A week-long European residential meeting for HIV+ young people was held in Zurich, Switzerland in July 2008. Over 60 delegates from twelve European countries attended the event sponsored by the Swiss NGO Aids & Child. Delegates participated in workshops about disclosure, medication, sexual health, and the media. The aim of the event was reducing social isolation, fostering self-esteem, forging links amongst HIV+ young people and facilitating the acquisition of skills to manage their condition in the long term.

This paper describes one of the workshops which was based on the work of the UK based ‘Looking Forward Project’. The project uses a group work approach and aims to equip young people with the emotional, psychological and behavioural skills necessary to face the challenges of living with HIV, increased self-management and development of sexual and romantic relationships.1-2

Challenges for HIV+ young people

Adolescence brings many challenges to HIV+ young people: increasing responsibility to manage their own healthcare, emerging sexuality, changes in role within the family and planning for an educational and vocational future. Many have grown up in a context of secrecy and stigma about their HIV. Much of the discourse about the sexual behaviour of HIV+ people is negative and focuses on HIV transmission risk and the potential of criminalization. In several European countries (e.g. Sweden, the UK, Switzerland) there have been cases of HIV+ people being prosecuted and/or jailed for not disclosing their HIV status to their sexual partners. This creates a very anxiety-provoking atmosphere for young people in which to commence their sexual lives. Psychosocial support and preparation for such challenges is rare.3-4

It is vital that young people are given essential information about sex and sexual health and skills with regard to negotiation around sexual relationships. Moreover, it is important that this work takes place in a context that facilitates their self-confidence, promotes the possibility of satisfying and fulfilling sexual lives. However, many HIV+ young people are not educated adequately about these issues. There are many reasons for this: parental and professional fears and embarrassment about discussing sex with fear of encouraging sexual experimentation, confusion on the part of health professionals about where responsibility for sexual education lies and lack of experience in dealing with this issue.

The workshop

The workshop was entitled “Sex, love and one-night stands: getting the
relationship you want”. The workshop emphasized that satisfying and honest sexual relationships are possible and the focused on the acquisition of new skills regarding disclosure of status and condom use. Aims were to:

~ Provide information about correct use of condoms by demonstration (using a banana)
~ Give participants personal experience of using condoms and lubricant (using bananas)
~ Explore personal attitudes and skills with relation to condom use employing a story to illustrate challenges to condom use
~ Explore attitudes, competency and appropriacy of HIV disclosure to sexual partners using prepared questions and small group discussion

The evaluation

Few evaluation materials are available on group focused psychosocial interventions with HIV+ young people so the authors designed a tool based on experience of designing evaluations from their work with young people in the UK. The questionnaire items were generated using clinician experience and psychosocial issues identified from the published literature.

The questionnaire was an 8 item tool to which participants responded using a 6-point “smiley faces” Likert scale to indicate the strength of agreement with the questionnaire item. A “smiley faces” scale was chosen to minimise translation of the responses into different languages and has been used to evaluate interventions in other disease areas. Higher scores reflected increased agreement/disagreement with the questionnaire item.

The questionnaire was translated in French and German from English by staff at AIDS & Child. Each questionnaire item was in these three languages.

At least three other languages were spoken by participants attending the workshop and in order to facilitate completion of the questionnaire it was translated verbally item by item. This was not an ideal situation but was the only practical solution in the circumstances.

Results

Table 1.

<table>
<thead>
<tr>
<th></th>
<th>14-19 years</th>
<th>20-29 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>15</td>
<td>11</td>
</tr>
<tr>
<td>Females</td>
<td>20</td>
<td>4</td>
</tr>
</tbody>
</table>

50 participants completed questionnaires (24 females and 26 males). There were 35 participants aged between 14-19 years (15 males, 20 females) and 15 participants aged between 20-29 years (11 males and 4 females).

For the purposes of analysis we separated the age groups into those below 19 years and above 20 years (Table 1). During the workshop it became clear that some of the participants aged over 20 years had been behaviourally/sexually infected in contrast to the younger members of the group who had acquired HIV vertically. We thought that to mix up the 2 different groups would make the evaluation difficult to interpret so two age categories were created.

t-tests were performed on the data to test for statistical differences.

Table 2 (page 25) shows that generally the participants felt that they were attractive to others, that HIV had not had a negative impact on the way they felt about themselves, and that following the workshop they were more confident about using condoms with sexual partners, having a satisfying sexual life, and talking about sexual feelings with their partners. They were confident that their sexual partners would accept their HIV. They were less confident in their ability to talk about HIV with their sexual partners.

Older participants seemed to have more confidence in their knowledge of correct
condom use and their ability to use them with sexual partners although this was not statistically significant.

There were no statistically significant differences between age groups for any question. However, there were some trends that may indicate that older participants were more confident in their sense of attractiveness and were less affected by HIV emotionally.

Table 3 (below) shows females felt they had learned more than males about condom use (*significance at p ≥ .05).

