

# Promoting safer sex among HIV-positive youth with haemophilia: theory, intervention, and outcome

R. B. BUTLER,\* J. R. SCHULTZ,† A. D. FORSBERG,‡ L. K. BROWN,§ J. T. PARSONS,¶ G. KING,\*\* S. M. KOCIK,†† D. JARVIS,‡‡ S. L. SCHULZ,‡‡ M. MANCO-JOHNSON,§§ and THE CDC ADOLESCENT HBIEP STUDY GROUP¶¶

\*Division of Hematology, The Children's Hospital of Philadelphia, Philadelphia, PA, USA; †Xavier University; ‡New England Regional Hemophilia Treatment Center; §Brown University School of Medicine; ¶Jersey City State College;

\*\*University of Connecticut Health Center; ††Puget Sound Blood Center; ‡‡Centers for Disease Control and Prevention; and §§University of Colorado

**Summary.** The goal of the project was to develop and evaluate theory-based interventions designed to change sexual behaviour and promote safer sex practices of HIV seropositive young men and adolescents with haemophilia to prevent transmission to sexual partners and offspring. Safer sex was defined as abstinence, consistent condom use, or 'outercourse' (intimate, non-intercourse sexual behaviour). This project utilized the Transtheoretical Model developed by Prochaska and DiClemente, which describes behaviour change as an incremental, stage-based process. The 1-year intervention protocol consisted of two individual sessions and two peer-centred activities. One hundred and four adolescents, residing in 22 states, participated. Pre- and post-intervention evaluations were conducted to measure

stage progression for participants. The number who were in the action or maintenance stage of change for safer sex was significantly greater at post-test than at pre-test (79 vs. 62%,  $P < 0.0001$ ). Participants also reported an increased use of outercourse. In addition, significant increases in self-efficacy and knowledge regarding safer sex were demonstrated. Following these stage-based interventions, participants were significantly more likely to be engaging in safer sex behaviours than they were previously. These intervention activities can be adapted for use with other adolescent populations and for other behaviour change goals in adolescents with haemophilia.

**Keywords:** adolescents, behaviour, haemophilia, HIV, safer sex

---

Correspondence: Regina B. Butler, RN, Division of Hematology, The Children's Hospital of Philadelphia, 34th and Civic Center Blvd., Philadelphia, PA 19104, USA.  
Tel.: +1 215 590 2198; fax: +1 215 590 3992;  
e-mail: butler@email.chop.edu

This work was supported by cooperative agreements from the Centers for Disease Control and Prevention (Cooperative Agreement U62CCU1061040).

¶¶Cooperative Agreement Sites: The Children's Hospital of Philadelphia, Hemophilia of Georgia, Rhode Island Hospital, University of Minnesota Comprehensive Hemophilia Center, New England Hemophilia Center, Children's Hospital Medical Center (Cincinnati, OH, USA), Children's Hospital of Los Angeles, Mt Sinai Medical Center (New York, NY, USA), Oregon Health Sciences University and Mountain States Regional Hemophilia Center (Denver, CO, USA).

Accepted after revision 2 January 2003

## Introduction

The prevalence of HIV infection is increasing among adolescents and young adults in the United States [1]. Although prevention programmes for adolescents have been shown to increase knowledge about HIV and its transmission [2], these programmes are often ineffective in changing risky behaviours [3–6]. This failure to change behaviour constitutes a major public health threat, considering the frequency of unprotected intercourse and the number of sexual partners typical among adolescents and young adults [7–9]. In 1990, adolescents and young men with haemophilia comprised the largest group of young people with AIDS [10]. Therefore, the Centers for Disease Control and Prevention provided funding for haemophilia care sites to develop and evaluate theory-based, behavioural interventions to prevent the transmission of HIV among seropositive adoles-

cents. This project was called the Adolescent Hemophilia Behavioral Intervention Evaluation Project (HBIEP).

Two prominent theoretical frameworks were employed to develop the interventions: The Transtheoretical Model of Behaviour Change (TM) and The Theory of Reasoned Action (TRA). The TM, developed by Prochaska and DiClemente [11,12], posits that behavioural change is marked by a progression through five incremental stages of change: pre-contemplation, contemplation, preparation, action, and maintenance. Movement through these stages is not necessarily linear in fashion and is described as gradual and dynamic. Developed originally from psychotherapy data, the TM has since been applied to health-related behaviours such as smoking cessation, diet, exercise, and safer sex [13,14].

