Ten years of research and publications about hospice and palliative care in Mainland China: a bibliometric study

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Research article

Keywords: China, bibliometrics, hospice, palliative care, publications, research

Posted Date: July 21st, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-41366/v1>

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Abstract

Background Research is a fundamental element in the sustainable development of hospice and palliative care. Mainland China is facing increasing demand for hospice and palliative care and has launched related policies over the past decade. However, the state of research and publications in this field in China remains largely unknown. This study aimed to provide an overall picture of hospice-and palliative care -related research and publications in Mainland China from 2010 to 2019.

Methods We searched Web of Science and China National Knowledge Infrastructure for hospice-and palliative care -related publications in English and Chinese for 2010–2019. We analyzed the production, repercussions, publishing journals, region and institution of origin, and themes and active topics.

Results A total of 3140 publications were identified, and 552 of them were of high quality. The production and repercussions showed a clear increase—especially after 2016. However, the regional disparity between East and Western China in production was conspicuous and closely linked to economic factors. Beijing and Shanghai were the most productive regions. The hospice providers in the first five pilot regions had no collaboration with leading universities in their publications. Hospice and palliative care for cancer patients was the most common publication topic; some essential themes were rarely explored.

Conclusion Research and publications of hospice and palliative care in Mainland China is developing faster than before; however, it remains at an early stage and should be promoted in terms of interregional equity. Collaboration among different disciplines, institutes, and regions should be encouraged.

Background

Hospice and palliative care (HPC) is a fundamental human right and a crucial part of an integrated, person-centered health service. The world as a whole has made rapid progress in this sector, but HPC in Mainland China has long been in a state of infancy [1]. According to the 2010 and 2015 Quality of Death Index by the Economist Intelligence Unit, China is among the countries with the lowest rank [2, 3].

Though HPC has developed slowly in Mainland China, the demand for it has undoubtedly increased. China has a rapidly aging population: in 2019, 17,599 million Chinese were aged over 65 years (12.6% of the total population) [4]; that proportion is estimated to reach 26.9% in 2050 [5]. Meanwhile, chronic non-communicable diseases (including stroke, ischemic heart disease, lung cancer, chronic obstructive pulmonary disease, and liver cancer) have become a major burden; they are the main causes of years of life lost [6]. Together with the aging society, those diseases mean that a large segment of the population is in great need of HPC. Furthermore, futile medication at the end of life is still prevalent in China [7], which has led to catastrophic expenditure for patients and families, leaving a significant number of people below the poverty line [8]. Most patients are willing to learn more about HPC, but few have access to it [9].

In light of this situation, the Chinese government has promoted related policies over the last decade. In 2012, Shanghai began promoting a community-based hospice service. In 2014, China, along with the other 194 countries in the 67th World Health Assembly, committed to enhancing HPC as a component of comprehensive care throughout the life course. In 2017, the former National Health and Family Planning Commission of China issued a guideline for hospice care; subsequently, five regions were chosen for a national pilot on hospice implementation. In 2019, the number of pilot regions expanded to 71.

Though China's policy making has become active in this regard, there has been no adequate promotion of research. The role of research has been identified as a fundamental element for sustaining the development of HPC [10]. The lessons learned from previous research have shaped and fueled the implementation of HPC within the standards of evidence-based medicine [11]. Thus, the state of research and publications should be regarded as a key measure when examining the development of HPC in a region. Previous reports have identified a growth in HPC-related publications, both globally and in the Asia-Pacific region [12–14]. However, documents in Chinese were not included owing to the language barrier. Recently, investigators from Hong Kong managed to avoid the "Tower of Babel" bias by searching in Chinese: they found a considerable knowledge gap related to HPC research in Mainland China [15]. However, the authors focused on original studies with a strict inclusion criterion and failed to provide a whole picture of the structural changes in the HPC-related literature that have occurred over recent years.

In the present study, we sought to remedy that deficit by analyzing HPC-related publications from Mainland China from 2010 to 2019, including both primary and secondary literature, in English and Chinese. Employing bibliometric tools, we investigated the production, distribution, repercussions, and development related to this young discipline. We aimed to depict a panoramic, yet detailed, view of HPC-related research and publications in Mainland China: that is crucial to understanding the present situation and future direction for the sustainable development of HPC. We also hope that the study could provide beneficial information for promoting research in China and other low- and middle-income countries.

