

# **The Forgotten Tragedy**

## **The Unforgettable Trauma**

Addressing the needs of people affected by haemophilia and  
HIV infection in Hong Kong

Final report of the Hong Kong Advisory Council on AIDS

November 2004



# **The Forgotten Tragedy**

## **The Unforgettable Trauma**

Addressing the needs of people affected by haemophilia and  
HIV infection in Hong Kong

Final report of the Hong Kong Advisory Council on AIDS

November 2004

## **Correspondence**

The Secretariat  
Hong Kong Advisory Council on AIDS  
5/F Yaumatei Jockey Club Clinic  
145 Battery Street  
Kowloon  
Hong Kong SAR

Tel: 2304 6100  
Fax: 2337 0897  
Email: [aca@dh.gov.hk](mailto:aca@dh.gov.hk)  
Website: [www.aca-hk.com](http://www.aca-hk.com)

## Contents

|   |           |
|---|-----------|
| Contents .....  | 3         |
| Boxes and figures .....                                     | 5         |
| Preface .....   | 7         |
| Acknowledgements.....                                       | 9         |
| Membership lists.....                                       | 11        |
| Executive Summary .....                                     | 13        |
| <b>Section A. Background .....</b>                          | <b>15</b> |
| <b>Section B. Aims and objectives .....</b>                 | <b>17</b> |
| <b>Section C. Methodology.....</b>                          | <b>19</b> |
| I. Study design and recruitment of subjects .....           | 19        |
| II. Study methods.....                                      | 21        |
| III. Facilitators and interviewers .....                    | 23        |
| IV. Data collection, analysis, and disposal .....           | 23        |
| <b>Section D. Results .....</b>                             | <b>25</b> |
| I. Statistical summary of responses.....                    | 25        |
| II. Patients' demography .....                              | 27        |
| III. Assessment of medical needs .....                      | 29        |
| IV. Assessment of social constraint .....                   | 34        |
| V. Assessment of psychological status.....                  | 38        |
| VI. Assessment of carers' stresses .....                    | 40        |
| VII. Short form 36 (SF 36) health survey .....              | 42        |
| VIII. Level of satisfaction with services .....             | 45        |
| <b>Section E. Study limitation .....</b>                    | <b>47</b> |
| <b>Section F. Summary of problems and unmet needs .....</b> | <b>49</b> |
| <b>Section G. Actions arising from the study.....</b>       | <b>53</b> |
| <b>Section H. Recommendations .....</b>                     | <b>55</b> |

|  |    |
|--|----|
| Appendix I. Referring agencies and services.....               | 65 |
| Appendix II. Informed Consent Form .....                       | 67 |
| Appendix III. Guiding questions for focus groups.....          | 69 |
| Appendix IV. Guiding questions for individual interviews ..... | 71 |
| Appendix V. Questionnaire .....                                | 73 |

## **Boxes and figures**

|  |    |
|--|----|
| Box 1. Patient's demography.....   | 28 |
| Box 2. AIDS in haemophilia patients.....   | 29 |
| Box 3. Level of severity of haemophilia.....   | 32 |
| Box 4. Isolation in patients with haemophilia and HIV infection..  | 35 |
| Box 5. Profiles of patients' social support network.....   | 37 |
| Box 6. Patients' psychological profile.....  | 38 |
| Box 7. Psychological distress among patients.....  | 39 |
| Figure 1. Distribution of SF36 scorings.....   | 42 |
| Box 8. Patients' satisfaction level of clinic services.....  | 45 |
| Figure 2. Model on the inter-relationship of psychosocial<br>influence from the double tragedy.....      | 50 |
| Box 9. Nine problem areas and their recommended responses....  | 55 |
| Box 10. Grants given to people with haemophilia and HIV<br>infection in UK.....                          | 61 |
| Box 11. Compensation scheme for HCV infection through<br>transfusion of contaminated blood products..... | 61 |



## Preface

At its forty-fourth meeting on 17 October 2003, the Hong Kong Advisory Council on AIDS (ACA) resolved to initiate a study to assess the needs of HIV infected haemophilia patients in Hong Kong. Supported by a panel of advisors, the study was then undertaken by professional staff of the Special Preventive Programme on behalf of the Council Secretariat. The investigating team met twice with the advisors to agree on methodology and to guide the analysis of findings. The results of the study have been presented and discussed in the subsequent ACA meetings before compilation of this final report. This report documents the study methods, describes the study process, the actions arising from the study, its limitation and the difficulties met. It also presents the study results and sets out the recommended strategies to meet the needs of this very community which unfortunately has long been *forgotten* by the society.

A report could never depict in full the tremendous pains and sufferings that our patients and their carers, particularly their mothers, have lived with in the past two decades. The unresolved psychological consequences and protracted isolation have already imprinted in the survivors of the tragedy, and would likely continue to be with them until the very end of their lives.

The study steering committee wishes that the study does not end here with this report, but looks forward to efforts to support every victim of the tragedy on the basis of the study results. The lessons painfully learnt should be remembered by the profession and the community to ensure that no similar incident could ever happen in the future. It has been an utterly distressful experience to witness the deaths of two patients in frustration, resentment and helplessness in the course of the investigation. Our society has owed them and their loved ones the right to live with dignity. Such should end.

Steering Committee  
September 2004



## **Acknowledgements**

The study coordinator would like to thank the following persons, without whom the study would not have been possible. They are: all patients affected by haemophilia and HIV infection; all their carers; all health care professionals who have taken part in the focus group; staff of Kowloon Bay Integrated Treatment Centre and Special Medical Service of Queen Elizabeth Hospital, Dr Susan Chiu of Queen Mary Hospital and staff of other agencies and services for recruitment of patients and carers and arrangement of interviews; members of advisory panel on planning of study and analysis of results; Prof WT Chan for conduction of training on focus group; Prof Cindy Lo Kuen Lam for approval of use of Chinese translation of Health Survey SF 36; Ms Frances Leung, Ms Lina Lau and Ms Teresa Lee for conduct of interviews and focus groups; Miss Wendy Yiu for providing medical social service support throughout the study, and Miss Christine Wong for statistical support.

The study coordinator would also like to express the deepest condolences to the family members, relatives and friends of the two patients who tragically died shortly after participating in the study.



## **Membership lists**

### **Steering Committee**

Chairman Dr TSO Homer  
(Chairman, ACA)

Members Prof CHEN Char-nie  
(Chairman, Committee on Promoting Acceptance of People  
Living with HIV/AIDS of ACA)

Mrs WONG IP Wai-ying, Diana  
(Chairman, AIDS Prevention and Care Committee of ACA)

### **Investigating Team**

Principal investigator Dr WONG Ka-hing  
(Senior medical officer, Special Preventive  
Programme)

Co-investigators Dr CHAN Chi-wai, Kenny  
(Senior medical officer, Special Preventive  
Programme)

Dr LEE Chi-Kei, Krystal  
(Medical officer, Special Preventive Programme)

Ms CHUNG Wai-yee, Rita  
(Nursing officer, Queen Elizabeth Hospital)

### **Study Coordinator**

Dr LEE Chi-Kei, Krystal

### **Advisory Panel**

Miss CHAN Chiu-ling, Ophelia

Prof CHAN Tai-kwong

Prof CHAN Wing-tai

Prof LAU Yu-lung

Dr LEE Shui-shan

Dr LI Patrick

Dr LIN Chi-kit

Amy

Dominique

Ringo

### **Authoring Team**

Dr LEE Chi-Kei, Krystal

Dr LEE Shui-shan

## **Executive Summary**

A study to assess the needs of people living with haemophilia and HIV infection was initiated in response to the resolution at the forty-fourth meeting of the Hong Kong Advisory Council on AIDS (ACA). The investigating team, consisting of professional staff of the Special Preventive Programme of the Department of Health, conducted the assessment with guidance from a panel of advisors. The objectives of the study were: to describe how persons living with haemophilia and HIV infection and their carers are coping with their medical and psychosocial stresses; to identify areas where these stresses are causing significant problems; and if any, to propose interventions in response to these problems.

The study employed three methods, namely focus groups, individual interviews and a questionnaire survey (using the short form 36 health survey questionnaire) to provide a detailed need assessment. Patients, their carers and health professional taking care of the patients were recruited from a range of clinical and social service providers ([Section C](#)). The study lasted between January and June 2004, the final report of which was adopted by September 2004.

A total of thirty-two people living with haemophilia and HIV infection were identified. Information on twenty-five patients was obtained from the patients and/or their carers. It was revealed that the patients have been facing a spectrum of debilitating psychosocial consequences of the double tragedy. Nine problem areas were identified and they were: multiple medical conditions; social isolation, constraints in mobility, limited access to treatment, lack of a coordinated service, financial difficulty, unemployment, psychological distress and difficulties encountered by the carers. Patients' health status as obtained in the short form 36 health survey was below that of the healthy population. ([Section D](#) & [Section F](#)).

Based on the study results, eight recommendations are set out to address the unmet needs of the patients and their carers. These are: regular monitoring of the needs of people affected by the tragedy, simplification of medical follow-up arrangement and enhancement in transport service; facilitation to the setting up of a peer support network, provision of long term financial support, ensuring access to treatment, formulation of a long term rehabilitation and care plan and addressing to needs of carers. ([Section H](#)).

Apart from identifying the needs in HIV infected haemophiliacs, the study by itself has served as a gesture to show concern to those affected. It has been a counselling as well as an educating process to those interviewed. Social service has been mobilized and access to treatment in some patients facilitated ([Section G](#)). The study was not without limitations, which included incompleteness and biases from responders. Inherent limitations of qualitative studies could have been augmented due to unstable medical and psychological conditions and personal interest of some of the responders ([Section E](#)).

## Section A. Background

1. Sixty-four haemophilia patients were known to have acquired HIV infection through transfusion of blood products as recorded in the Department of Health's HIV/AIDS reporting system. All these infections are believed to have taken place in Hong Kong prior to August 1985, before heat treated safer alternatives became available. They accounted for less than three percent of all HIV reported cases over the last two decades. Among them, twenty are known to have progressed to AIDS, fifteen died and five left Hong Kong. The Council for the AIDS Trust Fund has, as of the end of 2003, approved a total of 58 ex-gratia payments<sup>1</sup> to patients and families affected by this double tragedy.

2. Advances in medical treatment (most notably the highly active antiretroviral therapy, or HAART) introduced since mid-1990s have been highly effective in reducing morbidity and mortality associated with HIV infection. HIV infected individuals, once believed to have been given a death sentence, are now enjoying a long-awaited chance to live and establish goals of longer term ever since. However, many surviving HIV infected haemophiliacs and their carers have endured unpleasant experiences which could have long-lasting consequences. Their needs are due to be re-evaluated and addressed; so are the lessons learned from the assessment, which might be useful for the public health services in Hong Kong.

---

<sup>1</sup> The rates of payments were: HK\$1M for those infected, married with dependent children; HK\$0.75M for those infected, married without dependent and HK\$0.6M for those who are single. There is an additional HK\$ 0.3M for an infected spouse or child of the patient. The family of the infected who has died and was not eligible for the above would be given HK\$0.3M.

3. At its forty-fourth meeting on 17 October 2003, the Hong Kong Advisory Council on AIDS (ACA) resolved to initiate a study to assess the situation. The study, to assess the needs of HIV infected haemophilia patients in Hong Kong, was undertaken by professional staff from the Special Preventive Programme on behalf of the Council Secretariat with the support from a panel of advisors (see p.5-6 for [Membership lists](#)).

