

# Living Conditions and Palliative Care Needs among End-of-Life Former Commercial Plasma Donors Affected with HIV/AIDS in Rural Henan of China<sup>1</sup>

YU SHENG<sup>\*2</sup>, ZE-QI QIU<sup>#</sup>, YUN HE<sup>+</sup>, NAOMI JUNIPER<sup>±</sup>, AND YAN ZHANG<sup>\*</sup>

<sup>\*</sup>School of Nursing, Peking Union Medical College, Beijing 100144, China; <sup>#</sup> Department of Sociology, Peking University, Beijing 100871, China; <sup>+</sup> Center for Disease Control and Prevention, Zhengzhou 450016, Henan, China;

<sup>±</sup>National Center for AIDS/STD Control and Prevention, Chinese Center for Disease Control and Prevention, Beijing 102206, China

**Objective** China began providing antiretroviral therapy to people living with HIV/AIDS (PLWHA) in 2003. This study was to investigate the living conditions, including quality of life and happiness, and need for palliative care of end-of-life PLWHA in rural Henan. **Methods** One hundred end-of-life AIDS patients were selected from Weishi, Zhenping and Tanghe counties in Henan, using convenience sampling. The World Health Organization Quality of Life for HIV (WHOQOL-HIV) BREF Chinese Version was used to measure the quality of life and the Memorial University of Newfoundland Scale of Happiness (MUNSH) was employed to measure subjective welfare. Qualitative interviews and focus group discussions were undertaken to learn about the palliative care provided and the specific needs of the end-of-life patients. **Results** Patients' overall quality of life was moderate (12.62±1.97). Highest scores were in the spirituality/religion/personal beliefs, higher than the average scores in the Chinese population ( $P<0.01$ ), while psychological (13.58±2.06) and environment (12.50±3.28) domain scores were similar to the latter ( $P>0.05$ ). Both independence (12.15±2.15) and physiological (14.04±3.16) domain scores were lower than the average of the people living with HIV/AIDS in other studies ( $P<0.01$ ); however, all were in the moderate range. The average MUNSH score was 21.00±6.20, which was also moderate. The in-depth interviews indicated that the Henan Provincial Government's policy of treatment and care had a beneficial impact on end-of-life AIDS patients, although the care components could be improved. **Conclusions** Living conditions of the end-of-life AIDS patients were moderate, and the HIV/AIDS palliative care model used was beneficial to them. Care could be improved by assisting the family unit as a whole.

**Key words:** Living conditions; People living with HIV/ AIDS, PLWHA; End-of-life; China; Plasma donors

## INTRODUCTION

Plasma trading was common in some rural areas of China in the early 1990s, which caused an epidemic of HIV infection among former plasma donors in rural areas. According to a report from the National Ministry of Health, UNAIDS and WHO in 2005, 10.7% of the total estimated number of HIV infection was originated from plasma selling and transfusion of blood or blood products, and 22 000 of the 75 000 people living with HIV/AIDS had been infected in this way<sup>[1]</sup>. A substantial proportion of people infected with HIV is progressing to AIDS, and will eventually die<sup>[2]</sup>. The development of highly active anti-retroviral treatment (HAART) has

dramatically changed the course of the HIV epidemic, and resulted in significant declines in both AIDS-related mortality and incidence of opportunistic infections<sup>[3-4]</sup>. However, progression to AIDS can only be delayed by long-term appropriate care, which ensures comfort of the patients and is essential for those who are at their terminal stage<sup>[5]</sup>. Thus, it is important to understand the living conditions of people with HIV/AIDS and the factors affecting them<sup>[6]</sup>, because treatment and living conditions impact on each other<sup>[7]</sup>. Indeed, the provision of appropriate palliative care to end-of-life AIDS patients will become a significant standard in assessing future AIDS treatment<sup>[8]</sup>.

