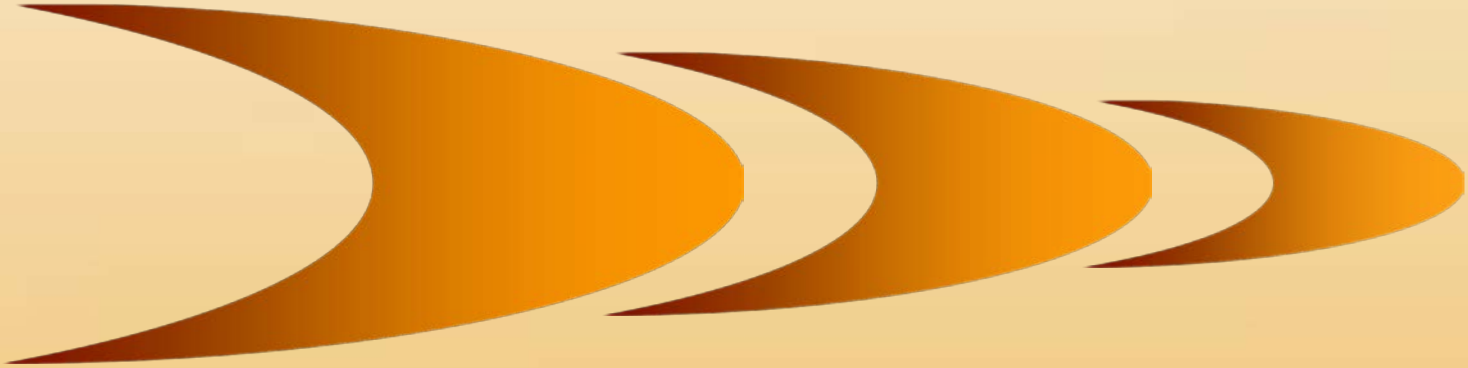
ASSOCIATION CANADIENNE
DES VICTIMES DE LA
Thalidomide
VICTIMS ASSOCIATION OF CANADA

REPORT

STUDY ON THE CURRENT LIVING CONDITIONS OF CANADIAN THALIDOMIDE SURVIVORS AND THEIR PROJECTIONS FOR THEIR FUTURE



THE THALIDOMIDE VICTIMS ASSOCIATION OF CANADA

Founded in 1988, the Thalidomide Victims Association of Canada (TVAC) is a nonprofit charitable organization. TVAC represents more than one hundred Canadians who were born with birth defects and disabilities as a result of the thalidomide drug, which was prescribed in the late fifties and early sixties to pregnant women to relieve morning sickness. TVAC was created to provide peer support, information exchange, programs and services, and to promote the interests of Canadian thalidomiders.

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EXECUTIVE SUMMARY

Founded in 1988, the Thalidomide Victims Association of Canada (TVAC) represents over one hundred Canadians born with significant congenital malformations caused by the drug thalidomide which, was prescribed in the late fifties and early sixties to pregnant women to combat morning sickness symptoms.

In light of the concerns and requests for assistance that thalidomide victims have communicated to TVAC in recent years, TVAC is very concerned about the physical and emotional well-being of thalidomide victims as well as their financial circumstances. Furthermore, since relevant information regarding the victims' changing health status is virtually non-existent, TVAC felt it necessary to create a picture of the experiences of its members and to attempt to assess, with reasonable accuracy, the degree of the concerns expressed by this group as a whole 50 years after the onset of this tragedy. This culminated in the ***Study on the Current Living Conditions of Canadian Thalidomide Survivors and their Projections for their Future***.

TVAC, in conjunction with professional advisors, created a self-assessment questionnaire, divided into three parts: *Identification and socio-demographic information; Health status and independence in performing daily activities;* and *Needs and projections for the future.* Of the 100 TVAC members who received the questionnaire, 65 completed and returned it. This demonstrates a 65% participation rate among this group. In particular, the response rate for the Western region of Canada was 65%; in Ontario it was 50%, in Quebec it was 73%, and in the Eastern region of Canada participation was at 50%.

Analysis of the data collected showed, first, that the proportion of Canadian thalidomide survivors living alone is significantly higher than the general population in Canada. 34.4% of respondents reported that they live alone whereas 26.8% of the rest of the adult Canadian population lives alone[1].

60% of respondents have a post-secondary diploma compared with 64% for the general Canadian population of the same age. Education level among the Canadian thalidomide victims is thus slightly lower than for the average Canadian, between 45 and 54 years old. Canadian thalidomide victims have a much higher rate of unemployment. 64.1% of respondents claim to be employed which is less that an employment rate of 71.3% for

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[1] According to Statistics Canada, 2006 census

other Canadian adults between the ages of 45 and 64. This study revealed that the employment rate among Canadian victims has decreased since the previous study was conducted by TVAC in 1999. The 1999 report revealed that 73.3% of respondents had a job. For 31% of respondents, the fear of needing to permanently quit their jobs due to their deteriorating health as thalidomide victims is at the forefront of their minds; 17% of the respondents advised that they were no longer able to hold down a job due to their thalidomide-related health problems. This is concerning, especially since 58% of respondents advised that their employment income is essential to meet their unique needs as thalidomide victims.

During the 70s, some Canadian families threatened and/or initiated legal action against the pharmaceutical firm, Richardson-Merrell, the company responsible for thalidomide distribution in Canada. These families acquiesced to an out-of-court settlement, the terms of which required them to submit to a gag provision. In 1991, following several years of demands by the War Amps of Canada and its thalidomide task force, the Canadian government, created the Extraordinary Assistance Plan (EAP). Under the EAP, the Canadian government granted small lump-sum sympathy grants to Canadian thalidomiders. Despite these payments, 19% of respondents are no longer receiving any compensation today and 50% reported receiving less than $10,000 per year. The mean net income deriving from compensation payments is currently approximately $13,790 per year. The median income level however is lower, between $5,000 and $9,999 per year. The study showed that 85% of the respondents are dissatisfied with the Richardson-Merrell pay-outs and 86% of respondents are dissatisfied with the financial assistance provided by the Canadian government.

This study has also revealed that thalidomide victims in Canada are progressively losing their independence. The ability of victims to continue to look after themselves and to properly maintain their homes has become increasingly challenging for them. 30% of respondents view household maintenance as being more difficult for them than it was 5 years ago. 26% of respondents require the partial or total assistance of another person to assist with the preparation of their meals and 14% require assistance for their personal hygiene care. In summary, 46% of respondents feel that they have lost abilities and are less independent than they were previously.

Another disturbing finding of this study is that pain and discomfort experienced by thalidomide victims is becoming increasingly present in their lives. Standing for an extended period of time and carrying an object seem to be the most painful and challenging activities for these victims. These conditions affect their general health and, consequently, their emotional health, their ability to work, and consequently, their financial circumstances.

Among the recurrent or persistent health problems the respondents reported, 80% indicated an increase in muscle pain; 71% reported an increase in joint pain; 49% of respondents advised that they are experiencing numbness and loss of sensitivity; and 76% reported that their general health is either worse or much worse than it was five years ago.

In terms of the respondents' needs and views about their future, 46% of the respondents feel that they have either insufficient or no access to treatments which would improve their health. Physiotherapy, massage therapy, psychological treatments, dental and eye care are the treatments most frequently desired. With respect to services, 45% advised that they needed certain services to improve their quality of life, including, without limitation, transportation, help with household chores and personal assistance. Cost is the main obstacle to obtaining these treatments and services when needed.

Finally, 49% of respondents have a rather pessimistic view of their future. When asked specifically about their predictions for their financial futures, 72% of respondents reported that they feel that their financial situations in the future will be either precarious or very precarious in the next ten years or so. When asked specifically about their health, 52% of the respondents reported that they anticipate experiencing many more health problems over the next ten years than the average Canadian in their age group. 69% of respondents also added that they were anxious at the substantial degeneration in their health associated with the effects of thalidomide. When questioned about their future in general terms, 66% reported that they feel either rather or very insecure.

CONCLUSION

The percentage of the general population in Canada affected by thalidomide is relatively small. Consequently, very little research has been devoted to considering the ongoing physical and psychological needs of thalidomide survivors and their families. This study demonstrates that the majority of respondents have been experiencing deterioration in their health due to the effects of thalidomide. It reveals that victims have had to use certain parts of their bodies more than the general population in order to compensate for one or more functional limitations. This is resulting in the premature onset of physical degeneration. Muscle pain and joint pain are now a part of the daily lives of nearly four out of five respondents. Nearly half reported the experience of numbness and a loss of sensitivity of some of their body parts. Deterioration in sight and hearing, migraines and headaches, as well as depression, are also worthy of note, especially since at least a quarter of the respondents identified every one of these health problems as being recurrent and persistent for them.

This degeneration, which is experienced by a large majority of respondents, affects their independence, their social lives, their ability to work and, their financial situation. Many respondents reported being concerned about needing to quit working before the usual retirement age. Respondents also expressed concern about their increased dependency on a close relative or on an external resource. This provides further insight into the negative emotional consequences associated with their prematurely deteriorating physical health.

Many thalidomiders need various treatments, services, assistive devices and specialized equipment. This report confirms that it is reasonable to predict that these needs will increase in years to come.

This study shows that a significant majority of respondents feel that their financial situation over the next ten years will be either precarious or very precarious. Furthermore, most respondent reported dissatisfaction with the compensation payments they received in the past. The pay-outs are not adequate to enable Canadian thalidomide victims to meet their specific needs. At the time when compensation payments were being provided, no one could predict the severity of the physical degeneration the survivors would be facing, nor could anyone predict the increases in the cost of living and services since the 70s.

