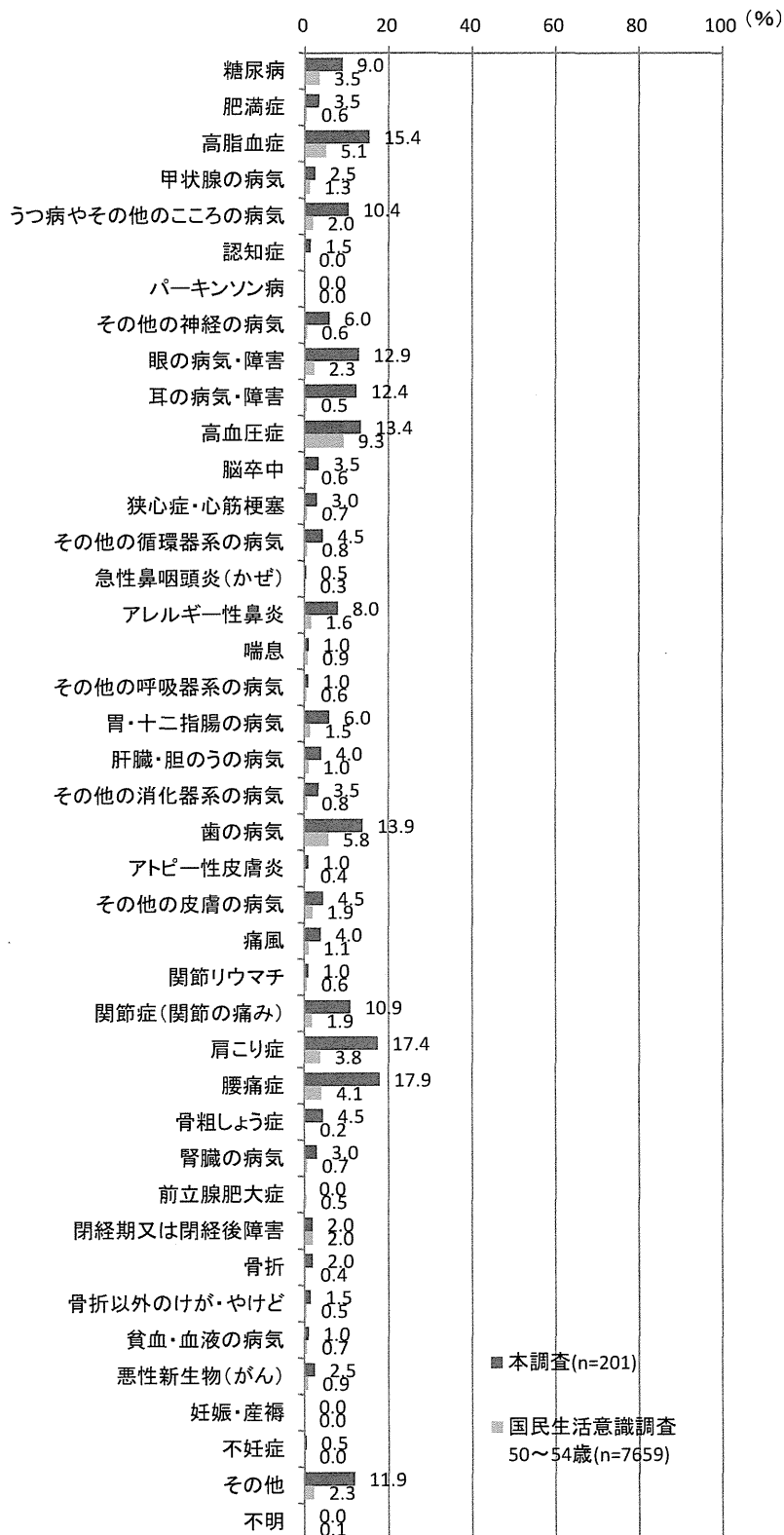


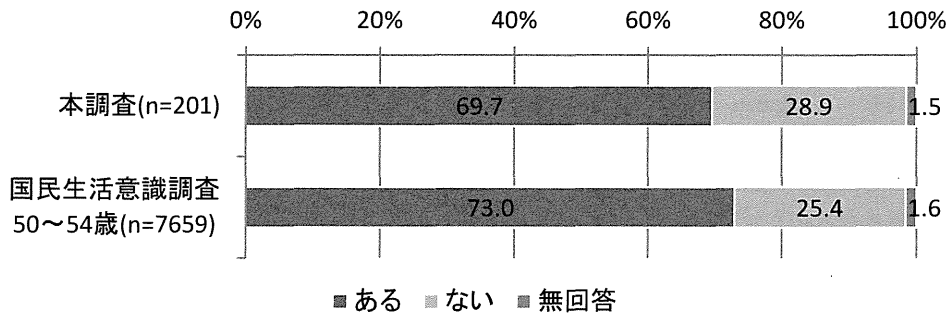
図表 56 通院している傷病の具体的内容；国民生活基礎調査結果（50～54 歳）との比較（複数回答）