HAART became widely available in China at the

<sup>1</sup>This study was supported by the China Global Fund Round 3 and the China Multidisciplinary AIDS Prevention Training Program with NIH Research Grant #U2R TW06918-01 funded by the Fogarty International Centre, the National Institute on Drug Abuse and the National Institute of Mental Health (China ICOHRTA, with Principal Investigator being Zun-You WU).

<sup>2</sup>Correspondence should be addressed to Yu SHENG. Tel: 86-10-88771100, 86-10-65295914; Fax: 86-10-88771020; E-mail: shengyu@nursing.pumc.edu.cn

Biographical of the first author: Yu SHENG, Ph.D, RN, Division of Fundamental Nursing, School of Nursing, Peking Union Medical College, Ba Da Chu Road, Beijing, 100144, China.

end of 2003 when the government initiated its “Four Free, One Care” policy (i.e. Free ARV drugs, Free VCT, Free PMTCT and FREE schooling to AIDS orphans, and care to PLWHA’ households ) to provide free HAART to the rural poor<sup>[9]</sup>. This program was launched in Henan Province, where a majority of people had been infected with HIV via unsafe commercial plasma donation in the mid-1990s<sup>[11]</sup>. In areas where HAART was provided, the fatality rate decreased from 15.4% in 2001 to 7.7% in 2005<sup>[10]</sup>. However, there were no hospice organizations for AIDS patients in China at the time when HAART was introduced<sup>[11]</sup>, and the situation remains so up to now. The Henan Province Government has established a care provision method in the villages supported by urban resources, which includes using HIV-positive peers as HAART supervisors for directly observed treatment (DOT) (hereafter referred to as Peer DOT supervisors) to help people living with HIV/AIDS to adhere to their treatments.

In this study, we used quantitative and qualitative methods to investigate the living conditions and palliative care needs of end-of-life AIDS patients in rural areas of Henan and to assess the Henan model of care.

## METHODS

This study was approved by the institutional review board of Peking Union Medical College.

### *Quantitative Survey*

*Sample* Convenience sampling was used to select 100 end-of-life AIDS (WHO Stage 4) patients from Weishi, Zhenping and Tanghe counties in Henan Province. All end-of-life AIDS patients were selected by village doctors based on criteria in the village health station or at the patient’s home. The criteria for enrollment of the end-of-life AIDS patients were those who received HAART treatment at home or in hospital with clinical symptoms of AIDS, with or without opportunistic infection, and those who were diagnosed as critically ill by their doctors. The subjects all expressed willingness to participate in the study and signed the consents.

*Data collection instruments* A quantitative survey to measure quality of life and happiness was developed to incorporate three components: (1) socio-demographic characteristics; (2) the World Health Organization Quality of Life for HIV (WHOQOL-HIV) BREF Chinese Version; (3) and the Memorial University of Newfoundland Scale of Happiness (MUNSH).

The questionnaires were administered by the investigators and trained research assistants. Oral and written consents were obtained. The self-reported

questionnaires were filled out by the patients unless they had difficulty in doing so.

*WHO QOLHIV-BREF chinese version* Quality of life was evaluated with the WHOQOL-HIV BREF Chinese Version<sup>[12]</sup>, which produces six domain scores (physical, psychological, level of independence, social relationships, environment, and spirituality/religion/personal beliefs) from 31 items denoting an individual’s subjective perception of quality of life, and has two domains which examine overall quality of life and general health status. Individual items are rated on a 5-point Likert scale with one indicating low and negative perception, and five indicating high and positive perceptions. A domain score between 14.7 and 20 indicates a high quality of life, 9.3 - 14.6 moderate quality of life , and 4 - 9.2 low quality of life.

The results of the WHOQOL-HIV BREF from the participants were measured against the average scores in the general population living in the Chinese mainland.

*The memorial university of newfoundland scale of happiness (MUNSH)* MUNSH<sup>[13]</sup> was used to measure the end-of-life AIDS patients’ happiness. It consists of 22 items, with a score between 29.3 and 44 indicating a high level of happiness, 14.9 - 29.29 moderate happiness and 0 - 14.8 low happiness. The investigators made minor modifications to MUNSH in reference to the population investigated.