This report is intended to lend a voice to the Canadian victims of thalidomide. It is our hope that the information herein will result in a call to duty and responsibility on the part of all authorities and organizations concerned in the thalidomide tragedy.

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WHY THIS STUDY NOW?

The full extent of thalidomide's teratogenic effects is still unknown even though it has been almost 50 years since the onset of this tragedy in the late 50s and early 60s. It is, therefore, challenging to obtain absolutely conclusive and accurate information with respect to thalidomide's effects on Canadian victims and these effects continue to unfold. Furthermore, there is no centralized medical data base in Canada that would provide an overall picture of this small population.

For the past twenty years, TVAC's consistent ongoing contacts with thalidomide victims provide valuable insight into their well-being. Many Canadian thalidomide victims have reported to TVAC that their degree of suffering and pain is more chronic and intense than it has been in previous years. Some victims have reported that in recent years, they are no longer able to accomplish certain activities which would seem routine for the average members of the population. The physical demand of such activities requires too great an effort on their part. Other victims have reported that the amount of compensation they received years ago has been exhausted for quite some time. Victims also report that until recently, they relied on assistance from their parents; however, their parents are now either aged with their own health conditions or deceased. These factors cause anxiety for many victims.

In light of the comments, concerns and requests for assistance addressed to TVAC over the latter years, TVAC felt it necessary to create a picture of what the members are currently experiencing in an attempt to assess the extent to which the worries expressed are shared by the group as a whole at this current point in time.

A LOOK BACK AT PREVIOUS STUDIES

Toward the end of the 90s, TVAC conducted a research entitled *"Thalidomide Survivors: a questionnaire survey on musculoskeletal abnormalities, general health status and quality of life"*. At that time, Canadian thalidomide survivors were already reporting that they were sensing degeneration in their joints and were afraid of experiencing greater mobility restrictions over time.

In Great Britain, a study presented in 2002 by the College of Health and the Thalidomide Society asked similar questions of Britain's survivors[2][3]. According to the survey, two-thirds of the respondents reported musculoskeletal deterioration, such as muscle pain, arthritis, joint pain or stiffness. Furthermore, 60% of respondents evaluated their degree of pain as moderate to severe. Finally, 73% of respondents reported that their health problems and disabilities were making it difficult for them to accomplish their daily tasks.

Among the Irish population, a study[3] entitled "46 Years after Thalidomide", reports that 65% of thalidomide victims who completed the questionnaire consider their thalidomide-related health conditions to have worsened. The deterioration developed mainly in injuries brought about by overusing their limbs [to compensate for one or more functional limitations]. Other conditions included foot, knee and back problems as well as hearing loss.

A LOOK AT THE HISTORICAL FACTS

It was in 1954[4] that the West Germany company, Chemie Grünenthal, synthesized thalidomide. The drug was marketed as of October 1st, 1957 in West Germany until December 1961. Thalidomide was made available under different names in at least 46 countries.

Since July of 1959, thalidomide was available in Canada in the form of sample tablets. On April 1st, 1961, it became an authorized prescription medication. Although the drug had been withdrawn from the West German, United Kingdom and Australian markets since December 2nd, 1961, it was still legally available in Canada up until March 2nd, 1962, three full months later. Despite the drug no longer being legally available in Canada in March of 1962, some Canadian victims of thalidomide were born as late as 1964. This is due to the fact that the drug's withdrawal from the market was neither immediate nor complete, throughout Canada.

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[2] Thalidomide-impaired People : Quality of Life. College of Health and the Thalidomide Society. 2002. London, United Kingdom.

[3] *Years after Thalidomide. Has the nature of the disabilities of those affected and their effect on their lives changed.* O'Carroll, Dr. Austin in association with the Irish Thalidomide Association.

[4] *SUFFER THE CHILDREN: The Story of Thalidomide by the Insight team of THE SUNDAY TIMES of London* -- THE VIKING PRESS, New York

The following outlines some further background information about Thalidomide:

- Thalidomide was described as a miracle drug that brought on deep, sound sleep. However, necessary testing was not appropriately done to confirm its innocuousness. It was eventually discovered that thalidomide molecules could cross the placental barrier and affect fetal development.
- Thalidomide was considered a sedative capable of combating many of the morning sickness symptoms experienced by pregnant women.
- Thalidomide later proved to cause disastrous teratogenic side effects. A percentage of the population who took thalidomide suffered from peripheral neuritis, a devastating and often irreversible side effect. Thalidomide use by pregnant women is also tragically known as the cause of death or disability in thousands of babies worldwide.
- Taken during pregnancy, more particularly during the first trimester, thalidomide affects the development of the fetus, causes severe congenital malformations and also death of the babies. Every part of the fetus undergoing development when the drug is ingested can be affected.
- The following are some of the congenital malformations found in surviving babies: deafness, blindness, disfigurement, malformations of internal organs and, abnormalities most often associated with thalidomide: phocomelia of the limbs (hands and feet attached to the trunk).

Given that no accurate census was taken during the tragedy itself, figures vary from one source to the next. However, it is claimed that between 10,000 and 20,000 babies have been born with thalidomide-caused disabilities. There are today about 5,000 surviving thalidomiders left in the world. A precise determination has never been made regarding the number of babies which were aborted or stillborn due to the effects of thalidomide. Furthermore, we may never know the vast number of family members and parents who suffered tremendously over the years because of thalidomide. They, too, are casualties of this tragedy.

Around the end of the 60s and during the 70s, thalidomide victims' parents from different countries engaged legal procedures against various pharmaceutical companies which manufactured and distributed the drug.

Scattered throughout a vast country, isolated, restricted by language barriers, and limited in financial resources, many families of Canada's victims had no choice but to deal with the pharmaceutical company involved on an individual, case by case basis. Although some families had the opportunity to be represented by the same lawyer, each settlement was concluded on an individual basis. Families who were suffering and in need of immediate assistance ended up accepting out-of-court settlements and consenting to mandatory gag provisions. As a consequence of this occurrence in Canada, widely unequal amounts were provided as compensation pay-outs. There were instances where individuals with the same degree of disability received vastly different settlements.

In 1987, the War Amps of Canada formed a thalidomide task force to try to secure compensation from the Canadian government for thalidomide victims born in Canada. Since the Canadian government had allowed the drug to be marketed at a time when numerous warnings about its side effects had already been issued and for several months after other countries took it off the shelves, it was concluded that the Canadian government also bore a moral responsibility to ensure that thalidomide victims were appropriately compensated. An important fact to mention at this point is that Richardson-Merrell, the American pharmaceutical company, was authorized by the Canadian government to market thalidomide (Kevadon) in Canada, although Richardson-Merrell did not obtain authorization to market the drug in its own country, since the American FDA was not fully satisfied that the data presented by the company proved that the drug was harmless.

In 1991, the National Health and Welfare Department (now Health Canada), through its Extraordinary Assistance Plan (EAP), granted small lump-sum sympathy payments to Canadian thalidomiders. These pay-outs were promptly used to cover some of the very high costs associated with severe disabilities and, for most of the victims, the amounts were soon exhausted.

METHODOLOGY

A questionnaire was sent out to 102 TVAC members on September 30, 2009. Of all the questionnaires mailed out, two were returned to TVAC due to the fact that those members no longer resided at those addresses. In spite of TVAC's investigations, it was not possible for TVAC to find the new address of these two members. The deadline for returning the completed questionnaire was set at January 29, 2010.
TVAC member participation was voluntary, unpaid and completely anonymous.

Nelligan O'Brien Payne LLP, a law firm based in Ottawa, Ontario collaborated with TVAC on various aspects of the questionnaire, including the collection of the completed questionnaires from respondents and the compilation of the data provided by each of the respondents who were identified by a number and general region of residence (Western Canada, Ontario, Quebec, Eastern Canada) to ensure their anonymity. Upon completion of this data compilation, Nelligan O'Brien Payne forwarded the results to TVAC.

A self-addressed, stamped return envelope was included with the questionnaire to make it easy for each member to send the completed questionnaire directly to the Nelligan O'Brien Payne LLP offices. The mailings also included a letter from the executive director outlining the context and objectives of the research in addition to a letter from the law firm explaining the data compilation process.

Of the 100 TVAC members who received the questionnaire, 65 completed and returned it, resulting in an overall response rate of 65%. The Canadian Western region's rate of response was 65%, Ontario's was 50%; Québec's was 73%; and the Canadian Eastern region, 50%.

Questions were divided into three separate categories:

- The questionnaire's first section, ***Identification and socio-demographic information***, was aimed at obtaining information regarding the member's region of birth and current region of residence, level of education, occupation, as well as the income level from their compensation payments received as thalidomide victims;

- the second section, ***Health status and independence in performing daily activities,*** was an attempt to create a general picture of TVAC members' health through posing questions particularly about their independence in accomplishing daily tasks, the degree of pain felt, the health problems they experienced and treatments received;

- the third and last section in the questionnaire, ***Needs and projections for the future***, asked respondents to speculate about their future and indicate how positively or negatively they viewed their future.

It should also be mentioned that some questions from the previous study TVAC conducted in the late 90s, entitled, *"Thalidomide Survivors: a questionnaire survey on musculoskeletal abnormalities, general health status and quality of life"* were reused in the present survey for comparison purposes ten years later. Some questions in the second section, *Health status and independence in performing daily activities,* were prompted by the *West Haven-Yale Multidimensional Pain Inventory*[5].

The study is not based on any in-depth medical tests but on self-assessments of what the Canadian thalidomide survivors themselves are experiencing with respect to their health, financial situation and perception of the future. The questions posed in the third section, *Needs and projections for the future*, can be considered subjective in nature, however, the information is important in helping to identify future needs and fears in the thalidomide survivor community.

