


RESEARCH ARTICLE

A nationwide survey regarding the life situations of patients with thalidomide embryopathy in Japan, 2018: First report

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Abstract

Background: Clinical studies on the effects of thalidomide-induced damage on thalidomide victims as they age have only recently started to be conducted, but no studies have examined socioeconomic differences in terms of healthcare and social status between thalidomiders and the age-matched general population in Japan. Therefore, we carried out a nationwide survey focusing on the life situations of thalidomiders.

Method: Questionnaires were sent to 274 thalidomiders in Japan. The questionnaire items basically matched those of the Comprehensive Survey of Living Conditions (CSLC) in the general population conducted by the Japanese Government. The results were compared with those of the CSLC for individuals aged 55–59 years, which was the cohort most similar in age to the average thalidomider living in Japan.

Results: More thalidomiders rated their health condition as relatively bad or bad compared with the general population (20.2% vs. 13.3%, respectively). A much higher percentage of thalidomiders reported having some health or physical problem caused by a disease or injury (68.8% vs. 32.6%, respectively), and thalidomiders reported visiting medical and healthcare-related facilities more frequently. A higher proportion of thalidomiders (9.2%) were unemployed, and thalidomiders tended to feel higher levels of worry and stress, especially in terms of the future.

Conclusions: The results of this nationwide survey of the life situations of thalidomiders in Japan clarified their health conditions and the related associations with socioeconomic status. These findings could be expected to help improve the provision of medical and healthcare, welfare measures, and financial support for thalidomiders in the near future.

KEYWORDS

health, life situations, nationwide survey, questionnaire, thalidomide embryopathy

1 | INTRODUCTION

This article was published online on 24 July 2019. An error was subsequently identified. This notice is included in the online and print versions to indicate that both have been corrected 07 August 2019.

Over 50 years have passed since infants exposed in utero to thalidomide (a-[N-phthalimido]-glutarimide) were born with

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a variety of visceral disorders and birth defects such as limb deformities, phocomelia, and hearing loss or impairment. The wide range of congenital defects caused by thalidomide is called thalidomide embryopathy (TE). It is speculated that there are about 3,000–4,000 thalidomide survivors currently living around the world and struggling with congenital physical disabilities, secondary diseases, and/or physical pain; among these thalidomide survivors, or thalidomiders, nearly 300 aged 50 years or older are thought to be currently living in Japan. However, studies on the effects of the damage upon the survivors as they age have only recently started to be conducted (Newbronner & Atkin, 2017). Therefore, the current health statuses of thalidomiders, even in countries with hundreds of thalidomiders, such as Germany, the United Kingdom (UK), and Japan, have seldom been reported, and never fully understood, possibly resulting in inefficient treatments (Newbronner, Glendinning, Atkin, et al., 2019; Peters et al., 2015). However, several surveys focusing on the physical or orthopedic situations of thalidomiders have recently been conducted (Ghassemi Jahani et al., 2016; Ghassemi Jahani et al., 2016; Ghassemi Jahani, Danielson, Karlsson, & Danielsson, 2014; Ghassemi Jahani, Danielsson, Karlsson, & Brisby, 2017; Kowalski, Sanseverino, Schuler-Faccini, et al., 2015). For example, one recent study focused mainly on lifestyle-related diseases among middle-aged thalidomiders (Shiga, Shimbo, & Yoshizawa, 2015), while a few others investigated internal organ and vascular anomalies using imaging screening (Tajima, Wada, & Yoshizawa, 2016; Weinrich et al., 2018). In addition, reports have been published on mental disorders and psychological problems in thalidomiders in Sweden and Japan (Ghassemi Jahani, Karlsson, et al., 2016; Imai et al., 2014), and on peripheral nerve dysfunction in thalidomiders in the UK (Nicotra et al., 2016). Moreover, in 2017, a practical guide was devised to aid understanding of and to discuss treatment for TE in all medical areas (Ohnishi & Hinoshita, 2017 in Japanese and 2018 in English).

A multicenter survey conducted from 2011 to 2014 in Japan by a previous research group (Shiga et al., 2015) organized by the Ministry of Health, Labour and Welfare (MHLW) aimed to clarify the medical health statuses of thalidomiders aged around 50 years in respect to the frequency of lifestyle-related diseases and associated problems. However, that survey did not investigate socioeconomic factors such as gaps in healthcare and social status between thalidomiders and the general population in the same age cohort in Japan. Therefore, the present research group on TE, which was newly reorganized in 2017 to grasp the health and living situations of and create a support infrastructure for thalidomide-impaired people in Japan, carried out a nationwide survey focusing mainly on the life situations of thalidomiders living in Japan, and then compared the results with those from the Comprehensive Survey of Living

Conditions (CSLC) in the general population carried out by the Japanese government in 2016 (MHLW, 2017a).

