

原 著

遺族の日々の困難と願い：日本のHIV感染血友病患者の遺族に関する研究

Daily Difficulty and Desire of the Bereaved: A Study of Bereaved Families of HIV-infected Hemophiliacs
in Japan

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非加熱血液凝固因子製剤により HIV 感染した血友病患者の遺族に対する支援への示唆を得るために、彼らの日々の生活における困難と要望を明らかにすることを目的として、無記名自記式調査票による配票調査を実施した。392 家庭に調査票を配布し、225 家庭 307 名から有効回答を得た。

調査により、約 60%の回答者に PTSD が疑われ、半数近くの回答者が精神健康における問題を有している可能性があること、回答者の 70%以上が現在でも差別不安により何らかの生活行動の自主規制を行っていること、そのようななかでも、大半の回答者が生きていく楽しみや支えとなるものをもっていること、死別経験を通じて、約 70%の回答者が、死別による何らかの「得たもの」があると感じていること、救済策の充実や偏見・差別の軽減とともに薬害の真相究明や再発防止が強く願われていることなどが明らかになった。以上の結果から、従来の支援事業の拡充とともに、質的な改善を行う必要性が示唆された。

In order to better design support systems for bereaved family of deceased HIV patients infected through contaminated blood coagulation factor products, we performed anonymous written survey to characterize the daily difficulties and desires of this population. Self-administered questionnaires were mailed to 392 families. Replies from 307 respondents in 225 families were valid and analyzed. The study revealed that PTSD was suspected in about 60% of respondents, and nearly half of respondents showed signs of psychological difficulties. More than 70% of respondents reported self-imposed restrictions due to fear of discrimination. In spite of this, most respondents reported sources of joy and reasons for living, and nearly all respondents reported activities meant to honor the memory of the deceased, and from the experience, about 70% of respondents reported perceived positive change. Finally, respondents harbored strong desires not only for better aid and elimination of prejudice and discrimination, but also more thorough disclosures about circumstances surrounding the contamination and prevention of recurrence. These results suggest the need for a qualitative improvement of current support efforts in addition to a mere expansion of them.

キーワード： 死別、HIV/AIDS、スティグマ、ポジティブチェンジ、日本

Keywords: HIV/AIDS; stigma; positive change; Japan

I Introduction

In the first half of the 1980s, about 1400 hemophiliacs,
or about 40% of Japan's hemophiliac population, became

infected with HIV through use of unheated blood coagulation factor products imported mainly from the United States. More than 500 of those infected have died thus far. More than half of these were under 30, as unheated blood products were used mostly by younger patients. Although AIDS-related deaths among hemophiliacs peaked in 1994-1995 and decreased significantly after 1998 because of the introduction of Highly Active Antiretroviral Therapy, most HIV-infected hemophiliacs also suffer from hepatitis C, leading to a recent small upsurge in mortality (Japanese Foundation for AIDS Prevention, 2005).

Self-injection of blood products by hemophiliacs was approved by the Ministry of Health and Welfare (MHW, currently the Ministry of Health, Labor and Welfare, or MHLW) in February 1983. Patients themselves welcomed self-injection for the convenience and effectiveness it offered, so imported unheated blood products became widely used by the hemophiliac community. However, in March 1983, the same year that MHW approved unheated blood products, the United States approved heated blood products instead and recalled unused unheated products for the danger of HIV infection they represented. Despite this fact, the MHW did not change its stance on unheated products until 1985, when heated blood products were approved.

HIV-infected hemophiliacs sued the Japanese government and five pharmaceutical companies for damages in Tokyo and Osaka courts in 1989. This was the first anonymous court case in Japanese history, with plaintiff numbers used in place of names to protect privacy (Cullinane, 2005). A settlement was reached in 1996 (Soda, & Mizushima, 1998), and although financial compensation was granted to the plaintiffs, no satisfying explanation of the source of the problem was obtained, nor was a meaningful apology issued to the HIV-infected hemophiliacs and their families (Tokyo HIV Litigation Lawyers Group, 2002a). Finally, the fundamental trilateral relationship between government, pharmaceutical companies, and the medical community that fostered the problem in the first place has yet to be reformed. Sadly, lessons have not yet to be learned and implemented from these events (Feldman, 1999).