## **Section B. Aims and objectives**

4. The aim of the study was to assess the stresses and current coping strategies of the HIV infected haemophiliacs and their carers in Hong Kong. The following objectives were defined:

- (a) to describe how persons living with haemophilia and HIV infection and their carers are coping with the medical and psychosocial stresses;
- (b) to identify areas where these stresses are causing significant problems currently, if any; and
- (c) to propose interventions in response to problems identified in the study.



## Section C. Methodology

### I. Study design and recruitment of subjects

5. The study design was referenced from WHO Rapid Assessment Response<sup>2</sup> and was akin to an action-based research<sup>3</sup>. Three study methods, namely focus groups, individual interviews and a questionnaire survey, were used to support a detailed assessment of the situation. Data were collected from patients, carers and health professionals who were taking care of HIV infected haemophilia patients. Ethical approvals for undertaking the study have been obtained from the respective ethics committees of the Department of Health and Hospital Authority.

6. The subjects were patients with haemophilia<sup>4</sup> who contracted HIV infection<sup>5</sup> through transfusion of blood products before 1985 in Hong Kong. They were recruited from the two major public HIV clinics and other agencies/services (listed in [Appendix I](#)) that have access to these patients. The two HIV clinics are (a) Integrated Treatment Centre of

---

<sup>2</sup> The WHO Rapid Assessment and Response (RAR) is a means for undertaking a comprehensive assessment of a public health issue in a particular study area, including characteristics of the health problem, population groups affected, settings and contexts, health and risk behaviours, and social consequences. It identifies existing resources and opportunities for intervention, and helps plan, develop and implement interventions.

<sup>3</sup> Action research refers to ‘any study in which researchers work explicitly with and for people rather than undertake research on them. Its strength lies in its focus on generating solutions to practical problems and its ability to empower practitioners’. From Sackett DL et al. Evidence-based medicine: how to practice and teach EBM. Edinburgh: Churchill Livingstone, 1997.

<sup>4</sup> Haemophilia is defined as blood disorders resulting from an inherited deficiency of a clotting factor. Haemophilia A, a sex-linked disease leading to factor VIII deficiency, is the commonest type.

<sup>5</sup> HIV infection is diagnosed in a laboratory as a positive HIV antibody screening assay confirmed by Western blot test.

Department of Health (Clinic A), and (b) Special Medical Service of Queen Elizabeth Hospital, Hospital Authority (Clinic B).

7. Nurses in-charge of the HIV clinics were given the study protocol, followed by a thorough explanation. They were asked to assist in the recruitment of subjects and to provide information regarding the following : total number of patients identified in the clinic, number of refusals and their reasons, participants' names/ nicknames, sex, date of birth (ddmm) and contact telephone number. Same data had to be collected for every carer identified. Investigators collected these data and then contacted them subsequently over phone.

8. Agencies or services that might be accessed by patients were identified and contacted. The study details were explained to the contact persons. Through these networks, patients were informed of the means of contacting the investigators, should they wish to participate in the study.

9. Patients not recruited from HIV clinics must verify their HIV and haemophilia status in order to be eligible to participate in the study. They had to either submit appropriate documents (such as letters from registered physicians), or undergo medical consultation or voluntary testing and then be channelled through the HIV clinics. Those whose HIV and haemophilia status could not be proven were excluded.

10. Carers<sup>6</sup> were recruited via nurses of HIV clinics or the recruited patients. Health professionals including nurses, medical social workers and clinical psychologists currently taking care of HIV infected haemophiliacs from the public HIV clinics, haematology clinics and an AIDS non-governmental organization were identified and invited to participate in the study.

11. Investigators then explained the study design to patients and carers. The following points were stressed: voluntary, confidential and

---

<sup>6</sup> Carers is defined as 'people who look after a relative or friend who need support because of physical or learning disability or illness, including mental illness', as adopted by the UK Department of Health.

anonymous nature of participation, and inability of investigators to guarantee implementation of their suggestions. They were reassured that data were recorded using unique personal identifiers (ddmm of date of birth + first two digits of HKID number). Subjects were subsequently identified as S1, S2 etc throughout the study. Carers were identified as S1a, S2a etc. Explanations were repeated and informed consent forms ([Appendix II](#)) signed by each patient and carer just before the start of focus groups or interviews.

## **II. Study methods**

### ***Focus groups***

12. All patients and carers identified were invited to join the focus groups. Three separate sessions for patients, carers and health professionals were conducted. The objectives were to (a) formulate framework of subsequent interviews; (b) identify the main problems arising from the 'double tragedy'; and (c) propose interventions for these problems on a group level. Guiding questions for focus groups are listed in [Appendix III](#).

### ***Individual interviews***

13. All patients recruited were invited for individual interviews. Carers were invited for interview individually only if patients were unfit for interview. Objectives of individual interviews were to: (a) identify medical and psychosocial stresses of individual patient; (b) explore their coping strategies; (c) identify areas of problems, if any, arising from the 'double tragedy'; and (d) explore possible intervention to alleviate such problems if needed.

14. A medical social worker from Social Welfare Department working at one of the HIV clinics was assigned to attend the interviews if patients

and carers accepted such offer. This aimed to mobilize existing social services if deemed possible, while avoiding the clients to go through the pain again if such service was to be arranged separately at a later timepoint. The interviews were semi-structured, during which questionnaires were administered by interviewers. Flexibility was allowed regarding the location and time of interviews as compromised arrangement was made between the interviewers and interviewees. Public venues that provided privacy and convenience for patients were preferred. Means were explored on individual basis so as to improve response rate. Guiding questions for interviews are listed in [Appendix IV](#).

### ***Questionnaire survey***

15. Questionnaires ([Appendix V](#)) were administered by interviewers during individual interviews to obtain demographic and essential clinical data; to quantify the level of satisfaction of medical and social services received; and to measure their quality of life (QoL) by a standard tool, short form 36 health survey questionnaire (SF36)<sup>7</sup>. Its Chinese translation has been validated locally in healthy individuals. Permission for use from the developer of Chinese (HK) Health Survey SF-36, Prof Cindy Lo Kuen Lam of The University of Hong Kong has been sought and approved.

16. Questions regarding the level of satisfaction of existing medical and social services were referenced from a questionnaire survey on the utilization of services provided by the Special Medical Consultation Clinic in 1994<sup>8</sup>.

---

<sup>7</sup> Short form 36 health survey questionnaire (SF-36) contains 36 health related questions in 8 dimensions. These are physical functioning, role limitation due to physical problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional problem and mental health. The scores are summed up into two aggregate scores: Mental Component Summary (MCS) and Physical Component Summary (PCS).

<sup>8</sup> A review of services provided to people with HIV/AIDS in Hong Kong published by AIDS Services Development Committee of Advisory Council on AIDS. Available at [www.aids.gov.hk](http://www.aids.gov.hk)

### ***Pilot interviews***

17. Pilot interviews with four heterosexually acquired HIV infected male patients from one HIV clinic were conducted to prepare the interviewers and to test the interviewing contents, its flows and the questionnaire. As a minimum, each interviewer observed and pilot tested one interview before the main study. Apart from standardization of wordings, there was no major change in interview design after the pilot testing.

### **III. Facilitators and interviewers**

18. The team of interviewers, including and led by one investigator (Ig), consisted of altogether four health professionals. They had experience working with HIV infected haemophilia patients but were not currently taking care of them clinically. Before the study, they enrolled in two training sessions on the conduct of interviews and focus groups.

19. Interviewers conducted the interviews and acted as the facilitator, recorder and observer in the focus groups. Interviewers received a set of protocol from the investigator and briefing sessions were held to ensure that the interviewers understand and strictly adhere to the protocol. Interviewers reported to and discussed with Ig for any necessary actions that needed to be taken promptly after the interviews. They then transcribed the interview, prepared a written report, and presented their results at a report back meeting where clarifications were made at the same time. All results were collected by Ig.

### **IV. Data collection, analysis, and disposal**

20. Focus groups and interviews were audio recorded unless subjects disagreed, in which case field note was taken. All study materials and

data collected were in Chinese (Cantonese). Audio recordings were transcribed in Chinese and/or English and repeatedly read to identify emergent themes. Recurrent themes were developed and categorised. Within case and across case analyses were performed using the framework approach, with input from the focus group findings, and as advised by members of the advisory panel.

21. Quantitative data of individual patient obtained from the questionnaire survey were described. Eight domains and two summary scores obtained from SF 36 were calculated and presented after standardization according to sex and age (with normal mean 50, SD 10 across all scales) for each individual.<sup>9</sup> Group medians were hence calculated and presented.

22. Interviewers worked with the subjects to generate possible solutions to practical problems identified during the study. Actions were then initiated when appropriate. Advice for appropriate management of specific cases that required particular concerns was sought from members of the advisory panel.

23. All study materials including audio recordings would be destroyed upon completion of the final report.

---

<sup>9</sup> Calculations of domain scores were based on formulas stated in SF-36 Health Survey Manual and Interpretation Guide by Ware JE, Snow KK, Kosinski MA and Gandek B. Nimrod Press: Boston, 1993. Calculations of summary scores were based on formulas stated in SF-36 Physical and Mental Health Summary Scales: A Manual for users by Ware JE and Kosinski M. Lincoln, RI: QualityMetric Incorporated, 2001.

## **Section D. Results**

### **I. Statistical summary of responses**

24. Apart from the two HIV clinics, twelve other agencies ([Appendix I](#)) were contacted and they agreed to assist in recruiting potential subjects. Hospital doctors and contact persons of NGOs were asked to identify subjects with HIV infection and haemophilia and their carers, and to provide them with the study leaflets. Access to practising haematologists was provided through the two professional bodies. Letters describing the study and leaflets were emailed to all members of one professional body, while the same notice was put up in the website of another. It is believed that the message about the study recruitment should have reached almost all haematologists via the above means. Reply forms had been sent to each agency but only two replies were received. Investigators received responses and enquiries from both private and public doctors, implying that the recruiting methods had been effective.

#### ***Patients' responses***

25. A total of thirty-two patients surviving the double tragedy were identified. Sixteen were recruited from Clinic B, fifteen from Clinic A (one in fact being followed up at both clinics). Another patient was recruited from one of the paediatric units and one from an AIDS NGO, who in fact had never attended any medical clinic for HIV treatment.

26. Six of the thirty-two patients refused to participate in the study because of 'nothing to say', 'poor health', and 'dissuaded by wife'. Another three who refused to participate in the study because of 'poor

health' had their carers recruited and *interviewed individually*. One patient defaulted two scheduled interviews and could not be reached by telephone thereafter.

27. Only eight patients agreed to participate in the *focus group*. Most of the others who refused did not explain reasons for refusal. A total of twenty patient interviews were conducted between April and June 2004. All interviews were held at the Clinics A and B except two that were conducted at the patient's home and hospital wards because of poor medical status of patients. Four interviews were attended by the designated medical social worker.

### ***Carers' responses***

28. A total of ten carers of nine patients were identified and recruited into the study. Six were mothers, one father, one girlfriend, one sister and one brother. Four were interviewed individually to obtain detailed data regarding the patients who did not participate in the study or to collect more in-depth data. Two carers of the same patient were interviewed at patient's home. Three of the rest participated in a focus group while one could not be reached by phone. The focus group was attended by the designated medical social worker.

### ***Health professionals' participation***

29. The focus group for health professionals was attended by three medical social workers, three nurses from two HIV clinics and one outreach nurse from an NGO.

## **II. Patients' demography**

30. Patients' demographic information is summarized in Box 1. All patients traced were male at prime time of their lives.

31. About one third of patients attained an education level of Form three or below, another third Form four to five and one fifth post secondary education, either in computer, information technology or design field. Most quitted school early because of frequent hospital admissions and expected mortality from HIV infection, say within a few years from diagnosis.

