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## CONTERGAN [THALIDOMIDE]

Regular surveys on problems, special needs and care deficiencies of thalidomide victims Synopsis of the final report presented to the *Conterganstiftung für behinderte Menschen* [Contergan Foundation for People with Disabilities]

> Presented by the Institute of Gerontology of the Ruprecht Karls Heidelberg University

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## INTRODUCTION

The following report provides a comprehensive overview of the results of a study of the current living situation and the future health care requirements of thalidomide-affected women and men commissioned by the Contergan Foundation. This study involves a questionnaire survey, in which N = 870 individuals participated, biographical interviews, in which N = 285 participated, 23 theme-centred focus groups, which were attended by a total of N = 112 individuals, as well as a survey of attending physicians, in which N = 62 individuals gave their contribution. Based on the comprehensive empirical data it was possible to arrive at more precise and specific conclusions regarding the current physical, psychological, social and health care situation of the thalidomide-affected women and men.

The results of our analysis show that across the focus groups created by us there are numerous differences in physical, psychological, social and health care-related characteristics, which explicitly validate the need to differentiate people into subgroups. This differentiation, however, mainly allows us a lot more precise and specific insight into the living situation of thalidomide-affected women and men than what would have been given through a generalisation of the whole group.

From a biographical perspective if one looks at the competency and the living situation of thalidomide victims, one finds that they learnt to be self-dependent and self-reliant quite early on and developed effective compensatory and communication strategies, through which they managed to be in a position where they could enjoy a self-determined way of life as well as have a sense of social participation, retrospectively perceived as satisfactory.

The findings from the questionnaire survey, interviews and focus groups consistently point to the fact that the self-developed compensatory strategies as well as the efficient handling of existing environmental conditions are, in the meantime, reaching their limit. As a result, the stability of living conditions once achieved now seems increasingly at risk. Damages to the affected joints as well as secondary damages and mostly chronic episodes of pain are to be held responsible for this development. This ever increasing threat to the existing living situation is accompanied by psychological pressure and stress, which could further increase with the perception that the future is uncertain and doubtful and perhaps even threatening.

The last section of the present report provides recommendations for action with regard to future health care and maintenance of thalidomide victims. These recommendations are based on the empirical analyses performed as part of the study.

The wording of the report does not specify the gender of the individual; therefore, expressions like 'thalidomide victim' or 'participant' address individuals of both genders.

## 1 AIM OF THE RESEARCH PROJECT

The aim of this study is to identify existing care deficiencies and future special needs of thalidomide victims and to derive precise and comprehensive recommendations for action from the findings keeping in view the care and support of these people.

Implementation of the study results will open up the possibility of timely initiation of preventative and rehabilitative measures and, thus, contribute towards maintaining a self-dependent and self-determined life for thalidomide victims. In addition, the implementation of the study results should also help to ensure social participation by thalidomide victims in the long term, as well as to improve the quality of their lives.

The study includes physical characteristics (thalidomide-induced damages, secondary damages and pain, functional abilities and skills), psychological characteristics (handling stress, quality of life, outlook on life, self-concept, depressiveness), social characteristics (social relationships, social network, circumstances), as well as environmental characteristics in terms of space and infrastructure. The empirical findings are based on (a) a questionnaire survey, (b) semi-structured interviews and (c) a focus group comprising the victims.

## 2 STUDY DESIGN AND PROJECT EXECUTION

## 2.1 THOUGHTS AND CONSIDERATIONS REGARDING METHODOLOGY AND STUDY DESIGN

## 2.1.1 QUANTITATIVE METHODS

The task in this part of the study was to determine the type and extent of prenatal damage caused by thalidomide, secondary damages, functional impairments, quality of life, daily routine, outlook on the future, social networks, subjective health care and maintenance needs and deficits by means of a thematically comprehensive and precise questionnaire. This part of the study was supplemented with a survey of the attending physicians, which was also carried out by means of a questionnaire.

## 2.1.2 QUALITATIVE METHODS

The method of semi-structured interviews was chosen in order to determine the biographical development, the subjectively experienced present, as well as the outlook of thalidomide-affected women and men along with the challenges and problems faced by them in their daily routine, in their lives and in their surroundings in reference to the prevailing health care situation. These characteristics cannot be illustrated adequately through a questionnaire alone.

## 2.1.3 PROJECT EXECUTION

The questionnaires were dispatched in the beginning of March 2011 by the Contergan Foundation for People with Disabilities. An information letter and a declaration of consent were enclosed with the questionnaire, through which the

victim could give his or her agreement to participate in a focus group and/or a personal interview and to release the attending physicians from their confidentiality obligation and disclose contact data as part of the physicians' survey. In addition, two postage-paid return envelopes were enclosed for the questionnaire and declaration of consent respectively. This procedure ensured anonymity of all participants.

## 2.2 METHODS EMPLOYED FOR THE STUDY

# 2.2.1 QUESTIONNAIRES FOR THE WRITTEN SURVEY OF THALIDOMIDE VICTIMS

Responses to 900 questionnaires were received in all, out of which 30 were specified as drop-outs. As a result, 870 questionnaires entered the final evaluation. All quantitative calculations were made using the statistics program SPSS, version 19.1.

#### 2.2.2 Focus Groups

From the total number of individuals to whom the questionnaire was sent 184 consented to participate in a focus group. Altogether 23 focus group sessions were held with 112 participants. 72 of the 184 participants were unable to participate either due to the long travel distance involved to reach the focus group venue, illness or schedule-related difficulties. Guidelines were formed for the respective focus groups, which were continuously fine-tuned in subsequent focus groups with identical topics.

#### 2.2.3 INTERVIEWS

338 individuals gave their consent to a personal interview. A total of 285 interviews were conducted, transcribed and evaluated. There were 53 drop-outs in the course of the entire survey period of approximately 16 months. Reasons for that were mostly illness of the participant or his/her relatives.

#### 2.2.4 SURVEY OF ATTENDING PHYSICIANS

The 236 questionnaires were dispatched in August 2012 along with a copy of the declaration of consent and the release from confidentiality obligation confirmed by the respective respondents. Responses to 62 questionnaires were received. Here, too, the statistics program SPSS, version 19.1 was used to enter the data and carry out the descriptive analyses.

## 2.3 SAMPLE DESCRIPTION

#### 2.3.1 SAMPLE TYPE: QUESTIONNAIRE PARTICIPANT

QUESTIONNAIRE SAMPLE (N=870)		
	Men	Women
Gender (%)	48.5 %	51.5 %
Marital status (%)		
Married*	48.1 %	49.2 %
Married but living separately, divorced*	10.0 %	20.1 %
Widowed*	1.4 %	1.6 %
Unmarried	39.0 %	29.1 %
Partnership (marriage and NEL**) (%)	60.0 %	65.2 %
Average number of individuals in the household (SD)	2.5 (+/- 1.4)	2.4 (+/- 1.2)
Children (%)		
None	52.7 %	46.8 %
1-2	34.9 %	44.8 %
> 2	12.4 %	8.4 %
Highest educational qualification (%)		
Hauptschule [~ secondary school for classes 5 - 9]	26.1 %	24.2 %
Realschule [~ secondary school for classes 5 or 7 - 9]	21.1 %	28.7 %
Fachhochschulreife/ Abitur [entrance certificate to university of applied sciences/secondary school leaving certificate]	45 %	41.8 %
Percentage of persons in employment (%)	63.4 %	57.7 %
Full-time employees	82.4 %	37.3 %
Average weekly working hours	37.5 h	26.8 h
Classification as severely disabled person (%)	96.4 %	95.3 %
Partial earning disability (%)	12.9 %	10.7 %
Complete earning disability (%)	32.3 %	36.2 %

#### TABLE 1: CHARACTERISTICS OF THE QUESTIONNAIRE SAMPLE

\* Each category also includes data on civil unions

\*\* Nichteheliche Lebensgemeinschaft [Cohabitation]

### 2.3.2 SAMPLE TYPE: INTERVIEWS

There are only minor differences between interview sample and total sample.

