Abstract

Purpose – The purpose of this article is to clarify the social burden of Japan’s three major diseases including Long-term Care (LTC) burden.

Design/methodology/approach – A modification of the Cost of Illness (COI)—the Comprehensive-COI (C-COI) was utilized to estimate three major diseases: cancer, heart disease, and cerebrovascular diseases (CVD). The C-COI consists of five parts: medical direct cost, morbidity cost, mortality cost, formal LTC cost and informal LTC cost. The latter was calculated by two approaches: opportunity cost approach (OC) and replacement approach (RA), which assumed that informal caregivers were substituted by paid caregivers.

Findings – The C-COI of cancer, heart disease and CVD in 2017 amounted to 10.5 trillion JPY, 5.2 trillion JPY, and 6.7 trillion JPY, respectively (110 JPY = 1 US$). The mortality cost was preponderant for cancer (61 percent) and heart disease (47.9 percent); while the informal LTC cost was preponderant for CVD (27.5 percent). The informal LTC cost of the CVD in OC amounted to 1.8 trillion JPY; while the RA amounted to 3.0 trillion JPY.

Social implications – The LTC burden accounted for a significant proportion of the social burden of chronic diseases. The informal care was maintained by unsustainable structures such as the elderly providing care for the elderly. This result can affect health policy decisions.

Originality/value – The C-COI is more appropriate for estimating the social burden of chronic diseases including the LTC burden and can be calculated using governmental statistics.

Keywords Aging, Health economics, Health policy, Long-term Care, Cost of Illness, Japan

Paper type Research paper

Introduction

Japan is the world’s most aged nations. In 2017, the percentage of Japanese people at least 65 years old was 27.7 percent, with 13.8 percent at least 75 years old (United Nations, 2019). By 2065, it is forecasted that 38.4 percent of the Japanese population will be at least 65 years old, with 25.5 percent at least 75 years old (National Institute of Population and Social Security Research, 2017).

Aging not only increases the demand for medical care and Long-term Care (LTC) but also is causing a variety of novel and inter-related social phenomena. For example, aging is changing Japan’s disease structure (Ministry of Health, Labour and Welfare, 2015); the elderly people are likely to have multiple chronic diseases, which can carry a greater social burden of LTC than acute disease.

In 2000, Japan introduced a public LTC insurance system (Ministry of Health, Labour and Welfare, 2002) in order to socialize the LTC against a background of increased elderly requiring LTC. This in turn reflects a decline in the caring ability of the elderly’s families due...
to decreasing household members; reduced average housing area due to urbanization; a diminished notion of having to care for elderly parents. Unlike medical insurance (universal health coverage was established in 1961), where patients are hospitalized and receive in-kind benefits, users of the public LTC insurance receive insurance payments without a doctor’s diagnosis, via a certification system. Patients (or their families) demanding public LTC insurance services can apply, and the local government will certify, based on the applicant’s data and the attending doctor’s assessment. Once certified, the applicant can receive subsidies for LTC services. There are seven levels of certification (requiring support 1–2 and requiring LTC 1–5) (Iwagami and Tamiya, 2018). “Requiring support 1” is certified for the mildest, while “requiring LTC 5” is for the most severely disabled. Up to 90 percent of the cost of LTC services is paid by the public LTC insurance, within the predetermined limits of each level.

However, even after the LTC insurance system has become established, the LTC burden on the families is significant. To understand the overall social burden of LTC, it is necessary to consider not only formal care, defined as the provision of services by the public LTC insurance, but also informal care by families.

In addition, the aging of family caregivers is also advancing. According to governmental statistics, in 2016, the proportion of caregivers over 60 years old exceeded two-thirds, and over 70 years exceeded one-third of all caregivers (Ministry of Health, Labour and Welfare, 2020). An apt keyword for today’s Japan is: “The elderly providing care for the elderly”. The number of elderly households whose head is over 65 and consisting of only a couple is expected to increase from 6,277 thousand households in 2015 (11.8 percent of all households) to 6,870 thousand households in 2040 (+9.4 percent, 13.5 percent of all households) (National Institute of Population and Social Security Research, 2018). The number of households whose head is over 75 and consisting of only a couple is expected to increase from 2,735 thousand households in 2015 (5.1 percent of all households) to 3,635 thousand households in 2040 (+32.9 percent, 7.2 percent of all households) (National Institute of Population and Social Security Research, 2018). This problem will be getting more serious.

