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Hemophilia in Taiwan: a Population-Based Study on Epidemiology, Age at Diagnosis, Mortality, and 13-year Trend by National Health Insurance Research Database 1997-2009

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Background

Epidemiology and demographics of hemophiliacs are very vital tools in healthcare planning, including setting priority, resources, and measurement of outcomes. Paucity of data about morbidity and mortality in hemophilia will hinder healthcare planning. The Annual Global Survey from WFH provides a whole view of hemophilia care in the world. The data of prevalence and occurrence of every country in the world is valuable to development of strategy for hemophilia care. However, epidemiologic and mortality data of hemophiliacs, especially with a nationwide scale, are relatively few in Asian countries.

In Taiwan, the first hemophilia comprehensive center was established at National Taiwan University Hospital in 1984 by professor Shen, MC; and National Health Insurance (NHI) started to provide the cost of coagulation factors for hemophiliacs since 1995. After the two major events, hemophilia care in Taiwan had entered into the new milestones. Here, we aim to investigate, by the NHI research database, the population-based epidemiology, diagnosed age and mortality of hemophilia in Taiwan that is a country with 23-million people.

Materials and Methods

We analyzed the data of male patients with International Classification of Disease Ninth Revision code 286.0 and 286.1 between 1997 and 2009, retrieved from National Health Insurance Research Database and Ministry of Interior in Taiwan.

Results

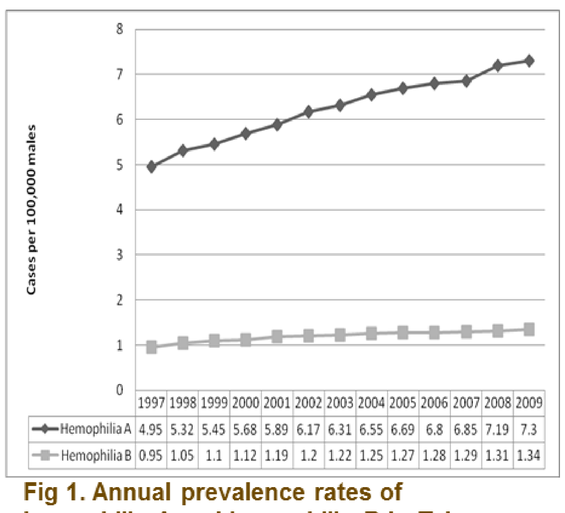

Fig 1. Annual prevalence rates of hemophilia A and hemophilia B in Taiwan

Table 1. Annual incidence rates of hemophilia in Taiwan

Birth cohort	Hemophiliacs born in birth cohort	Total males birth in Taiwan	Cases / 100000 males	Cases / births Ratio
1997	18	170,047	10.59	1:9,447
1998	12	141,462	8.48	1:11,789
1999	21	148,042	14.19	1:7,050
2000	16	159,726	10.02	1:9,983
2001	11	135,596	8.11	1:12,327
2002	12	129,537	9.26	1:10,795
2003	17	118,984	14.29	1:6,999
2004	14	113,639	12.32	1:8,117
2005	17	107,378	15.83	1:6,316
2006	14	106,936	13.09	1:7,638
2007	13	106,898	12.16	1:8,223
2008	8	103,937	7.70	1:12,992