*Data analyses* The WHOQOL-HIV BREF and MUNSH were scored by using an SPSS syntax file (SPSS Inc. Chicago, IL, USA), which automatically checked and recorded the data, and computed domain scores. Missing items were managed as recommended in the instructions. Descriptive statistics included percentages, mean or median values, standard deviations, and ranges for socio-demographic characteristics, clinical characteristics, quality of life scores and happiness scores. All statistical analyses were completed with SPSS Version 12.0.

### *Qualitative Methods*

To better understand the data on palliative needs and investigate the Henan model of care, in-depth qualitative interviews were conducted with end-of-life AIDS patients and Peer DOT supervisors. A focus group discussion was also carried out with local village doctors.

Based on the principle of the saturation, seven patients from Weishi, Zhenping and Tanghe counties, two Peer DOT supervisors from Guaiyang Village and four village doctors from Zhenping and Tanghe counties were chosen respectively by purposive

sampling for a qualitative interview. A focus group discussion with 11 local doctors from 11 villages in Weishi County was carried out in conjunction with the qualitative interviews to investigate the palliative care provided and the needs of the end-of-life patients.

*Outline development of qualitative interview and the focus group discussion* The investigators invited experts in HIV/AIDS, psychology and sociology researches to assist in the design of the interview outline, which was then piloted in the Number 6 Zhengzhou Hospital, Henan, and revised as necessary.

The interview covered: demographic characteristics; social and economic conditions; patient history of HIV/AIDS; the accessibility to HIV/AIDS treatment and care; items of the patients wished to be included in HIV/AIDS treatment and care; methods of seeking medical care; the attitudes of the family members, the general public, village administrators and health staff and support provided by them; and the patients' feelings and attitudes towards life and the future.

The focus group discussion involved the doctor's views on the psychological health of AIDS patients, the social support they received, and the roles and feelings of village doctors regarding their AIDS care work.

*Qualitative data collected from patient interviews and the focus group discussion* With permission, the interview was recorded. The content, methods and objectives of the interview were explained to the interviewees. Each interview lasted approximately 30-45 min. The interviewees were encouraged to make comments naturally and to fully express themselves. They should not be interrupted in the course of the interviews, nor be induced to give expected answers. After the interviewers confirmed that the interviewees had nothing more to say, the interview was terminated and a gift of appreciation, such as gloves or socks, was given to the end-of-life AIDS patients and Peer DOT supervisors.

*Qualitative interview data analyses (interviews and the focus group discussion)* The data from the qualitative interviews and the focus group discussion were recorded and coded according to the audio recordings, sorted based on the coding and interviewer notes. Claizzi's<sup>[14]</sup> Phenomenology Files 7-Step Analysis method was used to analyze the data.

## RESULTS

### *Quantitative Results*

*Demographic and medical information* One hundred questionnaires were issued and all were

returned; however, only 93 were valid. These 93 patients were probably infected with HIV between 1994 and 1995, but diagnosed as HIV infection or AIDS in 2002-2004. Seventy-six were married and one was a widow (whose husband died of AIDS). The average age was  $41.79 \pm 6.60$  years old, and 44 (47.3%) were male and 49 (52.7%) were female. All patients had  $CD^{4+}$  cell counts lower than  $400/mm^3$  and were receiving HAART.

*The end-of-life aids patients' quality of life (WHOQOL-HIV BREF)* Table 1 shows the scores on quality of life. The mean score was  $12.62 \pm 1.97$ , indicating a moderate quality of life. Scores for the six subscales were also in the moderate range. The patients' evaluation of their general health status and their general quality of life was fair. Details are provided in Table 2.

Table 3 shows the evaluation of patients' negative emotions experienced over the past two weeks with any level of frustration (74.2%), depression (76.4%), anxiety (89.3%) and desperation (35.5%) respectively.

*Subjective happiness of the AIDS patients (MUNSH)* Table 4 shows the MUNSH scores of 93 valid questionnaires. The highest score was 42 while the lowest was 2. The average score was  $21.00 \pm 6.20$ , which was in the moderate range.