Methods

Data source and document retrieval

In this study, we used the Web of Science (WoS) to search for publications in English and China National Knowledge Infrastructure (CNKI) for ones in Chinese. CNKI is the largest digital publishing platform in China, and it covers a whole category of academic resources, including China's largest academic database, the Chinese Journal Full-Text Database (CJFD). We retrieved relevant articles published from January 2010 to December 2019 from WoS if they contained "Chinese" or "China" in the affiliation address and contained any of the following terms: "palliative care," "hospice," "end-of-life care," or "terminal care." Similar methods were used to search for Chinese articles in CNKI. We applied various Chinese versions of "HPC" as follows: "*huan-he-yi-liao*," "*shu-huan-yi-liao*," "*shu-huan-liao-hu*," "*gu-xi-yi-xue*," "*gu-xi-zhi-liao*," "*gu-xi-guan-huai*," "*an-ning-liao-hu*," and "*lin-zhong-guan-huai*." All the above terms have appeared in Chinese literature at different times and in different regions. We restricted the literature

types to consensus, guidelines, editorials, original research, and case studies. To eliminate the possibility of duplication with original research, we excluded conference proceedings, master's theses, and doctoral dissertations. The document retrieval was conducted on March 22, 2020. After completing the retrieval, we reviewed the titles, abstracts, and author affiliations of the documents according to the following exclusion criteria: (1) The topic is curative medicine. (2) The article was in English and focused on Taiwan, Hongkong, Macao, and other places outside Mainland China. (3) The article was a translation of work that had already appeared in an international journal. We did not exclude articles if they were in Chinese and described the situation of HPC in places other than Mainland China: such articles play an essential role in distributing knowledge and reflect people's interest. Two reviewers (S.J. and S.L.) independently screened the documents for exclusion. Conflicts were resolved by discussion and mutual agreement. The procedure is shown in Fig. 1.

To conduct an additional quality and repercussion assessment and content analysis with a focused data source, we created a subgroup of high-quality publications: they included articles published in international journals cited by WoS and core journals of CNKI according to the standard of Peking University Library. Searching for articles within core journals is a built-in function of CNKI. The core journal list is renewed periodically; thus, some journals may become newly included as their quality improves. We did not consider articles published in those journals before the inclusion year in the high-quality subgroup. We assigned articles to a specific province or municipal city according to the affiliation address of the first author.

Bibliometric Indicators

We applied several bibliometric indicators to evaluate scientific activity. Production was assessed using the number of publications as well as that number per million inhabitants. We obtained socioeconomic parameters, such as the number of inhabitants and regional gross domestic product (GDP), from the National Bureau of Statistics of China on April 26, 2020 (5). To evaluate the pattern of growth, we conducted a linear adjustment and exponential adjustment. The repercussions of the articles published by a specific region were measured using the regional impact factor (RIF): that is similar to the impact factor of a journal and could be established each year based on the previous 2-year period. We determined the RIF of a given year as follows: the denominator signified the total number of articles published during the 2 years before the index year; the numerator signified the number of citations in the index year of the articles included in the denominator. Some regions produce few publications; thus, we introduced the 5-year RIF of 2019 as a more stable indicator for interregional comparison. The 5-year RIF was the same as the RIF, except it used a 5-year time window. To avoid excessive articles with no citations, the calculation of impact factors employed only the citation data of high-quality publications.

Content Analysis

To analyze the character and content of the publications, we categorized the articles in the high-quality subgroup according to literature types and themes. We regarded original research and case reports as primary literature and reviews, guidelines, and consensus studies as secondary literature. No editorial among our data followed an introduction-method-result-discussion format pattern, so we classified them as secondary literature. According to the subject and research theme described in the abstract, the two reviewers classified each article into the following categories with mutual agreement:

1. Aging and geriatric HPC
2. Pediatric HPC
3. HPC in cancer patients
4. HPC in non-cancer patients
5. Pain and symptom management
6. Rehabilitation and nutrition
7. Spiritual and psychological care
8. Complementary therapy
9. Humanity and art
10. Communication and advanced care planning
11. Family caregivers and volunteers
12. Bereavement
13. Self-care of the HPC team
14. Education and training
15. Nursing in HPC
16. HPC in primary care
17. HPC in other specialties
18. Ethics
19. Policy and program advocacy
20. Assessment of needs and implementation of HPC
21. HPC timing and screening

We adopted those categories following the advice of the Asia Pacific Hospice Palliative Care Network with some modifications [16]. Overlap was permitted, and so each article could fall into more than one category.