This model provided a framework to examine behaviours along a continuum from those that are unchanged, to those that have shown long-term changes. It allowed flexibility to encourage behaviour change in measurable increments for multiple behaviours. This avoided the pitfall of an 'all or nothing' approach, and could offer support and encouragement to subjects whose behaviours differed. It also aided in developing a repertoire of techniques to be utilized with subjects at the different stages, and allowed incorporation of strategies for relapse prevention.

The second set of theoretical concepts underlying the HBIEP interventions was the TRA [15,16]. According to the TRA, all actions are based on behavioural intentions; the immediate cause for any behaviour is the individual's intention to engage in or refrain from that behaviour. Intentions are, in turn, determined by an individual's attitudes toward the behaviour and his or her perception of social pressure (peer norms) to engage in or refrain from the behaviour in question. Adolescents are especially susceptible to the influence of subjective peer norms, particularly with regard to sexual behaviour [17–19]. Studies of college students have found that subjective peer norms for HIV prevention behaviours were predictive of later behaviour [20]. In addition, previous condom use has been associated with peer norms in cross-sectional surveys of adolescents [21,22].

These theories formed the foundation of the HBIEP intervention protocol. The goal of the HBIEP was to prevent HIV transmission from seropositive adolescents and young men with haemophilia to sexual partners and their offspring through interventions designed to change sexual behaviour and promote safer sex practices. Safer sex behaviours

targeted were abstinence, outercourse (sexual touch without penetration of vagina or anus) [23], and consistent condom use for vaginal intercourse.

## Materials and methods

### *Formative research*

The developmental phase of the HBIEP included qualitative and quantitative methods. A semi-structured, face-to-face qualitative interview focused on participants' beliefs, attitudes, and values about topics such as safer sex behaviours, discussing safer sex, and disclosure of HIV status [24]. A quantitative instrument was developed from these data to explore and test the relative importance of issues raised [25]. Stage of change for disclosure of HIV status, discussing safer sex, and safer sex behaviours were assessed [26–29]. In addition, participants were asked about their involvement in previous HIV risk reduction programmes and about types of intervention activities that would interest them in the future [29]. These data, TM and TRA theory, and results of a survey of health care providers' experiences with HIV risk reduction programmes with this population were used to plan content and format for the intervention protocol [25,29].

### *Study design*

A single arm, multi-site, longitudinal, observational study was conducted to evaluate the effectiveness of the HBIEP intervention protocol. A control or comparison group was not part of the research design because of the ethical issues of withholding interventions, considering the serious nature of the risk to sexual partners of all eligible adolescents and young men. In addition, the potential for participant dropout due to morbidity and mortality from HIV infection necessitated a single-arm study.

### *Sample description*

Beginning in the fall of 1993, adolescent and young adult males (age 12–25 years) with haemophilia and HIV infection and who knew their HIV status were recruited from 22 states through ten haemophilia care sites. Exclusion criteria included lack of parental consent or limited ability to participate because of developmental delay or severity of HIV disease, as determined by medical providers. After project approval by local Institutional Review Boards and Community Program Review Panels, written informed consent was obtained from each

**Table 1.** Socio-demographic characteristics of participants.

Variables/time	Pre % (n)	Post % (n)
Age		
Less than 18 years	38.5 (40)	28.8 (30)
18 years or older	56.7 (59)	61.5 (64)
Mean age	4.8 (5)	9.6 (10)
Missing	0.0 (0)	0.0 (0)
Marital status		
Married	1.9 (2)	3.8 (4)
Non-Married	98.1 (102)	95.2 (99)
Missing	0.0 (0)	1.0 (1)
Residence		
Urban	22.1 (23)	23.1 (24)
Suburban	48.1 (50)	47.1 (49)
Rural	25.0 (26)	25.0 (26)
Missing	4.8 (5)	4.8 (5)
Racial classifications		
White	73.1 (76)	75.0 (78)
Black	10.6 (11)	11.5 (12)
Hispanic	9.6 (10)	8.7 (9)
Other	5.8 (6)	3.8 (4)
Missing	1.0 (1)	1.0 (1)

participant, and from parents of participants less than 18 years of age (see Table 1).