## 2.3.3 SAMPLE TYPE: FOCUS GROUP PARTICIPANT

The focus group sample differs from the total sample in the following areas: gender, marital status, number of children, education, gainful employment. The percentage of men was smaller, the percentage of married individuals and the number of children were higher as compared to the total sample. Educational background and the percentage of individuals in employment was also higher in both genders.

## **3 STUDY RESULTS CLASSIFIED BY THEMATIC FOCUS POINTS**

# 3.1 FORMATION OF DAMAGE GROUPS AND DESCRIPTION OF DAMAGE SEVERITY

Owing to the high variability in the damages, individual damage patterns were differentiated and groups were formed accordingly. In doing so, not only prenatal damages but also secondary damages were surveyed in order to describe the current situation. For instance, if an individual does not exhibit any prenatal damage to the vertebral column but develops scoliosis later in life due to compensatory movements, then the individual is assigned to the damage group "vertebral column defects".

A total of 10 damage groups were defined, which comprised individuals with damage to different areas of the body. Each individual could exhibit multiple damage areas simultaneously. The severity of the damage was defined by the number of damage areas. The percentage of individuals in the total group falling in a particular damage severity category (number of damage areas) was calculated. Individuals with four concomitant damage areas form the highest percentage of 25.9% in the total sample. Three and five damage areas per individual also show high percentages of 22.1 % and 19.4 % respectively. 1.7% of individuals exhibit one damage; 12.6% show two damages. Six and seven damages are found in 13.9 % and 3.8 % respectively. Five individuals (0.6%) exhibit exceptional damage severity with eight concomitant damages.

The different damage areas cumulate to form the various damage groups. In the extremely small group with only one damage (15 individuals) 86.7%, i.e. 13 individuals, exhibit damages exclusively in the area of upper extremities; each individual shows damage in the head region or loss of hearing.

An additional key aspect, the vertebral column defect, is found in 76.4% of the victims in the group with two damage areas (110 individuals). Lower extremities are affected more in thalidomide victims with three damage areas; in victims with four damage areas the malformation of internal organs is more prominent, and in victims with five damage areas the damages of the sense organs cumulate in the head region.

## 3.2 FORMATION OF FOCUS GROUPS

The outcomes of the interviews and the focus groups revealed that it was necessary to take more characteristics into account to be able to illustrate the circumstances of thalidomide-affected women and men more comprehensively. The following groups were therefore formed:

- Individuals with quadruple limb damage
- Individuals with double limb damage, short arms
- Deaf victims
- Individuals with complete earning disability
- Individuals with lower incomes
- Individuals with severe functional impairment

This differentiation allows us to have a more specific understanding of the challenges and problems that thalidomide victims are confronted with.

## 3.3 SOCIO-DEMOGRAPHIC DATA AND SOCIAL NETWORK

Data on martial status, number of children, etc. are of great significance in terms of the type and extent of assistance and support provided by the social network. The social network assumes certain functions and responsibilities quite early on, often starting at birth, which in the general population are required to be undertaken only at a very old age.

## 3.3.1 MARITAL STATUS AND PARTNERSHIP

Half of the male and female respondents respectively are married (48.8% vs. 49.2%). In the group with divorced individuals or married individuals living separately there are approximately twice as many women (20.1%) as men (10.1%). In the 'unmarried' category there are approx. 40% men and only 29.1% women.

Overall, 60.7% of the male and 65.2% of the female respondents live in some form of partnership. Compared to the age group of 50-54-year-olds in the general population, around 2.4 times more people with thalidomide damage live without a partner (38%) as compared to the number in the rest of the population (15.8%).

What do these figures represent in terms of the described focus groups? The group of individuals with quadruple limb damage has the highest percentage of victims living without a partner (close to 50%), followed by the deaf victims (43.6%); the percentage is considerably lower in the case of individuals with short arms (29.7%). In the general population, the percentage of people living without a partner is almost half as much.

## 3.3.2 CHILDREN

Yet another important component of the social network is the individual's own or adopted children. The number of children of thalidomide victims is contrasted with the number of children of the female cohort in 1960-1964. The group of childless thalidomide victims has twice as many individuals as the general female population. When calculated separately according to gender, at 52.7%, men show a percentage nearly 6% higher than women (46.8%).

The respective percentages of the thalidomide-victim groups with one child are more or less comparable with those of the general population. However, the percentages of thalidomide victims with two, three or more children are significantly lower; they are only half as much as the number in the general population.

An analysis of the frequency of childlessness in the six focus groups revealed considerable differences. The group of deaf victims as well as of individuals with quadruple limb damage indicate approx. 65% childlessness. The group of individuals with double limb damage exhibit the lowest percentage of childlessness. At 40.9% the number of these victims lies below the total sample average of thalidomide victims; however, it is considerably higher than that of the female cohort in 1960-1964 (23.3%).

55.9% of thalidomide victims have minors in the household; for women the figure is 46.2%, and for men it is 67.7%. Data of the Federal Statistical Office for the year 2010 was used for comparison. In the age group of 45-55-year-olds in the general population, the percentage of minors in the household is estimated to be around 35%.

The highest percentage of minors in the household is found in the case of individuals with double limb damage (55.9%) and of individuals with quadruple limb damage (53.6%). At 40% the number of minors in the household is very low in the case of deaf victims; figures in the remaining three focus groups lie between 47.5% and 48.8%.

## 3.3.3 SIZE AND COMPOSITION OF THE HOUSEHOLD

Compared with the general population thalidomide victims rarely live in singleperson households, they more often than not live in households with three or more people. In the thalidomide sample, those people who can afford to stay alone without help owing to favourable circumstances in terms of health, location and infrastructure, live in single-person households. There are those thalidomide victims as well who have neither a life-partner nor an extensive social network, and are dependent on external assistance.

The group of individuals with quadruple limb damage has the highest percentage of single and childless individuals; this explains the high percentage (31.3%) of single-person households. This is followed by the group of deaf victims and individuals with complete earning disability with 27.8% and 27.7% of single-person households respectively and 33.3% and 31.9% of households with three or more people respectively.

The group of short-armed individuals has the lowest percentage (21.2%) of singleperson households and, in fact, reaches 49.7% when it comes to households with three or more people. Going by the acquired data for partnerships and number of children, it can be assumed that direct family members and relatives play a significant role and, therefore, of the six focus groups the group of individuals with double limb damage has the most tight-knit social network.

### 3.3.4 SOCIAL NETWORK

For 16 items in the questionnaire on social network the average value of each focus group is compared with the average value of another focus group. The results were presented for four focus groups, i.e. individuals with quadruple limb damage, thalidomide victims with lower income, thalidomide victims with complete earning disability as well as thalidomide victims with severe functional impairments.

The results show that a relatively high number of thalidomide victims personally experience being a part of the society. This is shown by items that discuss the extent to which one finds trusted people in the social environment, who express willingness to help, with whom one could do things together, who are there when one is in need, with whom one could share in both positive and stressful situations. Satisfaction with the acquaintances and the respect shown by one to another are indicators of a sense of social participation and good social integration; the conviction and belief of many thalidomide victims that they can also give something to others also points to the same.