2 | MATERIALS AND METHODS

2.1 | Study population and questionnaire

A nationwide survey was conducted on thalidomiders in Japan at the end of 2017. Questionnaires were sent to 274 thalidomiders living in Japan whose mail addresses were recognized by the ISHIZUE Public Interest Incorporated Foundation, which was established to promote the welfare of Japanese thalidomide victims. No exclusion criteria were used. The questionnaires included numerous items (38 items with related questions in detail), and those that basically matched the items of the CSLC conducted by the Japanese Government in 2016 (MHLW, 2017b) were selected and used in the present report. The CSLC is conducted annually, and specifically assesses individual health, welfare, and medical care in addition to basic variables every 3 years. The questionnaire items selected for the present study are shown in Table 1. The thalidomiders were instructed to complete each page of the questionnaire based on their current situation as of December 20, 2017. The results were then compared with those of the CSLC for individuals aged 55–59 years, which is the cohort most similar in age to the average thalidomider living in Japan (55.2 years). All of the completed and returned questionnaires were anonymized and analyzed without knowledge of private information such as name, address, or profession. Written informed consent was obtained from all participants, and the study protocol was approved by the Ethics Committee of The National Center for Global Health and Medicine (NCGM) (NCGM-G-002366-00).

2.2 | Study design

This cross-sectional study was conducted mainly to assess the differences between thalidomiders and the age-matched general population.

3 | RESULTS

3.1 | Basic characteristics

Among the 274 thalidomiders sent questionnaires, responses were received from 173 (response rate, 63.1%; 90 men, 83 women; mean age, 55.2 years; age range, 53–58 years) from December 2017 to February 2018. Of these survivors, 126 reported having an upper-limb deformity type of TE, 27 a hearing impairment type, 13 a mixed type, and five, other types. Two of the thalidomiders gave no response in regard to the type of TE. However, in the present study, the

TABLE 1 Items on the questionnaire survey conducted on thalidomiders living in Japan**The question items used for the present report are shown below**

1. How would you describe your current health condition?
* Good * Relatively good (not bad) * Average * Relatively bad (not good) * Bad
2. Do your health problems affect your daily life?
* Yes * No
3. If you answered "yes" to question No. 2, what types of activities are affected by your health problems? (multiple answers can be selected.)
* Activities of daily living (normal activities) * Going out * Work and housekeeping
* Exercise * Other
4. Have you been treated for any disease? If yes, please indicate which one. (free response; multiple answers are permitted.)
5. What type of medical or health facilities/treatments are you currently visiting/receiving? (multiple answers can be selected.)
* Hospital or clinic visits * Use of health services such as massage, acupuncture and moxibustion, or chiropractics * Use of over-the-counter medications * Use of other health services
* I have not been visiting/receiving any facilities/treatments.
6. Do you regularly participate in medical checkups?
* Yes * No
7. What is your annual income?
* Less than 2 million yen * 2–4 million yen * 4–6 million yen * 6–8 million yen
* 8–10 million yen * More than 10 million yen
8. How would you describe your family circumstances?
* Very difficult * Slightly difficult * Average * Slightly comfortable * Very comfortable
9. How would you describe your current working status?
* Regularly working * Regular housekeeping with some work
* Regularly going to school with some work * Other type of working status
* Unemployed or between jobs * Full-time housekeeper * Other
10. Is there anything you worry or feel stress about? (free response)

thalidomiders were not analyzed based on classification into these three types. A total of 172 survivors (90 men, 82 women) with TE responded to questions regarding marital status; of these, 48 men (53.3%) were married and 42 (46.7%) were not. Among the women, 42 (51.3%) were married and 39 (47.5%) were not. One female survivor did not respond to this item. The basic characteristics of the thalidomiders who responded to the questionnaire survey are shown in Figures 1–4.

3.2 | Health conditions

Regarding the thalidomiders' self-rated health conditions, 12.7% responded good, 24.9% relatively good, 39.9% average, 17.9% relatively bad, and 2.3% bad, compared with 15.0%,

17.3%, 53.7%, 11.8%, and 1.4% of the general population, respectively (Figure 5). A much higher rate of thalidomiders considered their health condition to be relatively bad or bad compared with the general population (20.2% vs. 13.3%, respectively). Many of the thalidomiders (40.5%) believed that their health problems affected their daily lives, compared with only 11.8% of the age-matched general population (Figure 6). In addition, a much higher percentage of thalidomiders believed that their health condition affected every element of their daily lives compared with the general population: 24.9% vs. 3.4% for normal activities, 11.0% vs. 2.8% for going out, 38.2% vs. 6.2% for work and housekeeping, and 11.0% vs. 4.5% for exercise, respectively (Figure 7).