Various measures have been implemented since the 1996 settlement to provide relief for the HIV-infected

hemophiliacs. These include payment of settlement funds, medical system improvements, medical care coverage for HIV patients, and awarding of handicapped status to HIV patients. Victims include not only living patients and their families but bereaved families as well. However, aside from monetary damages, the only concrete settlement received by bereaved families is small-scale counseling services (Tokyo HIV Litigation Lawyers Group, 2002b).

Deaths of HIV/AIDS patient are usually considered “untimely” and characterized by lack of support (Worden, 1991), both considered risk factors for impaired adjustment for bereaved families (Archer, 1999; Duran, et al. 1989; Stylianios, & Vachon, 1993). Though previous studies concerning the bereaved have revealed that AIDS death is associated with a higher rate of adverse psychosocial factors that may increase risk of psychological morbidity (Cadell, 2003; Kelly et al., 1996; Neugebauer et al, 1992; Rosengard, & Folkman, 1997; Summers et al., 1995), most studies have addressed AIDS bereavement among partners or families of HIV-infected patients through sexually transmission. Bereaved families of HIV-infected hemophiliacs are considered to be victims in the sense that it was caused by human activities. Mothers often feel guilt and regret for having given birth to hemophiliac children (Markova et al., 1980; Simon, 1984; Yanaga et al., 1996). From these points, the death of hemophiliacs with HIV is considered to be different from patients through sexually transmission.

Hemophilia, which is mainly genetically inherited from the mother, has been associated with stigma (Markova, & Forbes, 1984), HIV infection is associated with a much stronger stigma (Doka, 1997; Alonzo, & Reynolds, 1995). The stigma is thought to affect the way in which bereaved families experience the death of their loved ones. However, there has been no national survey performed of bereaved families of HIV patients aside from an informal questionnaire survey concerning difficulties and request given by the members of the Tokyo or Osaka HIV Plaintiff Corp before the 1996 settlement. In addition, because fear of discrimination and prejudice has prevented this population from discussing the death of their loved ones in public settings, and because these family members have had practically no interaction with each other, the current experiences and needs of the bereaved remain complete

mystery. It is impossible to gain any meaningful information about bereaved families either through the HIV Plaintiff Corps, the HIV Litigation Lawyers Group, or the families themselves.

Therefore, a better understanding of the current state that bereaved family members find themselves in is a prerequisite for designing better support systems and other concrete relief measures for this population. This study was undertaken to elucidate effects of death upon bereaved family members, various factors surrounding their current lives, and what their greatest desires are. It is hoped that the voices of the bereaved themselves can help shape support systems going forward.

II Methods

Design of the research

We adopted a methodological triangulation model (Creswell, 2003; Morse, 1991) consisting of interviews followed by written surveys. First we interviewed 42 family members from 32 families to make a qualitative assessment of surviving families and their experience, and then used results from these to develop written surveys, which followed. The written surveys were used chiefly to analyze patterns, distributions, and relationships between survey items. We report results of the written surveys in this article.

A committee called the “The Committee to Investigate the Lives of Bereaved Families of Iatrogenically Infected HIV Patients” was organized according to the method of participatory research (Chesler, 1991; Green, et al., 1995). The committee consisted of bereaved family members and HIV-infected hemophiliac patients belonging to Tokyo or Osaka HIV Plaintiff Corps, lawyers of the Tokyo or Osaka HIV Litigation Lawyers Group, and researchers. The objective, methods, and survey items were all determined following the discussion and approval by this committee and by incorporating opinions of the bereaved themselves. In ethical consideration of participants, we exercised the utmost caution for privacy protection.

