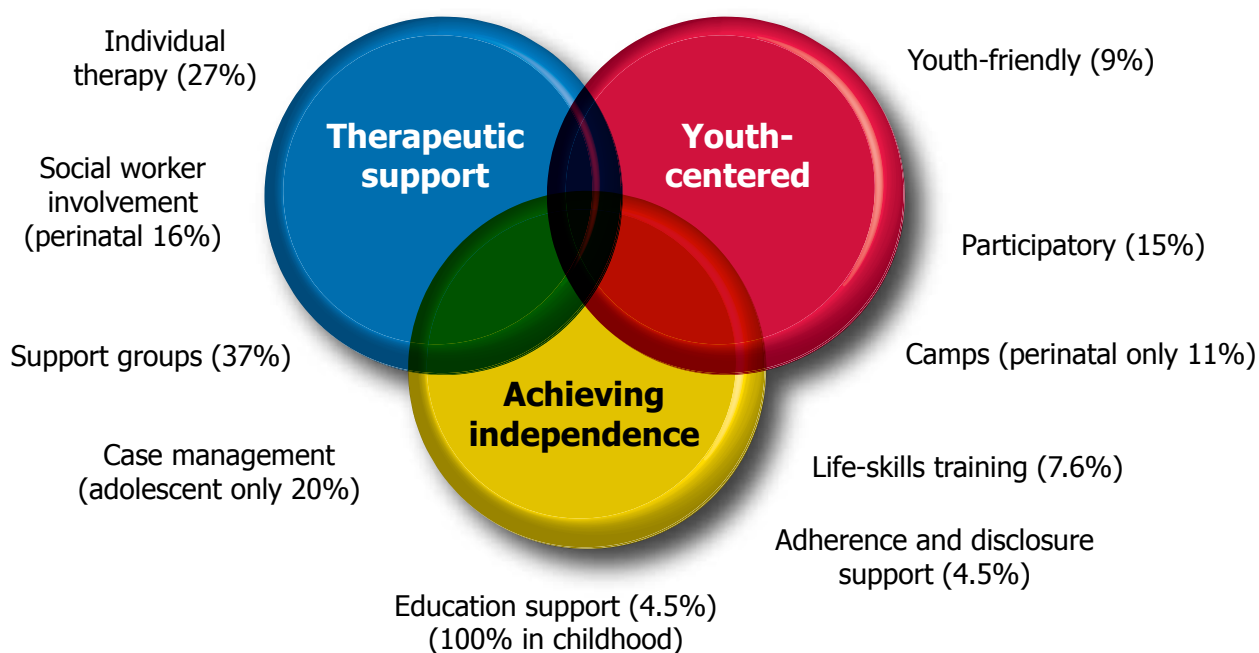
The responses to this question were stratified by mode of acquisition: HIV acquired perinatally or HIV acquired during adolescence. For the purposes of this analysis, organizations working with both groups but mainly with perinatally infected YPLHIV were clustered with the perinatal group, and similarly for adolescence. HIV acquired during early childhood through blood transfusions was looked at separately.

All three of the groups highlighted the effectiveness of support groups, individual support and therapy, and life skills education.

Of the organizations working with perinatally infected young people, three (11%) said that summer camps or retreats are very effective. Camps were not mentioned by the adolescence group or the early childhood group. Three organizations in the perinatal group also highlight the importance of social worker involvement, something that is reflected in one of the three responses from the early childhood group but none from the adolescence group. Two organizations from the adolescence group (20%) highlight case management and advocacy services, mostly pertaining to social and legal support, and one organization (10%) mentioned the importance of reducing environmental barriers to accessing services. Barrier reduction is not mentioned by the perinatal group. All three organizations working with young people infected with HIV during adolescence emphasize education support services, including tutoring, scholarships and education reintegration, as being the most effective services they offer.