SOCIO-DEMOGRAPHIC INFORMATION

Of the 65 respondents who participated in this study, 40 were women and 25 were men. Only one of the 65 respondents was born outside Canada but is now a Canadian citizen.

Among the respondents, 19% were born in Western Canada (British Columbia, Alberta, Saskatchewan and Manitoba); 20% in Ontario; 58% in Québec and 3% in Eastern

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[5] *The West Haven-Yale Multidimensional Pain Inventory*. Kerns, R.D., Turk, D.C. et Rudy, T.E. 1985. Pain 23, p.345-356.

Canada (Newfoundland and Labrador, Nova Scotia, Prince Edward Island and New Brunswick); none of the respondents reported being born in the Territories.

For some of the subjects that follow, we sometimes use the EAP categories (the Extraordinary Assistance Plan (EAP), created by the Canadian government in 1991 when the Canadian government was granting financial assistance to thalidomide victims born in Canada). Category 1 was for victims less severely affected and category 3 covered the ones with more severe effects. Among the respondents, 27% were classified as category 1, 8% in category 2 and 62% in category 3.

OCCUPATION AND FAMILY SITUATION

To create a general picture of Canadian thalidomide survivors, respondents were asked to answer socio-demographic questions on topics such as their marital status, education and members of the household.

We first asked TVAC members about the make-up of their households. Table 1.1 shows the distribution of the respondents, compared with data for the general Canadian population, as seen in Table 1.2. Although the population of respondents living in a couple relationship is similar to the Canadian population as a whole, **the proportion of thalidomide survivors living alone is significantly higher than among the general Canadian public.**

Table 1.1: Household structure among Canadian thalidomide victims

Household structure	N	%
Alone wo children	16	24,62%
Alone w child/children	7	10,77%
Couple wo children	11	16,92%
Couple w child/children	25	38,46%
With mother/father	5	7,69%
With friend	1	1,54%
Total	65	100,00%

Household structure	Canadian population*	Canadian victims

One person (with or without child)	26,8%	34,4%
Couple without child	26,1%	17.2%
Couple with child	31,4%	39,1%
Other	15,8%	9,4%

Table 1.2: Household structure – comparison between Canadian thalidomide victims and the general Canadian population ****According to Statistics Canada, 2006 census***

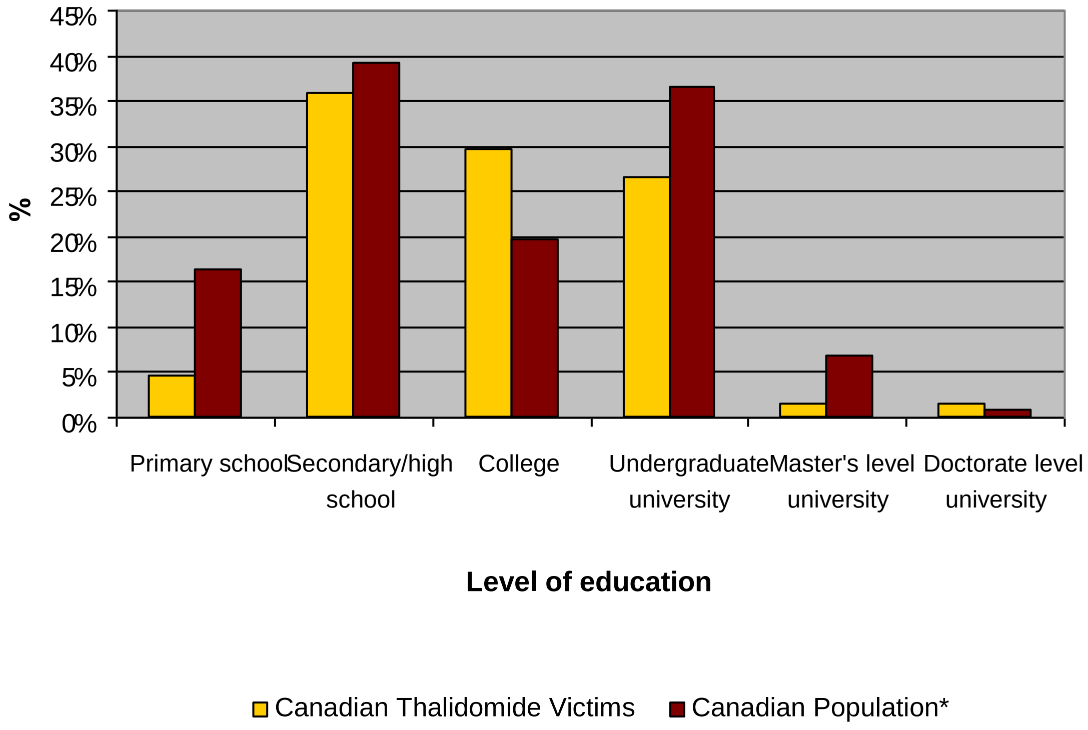
This issue is important to TVAC because, in its discussions with thalidomide victims, TVAC has learned that many of them fear for their autonomy and security if they were to end up alone and consequently, would suffer physically, emotionally and financially. The assistance of a partner, children or parents is crucial for many thalidomide victims, as the following statements, taken from respondents' comments, show:

> *" I am fortunate in that I have a wonderful husband who helps me out a lot, and is a great advocate of my health. He keeps me positive and on the right path to wellness. Because of him I am financially ok."*
>
> *" For now my husband is working but, if I were to lose him one day, I would be stuck in a tight corner and would have no other solution than welfare."*
>
> *" For the future, the level of my optimism is very shaky as my two children will have left home and my needs will increase with time."*
>
> *" I have no family that will look after me if I cannot look after myself nor will I be able to afford private care."*

The study's findings show that 28% of respondents live alone, with or without children, or with their parent(s) and belong to EAP category 3.

Next, we asked TVAC members about their last completed level of education. Results were compared with the Canadian public, aged between 45 and 54 years old (see graph 1): 60% of respondents have a post-secondary diploma compared to 64% for the rest of Canada. The thalidomide survivors' education level is thus slightly lower than the Canadian average.

Graph 1: Last completed level of education, comparison between Canadian thalidomide victims and the general Canadian population



**According to Statistics Canada, 2006 census*

In 2008, the percentage of Canadian adults between the ages of 45 and 64 who had a job was 71.3 %[6]. A reading of table 2.1 shows that among Canadian thalidomide survivors that percentage decreases to 64.1% (part-time, full-time or self-employed work). In 1999, 73.3% of respondents in the "Thalidomide Survivors: a questionnaire survey on musculoskeletal abnormalities, general health status and quality of life" had a job[7]. Looking more particularly at the primary occupation of the category 3 respondents (most severely affected by thalidomide

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[6] Human resources and the development of competency. Government of Canada. http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-fra.jsp?iid=13#M_6

[7] Thalidomide Survivors: a questionnaire survey on musculoskeletal abnormalities, general health status and quality of life.

according to the 1991 Canadian government classification system), we find a smaller proportion of respondents holding down a job, 57.1% (see table 2.2).

Table 2.1: Primary occupation of all respondents

Student	4	6,15%
Part-Time employee	6	9,23%
Full-Time employee	26	40,00%
Self-employed	9	13,85%
Homemaker	6	9,23%
Volunteer	2	3,08%
Job seeking	3	4,62%
Retired	2	3,08%
Other	5	7,69%
Did not answer	2	3,08%
Total	65	100,00%

Table 2.2: Primary occupation of category 3 respondents as per EAP

Student	2	5,41%
Part-Time employee	3	8,11%
Full-Time employee	11	29,73%
Self-employed	6	16,22%
Homemaker	4	10,81%
Volunteer	1	2,70%
Job seeking	0	0,00%
Retired	2	5,41%
Other	7	18,92%
Did not answer	1	2,70%
Total	37	100,00%

The employment rate among thalidomide survivors is lower than the rest of the Canadian population of the same age. Among (EAP) category 3 Canadian survivors, the difference is even more marked. It can be reasonably concluded that Canadian thalidomide survivors have encountered more employment barriers than the general population, especially in light of the fact that the difference between the employment rates (Canadian population vs. respondents) significantly exceeds the small difference in post-secondary education levels.

TVAC's investigations have revealed that for some victims full time work is out of reach due to their functional limitation(s). Some of these victims instead settle for part time jobs. **Being able to remain employed has become a major issue for many respondents who are troubled by pain. They are in fear of not being able to work until retirement age.**

The respondents had to answer the following question: "To what extent do your pain and your treatments affect your work or your ability to hold down a job?" This was on a scale from 1 to 7, where 1 meant that the pain and treatments had little impact and 7 indicated a great impact. For 26% of respondents, the pain and treatments had a very great impact (7 on the scale) whereas only 11% would have chosen this level 5 years ago. Furthermore, 31% state that they are afraid of having to quit their job prematurely and permanently because of their thalidomide related deteriorating health situation; 17% say they are no longer able to hold down a job as a result of their thalidomide-related health problems. 58% of respondents reported that their employment income is essential to meeting their special needs as thalidomide victims. Consequently, the compensation Canadian thalidomide victims received is inadequate to cover their particular needs. Some respondent comments give a clearer insight into the job-related issues that thalidomide survivors face:

> ***" I find it more difficult to manipulate the tools and material necessary to my work; I need help more often."***
>
> ***" If I go back approximately 5 years ago, I had suicidal thoughts and had no stable and fulfilling work. The fear of not having enough money and losing my autonomy can make me very anxious."***
>
> ***" I have had to change jobs at work because of this change [shoulder surgery]. At the rate I am going I will not be able to work within a short amount of time."***
> ***" The nature of my condition limited my career options at first so self-employed seemed logical but I have no pension."***
>
> ***" Can only work part-time hours as a result of my disability. Part-time employees are not allowed to contribute to pension and therefore, despite working for 21 years, I have no pension. I find this very scary for the future."***

"I will need to retire earlier than 65."