Respondents and data collection

About 95% of the patients themselves or bereaved families participated in the Tokyo or Osaka HIV Plaintiff Corps. Of the 524 bereaved families in these groups (as of March 2002), all 392 families able to be contacted were asked to respond to the questionnaires, which were mailed between October and November 2002. Responses from two members were requested from families with two or more members. Replies from 225 families (307 members) were valid and analyzed (response rate: 57.4%).

Survey items and measurements

The following survey questions were based on the results of preceding interviews and the literature.

1. Attributes: gender, age, relationship with the deceased, date and age of death of the deceased, and self-rated economic status.
2. Impact of Event Scale-Revised (IES-R): the IES-R (Weiss, & Marmar, 1997) is a self-rating scale with 22 items used for evaluating traumatic stress symptoms. Each item is scored 0-4 and the possible range of the score is 0-88. Higher scores suggest greater stress symptoms. The reliability and validity of the Japanese version (Asukai, 1999) and the validity and usefulness of a 24/25 cutoff for screening PTSD symptoms have been evaluated (Asukai, et al., 2002). Cronbach's α in this study was 0.96.
3. Twelve-item version of The General Health Questionnaire (GHQ-12): the GHQ (Goldberg, 1972) is also a self-rating scale for the screening minor psychiatric disorders. The reliability and validity of the Japanese version (Nakagawa, & Daibo, 1985) and the validity and usefulness of a cutoff 3/4 (Goldberg, et al., 1997) have been evaluated (Honda, et al., 2001). The items were scored according to a Likert scale (0-1-2-3; possible range of 0-36) to examine correlations among variables, and bimodally (0-0-1-1; possible range is 0-12) when a cutoff value was used (Goldberg, & Williams, 1988). Cronbach's α in this study was 0.89.
4. Self-imposed restrictions due to fear of discrimination (7 items): seven yes or no statements concerning the attitude and behavior that the responders took recently because of their awareness of the public eye including

“I tried to avoid talking about the disease,” “I thought up an excuse to hide the disease,” “I tried to change the disease mentioned as the cause of death,” “I avoided close association at workplace, school, and neighborhood,” “I avoided contact with my relatives,” “I chose a hospital where I was less likely to meet neighbors or acquaintances,” and “I felt it difficult to stay at the old residence and moved.”

5. Providers of support (13 items): of the four functional attributes of social support, i.e. emotional, instrumental, informational, and appraisal (Langford et al., 1997), support with emotional functions was selected, and whether or not there were emotional support providers was assessed in this study. Concerning “emotional support providers”, we asked the respondents to select the persons who listened to and supported their worries and troubles pertaining to bereavement from 13 items including “parents,” “spouse,” “HIV-infected acquaintances or their families,” and “doctors, nurses, counselors at the hospital” (multiple responses).
6. Perceived positive change (4 items): on the basis of the results of the interview survey and the literature, “I grew as a person,” “family ties became stronger,” “I became able to be supported by my family and friends,” and “I gained friends and acquaintances whom I can trust now” were suggested as positive changes or gains experienced as the bereaved (multiple responses).
7. Sources of joy and reasons for living (9 items): nine items including “family,” “work,” “hobbies, leisure activities, or sports,” and “religion” were suggested as persons and activities that support in living and gave you joy and opportunities that enlivened respondents (multiple responses).
8. Honoring of memories (6 items): six items including “visiting the grave or praying at the family altar,” “supporting my family,” “activities to support HIV-related lawsuits, patients, and their bereaved families,” were suggested as activities that respondents keep up to remember the deceased or to

realize their wishes (multiple responses).

9. Desires (7 items): things desired of society at large and government (multiple responses and free writing in “Other” category).

Analysis

The incidence and average score of all the items were calculated, with t-tests and χ^2 tests used for comparisons of two groups and one-way analysis of variance (ANOVA) used to compare three and more groups. Statistical software used was SPSS11.5J.