Statistically significant differences appear between groups of individuals with quadruple limb damage and without quadruple limb damage in the following characteristics: (I) Apprehension of being a burden on others (this apprehension is more pronounced in individuals with quadruple limb damage), (II) Frequency of meeting relatives (individuals with quadruple limb damage seldom meet their relatives), (III) Availability of people in whom one can confide (on an average, individuals with quadruple limb damage seldom meeting).

For each individual characteristic people with lower incomes displayed statistically significant differences as compared to people with adequate incomes.

Comparison between individuals affected with a high degree of functional impairment and individuals without such impairments reveals an almost identical picture. Notable differences are seen in the following characteristics: (I) Avoiding conflict (people with a high degree of functional impairment tend to avoid conflicts more often) and (II) Apprehension of being a burden on others (this apprehension is more pronounced in individuals with a high degree of functional impairment). Only the item 'Someone is always available to help' does not show any significant differences.

Hence, the following conclusions can be drawn: In the present situation thalidomide victims experience a relatively high sense of integration and social participation on average. However, there are specific groups that exhibit significant variations in individual characteristics of social integration and participation.

## 3.4 EDUCATION, OCCUPATION, RETIREMENT AND PENSION

## 3.4.1 SCHOOL EDUCATION

According to their statements in interviews and focus groups, thalidomide victims were from early on continuously encouraged by their parents or legal guardians to be independent and self-reliant in whatever they did. At the same time, they realised early that education offered them the possibility to gain autonomy at work in spite of severe physical limitations.

There are two fundamental differences between the victims and the general population: Firstly, in the case of thalidomide victims a significant percentage of individuals show delayed progress from graduate to post-graduate degrees. Moreover, gender-specific differences are less pronounced than observed in the general population.

Individuals with quadruple and double limb damage, as well as those with a high degree of functional impairment more or less correspond to the general average of the thalidomide-victim group. Individuals with quadruple limb damage exhibit especially low numbers in the "no degree" category (1.2%). In contrast, deaf victims show widely varying results; in their case, the extent of their ability to communicate mostly determines what educational degree they attain. These individuals predominantly attain a Certificate of Secondary Education; higher educational degrees are found less often than in other groups.

#### 3.4.2 PROFESSIONAL EDUCATION AND TRAINING

The trend seen in the school education data continues in professional education and training.

In the entire thalidomide-victim group, the percentage of individuals without professional education and training (12.1%) is lower than that in the general population (15.1%). In the case of universities of applied sciences or other university degrees, thalidomide victims exhibit a considerably higher percentage as compared to the general population (10.2% vs. 5,9% and 12.2% vs. 8.2%). The percentage of individuals completing doctoral studies is also noteworthy: Here 6.9% of thalidomide-affected men acquired a post-doctorate degree as compared to 1.9% of their reference group in the general population.

The school and professional education of individuals with quadruple and double limb damage more or less corresponds to the average results of the total group, though individuals with quadruple limb damage perform slightly worse than the average and the short-armed individuals slightly better. In the case of individuals with a high degree of functional impairment, school education more or less corresponds to the average value of the total sample; however, in professional education and training they fare rather poorly. An exception here is the number of individuals with doctorate degrees, which presents the highest percentage in this focus group. The situation of deaf thalidomide victims turns out to be the most unfavourable in the group. More than a quarter of these individuals were unable to complete any professional education or training, and except for one individual who was able to complete the doctorate programme, no other deaf victim was able to attain any academic degree.

#### 3.4.3 GAINFUL EMPLOYMENT

544 individuals from the sample reported being in gainful employment; this corresponds to 62.5%. Out of these, 59.2% are employed on full-time basis and 40.8% work part-time. To compare: In the corresponding age group in the general population, 81.5% of the population is working, 14.4% is non-working population (e.g. housewives); only 4.1% report being retired. Of the working population, 70.5% work full-time and 29% work part-time.

Similarities between the general population and thalidomide victims are seen in gender-specific distribution. More women work part-time than men. At 64.6% the number of female thalidomide victims is around 10% higher than in the reference group of female general population, which is at 54.4%; 19.4% of male thalidomide victims work part-time, the percentage in the total population is 6.1%.

The interviews shed some light on the above statistics. Everyone wants to pursue a regular job as far as possible. When one is unable to work the full-time employment hours, one switches over to part-time jobs until one can no longer work in another job due to pain or limitations. Ultimately, one applies for reduced earning capacity pension.

With reference to the percentage of individuals in employment the group of individuals with double limb damage corresponds to the average value of the total group. Somewhat lower are the deaf victims followed by individuals with quadruple limb damage.

At 39.8% and 42.9% respectively, victims with low incomes and severe functional impairment exhibit particularly low percentages of individuals in employment. 22% of individuals with functional impairments work in full-time jobs; at 11.6% this number is less almost by 50% in the case of low income earners.

## 3.4.4 REDUCED EARNING CAPACITY AND INCOME

11% of individuals in the entire group of thalidomide victims exhibit partial earning disability; 32.8% of the respondents stated complete earning disability. Comparative figures from the total population are at about 3% for this age group.

The distribution of reduced earning capacity is different in the focus groups. The groups that most often exhibit an early retirement from work are those comprising individuals with severe functional impairments (58.5%) and low income earners (51.1%).

In about 95% of cases the reduced earning capacity pensions are contingent on the thalidomide damage and its consequences. Based on the recent exponential development of complete earning disability in the sample studied by us it can be expected that in a few years a vast majority will exhibit complete earning disability. In

the case of early retirement from work or reduced earning capacity due to pain and/or functional impairments it becomes difficult to maintain and support family, and especially minors because of the considerably short period of employment.

Even today a high percentage of women and men faces problems financing their monthly expenses; 28% of men and 41.5% of women stated that they are incapable of earning their livelihood independently.

# 3.5 PRENATAL DAMAGES AND THE CURRENT SITUATION TODAY BY COMPARISON

The current situation is derived from the cumulation of prenatal damages and secondary damages. The present situation is no longer defined by prenatal damages alone, but also by the additional physical and functional impairments that have developed during the course of the victim's life. The current living situation needs to be reviewed against this background.

No changes can occur in the damage areas phocomelia, amelia and loss of hearing; these damages are predetermined at birth. Only a small percentage of victims experienced change in the area of upper extremities, as this damage area was already highly malformed by birth.

Major changes are seen in vertebral columns/pelvises. Because of the prenatal damage to the musculoskeletal system, the victims compensate for the missing functions through learned and extensively practised movement patterns. The consequence of this becomes evident after 50 years in the form of loss of movement, which is to be attributed to tensions, muscle weakness and arthritic changes in joints, as well as changes in the sinews and ligaments.

Prenatal damages of the internal organs that are not visible on the outside were often not diagnosed, as they were either not possible to detect with the diagnostic methods of that time, or because they caused discomfort and developed symptoms leading to medical examination only in the course of years.

As per our definition, 100% of the individuals with quadruple and double limb damage in the upper extremity area exhibit a damage; in the group of individuals with quadruple limb damage 100% cases exhibit damage in the lower extremities as well. The group of individuals with functional impairments shows damages in upper extremities in 97.1% of cases; damages in lower extremities, phocomelia and amelia of upper and lower extremities is seen the most in this focus group, which at 80.6% also exhibits the highest percentage of individuals with internal organ damages.