3.3 | Disease and medical service

A significantly greater number of thalidomiders reported having some health or physical problems caused by a disease or injury at the time of the survey compared with the age-matched general population (68.8% vs. 32.6%, respectively). Thalidomiders also reported having a greater variety of diseases and physical problems that were being treated at a hospital, clinic, or other medical facility (Figure 8). The most frequently reported problem under treatment was stiff shoulder (22.5%), followed by lumbago or low back pain (21.4%), ocular diseases (19.1%), dental problems (17.9%), hypertension (15.6%), arthropathy (15.0%), dyslipidemia (13.9%), diabetes mellitus (12.7%), and depression/other mental diseases (9.8%). Far fewer individuals in the general population had a specific disease currently being treated. However, the prevalence of hypertension was similar in both groups. Among the 119 thalidomiders who reported having some symptoms and/or physical problems, 52.9% visited a hospital or clinic, 28.6% utilized massage, acupuncture and moxibustion, or chiropractic, 26.9% used some over-the-counter medications, 3.4% used other health services, and 18.5% did not receive any treatment. Compared with the general population, a larger proportion of thalidomiders reported receiving treatment for their health/physical problems (Figure 9). Furthermore, a higher percentage of individuals in the general population reported receiving no treatment compared with the thalidomiders (25.7% vs. 18.5%, respectively).

3.4 | Medical checkups

In total, 72.8% of the thalidomiders were participating in regular medical checkups, compared with 75.2% of the general population.

3.5 | Income and family circumstances

Annual income was defined as the total of earned income, compensation payments, public financial support, and real estate income. No marked differences in the annual income distribution

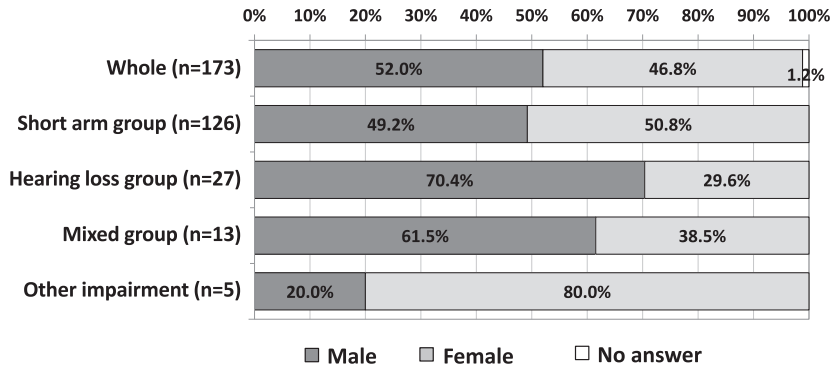


FIGURE 1 Classification of specific groups of thalidomiders

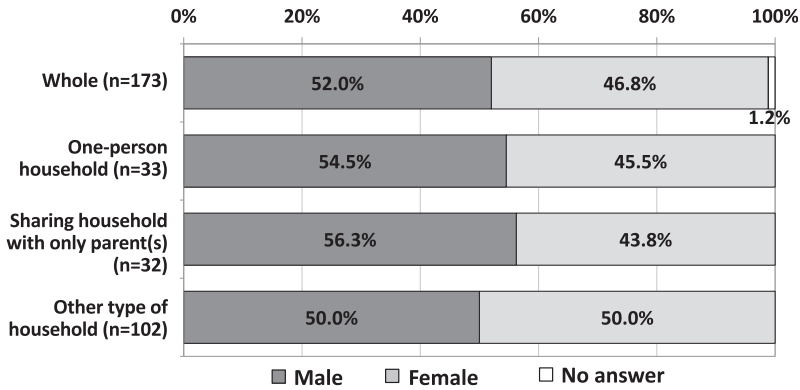


FIGURE 2 Family structure. Types of households are shown

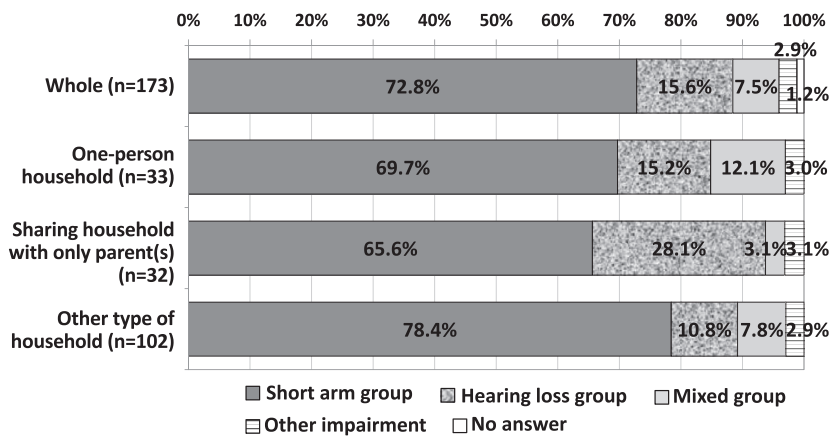


FIGURE 3 Family structure classified by specific groups of thalidomide embryopathy