III Results

1. Respondent attributes

Table 1 shows sociodemographic attributes of respondents to the written survey. Totaling 307 members of 225 families, respondents consisted of 119 mothers, 92 fathers, 48 wives, 35 siblings, 7 children, and 4 others (2 siblings-in-law, 1 uncle, and 1 NA). The average age of respondents was 58.2 ± 12.0 , with nearly half being over 60. Average age of the deceased was 31.7 ± 13.1 , and the average time since death was 8.9 ± 3.3 years. Although little information was available for those who failed to respond this survey, there was no regional difference between the respondents and non-respondents. There were no significant differences in age of the deceased at death, or years since death between study participants and the membership of the Tokyo or Osaka HIV Plaintiff Corps.

2. Mental health

Average IES-R score, used to screen for PTSD, was 32.9 ± 22.1 ($N=283$), with 59.4% of respondents scoring above the cutoff. When GHQ was calculated bimodally, the average was 4.1 ± 3.8 ($N=292$), with 45.9% exceeding the

Table 1

Sociodemographic characteristics of respondents of questionnaire

Variables	N ^c		n (%)
Relationship to deceased ^a	305	Mother	119 (39.0)
		Father	92 (30.2)
		Wife	48 (15.7)
		Sibling	35 (11.5)
		Child	7 (2.3)
		Other	4 (1.3)
Age of participant ^a	305	Mean ± SD	58.2 ± 12.0
Age of deceased ^b	221	Mean ± SD	31.7 ± 13.1
Years since death ^a	304	Mean ± SD	8.9 ± 3.3
		0-5	21 (6.9)
		5-10	198 (65.1)
		10-15	74 (24.4)
		15-20	11 (3.6)
Self-rated economic status	293	Enough to spare	8 (2.7)
		Can afford some luxuries	129 (44.0)
		Enough to live on, but no luxuries	120 (41.0)
		Can barely get by	36 (12.3)

 Note. ^aN = number of respondents (307 members)

^bN = number of the families (225 families)

^c Exclude missing values

Table 2

Self-imposed restrictions of daily living due to anxiety over discrimination (N=297)

Items	n (%) ^a
<i>Hiding the disease name (3 items)</i>	
I tried to avoid talking about the disease	172 (57.9)
I thought up an excuse to hide the disease	165 (55.6)
I tried to change the disease mentioned as the cause of death	128 (43.1)
<i>Avoiding association (4 items)</i>	
I avoided close association at the workplace, school, and neighborhood	28 (9.4)
I avoided contact with my relatives	26 (8.8)
I chose a hospital where I was less likely to meet neighbors or acquaintances	16 (5.4)
I felt it difficult to stay at my old residence and moved	16 (5.4)
<i>At least 1 of the 7 items</i>	205 (69.0)

 Note. ^a Numbers and percentages of the respondents who answered yes to each item

cutoff. When analyzed according to gender and relationship to the deceased, the only statistically significant result was a higher IES-R score for mothers than for siblings ($F=4.81$, $p<0.01$). A relatively weak negative correlation was observed between years since death and GHQ score (Pearson's correlation coefficient= -0.12 , $p<0.05$), but no significant correlation was observed between years since death and IES-R. A strong positive correlation was found between IES-R and GHQ (Pearson's correlation coefficient= 0.52 , $p<0.001$), with 30.9% of all respondents ($N=307$) exceeding the cutoff for both scores. Neither the IES-R score nor the GHQ score differed according to the gender or relationship to the deceased, except that the IES-R score was significantly higher in the mothers than in the siblings ($p<0.01$).

3. Self-imposed restriction of daily living due to anxiety over discrimination

Table 2 shows patterns of restrictions imposed by respondents upon themselves due to fear of discrimination. The table shows the percentage of respondents claiming various forms of behavior, with multiple answers possible. About half of respondents reported hiding the nature of the disease even recently, while 5.4-9.4% reported relationship avoidance. As many as 69.0% of respondents reported at least one form of self-imposed restrictions due to fear of discrimination.