### *Qualitative Results*

*Interviewees* Seven patients, five females and two males, were infected with HIV via blood donation from 1992 to 1996 and tested HIV positive in a mass survey in 2003 or 2004. Two Peer DOT supervisors were all males and married. Both of them sold blood from 1995 to 1996, and were tested HIV positive in 2002.

All the interviewees began receiving HAART in 2003 or 2004.

Village doctors: the 11 doctors were mostly educated in secondary specialized schools and all had received HIV/AIDS training for rural doctors.

### *Themes*

*Discrimination* When asked if there were any people who looked down on them, the patients responded with anecdotes of people refusing to accept food from them or of reduced contact with extended family members.

*Psychological condition* With the implementation of local prevention and education activities combined with treatment for people living with HIV/AIDS, these end-of-life patients felt that they were gradually accepted by society and that people stigmatizing

TABLE 1  
Quality of Life among Aids Patients ( $n=93$ ) (WHOQOL-HIV BREF)

Items	$\bar{X} \pm SD$	( $\bar{X} \pm SD$ ) Chinese Population	$t$	$P$	Level
Total Score	12.62 $\pm$ 1.97	17.46 $\pm$ 1.74	23.69	0.00**	Moderate
Physiological	14.04 $\pm$ 3.16	15.10 $\pm$ 1.14	3.23	0.00**	Moderate
Psychological	13.58 $\pm$ 2.06	13.89 $\pm$ 1.32	1.45	0.15	Moderate
Independence	12.15 $\pm$ 2.15	15.64 $\pm$ 1.60	15.65	0.00**	Moderate
Social Relationship	15.53 $\pm$ 2.82	13.93 $\pm$ 2.56	5.47	0.00**	Moderate
Environment	12.50 $\pm$ 3.28	12.14 $\pm$ 1.56	1.06	0.30	Moderate
Spirituality/Religion/Personal Beliefs	14.40 $\pm$ 2.96	11.05 $\pm$ 2.67	10.91	0.00**	Moderate
General quality of life	2.89 $\pm$ 0.75				Fair
General Health Condition	3.21 $\pm$ 0.96				Fair

Note. \*\* There is a significant difference.

TABLE 2  
AIDS Patients' Perceptions of Current Quality of Life and Health Condition ( $n=93$ ) (WHOQOL-HIV BREF)

Items	$n$	Percentage (%)
Patients' perceptions of Quality of Life		
Very Poor	0	0.0
Poor	13	14.0
Moderate	52	55.9
Good	24	25.8
Very Good	4	4.4
Patients' perceptions of Health Condition		
Very Dissatisfied	3	3.2
Dissatisfied	11	11.8
Moderate	32	34.4
Satisfied	45	48.4
Very Satisfied	2	2.2

TABLE 3  
Anxiety and Unease of Aids Patients in the Past Two Weeks ( $n=93$ ) (WHOQOL-HIV BREF)

Items	Frustration	Depression	Anxiety	Desperation
	$n$ (%)	$n$ (%)	$n$ (%)	$n$ (%)
Not at all	24 (25.8)	22 (23.7)	10 (10.8)	60 (64.5)
A few times	28 (30.1)	21 (22.6)	31 (33.3)	16 (17.2)
Occasionally	26 (28.0)	32 (34.4)	37 (39.8)	11 (11.8)
Often	15 (16.1)	15 (16.1)	12 (12.9)	6 (6.5)
Always	0 (0.0)	3 (3.3)	3 (3.3)	0 (0.0)

TABLE 4  
AIDS Patients' Feelings of Welfare ( $n=93$ ) (MUNSH)

Score	$n$	Percentage (%)	Highest Score	Lowest Score	$\bar{X} \pm SD$
0-14	23	25.0			
15-29	53	57.1			
30-44	17	17.9			
Total	93	100.0	42	2	21.00 $\pm$ 6.20

them because of HIV/AIDS were decreasing, especially in the villages with high morbidity. In these villages, the end-of-life patients said that they rarely experienced such feelings as loneliness and depression.