At 99.4% the groups of individuals with quadruple limb damage and functional impairments show a particularly high percentage of vertebral column/pelvic damage. The initial values of prenatal damages are extremely high in these groups (76.1% and 65.1%); however, today almost every victim is suffering from further damages or complaints in the vertebral column and pelvic area.

In the case of deaf victims, damages in the musculoskeletal system are not as pronounced as in other focus groups; however, they are far more affected by damages in the head region and sensory organs. With 89.4% of cases exhibiting damages in the head region and 89.4% of cases with visual impairment and blindness there is a huge gap between them and other groups.

#### 3.6 SECONDARY DAMAGES

Secondary damages are defined as physical impairments that develop in thalidomide victims during the course of their lives in areas of the body not damaged prenatally. These should be distinguished from the so-called long-term sequelae, which occurred prenatally but were detected only at a later point of time. Secondary damages are caused by some movement patterns practised early on to compensate for missing functions. Improper biomechanical stress or overstraining of initially healthy joints and limbs, through which it was possible to improve mobility, is the cause of severe osteoarthritis and wear and tear, which lead to tensions and pain as well as to considerably restricted mobility.

In the questionnaire the data on characteristics of damages in the musculoskeletal system, i.e. pain, osteoarthritis, muscle weakness and muscle tension, was collected at three different times; the degrees of severity of discomfort were divided into four categories (slight, moderate, considerable, extreme), and the mean values were calculated for each item and category.

The results of the survey show a considerable deterioration in the physical condition today as compared to the situation five years ago. The mean values of individual items were recorded on a scale of 1 (=slight) to 4 (=extreme). Five years ago the values for upper extremities in the total group were in an area between 1.4 and 1.9. Today – at the time of the survey – they already lie between 2.3 and 2.9 - 3. This implies that there are considerable damages and severe pain symptoms. In the case of lower extremities and vertebral column/pelvis the mean values of 2.4 to 2.8 and 2.6 to 2.9 respectively are at an even higher average level today.

The analysis of the damage progress reveals an increase in the mean values in all three areas of the body during the periods five years ago, two years ago and today. These results are in line with the statements of the victims in interviews and focus groups.

The data was calculated again for the various damage severity groups, and was differentiated by osteoarthritis, pain and muscle weakness and muscle tension for upper extremities, lower extremities as well as vertebral column and pelvis respectively.

In the case of upper extremities the results show that the severity of damage has an effect on the extent of development of osteoarthritis, pain, muscle weakness; the higher the severity of damage, the more pronounced are the said characteristics. The results pertaining to lower extremities show a more nuanced picture as compared to upper extremities. The group with the least damages, i.e. with one or two damage areas (SG1), mostly shows no prenatal damages in the lower extremities and reported neither muscle tension nor muscle weakness in the survey. However, this

## 3.7 DRUG THERAPY

46.0% of thalidomide victims do not take any medicines. 17.2% take one medicine, 12.3% two, 9.3% three, 6.2% four and 9.0% take five medicines regularly.

These numbers vary in the focus groups. Thalidomide victims with quadruple and double limb damage form the largest group of individuals, who do not take any medicines; at 48.5% and 46.5% respectively, they are slightly above the average value of the total group. The deaf victims seldom take medicines; 55.3% do not take any medicinal products.

The groups of individuals with complete earning disability, low income and severe functional impairment show similar distribution in terms of intake of medicines; they often take more medicines than the total sample. They take multiple tablets at the same time and regularly.

The deaf victims cannot be compared with the other focus groups, their medicine requirements are qualitatively very different. Consumption of analgesics is considerably below average; at 14.3% it is mainly ophthalmologic medicines that are consumed. In contrast, the consumption is at 2.1% in the total sample. 16.1% of the deaf victims reported taking neuroleptic/psychotropic drugs, in the total sample the numbers are at 10.1%. Even the consumption of antiasthmatics/antiallergenics (7.1%) is more frequent as compared to all reference groups.

Individuals with complete earning disability and those with low income take more analgesics (4-5%); these numbers are even higher in the case of individuals with quadruple limb damage and those with functional impairments (approx. 9-10%). Analgesics form a medicine group, in which several different compounds are most often ingested simultaneously. Up to four pain killers are used at the same time.

#### 3.8 PAIN

84.3% of thalidomide victims experience pain. Out of these 50% experience pain everyday and 39% suffer from persistent pain. In the groups with damage severity from one to eight, the percentage of victims experiencing pain increases considerably. 40% of victims report pain in the group with only one damage area, the numbers rise sharply in groups two to four, then the increase is slower and reaches 100% in groups seven and eight. In the groups with two to seven damage areas indications of a severe form of pain lie between 21% and 50%, whilst in the group containing the most severely damaged victims these are at 100%.

Pain can be attributed to wear and tear of prenatally damaged body areas under improper biomechanical stress or overstraining, as well as to secondary damages in areas of the body initially not affected. The progress of pain is mapped by means of periodically asked questions regarding the extent of pain 5 years ago, 2 years ago and today. A four-level scale was used for this purpose with the varying degrees indicated by 1 = slight to 4 = extreme.

For reasons of clarity two each of the total eight damage severity groups were taken together in the result, such that now there were four groups representing the damage severity I to IV in thalidomide victims. In group IV with most affected individuals 100% of the victims complained of pain, in group I with least affected individuals 61.6% victims reported symptoms of pain. This group consisted of victims that exhibited only one or two damage areas. The high percentage of victims reporting pain is attributed to the fact that in this group, which predominantly showed malformation of arms, a high percentage of individuals had developed vertebral column damages.

The percentage of victims experiencing pain is almost 25% higher in SSG II. In the following SSG III already over 90% of victims report pain; the extent of the damage has increased drastically in all areas and leads to intensified pain symptoms. People with high damage severity often suffer from pain more often, and have a higher degree of severity.

The reason for pain is both wear and tear or destruction of damaged joints, as well as tension in muscle attachments and tendon insertions. Pain is also the result of secondary damages that have developed in areas not affected prenatally. In practice, it is quite difficult to separate the two causes of pain and functional impairment. The current situation defines the everyday life of the victims and represents the situation that has shaped itself in the amalgamation and development of prenatal damages and secondary damages over the course of 50 years.

Most often painful muscle tensions occur in the spinal region, in 78.6% of cases in the total sample. In 43% of cases muscle tension occurs in the region of the arms, in 19.5% of cases in the leg region. The causes are compensatory malposition or improper biomechanical stress on the vertebral column.

40% of victims with one or more damage areas reported experiencing pain everyday, in the case of individuals with five or six damage areas the number is already more than half, in SSG IV almost three-quarters of the victims experience pain daily. The duration of pain episodes also increases in highly affected groups; a little more than half the victims in group IV report persistent pain. At 28.8% consumption of analgesics and antirheumatics is very low in the total group. Almost 97% of the victims requiring drug therapy report having adequate supply of medicines.

Outpatient care by pain therapists is also provided in almost 90% of cases. Despite this good health care provision victims are not free from pain.

There is, on the other hand, a very high requirement for physiotherapy and massage treatment (78.7% and 80.6% respectively). The existing discomfort and complaints can be significantly alleviated with these measures, provided that they are undertaken more than once a week. This requirement is fulfilled only in the case of around half or two-thirds of the victims.