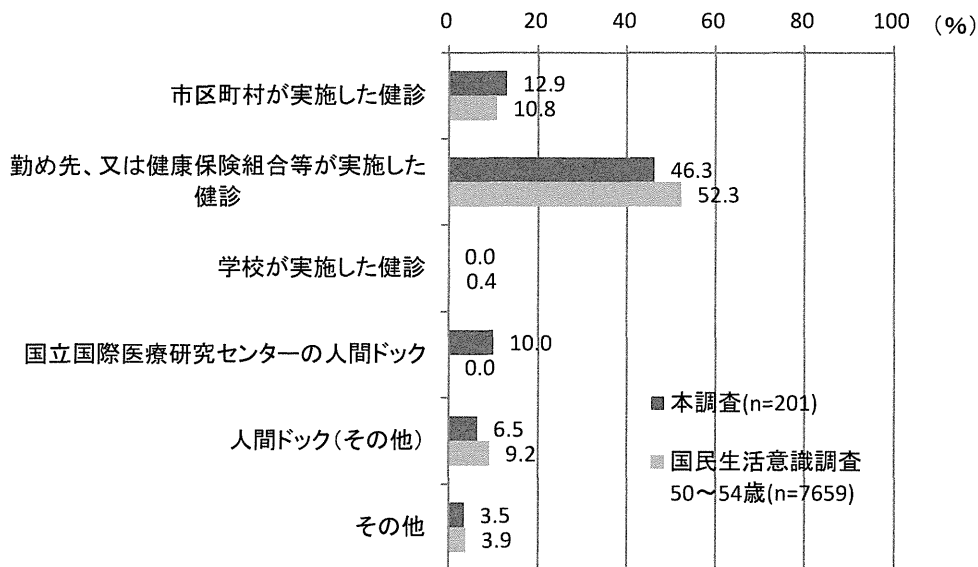
(3) 健診等の受診状況

- この1年間の健診等の受診が「ある」とした比率は、本調査 69.7%、国民生活基礎調査 73% であり、ほぼ同程度である。
- 健診等の受診機会は、本調査、国民生活基礎調査いずれも、「勤め先、又は健康保険組合等が実施した健診」が最も多く、次いで「市区町村が実施した健診」となっており、同様の傾向である。

図表 57 健診受診有無；国民生活基礎調査結果（50～54歳）との比較



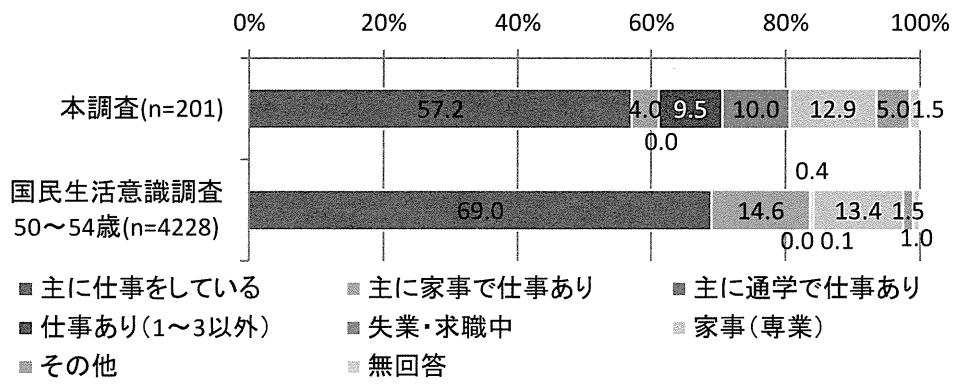
図表 58 健診等の受診機会；国民生活基礎調査結果（50～54歳）との比較（複数回答）



3. 仕事の状況

- 「主に仕事をしている」「主に家事で仕事あり」等を含め、何らかの仕事をしている比率は、本調査 70.7%が国民生活基礎調査 84.1%を下回っている。また、「主に仕事をしている」比率も、本調査 57.2%が国民生活基礎調査 69%を下回っている。
- 一方、本調査のみで項目設定した「求職・失業中」が 10%であり、同世代とは働き方、労働環境が異なることがうかがえる。