Most AIDS patients felt that their families shared the outcomes of their suffering owing to the nature of the disease, which would lead to poverty and affect children and their children's marriage prospects. Many patients blamed themselves for the negative

consequences of the disease to the family, and felt guilty. In addition, the patients felt upset and were under heavy pressure because of the increasing hardship of life due to HIV/AIDS, the incurability of AIDS, and the inevitability of death.

*Social support* With the implementation of HAART, anti-stigma programs and the decrease in rejection of AIDS patients, interviewees reported receiving more social support.

When Patient 3 was diagnosed as HIV (+), she had the courage to face the disease with support from people around her. Patient 2 indicated a high level of support from the people she came into contact with in her daily life. However, there was still some discrimination and rejection to AIDS patients, and although all expressed satisfaction with the support they received from healthcare providers, they thought healthcare providers could have been more friendly and sympathetic.

*Religion* Three of the seven end-of-life AIDS patients were religious, and they became religious only after they had been diagnosed as HIV positive. They became religious with the only aspiration to find something to depend on, or to be given more opportunities to interact with other people, and they believed that discrimination did not exist among religious people.

*Views about death and palliative care needs* AIDS patients in the countryside still hold traditional Chinese concepts of life and death. They are concerned about their children's livelihood after they die, and are ready to die once their children's livelihood has been assured (which usually means their children are married), but they are seldom concerned about themselves. As to the needs for AIDS patients during their terminal stage, all of them mentioned that they strongly wished to be accepted by others, especially by doctors and nurses. They wished that doctors and nurses joined them in the fight against the discrimination and provided them not only with medications but also with care and mental support, permitting them to choose the way to die when they had to face death.

On the other hand, AIDS patients wished that government could give them more material assistances, such as money, animals (piglet, calf, etc.) and farmland. And they also hoped that the local government could reduce medical expense of diseases other than AIDS.

#### *Results of Interviews with Peer DOT Supervisors*

The supervisors expressed positive emotions, such as hope, optimism, and responsibility for family and society.

*Full of hope and optimism* "Sometimes I think, one day some medication may cure this disease" Peer DOT 1 supervisor said [laughing].

*Responsibility for family* The supervisors were employed and were doing physically strenuous work. They expressed a desire to work hard to leave enough money for their children.

*Responsibility towards their peer DOT supervisory work* The supervisors were extremely conscientious and dedicated to their Peer DOT supervisory duties and willing to continue working as a Peer DOT supervisor even if they were not paid.

"What can I do when he doesn't listen to me? I even handed him a glass of water and I told him that I wouldn't leave if he wouldn't eat" (Peer DOT Supervisor 1).

#### *Focus Group Discussion with Village Doctors*

The focus group discussion with village doctors is summarized as follows:

*Discrimination* The village doctors reported that as most patients were infected with HIV by selling blood, it was easier for the general public to accept them, and that in general, discrimination towards people living with HIV/AIDS had decreased over time, especially owing to the sustaining public education campaigns. However, discrimination still existed as few non-AIDS patients came to the local clinic for treatment for fear of being infected.

*Religion* The village doctors considered religion a source of social support for AIDS patients. Some doctors said: "They are mainly looking for happiness. The religious faith makes them forget the disease, and helps them to make friends."

*Division of responsibility in HIV/AIDS treatment and care* The village doctors accepted the way in which the provision of treatment and care was divided among doctors, nurses and the Peer DOT supervisors, as they thought it essential to give full play to each side's initiative and provide psychological support to patients in an efficient and coordinated way. They viewed the use of Peer DOT supervisors important in improving HAART compliance and helping patients maintain their relationship networks, and were certain that their patients trusted them. As to their own specific role, the village doctors thought that they should act as bridges to transmit government policies to the patients and encourage the patients with psychological counseling and assistance. They also played an important role in educating the patients, their family members and the general community,

and in this way helped to reduce stigma and discrimination. The village doctors were proud of their work and the trust they received from the patients; however, they were aware that they were unqualified to provide psychological counseling to the patients, though they considered psychological counseling an important component of treatment and care. It was also felt that there was not enough nursing staff to meet needs.