COMPENSATION RECEIVED BY CANADIAN THALIDOMIDE VICTIMS

During the 70s and 80s, some Canadian families initiated approaches to RichardsonMerrell, the pharmaceutical company responsible for thalidomide distribution in Canada, and individual agreements were reached. We asked respondents whether they had received compensation (directly or through a third party) from the pharmaceutical company. Among the 64 Canadian-born respondents, 55 of them said that they had received compensation from Richardson-Merrell, while 5 claim never to have received anything, while 4 were unsure or did not answer the question.

In 1991, the National Health and Welfare Department (now Health Canada), through its Extraordinary Assistance Plan (EAP), granted small lump-sum sympathy payments to Canadian thalidomiders following efforts made by the War Amps of Canada and their thalidomide task force. Of the Canadian-born respondents, 60 state that they received this financial aid while 2 say they received nothing under the EAP; 2 people said that this was not applicable to their case or refused to answer.

At the time the EAP money was being doled out, the Canadian government had divided the Canadian thalidomide victims into 3 categories according to the extent of their congenital malformations. Category 1 covered victims less severely affected and category 3 was for the ones with more severe effects. Table 3 shows the distribution of respondents according to the EAP category and region of birth. Among the respondents who received financial assistance from the EAP, **the majority, 60%, were placed in category 3 by the Canadian government in 1991.**

Table 3: Canadian government EAP categories according to region of birth

Region of birth	Cat. 1	Cat. 2	Cat. 3	Do not know	No answer	Do not apply	**Total**
West	2	1	9	0	0	0	**12**
Ontario	3	0	9	0	1	0	**13**
Québec	11	4	17	1	2	2	**37**
East	0	0	2	0	0	0	**2**
Other country	0	0	0	0	0	1	**1**
	16	**5**	**37**	**1**	**3**	**3**	**65**

In order to assess how these compensation amounts play into the current financial situation of Canadian thalidomide victims, the following question was put to them: “Excluding all other sources of income and to the best of your knowledge, what is your net annual personal income (after deductions, where applicable) deriving solely from the compensation payments you received as a thalidomide victim?”

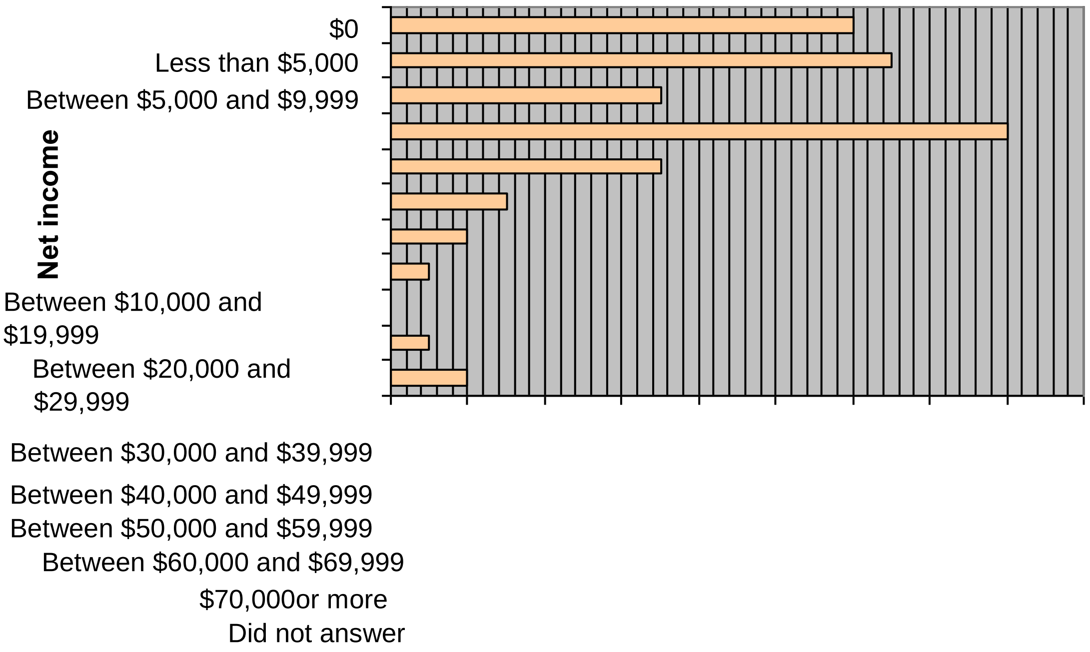
- **12 of the 64 Canadian-born respondents, 19% of the total, no longer receive any compensation today** as thalidomide victims.

- **More than 50% of respondents receive less than $10,000 per year.**

- **75% receive under $20,000 per year**, from total compensation payments received.

- Using the median figure in each of the income categories for calculation purposes, **the mean net compensation income is currently around $13,790 per year.** However the median figure is lower, between $5,000 and $9,999 per year.

Graph 2.1: Annual income from compensation payments of Canadian thalidomide victims born in Canada



0 2 4 6 8 10 12 14 16 18

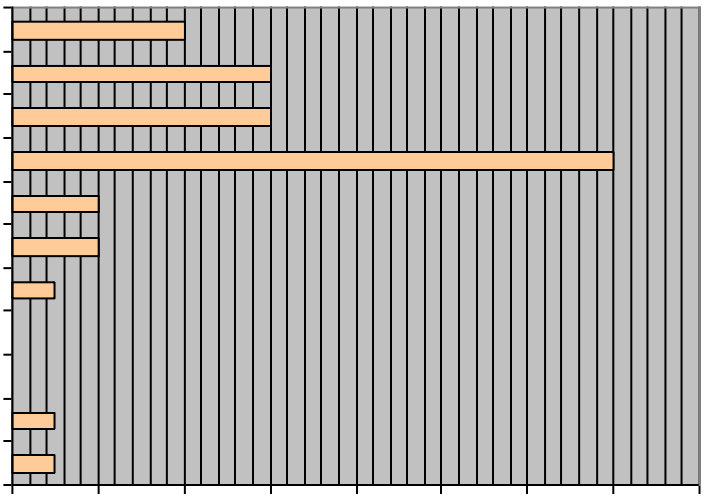
Number of respondents

It is also appropriate to look at the findings for this question among **category 3** (EAP ratings) respondents, that is, among respondents living with the severest malformations. Among this category of individuals:

- **11% no longer receive any compensation monies;**
- **44% receive less than $10,000 per year;**
- **81% receive less than $20,000 per year.**

Graph 2.2: Annual compensation income

0 **for respondents in EAP category 3**



The questionnaire also asked TVAC members to evaluate their current financial security on a scale from 1 to 7, where 1 indicated a very poor financial picture and

7 was very good. For **69% of the Canadian-born respondents, their current financial situation was between "very poor" and "average" (choices 1 to 4).**

Table 4: Current financial situation

Current financial situation	N	%
1 -	10	15,63%
2	8	12,50%
3	9	14,06%
4	17	26,56%
5	7	10,94%
6	8	12,50%
7 +	5	7,81%
Did not answer	0	0,00%
Total	64	100,00%

The Honourable J.W. Monteith, Health and Welfare (now Health Canada) minister, said in 1963 at the time that **"It is our job to ensure that these [thalidomide] victims are cared for in the best possible manner, that their needs are met to the fullest extent we can devise…"** This statement readily suggests serious doubts as to the ability of Canadian thalidomide survivors to meet their numerous unique needs through the compensation payments they received.

In response to the question, **"Do you consider the income from all the compensation funds you received as a thalidomide victim to be sufficient to ensure the financial security required to provide for your long-term needs?" 94% of Canada-born respondents answered "no".**

The following is what some members added in connection with this issue:

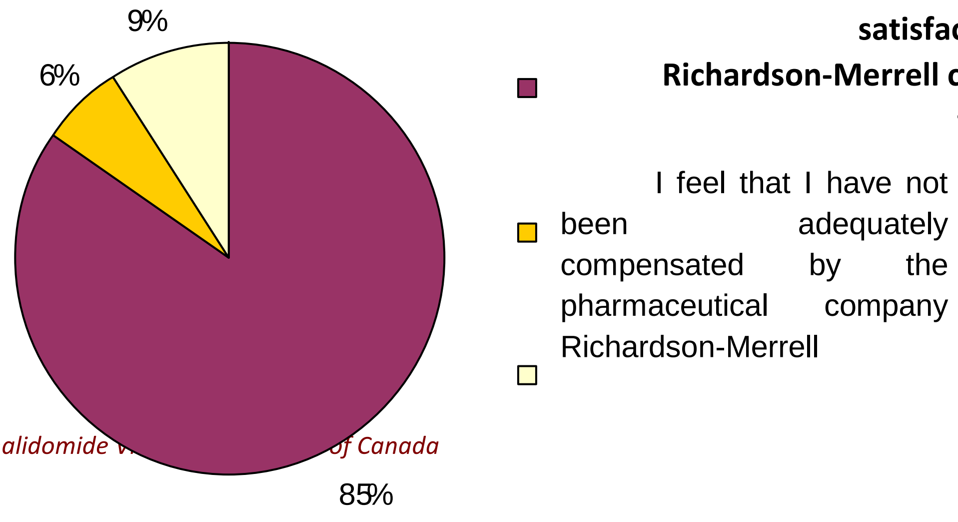
> ***" Not in any way, shape or form. For myself it is all about the unknown, which is very scary."***
>
> ***" Amount barely meets minimum needs. Have to rely on government assistance."***
>
> ***" I always had financial difficulties and my revenue has not been sufficient for a few years and I am able to survive thanks to my spouse's revenue."***

> *" This compensation did not take into account the degeneration of our muscles and bones, or the overuse of our limbs. I must continue to work hard, many hours per week, and my body is exhausted."*
>
> *" The money that I received was never used for me. My parents squandered my money, followed by a lawsuit against them, 2 years."*

More specifically, we asked TVAC members whether **the compensation received from Richardson-Merrell, the pharmaceutical company**, was adequate to meet their essential needs, now and in ten years' time. Some members receive a life annuity; others have income from investing the compensation amounts, administered or not by a trust, a few individuals receive both types of income.