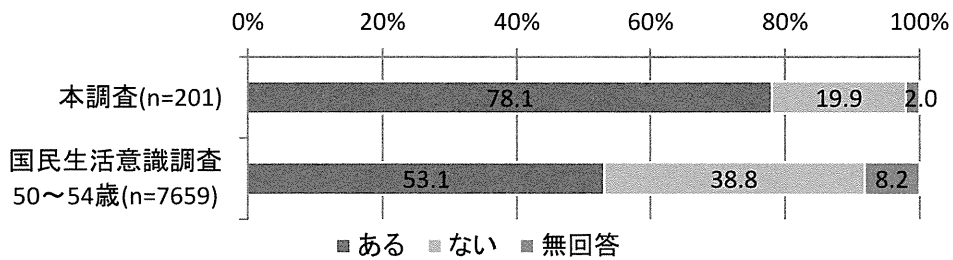
図表 59 6月中の仕事の状況；国民生活基礎調査結果（50～54歳）との比較



4. 生活上の悩みや困っていること

- 現在、生活上で悩みやストレスが「ある」と回答した比率は、本調査 78.1%が国民生活基礎調査 53.1%を上回っている。

図表 60 悩みやストレスの有無；国民生活基礎調査結果（50～54歳）との比較



本調査は、厚生労働科学研究「全国のサリドマイド胎芽病患者の健康、生活実態に関する研究（研究実施期間 2012 年 4 月～2015 年 3 月（予定）」の一環として実施したものです。

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(2011- Pharmaceuticals - Designation - 023)

Living Conditions Survey, Overview Edition

March 2013

Lead researcher: Atsuto Yoshizawa, National Center for Global Health and Medicine

Survey subcontractor: Mitsubishi Research Institute, Inc.

Table of Contents

Chapter 1 Overview

I. Overview of the Survey.....	4
1. Purpose of the survey.....	4
2. Target of the survey, survey period and methods, the number of respondents.....	4
(1) First stage: questionnaire survey.....	4
(2) Second stage: group interview survey.....	4
3. Survey items.....	6
(1) Specific survey items.....	6
(2) Points taken into account when designing the survey items.....	6
4. Composition and interpretation of this report.....	7
II. Survey Results.....	8
1. Basic attributes and household conditions.....	8
(1) Gender and age.....	8
(2) Main types of disability due to thalidomide harm.....	8
(3) Household composition.....	9
2. Conditions in daily life.....	11
(1) Current state of health.....	11
(2) The impact of health problems on daily life.....	11
3. Use of medical and health care services.....	18
(1) Physical problems due to diseases or injuries, etc. (subjective symptoms).....	18
(2) Hospital treatment due to disease or injury.....	27
(3) Respondents' difficulties and things they were unable to do when receiving treatment at medical institutions.....	37
(4) Undergoing medical examinations, etc.....	40
(5) Medical expenses paid by the respondents themselves in the last 3 months.....	40
(6) Whether or not there is a municipal medical expenses subsidy system.....	41
(7) Comprehensive assessment of the current lifestyles of the households.....	42
4. Use of welfare and caregiving services.....	43
(1) Status of acquisition of the identification handbooks for the disabled.....	43
(2) Recognition of classification of disability levels under the Services and Supports for Persons with Disabilities Act.....	44
(3) Status of use of disability welfare services.....	45
(4) Status of use of services based on the Long-Term Care Insurance Act.....	47
5. The status of public support, etc.....	48
(1) Status of monetary benefits based on the amicable settlement of thalidomide lawsuits.....	48
(2) Status of the receipt of public pensions, public officers pensions, etc.....	48

(3) Status of the receipt of public assistance	49
6. Job situation	50
(1) Job situation during June 2012	50
7. Status of family caregiving	52
8. Worries and difficulties in daily life	53
(1) Worries and stress in daily life.....	53
9. Current difficulties of the respondents in their daily lives, and their unease about the future (free comments).....	58
(1) The respondents' statements about their own work, their life design for the future, the prospects for income going forward, etc.....	58
(2) Use of medical and health care services, welfare and caregiving services, etc.	59
III. Comparison of the Comprehensive Survey of Living Conditions and the Results of the Questionnaire Survey	61
1. Conditions in daily life	61
(1) Current state of health.....	61
(2) The impact of health problems on daily life	62
2. Use of medical and health care services	63
(1) Physical problems due to diseases or injuries, etc. (subjective symptoms)	63
(2) Hospital treatment due to disease or injury	66
(3) Undergoing medical examinations, etc.	68
3. Job situation.....	69
4. Worries and difficulties in daily life	70
Figure 1: Gender of the respondents; by type of disability.....	8
Figure 2: Main types of disability of respondents due to thalidomide harm; by gender	9
Figure 3: Type of household; by type of disability	9
Figure 4: Relationship to housemates from the perspective of the respondents if the respondents have any housemates (multiple-answer question); overall	10
Figure 5: Current state of health; by type of disability.....	11
Figure 6: Whether or not health problems have an impact on daily life; by type of disability .	11
Figure 7: Specific impacts on daily life (multiple-answer question); overall	12
Figure 8: Specific impacts on daily life (multiple-answer question); by type of disability.....	12
Figure 9: Percentage of free comments about inconveniences and difficulties in daily life; by content	14
Figure 10: Change in the degree of impact on daily life over the last 5 years; by type of disability	15
Figure 11: Causes of the impacts on daily life (multiple-answer question); overall.....	15
Figure 12: Causes of the impacts on daily life (multiple-answer question); by type of disability	16
Figure 13: Whether or not health problems had an impact on ordinary activities in the past 1 month; by type of disability	17
Figure 14: Number of days on which there was an impact on ordinary activities; by type of disability	17

