

# **THALIDOMIDE SURVIVORS; A QUESTIONNAIRE SURVEY ON MUSCULOSKELETAL ABNORMALITIES, GENERAL HEALTH, AND QUALITY OF LIFE**

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## **Introduction**

The goal of this questionnaire was to survey individuals who had been affected by the congenital defects attributable to thalidomide teratogenicity. A general concern was that as individuals aged, more difficulties with their musculoskeletal and other organ systems would occur. In order to quantify these difficulties and interpret the responses in the setting of their general life setting, participants were asked to provide information on their educational level, current social situation, disability, quality of life, and their global health, as well as to detail the nature of their thalidomide teratogenicity.

## **Methods**

A survey was developed by selecting a series of valid and reliable instruments that had been used previously to assess musculoskeletal health, quality of life, and general health. In addition, a form was created to allow respondents to catalogue their deformities and organ anomalies. Each respondent was also asked to report their educational level, marital status, and occupation, along with their age, province of birth and present living situation. The survey was reviewed by individuals in the Thalidomide Victims Association of Canada and after suggestions for improvement were incorporated, the questionnaires were translated into French.

Questionnaires were sent to 120 individuals in Canada by the Thalidomide Victims Association of Canada. Respondents were provided with a letter from the President indicating that the purpose of this survey was to catalogue the existing situation with respect to health matters of its membership. Response to the survey was voluntary.

## **Results**

Forty-five questionnaires were returned. One questionnaire was filled in by the individual's parents. Respondents were from all across Canada (BC-6; AB-3; Man-1; Ont-14; Que-19; NS-1) and one was living in the UK. The demographic section reveals that 60% were female, 50% were married or living with their significant other, while 13 were living alone, 2 with children, 5 with parents, and 3 with friends. Thirty-seven had achieved Grade XII education (or CGEP in Quebec) or higher. Fourteen individuals had obtained university degrees. One had no formal education, 2 had less than grade 10, and 5 had grade 10 or 11. Current occupational status was interesting in that while 5 had no occupation, 3 were students, and 4 were homemakers, the remainder had positions such as bank manager, investor, businessman, retail store manager, pharmacist, and teacher's aid. One individual derived their income from artistic endeavours as a "mouth artist".

Respondents' global health was 67 (95% CI.-61 to 73) on average. The quality of life was reported across a wide range with 1 individual reporting a level and 5 a moderately severe disruption of quality, being completely or significantly dependent on others, troubled mentally, and in a hopeless situation. Fifteen individuals considered themselves to have a high quality of life in that they were physically and mentally

independent, communicating well with others, and "pulling their own weight with a hopeful, realistic attitude". The remaining 29 individuals had intermediate quality of life. The overall mean value was 77 (95% CI - 70 to 84) which is significantly lower than a cohort of healthy individuals who reported on the same scoring system who generally rate quality of life in the 90 to 100 range in Canada.

Twelve of 27 females had pregnancies; 3 with 1 pregnancy, 6 with 2 pregnancies each, and 3 with 3 pregnancies.

The anomalies identified were scored according to a severity level and are illustrated in the table below.

Level	Description	Number	Comment
1	Cosmetic Disfigurement	2	Head/neck, hand, foot appearance affected
2	Legs only with minor involvement	2	Able to walk but impaired
3	Legs only with major deformity	2	Great difficulty with walking
4	Arms only with minimal deformity	10	Limbs shortened and anatomical derangement
5	Arms only with major deformity	11	Severe upper limb function limitations
6	Arms and legs with minimal deformity	7	Upper/lower limb function mildly impaired
7	Arms and legs; major deformity	8	Major involvement of both arms and legs
8	Severe multiple deformities	2	Degree of involvement more severe
9	Deformities, organ failure, extreme	1	In addition has lung, liver, heart or other involvement
10	Incompatible with function	0	Severity of malformations precludes any activity

Pain was reported by a number of individuals. Back pain was a very common feature, although other musculoskeletal areas were also involved. No pain was reported by 10

individuals, 16 had mild pain (5 to 30), 8 had moderate (31 to 60), 6 had severe pain (61 to 80) and 4 had extreme pain.

The degree to which the deformities intruded on valued activities was quantified with the Illness Intrusiveness Rating Scale (IIRS).

Domain	Median	25 and 75%ile	#Maximum
Health Generally	3	1.75	5
Diet	1	1;2	2
Work	4	2;6	6
Active Recreation	3	1;5	7
Passive Recreation	1	1;3	4
Financial Situation	5	1.5;7	13
Relationship with Spouse	2	1;4	6
Family Relations	1	1;3	5
Other Social Relations	3	1;5	7
Self-Expression	2	1;4	7
Community/Civic Involvement	3	1;5	3

## Conclusions

Thalidomide ingestion during pregnancy is teratogenic. Musculoskeletal abnormalities are common and greatly affect the individuals' abilities to use their limbs and trunk in a normal fashion. Increased stress on joints can cause pain and progressive problems as individuals age. The age of these individuals was 38 to 39, a time when some individuals with normal musculoskeletal development may begin to experience early onset of degenerative joint disease. Although x-ray evidence has not been obtained, it would appear that "thalidomiders" likely have more rapid progression of joint degeneration and will continue to suffer more limitations in their mobility as years progress.

Despite these abnormalities and the pain they produce a number of respondents report surprisingly good quality of life on the scale provided. The response rate is in keeping

with mailed surveys to other organizations, although in this instance it may represent a bias toward members of the association with particular attributes such as being able to fill in questionnaires. Given the 37.5% response rate, it is possible that this sample represents a more robust group of individuals who have managed to overcome disability with innovative life approaches. An indication of this is that many have obtained higher levels of education and report working in a variety of occupational activities.

Their self-appraisal of their global health demonstrated that they felt their health was not good overall. They also indicated that intrusion of their health condition into particular domains of their life situation was often troublesome. This appears to be a realistic appraisal, given the deformities that are reported.