### Interventions

A multi-disciplinary team designed the protocol as a series of four interventions over 1 year (see Table 2). The protocol incorporated both individual and group formats. At the beginning of each session, the

participants' stages of change for safer sex practices were assessed. Then, each participant received feedback appropriate to his current stage, including a summary of his readiness to change and, finally, a plan to help move on to the next stage was discussed. Based on participants' stage(s), a variety of activities for each intervention were selected to encourage progression to the next stage and to provide opportunities for practicing new skills.

While all interventions contained the common steps of assessing stage of change and providing feedback to the participants, each intervention had additional, unique goals and activities. The first intervention, an individual session, was designed to establish initial rapport and elicit input into future programme planning. This session consisted of a brief interview that could be incorporated into a clinic visit. Suggested questions and templates for evaluation were provided. The second intervention combined a social activity with a group session to develop a supportive peer group among the participants. Vignettes developed according to stage of change concepts and HIV-related videos were used to stimulate discussion about negotiating and practicing safer sex. This intervention concluded with exercises to enhance self-efficacy for safer sex behaviours. The third intervention, an intensive weekend retreat, alternated recreational activities with group sessions. Emphasis was placed on self-efficacy, communication, decision-making, and assertion skill building, as well as problem solving related to obstacles impeding safer sex. The final intervention, an individual

**Table 2.** Description of interventions.

Format	Dose	Activities	Month
#1: Individual counselling session	1 h	Introduction to series Assess stage of change; give feedback Establish rapport with participant Identify needed social skills Develop behaviour change plan Elicit input regarding future interventions	1-2
#2: Group session with social activity	1.5-3 h (content)	Stage of change individually assessed; general feedback to group Individual written feedback Vignettes or video with stage-based discussion questions Self-efficacy exercises	4-5
#3: Intensive group session	2 days	Assess stage of change; feedback Group discussion using appropriate processes for stages Skills building Self-expression-communication-problem-solving Decisional balance regarding safer sex Mixed content with recreation	7-8-9
#4: Individual focused feedback	1 h	Stage of change assessment; written feedback Discussion about current behaviour, goals	11-12

session, was designed to facilitate continuing progress or to prevent relapse among those who had already adopted consistent safer sexual behaviours. Support was given for changes accomplished and a plan for future behaviour change was developed. Descriptions of activities may be found in the *Adolescent Behavior Change Manual* (available from the authors) [30]. Timelines and suggestions for planning more complex group interventions are included. Advanced planning and use of multiple team members as interveners, planners, and organizers are encouraged to reduce the time commitment of any one staff member.

To promote standardization of implementation, intervention activities were described in a detailed manual for interveners [31]. Intervenors included psychologists, social workers, health educators, and nurses with previous training and experience in counselling. All intervenors participated in a training session to become oriented to the protocol and to practice techniques.

Although the four interventions spanned a year, two of them were administered individually as health education is often delivered in clinics. The other two interventions were delivered more intensively, in groups, because the young people indicated that peer-based formats would be attractive to them. Those services were delivered in the context of an afternoon or evening activity and a weekend retreat; formats that are familiar to most haemophilia care providers. This series of interventions can be delivered in a variety of formats, which are easily integrated into a typical clinical visit.

### Measures

Participants completed a 162-item questionnaire (available from the authors) developed specifically for this study, administered prior to the intervention, upon completion, and 6 months after the yearlong intervention. Participants received reimbursement for their time and effort in completing the questionnaire, ranging from \$35 to \$75, depending on the site. The instrument was administered to 81.6% of the participants by trained telephone interviewers who were previously unknown to the participants. The remainder either returned the measures by mail or completed them at one of the haemophilia care sites.

Much of the survey was developed based on findings from earlier HBIEP formative research with the same population [24,26,28,29,32]. Demographic, health status, drug/alcohol use, and communication questions were included in the instrument. Sexual behaviour items included questions about