Figure 15: Whether or not the respondents had physical problems due to diseases or injuries, etc. (subjective symptoms) in the last few days; by type of disability	18
Figure 16: Specific content of the subjective symptoms (multiple-answer question); overall.	20
Figure 17: Specific content of the subjective symptoms (multiple-answer question); by type of disability	22
Figure 18: Subjective symptoms the thalidomide-impaired person is most concerned about (multiple-answer question); overall.....	24
Figure 19: Subjective symptoms the thalidomide-impaired people are worried are related to thalidomide harm (multiple-answer question); overall	26
Figure 20: Treatment status of the symptoms the thalidomide-impaired person is most concerned about (multiple-answer question); overall	27
Figure 21: Hospital treatment due to disease or injury (multiple-answer question); overall...	28
Figure 22: Specific diseases or injuries for which the thalidomide-impaired people are receiving treatment at the hospital (multiple-answer question); overall	29
Figure 23: Specific diseases or injuries for which the thalidomide-impaired people are receiving treatment at the hospital (multiple-answer question); by type of disability.....	31
Figure 24: Diseases or injuries the thalidomide-impaired people are most concerned about and are receiving treatment for at a hospital (multiple-answer question); overall.....	33
Figure 25: Diseases and injuries the thalidomide-impaired people are worried are related to thalidomide harm (multiple-answer question); overall	35
Figure 26: Respondents' difficulties and things they were unable to do when receiving treatment (multiple-answer question); overall.....	38
Figure 27: Respondents' difficulties and things they were unable to do when receiving treatment (multiple-answer question); by type of disability	39
Figure 28: Whether or not the respondents had to pay any medical expenses themselves (multiple-answer question); overall.....	41
Figure 29: Whether or not there is a medical expenses subsidy system; by type of disability	42
Figure 30: Comprehensive assessment of the current lifestyles of the households; by type of household.....	42
Figure 31: Status of acquisition of the identification handbooks for the disabled (multiple-answer question); by type of disability	43
Figure 32: Reasons for not acquiring an identification handbook (multiple-answer question); overall.....	44
Figure 33: Status of recognition of classification of disability levels; by type of disability.....	44
Figure 34: Status of use of disability welfare services; by type of disability	45
Figure 35: Content of the services the respondents are using (multiple-answer question); overall.....	46
Figure 36: Reasons the respondents are not using the disability welfare services (multiple-answer question); overall.....	47
Figure 37: Status of the receipt of monetary benefits based on the amicable settlement of thalidomide lawsuits (multiple-answer question); overall.....	48
Figure 38: Status of receipt of public pensions or public officers pensions (multiple-answer	

question); overall.....	48
Figure 39: Status of the receipt of public assistance; by type of disability	49
Figure 40: Job situation during June 2012; by type of disability	50
Figure 41: Considerations the respondents receive in the workplace (multiple-answer question); overall.....	51
Figure 42: Whether or not the respondents are receiving caregiving from their families; by type of disability.....	52
Figure 43: Whether or not the respondents have worries and stress in daily life; by type of disability	53
Figure 44: Whether or not the respondents have worries and stress in daily life; by type of household.....	53
Figure 45: Content of the worries and stress (multiple-answer question); overall	55
Figure 46: Content of the worries and stress (multiple-answer question); by type of disability	55
Figure 47: Content of the worries and stress; by type of household (multiple-answer question)	56
Figure 48: The people or organizations the respondents consult about their worries and stress (multiple-answer question); overall	57
Figure 49: Current difficulties of the respondents in their daily lives, and their unease about the future [their own work, life design for the future, income going forward, etc.]; figures by category.....	59
Figure 50: Current difficulties of the respondents in their daily lives, and their unease about the future [medical and health care services, welfare and caregiving services]; figures by category	60
Figure 51: Current state of health; comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old).....	61
Figure 52: Whether or not health problems are having an impact on daily life; comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old)	62
Figure 53: Specific impacts on daily life (multiple-answer question); comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old)	62
Figure 55: Specific content of subjective symptoms (multiple-answer question); comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old) ...	65
Figure 56: Specific diseases or injuries for which the thalidomide-impaired people are receiving treatment at the hospital; comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old) (multiple-answer question).....	67
Figure 57: Whether or not the respondents are undergoing medical examination; comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old) ...	68
Figure 58: Opportunities to undergo medical examinations, etc.; comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old) (multiple-answer question)	68
Figure 60: Whether or not the respondents have worries and stress; comparison with the results of the Comprehensive Survey of Living Conditions (50-54 years old)	70

Overview

This survey was implemented for the purpose of ascertaining the health of thalidomide-impaired people, the problems they face in their daily lives, and the medical care and welfare services they use, and is a part of the Health and Labour Sciences Research “Research into the Health and Living Conditions of Thalidomide Embryopathy Patients” (research implementation period: April 2012 to March 2015 (planned)).