We analyzed the trend in research interests using CiteSpace[®] (version 5.6.R3), a JAVA-based software that can detect the word bursts over a period of time [17]. A word burst is a surge in the frequency of the appearance of a word: it is a valuable indicator of active research topics [18]. Owing to language differences, we applied the burst detection to articles in English and Chinese separately.

Statistics

We performed regression analysis using IBM SPSS Statistics 26. We conducted a linear adjustment of all publications according to the equation $y = 39.842x - 79949$ and an exponential adjustment according to the equation $y = 9.804E-101e^{0.117x}$. We undertook a similar analysis with the high-quality subgroup according to the following equations: $y = 9.2364x - 18551$ versus $y = 1.325E-143e^{0.165x}$. We considered the difference significant at a P -value below .05.

Results

Growth of HPC-related publications

We identified 3140 documents as HPC-related publications for 2010–2019; among them, 552 were high-quality publications and 171 were in English. Irrespective of quality, the annual number of publications grew notably during the 10-year period (Fig. 2). According to the regression analysis of all publications, the R^2 was 0.863 when adjusted to an exponential curve; it was 0.780 with a linear adjustment. This finding indicates that exponential growth better explained the pattern of increase, thereby fulfilling Price's law [19]. A similar pattern was evident in the high-quality subgroup: the R^2 was 0.927 with an exponential adjustment and 0.841 with a linear adjustment. We also observed a sharp increase in total publications after 2016. A similar, though milder, trend was evident in high-quality publications after 2017. The repercussions of scientific production also rose during the study period.

Journals Publishing Hpc-related Articles

Table 1 shows the top 10 productive journals of total and high-quality publications. Notably, there is no specialized HPC journal in Mainland China. Thus, the fields of the listed journals may be interconnected with HPC. In the case of total publications, the articles were distributed among various journals: the 10 leading journals published 19.17% of all publications. Only 3 of those 10 are core journals according to the latest criterion of Peking University. This scattering pattern was not manifest with the high-quality subgroup: the leading 10 journals accounted for 43.84% of articles. There were two international journals on the list: *Journal of Pain and Symptom Control* and *American Journal of Hospice and Palliative Medicine*.

Regional Distribution Of The Publications

Although the overall growth of HPC-related publications during the 10-year period appears promising, the regional disparity was substantial (Fig. 3A). In decreasing order, the five most productive regions were Beijing (11.5% of total production in Mainland China), Shanghai (11.0%), Jiangsu (8.2%), Guangdong (7.3%), and Sichuan (5.4%). By contrast, China's northern and western provinces lacked publications. When adjusted by the number of inhabitants, the prominence of Beijing and Shanghai became greater: during the 10-year period, they contributed 16.7 and 14.2 articles per million inhabitants, respectively.

They were followed at a considerable distance by Tianjin (5.2), the city with the first-ever hospice center in Mainland China (Table 2). There was a strong correlation between annual production and regional economy (Fig. 3B). However, on that basis, Beijing and Shanghai were outliers and performed much better than could be expected. The regional difference in publication repercussions is indicated by the 5-year RIF (Table 2); there was no clear correlation between productivity and repercussions ($R^2 = 0.04$, $P = 0.27$).

The names and locations of the top 10 productive institutes appear in Fig. 3A: they are all universities and colleges with affiliated hospitals. It is noteworthy that four of the 10 institutes were located in Beijing and Shanghai; only one (Sichuan University) was in Western China. We also examined the production of the 41 institutes that provided HPC among the first five pilot regions for hospice implementation. Those institutes published 51 articles and had no collaborations with the leading institutes listed in Fig. 3.