32. Half the patients (13) were unemployed. Eight of them received comprehensive social security allowance (CSSA) at the time of study, while others were financially supported by family or own savings. Those employed (7) mainly worked on sedentary jobs, about half of them in specialised areas subsequent to the pursuit of post secondary education in particular fields. All patients received the ex-gratia payment given out by the AIDS Trust Fund, except one patient whose application was under process at the time of study.

33. Half of the patients were bachelors, nine with girlfriends, while three were married, two before and one after being diagnosed with HIV infection. Two patients had children. A total of three patients had not disclosed the HIV status to their girlfriends/ wives, otherwise all partners have been tested HIV negative.

### Box 1. Patients' demography\*

| Category   | Results  | Remarks   |
|--|--|---|
| <b>1. Sex</b>  | All male   |   |
| <b>2. Median age (range)</b>   | 35<br>(21-54)  |   |
| <b>3. Education level</b><br><i>Special education:</i><br><i>Primary level:</i><br><i>Form three or below:</i><br><i>Form four to five:</i><br><i>Post secondary:</i><br><i>Unknown:</i> | 2 (8%)<br>2 (8%)<br>6 (24%)<br>7 (28%)<br>5 (20%)<br>3 (12%) |   |
| <b>4. Employment status</b><br><i>Student:</i><br><i>Employed:</i><br><i>Employed in supported hostel:</i><br><i>Unemployed:</i><br><i>Undetermined:</i>                                 | 1 (4%)<br>7 (28%)<br>2 (8%)<br>13 (52%)<br>2 (8%)            | - Job nature: account trainee, designer, IT professional (2), stock keeper, property sale, office assistant, hotline operator |
| <b>5. Monthly income</b><br><i>\$5000-10000:</i><br><i>\$10000-20000:</i><br><i>\$&gt;20000:</i>   | 3 (38%)<br>3 (38%)<br>2 (25%)                                | - Including one student intern  |
| <b>6. CSSA recipients</b>  | 8 (32%)  |   |
| <b>7. DA recipients</b>  | 23 (91%)   | - Unknown for two patients  |
| <b>8. Ex-gratia payment recipients</b>   | 24 (96%)   | - All except one application in process   |
| <b>9. Living alone</b>   | 5 (20%)  |   |
| <b>10. Marital status</b><br><i>Married:</i><br><i>Not married but had stable girlfriend:</i><br><i>Single without girlfriend:</i>   | 3 (12%)<br>9 (36%)<br>13 (52%)                               | - Two married with children   |
| <b>11. HIV status of girlfriend/wife</b><br><i>Girlfriend/ wife unknown of patient's HIV status:</i><br><i>Disclosed, tested with negative results:</i>                                  | 3 (25%)<br>9 (75%)   |   |

\*Data obtained from 25 patients and or their carers  
CSSA: comprehensive social security allowance; DA: disability allowance

### III. Assessment of medical needs

34. All patients suffered, at varying levels of, morbidity from **HIV infection, haemophilia** and **hepatitis C infection**. All three diseases run a chronic course and carry with them multiple consequences which could be fatal. **Psychiatric symptoms** were not uncommonly found.

#### *HIV infection*

35. All, except one, patients were receiving regular care and treatment for HIV infection at the public service at the time of study. At least five were reported to have *AIDS*<sup>10</sup> (Box 2). One developed AIDS in 1996, just prior to the availability of HAART, three defaulted medical treatment until AIDS developed (chest infections and tuberculosis) and one had been unknown of his HIV status until AIDS was diagnosed. There were four other *defaulters* (only attended HIV clinic since 1999, 2002 and 2004 (two patients)). One patient had not been informed of his HIV status until half a year ago.

#### **Box 2. AIDS in haemophilia patients.**

- i. Mr. A defaulted follow-up between 1987 and 1999 when pulmonary tuberculosis was diagnosed. CD4 at that time was 70 only.
- ii. Mr. B developed severe chest infection in 1996 with a CD4 count of 40.
- iii. Mr. C only realized his HIV status when he developed severe chest infection with a CD4 count of 8 in 1998.
- iv. Mr. D defaulted medical treatment until he developed chest infection in 1999 with single digit CD4 count.
- v. Mr. E defaulted medical treatment until 2002 when he developed tuberculosis.

---

<sup>10</sup> AIDS is diagnosed clinically when there is evidence of immunodeficiency arising from HIV infection in a patient with a positive HIV test confirmed by Western blot. For surveillance purpose, 26 AIDS defining illnesses have been defined as recommended by the Advisory Council on AIDS in 1995 in Hong Kong. Details available at [www.aids.gov.hk](http://www.aids.gov.hk)

36. All except five patients (75%) were on *anti-retroviral therapy*. One patient had been taken off treatment half a year ago when he could not tolerate the side effects, including gastrointestinal upsets and tiredness. He remarked that taking drugs was 'troublesome'. His CD4 dropped significantly and he worried that treatment would soon need to be restarted. There was yet no indication to initiate anti-retroviral drugs in the other three patients. One patient had not attended any HIV clinic for assessment.

37. Latest CD4 levels of patients ranged from around 100 to 600 cells/ $\mu$ l. No patient presented with any acute HIV related complication at the time of interview. Side effects of medications (gastrointestinal upsets, diarrhoea, and dizziness), skin problems, complex regimen, strict adherence, resistance patterns, limited future drug options were commonly cited areas of concern. A few patients mentioned taking traditional Chinese medicines to boost up immunity (e.g. Lingzhi).

38. In sum, undue delay in receiving appropriate medical treatment for HIV infection appeared to be common, with morbidity subsequent to immunosuppression which could have been prevented, or delayed by appropriate use of anti-retroviral therapy. Most patients had already experienced immunologic failure and had been put on anti-retroviral therapy. The problems of drug resistance and limited drug options were foreseeable. Complaints about side effects of medication were often raised.

### ***Haemophilia and orthopaedic problems***

39. Seven patients did not attend regular follow-up at any haemophilia clinic. Most had not required Factor VIII injections for a long period of time as of the time of the interview. A few in fact avoided attending the 'clinic' which reminded them of their painful past experiences. Some considered it a waste of time and money when they had difficulty taking time off work; others would rather approach alternative therapy (bonesetter and over-the-counter medications). Some obtained the vials and injection equipment through brothers, other patients or the HIV

clinic.

40. The level of severity of haemophilia among the patients was wide-ranging as assessed by frequency and number of injections, limitation in mobility, use of analgesics, and undertaking of surgery (see [Box 3](#)). At the time of interview, about a quarter of patients required almost no *injection*, while about half needed more than one injection per week. The most severe cases required injections as frequent as thrice weekly.

41. Three quarters of patients had limitation in *mobility* as affected by haemophilia which had led to joint destruction. Among them, about half needed some form of walking aid. In fact, most people believed that it was better not to move or walk to minimize chance of injury and hence bleeding. Shoulder and elbow functions were affected in four patients.

42. A quarter of patients required either occasional or regular use of *analgesics*. Some of them obtained medication over the counter. One patient was put on regular morphine and physeptone for pain control.

43. Six patients have undergone some form of *orthopaedic surgery*, while three have been scheduled or planned for one in near future. Two of the six patients who had been operated on were now planning for replacement of the artificial joints, which normally functioned for 10 years only. One patient was only offered an early appointment recently in one orthopaedic unit, whose delay in offering operation was apparent for three years already.

44. Apart from bleeding in musculoskeletal system, bleeding in other organs occurred in three patients. One patient sustained an injury to his right eye while he was a child. It resulted in severe bleeding finally leading to *blindness*. He has put on an artificial eye for a few years. Another patient had an episode of upper *gastrointestinal bleeding* requiring partial gastrectomy. Yet another one patient sustained injury to his head at childhood and was diagnosed with mild to moderate *mental retardation* afterwards.

45. In summary, patients were affected by haemophilia at a wide ranging level of severity. While a few patients functioned as if they had

no haemophilia, some were severely debilitated as a result of it. Haemophilia led to pain which could be intractable, limitation in mobility and performing other daily activities, disfigurement, repeated operations, blindness and even mental retardation

### Box 3. Level of severity of haemophilia

| Category  | Results   |
|---|---|
| <b>1. Frequency of Factor VIII use</b><br><i>Almost nil:</i><br><i>Once every few weeks:</i><br><i>Once weekly:</i><br><i>More than once weekly:</i><br><i>Unknown:</i>   | <br>7 (28%)<br>5 (20%)<br>7 (28%)<br>3 (12%)<br>3 (12%) |
| <b>2. Mobility</b><br><i>Walk well unaided:</i><br><i>Crippled unaided:</i><br><i>Walk aided:</i><br><i>Unknown:</i>  | <br>5 (20%)<br>9 (36%)<br>8 (32%)<br>3 (12%)            |
| <b>3. Upper limb function</b><br><i>Affected (combing, or typing):</i>  | <br>4 (16%)   |
| <b>4. Analgesic use</b><br><i>Use when needed (non-opioid):</i><br><i>Regular use (non-opioid):</i><br><i>Regular use (physeptone and morphine):</i>  | <br>4 (16%)<br>2 (8%)<br>1 (4%)                         |
| <b>5. Surgery</b><br><i>Ever undergone joint replacement:</i><br><i>More than 1 surgery done:</i><br><i>Surgery planned/ indicated but not yet done:</i><br><i>Replacement of artificial joints planned/ indicated:</i> | <br>6 (24%)<br>2 (8%)<br>5 (20%)<br>2 (8%)              |
| <b>6. Internal bleedings</b><br><i>Gastrointestinal bleeding:</i><br><i>Intracranial bleeding:</i><br><i>Bleeding in eye (leading to blindness):</i>  | <br>1 (4%)<br>1 (4%)<br>1 (4%)                          |

### **Hepatitis**

46. All patients were positive for Hepatitis C (HCV) infection. One

patient had history of an acute episode of non-A non-B hepatitis in 1985. At least three were also known to be positive for Hepatitis B. Four patients were known to have abnormal liver functions at time of interviews. One patient had received interferon treatment in 1999 and another one currently being planned for treatment. Most patients admitted habitually taking alternative or traditional Chinese medicine to improve the liver function. One patient developed hepatocellular carcinoma in February this year and succumbed shortly after the study interview in April.

### ***Psychiatric problems***

47. Psychiatric symptoms were not uncommon among patients. One patient suffered from a psychotic disorder while at least eight patients demonstrated varying level of neurotic symptoms and even features suggestive of post-traumatic stress disorder. Details are described later in this section ([V. Assessment of psychological status](#)).

### ***Other problems***

48. Two patients were *mentally retarded*.

49. Two patients *succumbed* shortly after the interviews. Causes of death were liver cancer and renal cell carcinoma.

50. Access to dental care was another concern for patients. Currently the government only provided tooth extraction but not other dental care services, which patients considered essential to maintain or improve the dental health that was affected by haemophilia with gum bleeding.

## IV. Assessment of social constraint

51. The main social constraints identified are **isolation, financial constraints and unemployment**. Socioeconomic background summary can be found in [Box 1](#).

### *Isolation*

52. The major and universal social problem identified is isolation. On an individual level, this is rooted from the *multiple medical conditions* which directly limited the patients' *mobility*. Past *experiences of discrimination*, especially inadequate access to appropriate medical services, and more importantly, *perceived stigma* barred them from *disclosing* their HIV status to anyone. All except two patients never disclosed their HIV status to anyone. A few even refrained from talking about haemophilia which they perceived as being associated with the stigma of HIV infection. Painful discriminatory experiences occurring in the clinical setting on a few patients caused them to refrain from *receiving medical care and treatment* in the public service. Many avoided developing any *intimate relationship* as they considered themselves a burden, and for the very fact that HIV, still an incurable disease, transmits sexually. Their *limited education and employment* choices again precluded the formation of any form of support network.