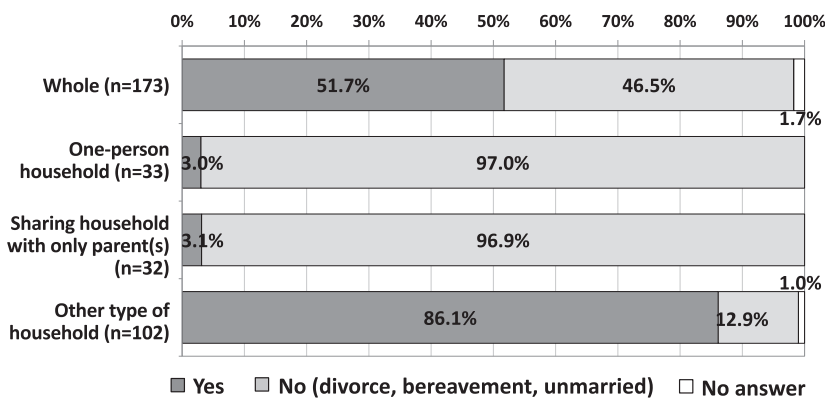


FIGURE 4 Family structure classified by marital status

FIGURE 5 Health condition. Health conditions were self-rated as good, relatively good, average, relatively bad, or bad

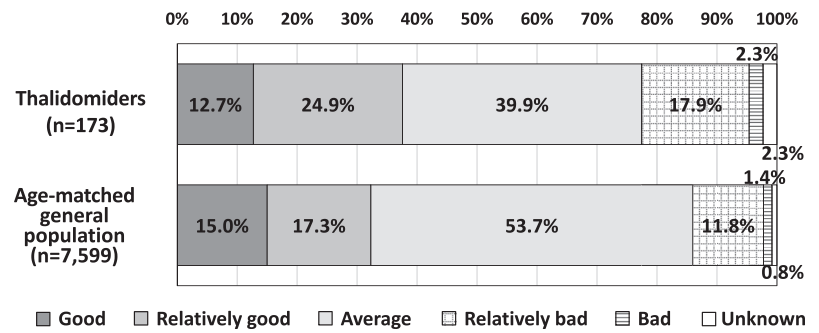


FIGURE 6 Influence of health condition on daily life

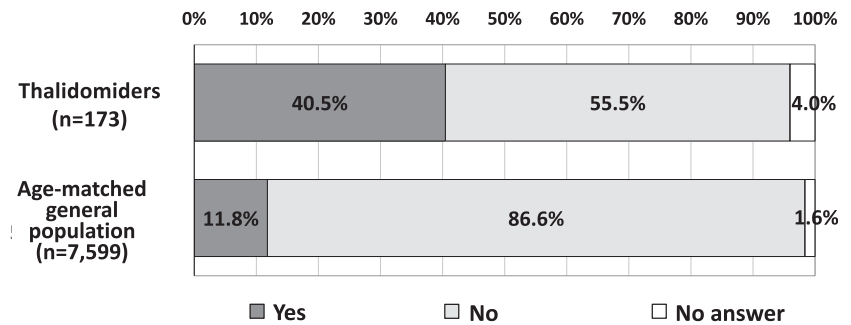
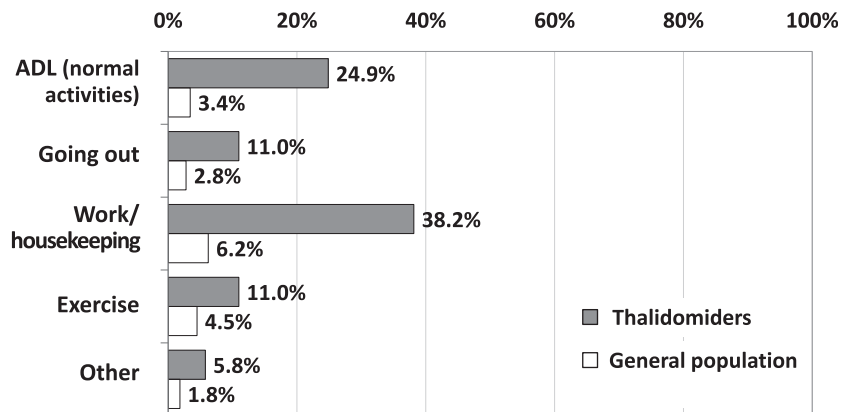


FIGURE 7 Detailed influence of health condition on daily life. Daily life is divided into activities of daily living (normal activities), going out, work/housekeeping, exercise, and other. ADL: activities of daily living



were found between thalidomiders and the general population (Figure 10). Among the thalidomiders, 26.3% and 28.8% reported having an annual income of less than 2 million yen and 2–4 million yen, respectively, compared with 32.8% and 21.6%, respectively, in the general population. In addition, 3.8% of the thalidomiders and 6.3% of individuals in the general population reported having an annual income of over 10 million yen.