- For **20% of respondents, there is nothing left** of the amount received at the time.
- Regardless of the type of income that came in, **the amount received is now inadequate** to meet essential needs for a majority of Canadian survivors, more specifically **for 54% of the respondents**.
- When the respondents look to the future, **73% believe that the amount will be inadequate in ten years' time.**
- Only 6% of the respondents feel that they have been adequately compensated by Richardson-Merrell, the pharmaceutical company. **85% say they are dissatisfied.**

Graph 3: Respondents' level of satisfaction with the Richardson-Merrell compensation they received



I feel that I have been adequately compensated by the pharmaceutical company Richardson-Merrell Did not answer

Some respondents wished to add comments on the compensation provided by the pharmaceutical company:

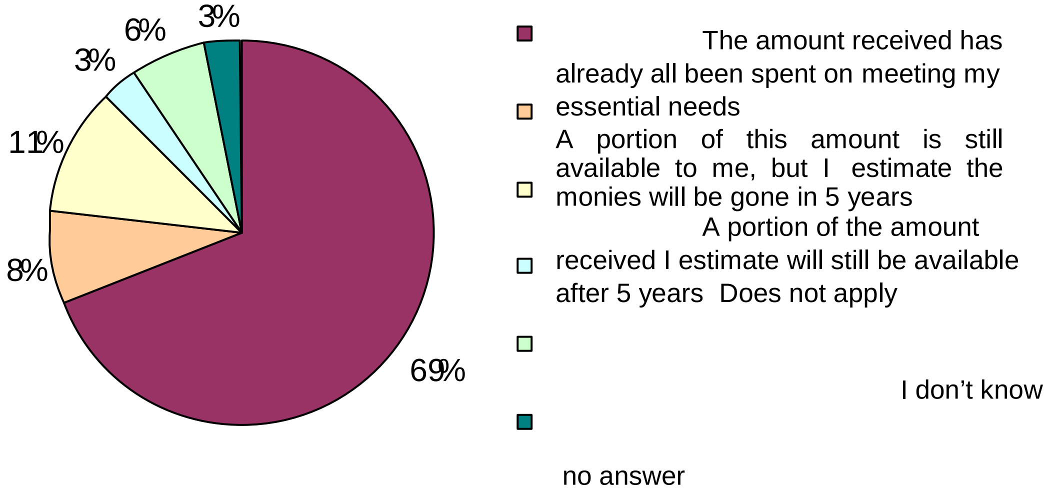
> ***"The amount that was given to me by the Richardson & Merrell pharmaceutical company in 1975 was $10,000.00 [Ten Thousand]. No no, I did not forget a 0, and the decimal point is in the right place."***
>
> ***"The sums of money that I received as compensation in the 70's were wrongly assessed. Let me explain… not believing that we, the Thalidomide victims, would aspire to a normal life, to having kids and to an active life."***
>
> ***"The compensation I personally received could not possibly take into account that (about) 40 years later my body is not of a normal 40 year old but that of someone 20 – 25 years older and that not only could $300.00 per month not be able to sustain my life as a "normal" person – this pittance can't even buy groceries or half of the prescriptions I need or (and I can keep going here) possibly have me retire on it. I will need to do that at the rate I am going sooner than a normal person would with the deterioration that I am experiencing."***

Next, we asked respondents to answer the following question: "**If you received financial assistance under the Canadian government's Extraordinary Assistance Plan (EAP) in 1991, what statement best describes your situation?**" The responses reveal the following:

- **For over two-thirds of the respondents, this money has already ran out, and in 5 years' time, it is expected that 77% of respondents will run out of this money.**

- **The financial assistance the Canadian government provided in 1991 is considered inadequate for 86% of respondents** born in Canada.

Graph 4: Respondents' situation as regards the Canadian government (EAP) financial assistance



Members are deeply concerned about the fact that in their view the Canadian government has never wanted to acknowledge its responsibility.

> *"I felt wronged because the government never recognised its fault, overall it means that I should have received a lot more from the government and the company with all the damage that it [thalidomide] caused me."*
>
> *"It is appalling that the Canadian government has always refused to admit its responsibility in this historic tragedy, that it forced us to sign a waiver in 1991 to be eligible for peanuts, $80,000 for life, and that it refuses to secure the future of the Canadian Thalidomide survivors."*
>
> *"What I need is a monthly income that will cover basic living costs, as they provide thalidomiders in other countries."*

"I felt and still maintain the feeling that the victims of Canada were short-changed at the expense of publicity and political gain."

HEALTH STATUS AND LEVEL OF INDEPENDENCE

The data regarding this section "Health Status and Level of Independence" were analyzed by Neil Rehill, under the supervision of Doctor Steven Edworthy, from the University of Calgary.

The effects of thalidomide as a teratogen are, today, well documented both empirically in animal models as well as the cases of thousands of human victims globally born to mothers who used thalidomide as a sedative for morning sickness without knowing its consequences.[8][9] Thalidomide's effect on limb and organ dysgenesis is contributed to several mechanisms, including the inhibition of blood vessel development in embryonic limbs, induction of cell death and neurotoxicity[9].

The purpose of Part II of this questionnaire was to catalogue information about the health status and the level of independence of Canadians who have been living with congenital defects as consequence of thalidomide teratogenicity (thalidomiders). This was a follow up to the 1999 quality of life survey conducted by TVAC. However, this survey is broader in scope and the respondents are ten years older. It was anticipated that the gradual loss of function that comes with old age would occur earlier in this population due to the Thalidomiders' musculoskeletal impairments and organ defects.

SPECIFIC METHODS

A comprehensive questionnaire was created to assess the functioning, disability and health of our population. Although this survey is unique, it borrows heavily from

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[8] CBC Archives- Thalidomide <http://archives.cbc.ca/health/public_health/topics/88/>. Accessed on August 8, 2010 9 Vargesson, Neil. (2009) Thalidomide-induced limb defects: resolving a 50-year-old puzzle. BioEssays

[9] :1327–1336

other valid and reliable surveys such as the World Health Organization's ICF[10], Late Life Function and Disability Instrument (LLFDI)[11][12], and Illness Intrusiveness Ratings Scale (IIRS)[13]. While the self-reported nature of surveys do have drawbacks, Haley et al., report such surveys still to be reliable. The survey was divided into the following sections:

- Height and Weight
- Types of Structural Defect
- Independence

  Independence is based the ADL (activities of daily living) and IADLS (instrumental activities of daily living). ADLs include self care elements of feeding, toileting, dressing, personal grooming, and bathing. IADLs include domestic care items such as food preparation, housework, laundry and transport. These elements assess the functional status of an individual. Respondents were asked to evaluate their current status and retrospectively from 5 years ago.
- Effect of Pain and the Accompanying Treatment

  ADL and IADL elements were assessed with respect to pain as well as the intrusion of pain and treatments into the domains of the IIRS, such as, health, diet, work, recreation, financial situation, relationship with partner and family and community involvements. Respondents were asked to evaluate their current status and retrospectively from 5 years ago.
- Types of Equipment and Aids utilized
- Medical Treatments, Hospitalizations and Comorbidities
- Overall Health

A modified Lickert measurement scale was used to quantify independence and pain. Specifics on the scaling system are described in the "Results" section. To qualify the difference in pain and independence between now and five years ago as significant,

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[10] WHO ICF database: <http://apps.who.int/classifications/icfbrowser/>. Accessed on Sept 2, 2010

[11] Haley, Stephen M. Jette, Alan M. Coster, Wendy J. Kooyoomjian, Jill T. Levenson, Suzette. Heeren, Tim. Ashba, Jacqueline (2002) Late Life Function and Disability Instrument: II. Development and evaluation of the function component. Journals of Gerontology Series A-Biological Sciences & Medical Sciences.

[12] (4):M217-22

[13] Devins GM. (2010) Using the illness intrusiveness ratings scale to understand health-related quality of life in chronic disease. Journal of Psychosomatic Research. 68(6):591-602

a p value of <0.05 (obtained with paired t-tests) was used since this limit is used in conventional scientific studies.

SELF-REPORTED THALIDOMIDE DEFECT(S) DIAGNOSED AS A CHILD

The following table recounts the self-reported thalidomide defect(s), diagnosed as a child. Among the respondents, 7 reported being affected by phocomelia of all 4 members.