4. Providers of support

Table 3 shows providers of social support for respondents in the form of consolation and advice, with multiple responses possible. The most common provider of such was other family members, followed by other HIV patients, their families, HIV groups, and lawyers. Only 9.5% reported social support from doctors, nurses, or counselors. Of these, 43.7% reported that they could only be supported talk by to family about the matter, while as many as 10.2% reported no one to provide this form of social support.

Table 3

Providers of support	(N=295)	
	n	(%) ^a
Parents	48	(16.3)
Spouse	124	(42.0)
Children	93	(31.5)
Siblings	67	(22.7)
Relatives	16	(5.4)
Colleagues at the workplace	5	(1.7)
Friends or acquaintances	37	(12.5)
HIV-infected acquaintances or their families	58	(19.7)
Volunteers	11	(3.7)
Doctors, nurses, counsellors at the hospital	28	(9.5)
HIV-related group	58	(19.7)
Lawyers	46	(15.6)
Other	5	(1.7)
None	30	(10.2)
Only families or relatives	129	(43.7)

Note. ^aNumbers and percentages of the respondents who answered yes to each item

5. Perceived positive change

Table 4 shows what respondents reported as "silver linings," or positive changes or gains emerging through their experience of loss. More than one-third of the respondents reported "I grew as a person" and "family ties became stronger," while 67.7% answered yes to at least one of the four items.

Table 4

Perceived positive change	(N=269)	
	n	(%) ^a
I grew as a person	92	(34.2)
Family ties became stronger	101	(37.5)
I became able to be supported by my family and friends	73	(27.1)
I gained friends and acquaintances whom I can trust now	35	(13.0)
At least 1 of the 4 items	182	(67.7)

Note. ^aNumbers and percentages of the participants who answered yes to each item

Table 5

Sources of joy and reasons for living	(N = 275)	
	n	(%) ^a
Family	177	(64.4)
Lover	3	(1.1)
Friends	90	(32.7)
Hobbies, leisure activities, or sports	115	(41.8)
Association with people through hobbies, leisure activities, or sports	74	(26.9)
Work	85	(30.9)
Religion	21	(7.6)
Social welfare activities such as community activities and volunteer activities	26	(9.5)
HIV-related activities, or supporting patients and bereaved families	18	(6.5)
None	13	(4.7)

Note. ^aNumbers and percentages of the participants who answered yes to each item

6. Sources of joy and reasons for living

Table 5 shows people and activities described by respondents as sources of joy and reasons for living, with multiple answers possible. Most common was “Family,”

(64.4%) followed by “Hobbies, leisure activities, or sports” (41.8%) and “Friends” (32.7%), while 4.7% reported “None.”

7. Comparisons of IES-R and GHQ scores (Table 6)

IES-R and GHQ scores were higher for respondents reporting self-imposed restrictions of daily living due to anxiety over discrimination compared to those who reported no restriction. Although not shown in the table, an examination of the partial correlation between such self-imposed restriction and mental health yields a significant positive correlation (when controlling for age, sex, years since death, and financial status) with IES-R scores (partial correlation coefficient=0.283, $p<0.001$) and GHQ scores (partial correlation coefficient=0.234, $p<0.001$). Neither IES-R score nor GHQ score differed according to the support.

GHQ score was higher for respondents reporting no positive change compared to those who reported some benefits, although the difference of IES-R score was not statistically significant.