## DISCUSSION

The WHOQOL-HIV BREF score ( $12.62 \pm 1.97$ ) indicates that the participants had a moderate quality of life, and is higher than the  $10.44 \pm 2.48$ <sup>[19]</sup> and lower than the  $13.20 \pm 3.61$ <sup>[12]</sup> reported by two other studies of former HIV-infected plasma donors in China. However, it may not be suitable to compare with the results of these studies, as neither of them specified at what stage of HIV/AIDS their participants were. The MUNSH shows that participants had good levels of happiness with 57 percent reporting moderate levels of happiness and nearly 18 percent indicating high levels of happiness. Participants' perceptions of quality of life and health condition were also firmly rated as moderate or above with only 14 percent saying that their quality of life was less than moderate, and 15 percent reporting to be either dissatisfied or very dissatisfied with their health condition. This indicates that the majority of participants has largely accepted their current health status and found ways to cope with their progression to AIDS and their impending death. This conclusion is supported by the data in Table 3, where only a minority of participants reported always or often feeling frustration, depression, anxiety or desperation.

Half of the participants expressed satisfaction with their current health situation (Table 2). This is probably due to the policies designed and implemented by the government of Henan Province, which established the HIV relieving mode. This mode offers the patients in the rural area all free treatments of common opportunistic infections and therefore, has ensured that patients living in rural areas are treated in their own villages and receive frequent visits from Peer DOT supervisors and village doctors. It may also be related to the fact that end-of-life AIDS patients have realized the critical conditions of their illness. Additionally, research in China has indicated that the economic condition of people living with HIV/AIDS is closely related to quality of life<sup>[15-16]</sup>. Free HAART, which is mandated in the Four Frees and One Care policy, and free treatment of opportunistic infections in Henan Province, have undoubtedly relieved some of the financial burden associated with HIV infection and

potentially improved feelings of welfare and quality of life to some degree due to higher levels of social support. More researches<sup>[17-18]</sup> showed that the worse the economic condition is, the worse their quality of life gets.

It is interesting that out of the 6 domain scores in the WHOQOL-HIV BREF, participants' recorded scores in 2 domains are much higher than the Chinese population average. These higher domain scores were for spirituality/religion/personal beliefs and social relationships. The highest WHOQOL-HIV BREF domain score was for the spirituality/religion/personal beliefs domain ( $14.4 \pm 2.96$ ), which is consistent with another study of people living with HIV in this region of China<sup>[12]</sup> where it was also the highest domain score. In both studies, the spirituality/religion/personal beliefs domain score was higher than the Chinese population average, suggesting that those infected with HIV may have become religious as a consequence of their infection. The incurability of HIV/AIDS and the lack of wider social support may have added to the trend of participants becoming religious. The qualitative interview and the focus group discussion with the village doctors reinforce this finding.

The spirituality/religion/personal beliefs domain is also comprised of the facets of forgiveness and blame, concerns about the future, and death and dying. The qualitative interviews show participants' future concern for their family members rather than for themselves, and if they were assured that their family members would be taken care of after their death, then death "became unmeaningful to them". This indicates that providing social support to the family unit as a whole should have a beneficial impact on quality of life and happiness. The in-depth interviews did not elicit information pertaining to forgiveness and blame; however, other researches<sup>[20]</sup> have shown high levels of emotional distress towards the person who infected them. Therefore, researches into end-of-life attitudes towards those who infected them may be of use for design of appropriate psychological counseling.