sexual abstinence, intimate touch, vaginal intercourse, and condom use. Scales were constructed to reflect behavioural intentions (e.g. 'In the next month or so, how likely do you think it is that you will use condoms every time you have intercourse with a serious partner?'), self-efficacy (e.g. 'How sure are you that you could use a condom when ... you have a new partner?'), decisional balance (e.g. 'How important is each of these reasons to you in deciding whether or not you will use a condom? ... It would make you feel more responsible ... It would be too much trouble ...'), and peer norms (e.g. 'How many of your friends do you think approve of you using condoms every time you have intercourse?') for each safer sex behaviour. In addition, scales measured knowledge about HIV, risk behaviours, and general emotional distress and were confirmed using principal components factor analysis and inter-item reliability analysis (see Table 2). Items for these scales were derived from previous qualitative and quantitative work with this population [24,26]. The measure included four items to assess participants' stage of change for three behaviours: (i) safer sex, defined as consistent condom use, outcourse, or abstinence; (ii) consistent condom use with a main partner; and (iii) consistent condom use with a casual partner. Staging items were derived from previously established measures and have been shown to be reliable and enabled classification of participants into one of the five mutually exclusive stages of change for each of the three categories. This staging algorithm was also used to assess stage of change at each intervention [33–35].

Fidelity to protocol was monitored by processing data report forms, completed by each intervener. These measures catalogued activities implemented and steps followed. Reported compliance for use of specified materials ranged from 93 to 100% for the four interventions, revealing adherence across sites. In addition, reported compliance for implementation of intervention content across sites ranged from 87 to 99% for the four interventions.

### Data analysis

Responses to questionnaires were confidential, with data coded by participant number. For purposes of verification, data were entered twice using the Statistical Program for Social Sciences (SPSS-PC) data entry package. Group comparisons were made, using chi square or Student's *t*-test, as appropriate. Change between pre- and post-test was assessed using McNemar's tests for categorical data and paired *t*-tests for scale values.

## Results

There were 364 eligible participants at the ten HBIEP sites. Of those, 167 consented to participate in the study. Haemophilia care sites provided demographic information on individuals who agreed to participate and those who declined. Comparisons revealed that the two groups were similar in ethnicity, residency, and sexual experience. They differed only by age (mean of 19.6 years for non-participants vs. 18.8 years for participants;  $t = 2.30$ ,  $P < 0.05$ ). In 122 cases (62%), staff could identify reasons for refusal to participate. Reasons included the following: 22% were 'too busy', 8% did not want to discuss HIV, 15% considered themselves too ill to participate, 9% did not obtain parental consent, and 8% generally did not participate in haemophilia care site activities.

Of the 167 adolescents and young men who consented to participate, 104 completed pre- and post-instruments and participated in at least one of the four interventions, forming the sample for these analyses. Of these participants, 48 (46%) completed all four interventions and 74 (72%) completed at least one of the individual intervention sessions as well as one or both group activities. The 104 participants were compared with the 63 who did not participate. Comparisons revealed no differences in demographics or severity of HIV illness at baseline. At post-test, treatment sites reported that 12% of the sample did not participate because of mortality ( $n = 15$ ) and morbidity ( $n = 5$ ).

At entry into the study, the mean age of the participants was 18.5 years, with a range of 13–24 years. Participants were predominantly white, suburban, unmarried males. At baseline, 59 (57%) participants reported previous sexual intercourse and 43 (42%) reported intercourse during the previous 6 months. A small proportion (15%) of participants described themselves as 'too sick for sex'. Additional demographics for the sample are presented in Table 1.

Stages of change for the 104 participants were examined. Safer sex behaviour (consistent condom use, outercourse, or abstinence) was more frequently reported at post-test than at pre-test. After the intervention, 79% of all participants were in the action or maintenance stage for safer sex, compared with 62% at pre-test (McNemar,  $P < 0.0001$ ). Sexually active participants at post-test were more likely to be in the action or maintenance stage for condom use with a main partner than at pre-test (68 vs. 44%,  $P < 0.05$ ). Similarly, there was a significant increase in the proportion of those in the action or

maintenance stage for condom use with a casual partner (77 vs. 69%,  $P < 0.01$ ). In general, participants were more likely to progress rather than relapse. For example, 28% of the sample progressed along the stages of change for safer sex, in contrast with only 10% who relapsed. Participants who received only individual sessions ( $n = 30$ ) were less likely to be in action or maintenance for safer sex at post-test than those who received individual plus group activities ( $n = 74$ ; 61 vs. 80%,  $P = 0.05$ ). In general, safer sex behaviour was maintained over a 6-month follow-up period. Of those in Action or Maintenance for safer sex behaviour at post-test, 88% remained in that stage during the follow-up period.