53. On the family level, discrimination was painfully experienced, perceived, and was remembered by the carers (especially mothers). The psychological consequences were deep-seated and persisted to this day. Family members often *feared* about patients sustaining any injury (leading to uncontrolled bleeding episodes) and at the same time, were *fond* of their sons despite the medical trauma of haemophilia and HIV infection. These often led to the shaping of a family that was secluded and encapsulated. The families typically *over-protected* the patients and received little support from their extended families. The relationship between mothers and sons enmeshed where love of the mother was

returned with agitation and dependence of a socially handicapped son. The problem of isolation can be illustrated by the following most 'extremely isolated' cases (Box 4).

#### **Box 4. Isolation in patients with haemophilia and HIV infection**

- i. Mr. A did not participate in the study to avoid meeting any stranger. He has studied up to Form three, has few friends and seldom left home. Mother described Mr. A as *shy, immature, had poor communication skill*. He walks with a crutch and always idles at home watching television or playing computer games. His mother blamed herself for failing to enable Mr A to lead a more independent life. She believed that their family was inferior because it carried a heritable disease and the perceived stigma with HIV infection.
- ii. Mr. B faces *discrimination by his family members*. His clothes are washed in a separate washing machine. He uses disposable cups and he never shares meal with his family. The family receives inadequate information regarding caring for a family member with HIV infection. Mother has never expressed her fear and worries. She feels helpless and does not know what to do.
- iii. Mr. C recalls his mother saying that 'never dare think anyone would help us', as relatives looked down on a family with haemophilia in Mainland China one or two decade ago. His joints are severely affected by haemophilia, limiting his mobility and self care abilities. His painful experiences as a 'problematic child with haemophilia' has reinforced his perception of being inferior, aggravating mutually his passivity and pessimism. He now *enjoys nothing* about life, spending most time idling at home and has no pastimes. He has never developed any intimate relationship since he considers himself a burden to others.
- iv. Mr. D led a completely isolated life alone in a rural village in New Territories in the first *four years* after HIV diagnosis was made, for fear of transmitting the virus to his family members. He was only occasionally visited by his mother who bought him food during that time.
- v. Mr. E spent three years in a hospital 'waiting for an operation'. Intractable pain made him dependent on regular morphine and physeptone after the long awaited surgery. Another operation has been planned for 'a few years already', as it has always been. He is unemployed and living on CSSA. He prefers staying at home than going out (which increases level of pain) and being alone than meeting friends (which increases expenses). He describes himself as if being *incarcerated*, especially when he looks out through the iron gate of his flat.

### ***Financial Constraints***

54. In all except four patients who were in better socioeconomic background, financial constraint was expressed as a major concern (84%). Patients affected by haemophilia and HIV infection often had low income due to lower education background, limited employment options, multiple medical problems and disability (see Box 1). They had higher expenditure for traveling to and from clinics (disabled persons carrying large amounts of factors VIII), purchase of health related services (consulting private doctors such as dermatologist, dentists, traditional Chinese medicine practitioners, alternative medicines practitioners and bonesetters) and products (alternative or traditional medicines- mainly for 'immune and liver function boosting').

55. Most recipients of ex-gratia payments reported having spent almost all of the money, except a few who received the payment in recent few years. Current financial support system through CSSA, support fund for HIV/AIDS patients and their families, and disability allowance was considered as 'inadequate', 'inflexible', and 'a disgrace'. As patients frequently took taxi to travel to and from clinics, procedures for redemption of its fee were 'inefficient' and 'humiliating'. Many patients refused to apply for government subsidy as the process was akin to 'begging', signifying 'a loss of dignity'.

### ***Unemployment***

56. Thirteen patients (52%) were unemployed at time of interview. About half of them expressed a strong desire to earn and sustain their own living, while others expressed that 'it's difficult to earn as much as that from government subsidies'. Among those employed, almost all showed concerns regarding sustainability of current employment. The poor economic environment in general, possible decline in general health and changes in job nature (e.g., requiring frequent overseas trips, not an uncommon finding nowadays or manual work) are contributing factors. All these have led to poor self-esteem and psychological distress among the patients.

### ***Patients with better social function***

57. A number of patients managed to lead a relatively decent social life. This is largely associated with better medical condition, better socioeconomic background, positive coping strategy, presence of religious background and the support from family. Examples of such are illustrated in [Box 5](#).

#### **Box 5. Profiles of patients' social support network**

- i. Mr. A, who holds a master degree, works as an IT professional. His mobility is preserved and he functions well socially with support network from colleagues, friends and *his religious group*. He has one *confidant* who knew his seropositive status and is supportive to him.
- ii. Mr. B is a *Buddhist*. Meditations help him face life positively to all his adversities.
- iii. Mr. C has been active to participate in a variety of voluntary work and he continued his education by studying accounting. He has lots of friends and he enjoys group activities such as barbecue. He donated half of the ex-gratia payment to a charity organization years ago. Though living on CSSA, he does not express any financial difficulty as he regarded the basic living expenses were adequately covered.

## V. Assessment of psychological status

58. Psychological status of patients is summarized in [Box 6](#). Examples of patients with apparently less psychological distress are described as in [Box 5](#).

59. One patient displayed frank *psychotic* symptoms during phone interviews. He was not receiving any psychiatric treatment. Referral to the Community Psychiatric Team was hence made with his relative's consent.

### Box 6. Patients' psychological profile

|  |          |
|--|----------|
| 1. Apparently psychologically well                                   | 6 (24%)  |
| 2. Presence of psychological distress                                | 16 (64%) |
| <i>Anxiety-depressive symptoms:</i>                                  | 8 (32%)  |
| <i>Anger, feelings from being treated with unjust and absurdity:</i> | 9 (36%)  |
| <i>Odd personality:</i>  | 2 (8%)   |
| <i>Psychotic:</i>  | 1 (4%)   |
| 3. No assessed   | 3 (12%)  |

60. *Neurotic* symptoms were common among patients. Two thirds of patients exhibited some form of psychological distress, about half of them expressed predominantly anxiety-depressive symptoms (low mood, sense of uselessness, hopelessness and helplessness, low self esteem, anxiety, poor sleep, anhedonistic and pessimistic attitude etc), while half demonstrated varying levels of anger, mistrust towards medical system and medical profession, and feelings of being treated unjustifiably. All were congruent to personal painful experience and physical disability. One patient was in the stage of adjusting to his recently informed HIV status. Two patients demonstrated odd behaviours such as inappropriate smiles and inappropriate answers during interviews. None received any psychiatric treatment or clinical psychological service ([Box 7](#)).

61. Factors associated with level of psychological distress included health status, mobility level, personal experiences, socioeconomic status, coping skills, strength and breadth of support network (from family, intimate relationship and other social network), and presence of religious belief.

### **Box 7. Psychological distress among patients**

- i. Mr. A is unemployed and has severe haemophilic arthropathy. ‘Nothing in my life I feel happy about, I was born to bear pain only, only if my health is better, or my joints are less painful then I may feel better. I am so useless, I can just sit at home and every activity I need to do I depend on my mother, it is so painful to see my mother working, doing household chores, but I could not help in anyway. I am so useless.’
- ii. Mr. B requested an early interview just before his death. His last words were meant to express his anger towards the ‘government’ and his plea to strive for the dignity that he, and other patients should have deserved. He believed that he was not treated with respect in the past years. The financial difficulty he and many other patients have been facing was what he was chiefly referring to. The tedious procedure to apply for refund for daily expenses e.g. taxi fee, and the diminution of amount of subsidy from government (e.g., nutritional supplement) spoiled his self esteem. There seemed to be a lot of anger deep within Mr. B, but in his last days, he was much impressed by and thankful to his girlfriend for taking care of him.
- iii. Mr. C only became aware of his HIV status when he developed AIDS in 1998. He had studied and worked through his career despite his disability from haemophilia (with his left leg amputated). However, his sense of security and self-esteem is demolished by having HIV infection, causing great debilitation to his physical health. He is anxious, sensitive to bodily changes (skin ailments and lipodystrophy) and preoccupied by negative experiences. He blames and shows his anger against the medical profession and government. Uncertainty in prognosis has led him losing life direction, and his life goal is yet to be re-established. He admitted that he never had his thoughts and feelings disclosed to anyone—the study interview was the first and last time of his life. It was too painful for him to remember all these.
- iv. Mr. D blames the government for having contracted HIV infection. He believed it was unfair for patients to pay for all the medical expenses. ‘It was their fault, not ours.’

## **VI. Assessment of carers' stresses**

62. Caring for patients affected by haemophilia and HIV infection has been a traumatic event for many of those interviewed. The experience generally **limits one's social function**, creates significant **psychological stresses** and even affects the mental and physical health of the carers. The following assessment was obtained from individual interviews and focus group interviews with ten carers of nine patients. They were one father, one brother, one girlfriend, one sister and six mothers.

### ***Psychological stresses***

63. Stresses stemmed from concerns about health status of patients (injury and frequent emergency admissions relating to haemophilia), fear and uncertainty about HIV infection, misconceptions about the diseases and problems in handling of disclosure to patients (when and how) and to other relatives especially early in the epidemic. In addition, the shameful feeling of having an inheritable and potentially fatal disease, haemophilia and the guilty feeling associated with over-protection were expressed by a few mothers.

64. The fact that having more than one child with haemophilia who may also be HIV infected was not a rarity and it posed particular stresses on the carers and family. Among the thirty-two patients traced, there were five pairs of brothers. There were two other patients' brothers who had died from or with the double tragedy. One carer interviewed was the younger brother of the index patient who was mentally retarded. The carer was himself a haemophilia patient and walked with difficulty. In fact, he cared for his mother who had mental disorder and sustained a stroke recently, and the other brother, who was also affected by haemophilia and HIV infection, and succumbed few years ago.

65. At least two carers were known to suffer from *depression*, one with episodes of attempted suicides many years ago, related to stresses

arising from caring of patients.

### ***Social limitation***

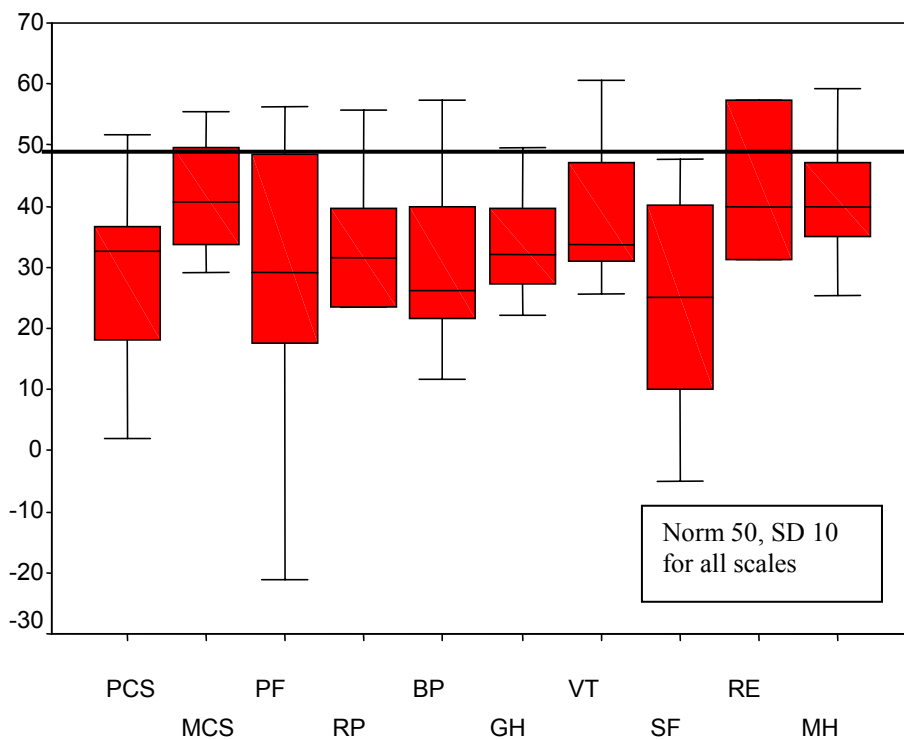
66. Similar to that of patients, carers also faced a number of social constraints. **Isolation** of the carers results from devotion of much time in taking care of patients, experiences of discrimination in hospitals and from other relatives, perceived stigma associated with HIV infection, and the sense of inferiority within the family. All these prevented the family from seeking help from any person, thus refraining from disclosing their painful experiences to anyone. A family with haemophilia is often looked down by other relatives. **Financial difficulty** is a particular concern for carers who allow patients to idle at home, while taking care of them. Carers are also willing to spend much money on their sons as they think that their life-span is limited. The need for taking care of the patients may also limited the carers' **employment options**. One carer expressed that he actually could not concentrate on work since his son was diagnosed with haemophilia and then HIV infection. He often needed to take time off from work, and basically could not perform well. He believed that was the reason for his failure for promotion in his career.