The knowledge that the children have acquired has provided them with the active tools of change, those which will be integrated into strategies that will enable them to become peer supporters. (Survey response from Venezuela)

Figure 5. Target outcomes for YPLHIV



Question: What programmes or elements of programmes supported by your organization have been least effective in providing psychosocial support for young people living with HIV?

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. (Survey response from the United States of America)

Of the 46 organizations that responded to this question, 10 (22%) listed information-only services. 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. In conjunction with this point, nine organizations (20%) recognized that services that are not youth-friendly and not participatory are not effective. Another five organizations (11%) listed direct mental health care including individual therapy, and four organizations (9%) mentioned the provision of generic services without clear objectives.

Ineffective interventions stratified by mode of acquisition

When stratified by mode of acquisition, three organizations from the perinatal group (11%) have found individual support and therapy ineffective, although this did not seem to be a problem for the other two groups. Two of the organizations in the perinatal group (7%) listed support groups as ineffective, but closer analysis reveals that these organizations had trouble motivating young people to attend support groups on a regular basis, suggesting that motivation to access services was the main obstacle to delivering group support, rather than the support groups themselves.

Question: What do you think are the three most important things that need to be included in any guidance on psychosocial support that is developed for service providers?

Remaining consistent with the responses to the previous two questions, 25 organizations (40%) responded that service providers must ensure that services are youth-friendly, are youth-led and involve young people at all levels of planning, implementation and evaluation. Eighteen respondents (28%) said that service providers need to be empathetic, non-judgmental and culturally competent in order to provide effective services. This includes providing confidential services, keeping flexible hours, and treating young people as young adults rather than as big children. Ten organizations (22%) emphasize the need for a multidisciplinary approach that includes people from primary care, mental health, social work, legal advocacy and peer groups.

Recommendations from different service sites

In looking at responses stratified by service sites (i.e. hospital or clinic, community site, NGO office), there are no major differences in the recommendations organizations make for service provision. All stress the importance of using a multidisciplinary approach with participatory planning, implementation and evaluation.

Service providers based in health clinics recommend the need for individual psychological assessments and professional mental health support more often than do service providers based in NGOs. Service providers based in health clinics also highlight the importance of collaboration with services outside the clinic and strong referral networks. Service providers based in NGOs and community sites stress slightly more than those in clinic-based settings the importance of providing and exchanging up-to-date and accurate information with one another and with the young people, as well as being flexible, culturally competent and empathetic toward the population with whom they are working.

Question: What do you think are the three most important things that need to be included in any guidance on psychosocial support that is developed for policy-makers?

Focus on effective actions, not on paperwork. It is still a disease of our society that paperwork is often more valued than actual activities. (Survey response from Romania)

Forty-five per cent of respondents say that policy-makers need better understanding of adolescent development in the context of HIV. This includes recognizing that adolescents' needs are different from children's 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. Survey respondents also stress that a better understanding of these issues will help policy-makers foster a deeper appreciation of psychosocial support as a *necessity* in caring for YPLHIV, rather than a luxury.

A further 25% of organizations answered that funding and sustainability issues are crucial for policy-makers to address. This includes making long-term commitments to funding and understanding that psychosocial health is not a short-term outcome for anyone living with HIV. Organizations need time if they are to produce significant results. Twenty per cent answered that improved access to treatment and health services is vital, including improved access to psychosocial support.

Thirteen per cent of organizations said that policy-makers must focus on addressing and combating HIV discrimination in health care, the workplace and society as a whole. Seven organizations (12%) stressed that sexual health education, particularly in schools, is a key issue for policy-makers to address.

Question: Please describe how you have involved young people living with HIV in the development and implementation of your activities.

All of the participating organizations involve young people in various areas of programme development, implementation, evaluation and outreach. Forty-six organizations (68%) involve youth in programme development through needs assessments, focus groups and creating programme support tools. Fifteen organizations (22%) have young people sitting on advisory boards, and 15 organizations also train young people as peer counsellors. Nine organizations (13%) have young people raising awareness in the community through campaigns and education in schools, including four organizations (6%) who involve young people in public speaking and press briefings. Nine organizations have young people volunteering as staff support.