Themes Of The Publications

We further analyzed high-quality publications concerning their literature type and content. In this subgroup, 368 of 552 articles were original research and eight were case reports; thus, primary literature accounted for 68% of the total. Secondary literature comprised of 173 reviews or editorials and three consensuses. We categorized the articles according to their themes. As shown in Table 3, HPC in cancer patients was the leading topic; that was followed by pain and symptom management, assessment of needs and implementation of HPC, and policy and program advocacy. The topics that received minor attention were bereavement, HPC screening and timing, rehabilitation and nutrition, self-care of the HPC team, and pediatric HPC.

Discussion

In this study, we attempted to provide an overall assessment of research and publications related to HPC in Mainland China over a 10-year period. During that time, both the production and repercussions of the publications increased; however, regional disparities were conspicuous. There was also a lack of a discussion of some important areas of HPC.

Growing Out Of Infancy

The first hospice in Mainland China was founded in the municipal city of Tianjin in 1988 [20]. But the adoption of HPC in Mainland China has been slow. Even among health professionals, there is still insufficient knowledge of the subject [21]. However, the present study found that the number of HPC-related publications in 2019 was almost three times that in 2010. The exponential rise of the production and repercussions of HPC-related publications is a sign of academic attention and discussion, which are vital for professional education as well as research innovation. In our opinion, this trend will lead HPC in Mainland China out of its infancy.

There are several reasons for the growth. In the 2010 Quality of Death Index, China ranked 37th among the 40 countries and regions investigated [2]. In 2015, the second edition of the Quality of Death Index ranked China 71st among 80 countries and regions [3]. All three countries with a lower ranking than China in 2010 surpassed it in 2015. This was widely covered by Chinese media and elicited broad discussion, stimulating health-care workers and policy makers to reexamine the medical system and service. At the same time, a series of new policies prompted the promotion of knowledge about HPC. For example, community care, which burst as a key word in 2015, has been promoted by the government since 2012. The burst detection also showed a promising shift of key words from main concepts to practical issues, such as pain management and negative emotions, which may lead to more clinically relevant research.

Despite its growth, research into HPC in Mainland China remains at an early stage. First, the number of high-quality publications per million inhabitants is meager compared with other parts of Asia [14]. Second, a large number of those publications are secondary literature, which introduces ideas and knowledge but does not explore the unknown. Third, HPC for non-cancer patients is far less discussed than for cancer patients, and end-of-life care or hospice receives greater attention than integrated palliative care in an early stage. Thus, many professionals may be unaware of the latest concept of palliative care [22]. Accordingly, policies should be designed to support original research and education in HPC.

Conspicuous Regional Disparity

Imbalanced development in China has long been recognized—especially between East and Western China [23]. This inequality is evident in many areas, including the economy, human capital, public facilities, and science and innovation. Studies have observed that economic factors are closely linked to a country's production of HPC-related publications [24]. We found that relationship also applies on a provincial scale. When residents in less prosperous regions have limited access to curative medicine [25], an insufficient HPC service will close the door to relief. Thus, the regional disparity in research and publications is both a result and a component of that imbalance, which would produce the Matthew effect and cause inequity in HPC.

China's great cultural richness warrants more research in different regions and populations. Chinese attitudes toward death are heterogeneous. One study among Christians in a northern rural region of China determined that 95% could freely talk about death at home; 85% felt joyful when thinking about death [26]. That finding is against the stereotype of Chinese people. Another study from urban areas showed that older people were more willing to die in hospital than younger ones [27]; that is also against the stereotype of the elderly. Owing to different cultural and social factors, patients' attitudes to HPC varied from hostility to embracing the approach [28, 29]. Some of China's least productive regions (such as Tibet, Hainan, Xinjiang, and Inner Mongolia) covered in the present study are home to various ethnic groups. Thus, in a rapidly changing, culture-rich society, we believe that more research is needed to understand local needs and promote culture-sensitive care.

Call For Collaboration

The study identified a lack of collaboration at different levels. From the names of journals publishing HPC-related articles, nurses, general practitioners, and geriatricians are especially active in this field. However, researchers from other specialties, such as emergency medicine and intensive care, were scarce. Nurses have done excellent work in HPC research. However, in Mainland China, nurses are not allowed to prescribe medications, which compromises their ability to conduct intervention studies. More doctors from different specialties, nutritionists, physical therapists, psychologists, social workers, and other related professionals should be involved in multidisciplinary HPC research.