The CSLC includes a question regarding “family circumstances” or “life circumstances”. Family circumstances involve both the financial and psychological life situation. In other words, it refers to how difficult or easy one feels their own life situation is. Only 4.0% of the thalidomiders described their family circumstances as very difficult, compared with 24.3% of those in the general population (Figure 11). In addition, over 10% of the thalidomiders described their family circumstances as slightly or very comfortable, compared with less than 5% among the general population.

3.6 | Work situation

Concerning work, 58.4% of the thalidomiders described their current situation as working regularly, 4.0% as regular housekeeping with some work, and 8.1% as another type of working status (Figure 12), compared with 67.4%, 10.3%, and 0.8%, respectively, among the general population. The results also indicated that 9.2% of the thalidomiders were unemployed or between jobs, compared with only 0.8% of the general population.

3.7 | Worry and stress

Finally, 79.2% of the thalidomiders reported having some worry or stress in their lives; this proportion was substantially higher than that among the general population (52.3%) (Figure 13). We also asked thalidomiders to list their specific worries in free text responses. A total of 137 thalidomiders

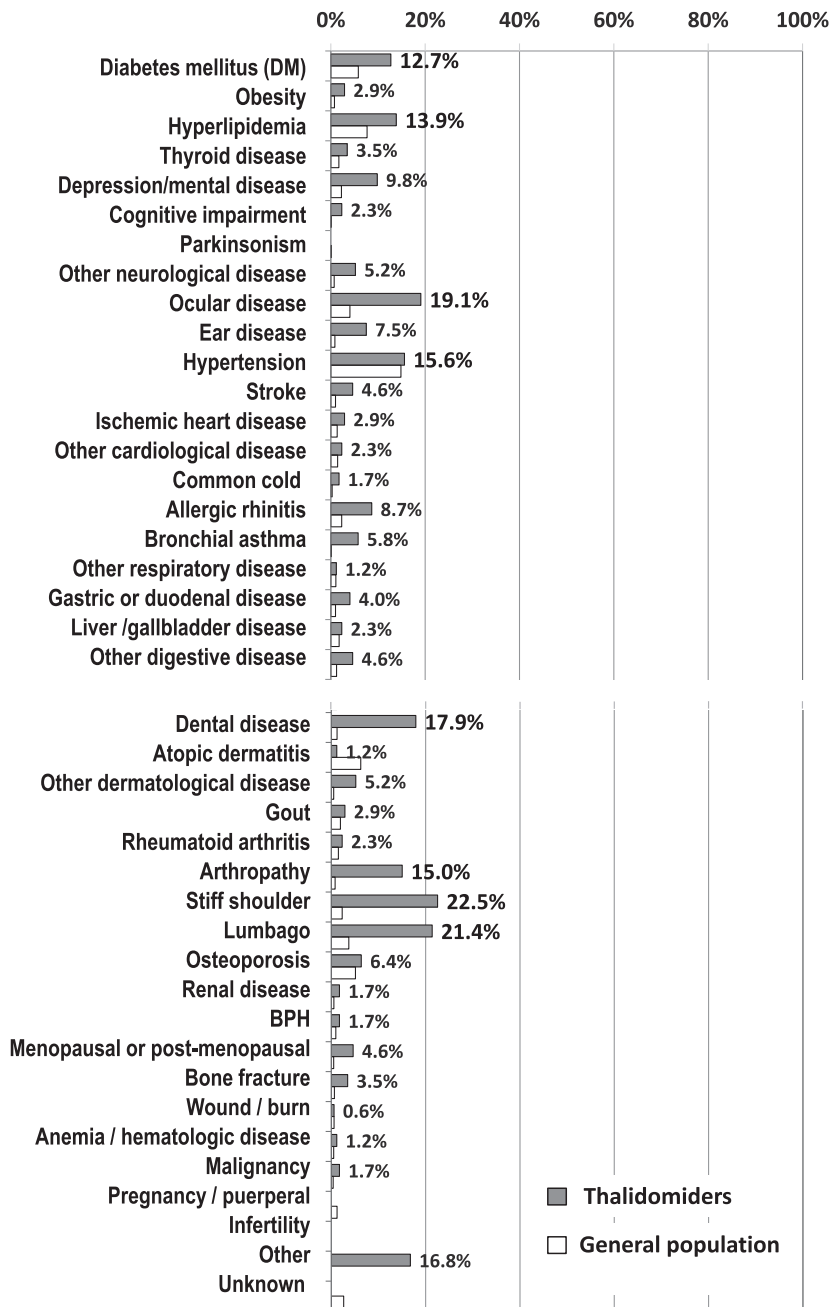


FIGURE 8 Diseases and physical problems under treatment at the time of the survey. BPH: benign prostatic hypertrophy; DM: diabetes mellitus