Question: How do you monitor and evaluate your programmes that provide psychosocial support for adolescents living with HIV?

All 68 of the participating organizations have some monitoring and evaluation mechanisms in place. The majority of organizations use multiple approaches to ensure consistent and accurate outcome measurement. Twenty-six organizations (38%) perform individual assessments of young people. These include one-on-one interviews, checklists, follow-up and home visits. Twenty-four organizations (35%) use self-administered questionnaires, such as patient satisfaction and quality of life surveys.

Close to 30% of respondents monitor programmes through direct observation and site visits. Thirteen organizations (19%) generate periodic reports for their programme activities, which include monthly, quarterly and annual reviews of data collected by health workers, caregivers and programme staff. These reports also highlight field notes, journal entries and photography from the programme. Twelve organizations (18%) use a monitoring and evaluation framework based on those designed for clinical care, family planning and quality improvement.

Twenty organizations (29%) use quantitative data as part of their evaluation plan. These data include school attendance records, exam scores, grade completion, number of referrals made, CD4 count (a measure of immune system health), viral load and chart reviews. Ten organizations (15%) use informal dialogue, suggestion boxes and focus groups to provide feedback on interventions. Two organizations monitor their health workers through pre- and post-training surveys.

Table 1. Methods of monitoring and evaluating psychosocial support for YPLHIV

Questions and responses	Frequency	Percentage (%)
Q. How are YPLHIV involved in the development and implementation of activities?		
Programme development (e.g. needs assessments, focus groups, developing tools)	46	67
Participate on youth advisory board	15	22
Serve as peer counsellors	15	22
Community awareness raising	9	13
Staff support and/or volunteering	9	13
Public speaking and/or press interviews	4	6
Q. How do you monitor and evaluate programmes?		
Individual assessments	26	38
Self-administered questionnaires	24	35
Direct observation and/or site visits	21	30
Monitoring and evaluation clinical framework	20	29
Periodic reporting	13	20
Suggestion boxes and/or dialogue	10	15
Q. What are the most important research issues regarding psychosocial interventions for YPLHIV?		
Effectiveness of interventions	14	22
Disclosure, including barriers to disclosure	10	16
Stigma and discrimination	10	16
Treatment adherence	9	14
Behaviour change and positive prevention	9	14
Issues relating to sex and sexual and reproductive health	9	14

Question: What three things would most help your organization improve the quality and coverage of your psychosocial support interventions for adolescents living with HIV?

The overwhelming response to this question was funding. Seventy-eight per cent of respondents claim that with additional funding for programmes, staff, programme support materials, transportation, partnerships, housing, etc., they would vastly improve the quality and coverage of their services. Second to funding, the need for qualified and trained staff was highlighted in 30 responses (45%). Twenty-two organizations (32%) would like programme-support materials, including audio-visual materials and web-based information and training, and a further 11 organizations (16%) mention the need for stronger capacity building.

Question: What do you think are the major obstacles to providing psychosocial support for adolescents living with HIV?

The major obstacles that organizations report in providing psychosocial support for YPLHIV are lack of funding (25, 37%), lack of trained staff (16, 24%), lack of family and social support (13, 19%), motivating youth to stay involved (15, 24%) and the need for programme guidance and tools (8, 12%). Organizations emphasized 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 wanting to work with adolescents, as well as wanting to work with YPLHIV. Youth involvement is a major challenge, particularly with evidence suggesting that youth participation is a must for effective service provision. Organizations 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.

Question: What do you think are the most important research issues regarding interventions to provide psychosocial support for adolescents living with HIV?