Paired *t*-test comparisons for participants revealed a significant increase over the intervention year in self-efficacy scale scores for all three safer sex behaviours (all *ts* > 2.4; all *Ps* < 0.02). For the whole sample, the number of participants reporting having ever engaged in outercourse increased significantly from 63.7 to 72.5% (McNemar,  $P < 0.01$ ). In addition, while knowledge of HIV risk behaviours did not change, there was a significant increase in participants' knowledge of safer sex behaviours ( $t = -2.4$ ;  $P < 0.02$ ). No changes were detected in decisional balance, peer norms, or emotional distress scale scores (see Table 3).

Two individual items dealt with perceived family attitudes about safer sex but did not appear in scales. Participants after the intervention perceived significantly greater family support for outercourse (71.6–86.6%, McNemar,  $P < 0.05$ ) and there was some evidence of increased support for discussing safer sex (76.9–89.4%, McNemar,  $P = 0.10$ ).

## Discussion

Fewer sexual partners and potential offspring were at risk for HIV infection because participants more consistently practiced safer sex. Over the course of the intervention period, more participants were classified at the action or maintenance stages. Despite the barriers to recruitment, retention, and participation, the goals of the HBIEP were achieved.

The HBIEP, unlike many behavioural intervention efforts, used a systematic, theory-based approach to promote adolescent behaviour change. In addition to guiding the intervention formation, the stage of change framework was utilized to assess progress by measuring incremental changes in participants' behaviour. The extensive formative research prior to the development of the intervention protocol was an important strength of the HBIEP. Although the

Table 3. Survey results.

Scales	No. of items	$\alpha$	Ranges	Pre	Post	SD	<i>P</i>	<i>t</i> (df)
Condom use								
Self efficacy	11	0.90	0–33	29.2	30.2	3.5	0.017	–2.43 (96)
Pros	3	0.66	0–6	4.7	4.5	1.3	0.168	1.39 (103)
Cons	5	0.82	0–10	2.3	2.3	2.8	0.722	0.36 (101)
Peer norms	2	0.45	0–4	2.4	2.4	1.3	0.667	–0.43 (98)
Outercourse								
Self efficacy	6	0.93	0–18	12.7	14.8	3.0	0.000	–4.44 (96)
Pros	2	0.68	0–4	2.3	2.6	1.2	0.069	–1.84 (97)
Cons	4	0.73	0–8	2.8	2.9	1.9	0.896	–0.13 (96)
Peer norms	2	0.67	0–4	1.8	1.9	1.5	0.703	–0.38 (97)
Abstinence								
Self efficacy	5	0.91	0–15	8.9	10.3	3.9	0.003	–3.05 (101)
Pros	3	0.57	0–6	4.2	4.4	1.3	0.139	–1.49 (100)
Cons	3	0.54	0–6	3.3	3.3	1.8	0.924	0.10 (100)
Peer norms	2	0.78	0–4	1.8	1.6	1.7	0.289	1.07 (97)
Knowledge								
Risk behaviours	5	0.56	0–15	10.9	11.2	2.7	0.252	–1.15 (96)
Prevention behaviours	4	0.69	0–12	9.1	9.7	2.3	0.017	–2.42 (98)
Emotional distress with main partner	6	0.78	0–12	8.4	8.3	2.5	0.881	0.15 (102)

population was well known to many study investigators, these data provided new information that was essential to the development of format as well as content of the interventions [24–26]. This project emphasized the development of a detailed protocol manual, consistent training of facilitators, and documented adherence to protocol for each site. This standardization reduced the number of confounding variables and facilitated cross-site analyses.

Interventions focused on safer sex options, including abstinence and outercourse (non-penetrative, intimate touching). The majority of participants who were abstinent remained abstinent, despite an expected increase in sexual activity that normally accompanies adolescent development [9,32]. An increase in knowledge about abstinence, outercourse, and condom use was reported and an increase in outercourse behaviours reflected an expanded repertoire of safer sex practices for the participants. Outercourse was presented as an appealing and satisfying safer sex alternative to condom use. In addition, participants were significantly more likely to report that their families approved of their practice of outercourse. From these data, however, it is not possible to determine whether the increased rate of outercourse was the result of intervention activities or because of other factors unrelated to the intervention protocol.