Japan’s three major diseases are: cancer, heart disease, and cerebrovascular diseases (CVD), for which a high number of deaths have occurred and have been Japan’s three leading causes of death since the 1950s. Each disease is strongly associated with aging. Since the 1980s, cancer has been Japan’s preponderant cause of death, which has been consistently increasing. The second leading cause of death is heart disease, which has also been increasing. CVD is the third leading cause, which, since the 1970s has declined from its then top position (Ministry of Health, Labour and Welfare, 2019a).

Since each disease has its characteristics, it is expected that the social burden of various diseases will be structurally different. For example, CVD is a chronic disease with a potentially long clinical course including sequelae, and the deterioration of daily living.

The Global Burden of Diseases (GBD) is a representative international study on the social burden of diseases. The GBD showed that cancer, heart disease, and CVD were in the upper ranks in the ranking of burden of all diseases (World Health Organization, 2018; Murray and Lopez, 1996). However, the calculation method of Disability-adjusted life year (DALY), which is an index of GBD, is complicated and many assumptions must be made (Sayers and Fliedner, 1997). In addition, DALY is estimated as the time lost by patients, so the burden of providing LTC cannot be included. As a result, the social burden of chronic diseases may be underestimated.

The Cost of Illness (COI) (Rice, 1967) is also a method of estimating a disease’s social burden, but its approach is different from DALY. The COI method is a relatively simple method to estimate the total cost to be borne by society and has been widely used. It includes the cost of medical care, while excluding the LTC costs, thus underestimating the social burden of chronic diseases.
The purpose of this study is to examine and compare the structure of the social burden of the three major diseases, based on realistic assessments of the burden of chronic diseases and including all calculable costs.

Research methodology
The ICD-10 code defines the three major diseases as: Cancer (C00–C97, D00–D09); Heart disease (I01–I02.0, I05–I09, I20–I25, I27, I30–I52); and CVD (I60–I69). The COI proposed by Rice DP, estimates the social burden as monetary value, via direct costs and indirect costs such as lost opportunities to work (Rice, 1967). Although the COI has been criticized (Currie et al., 2000; Drummond, 1992; Shiell et al., 1987), its methodological advantages have been noted (Tarricone, 2006; Rice, 2000; Rice, 1994; Hodgson, 1989). In particular, the social burden can be easily calculated from readily available governmental statistical data, rendering it useful. It has influenced the decision-making of the US government for more than 30 years. Rice stated that the COI has continued to be in demand by health planners and policymakers; she updated her research to estimate the social burden of various diseases (Rice et al., 1985). Kirschstein (2000) reported the COI calculation of major diseases to the US Congress. The studies of COI of tobacco-caused diseases in Medicaid were then used to revise the state laws pertaining to the tobacco industry (Miller et al., 1998; Warner et al., 1999). The COI study of trauma motivated the Centers for Disease Control and Prevention (CDC) to launch a trauma center (Max et al., 1990). Outside the USA, Tarricone (2006) reported that the COI studies were typical in Italy and other countries, and were commonly used by The World Bank, World Health Organization, and the US National Institutes of Health. The COI has also been used to estimate the social burden of various diseases in Japan (Hirata et al., 2019; Hayata et al., 2015; Kitazawa et al., 2015; Matsumoto et al., 2014; Haga et al., 2013). However, the COI does not include the LTC burden. The original COI method was not suitable for comparison of the three major diseases because it could underestimate the burden of CVD, which has the aspect of chronic disease.

In this study the social burden of the three major diseases was estimated using the Comprehensive Cost of Illness (C-COI) method, a revised (and expanded) version of the COI, which includes the social burden of the LTC. The C-COI method was established by our team and has been widely used (Hanaoka et al., 2019; Matsumoto et al., 2017; Matsumoto and Hasegawa, 2019). The advantage of this study is that detailed estimates of the burden of the three major diseases were made using the latest data, while following the method of previous studies. Figure 1 shows the structure of social burden of a disease, broadly divided into the “cost for establishment and administration of health sector” (I), and the “cost for patients and their families” (II). Of these, the “cost for establishment and administration of health sector” excluding that of LTC, and the “cost of medical care and drugs” (④) in the “cost for patients and their families” is included in the Medical Direct cost (MDC). “Morbidity cost” (MbC, ⑤) is the loss of opportunities to work and the labor value due to outpatient visits and hospitalizations. “Mortality cost” (MtC, ⑥) is the loss of labor value due to death from a disease.