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. (Survey response from the United States of America)

Fourteen respondents (22%) recommend that further research into effective interventions for YPLHIV is warranted in order to provide guidance. This includes updated tools and resources as well as evaluations of programme effectiveness. Ten organizations (16%) list further research about disclosure, including barriers to disclosure, and nine (14%) would like further research on treatment adherence, including understanding the link between adherence and adolescence. Ten organizations (16%) believe that stigma and discrimination are among the most important research issues, including how to address stigma in the workplace. Nine organizations (14%) listed behaviour change and positive prevention, including investigating health-seeking behaviour in young people, and nine organizations recommended further research into sexual and reproductive health and issues relating to sex among YPLHIV.

Strengths and limitations

This review is very strong in its response rate. Nearly eighty per cent of the organizations contacted returned the completed questionnaire before the deadline. The review provides a clear understanding of broad themes and key points for action, and overall was very consistent in its findings in terms of different types of organizations and different groups of YPLHIV. It provided a rich qualitative response from a wide range of people working directly with YPLHIV.

However, the review does have limitations. Firstly, it includes only a sample of organizations working with YPLHIV and is not a census. Using a snowball approach to identify organizations inevitably left some out. Secondly, it was not possible to stratify the responses to reflect gender differences. Thirdly, the review reflects the opinions of organizations working with YPLHIV, rather than of the young people themselves. Lastly, being a qualitative review, it has weaknesses as well as strengths, including the fact that respondents could interpret questions differently from investigators, and the investigators could interpret the responses differently from what the respondents had intended, though the principal investigator made every effort to reflect the voices of the respondents as accurately and comprehensively as possible.

Discussion

One of the most positive elements of this project was the enthusiasm and vigour with which organizations responded to the questionnaire. Not only did most of those contacted respond, but the majority of respondents also indicated the great need for this review and their plans to make use of the results.

Overall, there is broad consistency regarding priority problems, effective approaches, challenges to service provision, and recommendations for policy and programming across organizations, geographic regions and groups of YPLHIV (i.e. age groups and modes of acquisition). It is clear from the data that the key challenges, goals and focus for organizations 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 achieved through individual and group therapy;
- independence, including school and/or employment integration through educational support, life-skills training, scholarship opportunities and career counselling;
- social integration through coping and life skills, leadership opportunities, peer mentorship, strengthening capacity and social networks.

Youth involvement and the emphasis on providing youth-friendly and youth-led services indicate the direct psychosocial benefits that young people obtain from being given opportunities to express themselves and take part in the activities that meet their needs.

Drawing comparisons with psychosocial support for adolescents with chronic illness

HIV is now a chronic illness in adolescents, and there are a number of lessons from the general provision of psychosocial support to adolescents with chronic illness that can be adapted to meet the needs of YPLHIV. Equally, the lessons from working with YPLHIV will clarify and contribute to scaling up the whole area of psychosocial support provision for young people.

In their investigation of the effects of psychosocial support interventions for adolescents with diabetes, Hampson et al. (3) found that educational and psychosocial interventions have a small to medium beneficial effect on various diabetes management outcomes, and that interventions are more likely to be effective if they demonstrate the inter-relatedness of the various aspects of diabetes management. As this review's conclusions highlight, young people with HIV and other chronic illnesses benefit most when multidisciplinary forms of support are provided and when interventions are structured around a range of specific and inter-related outcomes.

In another study of psychosocial interventions for adolescents suffering from depression (4), cognitive behavioural therapy and interpersonal psychotherapy were found to be the most promising in reducing depressive symptoms in both adolescents and children. With a majority of organizations highlighting mental health as a priority challenge for YPLHIV, with specific emphasis on depression and anxiety, it would be useful for service providers to consider the integration of cognitive behavioural therapy and interpersonal psychotherapy with other evidence-based mental health interventions as part of their overall psychosocial support package.

In its report on adolescents with chronic illness, WHO stresses the importance of a multidisciplinary team approach that combines primary health care with preventive intervention and counselling (5). An integrated and coordinated set of interventions coupled with continuity of care and confidentiality are crucial to establishing long-term and trusting relationships with providers.