Table 5: Thalidomide defect(s), diagnosed as a child

Defect	Left	Right		Defect	
Missing Upper Limb	6	6		Facial Paralysis	6
Shortened Upper Limb	38	32		Flattened Nose	10
Malformed Shoulder	25	24		Cleft lip and/or palate	0
Malformed Hand	43	37		Scoliosis or spinal cord abnormality	21
Missing/ extra finger (s)	35	32		Heart abnormality	3
Missing lower limb	3	5		Lung abnormality	5
Shortened lower limb	15	11		Esophageal/stomach abnormality	2

Malformed knee	8	9	Missing/abnormal kidney(s)	4
Malformed foot	11	13	Liver abnormality	1
Missing/extra toe(s)	9	9	Missing appendix	0
Malformed hip	13	14	Bladder abnormality	3
Malformed inner/outer ear	16	16	Intestinal abnormality	5
Total deafness	3	4	Anal and/or genital system malformation	4
Partial Deafness	11	12	Mental health problems	3
Total Blindness	0	0	Nervous system damage/abnormality	5
Partial Blindness	4	4	Others*	9
Strabismus	3	3		

(* includes sole cases of a missing spleen, growth on neck, smaller floating ribs, one femur shorter than the other, right leg with circulation deficiency, false breast under arm, left and right radial arteries absent, an absent cranial nerve, missing tongue.)

Since 1991 (the year the Canadian Government implemented the EAP), the discovery of additional thalidomide related defect(s) was reported by 34% of the respondents. Musculoskeletal problems were the most common discovery but several cases of missing or abnormal internal organs were reported as well.

HEIGHT

The mean height of the thirty eight females who responded to this question is 147 cm (95% CI- 139 to 155). This figure height is lower than the self-reported average height of 45-64 age group cohort of other Canadian females, which is of 162 cm.[14] The other Canadian males in the same age group self-reported a mean height of 175 cm, whereas the self-reported mean height of twenty five male Thalidomiders is 163 cm (95% CI- 154 to 171). Even if we negate the influence of the extreme values in height on the average by calculating the median average, we find that the height of female and male Thalidomiders is 155 cm and 170 cm, respectively. This evidence shows that the victims of thalidomide are several centimeters shorter than the average Canadian population.

INDEPENDENCE

Participants were given forty-one tasks, in line with ADLs and IADLs, for which they were asked to evaluate their level of independence. They were asked to select one of six descriptions for each task as follows, from most independent to least (score in parenthesis): alone, without difficulty (1); alone, but with difficulty (2); with technical assistance (3); with human assistance (4); performed by another person (5). There was also the option of “does not apply”. The activities that were ranked as the most difficult to do by oneself were: maintaining the exterior of home (i.e., lawn-mowing, snow removal), maintaining the home (i.e., laundry, housecleaning), taking objects from a high kitchen cupboard, taking an object placed in the back of a pantry, and preparing meals, with mean scores of 3.5, 2.9, 2.7, 2.6 and 2.2, respectively (see table 6). A statistically significant difference was noted between the mean scores of how the participants viewed their independence now (1.8; 95% CI - 1.6 to 2.0) intervals in comparison to five years ago (1.6; 95% CI - 1.4 to 1.7). Among the specific tasks, maintaining the home showed the greatest deterioration as 30% of

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[14] Connor Gorber, S., Tremblay, M., Moher, D., and Gorber, B. (2007). A Comparison of Direct vs. Self-Reported Measures for Assessing Height, Weight and Body Mass Index: A Systematic Review, Obesity Reviews, 8(4), 307-326.

participants rated this task as having become more difficult now than it was five years ago.

Table 6 : Most difficult tasks to do by oneself

Tasks	Average
Maintaining the exterior of home	3.5
Maintaining the interior of home	2.9
Taking objects from a high kitchen cupboard	2,7
Taking an object placed in the back of a pantry	2,6
Preparing meals	2,2

Certain essential markers of independence such as meal preparation, showering, and dressing demonstrate some serious areas of concerns:

- **26% require partial or full assistance of another person in preparing meals;**
  - **14% require the same for showering.**

The basic physical risks which stem from improper diet and inadequate hygiene are well known, but the social isolation that results from loss of independence must also be considered. The inability to dress and to properly care for oneself without assistance results in increased confinement to the home.

- **Almost one-quarter (22%) of the respondents cannot do their hair by themselves;**
- **46% of respondents feel that they have lost some abilities and are now less independent;**
- **45% of respondents say they depend on a family member, a spouse, a child or a close friend** to meet their particular needs as thalidomide victims;
- **26% depend on one or more external resources** to meet their particular thalidomide related needs.

In conclusion, respondents are slowly losing their independence in self-care but this loss is particularly accelerated in activities pertaining to domestic care.

PAIN

People who are living and aging with nervous system and degenerative muscle diseases often experience pain and fatigue due to their physical impairment that deteriorates over time, resulting in greater disability and diminished quality of life.[15] Respondents were asked to quantify their general level of pain over the last week on a scale of 1 to 7, where 1 is no pain and 7 is intense pain. 63 participants responded and with a mean score of 4.0 (95% CI - 3.6 to 4.4). 13 (20%) respondents rated their degree of pain at high end of six and seven.

Secondly, respondents were asked to rate the level of pain associated with some common tasks involving different muscle groups and different levels of manual dexterity. They were asked to select one of four descriptions for each task, as follows (score in parenthesis): never (1); sometimes (2); most of the time (3); and always (4). Standing for an extended period of time (2.7) and carrying objects (2.2) were reported to be most painful. A statistically significant increase was noted between the mean scores of pain experienced now (2.0; 95% CI - 1.8 to 2.2) in comparison to five years ago (1.6; 95% CI - 1.4 to 1.7). Among specific tasks, standing for an extended period of time showed the most marked exacerbation as 55% of participants rated this task to have become more painful now than five years ago. In particular, 26% of respondents feel pain most or all the time while dressing. Only 8% reported feeling pain when dressing felt the same five years ago.

Lastly, the respondents rated the intrusion of pain and treatments on the physical, social, financial, and emotional aspects of their lives. Respondents were asked to score the different life domains on a scale of 1 to 7, where 1 indicates not much impact of pain and treatments and 7 is a great deal of impact. Financial situation (4.4), general health (4.4), and ability to work (4.3), were the three elements that were rated as having been most impacted by pain and treatments. A statistically significant difference was noted between the mean scores impact now (3.8; 95% CI - 3.3 to 4.2) in comparison to five years ago (2.7; 95% CI - 2.3 to 3.1). More specifically, the data shows that the respondents scored the effect of pain and treatments on their "general health" to worsen most over the five years as the average score increased from 2.8 to 4.4.

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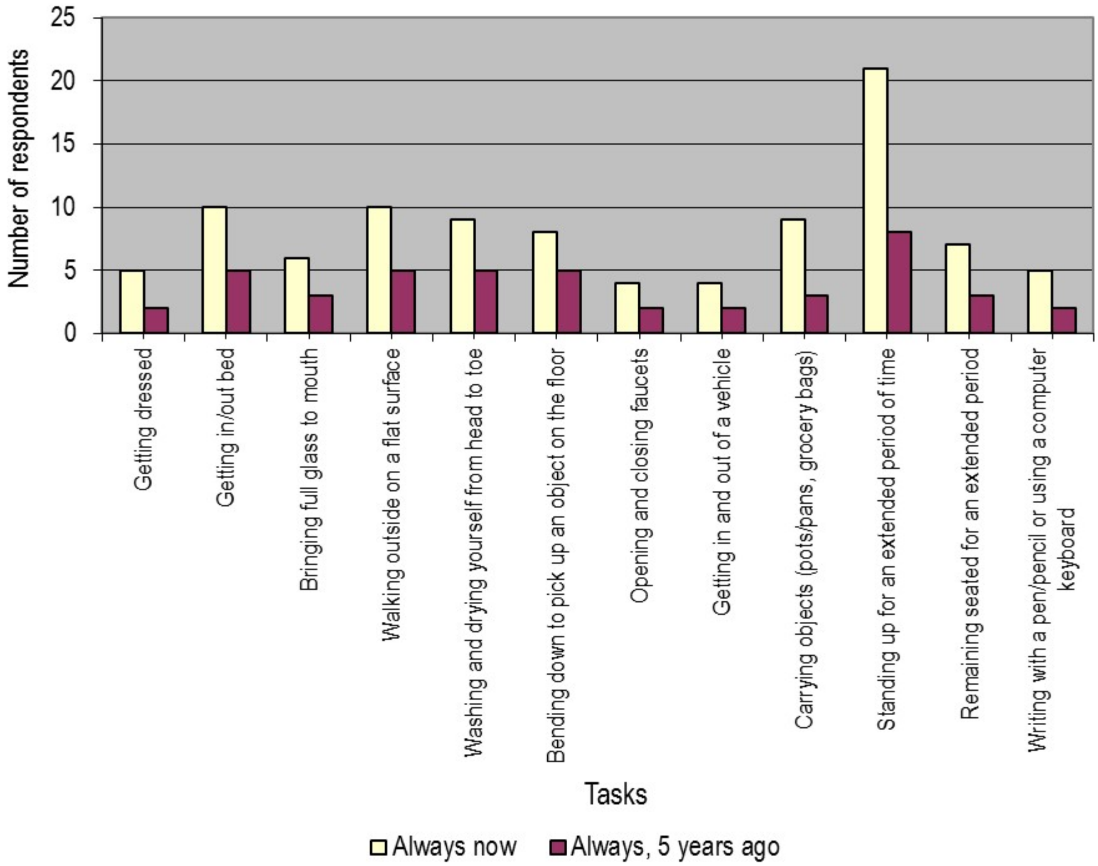
[15] Widerstrom-Noga E. Finlayson ML. (2010) Aging with a disability: physical impairment, pain, and fatigue. Physical Medicine & Rehabilitation Clinics of North America. 21(2):321-37

Graph 5: Pain associated with everyday tasks (always)



Clearly the respondents are living with pain, some evidently more affected than others. Tasks involving standing for extended periods of time and carrying objects are particularly excruciating. Enduring pain and undergoing the treatments to try to manage and decrease such pain has become commonplace in the lives of the participants. This causes a profound effect on their physical and emotional health as well as their ability to earn an income, which ultimately affects their financial situation. Unfortunately, the pain is a greater burden on the respondents now compared to five years ago.