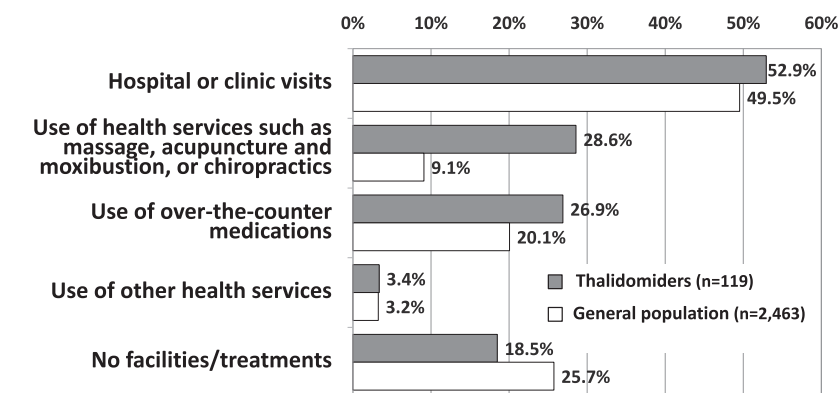


FIGURE 9 Situation regarding visits to medical and health facilities among thalidomiders and the general population with symptoms and/or problems

FIGURE 10 Distribution of annual income. Income amounts are shown in Japanese yen (¥) and US dollars (\$). No significant difference in income was found between thalidomiders and the general population

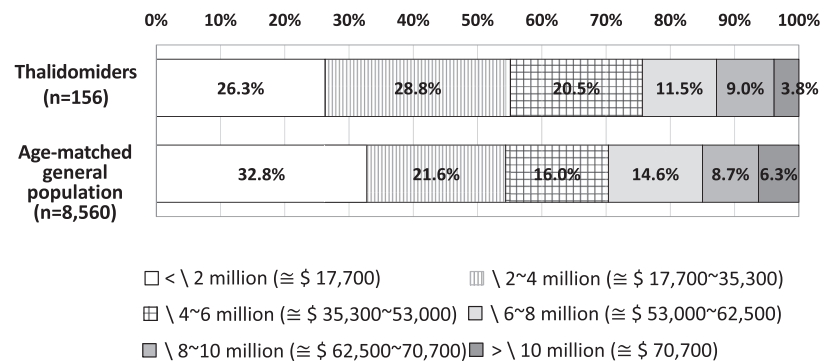


FIGURE 11 General family circumstances. A significantly higher percentage of thalidomiders compared with the non-age-matched general population (age-matched controls were not analyzed) felt that their family circumstances were less difficult

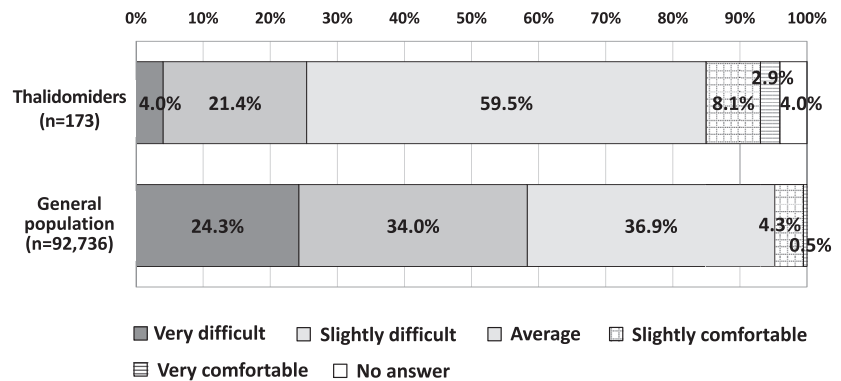
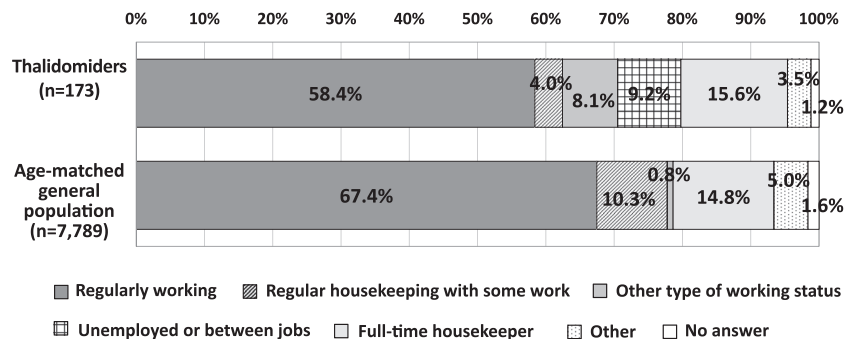


FIGURE 12 Current work situation



provided such free responses. Multiple answers were allowed and subsequently analyzed. The thalidomiders' own health was the most frequent worry (73.0%), followed by life planning for old age or retirement (54.7%), family members' health (46.7%), future income and financial standing (39.4%), work and/or human relations in the workplace (33.6%), and so on.