Finally, the report presents the results of personal health evaluation. The main focus is on the connection between pain and its consequences or its causes. At 44.6% the focus group of individuals with limited functionality exhibits the highest

number of victims evaluating their personal health as "bad/very bad". These numbers are also considerably higher in the case of the focus group of individuals with complete earning disability and that with low income (31.3% in each group) as compared to other groups.

Pain defines the everyday life of a high percentage of thalidomide victims. Therefore, it is essential to have adequate and easy access to all aids and measures that help alleviate pain in order to attenuate the developing situation that is leading to further impairment of functionality.

## 3.9 FUNCTIONAL ABILITIES

#### 3.9.1 FUNCTIONALITY PROFILE

Functionality profiles depict the percentage of thalidomide victims having problems performing individual activities. The profiles consist of 26 items, including activities of daily living that are in fact associated with the need for long-term nursing care, instrumental activities of daily living that mostly imply need for assistance, as well as items regarding mobility. The results for the total group and for other focus groups are represented graphically and can be compared with each other. They are available for review in the final report.

The profiles illustrate the respective percentages of thalidomide victims facing problems performing individual activities. Abilities that are retained well include eating, drinking and moving about in the house. The total sample exhibits a relatively better mobility as well. The ability to perform all other normal and intellectual activities of daily living is rendered impaired in 40 to 60% of the sample. Most of these activities require fine-motor skills, e.g. activities pertaining to daily personal care and hygiene and the work involved during preparation of food, or laborious or physically demanding activities, like e.g. cleaning up the house. Both these areas – fine-motor activities and physically strenuous activities – were mostly described as no longer feasible in the interviews.

## 3.9.2 FUNCTIONALITY IN FOCUS GROUPS

The total value of the estimation of functional abilities takes into consideration the extent and form of impairment, or refers to individual special needs. Normal and intellectual activities of daily living are depicted separately in order to differentiate nursing care-related special needs from assistance-related special needs. The total values differ depending upon the damage pattern. The values are lowest in the case of deaf victims; they are higher in the case of individuals with double and quadruple limb damage. The loss of ability in the case of thalidomide victims with phocomelia is almost as pronounced as in individuals with the highest functional impairment. Individuals with complete earning disability and those with low income show above-average loss of functionality, which constitutes the main reason for the living situation. In the total group there are hardly any differences in the values for normal and intellectual activities of daily living. Deaf victims find it considerably more difficult to perform instrumental activities of daily living, as physical damages are less frequent in their case.

## 3.9.3 FUNCTIONALITY IN DAMAGE GROUPS

The percentage of individuals facing problems performing everyday activities increases with a higher number of damage areas. With a higher degree of damage, the ability to dress and use the toilet are restricted predominantly. 58% of the respondents have problems dressing the lower body, 53% face problems using toilets outside the house. Over half the respondents in the most common damage group with four damage areas report facing problems performing activities like bathing, taking a shower, washing, dressing the upper and lower body, using the toilet and most household activities. The ability to move is retained the most; the percentage of people facing problems in this area is relatively low. This is also due to the fact that certain modes of mobility are not practised at all. So, for example, walking is no longer indicated as a problem by people who always need a wheelchair to move. The extent of functional impairment was sampled across four damage groups. Here, too, the total values continued to increase according to the number of damage areas, especially markedly in the severely affected damage groups.

## 3.10 UNCOVERED MEDICAL COSTS

A section of thalidomide victims, for whom a medical requirement is not covered by the health insurance fund, finance their medical care needs on their own whenever possible to be able to fulfil their family and professional obligations and duties.

In the total sample, only 29.5% of the respondents reported no additional financial load due to uncovered costs. Additional costs are mostly incurred in cases with a high degree of physical damages, but also by individuals with low income and complete earning disability. The option of absorbing these costs through one's own income is also often not available in these groups.

## 3.11 NEED FOR ASSISTANCE

Assistance should not be equated with nursing care. The need for assistance usually develops in thalidomide victims in their middle adulthood depending upon the extent of prenatal damage and secondary damages. Need for assistance includes supports, assistance and services that are not included in the nursing insurance. 44.9% of the respondents reported the need for assistance. In the validation process, many thalidomide victims expressed their misgivings about this value and described it as being very low. That this is an underestimated value is confirmed by the fact that in the case of instrumental activities of daily living 59.4% of the respondents expressed a need for personal help, which implies a need for assistance. Furthermore, it should be noted that assistance in instrumental activities of daily living completely excludes services like accompanying the individual to recreational activities, on excursions, to parties, to education and learning events and to the work place.

## 3.11.1 WHO PROVIDES ASSISTANCE?

Mostly it is the partner, relatives or friends who support and help the victims in their everyday life. These people either live in the same household or in the neighbourhood. Only 13.4% of the cases receive support from professional outpatient services. These services are most often availed by deaf victims.

Parents are also involved in assistive support. Most of the times they themselves have special needs and require support. Therefore, many thalidomide victims have to take care of their own parents. In the case of deaf victims, it was often not possible to have a family of their own; thus, their original family was of particular importance. Often children help around. However, the assistance relationship is in jeopardy even in this case, as children leave their parents' house. Moreover, many thalidomide victims do not wish to burden their children too much.

## 3.11.2 Assistance Effort in Terms of Required Time

For individuals requiring assistance, the need for such assistance in terms of time was recorded in ten-hour increments. Groups with more pronounced damage patterns or with severe functional damages have the highest need in terms of time. 41 hours or more per week are required by 8% of individuals with quadruple limb damage, 12.1% of thalidomide victims with phocomelia and 18.3% of thalidomide victims with severe functional impairments.

## 3.11.3 COSTS OF UNCOVERED NEED FOR ASSISTANCE

Most of the respondents reckoned a sum of over  $10,000 \in$  for their need. In interviews and focus groups the amount of  $15,000 \in$  was mentioned as the sum required to cover the costs for 24-hour assistance service per month. The percentage of individuals who can finance the uncovered needs on their own does not exceed the 10% mark. Thalidomide victims with low income are least of all in a position to self-finance assistance services.

## 3.11.4 NEED FOR ASSISTANCE IN DAMAGE GROUPS

With an increasing number of damage areas, which also included secondary damages, not only does the severity of damages rise, but also functional damages and pain; the ability to cope with stress and strain reduces steadily. These changes result in a higher need for assistance. It is at 100% in the case of thalidomide victims with 8 damage areas, between 55 and 80% in the case of 5-7 damage areas, and at 50% in thalidomide victims with 1 to 4 damage areas.

3.11.5 NEED FOR ASSISTANCE AND SENSE OF SOCIAL PARTICIPATION The need for assistance is not limited to performing everyday activities, but also involves being able to participate in public and social life, as well as take advantage of education and learning events and indulge in personally meaningful activities. The extent of thalidomide-damage determines the need for assistance in enabling participation and integration into society. A comparison between focus groups in terms of the most important area of social participation, namely a self-defined routine, reveals the need for assistance in varying degrees. The need for assistance is highest in thalidomide victims with the highest functional damage. In the low income group, which shows a 37.1% need for assistance and in which only 2.6% of the individuals are in a position to meet the costs towards assistance, it is particularly difficult to put a self-defined routine plan into action.

## 3.11.6 ANTICIPATED NEED FOR ASSISTANCE

Finally, the thalidomide victims were asked what they imagined the need for assistance to be in the future. Most of the respondents feared that the need for assistance would increase in the future; 65% of victims in the total sample expressed this apprehension.