At the institutional level, the hospice providers in the first five pilot regions had no collaboration with leading universities in their publications. HPC is highly practical, so we strongly recommend collaboration between HPC providers and professional researchers. Future policies and funding should support this collaboration.

International collaboration is also important for HPC practitioners and researchers in Mainland China: they should seize opportunities to communicate with researchers from the rest of the world, especially other Asian regions. Overall, collaboration is the way to make more people heard.

Strengths And Limitations

To our knowledge, this is the first study that provides a whole picture of HPC-related research and publications in Mainland China. Our study has several limitations. First, the terminology for HPC in Mandarin Chinese is not unified, and so we included various versions. We may have missed articles that did not mention those terms. Second, it was difficult to determine the actual quality of an article. A high-quality article can be published in a non-core journal [30]. Third, some excellent HPC centers dedicated themselves to delivering care rather than research. Their efforts were largely invisible in our study. Future investigations should aim to determine the factors that hinder or promote research in HPC.

Conclusion

China is a good example of a low- and middle-income country with limited, yet highly demanded, implementation of HPC. The 10-year study period witnessed a considerable increase in HPC-related publications in Mainland China. However, regional disparity in production was conspicuous, and HPC research is at an early stage. Research is essential for the sustainable development of HPC and should be promoted with interregional equity. Policies should be made to encourage collaboration among different disciplines, institutes, and regions. Future research is needed to identify the factors that hinder or promote research in HPC.

Abbreviations

HPC

Hospice and palliative care

WoS

Web of Science

CNKI

China National Knowledge Infrastructure

RIF

Regional impact factor

GDP

Gross domestic product

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

The data analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

The work was supported by Irma and Paul Milstein Program for Senior Health of the Milstein Medical Asian American Partnership Foundation (No grant number was available). With this support we were able to pay for the editing fee.

Authors' contributions

S.J., X.L., and X.N. developed the concept and design of the study. S.J. and S.L. collected the data and reviewed the publications. J.L. did the statistical analysis. J.S. wrote the manuscript. All authors read and approved the final manuscript.

Acknowledgements

We thank Liwen Bianji, Edanz Group China (www.liwenbianji.cn/ac), for helping us edit a draft of this manuscript.

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Tables

Table 1
Top 10 journals publishing HPC-related articles

Total Publications			High-quality Publications		
Journal	Number of Publications	%	Journal	Number of Publications	%
World Latest Medicine Information	93	3.0	Chinese general practice ¹	46	8.3
Chinese Medical Ethics	83	2.6	Medicine and philosophy ¹	33	6.0
Electronic Journal of Practical Clinical Nursing Science	66	2.1	Chinese Journal of Gerontology ¹	29	5.3
Chinese Nursing Research ¹	60	1.9	Chinese Journal of Nursing ¹	27	4.9
Guide of China Medicine	57	1.8	Chinese Nursing Research ¹	27	4.9
Electronic Journal of Clinical Medical Literature	56	1.8	Journal of Pain and Symptom Management ²	20	3.6
Chinese General Practice Nursing	51	1.6	Chinese Nursing Management ¹	20	3.6
Shanghai Medical and Pharmaceutical Journal	51	1.6	Journal of Nursing Science ¹	18	3.3
Chinese General Practice ¹	46	1.5	American Journal of Hospice & Palliative Medicine ²	12	2.2
Journal of Nursing Science	39	1.2	Chinese Journal of Cancer Prevention and Treatment ¹	10	1.8
In Total	602	19.2	In Total	242	43.8

Note

¹ The Chinese Core Journals. ² International Journals in English.