The participants in this study also scored much higher than the Chinese population average on the social relationship domain. This domain encompasses the facets of personal relationships, social support, sexual activity and social inclusion. It is possible that the use of Peer DOT supervisors and frequent visits by doctors positively influenced perceptions of social support. In China, emotional healing may be the most important treatment besides medical care.<sup>[21]</sup> Stigma and discrimination have impact on emotional healing and the qualitative data show that participants still experience some stigma and discrimination, and some participants have expressed self-abasement in

their interactions with others. This indicates a continuing need to reduce stigma and discrimination towards HIV and thus, to promote emotional healing.

Commensurate with the Chinese population average were the participant environment ( $12.50 \pm 3.28$  vs.  $12.14 \pm 1.56$ ) and psychological ( $13.57 \pm 2.06$  vs.  $13.89 \pm 1.32$ ) domain scores. The participants' domain scores for physical health and independence, as one would expect for a group of people suffering from an incurable disease, were lower than the average scores in the Chinese population. While the quantitative data indicate a relatively higher psychological domain score, the qualitative data show that any depression and anxiety experienced were mainly in relation to concern about the future welfare of their children and their decreased independence/ability to do the activities necessary for normal daily life, such as household chores or farming. This also indicates an important role played by the support given to the family unit.

The village doctors and the end-of-life AIDS patients had different perspectives on their social inclusion, and the latter believed that their social inclusion was not as high as the former thought. Participation in religious activities will have improved levels of social inclusion, as evidenced by the qualitative interview results; however, although many qualitative interviewees were religious, information concerning religious belief was not collected on the socio-demographic section of the quantitative questionnaire. Therefore, a conclusion as to the strength of the link between religion and high scores on social relationships (and spirituality/religion/personal beliefs) cannot be made. Future research should collect this information to assist in data interpretation.

Although the quality of life and happiness of participants in our research is moderate, there are ways in which this could be improved if more attention is paid to the care and support given to people living with HIV/AIDS and their families. If local organizations including people living with HIV/AIDS and their family members are to be established in every village, then the end-of-life circumstance among them will be improved, social support could be provided and dialogues about their needs between health care providers at the local, prefectural and provincial levels might be carried out in a smooth way. These local organizations would be beneficial as treatment and care could then be tailored to local needs, resulting in optimal use of limited resources and improving feelings of self-esteem and perceptions of social support and social inclusion.

There are a number of limitations to this research. First, this research relates to AIDS patients in the final stages of their life, and therefore, the results are

not relevant to people living healthily with HIV or those in the earlier stages of AIDS. Second, it is a cross-sectional survey, in which, conclusions about cause and effect can not be drawn. Despite these limitations, it is believed that this research sheds some light on the life conditions (quality of life, happiness) of end-of-life AIDS patients in Henan, something that has not been done before, and provides a foundation for further investigation.

In conclusion, the quality of life and happiness of the end-of-life HIV/AIDS patients infected via unsafe commercial plasma donation in Weishi, Zhenping and Tanghe counties of Henan Province is moderate. Participants recorded higher scores than expected for the quality of life, social relationships and spirituality/religion/personal belief domains. The role of religious belief, free treatment of opportunistic infections and the intensive interaction with medical personnel (village doctors/nurses, and Peer DOT supervisors) in these higher domain scores than expected and in general quality of life and happiness needs to be further investigated. The qualitative interviews illustrate that support provided to the family unit as a whole is important, and could be improved. Efforts to reduce stigma and discrimination should be maintained and exploration into the feasibility and type of psychological counseling should begin. The role of religion in providing care to people living with HIV/AIDS in rural China has not been investigated and the exploratory results from this study indicate that indigenous religious organizations may be a care resource which should be investigated. The model of treatment and care used by the Henan Provincial Government, which utilizes intensive contact with medical personnel, is worth further exploration so that China can continue to improve the quality of treatment and care provided to people living with HIV/AIDS in all stages of the disease.

## ACKNOWLEDGEMENTS

The authors extend their appreciation to Dr. Zun-You WU for his encouragement and support while this article was being written. We would also like to thank Prof. Zhong-Dan CHEN, Dr. Ke-Ming ROU, and all of the patients, Peer DOT supervisors and the village doctors and nurses for their support and participation in our research.