## 3.12 NEED FOR LONG-TERM NURSING CARE

49.9% of thalidomide victims in the total sample require long-term nursing care. The need for long-term nursing care is primarily dependent upon the severity of thalidomide damage. Even thalidomide victims with very low income or with complete earning disability show an above-average need for long-term nursing care. Almost all individuals of the group with the most severe functional damages require long-term nursing care; the percentage of thalidomide victims with phocomelia needing long-term nursing care is almost equally high. The lowest percentage of individuals needing long-term nursing care is that of deaf victims (29.8%). They are the group that requires the highest percentage of inpatient or clinical care. The reason could be that in the case of deaf victims there is often a high cumulation of internal organ damage.

## 3.12.1 NURSING INSURANCE BENEFITS

37.6% of thalidomide victims receive nursing insurance benefits. The percentage of individuals requiring long-term nursing corresponds to the age group of 85 to 90-year-olds in the general population. While domiciliary care level I predominates in the case of all recipients of nursing insurance benefits (53.3%, long-term nursing statistics 2011), at 52.9% thalidomide victims mostly fall under domiciliary care level II.

There are variations within the focus groups. Individuals with quadruple limb damage most often exhibit domiciliary care level III. It is noteworthy that thalidomide victims with the highest functional impairments and with phocomelia rarely exhibit the highest domiciliary care level, especially when one clearly states the high need for aid and support. This need for assistance is not a part of nursing insurance and, therefore, remains uncovered.

### 3.12.2 WHO PROVIDES LONG-TERM NURSING CARE?

Most often the (martial) partners provide long-term nursing care, parents and children come second in line, neighbours and friends play a significant role in the provision of nursing and care services in varying degrees. It is mainly one or two groups of people that provide nursing care, more than two groups of people are rarely involved, though involvement of up to five groups of people has also been reported.

# 3.12.3 COVERED AND UNCOVERED NEED FOR LONG-TERM NURSING CARE

40.1% of the thalidomide victims stating the need for long-term nursing care view it as having been covered, 59.9% feel the need is not covered. Out of these, 63.9% are classified under a domiciliary care level.

If for instance an individual belonging to the domiciliary care level II and exhibiting a functional competence of 20.7 points considers the need for long-term nursing care as covered, then it can be assumed that in the reference group with an average functional competence of 26.0 points the need in domiciliary care level II is not covered. This is an indication of an extremely varied and to some extent quite restrained and non-committal provision of nursing insurance benefits.

## 3.12.4 Costs of Uncovered Long-term nursing care

All thalidomide victims who stated the need for long-term nursing care were asked what the yearly financial load would be if they had to pay for the nursing services privately, and ultimately, whether this amount could be arranged using their own resources.

In all focus groups except the group of deaf victims an exceptionally high percentage of individuals are found to be without covered costs for long-term nursing care. The percentage is highest in the case of the thalidomide-victim group with the highest functional damages; it is at 68%. However, even in the case of individuals with phocomelia of upper extremities this number is quite high, i.e. 51.6%. 42.9% of individuals with quadruple limb damage have reported uncovered costs of long-term nursing care. This is the case not only in groups comprising individuals with severe physical impairments. The costs of long-term nursing care often remain uncovered even in the case of people with a restricted financial situation.

From the individuals stating uncovered costs of long-term nursing care, 22.3% reported these costs to be to the tune of  $10,000 \in$  or more. Individuals with quadruple limb damage, with complete earning disability and the group with very low income were above the average in their estimation. Regarding the question of bearing these costs personally, the focus groups with high physical limitations and in a difficult financial situation are again at a disadvantage.

### 3.12.5 NEED FOR LONG-TERM NURSING CARE IN DAMAGE GROUPS

The need for long-term nursing care increases depending upon the number of damage groups. Damage groups take prenatal damages as well as secondary damages into consideration and appropriately describe the current situation and the resultant need for long-term nursing care. The need for long-term nursing care is below 20% in groups with one to two damage areas, groups with three to six damage areas exhibit a need for long-term nursing care between 40 and 70%, victims with seven or eight damage areas are between 80 and 100%.

#### 3.12.6 ANTICIPATED NEED FOR LONG-TERM NURSING CARE

Thalidomide victims were asked about their anticipation of the need for long-term nursing care. Most of them fear a higher need for long-term nursing care; in the total sample the number was 71.8%, 24% estimated it to remain unchanged. 88.4% of the cases with an already existing need for long-term nursing care stated that the need would increase in future; only 7.8% expect the situation to remain the same.

## 3.13 DENTAL CARE

Jaw deformation and malformation of teeth occurs predominantly in the group of hearing-impaired victims. 39.6% of deaf victims and 31% of hearing-impaired victims reported jaw deformation; another 36.2% and 28% respectively reported malformation or inappropriate position of teeth. In the total sample 22.6% show malformation of the jaw and 15% of the teeth. These prenatal damages require costly dental and/or maxillofacial surgical treatment, which is either not covered at all or covered only by very few health insurance companies. It is absolutely essential to correct a defective or improper jaw positioning for linguistic development and communication, as well as for unimpeded eating function.

Furthermore, thalidomide victims with short arms and/or malformed hands use their teeth to carry out a number of other activities meant to replace the missing grasping function of the hands, which however harm the teeth.

Due to limited functionality thalidomide victims with malformed arms and/or hands are often not in a position to do the daily cleaning of their teeth independently and in a correct manner. The grasping function of the teeth is also limited due to tooth loss, which leads to further loss of independence, as now external help becomes necessary. Therefore, dental prostheses or implants are of central importance.

In the total sample the requirement for dental prostheses is at 23.5%. The requirement in the case of individuals with double and quadruple damage is comparable, whereas the highest requirement is shown by deaf victims at 44.4%; they exhibit the highest percentage of jaw deformations and malformations of teeth. At 34.8% thalidomide victims with malformations in the head region – this also includes hearing-impaired victims but not deaf victims – indicate an equally high requirement. In their case, too, the extent of malformation in the tooth and jaw area is high.

The groups of individuals with complete earning disability, with low income and with functional impairments exhibit a higher need for dental prostheses than that of the total sample; it lies between 31% and 33%. In these three groups, the percentage of victims with prenatal damage in the region of the head and sensory organs lies between 34% and 39%.

## 3.14 MEDICAL CARE BY PHYSICIANS AND THERAPISTS

The highest requirement exists in the area of general practitioner care (89.9%); the requirement is uncovered only in 5.5% of cases. This is followed by dentists with a requirement of 83.4%. The uncovered requirements are between 3% and 8.4%, an exception being orthopaedic care, which is indicated as uncovered by 24.9% of the respondents. Likewise, there is a high requirement for ENT specialists, ophthalmologists, gynaecologists and physiotherapists.

The focus groups show a varied requirement for general practitioner care. While deaf victims manage with few visits, it is mostly individuals with severe functional impairment (around 35%), who visit a general practitioner more than nine times a year. They are followed by individuals with low income (29.6%) and with complete earning disability (27.4%).

A similar result is seen in the case of visits to a specialist. Here, too, deaf victims get by with the least number of visits in a year and individuals with severe functional disability show the highest percentage with ten or more visits to a specialist per year, and are therefore just a little ahead of individuals with low income and with complete earning disability (20.6%, 18.0%, 18.3%).

75.3% of cases in the total sample expect an increased need for medical services in future. This underlines the results presented already with regard to secondary damages and pain. In the last few years, the ever increasing discomfort, impairment of functionality and secondary damages have reached a level that can be handled only by taking more intensive medical, therapeutic and medicinal help, as well as more assistance.