67. Their main areas of concerns were **long term care plan for patients** and the **financial condition of the family**. Almost all expressed the fear that the patients would be abandoned if carers failed to take care of them in any case.

## VII. Short form 36 (SF 36) health survey

68. A total of 17 patients had the SF36 health survey completed. Patients who were too ill did not have the questionnaires administered and those who had difficulty in completing all the questions were not included. The group statistics are described using a box plot<sup>11</sup> (Figure 1). These results may have overrated the overall quality of life as the relatively well-off participants have self selected to join the study, and those who were sick did not participate in this survey.

**Figure 1. Distribution of SF36 scorings\* (N=17)**



<sup>11</sup> A box plot, also known as a box and whisker diagram, provides an visual summary of a distribution. The box stretches from the 25th percentile to the 75th percentile. The 50th percentile (median) is shown as a line across the box. The whiskers showed the lowest and highest values.

*\*Norm – based scoring* means that subjects' scores are compared to sex and age specific results from general healthy population in Hong Kong<sup>12</sup>. The general population scores are standardized to give a mean 50 and standard deviation 10 across all scales. Scores below 50 can be interpreted as below the general population norm.

***Explanatory notes on individual domain***<sup>13</sup>

- PF (Physical Functioning) measures ability to perform vigorous exercise, walking and climbing stairs.
- RP (Role-Physical) measures time off work, loss in accomplishment in work and being 'less careful in work' due to physical distress.
- BP (Bodily Pain) measures magnitude of pain and its effect in social functioning.
- GH (General Health) measures perceived health status.
- VT (Vitality) measures feelings dichotomized into 'energetic' and 'tired'.
- SF (Social Functioning) measures the time and extent off social activities.
- RE (Role-Emotional) measures time off work, accomplished less in work and worked less carefully due to emotional distress.
- MH (Mental Health) measures perceived level of mental distress.
- PCS (Physical Summary Score) summarizes the physical component of the domains.
- MCS (Mental Summary Score) summarizes the mental component of the domains.

69. The medians of all scores are generally lower than those of the general healthy population, indicating that the patients' quality of life were generally lower. The median physical component score (PCS) was 33 while the median mental component score was 41. This largely corresponds to the patients' very low scores in physical functioning (median 27), role-physical (median 27) and bodily pain (median 26) most likely due to arthropathies from haemophilia.

70. Across the eight individual domains, median social functioning (SF) scored lowest at 25 only. This reflects that the physical limitation of

---

<sup>12</sup> Lam CLK, Lauder IJ, Lam TP, Gandek B. Validation and norming of the MOS 36-item Short Form Health Survey (SF 36) on the Chinese Adult Population in Hong Kong. Final Report, Health Services Research Committee Grant #711026, HK: HSRC 2000.

<sup>13</sup> Ware J.E., & Kosinski M. SF-36 Physical and Mental Health Summary Scales: A Manual for users. Lincoln, RI: QualityMetric Incorporated, 2001.

patients, mainly in terms of poor mobility and pain has significantly limited their social function. The observation in fact, echoes one of the main findings in the qualitative part of the study – isolation. However, there is difference in SF between individual patients as reflected by the wide range in the scores. It is, however, obvious that even the patient with the best SF score was below the mean of the general healthy population.

71. The mental composite score (MCS), mental health (MH) and role-emotion (RE) scored relatively higher than physical component, even though it was still below general population. It could be explained by the patients' self-exclusion (those with poorer mental health were not included while recruited patients could already have better coping strategy) and insensitivity of the survey in identifying emotional problems that were prevalent among the patients as obtained from qualitative part of the study. These include feelings predominated by anger, bitterness and solitude.

## VIII. Level of satisfaction with services

72. [Box 8](#) showed the patients' satisfaction level with clinical services. In general, patients had high level of satisfaction with HIV clinics and a moderate level with the haemophilic clinics. There was almost minimal counselling (structured or informal) offered in the haemophilia clinics. Patients perceived that doctors and nurses in HIV clinics were more willing to answer their questions. Counselling was however rated lower compared to the overall clinical service, implying that the existing counselling may not have met the needs of these patients. As illustrated by the patient who rated 'poor' for counselling services, he explained that the counsellor (clinical psychologist) did not understand his problem and could not share his views. He felt like educating the counsellor, instead of being counselled professionally.

### Box 8. Patients' satisfaction level of clinic services

| HIV clinics                  |           |     |      |     |      |     |      |    |
|------------------------------|-----------|-----|------|-----|------|-----|------|----|
|                              | Excellent |     | Good |     | Fair |     | Poor |    |
| Overall (n=16)               | 5         | 31% | 9    | 56% | 2    | 13% | 0    | 0% |
| Medical service (n=16)       | 5         | 31% | 10   | 63% | 1    | 6%  | 0    | 0% |
| Nursing service (n=16)       | 7         | 44% | 8    | 50% | 1    | 6%  | 0    | 0% |
| Counselling service (n=13)   | 2         | 15% | 6    | 46% | 4    | 31% | 1    | 8% |
| Medical social service (n=7) | 0         | 0%  | 5    | 71% | 2    | 29% | 0    | 0% |
| Haemophilia clinics          |           |     |      |     |      |     |      |    |
|                              | Excellent |     | Good |     | Fair |     | Poor |    |
| Overall (n=14)               | 0         | 0%  | 10   | 71% | 4    | 29% | 0    | 0% |
| Medical service (n=14)       | 2         | 14% | 9    | 64% | 3    | 21% | 0    | 0% |
| Nursing service (n=14)       | 0         | 0%  | 11   | 79% | 3    | 21% | 0    | 0% |
| Counselling service (n=3)    | 0         | 0%  | 2    | 66% | 1    | 33% | 0    | 0% |
| Medical social service (n=4) | 0         | 0%  | 3    | 75% | 1    | 25% | 0    | 0% |

Notes:

Total number of response is less when patients did not use such service.

HIV clinics include Kowloon Bay Integrated Treatment Centre and Queen Elizabeth Hospital Special Medical Service.

Haemophilia clinics include the ones in Queen Elizabeth Hospital, Queen Mary Hospital and Prince of Wales Hospital.



## Section E. Study limitation

72. The investigating team adopted different means of subject recruitment and triangulation of methods to allow a detailed needs assessment of the subjects affected by the double tragedy. However, there are several limitations of the study that worth particular concerns.

73. Overall completeness: a total of thirty-two patients were traced, representing half of all the reported cases as recorded by the Department of Health, a proportion that is similar to (or higher than) data in the UK.<sup>15</sup> The recruitment process was intended to cover all possible contact points but was by no means exhaustive. It is possible, though slim, that some eligible subjects had not been informed of the study.

74. Responder bias: all information described in the report has been collated from twenty-five patients only (78% of the thirty two patients traced). It is difficult to assess if those who opted out were better off (e.g., when no assistance considered needed) or worse (e.g., when severe mistrust exists towards the government or living in severe isolation). The SF36 and satisfaction survey may, however, over-estimate the overall situation when the patients in poor medical condition or emotional states could not complete the questions.

75. Aggravated inherent problems of qualitative study: these include those relating to *data quality (accuracy, completeness, validity and reliability)*, *interviewer bias and inter-interviewer bias*. These problems could have been aggravated due to the exceptional circumstances of patients, the complex dynamics between patients, and between patients

---

<sup>15</sup> Less than 400 of the 1200 patients with haemophilia and HIV infection were alive, according to a piece of news from British Broadcast Company dated 2 December 2003. Accessible at <http://news.bbc.co.uk/1/hi/health/3251822.stm>

and investigators (perceived as representing or messengers to the government). Data quality was particularly liable to be influenced by:

- difficulty in building rapport due to lack of trust towards the medical system, medical staff and the government, and perceived stigmatization;
- unstable medical and psychological status limiting amount of data collected and content of interviews; and
- vested interest of the subjects which may lead to exaggeration of the problems concerned.

## Section F. Summary of problems and unmet needs

76. About thirty people are now living with haemophilia and HIV infection in Hong Kong. Some patients are coping well notwithstanding the medical problems and its psychosocial impact. They are able to enjoy life by adopting positive coping skills such as joining voluntary work, seeking peace of mind from religion, against the background of a relatively healthier status or a better socioeconomic environment ([Box 5](#)). Unfortunately, a significant proportion have been brought into an abyss of despair and isolation with prolonged sufferings triggered off by the double tragedy, in line with the literature finding<sup>16</sup>. This is illustrated by the model in [Figure 2](#)

77. **Multiple medical problems** spin off a spectrum of challenges to the physical, social and psychological well-beings of the patients. These challenges are characterized by their interdependency stemming from deteriorating general health from HIV infection and its treatment, often *progressive disability* from haemophilia and progression of HCV infection. The fact that these problems have spanned over two decades, from childhood period, through adolescence into adulthood, even middle age is often exceedingly overwhelming to anyone (**Problem area 1**).