Table 6

Comparisons of IES-R and GHQ scores

		IES-R			GHQ-12		
		N ^a	Mean	SD	N ^a	Mean	SD
Self-imposed restrictions of daily living due to anxiety over discrimination							
	At least 1 of the 7 items	198	35.12	21.16 ***	197	16.43	5.95 ***
	None	67	24.06	20.27	71	13.52	5.13
Support							
	At least 1 of the 7 items	250	32.51	21.65	257	15.68	5.72
	None	28	33.81	23.61	29	15.72	7.60
Perceived positive change							
	At least 1 of the 7 items	189	31.73	21.20	189	15.05	5.48 *
	None	87	33.88	23.10	95	16.85	6.71
Sources of joy and reasons for living							
	At least 1 of the 9 items	263	31.77	21.75 *	276	15.35	5.72 **
	None	13	49.68	21.16	14	22.13	6.61

Note. ^a Exclude missing values
***: $p<0.001$, **: $p<0.01$, *: $p<0.05$

The mean IES-R score and mean GHQ score for respondents reporting no reasons for living were significantly higher than the mean score of those reporting at least one.

8. Honoring of memories

Table 7 shows ways of giving offerings or otherwise honoring the memory of the deceased. More than 90% of respondents reported visiting graves or praying at a family altar. When six survey items were divided into the three categories of "Offerings to the deceased," "Living positively," "HIV-related activities," 29.4% of respondents claimed only one category and about 70% reported two or more categories. The majority of these included "Offerings to the deceased" in addition to some form of activity. Only three respondents (1.0%) reported no such honoring of memory in any form.

Table 7

Honoring memories	(N=196)
	n (%) ^a
"Offerings to the deceased"	
Visiting the grave or praying at the family altar	273 (92.2)
Thinking of the deceased and leaving a token of the life of the deceased	107 (36.1)
"Living positively"	
Living with a positive attitude	178 (60.1)
Supporting my family	111 (37.5)
"HIV-related activities"	
Activities to support HIV-related lawsuits, patients, and their bereaved families	29 (9.8)
Activities to make the truth of drug-induced HIV infection known to the public	18 (6.1)
None	3 (1.0)

According to category

only one category	
"Offerings to the deceased"	75 (25.3)
"Living positively"	12 (4.1)
"HIV-related activities"	0 (0.0)
two category	
"Offerings to the deceased" + "Living positively"	169 (57.1)
"Offerings to the deceased" + "HIV-related activities"	8 (2.7)
"Living positively" + "HIV-related activities"	1 (0.3)
three category	
"Offerings to the deceased" + "Living positively" + "HIV-related activities"	28 (9.5)

Note. ^aNumbers and percentages of the participants who answered yes to each item

9. Desires of the bereaved

Table 8 shows desires harbored by the bereaved. Most common was "Prevention of further medical disaster," (87.0%) followed by "Elimination of prejudice and discrimination against HIV and hemophilia" (64.0%) and "Support for the victims of drug-induced HIV infection" (59.6%). Responses of "Admitting responsibility for the occurrence of drug-induced HIV," "Clarification the truth of drug-induced HIV infection," and "Propagating correct understanding about drug-induced HIV to the public" were also selected by 46.9-58.6% of respondents. Free responses in the "Other" section included such sentiments as "I would like a museum built to ensure the history of drug-induced HIV infection is passed on," "I want to be left alone already," and "I want this given continuous attention, not treated as a temporary issue."

Table 8

Desire of the bereaved	(N=191)
	n (%) ^a
Prevention of further medical disaster	254 (87.0)
Elimination of prejudice and discrimination against HIV and hemophilia	137 (64.0)
Support for the victims of drug-induced HIV infection	174 (59.6)
Admitting responsibility for the occurrence of drug-induced HIV	171 (58.6)
Clarification the truth of drug-induced HIV infection	162 (55.5)
Propagating correct understanding about drug-induced HIV to the public	137 (46.9)
Other	5 (1.7)
None	6 (2.1)

Note. ^aNumbers and percentages of the participants who answered yes to each item

IV Discussion

1. Aging of the bereaved and psychological problems

Average age of written survey respondents was 58.2 years. A relatively long period of time had already passed since death; an average of 8.9 years, and 5 or more years in more than 90% of cases. Reasons for the advanced age of the respondents include the fact that about 70% of them were parents of the deceased, and that about 20 years has

already elapsed since the original drug-induced HIV infection.