For this survey we implemented a mailed-out and mailed-back questionnaire survey over the period June to October 2012 to quantitatively assess the living conditions of thalidomide-impaired people. The target of the survey was the 286 Japanese thalidomide-impaired people of the 295 living as of June 2012 for which a group that aims to improve their social welfare (the Ishizue Foundation) had addresses. (Number of respondents: 201)

Moreover, from September to December 2012 we allocated some of the time in the “Ishizue Regional Exchange & Consultation Meeting” regularly held in regional blocks throughout Japan to interview surveys, and implemented group interview surveys of the thalidomide-impaired people participating in the meeting in order to ascertain qualitative information to supplement the numerical data from the questionnaire survey. (Number of respondents: 33)

As a result of these surveys, the following living conditions of the thalidomide-impaired people were revealed.

(i) Basic attributes

- The gender of the respondents was 49.8% males and 49.3% females, with an average age of 49.9 years old.
- Furthermore, the main types of disability due to thalidomide harm were upper limb disability (76.6%) and hearing disability (17.4%).
- Looking at household composition, there are 14.9% single-person households, 22.4% of people are living with their parents only and 61.7% live in other kinds of households (nuclear families with a spouse and children, three generations living together, living with siblings, etc.).

(ii) Conditions in daily life

- The respondents’ most frequent answer regarding their current state of health is “average” at 39.8%. The combined percentage of people saying “not very good” and “not good” is 28.4%. Comparing this with other people in the same generation¹ (12.6%), a relatively high proportion of respondents feel that their state of health is not good.
- Furthermore, 40.8% of the respondents stated that their health problems had an

¹ “Same generation” refers to people 50-54 years old in the 2010 Comprehensive Survey of Living Conditions conducted by the Ministry of Health, Labour and Welfare. Refer to Chapter III, p.44

impact on their daily life. Comparing this with other people in the same generation (9.7%), it is apparent that their poor state of health is manifested as specific obstacles in daily life.

- The highest percentage of respondents, 61%, answered that the degree of impact on their daily life has grown (become worse) over the last five years. The causes of the impacts on their daily life are thought to be thalidomide harm (65.9%) and the aging process (45.1%).
- ◆ We can deduce that thalidomide-impaired people approaching their 50s are facing new challenges in their daily lives. Responses tailored to the cause of these challenges, such as thalidomide harm, aging, etc., are required.

(iii) Use of medical and health care services

- The proportion of respondents saying that in the last few days they had some physical problems (subjective symptoms) was 64.7%, and the number of symptoms was 7.1. Comparing this with other people in the same generation (32.4%, 3.8), we can deduce that the thalidomide-impaired people also have specific subjective symptoms reflecting the fact that their current state of health is not good.
- Moreover, comparing the percentage of thalidomide-impaired people with a disease or injury currently being treated at a hospital with other people in the same generation, the thalidomide-impaired people have a higher morbidity rate for both disease and injury. Specifically, shoulder stiffness and lower back pain (both between 17% and 17.9%), tooth disease (13.9%) and ear disease or disability (12.4%) which are all thought to be related to thalidomide harm, and in addition diabetes (9%), hyperlipidemia (15%) and high blood pressure (13.4%) all had morbidity rates two or three times higher than other people in the same generation. Furthermore, obesity (3.5%) had a morbidity rate six times higher than other people in the same generation.
- However, currently when thalidomide-impaired people receive treatment at medical institutions, in the case of upper limb disability they have difficulty with blood collection (22.1%) and blood pressure measurement (7.8%). Furthermore, in the case of a hearing disability they have difficulty with communication (28.6%) and the upper gastrointestinal endoscope (14.3%).
- ◆ The above facts reveal the importance for thalidomide-impaired people of health checkups and when necessary receiving treatment at medical institutions. Furthermore, it is necessary to write guidelines for medical professionals, including appropriate blood collection procedures, blood pressure measurement methods, and precautions to take when performing endoscopies, etc. in order to eliminate difficulties for thalidomide-impaired people undergoing treatment at medical institutions.

(iv) Use of welfare and caregiving services

- Using medical and health care services in combination with welfare and caregiving

services that meet the various needs of the thalidomide-impaired people in their daily lives is effective for reducing the impact of health problems on daily life.