## 3.15 MOBILITY, AIDS AND LIVING ENVIRONMENT

#### 3.15.1 MOBILITY WITHIN THE HOUSE

An important element of the quality of life and social participation is mobility inside and outside the house. One-fifth of the respondents report having problems moving about within the house. In focus groups with severe functional impairments 44% of the cases have trouble moving about. In the case of individuals with quadruple limb damage the number is in fact 50%. 11.7% require a walking aid to move about in the house, 12.3% can move about only with the help of another person. Individuals with the highest functional impairments require significantly more aid or assistance; the percentage of such individuals is 17.7%. These differences in the form of special need between both focus groups result from the type of thalidomide damage. There is no specific damage profile in the case of thalidomide victims with severe functional impairments, many bodily functions are affected in their case. 97% of these individuals report decreased ability to cope with strain and stress. This clarifies why these thalidomide victims more often than not require the help of another person for mobility and why aids and supports are of not much use in their case.

## 3.15.2 MOBILITY OUTSIDE THE HOUSE, SOCIAL PARTICIPATION

Mobility outside the house can, on the one hand, be described as movement either with public transportation systems or in one's own vehicle, and on the other hand as pursuing activities outside the house that are important for social participation and require mobility.

Almost equal numbers of thalidomide victims reported problems using their own vehicles (40.6%) or public transportation systems (39.5%). However, on being specifically asked whether the help of another person is needed for using the respective modes of transport, the responses were considerably different. The percentage of thalidomide victims requiring assistance for using public transport systems is more than three times the percentage of those using a car (26.2% vs. 8.2%). The customised technical features of one's own vehicle helps avoid the need for assistance and, thereby, ensure self-dependence to a great extent.

The group with the least mobility issues are the deaf victims, so long as it purely involves movement. However, if the activities involve communication, for instance visiting public authorities or physicians, then even these victims need assistance in 44.7% to 48.9% of the cases.

#### 3.15.3 WHEELCHAIR

Individuals with quadruple limb damage report having the maximum number of problems using a wheelchair. This is the group that uses wheelchair the most; 36.2% of the individuals face difficulties using their wheelchair. An above average percentage of thalidomide victims with severe functional impairments and with phocomelia also often face problems moving with a wheelchair (28.6% and 18.7% respectively). Individuals with severe functional impairments require most assistance with movement using wheelchairs; this involves 20.6% of the individuals of this focus groups. Thalidomide victims confined to a wheelchair often require an electric wheelchair with customised control, as in principle upper extremities too are able to contribute to movement to a limited extent only.

## 3.15.4 PASSENGER CARS

## 3.15.4.1 PASSENGER CAR USAGE

83.5% of thalidomide victims responded in the affirmative to the question whether they used a car. This number is slightly higher than the German national average car density for a population above 18 years, which is 81.5%. Passenger cars are very important for thalidomide victims. They represent a central means for coping with everyday life. Thalidomide-induced disabilities can to some extent be compensated for by making modifications to the car. The highest percentage of personal cars is seen in the group of individuals with double limb damage. Even in the focus groups of individuals with severe prenatal thalidomide damages or severe functional impairments the percentage of personal car users is as high as in the total sample or the general population.

42.5% of the thalidomide victims having a personal car at their disposal report problems using their car. 5.4% of all thalidomide victims possessing a vehicle can use them only with the help of another person, i.e. they need assistance. 2.9% need complete assistance and cannot drive the car on their own. Out of those thalidomide victims who do not have their own vehicle, 21.1% require assistance for using a car.

On average, 81.4% of the thalidomide victims having a personal car at their disposal use it daily. The more severe the disability, the more important the car becomes for them. The frequency of use is highest in the case of severe functional impairment or phocomelia of upper extremities. 90% of car-driving thalidomide victims with phocomelia use their vehicle daily.

# 3.15.4.2 IMPORTANCE OF A PERSONAL CAR FOR SOCIAL PARTICIPATION

Personal vehicles are required not only for transport purposes, but also for maintaining social contacts. People who do not have a personal vehicle were asked whether they felt negatively affected because of that in terms of maintaining social contacts. 25% of the respondents felt negatively affected to a large extent, 24.3% moderately, 27.2% marginally and 16.2% not at all. The magnitude of this negative effect – at least half of the respondents indicate a negative effect on social contacts – points to the importance of a car for independence and social participation.

## 3.15.4.3 PERSONAL CAR FINANCING

The average life of a personal car is 8 years; this almost exactly corresponds to the German national average, which is 8.5 years. Buying a new vehicle is associated with various modifications depending upon the need: Depending upon the damage modifications may be required in the hand or foot controls, or there could be a requirement for lifting devices, ramps or automatic operations. In 62.7% of the thalidomide victims with a personal car there is no health insurance available for vehicle modification.

Individuals with low income, severe damages or functional impairments are seldom in a position to finance the necessary modifications. This can be explained with the argument that the scope of modification measures is also dependent on the severity of thalidomide damage: For instance, purchase and modification of a car suitable for wheelchair users costs several additional 10,000  $\in$ 

#### 3.15.5 AID AND SUPPORTS

Thalidomide victims often require special aids and supports, which are often not included in the aid catalogues of health insurance companies. This includes not only special visual and hearing aids, but also simple practical aids such as dressing rods, wall hooks or grips. Prostheses are equally a part thereof as are technical special equipment that aid communication. Aids and supports for personal use that entail high costs for the victims are made-to-measure clothing and shoes or customised changes to clothing.

Health insurance companies often refuse to bear the costs for aids and supports, and make it necessary for the victim to contribute heavily from own funds. Many of the special devices or technologies are not included in the aids catalogue of the health insurance schemes by default. Therefore, reimbursement of costs is not possible for technical reasons. 50% of the thalidomide victims have uncovered costs for aids and supports. Only 33% of the respondents are in a position to finance these costs on their own.

#### 3.15.5.1 AIDS AND SUPPORTS IN THE CASE OF LIMITED COMMUNICATION ABILITY

The findings with regard to communicative ability in the total sample and in the various focus groups highlight the problem areas. Participants were asked to what extent they had difficulties in understanding spoken words, speaking, having a conversation with a person, reading a written communication and preparing a written communication. The impairments in communicative abilities are almost exclusively limited to individuals with damages in the head region and in sensory organs. Only the ability to prepare a written communication is limited to a considerable extent in the case of individuals with damages in upper extremities. Therefore, the group of individuals without damages in the head region (N=412) was taken as reference group and compared against individuals with damages in the head region and other focus groups.

Deaf victims form a special group. Almost every third individual is unable to have a conversation with another person, even reading and compiling written communications is not possible in the case of a majority of victims. Focus groups that are defined by physical damages other than in the head region could also have difficulties in communication, as there are multiple damage profiles and overlapping of the groups.

16.0% surveyed individuals problems of the have preparing written communications. Accordingly, 13.9% of the respondents expressed the need for a voice recognition program. An appropriate technology was available only in the case of 5.3% of the total sample. One-third of the thalidomide victims with severe functional impairments and with phocomelia of upper extremities expressed the need for voice recognition programs. For 51.1% of the deaf victims a sign language interpreter was required for communication. Only 29.8% had such an interpreter available to them.

19% of all surveyed thalidomide victims have been using a hearing aid for the last 28 years on average. It often requires special or custom-made designs, as standardised devices can often not be used for reasons of multiple thalidomide damages and anatomically difficult circumstances.