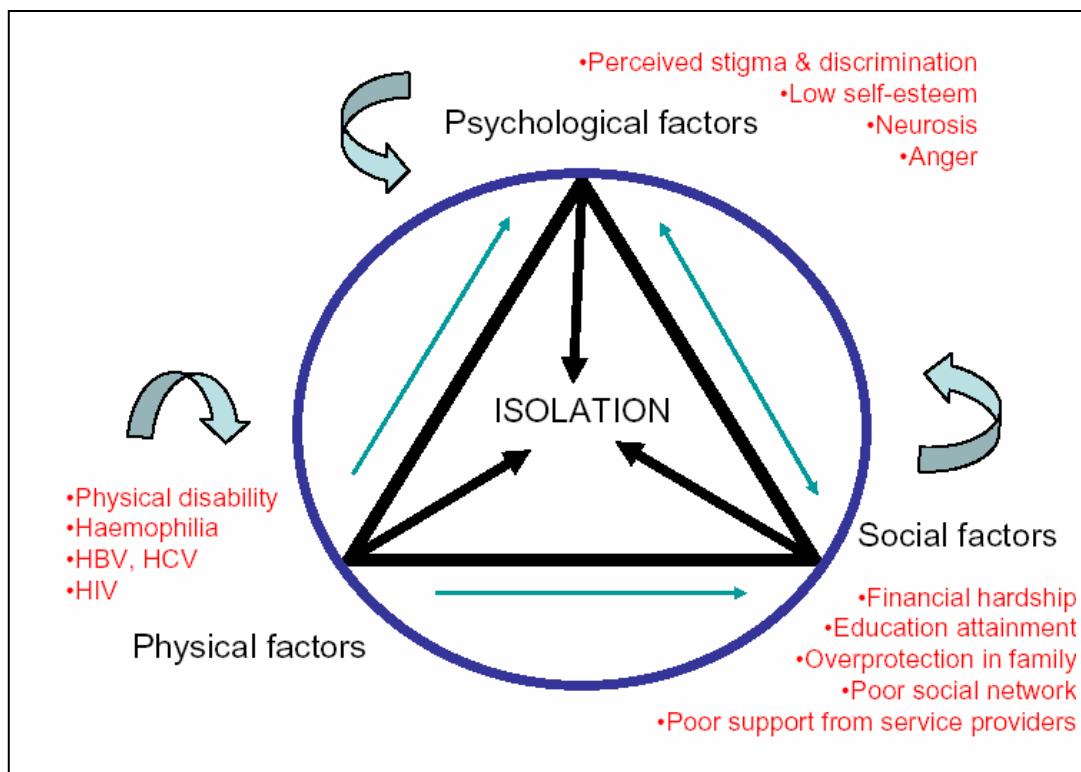
---

<sup>16</sup> Stewart M.J., Hart G. & Mann K.V.. Living with haemophilia and HIV/AIDS: support and coping. *Journal of Advanced Nursing* 1995;22(6):1101-11. Tanaka S., Hachisuka K. & Okazaki T. et al. Health status and satisfaction of asymptomatic HIV-positive haemophiliacs in Kyushu, Japan. *Haemophilia*. 1999;5:56-52. Troppoli S., Vaiani M. & Linari S. et al. Multivariate analysis of factors influencing quality of life and utility in patients with haemophilia. *Haematologica*. 2001;86:722-8

<sup>18</sup> Economic benefits of comprehensive hemophilia care. A fact sheet by World Federation of Haemophilia. Retrieved at [http://www.wfh.org/Content\\_Documents/Other\\_Publications/Fact\\_sheet\\_3\\_Apr04.pdf](http://www.wfh.org/Content_Documents/Other_Publications/Fact_sheet_3_Apr04.pdf) on 2 September.

78. **Isolation** at individual and family level resulting from disability, discrimination experiences, mistrust towards the government, avoidance to receive medical treatment, failure to develop any long term intimate relationship, financial problem and poor coping skills is one major social debilitation among this group of patients. It triggers a vicious cycle leading to a florid display of depressive symptoms with low mood, poor self esteem, helplessness and hopelessness, against the backdrop of a frail support system and amplified perceived stigma. All these further compounded the already existing problems, which were left unknown to anyone and hence untackled always (*Problem area II*).

**Figure 2. Model on the inter-relationship of psychosocial influence from the double tragedy**



79. **Mobility** problems resulting from haemophilia and poor financial support are one major determinant leading to isolation of patients. It lowers the patients' self-esteem, limits their social network, decreases

their employment options and increases the financial burden in terms of travel expenses (***Problem area III***).

80. **Access to care** unfortunately has continued to be an area of concern. Access to orthopaedic service is particularly problematic. Treatment for viral hepatitis has never been accessible and affordable to HIV infected haemophiliacs in the public service. Worries regarding future access to HAART and haemophilia treatment, joint replacement in the shadow of budget cuts are constantly in the minds of the patients and their carers. Sadly enough, discrimination from medical professions is still present. It's a shame that medical doctors and service providers are still avoiding HIV patients, making non-HIV medical problems relatively inaccessible to patients. Dental care was not made accessible to many of them (***Problem area IV***).

81. There is also a **lack of a coordinated medical service** for facilitating patients' access to treatment, overshadowed by the problems of isolation, perceived stigma and reduced mobility (***Problem area V***).

82. **Financial needs** arising from medical problems and poor socioeconomic backgrounds are common. More than half of the patients are facing the problem of **unemployment**, or displaying high level of anxiety relating to job security. These pose significant amount of stress on patients psychologically (level of self esteem, mood changes and anxiety), limiting their access to social network forming, further aggravating the problem of isolation (***Problem areas VI & VII***).

83. **Psychological problems** are present in more than half of the patients at varying level of severity. These have stemmed from both medical and social constraints arising from the double tragedy and again the low self esteem, depressive mood, and *perceived stigma*, all leading to the reinforcement of one's negative thought, and a never-ending vicious cycle (***Problem area VIII***).

84. The **psychological and social stresses faced by carers** are no less than those faced by the patients. *'In no way I can be abused, except by my sorf'*. The guilty feelings about having an inheritable disorder, the burden of taking care of more than one family member with haemophilia

and even HIV infection, the cultural taboos and helplessness, have all led to isolated families which are left alone to face the tremendous stress. The mothers, who very often are the only carers of patients since the day the children were born, never stop taking care of and worrying about their beloved sons, even to the day when they themselves die before the patients do. The financial burden on the family in taking care of one or more sons with haemophilia and HIV infection (poorly educated, unemployed, increased medical expenses) can be enormous (***Problem area IX***).

85. *'Nothing I feel happy about, I was born to suffer'*. It is true that nobody can change the natural course and offer a cure for HIV infection, haemophilia or HCV infection overnight. Yet, this very fact should not stop medical professionals and policy makers seeking alternative solutions to help improving the quality of life of this neglected group of people who have painfully hidden themselves up from the society in the past twenty years. The social support services should be mobilized to provide a set of structured interventions targeting at individual problem areas, as identified from this study.

86. *'I just want to live a life with dignity and respect, but it's too late'*. As a matter of fact, some progress has become evident after launching of the present study. To take another step forward, a set of recommendations corresponding to these problem areas identified are set out in [Section H](#).

## **Section G. Actions arising from the study**

87. Through personal and intensive interactions with patients, carers and service providers, the study has itself served a unique and critical role to offer help and show concern to this special community in the society. The study has also been a counselling, educating and facilitating process.

88. Counselling process: subjects' medical and psychosocial situations were assessed during individual interviews. Interviewers organized and summarized the findings according to the study framework. Problems were listed out, clarified and discussed and options suggested. Many subjects reported the interview would very likely be the first and last chance that he would offer to have his personal concerns disclosed, emotions released and worries shared.

89. Educating process: misconceptions relating to HIV infection and other medical conditions were identified and clarified by interviewers (who are health professionals) and peers during focus groups (including patients and carers).

90. Facilitating process: social and care services were mobilized; examples included application to special fund, referral to community psychiatric nurse and initiating discussion of problems to existing service providers.

91. Advocacy: the study has itself served as an advocate for promoting acceptance of patients, leading to the rescheduling of medical appointments in some cases and possibly, access to a treatment plan for HCV coinfection.

92. Demonstration of concern: as reflected from the subjects, many appreciated and were grateful to witness and have participated in the study, even though it was perceived by many to be late for those who have not survived.

93. A discussion meeting was held with the carers of the deceased patients (who were not included in the present study), a member of the Advisory Council and one investigator of the study. These included one mother and three widowers. It was recognized that the breadth and severity of problems they were facing were no less after the death of the patients. In fact in addition to the findings aforementioned, special problems could be elicited. These include: the pain from bereavement, aloofness from being widowed, difficulty faced by single mothers and out of contact with social service following death of patients. Features suggestive of post-traumatic stress disorder were present (avoidance of activities and situations reminiscent of the trauma, acute bursts of fear and frequent recollection of the event in memories). Their needs would need to be followed up individually.

## Section H. Recommendations

94. About thirty people are now living with haemophilia and HIV infection in Hong Kong. Advancement of treatment not only prolongs their lives, but also the sufferings from the double tragedy. Their unmet needs are categorised into nine problem areas (Box 9).

95. On the advice of the study advisory panel, three short term recommendations and five long term recommendations are put forward to address these unmet needs. The short term recommendations are regarded as relatively straight forward and should be executed by agencies concerned without delay, whereas the long term recommendations however, may require more detailed planning. The problem areas are inter-related and collective efforts would be needed. Specifically, each problem area could be watched with a number of the recommendations as shown below.

### Box 9. Nine problem areas and their recommended responses

***Problem area (I):*** MULTIPLE MEDICAL CONDITIONS and the vicious cycles of aggravation of physical, psychological and social problems

*Responded by*

Short term recommendations ONE & TWO

Long term recommendations ONE, TWO & FOUR

***Problem area (II):*** Social ISOLATION of patients and their families with very limited support network

*Responded by*

Short term recommendations ONE & THREE

Long term recommendations ONE, TWO & FIVE

|  |
|--|
| <p><b>Problem area (III):</b> MOBILITY and transport constraints related to poor joint functions and financial hardship</p> <p><i>Responded by</i><br/>Short term recommendations TWO &amp; THREE<br/>Long term recommendation TWO</p> |
| <p><b>Problem area (IV):</b> Failure to ACCESS affordable and appropriate medical treatment, now and in the long run</p> <p><i>Responded by</i><br/>Long term recommendations TWO &amp; THREE</p>                                      |
| <p><b>Problem area (V):</b> Lack of a COORDINATED COMPREHENSIVE MEDICAL SERVICE</p> <p><i>Responded by</i><br/>Short term recommendation TWO</p>   |
| <p><b>Problem area (VI):</b> FINANCIAL difficulty resulting from limited education and employment opportunities</p> <p><i>Responded by</i><br/>Short term recommendation THREE<br/>Long term recommendations TWO, FOUR &amp; FIVE</p>  |
| <p><b>Problem area (VII):</b> High UNEMPLOYMENT rate leading to low self esteem and financial difficulty</p> <p><i>Responded by</i><br/>Long term recommendations TWO &amp; FOUR</p>   |
| <p><b>Problem area (VIII):</b> PSYCHOLOGICAL stresses in terms of depressive and anxiety symptoms</p> <p><i>Responded by</i><br/>Long term recommendations ONE, TWO &amp; FIVE</p>   |
| <p><b>Problem area (IX):</b> Psychological stresses, social debilitation and concerns of CARERS of the surviving and deceased patients</p> <p><i>Responded by</i><br/>Long term recommendations ONE &amp; FIVE</p>                     |

## **Three short term recommendations**

### **ONE: MONITOR AND FOLLOW UP, REGULARLY AND CONTINUALLY, THE NEEDS OF PEOPLE AFFECTED BY THE TRAGEDY**

96. The problems faced by people affected by the tragedy are multi-faceted, resulting from a vicious interaction of changing medical and psychosocial factors (Problem area I). They demand facilitation and cooperation between different service providers. The present system is reckoned to have failed to address to the needs of this particular group of individuals requiring special care and understanding. It is recommended that a new mechanism to monitor their changing needs with appropriate follow-up is necessary to prevent the situation from worsening. For example, regular case conference can be set up with service providers between the Hospital Authority, Department of Health and Social Welfare Department to work for the best interest of the affected individuals until, e.g. their end of lives.

### **TWO: SIMPLIFY ARRANGEMENT FOR MANAGING MULTIPLE MEDICAL PROBLEMS**

97. Patients with multiple medical problems are currently attending follow-up at three or four different services (including specialty clinics) which may be of different hospitals. This arrangement has led to unnecessary travel time and expenses and has posed difficulty for patients with disability and to take extra time off work (Problem areas I, III & V). Moreover, due to regionalization of services under the Hospital Authority, many patients have been recently transferred to regional hospitals for haemophilia care, which is in a different location as that of their HIV clinics. In short of specialised haemophilia treatment centres, haemophilia has been thought to be inadequately treated in a general haematology department.<sup>18</sup>

98. It is proposed to simplify arrangement of medical consultations specifically for patients with haemophilia and HIV infection. The options are: (a) centralized service provision for all patients at a designated hospital to facilitate access to haemophilia treatment, and management of orthopaedic conditions, liver complications, HIV infection and psychiatric consultation, (b) supply of Factor VIII at HIV clinics so as to decrease the frequency of follow-up at haemophilia clinics, or (c) vice versa – HIV treatment at haemophilia clinics. The final decision should however rest with individual patient, in consultation with his service provider(s).