The original COI estimates these three components. The C-COI method additionally estimates the LTC cost, which includes the Formal care cost (FCC, ⑦) and the Informal care cost (ICC, ⑧). FCC is defined as the cost of services provided by the public LTC insurance, which can also be expressed as a direct cost of LTC. The ICC is defined as the private burden on the family providing care for elderly, i.e., the family’s labor value lost by caring. In addition, loss of quality of life and mental burden are part of the social burden, but is difficult to estimate and, thus, not included in our study.
The C-COI is defined as:

\[
\text{C-COI} = \text{Medical direct cost (MDC)} + \text{Formal care cost (FCC)} + \text{Morbidity cost (MbC)} + \text{Mortality cost (MtC)} + \text{Informal care cost (ICC)}
\]

The C-COI is composed of two direct costs and three indirect costs, for a total of five components. Table 1 illustrates the detailed calculation method. The MDC is calculated from the medical insurance reimbursement data because almost all medical services are covered by Japan’s public medical insurance. The FCC is also calculated from the public LTC insurance reimbursement data. The cost for establishment and administration of LTC is included in the LTC reimbursement. The MbC is calculated by multiplying the number of days of outpatient visits or hospitalization by the labor value by gender age group. The labor value includes not only salary income but also the value of domestic work. The calculation assumes that the patient had lost one day of work for hospitalization and half a day for outpatient visits. The MtC is measured as the loss of human capital (human capital method): multiplying the number of deaths from a disease by the lifetime labor value by gender age group. Lifetime labor value is the income that a patient who died from a disease would have earned if he/she had survived to average age, calculated as the present value by accumulating the average income by gender age group. The discount rate for calculating the present value was 2 percent, recommended by Japan’s economic valuation guidelines (Fukuda et al., 2013).

| Direct cost | Indirect cost |
|-------------|---------------|
| Medical direct cost | Morbidity cost |
| Formal care cost | Informal Care Cost |
| Indirect cost | Mortality cost |

Table 1. The detailed calculation method of the Comprehensive Cost of Illness

- Annual medical expenses based on reimbursement data
- Long-term care (LTC) cost covered by the public LTC insurance
- (Total person-days of hospitalization × One day labor-value) + (Total person-days of outpatient × One day labor-value × 1/2)
- The number of family caregivers × Average time for care a day × 1-hour labor value per person × 365
- The number of deaths × Life time labor-value per person

*With the introduction of the public LTC insurance, the establishment and administration cost of health sector expanded to include that of the public LTC insurance, which was not included in the original COI. The medical insurance and the public LTC insurance reimbursements cover costs for establishment and administration of each insurance scheme, respectively.

Figure 1. The structure of social burden of a disease
The ICC is calculated via two approaches: Opportunity cost approach (OC) and replacement approach (RA).

**Opportunity cost approach:**

\[
ICC_{OC} = \sum NFC_i \times ATCd \times LVh_i \times 365
\]

**Replacement approach:**

\[
ICC_{RA} = NFC \times ATCd \times \overline{LVh} \times 365
\]

ICC: Informal care cost  
NFC: The number of family caregivers  
ATCd: Average time for daily care  
LVh: 1-hour labor value per person of caregiver  
i: Sex, j: Age class  
\(\overline{LVh}\): Average wage per hour of professional care workers

OC is based on the family opportunity costs lost for caring for the elderly, calculated by multiplying the time spent on care for the elderly by the labor value of the family caregivers by gender age group. In RA, the average wage per hour of professional care workers was used instead of the labor value of family caregivers.