Participants' confidence in their ability to perform safer sex behaviours (self-efficacy) increased for condom use, outercourse, and abstinence, which is

especially significant considering the high self-efficacy score found prior to the intervention. Compared with their confidence in ability to use condoms, participants initially felt less certain about practicing outercourse, and the greatest improvement in self-efficacy was related to outercourse. These changes in self-efficacy are consistent with the important role that self-efficacy has been shown to play in previous health behaviour research [36–39]. In addition to encouraging condom use, a novel aspect of this project was the introduction of outercourse as an alternative to condom use for adolescents.

In contrast, other theory-based variables were unchanged. There was no change in decisional balance, consistent with previous TM research indicating that this variable changes most with movement toward the preparation stage [13]. Contrary to the TRA, peer norms did not change even though the interventions afforded the opportunity to develop an alternative peer group. This stability may reflect the difficulty to influence perceptions central to adolescent development within the natural peer group. This finding also could be attributed to imprecise measurement because norms were assessed with only two items. Finally, the wide age range of the participants may be a consideration. However, the participants constitute a peer group because of their commonalities: haemophilia and HIV infection, treatment at paediatric comprehensive haemophilia centres, and previous opportunities to interact in various local,

regional, and national functions. In addition, the interventions provided opportunities for the older participants to provide support and serve as role models for the younger ones.

The variable measuring global emotional distress also showed no change over the course of the interventions. Participants reported a generally positive emotional outlook, despite their HIV seropositivity and their awareness of the deaths of peers at their treatment sites. This continued sense of well-being may be related to the support received from their families and haemophilia centre staff. Lastly, individuals with more positive outlooks may have had a higher tendency to enrol than their more distressed peers. Although the variables of decisional balance, peer norms, and emotional distress remained unchanged for the entire sample, they may be associated with behaviour change of individuals within the group. While there was not an overwhelming dose effect, there is some evidence that more adolescents were practicing safer sex at post-test and safer sex behaviour was maintained in the follow-up period.

Limitations of this study include lack of a comparison group, self-selection of participants, and use of self-report data. The absence of a control group prevents attribution of causal relationships. However, there were several factors, which contributed to the decision to conduct the intervention without a control group. Owing to the high risk to potential sexual partners of these adolescents and young men, there was an urgency and ethical responsibility to offer these interventions to all eligible participants. In addition, the short intervention period and the small sample available from a limited pool of participants contributed to the decision to proceed without a control group. Although self-selection may have influenced participants' tendency to complete the study, no demographic differences were identified among participants who completed the project, those who dropped out and those who declined to enrol. While self-report data should always be viewed with caution, no alternatives for assessing sexual behaviours are easily available. Anonymous questionnaires administered by staff not familiar with participants were used to minimize distortion of the self-reports.

No practical option for using of a 'standard of care' control group was available, due to the wide range of 'standard of care' at the time of the study. Further, using the stage of change model employed and the measurement of the outcome of this study, 'control' subjects would have required to be recruited into the study as well. Given the recruitment difficulties, resulting in a small  $n$ , and ethical

concerns, all subjects were in the active arm of the study.

Because of the small sample size, an intent-to-treat analysis was judged to be an overly conservative analytic approach. These analyses did include all subjects attending at least one intervention and so the findings probably estimate the impact of those willing to attend such interventions.

Attrition was also a major concern throughout this project, because of morbidity and mortality among participants. Infected individuals died and no new cases of HIV in haemophilia have been reported. Recruitment was especially challenging because formative research revealed this population had been given considerable information and was reluctant to participate in any further HIV risk reduction interventions. Opportunities to meet with peers and to engage in recreational activities were among the few incentives for participation [25].

The interventions in this project were standardized and consistent training of facilitators was ensured for research purposes. The approach is easily adaptable to current settings in the haemophilia community. The multi-disciplinary teams in HTC's and the National Hemophilia Foundation Chapter staff can adapt the exercises and activities of the HBIEP to camp settings, patient/family retreats, outreach clinics, and consumer education programmes. The National Prevention Programme initiative has a current focus on effecting behaviour change in adolescents with haemophilia in areas such as exercise and participating in preventative care. The TM and the intervention activities may provide guidelines for care givers to develop effective programmes and to evaluate progress in these initiatives.

Although the HBIEP was planned as a yearlong project for the purposes of this research study, the interventions were designed to be useful as individual components to supplement routine clinical activities.