### **THREE: ENCOURAGE EXPLORATION OF MEANS TO FACILITATE TRANSPORTATION**

99. Mobility is a major area of concern in patients with haemophilia (Problem area III). The existing provision of transport services include: coverage under comprehensive social security allowance (CSSA), free ride service by an AIDS NGO and non-emergency ambulance transport service (NEAT). All have their limitations and are currently suboptimal in meeting the specific needs of the patients, most of whom were in financial constraints (Problem area VI).

100. Patients regarded redemption of fees under the routine CSSA administration inefficient, free ride by NGO and NEAT inadequate and inconvenient. The high level of perceived stigma and sense of isolation of the patients basically make them unwilling to receive services by AIDS NGOs. Development of new approaches to facilitate transportation of patients is needed, which is important to overcome the sense of isolation (Problem area II). Suggested options include simplification of redemption of taxi fees under CSSA, provision of extra fund for transport, innovative services by NGOs, and encouraging driving in selected patients.

## **Five long term recommendations**

### **ONE: SUPPORT THE SET UP AND MAINTAINANCE OF A PEER SUPPORT NETWORK FOR PATIENTS AND THEIR CARERS**

101. Isolation is one major social disability prevalent among patients as well as their families (Problem area II). A peer support network is proposed to be an important way of improving the social support network, facilitating effective information flow and instilling positive coping strategies among those affected. It can also become a channel for patients to express their concerns and needs and thereby lessen their psychological burden both of themselves and that of the carers (Problem areas VIII & IX). It is proposed that the relevant agency or the government should support the formation and maintenance of such network.

### **TWO: SET UP A LONG TERM FINANCIAL SUPPORT SCHEME**

102. The Council for the AIDS Trust Fund set up in 1993 has so far approved 58 one-off ex-gratia payments on compassionate ground to individuals who had contracted HIV infection through the use of contaminated blood and blood products. As the study revealed, most patients have used up all the payments. Financial difficulty (Problem area VI) is one major concern among patients and their carers due to a spectrum of inter-related medical and social reasons arising from the tragedy which has not only lasted for twenty years, and been aggravating with time (Problem area I).

103. Despite advances in HIV treatment, physical disability has worsened, new complications (e.g. hepatitis C) emerge, while the support from the family weakens with aging parents. The World Federation of Haemophilia has called on all governments to make available suitable recompense to all haemophilia infected with HCV and

their families.<sup>19</sup>

104. Treatment for haemophilia patients has been suggested as 'high cost, low volume'. Reverting to central funding may be the only option.<sup>20</sup> Due to the chronic nature of HIV infection, haemophilia and HCV infection, together with the uncertainty in their prognoses, deep-seated psychological distress (Problem area VII) and array of social problems (Problem areas II & VII), it is proposed that a long term financial support scheme should be set up. This should include not just one-off payments but regular disbursement to patients and widows, in line with schemes operating in other overseas countries such as the system operating in the United Kingdom (Boxes 10 & 11).

105. Based on the study finding, the one-off payment shall be set out on compassionate ground and to ease the long-standing financial burden that has been accumulating over the past decade. Additional expenses due to multiple chronic medical problems requiring expensive and long term treatment, extra expenses on transport, psychological distress, limited education and employment options, physical and psychosocial burden on carers and the possible need for long term personal care should be taken into account when formulating the financial support scheme. Basis for calculating such payment would need to be established in order to provide a fair justification to assistance, and to ensure that there is no discrepancy with the approach to other vulnerable communities in the society.

---

<sup>19</sup> XXVI General Assembly of the World Federation of Haemophilia. May 2002. Retrieved from [www.mhe.ngo.hu/english.htm](http://www.mhe.ngo.hu/english.htm) on 25 November 2003.

<sup>20</sup> Lee, C., Sabin, C. and Miners, A.. High cost, low volume care: the case of haemophilia. *BMJ* 1997; 315:962-3

### **Box 10. Grants given to people with haemophilia and HIV infection in UK**

The Macfarlane Trust was set up to administer grants received from the government to make payments to people who have haemophilia and have become HIV positive because of infected blood products. (Payments are also made to widows of the Trust with children or to widows without children but who are incapacitated.) The Trust has been administering the grants and making payments since 1989 and continues to provide financial assistance in the following ways to people with haemophilia infected with HIV.

- Regular payments of between £255 and £450 a month to subsidise the extra costs of living with HIV.
- Winter payments to help with winter heating bills and the cost of warm clothing.
- Single payments for expenditure beyond the scope of regular payments. Generally, these are only made for necessities arising from health issues, and especially for assistance in care of those who become ill.

In addition to financial aid the Trust provides advice and information via the helpline number above on a number of subjects, particularly on the availability of welfare benefits. Newsletters giving up-to-date information about Trust affairs are circulated to all persons registered every three months. A Handbook and summary annual report is also circulated to persons registered each year.

Source: PRODIGY, UK. Retrieved on 19 November 2003 from <http://www.prodigy.nhs.uk/ClinicalGuidance/ReleasedGuidance/webBrowser/pils/PS492.htm>

### **Box 11. Compensation scheme for HCV infection through transfusion of contaminated blood products (press release excerpt)**

Every person in the UK who was alive on the 29 August 2003 and whose Hepatitis C infection is found to be attributable to NHS treatment with blood or blood products before September 1991 will be eligible for the payments. The ex-gratia payment scheme means that:

- people infected with Hepatitis C will receive initial lump sum payments of £20,000
- those developing more advanced stages of the illness - such as cirrhosis or liver cancer - will get a further £25,000; and
- people who contracted Hepatitis C through someone infected with the disease will also qualify for payment

Source: Department of Health, UK. Retrieved on 2 September 2004 from [http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT\\_ID=4070554&chk=rFvkhI](http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4070554&chk=rFvkhI)

### **THREE: ENSURE ACCESS TO APPROPRIATE MEDICAL TREATMENT**

106. Treatment for haemophilia is expensive. Due to fear of increasing costs to medical treatment under the government medical services, it is of utmost importance to ensure access to affordable or free medical treatment for haemophilia patients with HIV and HCV infection. Essential treatment modalities should include HAART for HIV infection, Factor VIII for haemophilia, joints replacement surgery for its complications, and medical treatment for HCV infection (Problem areas IV). Means to ensure access to appropriate dental service should also be formulated.

### **FOUR: FACILITATE A STRUCTURED REHABILITATION AND LONG TERM CARE PROGRAMME, PARTICULARLY OCCUPATIONAL REHABILITATION**

107. Employment serves not only to support haemophilia patients and their family financially, but is also an important asset to help re-establish self-esteem and social network. It is proposed that the government should facilitate occupational rehabilitation and employment of patients who have difficulty in getting a job due to physical disability, frequent time off for follow-up and relatively poor educational background (Problem areas I, III, VI & VII). One option is to set up a designated occupational rehabilitation service providing counselling, training and employment options for patients, whose special needs regarding mobility and frequent time off for medical consultation have to be taken into consideration.

108. To tackle the chronic physical and psychosocial problems arising from the tragedy, a structured rehabilitation programme is desirable. Long term care plan specific to the needs of this particular group of patients shall be available, through the efforts of the respective multidisciplinary team. Provision of residential service offering assistance to daily activities and hospice care should be secured, in view of the debilitating consequences of haemophilia and the mitigation to the burdens to the patients' carers.

## **FIVE: ADDRESS THE NEEDS OF CARERS, WIDOWS AND THEIR CHILDREN**

109. The needs of HIV infected haemophiliacs do not stop at the doorstep of patients alone. The specific needs of carers, the mothers, widows and children in terms of psychological, social and peer support and financial constraints should be addressed to (Problem area IX). This should be taken into consideration and incorporated in the development of services proposed above, including but is not just limited to the building up of a peer network and financial support scheme.



## **Appendix I. Referring agencies and services**

### **Haematology units**

Pamela Youde Nethersole Eastern Hospital

Prince of Wales Hospital

Queen Elizabeth Hospital

Queen Mary Hospital

Tuen Mun Hospital

### **Paediatric units**

Queen Mary Hospital

Princess Margaret Hospital

### **AIDS non-governmental organizations**

AIDS Concern

Hong Kong AIDS Foundation

The Society for AIDS Care

### **Professional bodies**

The Hong Kong Paediatric Haematology and Oncology Study Group

Hong Kong Society for Haematology



## Appendix II. Informed Consent Form

### 受愛滋病毒之血友病患者所面對的壓力及其處理方法評估參與同意書

此評估是由香港愛滋病顧問局發起之一項研究。研究目的是要了解愛滋病病毒之血友病患者及其照顧者現時所面對的壓力及其處理情況；評估處理不善之處；並提出建議以改善病者及其家屬的生活素質。

全港所有受愛滋病病毒之血友病患者及其照顧者均被邀請參與是次研究。參與是完全自願的，與病人日後接受的服務並沒有影響。

此研究共分三部分。包括小組討論會、個別訪問、及問卷調查(於個別訪問同時進行)。

研究過程中，你需要提供你的個人資料包括出生日期、病歷、社會經濟狀況及使用有關醫療及社會支援服務的滿意程度。相關的病症資料(愛滋病機會性感染、CD4 及病毒數量、丙型肝炎等等) 會在得到你的同意後由你的醫生提供。有需要時，小組討論會及訪問時會進行錄音以便記錄。參與者所提供的資料必需是真實的。

研究所得資料及結果均不記名處理，**絕對保密**，只作研究之用，並於報告完成後銷毀。研究報告將會呈交向香港愛滋病顧問局，而報告的進一步處理必須在參與者同意後進行。參與者並必須明白研究結果會有助於有關服務發展，與參與者日後所得到的服務並沒有必然的關係。

如病患者或照顧者同意，研究員會安排一名社會福利署醫務社工出席訪問，目的是希望有效運用社會資源，並減少病患者及照顧者在有需要時重複敘述事件的必要。如情況需要，醫務工會就病患者或照顧者提出的困難安排適當服務並就個別個案作出跟進。

本人已明白本研究的目的是及研究方法，並 \* 不願意 / 願意 / 不適用 參與小組討論會，\* 不願意 / 願意 / 不適用 參與個別訪問/ 問卷調查研究，及 \* 不同意 / 同意 / 不適用 醫務社工出席個別訪問/問卷調查研究。

#### 訪問員

簽名 \_\_\_\_\_

姓名 \_\_\_\_\_

日期 \_\_\_\_\_

#### 見證人

簽名 \_\_\_\_\_

姓名 \_\_\_\_\_

日期 \_\_\_\_\_

\*請刪除不適用者

#### 病患者

簽名 \_\_\_\_\_

姓名 \_\_\_\_\_

出生日期 \_\_\_\_\_(ddmm)

日期 \_\_\_\_\_

#### 照顧者 (需要時填寫)

簽名 \_\_\_\_\_

姓名 \_\_\_\_\_

出生日期 \_\_\_\_\_(ddmm)

日期 \_\_\_\_\_



## **Appendix III. Guiding questions for focus groups**

### Patients:

- (a) How is the double tragedy (HIV infection and haemophilia) affecting you?
  - i. Problem areas (Employment, education, housing, recreational, transport and mobility, family and interpersonal relationship)
  - ii. Health (physical, mental)
- (b) How are you coping with these problems?
- (c) What can be done to improve your quality of life, alleviate the problems or reduce the harm arising from the double tragedy?
- (d) Please provide other opinion on the improving the care and support services
- (e) Please comment and advise on the structure and content of the interview and questionnaire to be used

### Carers:

- (a) From a carer's point of view, how is the double tragedy affecting the patient?
- (b) In your opinion, how are they coping with that?
- (c) How is the double tragedy of the patient affecting you and/ or the family?
- (d) How are you and/ or the family coping with the problems?
- (e) What can be done to alleviate the problems or reduce the harm arising from the double tragedy?