The C-COI of the three major diseases in 2008, 2011, 2014 and 2017 was calculated respectively. All data are based on governmental statistics: Statistics of Medical Care Activities in Public Health Insurance, Patient Survey, Labour Force Survey, Basic Survey on Wage Structure, Monetary Valuation of Unpaid Work, Vital Statistics, Life Tables, Statistics of Medical Care Activities in Public Health Insurance, Comprehensive Survey of Living Conditions, LTC Insurance Status Report, Survey of Institutions, Establishments for LTC, and Basic Survey on Wage Structure. Due to the availability of statistical data, the LTC costs were replaced with data from a year ago. Whereas the “Patient Survey” for calculating the medical costs was conducted in 2008, 2011, 2014, and 2017, the “Comprehensive Survey of Living Conditions” used for calculating the informal care costs was conducted in 2007, 2010, 2013, and 2016. Therefore, the statistics for the closest available year were used. It was considered that the LTC burden would not change dramatically in the short term. Actually, when checking the data used to estimate the LTC costs, there was a tendency for long-term changes, but the amount of change per year was small.

**Research findings**

Table 2 displays the results of this study. Figure 2 indicates the time trends of the C-COI for the three major diseases. The line graph is the average age of death for each disease (right axis). Over time, the total C-COI increased in both cancer and heart disease, while almost flat for the CVD. Comparing the composition ratios of the C-COI, the proportion of medical costs was high in cancer and heart disease, with the proportions of LTC costs 2.7 percent–4.5 percent and 10.9 percent–14.2 percent, respectively.

The MDC of cancer and heart disease increased drastically between 2008 and 2014, while the number of patients with both diseases increased only slightly. On the contrary, the MtC of cancer and heart disease had the highest composition ratio, accounting for 61.0 percent–66.9 percent and 47.9 percent–56.6 percent of the total C-COI, respectively. The ratio of MtC in CVD was 20.8–23.6 percent, almost equal to the MDC (20.5 percent–22.7 percent). Thus, the proportion of mortality cost was higher for cancer, heart diseases, and CVD. The number of
An overview of the results: the Comprehensive Cost of Illness, the number of patients, the number of deaths and average age of death of three major diseases

|                          | Cancer            | Heart diseases   | Cerebrovascular diseases |
|--------------------------|-------------------|------------------|--------------------------|
|                          | 2008  | 2011  | 2014  | 2017  | 2008  | 2011  | 2014  | 2017  | 2008  | 2011  | 2014  | 2017  |
| The number of patients*  | (thousand)        |                  |                  |       |       |       |       |       |       |       |       |       |
| Total                    | 297.8            | 298.3            | 300.8            | 309.8 | 188.5 | 192.3 | 193.9 | 198.2 | 319.3 | 283.8 | 253.4 | 231.9 |
| Inpatient                | 141.4            | 134.8            | 129.4            | 126.1 | 58.2  | 58.1  | 59.9  | 64    | 199.4 | 172.2 | 159.4 | 146   |
| Outpatient               | 156.4            | 163.5            | 171.4            | 183.6 | 130.3 | 134.1 | 133.9 | 134.2 | 119.9 | 111.6 | 94    | 85.9  |
| The number of deaths*    |                  |                  |                  |       |       |       |       |       |       |       |       |       |
| Total                    | 342,963          | 357,305          | 368,103          | 373,334 | 181,928 | 194,926 | 196,923 | 204,837 | 127,023 | 123,867 | 114,207 | 109,880 |
| Inpatient                | 73.4             | 74.2             | 75.0             | 75.8  | 78.7  | 79.2  | 79.7  | 80.7  | 78.6  | 79.4  | 80.0  | 79.9  |
| Outpatient               |                  |                  |                  |       |       |       |       |       |       |       |       |       |
| Average age of death*    | (years old)       |                  |                  |       |       |       |       |       |       |       |       |       |
| Total                    | 2,227            | 2,419            | 2,816            | 3,169 | 1,265 | 1,305 | 1,514 | 1,757 | 1,436 | 1,367 | 1,444 | 1,511 |
| Inpatient                | 48.1             | 47.5             | 46.3             | 46.1  | 158   | 149   | 141   | 199   | 378   | 351   | 322   | 314   |
| Outpatient               |                  |                  |                  |       |       |       |       |       |       |       |       |       |
| Medical direct cost       | (billion JPY)     |                  |                  |       |       |       |       |       |       |       |       |       |
| Total                    | 5,943            | 6,450            | 6,231            | 6,409 | 2,184 | 2,451 | 2,257 | 2,473 | 1,503 | 1,573 | 1,352 | 1,443 |
| Inpatient                | 117              | 144              | 146              | 213   | 196   | 191   | 259   | 306   | 1,570 | 1,652 | 1,733 | 1,564 |
| Outpatient               |                  |                  |                  |       |       |       |       |       |       |       |       |       |
| Mortality cost           | (billion JPY)     |                  |                  |       |       |       |       |       |       |       |       |       |
| Total                    | 126              | 159              | 158              | 255   | 244   | 237   | 291   | 424   | 1,730 | 1,714 | 1,651 | 1,832 |
| Inpatient                |                  |                  |                  |       |       |       |       |       |       |       |       |       |
| Outpatient               |                  |                  |                  |       |       |       |       |       |       |       |       |       |
| Comprehensive Cost of    | (billion JPY)     |                  |                  |       |       |       |       |       |       |       |       |       |
| illness*                 | 8,894            | 9,646            | 9,815            | 10,505 | 4,047 | 4,334 | 4,461 | 5,159 | 6,616 | 6,658 | 6,501 | 6,664 |