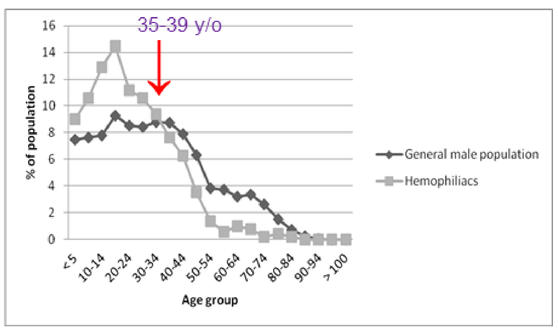

Fig 2A. Age distribution of hemophilia A in 1998

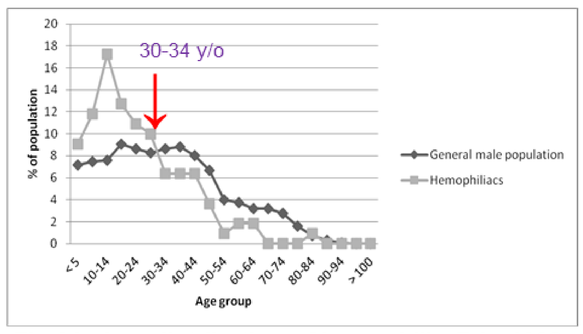

Fig 3A. Age distribution of hemophilia B in 1998

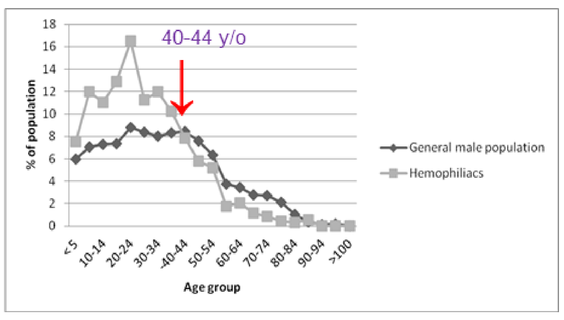

Fig 2B. Age distribution of hemophilia A in 2003

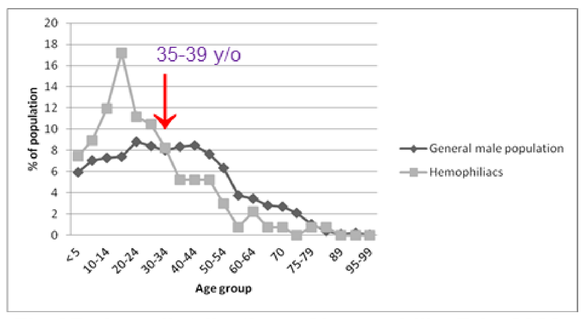

Fig 3B. Age distribution of hemophilia B in 2003

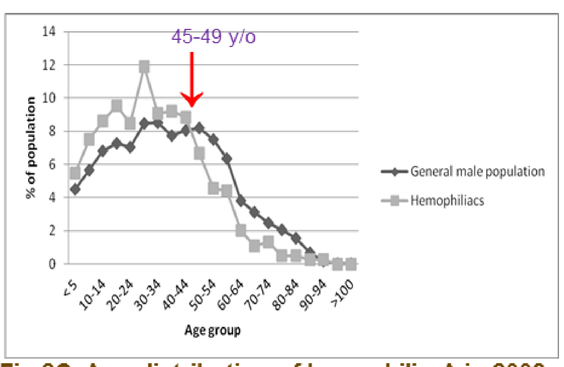

Fig 2C. Age distribution of hemophilia A in 2008

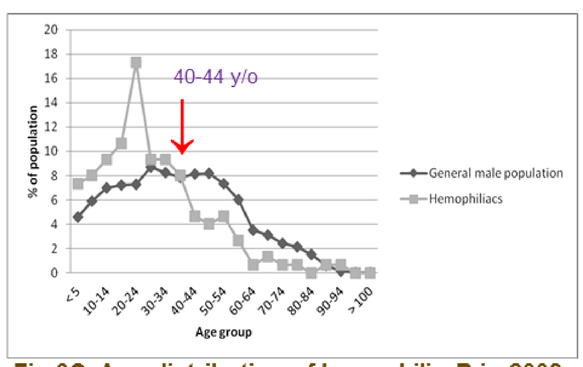

Fig 3C. Age distribution of hemophilia B in 2008

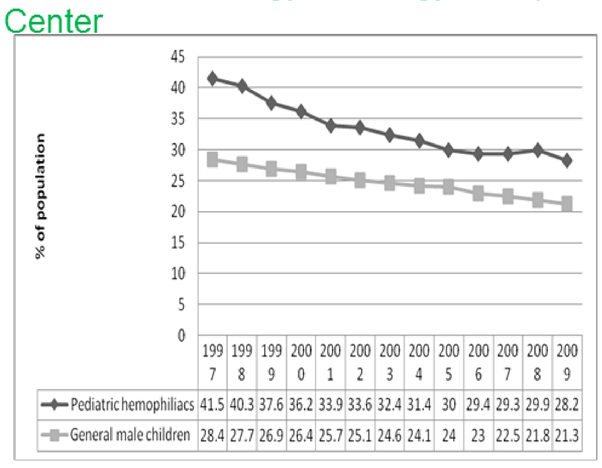

Figure 4. Pediatric hemophiliacs (< 18 y/o): ratio↓ year by year in Taiwan [General male children: average ↓ 0.60% / year. Pediatric hemophiliacs: average ↓ 1.10% / year (1.85 times ↓)]

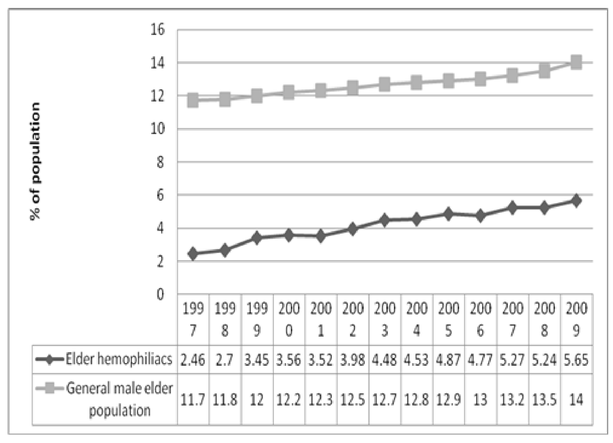

Figure 5. Elder hemophiliacs (≥ 60 y/o) ratio↑ year by year in Taiw [General male elder: average ↑ 0.19% / year. Elder hemophiliacs: average ↑ 0.27% / year (1.39 times ↑)]