With regard to treatment adherence, the report states that patient education and self-care are the most promising facets of adherence interventions. When young people have information about their disease and the ways to control the treatment of it, they are more likely to engage with their treatment and comply with difficult treatment regimes. Peer support is found to be highly effective in helping young people adhere to treatment, as is a communication style that is open, straightforward and trusting.

Young people suffering from chronic illnesses benefit immensely from peer support, as well as from the type of support that self-help organizations offer. In addition, during the transition process from paediatric health care to adolescent and then adult health care, service providers should start communicating about the process with young people and their families early on. Supportive professionals should be identified who will assist the adolescent during these transitions and provide resources and information that will aid in the process.

The WHO report also stresses the importance of youth-friendly services and continuity of care. 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-setting environment are useful tools for engaging youth and retaining them in services.

Recommendations

Recommendation 1: Programme support materials 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. WHO, UNICEF and partner organizations should continue to develop programme- and capacity-development 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.

Recommendation 2: Organizations 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. However, such approaches need to be tailored to the reality of different settings and may be particularly challenging in resource-poor settings.

Recommendation 3: Guidance for improved monitoring and evaluation mechanisms should be developed and disseminated, including quantitative and qualitative approaches.

Recommendation 4: Organizations should use the evidence from this review, in combination with their own data and research, to strengthen advocacy for YPLHIV, in order 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.

Recommendation 5: It is clear from the responses to the questionnaire that many organizations working with YPLHIV feel relatively isolated. There is a need for better information exchange among them. This review is the first step in providing a synthesis of the work that is being done and a database of organizations that are involved in providing psychosocial support for YPLHIV. This database could form the foundation for a network of professionals working with YPLHIV, through which they can share ideas, experiences and current research.

Recommendation 6: 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 underrepresented at larger AIDS conferences and meetings.

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Appendix B: Literature review

Psychosocial interventions for young people living with HIV: review of the literature

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Introduction

Adolescents aged 10–19 years are among the most vulnerable, yet overlooked, populations affected by the human immunodeficiency virus (HIV) pandemic. The persistent spread of new infections among young people and continuing mother-to-child transmission, coupled with increased access to highly active antiretroviral treatment (HAART) for paediatric AIDS and the subsequent longer survival of those infected, means that 21.5 million adolescents will be living with the virus by 2010.

The Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV, sponsored by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) in Malawi in November 2006, highlighted the need to strengthen the provision of psychosocial support for young people living with HIV (YPLHIV) in order to improve adherence, strengthen their capacity to deal with disclosure and stigma, and prevent risk-associated behaviour. As a follow-up to the consultation, a comprehensive review of effective interventions for providing psychosocial support for YPLHIV has been called for.

Since the early 1990s, a number of studies have been published on the psychosocial implications of HIV in children and adolescents. Far fewer, however, have analyzed the interventions designed to help young people improve treatment adherence, strengthen their capacity to deal with disclosure and stigma, and prevent risk-associated behaviour. This literature review provides an overview of the existing literature documenting psychosocial interventions for YPLHIV, and offers an analysis of these studies including limitations, and recommendations for further research.

Literature review

In response to the unmet need for social support for children with HIV, Bacha et al. (1) conducted a pilot project to test the efficacy of a developmentally specific, psychoeducational group intervention for children with HIV. Information about HIV was combined with play therapy techniques in order to affect children on a cognitive and emotional level. The goals of the project were to increase self-esteem and feelings of self-control, as well as to alleviate hopelessness and depression. Secondly, the project aimed to help children gain a greater understanding of their illness. The project was carried out in a paediatric infectious disease clinic in Florida.

Caregivers noted overall satisfaction with the project and children's increased awareness of their illness. They also reported an increase in children's positive dispositions and a sense of "not being the only one". One limitation was the lack of pre-test analysis other than a short interview with caregivers and children following the programme. The authors do not provide the ages of the children involved, but we can assume they were younger than adolescent. Only six children participated, and no quantitative data were collected.