Table 2
Regional indicators of production and repercussions

Province /Municipal city	Total number of publications	%	Number of publications per million inhabitants	Number of high- quality publications	%	5- year RIF of 2019
Beijing	360	11.5	16.7	88	15.9	4.3
Shanghai	344	11.0	14.2	89	16.1	2.9
Jiangsu	259	8.2	3.2	35	6.3	1.9
Guangdong	228	7.3	2.0	35	6.3	2.9
Sichuan	169	5.4	2.0	36	6.5	2.2
Hubei	163	5.2	2.8	39	7.1	1.7
Shandong	157	5.0	1.6	24	4.3	4.5
Henan	153	4.9	1.6	22	4.0	2.2
Zhejiang	152	4.8	2.6	19	3.4	2.9
Jilin	116	3.7	4.3	10	1.8	5.3
Liaoning	105	3.3	2.4	10	1.8	9.3
Hebei	98	3.1	1.3	12	2.2	3.6
Shanxi	85	2.7	2.3	9	1.6	2
Anhui	81	2.6	1.3	6	1.1	1.5
Tianjin	81	2.6	5.2	26	4.7	5
Chongqing	68	2.2	2.2	20	3.6	1.8
Hunan	63	2.0	0.9	17	3.1	5.9
Shaanxi	57	1.8	1.5	6	1.1	2
Fujian	51	1.6	1.3	6	1.1	1.8
Heilongjiang	50	1.6	1.3	7	1.3	2.5
Yunnan	45	1.4	0.9	4	0.7	1
Xinjiang	44	1.4	1.7	2	0.4	1
Guizhou	43	1.4	1.2	8	1.4	4.8
Guangxi	42	1.3	0.8	7	1.3	1

Province /Municipal city	Total number of publications	%	Number of publications per million inhabitants	Number of high- quality publications	%	5- year RIF of 2019
Inner Mongolia	34	1.1	1.3	1	0.2	0
Jiangxi	24	0.8	0.5	2	0.4	4
Gansu	22	0.7	0.8	4	0.7	0.7
Qinghai	21	0.7	3.5	2	0.4	3
Ningxia	16	0.5	2.3	4	0.7	1.7
Hainan	9	0.3	1.0	1	0.2	0
Tibet	0	0.0	0.0	0	0.0	N/A

Table 3: Themes in high-quality publications

Theme	Number of publications	%
HPC in Cancer patients	212	38.4
Pain and symptom management	98	17.8
Assessment of needs and implementation of HPC	80	14.5
Policy and program advocacy	66	12.0
Spiritual and psychological care	53	9.6
Nursing in HPC	50	9.1
Humanity and art	43	7.8
Education and training	40	7.2
HPC in primary care	37	6.7
Aging and geriatric HPC	36	6.5
Communication and advanced care planning	32	5.8
HPC in non-cancer patients	31	5.6
Complementary therapy	29	5.3
Ethics	22	4.0
Family care givers and volunteers	22	4.0
HPC in other specialties	12	2.2
Pediatric HPC	10	1.8
Self-care of the HPC team	8	1.4
Rehabilitation and nutrition	7	1.3
HPC screening and timing	4	0.7
Bereavement	2	0.4

Figures

Figure 1

Flow chart of the bibliometric analysis

Figure 2

Annual development of production and repercussions of publications

Figure 3

Regional distribution of publications Note: A, A heatmap of regional production, and locations and ranks of the top-10 productive institutes; B, an example of the correlation between annual regional GDP and number of publications in 2019. Beijing and Shanghai were excluded from the regression model as outliers. The heatmap was generated by Microsoft Excel, and the map was adapted from Bing@GeoNames, HERE, MSFT, Microsoft, NavInfo, Wikipedia with permission from Microsoft Corporation. Note: The designations employed and the presentation of the material on this map do not imply the expression of any opinion whatsoever on the part of Research Square concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. This map has been provided by the authors.

Key Words	Strength	Begin	End	2010-2019
HPC ¹	13.0542	2015	2017
Community health care	11.3629	2015	2017
Validity ²	3.968	2015	2016
Advanced gastric cancer	3.7806	2015	2016
Gastric cancer	3.2397	2015	2016
Perspective ²	2.9142	2015	2016
Family member	2.5715	2015	2016
Chinese patient ²	2.6981	2015	2017
Quality nursing care	4.5162	2016	2017
Medical staff	4.1786	2016	2017
Negetive emotions	3.1845	2016	2019
Pain management	5.328	2017	2019

Figure 4

Key words and burst periods from 2015 Note: 1 One Chinese version of HPC (shu-huan-liao-hu); 2 original terms in English-language articles not translated.