* Based on governmental statistics

Source(s): Compiled from data extracted from e-Stat (2020), including Patient Survey and Vital Statistics
deaths from each disease was in the same order as MtC. The number of deaths from cancer and heart disease was increasing, while decreasing for the CVD.

The average age of death for cancer was lower than the other two diseases. The average age of death for cancer and heart disease was increasing. The average age of death for CVD was also increasing, although it leveled off in 2017.

The CVD had a higher percentage of LTC costs in the total C-COI compared to the other two diseases. The FCC and the ICC of CVD were almost equivalent. FCC slightly decreased, while ICC, which had been declining, rebounded in 2017.

Figure 3 compares the calculated results of the ICC of CVD using the two approaches. The results of the RA were 1.51–1.61 times that of the OC.

Discussion
In our study, the C-COI method was used to clarify the changes in the total amount and composition of the social burden of Japan’s three major diseases. The total C-COI of cancer
and heart diseases was increasing, primarily due to the increase in MDC. The number of patients with these two diseases increased, but the MDC of these two diseases increased more. It was assumed that aging may have increased the MDC per patient. According to government statistics, the per capita medical expenses for people at least 65 years old, were about four times higher than those under 65 (Ministry of Health, Labour and Welfare, 2019b). It was also pointed out that newly introduced expensive drugs have increased the medical costs for cancer (Dahl, 2016; Pages et al., 2017). In Japan, there are no regulations limiting expensive medical care or drugs for the elderly. On the contrary, the ratio of MtC in total C-COI was decreasing. The number of deaths from both diseases was increasing, as was the average age of death; and the MtC might be compressed by the aging of patients. The proportion of MtC in cancer, which might be affected by the lower average age of death, was higher than in the other two diseases.

LTC costs for CVD were higher than for the other two diseases. This is because estimating the social burden of chronic disease such as CVD using the original COI method underestimates the true social burden. When discussing chronic disease, it is not be enough to evaluate only the medical costs.

In 2016, the FCC, which had been increasing, decreased; while the ICC was increasing. Figure 4 shows the number of people who have been certified by the public LTC insurance system due to CVD, along with their certification levels. Compared to 2013, the total number of certified people dropped, and the level declined generally in 2016. It is suggested that the certification criteria might be more stringent, and the support for people with CVD might have been reduced in 2017. Furthermore, the public LTC insurance system was revised in 2015 to become a sustainable system given the dearth of care resources due to the increase in the number of elderly people. As a result, more conditions have been set for admission to LTC facilities and only people with certification level “requiring LTC 3” or higher can be admitted, basically.

People who are unable to enter LTC facilities may be forced to stay at home. The increased ICC indicates that such people have increased the burden on their families. The introduction of the public LTC insurance system originally socialized the LTC. However, the increase in the demand for LTC due to the increase in the elderly cannot be covered by the public LTC insurance services alone, and the burden on families may increase once again.