In their analysis of home-based treatment for children and families, Gewirtz and Gossart-Walker (2) argue that an ongoing relationship with the clinical team is crucial for children and parents to cope with the complicated implications of living with HIV. They write that "clinically informed case management services can offer respectful and thoughtful concrete help" and that "psychotherapy can offer the opportunity for children to pull together the often fragmented narratives of their family lives and integrate object loss to be free to continue on a normative developmental path".

Providing mental health services in the home ensures that the most vulnerable children are reached. Further, regular communication with other health-care providers (AIDS clinics and agencies, nurses, etc.) promotes a comprehensive and integrated environment where children do not fall through the cracks.

Gossart-Walker and Moss (3) write that the group dynamic is powerful for individual and collective healing. In their intervention, the authors found that children learned to cope with rage and sadness, particularly about the loss of their mothers. "Most interestingly, they all began to talk about their mothers and their early childhoods calmly, with a profound sense of connection with each other, even with silliness and age-appropriate fun," the authors report. Children used one another as sources of comfort. The authors argue that groups are an effective strategy for work with HIV-affected children in helping them deal with losses in their families and the issues of growing up.

In their studies of clinical opportunities for youth affected by HIV, Wright and Draimin (4) write that individual counselling is just one forum where young people can gain support. Youth-centred programmes offering a non-threatening atmosphere and opportunities for participation are crucial. They argue that, when children 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. These can include peer mentoring, community service and community outreach programmes. Collaboration with other agencies can help alleviate isolation. The authors conclude that programmes must address a balance between the challenges adolescents face and the strengths they possess to increase resilience and live healthy lives.

Kmita et al. (5) recognize the dearth of evidence for empowerment and treatment programmes for families affected by HIV, both in Poland and around the world. In Warsaw, the Family Health Department programme identifies the family as a whole unit that warrants interventions tailored to its strengths and weaknesses. It also argues that interventions need to run outside the clinic to prevent focusing on infected members of the family exclusively and neglecting the family as a unit.

The intention of Kmita et al. (5) is to develop and implement interventions proven to be effective with other chronic health conditions. The aims of their initiative are to alleviate isolation and

provide families with the resources and skills to combat discrimination; support families and children in the coping process; promote self-esteem, self-efficacy and control; facilitate reintegration with the community and peer group; and promote support networks on the family, community and institutional levels. Their target population was 30 children between 2 and 15 years old. The intervention was either medical (family counselling outpatient unit or children's hospital) or non-medical (vacation therapeutic camp for families organized by a local nongovernmental organization (NGO)). The programme consisted of separate therapeutic interviews with adults and children, group meetings for children focusing on creativity and art, support meetings for parents, and family therapy sessions.

Through qualitative evaluation, the authors found that play using medical equipment helped children work through their painful medical procedures, and that drawing and art helped children to resolve their grief. Adults benefited from telling their stories over and over, with permission to reframe their stories and find solutions in a respectful atmosphere. Group activities were most effective in the non-medical setting. Younger children were separated from older children. Psychodrama, art and psychoeducation were all used and shown to be beneficial.

The data show that interventions that combine adults and children within a mix of clinical and non-clinical settings were most effective. Equally important was the collaboration between service-providers and NGOs. One limitation was that the programme was not evaluated in depth, but with only some post-intervention qualitative research. The most efficacious interventions were those with families in which the children themselves were not living with HIV. Further, the children were younger than those that are the focus of this review.

Lightfoot et al. (6) discuss an intervention programme that engages youth in small group activities with other infected peers in order to modify behaviour. It aims to reduce substance use and risk-associated sexual behaviour; reduce the negative impacts of substance use on seeking health care, assertiveness and treatment adherence; and enhance the quality of life to maintain behaviour change.