With the increased prevalence of HIV seropositivity among youth, an increase in sexually active adolescents who were infected perinatally, and improved treatments for HIV/AIDS, there will be a continued need to address safer sex issues among long-term HIV-infected populations, beyond the haemophilia community. As demonstrated by this study, long-term HIV infection does not preclude sexual activity. In addition, new cases of HIV will continue to be diagnosed among sexually active adolescents and young adults, further necessitating the need for interventions, which emphasize both prevention of transmission and safer sexual practice.

As a result of safer treatment products, HIV is no longer an issue for most adolescents with

haemophilia. However, adolescent behaviour change remains a significant goal in the health care of these patients. HTC staff struggle with supporting adolescents regarding behaviours such as alcohol and drug use, safer sex, and adherence to treatment recommendations. Effecting behaviour change in these areas is essential to the health of these adolescents, especially those affected by hepatitis.

This study provides caregivers with guidelines to help effect behaviour change in a consistent format and to measure small steps in progress toward adolescent behaviour change goals. Therefore, HBIEP interventions may still have substantial applicability for adolescents with haemophilia as well as for other groups of adolescents and young adults at risk.

The study suggests that the elements of theory-based interventions, formative research, and measurement of incremental steps in behaviour change were instrumental in determining positive outcome for adolescents and young adults with haemophilia.

### Acknowledgements

Other members of the Adolescent HBIEP Intervention Committee included Laurel McKernan, Roxanna Boelsen, Leonard Haas, Kevin Cwayna, Alison Reiche, and Jody Wood.

### References

- Centers for Disease Control. HIV/AIDS Surveillance (CDC), 1995.
- Morton M, Nelson L, Walsh C, Zimmerman S, Coe RM. Evaluation of HIV/AIDS education program for adolescents. *J Community Health* 1996; **21**: 23–35.
- Huszi HC, Clopton JR, Mason PJ. Acquired immunodeficiency syndrome educational program: effects on adolescents' knowledge and attitudes. *Pediatrics* 1989; **84**: 986–94.
- Bellingham K, Gillies P. Evaluation of an AIDS education program for young adults. *J Epidemiol Community Health* 1993; **47**: 134–8.
- St Lawrence JS, Jefferson KW, Alleyne E, Brasfield TL. Comparison of education versus behavioral skills training interventions in lowering sexual HIV risk behavior of substance dependent adolescents. *J Consult Clin Psychol* 1995; **63**: 154–7.
- Overby KJ, Lo B, Litt IF. Knowledge and concerns about acquired immunodeficiency syndrome and their relationship to behavior among adolescents with hemophilia. *Pediatrics* 1989; **83**: 204–10.
- Sonenstein FL, Pleck JH, Ku LC. Sexual activity, condom use and AIDS awareness among adolescent males. *Fam Plann Perspect* 1989; **21**: 152–8.
- Centers for Disease Control. Sexual behavior among high school students – United States. *Morb Mortal Wkly Rep* 1992; **40**: 885–8.
- Leigh BC, Morrison DM, Trocki K, Temple MT. Sexual behavior of American adolescents: results from a U.S. National Survey. *J Adolesc Health* 1994; **15**: 117–25.
- Centers for Disease Control. HIV/AIDS Surveillance (CDC), 1992.
- Prochaska JO, DiClemente CC. Stages and processes of self-change of smoking: toward an integrative model of change. *J Consult Clin Psychol* 1983; **51**: 390–5.
- Prochaska JO, DiClemente CC. *The Transtheoretical Approach; Crossing the Traditional Boundaries of Therapy*. Homewood: Dow Jones-Irwin, 1984.
- Prochaska JO, Velicer WF, Rossi JS *et al*. Stages of change and decisional balance for twelve problem behaviors. *Health Psychol* 1994; **13**: 39–46.
- Prochaska JO, Redding CA, Harlow LL, Rossi JS, Velicer WF. The transtheoretical model of change and HIV prevention. *Health Educ Q* 1994; **21**: 471–86.
- Fishbein M, Ajzen I. *Belief, Attitude, Intention, and Behaviour*. Reading, MA: Addison-Wesley, 1975.
- Ajzen I, Fishbein M. *Understanding Attitudes and Predicting Social Behaviours*. Englewood Cliffs, NJ: Prentice Hall, 1980.
- White JL. *The Troubled Adolescent*. Elmsford, NY: Pergamon, 1987.
- Brooks-Gunn J, Furstenburg FF. Adolescent sexual behavior. *Am Psychol* 1989; **44**: 249–57.
- Petosa R, Wessinger J. The HIV educational needs of adolescents: a theory-based approach. *HIV Educ Prev* 1990; **2**: 127–36.
- Fisher WA, Fisher JD. A general social psychological model for changing AIDS risk reduction via behavioral training. In: Pryor JB, Reeder GDD, eds. *The Social Psychology of HIV Infection*. Hillsdale, NJ: Lawrence Erlbaum, 1993.
- DiClemente R, Durbin M, Siegel D, Krasnovsky F, Lazarus N, Comacho, R. Determinants of condom use among junior high school students in a minority inner-city school district. *Pediatrics* 1992; **89**: 197–202.
- Di Clemente R, Lodico M, Grinstead O *et al*. African-American adolescents residing in high risk urban environments do use condoms: correlates and predictors of condom use among adolescents in public housing developments. *Pediatrics* 1996; **98**: 269–78.
- Schuster MA, Bell RM, Kanouse DE. The sexual practices of adolescent virgins: genital sexual activities of high school students who have never had intercourse. *Am J Public Health* 1996; **86**: 1570–6.
- Nuss R, Smith PS, Cotton D, Kisker T. Communication about safer sex and serostatus disclosure in HIV-positive adolescents with haemophilia. *Haemophilia* 1995; **1**: 126–30.
- Schultz JR, Butler RB, McKernon L, Boelsen R. Developing theory based HIV interventions. *Haemophilia* 2001; **7**: 64–71.