Events of the case also severely impacted the mental health of the respondents, with PTSD suspected in 59.4% and impaired psychological health likely in 45.9%. Many of the respondents are thought to require specialized psychological care.

Preceding research on the mental health of bereaved family reports a tendency for prolongation of grief, difficulty adjusting (Raphael, et al., 1993; Spooren, et al., 2000-2001), mental distress (Murphy, et al., 2002; Parkes, 1993; Spooren, et al., 2000-2001), and symptoms associated with PTSD (Kaltman, & Bonanno, 2003; Simpson, 1997; Zisook, et al., 1998) when the death of the loved one is a traumatically violent one involving accident, suicide, or murder. Death of hemophiliacs with HIV is, strictly speaking, a natural one due to disease, but it also shares attributes of violent death due to the fundamental fact of human agency in it. Further, AIDS death itself is considered risk factor for impaired adjustment for bereaved families (Archer, 1999; Duran, et al. 1989; Stylianos, & Vachon, 1993). This contextual nature of bereaved families' experience may be responsible for the psychological problems widely observed in this population.

2. Widespread fear of discrimination and lack of support

Goffman (1963) reports that stigmas are attached not only to those bearing the original stigmatized characteristic, but also to those in close relationship to them. This "courtesy stigma" (Goffman, 1963) is directed towards family members and close acquaintances. Numerous reports describe stigmatization of family members of stigmatized individuals (Angermeyer, et al., 2003; Gray, 1993; Green, 2003; Norvilitis, et al., 2002). This phenomenon is also observed in family members of HIV patients and exerts a strong influence on their daily lives (Demi, et al., 1997; Poindexter, & Linsk, 1999; Powell-Cope, & Brown, 1992; Wight, et al., 2006).

In this study, despite the fact that an average of about nine years had passed since the death of their loved one, about 70% of bereaved family members still suffered self-imposed restrictions on daily activities due to fears of

discrimination. This reveals that bereaved families still feel stigmatized, and that the courtesy stigma applied to families of HIV patients does not pass away with the patients themselves, but persists long after their death. Higher levels of such self-imposed restriction were associated with higher IES-R and GHQ scores, suggesting that fear of discrimination is strongly correlated with PTSD-like symptoms and deteriorating psychological health. This fear of discrimination, combined with specific contextual facets described above, makes the fact of death even more traumatic and leads to difficulties for bereaved family members later in life.

The support networks available to this population are extremely limited; 43.7% of respondents reported being able to go to only other family members for consolation and advice, while 10.2% reported total absence of such support. Behind this lies fear of discrimination, for unwillingness to admit that they are the relatives of a hemophiliac who died of HIV severely limits opportunities for appropriate support. The fact that only 9.5% of respondents claimed support from doctors, nurses, or counselors despite the widespread signs of psychological problems in this group speaks to the lack of necessary support networks in the medical community. The first remedy for this must be medical support incorporating the specific contextual nature of this population's needs, while social prejudice and discrimination must also be eliminated in order for bereaved families to live free from fear and self-imposed restrictions. The aging of bereaved families makes the issue of isolation even more important, and the improvement of support systems going forward even more pressing.

Problems related to anxiety over discrimination and lack of support are also thought to be shared by surviving HIV-infected hemophiliacs and their families.

3. Perceived positive change, sources of joy and reasons for living, and honoring the memory of the deceased

About 70% of bereaved family members reported feeling that they did gain something from their experience of loss. Most respondents were attempting to recast the meaning of the death of their loved one and find meaning in their own lives as they found reasons for living and honored

the memory of the deceased through offerings and other activities. However, despite efforts to “find a silver lining” and create meaning in other ways, about half of respondents displayed signs of psychological problems, and still harbored internal feelings of tension and crisis surrounding the death of their loved one. Although these issues were observable even in those respondents striving to find various sources of meaning, nearly 5% of bereaved family members described neither sources of joy nor reasons for living at all, highlighting this population’s need for support.