## REFERENCES

1. Ministry of Health, UNAIDS, WHO (2006) [pdf] "2005 update on HIV/AIDS epidemic and response in China".
2. State Council AIDS Working Committee Office and UN Theme Group on HIV/AIDS in China. A Joint Assessment of

- HIV/AIDS Prevention, Treatment and Care in China 2005. December, 2005
3. Krenz HB, Gill MJ (2003). The impact on health-related quality of life of treatment interruptions in HIV-1 infected patients. *AIDS* **17**, 631-633.
  4. Robinson L, Dugger K, Fong G, *et al.* (2006). Palliative home nursing interventions for people with HIV/AIDS: a Pilot study. *J Assoc Nurses AIDS Care*. **17**, 37-46.
  5. Corless I B, Nicholas P K (2000). Long-term continuum of care for people living with HIV/AIDS. *J Urban Health*. **77**, 176-186.
  6. Jones S. G. Symptom Management and Palliative Care in HIV/AIDS. <http://www.medscape.com/viewarticle/445637> (Last accessed August 10, 2007).
  7. Ruiz Perez J, Rodriguez Bano M A, Lopez R (2005). Health-related quality of life of patients with HIV: impact of sociodemographic, clinical and psychosocial factors. *Qual Life Res*. **14**, 1301-1310.
  8. UNAIDS. AIDS Epidemic Update. <http://www.unaids.org/epi> 2006 (Last accessed December 29, 2006).
  9. Zhang F J, Wen Y, Yu L (2005). AIDS anti-viral treatment and the Free Treatment Situation in Our Nation. *Tech Herald [Chinese]* **23**, 24-29.
  10. Zhou W, Wei J A, Sun L M (2005). The side effect of highly active anti-retroviral therapy of AIDS, *Chinese Journal of AIDS & STD*. **11**, 73-75.
  11. China- UK HIV/AIDS Prevention and Care Project. Report on requirements for hospice care. October 2002.
  12. Sun J. An Investigation into the Quality of Life and an Analysis of Factors for Former Plasma Donors with HIV/AIDS patients in Hubei Province. Ph.D. dissertation. Hua Zhong Science and Technology University. 2006.
  13. Kozma A Stones M J (1980). The measurement of happiness: development of the Memorial University of Newfoundland Scale of Happiness (MUNSH). *J Gerontol*. **35**, 906-912.
  14. Burns N, Grove S K (2001). The practice of nursing research: conduct, critique and utilization. 3<sup>rd</sup> ed. Philadelphia: WB Saunders Company, 542-547.
  15. Yang J Z, He H X, Zhang Y, *et al.* (2007). Life quality and relevant factors of HIV/AIDS patients. *Practical Preventive Medicine* **14**, 1740-1741.
  16. Ma L, Ye D Q, Zhang G D, *et al.* (2007). Study on the quality of life and social support among people living with HIV/AIDS and their family members. *Chin J Epi [Chinese]* **28**, 254-257.
  17. Yang Y, Zhang K L, Wang K R, *et al.* (2005). Study on quality of life and related factors among people living with HIV/AIDS. *China J AIDS STD [Chinese]*. **11**, 244-246.
  18. Yang F, Liu Q (2005). The research review for quality of life of HIV/AIDS patients. *Foreign Medicine, Social Medicine*. **22**, 49-53.
  19. Xie J, Shi X Z, Wang F (2006). Logiest regression analysis for the quality of life and effective factors of HIV/AIDS patients. *Chinese J Clin Rehab [Chinese]*. **38**, 14-16.
  20. Meng Y J, Li N X, Liu C J, *et al.* (2008). Quality of life and hostile mentality trend of patients with HIV/AIDS in China. *J R Inst Public Health*. **122**, 404-441.
  21. Xu Z W, Tan Y D (2003). The care and reducing discrimination for PLWH and AIDS patients. *Zhejiang J Preventive Med [Chinese]*. **15**, 52-54.

(Received June 4, 2010 Accepted August 12, 2010)