Using data from a qualitative study, they developed a two-pronged module. The first tier, "Stay Healthy", is designed to increase positive behaviours in YPLHIV. "Stay Safe", the second tier, aims to increase altruistic acts that prevent transmission. The intervention was grounded in the Social Action Model and recruited 310 young people from nine adolescent clinics in New York, San Francisco, Los Angeles and Miami. The intervention consisted of coping with learning of one's serostatus, implementing a daily routine to stay healthy, addressing issues of disclosure and participating in health-care decisions. It then included reducing substance abuse and risk-associated sexual acts, having the young people identify triggers and build self-efficacy to negotiate condom use. At baseline, 88% of the males were gay or bisexual, ranging in age from 13 to 24 years. "Stay Safe" elicited a 50% reduction in the number of HIV-negative partners and an 82% decrease in unsafe sexual acts at 15-week follow-up. Fewer benefits were noted with the Stay Healthy programme, which aimed to affect positive behaviour change.

This study reflects positive results from previous research, such as the study by Rotheram-Borus and Miller (7) that focused on secondary prevention interventions for youths living with HIV.

This is possibly the most robust study in the literature, containing quantitative data and statistically significant outcomes. It has been implemented in a number of settings over a number of years and continues to yield positive results, regarding both behaviour change and overall self-efficacy and well-being. However, further research is warranted into the use of this module with other populations, particularly outside the gay and bisexual community.

Tenner et al. (8) provide an overview of three programmes serving HIV-positive youth: Youthcare in Seattle, Washington; Teen Outreach and Primary Services in Bridgeport, Connecticut; and the Boston HIV Adolescent Provider and Peer Education Network for Services in Boston, Massachusetts. The programmes were designed to connect hard-to-reach youths with the services they need. Each of these programmes provides outreach, case management, early intervention, medical services and youth development programming, as well as connections with other youth and welfare referral programmes. The paper contains a literature review that states the following:

All three programs gained from the knowledge and experience of other programs for HIV-positive and homeless youths. The Adolescent AIDS Program at Montefiore Medical Center in New York City demonstrated the importance of outreach to referring agencies to connect youths to sources of care (Futterman et al. 1993; DiLorenzo et al. 1993). The Los Angeles system of care for homeless youths demonstrated the importance of collaborating with agencies in a defined geographic area, solidified by frequent network functions, to care for homeless and street youths (Yates et al. 1991; Kipke et al. 1993; Kipke et al. 1995).

Larkin Street Youth Center in San Francisco established a central drop-in center and medical clinic for HIV-positive street youths (Goulart & Madover 1991). The Centers for Disease Control and Prevention (1996) demonstrated the need for HIV interventions in specific communities to be “based on local needs” and the importance of using a theoretical framework to develop prevention.

The Health Resource Service Administration has provided guidelines from the Ryan White Title I programs for evaluation of local HIV service delivery programs that emphasize the importance of using qualitative and quantitative methods to evaluate service provision, consumer opinions, and HIV-related outcome measures.

The inherent limitation here is that all of these programmes are from the early-to-mid 1990s. Further research is warranted into the sustainability of these programmes and whether or not they continue to exist today, how they have been modified, and if robust evaluations were carried out at the time of programme implementation.

Conclusions

There is clearly a paucity of research focusing on effective psychosocial intervention programmes for adolescents living with HIV, and the research that does exist on the provision of psychosocial support to children and youths affected by HIV rarely focuses specifically on young people living with HIV. For instance, we can find evidence of programmes designed for younger children, families

and the HIV-negative children of HIV-positive parents. The research is mostly qualitative and non-experimental, and the evaluations of programmes are very limited.