The ICC by RA was 1.51–1.61 times the ICC by OC. Figure 5 displays the labor value of Japanese people by gender age group. As mentioned earlier, two-thirds of caregivers were over 60 years old. The labor value of elderly family caregivers is less than the average wage of professional care workers (1,666 JPY /hour) (Ministry of Health, Labour and Welfare, 2020). The amount of burden of care for the elderly does not inherently depend on the age of the

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**Figure 4.**
The number of people certified by the public Long-term Care insurance system for cerebrovascular disease, with their certification levels

Source: Ministry of Health, Labour and Welfare (2016)
caregiver. On the contrary, as the phrase “the elderly providing care for the elderly” has become common in Japanese society, the care imposes a greater burden on older and fragile families. Nevertheless, as the elderly family caregivers with low labor value have accepted the burden of informal care, the ICC has been apparently compressed in Japan. This situation seems unsustainable.

Considering the present situation, the window of families to accept the LTC burden has decreased. In the near future, informal care will reach its limits and more professional caregivers will be required. Then, the social burden of CVD is assumed to converge on the estimation based on RA.

This study clarified the actual social burden of LTC. The cost of LTC is important in Japan, which is the world’s most aged nations; likewise, similar problems will occur in other countries where rapid aging is expected in the near future. In particular, the burden of informal care is unpaid work, so it is difficult to grasp it. As mentioned above, the problem is becoming more serious. Researchers in other countries have also attempted to estimate informal care cost. Studies of the social burden of the CVD in the US, the UK, Germany, Australia, and the EU found that the proportion of informal care in the total burden was significant (Joo et al., 2014; Heidenreich et al., 2011; Gustavsson et al., 2011; Cadilhac et al., 2009; Saka et al., 2009; Rossnagel et al., 2005; Youman et al., 2003; Hickenbottom et al, 2002). However, the definition of indirect costs varied and no standardized method has been developed yet. Availability of governmental statistics varied among countries, which contributed to the lack of standardized method. Based on the best available governmental statistics, this study provides more detailed estimates than previous studies. For example, the number of people who received informal care, and the average time for daily care were calculated by severity (certification levels of the public LTC insurance), and the sex age group of family caregivers were among the data which are difficult to use in previous studies. Therefore, the lost opportunity cost of family caregivers could be estimated more accurately.

This study also suggested that the aging of caregiver compressed the apparent ICC. Previous studies tended to use a small sample for cost calculations (Lopez-Bastida et al., 2012, Dodel et al., 2010, Navarrete-Navarro et al., 2007, Zethraeus et al., 1999) with few studies calculating

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**Sources:** Ministry of Health, Labour and Welfare (2017); Cabinet Office (2018)

**Figure 5.** The labor value of Japanese people by gender age group

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Changing social burden in Japan

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2000
1500
1000
500
0

Male Female

0 4-9 10-14 15-19 20-24 25-29 30-34 35-39 40-44 45-49 50-54 55-59 60-64 65-69 70-74 75-79 80-84

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Changing social burden in Japan
the total illness cost including the LTC. The C-COI method advantageously calculated the national total value of the social burden using available governmental statistics.

This study is not free from limitations. The C-COI for the three major diseases in 2008, 2011, 2014 and 2017 was calculated. However, as explained in the section of Research Methodology, the yearly LTC costs were replaced by ones from the previous year. It implies that this study may not correctly reflect the social burden of the three major diseases in Japan. Moreover, the LTC cost estimates didn’t cover people who weren’t certified for some reasons, such as not knowing the public LTC insurance system, or not having the ability to apply. Therefore, their burden is not included as such information was difficult to assess.

Conclusion
The burdens of Japan’s three major diseases differed in total amount and breakdown. It was suggested that the LTC burden should have been included when evaluating the social burden of chronic disease because LTC burden as a percentage of the total social burden of chronic disease was higher than that of acute disease. The C-COI, which includes the LTC burden, could be used to measure the impact on health policy decisions in an aging society where the importance of chronic disease has increased compared to acute disease.

The burden of informal care accounted for a significant percentage of the social burden of LTC; and it was increasing. The current informal care system, including the problem of “the elderly providing care for the elderly,” may be unsustainable, and it is possible that informal care may collapse in the near future, shifting the burden to formal care. This finding may give a lesson to policymakers and researchers in countries which will enter the super-aging society following Japan, and to enable them to take action.

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