- 90% of the thalidomide-impaired people have obtained the physical disability certificate that is a requirement for using the services. However, only 6.5% have received recognition of classification of their disability level under the Services and Supports for Persons with Disabilities Act and overall a mere 10% were using the disability welfare services.
- The most common reason the respondents gave for not using the services was “I don’t have any problems even if I do not use the services” at 81.6%. On the other hand, 8.9% said “I do not understand the procedures for using the services” so we can conclude that development of information provision and consultation and support structures for the complicated welfare system is necessary. Furthermore, 5% said “I do not satisfy the criteria for using the services” and 4.5% said “there are no services that I want to use.”
- ◆ Based on the above facts, and based on the results of our examination, revision of the current service structure and flexible management of the system are required. Note that there is a need for further verification of whether or not the respondents who answered “I don’t have any problems even if I do not use the services” really do not need the services and whether or not there is any risk that the thalidomide-impaired people are overexerting themselves in a variety of situations to run their daily lives, causing secondary disabilities, etc.

(v) Worries and difficulties in daily life

- 78.1% of respondents said they had worries and stress in their daily life. This is much higher than other people in the same generation (53.1%).
- The worries and stress included their own health (72%), post-retirement life design (52.9%), the health of their family (41.4%), and prospects for future income and assets (35.7%), etc. so health problems and unease about the future accounted for most of them.
- The morbidity rate of “depression and other mental illnesses” is five times higher for thalidomide-impaired people than other people in the same generation. Furthermore, 11.5% said about their worries and stress that they “want to but are unable to consult with someone about it.”
- ◆ Based on the above facts, comprehensive consultation and support structures which can respond meticulously to the diverse disabilities, lifestyles and support needs of thalidomide-impaired people will be required going forward.

I. Overview of the Survey

1. Purpose of the survey

- The purpose of this survey is to ascertain the health of thalidomide-impaired people, the problems they face in their daily lives, and the medical care and welfare services they use, and is a part of the Health and Labour Sciences Research “Research into the Health and Living Conditions of Thalidomide Embryopathy Patients” (research implementation period: April 2012 to March 2015 (planned)).

2. Target of the survey, survey period and methods, the number of respondents

(1) First stage: questionnaire survey

- Target of the survey: We implemented a questionnaire survey to quantitatively assess the living conditions of thalidomide-impaired people. The target of the survey was the 286 Japanese thalidomide-impaired people of the 295 living as of June 2012 for which a thalidomide-impaired person welfare group (the Ishizue Foundation) had addresses
- Survey period: June to October 2012.
- Survey method: We mailed the survey forms to the survey subjects through the Ishizue Foundation and recovered them by mail addressed to the lead researcher.
- Number of respondents: there were 201 respondents (response rate 70.3%). Note that four of the respondents were unable to fill out the survey form themselves due to their disability, etc. so the caregiver, etc. filled it out on their behalf.

(2) Second stage: group interview survey

- Target of the survey: We allocated some of the time in the “Ishizue Regional Exchange & Consultation Meeting” regularly held in regional blocks throughout Japan by the Ishizue Foundation to interview surveys, and implemented group interview surveys of the thalidomide-impaired people participating in the meeting in order to ascertain qualitative information to supplement the numerical data from the questionnaire survey.
- Survey period: September to December 2012.
- Survey method: At the beginning of the meeting the survey secretariat gave a

20-minute presentation on the overall approach of the research and the provisional figures from the questionnaire results and then one-hour group interviews were held to ask the respondents their views regarding the presentation.

- Number of respondents: a total of 33 including two at the Sapporo venue, ten at the Tokyo venue, seven at the Nagoya venue, nine at the Kyoto venue, and five at the Fukuoka venue.

3. Survey items

(1) Specific survey items

We surveyed the following items.

- * Basic information: age, types of disability, family composition, etc.
- * Impact on state of health and daily life
- * Physical problems (subjective symptoms), disease and injuries
- * Hospitals, etc. visited regularly
- * Difficulties when receiving treatment at hospitals, etc.
- * Cost burden due to disease and injuries, etc. and subsidies from local governments
- * Use of disability welfare services, etc.
- * Job situation
- * Family caregiving conditions
- * Worries and difficulties in daily life

(2) Points taken into account when designing the survey items

- When designing the survey items, we took care to achieve consistency with the items in the Comprehensive Survey of Living Conditions published by the Ministry of Health, Labour and Welfare in order to analyze the differences and similarities in the living conditions and challenges of the thalidomide-impaired people compared to other people in the same generation.
- Furthermore, in order to verify the appropriateness of the questionnaire survey items we asked the 8 thalidomide-impaired people who entered hospital for the pilot health checkups implemented as a part of this study from November 2011 to January 2012 (3 males and 5 females, 7 with upper limb disability and 1 with a hearing disability) to fill out the survey form as a trial, and conducted a preliminary survey in which we asked these thalidomide-impaired people in individual interviews if there were any questions that were difficult for them to understand or were difficult to answer. We were planning to survey 15 thalidomide-impaired people in the preliminary survey but some of the matters indicated by the survey subjects were the same so the survey ended with 8 thalidomide-impaired people.
- We completed the survey form after taking into account the results of the preliminary survey, and confirming the views of the director of the Ishizue Foundation (also a thalidomide-impaired person) from February to May 2012.