### Table 2. Questionnaire items by age group

<table>
<thead>
<tr>
<th>Item</th>
<th>Overall</th>
<th>12-19 years</th>
<th>20-29 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I believe that other people find me attractive.</td>
<td>3.92</td>
<td>3.85</td>
<td>4.00</td>
</tr>
<tr>
<td>2. My HIV status has had a bad effect on the way I feel about myself.</td>
<td>1.75</td>
<td>1.79</td>
<td>1.69</td>
</tr>
<tr>
<td>3. After today's workshop I know more about how to use condoms correctly.</td>
<td>2.81</td>
<td>2.94</td>
<td>1.85</td>
</tr>
<tr>
<td>4. After today's workshop I feel more confident about using condoms with a sexual partner.</td>
<td>2.98</td>
<td>3.19</td>
<td>2.00</td>
</tr>
<tr>
<td>5. After today's workshop I feel more optimistic that I will meet a boy/girlfriend who will accept my HIV status.</td>
<td>2.76</td>
<td>2.87</td>
<td>2.15</td>
</tr>
<tr>
<td>6. After today's workshop I feel more confident that I will be able to have happy and satisfying sexual relationships.</td>
<td>3.49</td>
<td>3.50</td>
<td>3.00</td>
</tr>
<tr>
<td>7. After today's workshop I feel more confident about talking about my HIV status with a sexual partner.</td>
<td>2.35</td>
<td>2.19</td>
<td>2.15</td>
</tr>
<tr>
<td>8. After today's workshop I feel I have learnt more about how to talk about sexual feelings with my sexual partners.</td>
<td>3.12</td>
<td>3.22</td>
<td>2.31</td>
</tr>
</tbody>
</table>

### Table 3. Difference between males and females regarding condom use

<table>
<thead>
<tr>
<th>Sex</th>
<th>Mean</th>
<th>Std. Dev.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>2.00*</td>
<td>2.132</td>
</tr>
<tr>
<td>Female</td>
<td>3.20</td>
<td>1.848</td>
</tr>
</tbody>
</table>

Discussion

The evaluation suggests that participants had good pre-existing levels of self-esteem as indicated by their responses to questionnaire items regarding attractiveness to others and the impact of HIV on their lives. The results indicate a trend in which older participants seemed to have better self-esteem. Overall, this is an encouraging result and may reflect the impact of participation in such workshops as this and attendance at events such as the week long residential meeting which are aimed at increasing self-esteem, mitigating the effects of HIV stigma and providing an environment where HIV issues can be discussed within an empowering framework. Age and maturity may also be contributing factors and older participants may have had longer to come to terms with their diagnosis and may have had more professional intervention to assist this process. However, some of the older participants were infected sexually (these tended to be young gay men) and perhaps they had already good levels of self-esteem which were not too badly affected by their HIV diagnosis.

There was strong agreement with the items relating to confidence about having happy and satisfying sexual relationships, ability to talk to sexual partners about sexual feelings, condom use and optimism that a
sexual partner will accept their HIV status.

However, participants had less confidence in their ability to talk about their HIV status with their sexual partners. These results may also reflect the benefits of participation in structured residential workshops where there is a strong focus on peer support, development of self-esteem and the normalization of being a young person with HIV. However, confidence in their ability to talk about their HIV status with a sexual partner was weaker and may reflect the situation that this is actually a very difficult thing to do. Many adults have great difficulty with this issue because of the possible negative consequences e.g. rejection, gossip, violence, loss of employment, social ostracisation. It is unsurprising that younger people with much less life experience should also find this a difficult prospect.

The results showed that females knew more about condom use than males following the workshop. This is also an encouraging result which may indicate that young women have not had a lot of previous education about condom use and as they are not male (i.e. they do have penises) they have not had the opportunity to practice using condoms on themselves. As young people with HIV it is vital that they have the knowledge and skills to use condoms correctly to prevent sexually transmitted infections both for themselves and their sexual partners. Additionally, many countries now legally require people who know their HIV+ status to inform their sexual partners in advance of unprotected sex. The correct and consistent use of condoms becomes even more important in this context.

However, there are some methodological considerations with regard to this evaluation which must be considered. We do not have any baseline data with which to compare post-workshop scores. The scale began with a neutral face moving towards an increased smile. Given the scale started from neutral, it may have been difficult for someone to express dissatisfaction rather than simply a neutral feeling. It is possible that some individuals may have interpreted the scale as neutral in the centre in order to affirm a negative.

Question 2 may have been confusing due to being phrased in the negative and may have confused participants as to which end represented strong agreement with the statement.

These methodological points must be borne in mind when considering these evaluation data. However, verbal feedback and enthusiastic participation in the workshop indicated that it was an enjoyable experience and generated useful discussion.

Future workshops of this kind might benefit from separating younger adolescents from the older participants in order to focus more on such issues as disclosure to friends, how HIV affects one emotionally, and self-esteem issues. Issues for older adolescents include condom use, issues around sexual fidelity, sexual experimentation and partner change.

Conclusion

Given the importance of sexuality, sexual behaviour and relationships much more time could have usefully been spent exploring aspects of these issues. Verbal feedback indicated that the participants enjoyed this straightforward approach very much but there was not enough time to have an in-depth exploration of the workshop topics.

Participation in events such as this may be very important in developing and preserving good self-esteem and in acquiring new skills around sexual behaviour. However, it is impossible to say with any certainty what the longer term impact of participation in such events and this is clearly an area for further research.

Acknowledgements

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workshop and for financial support to attend the meeting in Switzerland and the workshop participants for taking part so enthusiastically.

References