### Doctors and nurses & medical social workers:

- (a) From a doctor/nurse/medical social worker's point of view, how is the double tragedy affecting these patients and/or their family? What are their medical/ nursing problems?
- (b) What are the current medical or other services providing to meet their needs? How are they coping with these problems?
- (c) What intervention would you propose to alleviate the problems they are facing ?



## **Appendix IV. Guiding questions for individual interviews**

### Patients:

- (a) How is the double tragedy affecting you?
  - i. Problem areas (Employment, education, housing, recreational, transport and mobility, family and interpersonal relationship)
  - ii. Health (physical, mental)
- (b) How are you coping with these problems?
- (c) What can be done to alleviate the problems or reduce the harm arising from the double tragedy?

### Carers:

- (a) From a carer's point of view, how is the double tragedy affecting the patient?
- (b) In your opinion, how is he/the family coping with that?
- (c) What can be done to alleviate the problems or reduce the harm arising from the double tragedy?

### Clinical psychologist:

- (a) From a clinical psychologist's point of view, how is the double tragedy affecting the patient?
- (b) In your opinion, how are the patients /the carers coping with that?
- (c) What can be done to alleviate the problems or reduce the harm arising from the double tragedy?



## Appendix V. Questionnaire

CONFIDENTIAL

### Assessment of stresses and coping strategies of people living with haemophilia and HIV infection in Hong Kong

#### Questionnaire survey

*to be completed by interviewers*

**Please**

1. Check/obtain informed consent before filling the questionnaire
2. Write clearly
3. Put down the date of birth and first 2 digits of HKID on every page.
4. Put the completed questionnaire in a sealed envelop and return directly to investigator \_\_\_\_\_ (name)

#### **Interviewer**

Name

Signature

Clinic

Date of administration

\_\_\_\_\_  
\_\_\_\_\_  
QEH/ITC/QMH/nil  
\_\_\_\_\_

#### **Patient**

Date of birth

First two digits of HKID

\_\_\_\_\_  
\_\_\_\_\_  
(ddmm)

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

**A. Demography and socioeconomic status**

---

101. Education level
- None
  - Primary
  - Secondary
  - Tertiary or above
- 

102. Occupation \_\_\_\_\_

---

103. Monthly income (excluding allowance)
- |                                       |  |
|---------------------------------------|--|
| <input type="checkbox"/> \$0          | <input type="checkbox"/> \$10001-20000 |
| <input type="checkbox"/> <\$5000      | <input type="checkbox"/> \$20001-30000 |
| <input type="checkbox"/> \$5001-10000 | <input type="checkbox"/> \$>30000      |
- 

104-5. Ex-gratia payment \$ \_\_\_\_\_ (received in year \_\_\_\_\_)

---

- 106-115. CSSA/DA/ other allowance that you are currently receiving
- CSSA \$ \_\_\_\_\_ monthly
  - DA \$ \_\_\_\_\_ monthly
  - Other allowance
- Please specify source and amount \_\_\_\_\_
- 

116. Marriage
- |  |                                   |
|--|-----------------------------------|
| <input type="checkbox"/> Single        | <input type="checkbox"/> Divorced |
| <input type="checkbox"/> Married       | <input type="checkbox"/> Widower  |
| <input type="checkbox"/> Co-inhabiting |                                   |
- 

- 117-119. HIV status of wife/partner
- Tested
- Date of testing \_\_\_\_\_
- Result positive/ negative /unknown
- Not tested, reason \_\_\_\_\_
  - 'Don't know
- 

120-127. Number and age of children \_\_\_\_\_

---

- 128-129. Housing
- Public estate (monthly rent approx \_\_\_\_\_)
  - Private and rent (monthly rent approx \_\_\_\_\_)
  - Private and owned (monthly contribution approx \_\_\_\_\_)
  - Others, please specify \_\_\_\_\_

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

**B. Quality of Life (SF36) health survey**

---

1. In general would you say your health is:
- Excellent
  - Very good
  - Good
  - Fair
  - Poor
- 

2. Compared to one year ago, how would you rate your health in general now?
- Much better
  - Somewhat better
  - About the same
  - Somewhat worse
  - Much worse
- 

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
- 

- a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.
- Yes, limited a lot
  - Yes, limited a little
  - No, not limited at all
- 

- b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.
- Yes, limited a lot
  - Yes, limited a little
  - No, not limited at all
- 

- c. . Lifting or carrying groceries.
- Yes, limited a lot
  - Yes, limited a little
  - No, not limited at all
- 

- d. Climbing several flights of stairs.
- Yes, limited a lot
  - Yes, limited a little
  - No, not limited at all

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

- |                                    |  |
|------------------------------------|--|
| e. Climbing one flight of stairs.  | <input type="checkbox"/> Yes, limited a lot<br><input type="checkbox"/> Yes, limited a little<br><input type="checkbox"/> No, not limited at all |
| <hr/>                              |  |
| f. Bending, kneeling, or stooping. | <input type="checkbox"/> Yes, limited a lot<br><input type="checkbox"/> Yes, limited a little<br><input type="checkbox"/> No, not limited at all |
| <hr/>                              |  |
| g. Walking more than one mile.     | <input type="checkbox"/> Yes, limited a lot<br><input type="checkbox"/> Yes, limited a little<br><input type="checkbox"/> No, not limited at all |
| <hr/>                              |  |
| h. Walking several blocks.         | <input type="checkbox"/> Yes, limited a lot<br><input type="checkbox"/> Yes, limited a little<br><input type="checkbox"/> No, not limited at all |
| <hr/>                              |  |
| i. Bathing or dressing yourself.   | <input type="checkbox"/> Yes, limited a lot<br><input type="checkbox"/> Yes, limited a little<br><input type="checkbox"/> No, not limited at all |

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- |  |   |
|--|---|
| a. Cut down on the amount of time you spent on work or other activities                        | <input type="checkbox"/> Yes<br><input type="checkbox"/> No |
| <hr/>  |   |
| b. Accomplished less than you would like.  | <input type="checkbox"/> Yes<br><input type="checkbox"/> No |
| <hr/>  |   |
| c. Were limited in the kind of work or other activities.                                       | <input type="checkbox"/> Yes<br><input type="checkbox"/> No |
| <hr/>  |   |
| d. Had difficulty performing the work or other activities (for example, it took extra effort). | <input type="checkbox"/> Yes<br><input type="checkbox"/> No |

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

5. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

---

a. Cut down on the amount of time you spent on work or other activities  Yes  
 No

---

b. Accomplished less than you would like.  Yes  
 No

---

c. Didn't do work or other activities as carefully as usual.  Yes  
 No

---

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?  Not at all  
 Slightly  
 Moderately  
 Quite a bit  
 Extremely

---

7. How much bodily pain have you had during the past 4 weeks?  None  
 Very mild  
 Mild  
 Moderate  
 Severe

---

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?  Not at all  
 Slightly  
 Moderately  
 Quite a bit  
 Extremely

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks:

- |  |   |
|--|---|
| a. Did you feel full of pep?               | <input type="checkbox"/> All of the time          |
|  | <input type="checkbox"/> Most of the time         |
|  | <input type="checkbox"/> A good bit of the time   |
|  | <input type="checkbox"/> Some of the time         |
|  | <input type="checkbox"/> A little bit of the time |
| b. Have you been a very nervous person?    | <input type="checkbox"/> All of the time          |
|  | <input type="checkbox"/> Most of the time         |
|  | <input type="checkbox"/> A good bit of the time   |
|  | <input type="checkbox"/> Some of the time         |
|  | <input type="checkbox"/> A little bit of the time |
| c. Have you felt so down in the dumps that | <input type="checkbox"/> All of the time          |
|  | <input type="checkbox"/> Most of the time         |
|  | <input type="checkbox"/> A good bit of the time   |
|  | <input type="checkbox"/> Some of the time         |
|  | <input type="checkbox"/> A little bit of the time |
| d. nothing could cheer you up?             | <input type="checkbox"/> All of the time          |
|  | <input type="checkbox"/> Most of the time         |
|  | <input type="checkbox"/> A good bit of the time   |
|  | <input type="checkbox"/> Some of the time         |
|  | <input type="checkbox"/> A little bit of the time |
| e. Have you felt calm and peaceful?        | <input type="checkbox"/> All of the time          |
|  | <input type="checkbox"/> Most of the time         |
|  | <input type="checkbox"/> A good bit of the time   |
|  | <input type="checkbox"/> Some of the time         |
|  | <input type="checkbox"/> A little bit of the time |

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

- f. Did you have a lot of energy?
- All of the time
  - Most of the time
  - A good bit of the time
  - Some of the time
  - A little bit of the time

- 
- g. Have you felt downhearted and blue?
- All of the time
  - Most of the time
  - A good bit of the time
  - Some of the time
  - A little bit of the time

- 
- h. Did you feel worn out?
- All of the time
  - Most of the time
  - A good bit of the time
  - Some of the time
  - A little bit of the time

- 
- i. Have you been a happy person?
- All of the time
  - Most of the time
  - A good bit of the time
  - Some of the time
  - A little bit of the time

- 
10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
- All of the time
  - Most of the time
  - A good bit of the time
  - Some of the time
  - A little bit of the time

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

11. How TRUE or FALSE is each of the following statements for you?

- 
- a. seem to get sick a little easier than other people.
- Definitely true
  - Mostly true
  - Don't know
  - Mostly false
  - Definitely false

- 
- b. I am as healthy as anybody I know
- Definitely true
  - Mostly true
  - Don't know
  - Mostly false
  - Definitely false

- 
- c. I expect my health to get worse.
- Definitely true
  - Mostly true
  - Don't know
  - Mostly false
  - Definitely false

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm  
HKID first 2 digits \_\_\_\_\_

**C. Use and satisfaction of existing service provision\***

301-305. Are you satisfied with the service provided by your **HIV clinic**?

---

Overall service  Never used  
 Excellent  
 Satisfied  
 Fair  
 Poor

---

Medical service  Never used  
 Excellent  
 Satisfied  
 Fair  
 Poor

---

Nursing service  Never used  
 Excellent  
 Satisfied  
 Fair  
 Poor

---

Counselling and psychological support  Never used  
 Excellent  
 Satisfied  
 Fair  
 Poor

---

Medical social service  Never used  
 Excellent  
 Satisfied  
 Fair  
 Poor

**CONFIDENTIAL**

Date of birth \_\_\_\_\_ Ddmm

HKID first 2 digits \_\_\_\_\_

306-310. Are you satisfied with the service provided by your **Haemophilia clinic**?

Overall service                       Never used  
    Excellent  
    Satisfied  
    Fair  
    Poor

---

Medical service                       Never used  
    Excellent  
    Satisfied  
    Fair  
    Poor

---

Nursing service                       Never used  
    Excellent  
    Satisfied  
    Fair  
    Poor

---

Counselling and psychological support                       Never used  
    Excellent  
    Satisfied  
    Fair  
    Poor

---

Medical social service                       Never used  
    Excellent  
    Satisfied  
    Fair  
    Poor