- 26 Brown LK, Schultz JR, Gragg RA. HIV infected adolescents with hemophilia; adaptation and coping. *Pediatrics* 1995; **96**: 459–63.
- 27 Forsberg AD, King G, Delaronde R, Geary MK. Maintaining safer sex behaviours in HIV infected adolescents with hemophilia. *AIDS Care* 1996; **8**: 629–40.
- 28 King G, Delaronde S, Dinoi R, Forsberg A. Substance use, coping, and safer sex practices among adolescents with hemophilia and human immunodeficiency virus. *J Adolesc Health* 1996; **18**: 435–41.
- 29 Parsons J, Butler R, Kocik S, Norman L, Nuss R. The role of the family system in HIV risk reduction: youth with hemophilia and HIV infection and their parents. *J Pediatr Psychol* 1998; **23**: 57–65.
- 30 Butler R, Cornett J, Forsberg A, Kocik S, Malamut J, Schultz J, eds. *The Adolescent Behavior Change Manual: Activities to Promote Safer Sex*. Worcester, 1996 (available from HANDI 1800-42-HANDI).
- 31 Butler R, Cotton D, Haas L *et al.* *The Adolescent Intervention Manual*. CDC, 1993.
- 32 Remafedi G, Parsons JT, Schultz JR, Schultz SL, Study Group. The sexual behavior of HIV-seropositive coagulopathies. *J Adolesc Health* 1997; **21**: 232–7.
- 33 Galavotti C, Cabral RJ, Lansky A, Grimley DM, Riley GE, Prochaska JO. Validation of measures of condom and other contraceptive use among women at high risk for HIV infection and unintended pregnancy. *Health Psychol* 1995; **14**: 570–8.
- 34 Grimley DM, Riley GE, Prochaska JO. Condom use assertion and the stages of change with main or other partners. *J Appl Biobehav Res* 1993; **1**: 152–73.
- 35 Grimley DM, Riley GE, Bellis JM, Prochaska JO. Assessing decision-making and contraceptive use of men and women for the prevention of pregnancy and sexually transmitted diseases/AIDS. *Health Educ Q* 1993; **20**: 455–70.
- 36 Bandura A. Perceived self-efficacy in the exercise of control over AIDS infection. In: Mayes V, Albee GW, Schneider SF, eds. *Primary Prevention of AIDS: Psychological Approaches*. London: Sage, 1989: 128–41.
- 37 O’Leary A, Goodhart F, Jemmott LS, Boccher-Lattimore D. Predictors of safer sex on the college campus: a social cognitive theory analysis. *J Am Coll Health* 1992; **40**: 254–63.
- 38 Fisher JD, Fisher WA. Changing AIDS-risk behavior. *Psychol Bull* 1992; **111**: 455–74.
- 39 Goldman JA, Harlow LL. Self perception variables that mediate AIDS-preventive behavior in college students. *Health Psychol* 1993; **12**: 489–98.