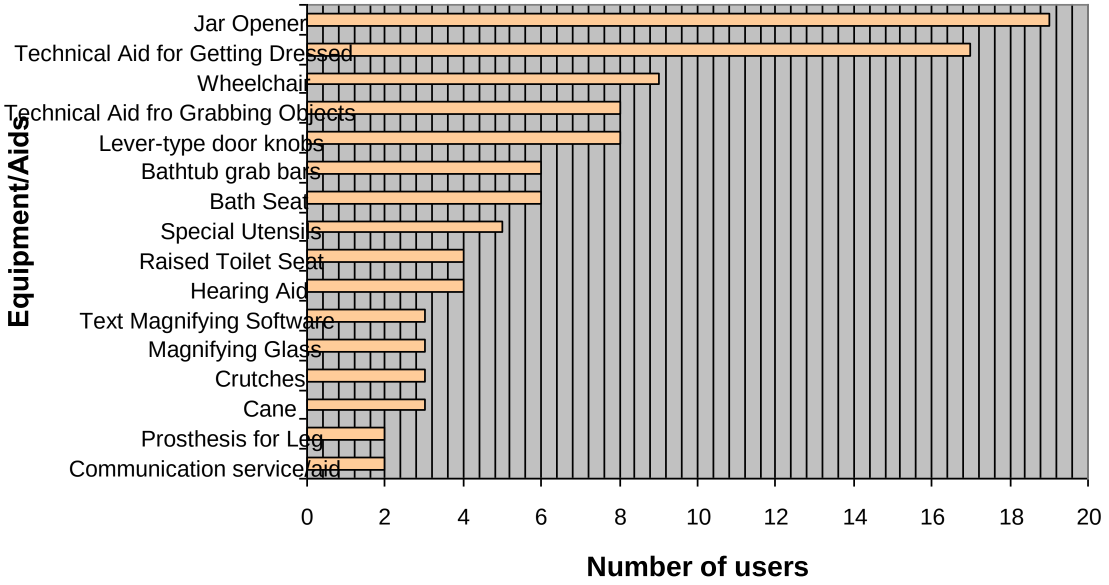
Some members added comments in regard to the pain experienced, here are a few:

> ***"With the cold weather starting my hands, elbows, shoulders and hips ache a lot. I am very concerned about the right hand as it is my better one. It is becoming quite painful."***
>
> ***"My back always hurts; I wake up and go to sleep with a backache. Everything I do gives me a backache. This is exhausting me. I also have pain in my right hip and in the neck (repetitive torticollis)."***
>
> ***"Pain in my right shoulder and right arm caused by the overuse of that side of my body."***
>
> ***"Increased back pain and loss of energy. More recurrent fatigue, loss of capacity in the right arm, epicondylitis, tendinitis and numbness."***

USE OF EQUIPMENT AND AIDS

Respondents reported the regular use of equipment and aids to facilitate and assist in a range of activities from dexterous work such as opening jars to basic mobility with the help of wheelchairs. The bar graph below portrays the use of different aids:

Graph 6: Equipment and aids used by respondents



Other equipment has been mentioned by the respondents in the "Other" category:

Toileting device (2), glasses (3), bidet (2), modifications on car (2), elevator (1), heelpiece (1), cushion for car seat (1), tricycle (1), adapted shower (1), walking boots (1), chin strap (1), bench (1), leg brace (1), pushable faucets (1), indicator lights (1).

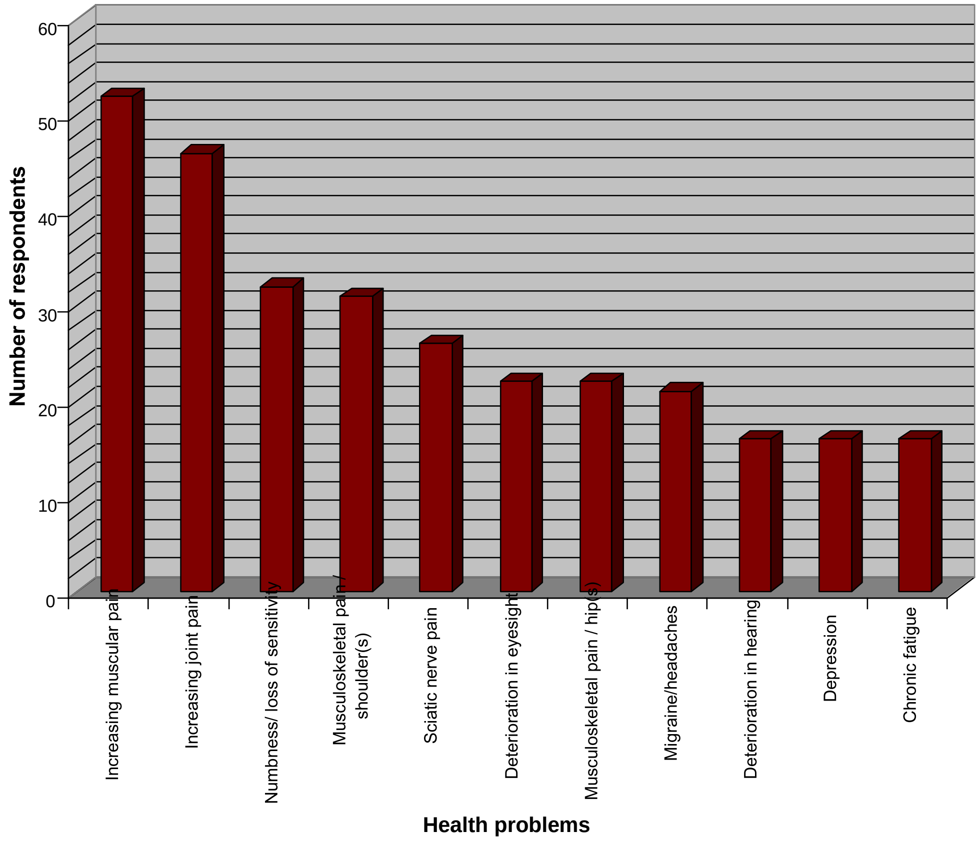
MEDICAL TREATMENTS, HOSPITALIZATIONS AND COMORBIDITIES

22% of respondents received treatments from a physiotherapist and their number of visits averaged eleven per year. 8% visited a physiotherapist at least thirty times during the last year. 18% sought treatment from an ophthalmologist and another 18% from a chiropractor. An ear-nose-throat specialist was consulted by 17% of respondents. 14% were treated by a massage therapist. Various other treatments were sought by individual respondents.

Roughly one third (21/65) of the respondents had been hospitalized in the last five years and their hospital stays ranged from one to twenty-five days. Non-opioid painkillers and anti-inflammatories were regularly used by over 65% of the respondents. 77% of the respondents report having a persistent health problem:

- **80% have noticed an increase in muscular pain;**
- **71% noticed an increase in joint pain;**
- **49% said that they experience numbness and loss of sensitivity.**

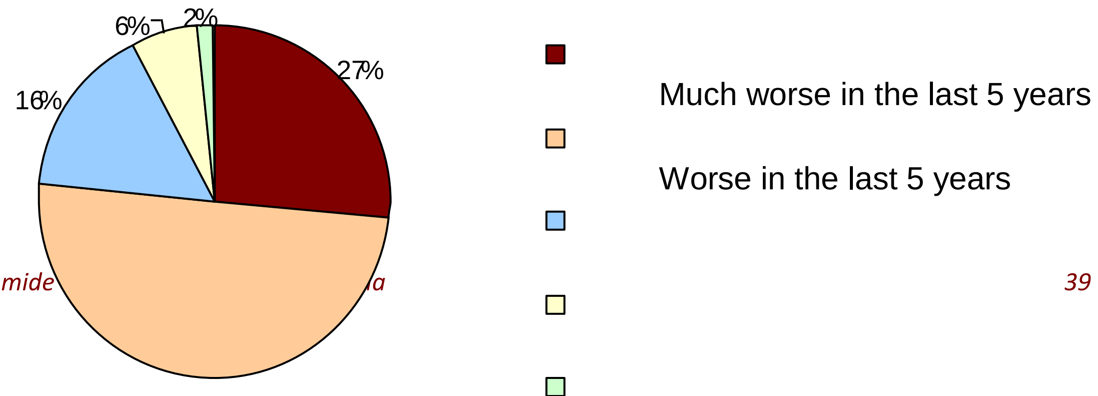
Graph 7: Respondents' recurrent or persistent health problems



GENERAL HEALTH STATUS AND WELL BEING

The respondents were asked to compare their current overall health and well-being to what it was five years ago. Graph 8 clearly shows that **76% of the respondents saw their overall health and well-being worsen in the past 5 years**:

Graph 8: Self-assessment of health status and well-being compared to 5 years ago



Same as 5 years ago

Better than 5 years ago

49%Much better than 5 years ago

The common concerns regarding the respondents' current health status are decreasing mobility, worsening pain and stiffness, a greater reliance on equipment and aids, and a general difficulty carrying out routine tasks. Some respondents also stated that they noticed their bodies were deteriorating faster than those around them who were not affected by Thalidomide.