4 | DISCUSSION

The results of the present study help clarify the life situations of thalidomiders living in Japan. The findings are considered valid because survey responses were received from 173 out of 274 thalidomiders (valid response rate, 63.1%). These data on the lives of thalidomiders from both the socioeconomical and

health-analytical points of view are considered highly useful because the obtained results could be compared with those of the age-matched general population in Japan. Therefore, we believe these findings could contribute to improved socio-economic policies and health support for thalidomiders by the government and public organizations.

More thalidomiders rated their health condition as relatively bad or bad compared with the general population (20.2% vs. 13.3%, respectively). The reason for this might be that, in addition to lifestyle-related and other diseases, as well as common physical changes resulting from aging, thalidomiders also tend to suffer from congenital health problems such as limb deformities and hearing impairment. Compared with the general population, a substantially higher percentage of thalidomiders felt that their health problems affected their daily lives in terms of normal activities, going out, work and housekeeping, and

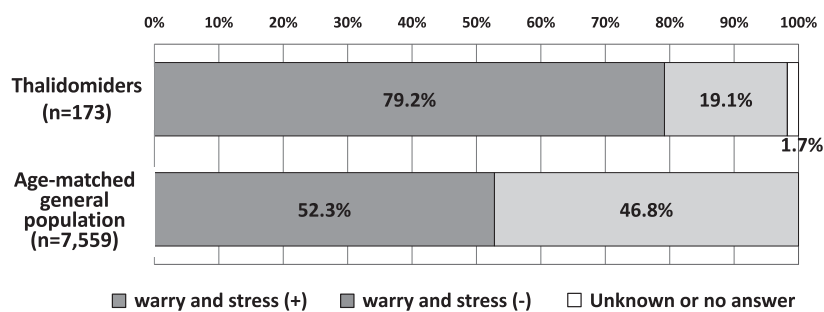


FIGURE 13 Worry and stress at the time of the survey

exercise. This finding indicates health problems impair the ability of many thalidomiders to perform activities of daily living (ADL), and further suggests that an unhealthy condition might be a great burden in the daily lives of many thalidomiders.

A much higher percentage of thalidomiders reported having some health or physical problem caused by a disease or injury compared with the general population (68.8% vs. 32.6%). The rate of thalidomiders with a specific health problem was more than twice as high as that of the general population. Persistent pain and musculoskeletal problems were the main complaints among the thalidomiders living in Japan, in addition to primary congenital problems, as reported in Germany and the UK (Newbronner et al., 2019; Peters et al., 2015). Next, we investigated specific diseases or health problems in thalidomiders that had been treated at a medical or healthcare-related facility. Compared with the general population, a much higher proportion of thalidomiders reported suffering from stiff shoulder, low back pain, ophthalmic disorders, dental problems, arthropathy, dyslipidemia, diabetes mellitus (DM), and depression or other mental diseases. Thalidomiders around the world have been thought to suffer from persistent pain, musculoskeletal problems and hearing impairments; these symptoms are directly associated with their congenital defects. However, lifestyle-related diseases such as dyslipidemia, DM, and hypertension were not greatly expected in thalidomiders a few decades ago. Actually, a substantial portion of thalidomiders suffers from these lifestyle-related diseases. Therefore, it should be recognized that thalidomiders are at a high risk for the development of lifestyle-related diseases, as reported elsewhere (Shiga et al., 2015). As for other comorbidities, the rate of bowel and digestive problems is smaller in Japan (10.9%) than in Germany and the UK (43.1% and 28%, respectively), which shows that the distribution of comorbidities among thalidomiders varies by country. It is also possible that the digestive system is congenitally affected by thalidomide among thalidomiders in Europe. Interestingly, in Japan, the proportions of individuals with hypertension were similar between the general population and the thalidomiders. An explanation for this could be that thalidomiders tend to be more health-conscious and restrict their salt intake in their daily lives compared with the general population. The results also

