Journal of Clinical Lipidology (2015) 9, 42–48

Journal of Clinical Lipidology

Significant gaps in awareness of familial hypercholesterolemia among physicians in selected Asia-Pacific countries: A pilot study

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KEYWORDS:
Familial hypercholesterolemia;
Awareness;
Knowledge;
Practices;
Perception;
Asia;
Physicians;
Models of care

BACKGROUND: Familial hypercholesterolemia (FH) is a dominantly inherited disorder characterized by high plasma cholesterol levels and a very high risk of early heart disease. The prevalence of FH is estimated to be at least 1:500, with at least 3.6 million individuals in the Asia-Pacific region.

OBJECTIVE: To assess awareness, knowledge, and perception of FH among practicing physicians in Japan, South Korea, and Taiwan.

METHODS: Physicians from 3 economically developed Asian countries were requested to anonymously complete a structured Internet-based survey regarding FH. This survey sought responses on the clinical description, inheritance, prevalence, cardiovascular disease risk, practices, and opinions on screening.

RESULTS: Of 230 physicians surveyed, 47% were aware of the heritability, 27% of the prevalence, and 13% of the risk of cardiovascular disease relating to FH. The majority (70%) perceived themselves to have an above-moderate familiarity with FH. Primary care physicians (59%) and lipid specialists (41%) were perceived as the best providers for caring for FH, including cascade screening services, with a lesser role perceived for cardiologists, endocrinologists, and no significant role for nursing staff. Only 35% of physicians were aware of specialist clinical services for lipid disorders in their geographic area.

CONCLUSION: Extensive education and training programs are required to complement the implementation of region-specific models of care for FH in Asia. Further enhancement of existing lipid services and facilities are also warranted to optimise service models.

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Submitted June 26, 2014. Accepted for publication September 23, 2014.

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http://dx.doi.org/10.1016/j.jacl.2014.09.011

Familial hypercholesterolemia (FH) is a dominantly inherited disorder characterised by elevated low-density lipoprotein cholesterol (LDL-C) levels and a very strong risk of premature atherosclerotic cardiovascular disease (CVD). Recent international guidelines[1,2] recommend comprehensive and coordinated action to identify and manage patients affected by FH, which is readily preventable with early screening, diagnosis, and appropriate treatment. The prevalence of FH is thought to be at least 1:500,[3–5] with an estimated 3.6 million individuals in the Asia-Pacific region alone (Fig. 1), although fewer than 1% are considered to have been diagnosed.[1,6] The International FH Foundation[7] has recently presented a guidance on FH, and in Asia, the Japanese guidelines have been published.[8] Implementation of guidelines requires an assessment of current knowledge and practices regarding FH. In this pilot study, we investigated several aspects of the awareness and perception of FH among physicians in 3 Asian countries.

Method

We targeted a random group of primary care physicians (PCPs) and specialist physicians from Japan, South Korea, and Taiwan who met the following eligibility criteria: (1) 2 or more years in practice since residency; (2) attend to 75 or more patients per month; and (3) at least 50% of practice time spent in a clinical setting. From December 2011 to January 2012, these physicians were asked to complete an anonymous Internet-based survey in their native language via a unique web link. Physicians were compensated for their participation and completion of the survey. The survey questions were developed based on expert recommendations and guidelines[9] on FH in collaboration with a lipid specialist.

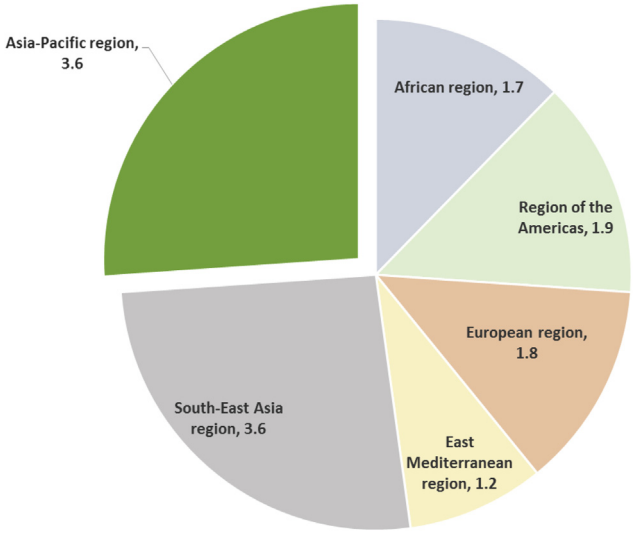

Figure 1 Estimated number (in millions) of individuals with familial hypercholesterolemia (FH) in World Health Organization–defined regions based on the theoretical prevalence of 1:500 for heterozygous FH. (Adapted from Nordestgaard et al[4]).

Approximately 10,300 physicians were invited to participate in the survey from Japan, South Korea, and Taiwan.

The survey was completed voluntarily and inquired about the following aspects of FH: familiarity with the condition; the clinical description, prevalence, inheritance, and cardiovascular disease risk factors (such as diabetes, smoking and elevated lipoprotein(a) [Lp(a)]); and their preferences and awareness of FH clinical services. Demographic data were also recorded. Details of the survey are presented in the electronic supplementary material. Data were analyzed using STATA 12 (StataCorp). Chi-square and Kruskal-Wallis equality-of-populations rank tests were used to determine differences between countries and medical specialties. Significance was defined at the 5% level.

Results

A total of 285 physicians accessed the online survey during the data collection period; 31 did not meet the eligibility criteria and 24 did not fully complete the survey. A total of 230 physicians (ie, a 2.2% response rate) from Japan (n = 77), South Korea (n = 76), and Taiwan (n = 77) completed the survey (92% male, 8% female; 33% PCPs, 67% specialists). There was a greater proportion ($P = .026$) of male respondents from South Korea (97%) compared with Japan (94%) and Taiwan (86%). Medical specialties did not differ among countries ($P = .169$). Practice location was spread over urban (66%), suburban (15%), and rural (19%) areas and was significantly different among countries ($P < .001$), with a higher proportion of South Korean physicians from urban areas (84%) and a higher proportion of Japanese physicians from suburban and rural areas (56%). Figure 2 shows the physicians' perceived familiarity with FH on a scale of 1 to 7. Seventy perdent of physicians rated their familiarity with FH as above average (>4), with a significantly greater ($P < .001$) percentage of South Korean (80%) and Taiwanese (77%) physicians compared with Japanese (52%) physicians.

The results of the questionnaire concerning clinical description, prevalence, inheritance, and cardiovascular risk are summarized in Figures 3 and 4. Sixty-eight percent of physicians selected the correct clinical description of FH, with no significant difference across countries (70% in Japanese and Taiwanese physicians; 61% in South Korean physicians; Fig. 3A). Only 27% of physicians identified the prevalence of FH as 1:500, with a significantly greater percentage of Japanese physicians selecting this response ($P < .001$). Of note, 32% selected "Don't know" to the prevalence question (Fig. 3B). Only 47% of respondents correctly identified the heritability of FH as an autosomal dominant disorder with no significant intercountry differences ($P = .07$, Fig. 3C). Thirteen percent of physicians identified the CVD risk in untreated FH patients as 20 times greater than the general population,[2,10] with 70% selecting a lower risk and 48% selecting a greater than 10-fold risk (Fig. 3D).