4. Composition and interpretation of this report

- The composition of this report is as follows.
- In Chapter 2, we present the summary of the results of this survey.
- In Chapter 3, we present the results of the comparisons of the indicators that can be compared with the fiscal year 2010 Comprehensive Survey of Living Conditions.
- Note that for the diseases and injuries used in the survey items we adopt the diseases and injuries adopted in the Comprehensive Survey of Living Conditions in order to perform comparisons with the Comprehensive Survey of Living Conditions. In addition, the itemized free comments in the report are all verbatim statements from the original text.

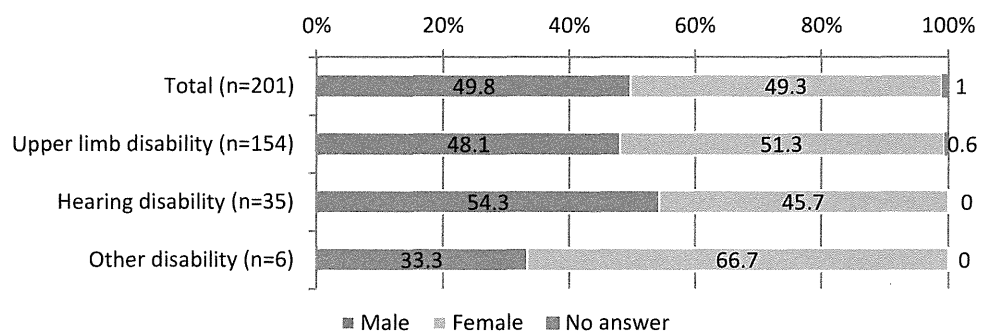
II. Survey Results

1. Basic attributes and household conditions

(1) Gender and age

- Looking at the overall gender breakdown of the respondents, there are 100 male respondents (49.8%) and 99 female respondents (49.3%).
- According to Ishizue Foundation data, the gender breakdown for thalidomide-impaired people is 55.3% male and 44.7% female so in this survey there was a slightly higher response rate from females.
- The overall average age of the respondents is 49.9 years old (males: 50.0 years old, females: 49.8 years old).

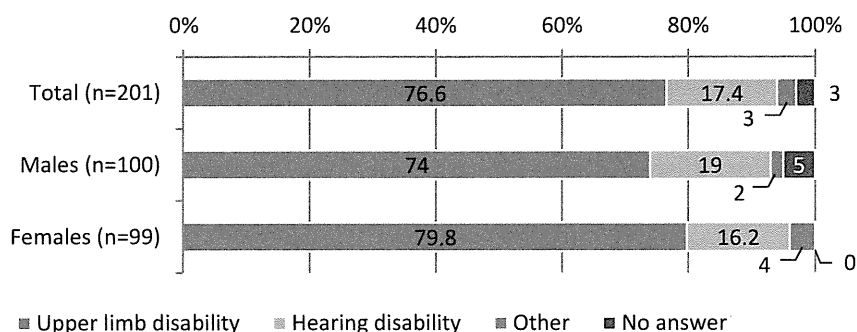
Figure 1: Gender of the respondents; by type of disability



(2) Main types of disability due to thalidomide harm

- Overall the main types of disability due to thalidomide harm were disabilities of the upper limbs, 154 respondents (76.6%), and hearing disabilities, 35 respondents (17.4%).
- According to Ishizue Foundation data, the main types of disability of thalidomide-impaired people are upper limb disability, 73.5%, hearing disability, 20.4%, and multiple disabilities, etc. at 6.1%, so the percentage of respondents indicating upper limb disability was slightly higher in this survey.
- Other disabilities mentioned by the respondents included “no language due to cerebral palsy (intellectual disability at the time of birth),” “paralysis of the right side of the face,” “imperforate anus,” “deformation of the eyes, fingers, or internal organs, lack of a gall bladder, appendicitis,” etc.