showed that thalidomiders visit medical and healthcare-related facilities more frequently than the general population. It is interesting to note that fewer thalidomiders reported not receiving treatment or visiting a medical/healthcare-related facility compared with the general population. It has been considered, especially in Europe, that thalidomiders feel as though conventional treatments do not meet their needs. Consequently, they tend to depend on other types of treatment, such as massage. The results of the present study indicate that Japanese thalidomiders seem to rely more heavily on general practitioners and regular medical facilities such as hospitals. However, the results also indicate that thalidomiders in Japan utilize massage, acupuncture and moxibustion, or chiropractic more frequently than the general population. This finding suggests that they are more concerned with pain, myalgia, fatigue, and reduced ADL than the general population. Therefore, public health and welfare organizations should try to provide future support and assistance for thalidomiders in accordance with their health status and specific tendency to visit medical and healthcare facilities. It might also be necessary to provide financial support for visits to facilities involving massage, acupuncture and moxibustion, or chiropractic in the near future.

Regular medical examinations can range from “basic” to “complete” (including gastroendoscopy and abdominal ultrasonography). Naturally, regardless of the type of medical examination they participate in, most of these examinees are considered to be health-conscious. In the present study, no significant difference was observed between thalidomiders and the general population in terms of the percentage participating in annual medical checkups. In this respect, thalidomiders might not be more likely to participate in such health examinations, which may be because thalidomiders suffering from serious diseases, as well as those with substantial physical disabilities, might find it difficult to visit the hospital. To address this problem, a TE research group in Japan has been carrying out free complete medical checkups for thalidomiders for the past several years, accepting more than 20 individuals with TE at three separate medical centers in Tokyo and Kyoto annually (Shiga, 2017). Complete medical checkups are part of a unique and well-established method that examines health conditions and latent or undetected diseases in middle-aged and older people in Japan (Japan Society of Ningen Dock, 2018).

On average, approximately 3.2 million people participate in a complete medical checkup every year in Japan (Japan Society of Ningen Dock, 2015). We think that free complete medical checkups such as these have helped clarify the health conditions of and detect unknown medical problems in thalidomiders. Without these free complete medical checkups, the number of thalidomide survivors participating in medical checkups might significantly decrease compared with the general population.

Thalidomiders in Japan have annual incomes that are not significantly different from those in the general population, which means that most thalidomiders do not face substantial financial burdens in relation to income. However, compared with the general population, a higher proportion of thalidomiders suffers from various diseases and physical problems, and thus, inevitably spends more for treatment. To the best of our knowledge, there is no official report regarding the extra expenses of persons with physical deformities in Japan. However, it is easy to understand that compared with the general population, thalidomiders must pay for additional medical expenses, massage, equipment such as hearing aids, and modifications to their homes and cars. Therefore, in reality, many thalidomiders do face financial difficulties. However, interestingly, thalidomiders are far less likely than the general population to consider their general family circumstances as difficult; this is likely because thalidomiders have become accustomed to dealing with various difficulties and hardships throughout their lives, and because they might not expect to have a very high standard of living.

Importantly, a relatively high proportion of thalidomiders in Japan (9.2%) were unemployed or between jobs compared with the general population, even if they wanted to work; this suggests that thalidomider-friendly work environments are still lacking in Japan. In Germany, however, it was reported that fewer thalidomiders (82.3%) were working (Peters et al., 2015). According to a recent report from the UK (Newbronner et al., 2019), 41.4% of thalidomiders cannot work because of their disabilities and health problems. Taken together, these findings suggest that thalidomiders in Japan have more chances to work and might generally have less disability than those in European countries.

Finally, in general, thalidomiders tend to feel higher levels of worry and stress, especially in terms of the future; this is likely because they tend to be physically disabled and constantly struggling with a variety of complications, pain, fatigue, and reduced ADL. In addition, aging might advance faster in thalidomiders compared with the age-matched general population. Thalidomiders tend to feel that their ADL have been declining year by year, and that this decline, accompanied by their deformed limbs and other impaired body parts, has substantially limited their physical function and caused more pain compared with 10 years previously.

Considering these facts, it is necessary to enhance social welfare measures for thalidomiders in Japan. In the UK, thalidomide survivors have been awarded a 10-year health grant (2013–2022) to help them cope with their additional health and health-related needs. In Germany, following the additional health grant established in the UK, the law on the Contergan Foundation for Disabled People (Contergan Foundation Act—ContStifG) was amended (the fourth amendment) to provide additional support to thalidomiders. It may also be necessary for other countries to enhance social welfare measures and provide additional financial support to aging thalidomiders, who often face increasing physical, clinical, and mental problems requiring treatment.

In conclusion, this nationwide survey of the life situations of thalidomiders in Japan clarified their health conditions and associations with socioeconomic status. The obtained findings are considered highly valid because they are the result of a comparison between thalidomiders and the age-matched general population. Furthermore, the findings of the present survey could be expected to help improve health and medical care, welfare measures, and financial support for thalidomiders in the near future.

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CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

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