Table 2. Age at diagnosis among different periods and types of hemophilia in Taiwan

Age at Diagnosis	Mean (y/o)	SD (y/o)	Median (y/o)	P value
Hemophilia 1997-2009 (newly diagnosed, n=493)	21.48	21.65	16.26	-
Hemophilia A (n=423)	22.16	21.81	16.97	0.0367*
Hemophilia B (n=70)	17.36	20.34	12.38	
1997-1999 (n=141)	24.10	22.09	19.44	0.0351*
2006-2009 (n=132)	19.28	21.62	10.42	
1997-2000 (n=182)	23.76	21.48	19.37	0.0350*
2006-2009 (n=132)	19.28	21.62	10.42	

Table 3. Age at death among different periods and types of hemophilia in Taiwan

Age at Death	Mean (y/o)	SD (y/o)	Median (y/o)	P value
Hemophilia 1997-2009 (death cases, n=76)	44.44	21.16	45.08	-
Hemophilia A (n=66)	45.34	21.26	45.68	0.365
Hemophilia B (n=10)	38.51	20.53	39.83	
1997-2003 (n=35)	40.90	18.99	37.01	0.0399*
2005-2009 (n=30)	49.98	22.15	51.77	
1997-2004 (n=46)	40.83	19.91	36.29	0.0325*
2005-2009 (n=30)	49.98	22.15	51.77	

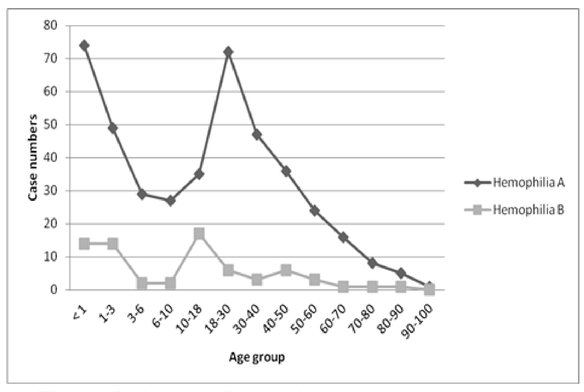

Figure 6. Age at diagnosis in newly-diagnosed hemophiliacs 1997-2009 (n=493)

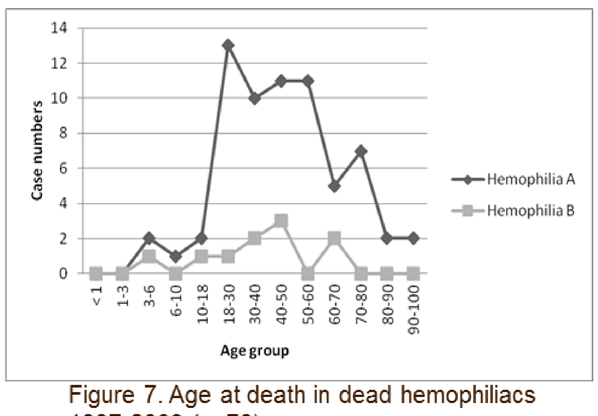

Figure 7. Age at death in dead hemophiliacs 1997-2009 (n=76)

Table 4. Average mortality age and age-specific crude death rates of hemophiliacs in Taiwan

Crude death rate	0-14 (y/o)	15-29 (y/o)	30-44 (y/o)	45-59 (y/o)	60-74 (y/o)	75-89 (y/o)	> 90 (y/o)	Mortality age (y/o)
Hemophiliacs	1.762	4.582	7.108	17.271	33.459	45.233	44.872	46.61
General population	0.564	0.719	1.862	5.075	18.66	66.268	191.801	67.67
Mortality ratio	3.125	6.371	3.817	3.403	1.793	0.683	0.234	-

Overall standarized crude death rates:in Taiwan :

Hemophiliacs : 10.223 / 1000 population v.s. General population : 5.164 / 1000 population (in 2009)

Standardized Mortality Ratio of Hemophiliacs in Taiwan = 1.98

Discussion

To compare our data with those of other countries, prevalence and incidence rates in Taiwan showed less than data in Europe and US, but similar to the data in Asian countries. Demographics showed ageing of hemophilic population year by year. Age at diagnosis was significantly earlier in recent years than that before. Mortality age was significantly delayed in recent years than that before. Age-specific crude death rate were similar to the data in UK. Standardized mortality ratio of 1.98 was similar to data in developed countries.

Conclusion

To our best knowledge, this is the first nationwide population-based epidemiologic study of hemophilia in Asia. The 13-year trend showed that advances of hemophilia care in Taiwan were evident. Due to the similarity between races in Taiwan and races in China, we believed that our report will provide the insight into the epidemiology of Chinese hemophiliacs.

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