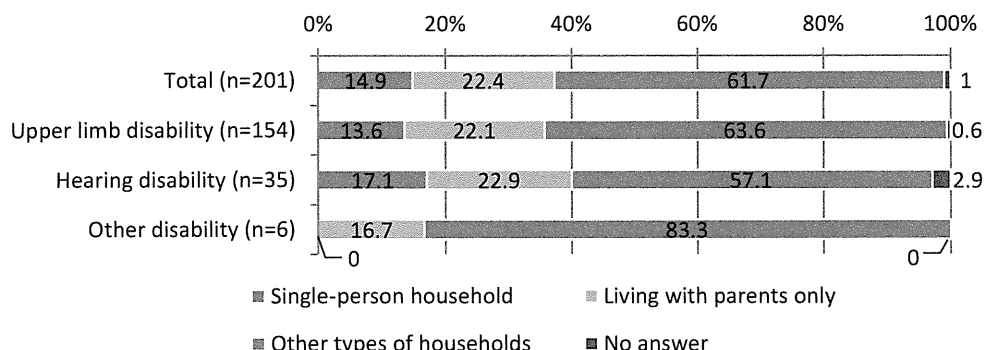
Figure 2: Main types of disability of respondents due to thalidomide harm; by gender



(3) Household composition

- Looking at the overall type of household of the respondents, 30 respondents (14.9%) were in single-person households, 47 respondents (22.4%) were living with parents only, and 122 respondents (61.7%) were in other types of households (nuclear families with a spouse and children, three generations living together, living with siblings, etc.).
- Looking at type of household by type of disability, among respondents with an upper limb disability “other types of households” ranked first with 96 respondents (63.6%), followed by “living with parents only” with 36 respondents (22.1%), and “single-person household” with 21 respondents (13.6%). On the other hand, among respondents with a hearing disability there were slightly more single-person households, with 20 respondents (57.1%) in “other types of households” followed by 8 respondents (22.9%) “living with parents only” and 6 respondents (17.1%) in “single-person households.”

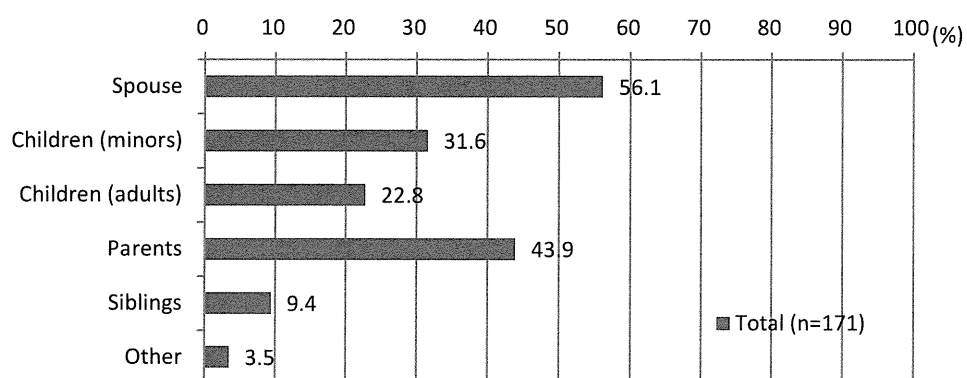
Figure 3: Type of household; by type of disability



(i) Relationship to housemates

- In the case that the respondent has housemates, looking at the relationship to the housemates from the perspective of the respondents overall, “spouse” ranked first with 96 respondents (56.1%), followed by “parents” for 75 respondents (43.9%), and children (minors) for 54 respondents (31.6%).

Figure 4: Relationship to housemates from the perspective of the respondents if the respondents have any housemates (multiple-answer question); overall

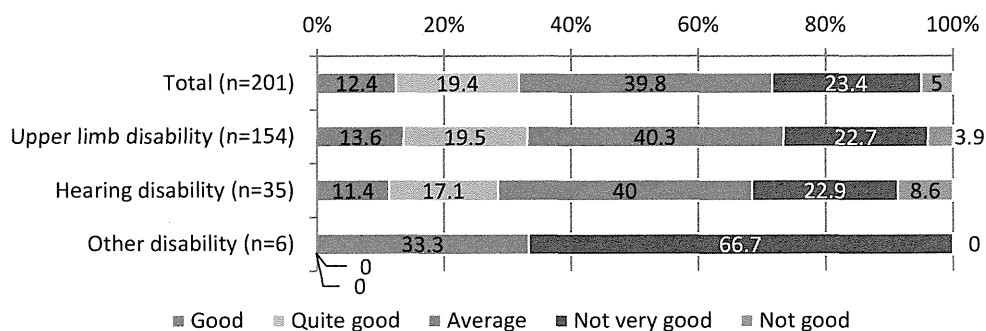


2. Conditions in daily life

(1) Current state of health

- Looking at the current state of health with regard to the respondents overall, “average” ranked first with 80 respondents (39.8%), followed by “not very good” with 47 respondents (23.4%), and “quite good” with 39 respondents (19.4%).
- Looking at current state of health by type of disability, the pattern is similar but a slightly higher percentage of respondents with a hearing disability answered “not good” than respondents with an upper limb disability.

Figure 5: Current state of health; by type of disability



(2) The impact of health problems on daily life

- Looking at whether or not the health problems have an impact on daily life with regard to the respondents overall, 82 respondents (40.8%) said “yes.”
- Looking at the results by type of disability the pattern is similar.

Figure 6: Whether or not health problems have an impact on daily life; by type of disability