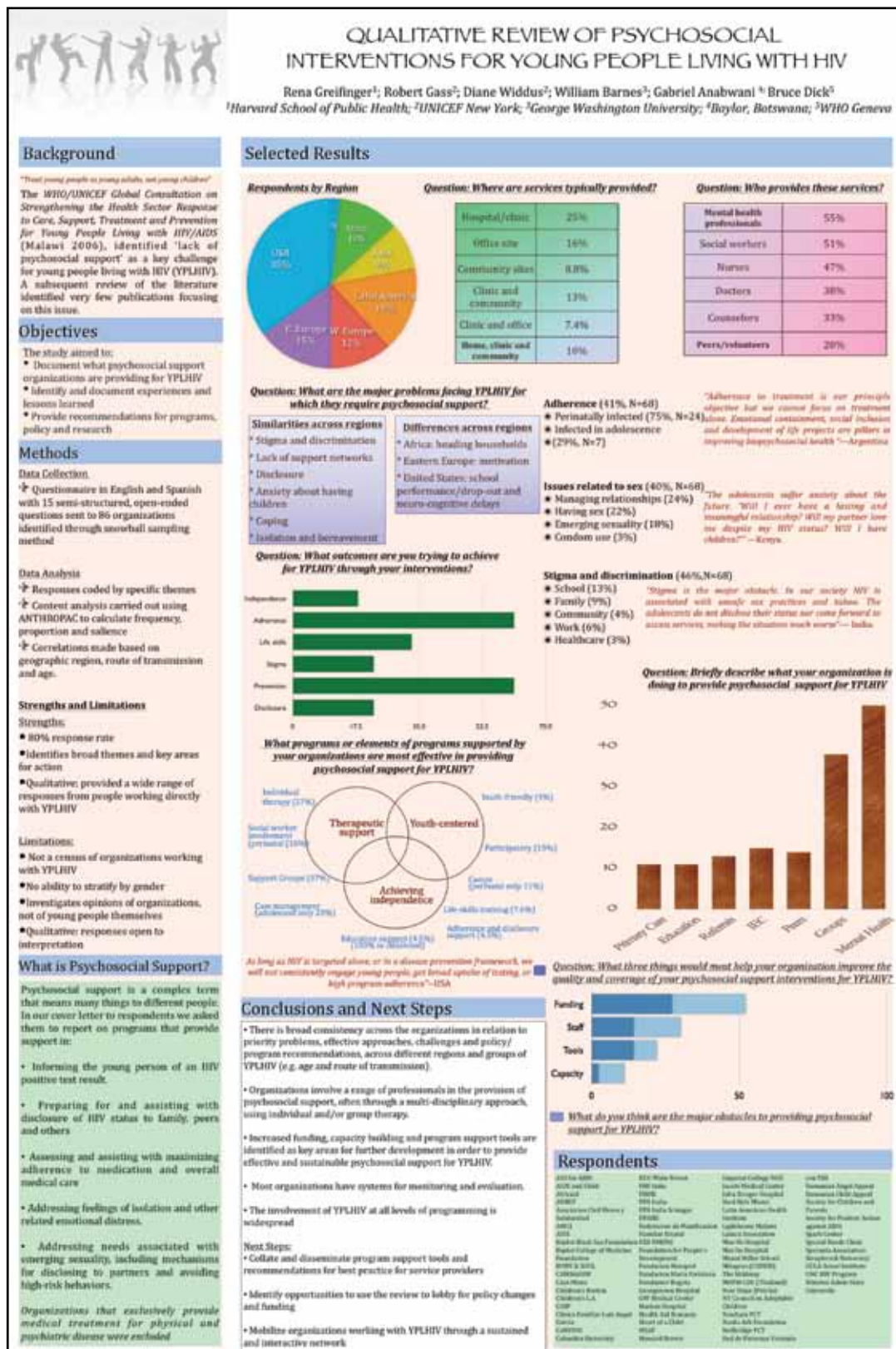
Overall themes emerging from the literature point to the positive effects of collaboration between health-care providers and NGOs, the importance of peer support provided in non-threatening and often non-clinical settings, the benefits of narration and leadership opportunities for youth, and programmatic focus on secondary prevention.

The lack of robust, quantitative data reflects the complexity and sensitivity of working with adolescents affected by HIV. It was as a result of this review that a decision was taken to carry out a detailed review of what providers are currently doing and what elements of programmes they think are most effective. The results from this review are anticipated to guide further investigation methods and recommendations for best practice.

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Appendix C: Poster for the International AIDS Conference, Mexico City, 2008



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