The following explains how some respondents summarized the evolution of their health status trough the last five years:

> ***"I have pain in my neck and upper shoulders because of years of over compensating for shorter limbs. I am always hunched over!!"***
>
> ***"Increasing lack of mobility, hearing, weight gain related to immobility, joint deterioration, muscular and skeletal wear and pain."***
>
> ***"Because of my physical damages caused by Thalidomide since my birth I have had to make extreme efforts to extend my backbone, resulting in vertebrae displacements and compressions. After 47 years of efforts, my musculoskeletal health has quickly degenerated, especially over the last 10 years. I also have permanent pain in my fingers, hands, shoulders and***

> ***nape, which has contributed to my loss of autonomy over the past 10 years."***

The general well-being, particularly the musculoskeletal health of the Thalidomiders, is deteriorating with age. In all likelihood the current trend in diminishing health and function will continue and these individuals will need greater access to equipment, doctors, community and clinical nurses, physical and occupational therapists, and pharmacists. Thalidomiders in Canada are or within a year of turning fifty. Average fifty year-olds should not feel that their independence is diminishing and live with musculoskeletal and neuropathic pain that is restricting their ability to self-care and furthermore place a heavy burden on the physical, social, financial and emotional domains of their lives.

NEEDS AND PROJECTIONS FOR THE FUTURE

Although no one can predict what the future holds with any accuracy, TVAC felt it appropriate to question Canadian thalidomide victims about their views on their future. TVAC also wished to find out to what extent respondents had access to treatments and services that could improve their quality of life, degree of independence and general well-being.

TREATMENTS AND SERVICES NECESSARY FOR AN ENHANCED QUALITY OF LIFE

A universal publically funded health-care system, such as Canada's, provides all Canadians with health-care services, regardless of their financial situation. However, some treatments are not always available or covered and this is confirmed by a large proportion of respondents.

In fact, 46% of respondents report either insufficient or no access to certain treatments that would improve their physical and/or psychological health. The main treatments desired but not always covered are physiotherapy, massage therapy, psychological counseling, and dental and eye care. Among respondents with one or more deformations of the upper limbs, it is easily conceivable that the dental and eye care needs are at least partially due to use of the teeth to grasp and hold objects and to reading documents often very close to the eyes. The need for physiotherapy and massage therapy is not surprising if we accept members' responses when asked about their recurring health problems. **80% of respondents reported an increase in muscle pain and 71% indicated an increase in joint pain (see details on page 37).** Almost all respondents indicated that **the cost of these treatments was the main obstacle** to them availing themselves of these services more often, if at all. A lack of accessible transportation was also cited on many occasions as a challenge to accessing these services.

Among the comments the respondents added are:

> ***"Massage therapy to alleviate stress due to repetitive movements and overuse of my left arm. – Not covered by our health care system and I must assume the cost personally when my budget allows me to."***
>
> ***"Psychologist – not enough money to go. The CLSC no longer takes emergencies."***

Concerning services that could support respondents' independence and enhance their quality of life, 45% indicated that they felt a need for them. Among the services the respondents do not have any access or adequate access to, we could mention transportation, help with household chores and personal assistance. Once again, the cost of these services represents the most significant barrier to access**.**

Some respondents reported:

"Home support from the CLSC – not enough hours, service not customised to my needs."

"Household chores, paratransit, meal preparation, personal assistance – not enough hours, services or availability."

HOW DO CANADIAN THALIDOMIDERS ENVISION THEIR FUTURE?

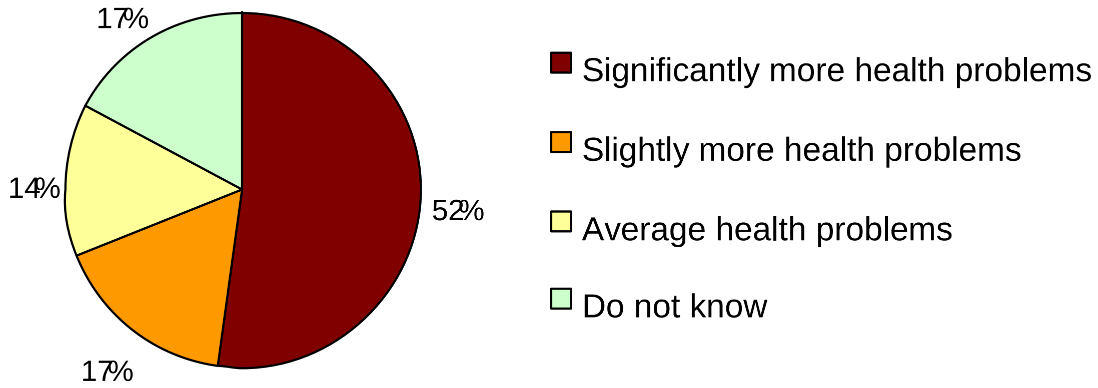
The respondents were asked to evaluate their degree of optimism about their personal future on a scale from 1 to 7, where 1 meant that, when considering their physical and emotional condition and financial situation, they viewed the future in a very negative light and 7, a very positive one.

A reading of graph 9 shows that 49% of respondents envision their future rather pessimistically (choices 1 to 3), whereas 32% saw their future fairly optimistically (choices 5 to 7). The average, 3.4, revealed that Canadian thalidomiders have quite a negative vision of their future.

Graph 9: Respondents' degree of optimism about the future

As to their health, **52% of respondents anticipate experiencing significantly more health problems than the average person of their age over the next 10 years.**

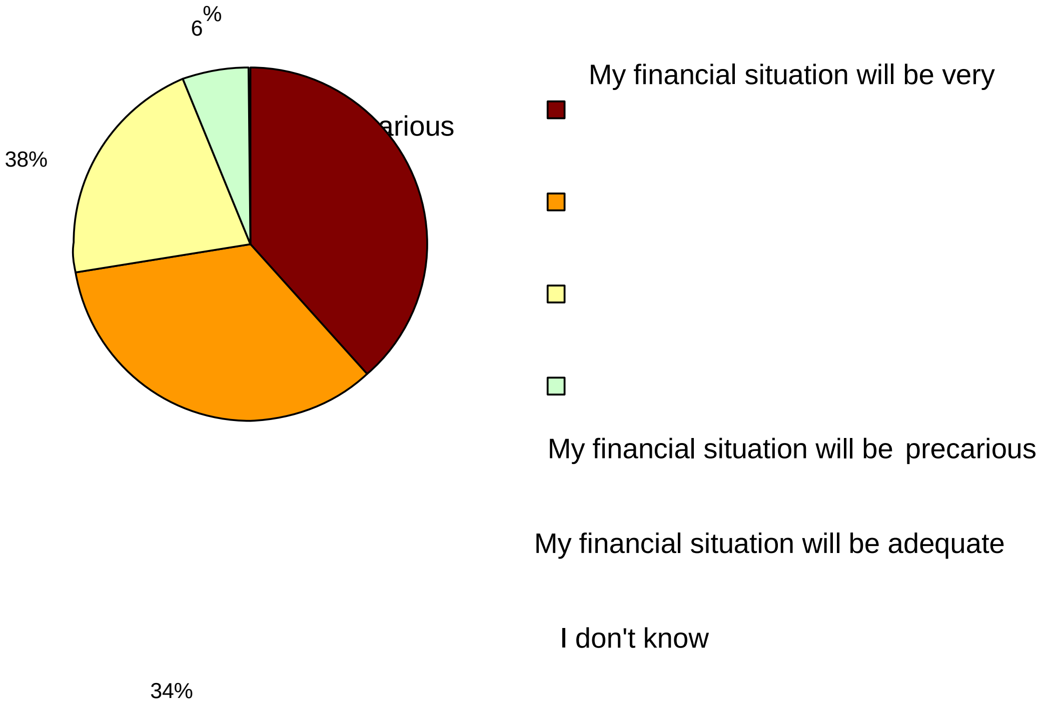
Graph 10: Anticipating health problems over the next ten years compared with others in the same age group



Moreover, the respondents who noticed their health deteriorating over the last 5 years anticipate, in a larger proportion, many more health problems in the future, compared with other people in their age group. In fact, among the 76% of the respondents who noticed their health deteriorating over the last 5 years, 63% anticipate many more health problems in the future, in comparison with other people their age.

As to their **future financial situation, 72% of respondents feel it will be precarious or very precarious** over the next ten years.

Graph 11: Assessments of respondents' financial situation over the next ten years



Finally, we offered a series of statements to the respondents where each respondent was asked to choose the statement(s) that applied most accurately to their situation.

- The following statement that was most frequently selected by respondents is: **"I am worried about the substantial deterioration I notice in my health due to the effects of thalidomide"; 69% of respondents are experiencing this anxiety.**

- When they think about their future in general, **66% of respondents reported that they feel either rather or very insecure.**

Here are some comments the respondents shared with us about their views for the future:

"I worry not only for myself but for all the other victims. It is the unknown. Every year there are more aches and pain. Even though I was compensated twice, both were small amounts."

"I was positive, but I never thought that my health would deteriorate to this point, particularly at 47. I never thought that I would live in solitude and isolation as I do. Since I was very young, I always liked to walk through nature. I never imagined that, at 47, I would hardly be able to do so anymore."

"I am afraid that my physical condition will deteriorate even more and that I will no longer be able to provide for my needs and those of my family. Presently I force myself into living one day at a time, pain is now part of my life and I try to learn to live with it. I hope that the future will be brighter."

"I feel I have no financial future when the time comes that I am no longer able to work. I have no pension as a result of only being able to work part-time because of my disability. My parents are in their mid-70's and are my main emotional support. I have very little

> ***support from any other family. My mom and dad live with me and we split on financial issues to make ends meet."***
>
> ***"I hope that this study will be fruitful as our future is very hard to face, even the present is difficult to live. Sometimes I feel like I am 95 rather than 47 because of the restrictions that I must endure. The pain, limitation and psychological aspect of seeing oneself in this way reduced is so painful. Thank you."***

The Thalidomide Victims Association of Canada sincerely thanks all its members who participated in this study.

LIST OF TABLES AND GRAPHS