It has been reported that experiences of traumatic loss can have both negative effects, such as PTSD and depression, and positive effects, where meaning is gained through the experience (Cadell, 2003; Davis, et al., 1998; Davis, & Nolen-Hoeksema, 2001; Frantz, et al., 1998; Lehman, et al., 1993). It has also been reported that these negative and positive effects can coexist in individuals (Cadell, 2003; Park, et al., 1996). Several studies have reported associations between positive change and improved mental health (Davis, et al, 1998; Davis, et al, 2001; McMillen, et al, 1997), and a similar tendency was observed in this study. Focusing on positive effects is likely to prove useful in treatment and overcoming trauma (Calhoun, & Tedeschi, 1999), further work is needed to expand the theory.

4. Bereaved families’ desires

The most commonly expressed desire of the bereaved toward the world, society, and government was a prevention of reoccurrence of medical disaster in the future, followed by aid for victims, damages, increased understanding, and elimination of prejudice and discrimination. More than half of respondents also desired further disclosures about the drug-induced HIV infection.

Desires for preventing reoccurrence was expressed not only in terms of bereaved family members themselves, but also for the purpose of not letting their loved one’s death go to waste, creating a lesson from it, and having society benefit from that lesson. This strong desire for a “*isi no shakai ka*” (Noda, 1997) or “socialization of will” is also shared with bereaved families of accidents, medical malpractice, and other victims (Imai, 1997; Noda, 1992;

Vincent, et al., 1994). It was also the reason given by the respondents of several bereavement studies for their willingness to participate (Cook, & Bosley, 1995; Cooper, 1999; Dyregrov, 2004).

Traditionally, the focus of support for the victims has been on financial damages and psychological counseling; in short, a direct, unilateral model that placed victims squarely in the role of recipients. Although the importance of aid directed at individuals is not disputed, working together with society to reform the fundamental causes of the drug-induced HIV infections is also a crucial way of supporting the bereaved. This study has shown that activities in which bereaved family members team up with other parts of society to reform structures responsible for the infections, carry investigations further, and prevent recurrence, will be connected to healing.

This study has also shown the insufficiency of a sincere apology to bereaved families for the deaths of their loved ones and the full explanation about HIV infection of hemophiliacs. The satisfaction with the treatment by the criminal justice system and factual information are considered to be the important determinants of bereaved families’ mental health (Amick-McMullan, et al., 1989; Winje, 1998; Worden, 1992). We have shown that a sincere apology from the government, pharmaceutical companies, and doctors, together with full and honest explanation about the case, and further measures to prevent a recurrence, are an indispensable aspect of true aid to the bereaved.

5. Future directions

Of the 42% of survey recipients who did not respond, it is assumed that many of them failed to do so because of the pain associated with recalling and discussing their experience. Because this segment of the population may suffer from even greater difficulties, different ways of approaching them must be considered going forward. However, this study was the first comprehensive, national survey of bereaved family members of hemophiliacs with drug-induced HIV, and we consider it significant that their long silence has been breached. Results suggest that the contextual nature of their experience, mental health, and other lifestyle factors must be taken into account for a

qualitative reform of support to this group. These results also highlight the importance of removing the social stigma surrounding HIV and hemophilia, and the prejudice and discrimination underlying this stigma.

This study also suggests the necessity for transcending the bounds of traditional aid and giving the victims agency in their own support. In other words, formation of partnerships between bereaved families and society to obtain sincere apologies, further factual explanations and investigations, and work towards prevention of recurrence, is an indispensable aspect of true aid to the bereaved. Our study also suggests that the medical community must fundamentally re-think its relationship to bereaved families from the perspective of responsible social citizens rather than merely as providers of care. These insights should be of use in forming support systems for other types of victims as well.

It is our hope that the insights gained from this study may contribute to the understanding of surviving hemophiliacs with HIV, their families, and other victims, so that support systems for these groups may be improved and their QOL enhanced.

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