48.6% of all respondents require a visual aid on account of the thalidomide damage. This extremely high figure mainly suggests that in response to this particular question it was difficult to differentiate visual impairments related to age. However, in only 5% of the cases these visual aids had become indispensable in the last 5 years. Visual aids had already been essential for the past 30 years on average.

#### 3.15.5.2 INTERNET

77.1% of the thalidomide victims use the internet regularly. The number of internet connections is accordingly higher. The usage is slightly higher than in the general population: 89% of individuals between 30 and 49 years and 68% of individuals between 50 and 64 years use the internet. The internet is used by a high percentage of thalidomide victims with severe functional impairment as well. The internet is mainly a means to gain information and maintain personal contacts. The option of shopping online is also used extensively, especially by individuals with severe functional impairments and severely affected thalidomide victims. Thus, the internet is both a means of communication and also offers an option to manage shopping independently and without assistance.

## 3.15.6 LIVING CONDITIONS

#### 3.15.6.1 SATISFACTION WITH LIVING CONDITIONS

Thalidomide victims were asked about their satisfaction level with respect to their living conditions. Thalidomide victims with acute limitations and with quadruple limb damage, along with individuals in a difficult financial situation are particularly dissatisfied with the layout and furnishing, the level of freedom from barriers and accessibility of their house. Living comfort and location of the house were not so much in focus.

## 3.15.6.2 NEED FOR HOUSE RECONSTRUCTION AND COST COVERAGE

The results of the survey on satisfaction with living conditions reveal that the focus is primarily on very practical issues. Reconstruction of the house is an urgent requirement in the case of 33% of the respondents owing to the thalidomide damage. Particularly important here are the kitchen furnishings, e.g. it is important to have a kitchenette at a specifically suitable height or cabinets to be of appropriate depth, in the bathroom there should be a barrier-free shower or bathtub near the shower-toilet and the height of the wash basin should be appropriately adjusted. Access to living areas should be barrier-free; electronic door-openers or sliding shutters help to manage without assistance or risky movements.

92% of the thalidomide victims requiring house reconstruction state that the costs for the same are not assumed by any third-party. Only 7% of the cases are in a position to finance the reconstructions themselves; accordingly, important reconstructions remain undone in most cases.

Functional impairments constitute a high need for adjustments and customisations in the surroundings. Therefore, the need for house reconstruction is above average in the case of individuals with quadruple limb damage and with severe functional impairment, and is required by 47.5% and 40.6% of the surveyed individuals respectively. There is a close relation between the degree of thalidomide damage and the need for house reconstruction: The more simultaneously occurring damage areas an individual has, the more urgent is the need to make modifications and adaptations to the house.

## 3.16 Episodes of Depression/Major Depression and Thalidomide Damage

#### 3.16.1. COMPARISON WITH GENERAL POPULATION AND GENDER-SPECIFIC ASPECTS

As per the results of the study, the percentage of thalidomide victims suffering from a depressive disorder (11.7%) is considerably higher than that of the comparable cohort of 50-65-year-olds in the general population (8.1%). As compared to the general population, where depression-related diseases are twice as much in women than in men (11.3% vs. 4.8%), gender-specific difference in the thalidomide sample is low (14.1% vs. 10.8%).

#### 3.16.2 SOCIAL NETWORK

Contingent upon the limitations that thalidomide damage brings in its wake, victims are often dependent on the support of their social network. The spectrum of these supports ranges from help in everyday matters right up to coping with crisis situations. However, if an individual suffers from a depressive disorder, then the main symptoms of avolition and dejection could lead to a situation where such an important network can neither be maintained nor developed further.

In 98% of the cases who exhibited values within normal limits in the MDI (78.6% of the total sample), it was true that they had someone "with whom they like to do things". On the other hand, a weak social network could encourage a depressive disorder. Subjects who responded to the question "someone who takes the effort to help in the case of difficulties" with "strongly disagree" and "somewhat disagree ", were significantly more often of a depressive disposition or suffered from major depression than those subjects who responded to the question with "somewhat agree" or "strongly agree". Even those individuals who evaluated the question "someone who could help anytime" as not applicable had significantly more frequent symptoms of depressive episodes.

#### 3.16.3 GAINFUL EMPLOYMENT

Under gainful employment differentiation was made between full-time workers, parttime workers, occasionally or marginally employed and unemployed. Unemployed thalidomide victims had the poorest functional ability in comparison. 73% of them are completely unable to earn. The number of individuals with symptoms of major depression is almost three times as high in the case of unemployed thalidomide victims (12.9%) as compared to full-time workers (3.7%).

#### 3.16.4 PAIN AND DEPRESSION

Another risk factor for the occurrence of depressive disorders is pain, which is experienced by 84% of the thalidomide victims in varying degrees of severity. Going by the severity of pain it is found that 18.4% of the patients reporting pain in the category "severe to extremely severe pain in the last 2 weeks" show signs of major depression. Another 19.3% suffer from a depressive disposition. In cases where the pain in the last two weeks was at the most moderately severe only 5% of the respondents reported symptoms of a major depression. 7.6% were found to have indications of a depressive disposition. The risk of developing a depressive disorder was nearly tripled for all degrees of severity when the pain was severe. These results emphasise the importance of pain therapy for good psychological health.

# 3.16.5 NEED FOR LONG-TERM NURSING CARE AND ASSISTANCE AND DEPRESSION

In the case of people requiring long-term nursing care the number of individuals with symptoms of a major depression was 15.5% and was almost double the number of people not requiring long-term nursing care, which was 8.5%. Here, an important criterion for depression to be present was mainly the assessment as to whether the need for long-term nursing care is covered or not. The percentage of severe depression in individuals with uncovered long-term nursing care need (8.2%) was four times as high as in the case of thalidomide victims who rated their need for long-term nursing care as covered (1.8%).

Symptoms of depression follow a similar pattern with respect to the need for assistance as in the case of need for long-term nursing care. Even here, the number of individuals with symptoms of a major depression was the highest due to uncovered need for assistance (20.4%); 15.5% of the cases exhibited a depressive disposition. At 11.9% major depression was higher in individuals who considered their need for assistance as covered than in individuals with no need for assistance (8.1%).

#### 3.16.6 DAMAGE GROUPS

The more the number of simultaneously occurring thalidomide-induced damages, the higher is the risk of developing symptoms of depression. In the case of seven to eight damage areas the percentage of thalidomide victims with severe depression is over 10%.

#### 3.16.7 FOCUS GROUPS

The focus groups comprising individuals with reduced earning capacity, complete earning disability, damages in head region and functional impairments suffer from particularly severe episodes of depression. The high percentage of severe depression in the deaf victims' group points to the role of communication problems in the development of depression. Depressive disorders are most often seen in the group of thalidomide victims with functional impairments. It should be noted here that in these individuals the risk factors for the development of depression such as multiple thalidomide-induced damages, loss of self-reliance and dependence on other people due to strong need for long-term nursing care and assistance, severe pain, reduced ability to cope with strain and stress and limited capacity to earn very often occur together.

## 3.17 QUALITY OF LIFE

#### 3.17.1 MEASURE OF THE QUALITY OF LIFE

The survey results of the quality of life in thalidomide victim group were initially compared with the values of the general population in the age-group of approx. 50 years. Significant differences were seen here: Thalidomide victims exhibit considerably poorer values for subjective appreciation of the quality of life; the values in their case correspond to the quality of life values of approx. 80-year-olds.

The results also express poorer health conditions of thalidomide-affected women and men on average. The overall evaluation of the quality of life is particularly indicative of this. In this case, the value deviates significantly from the age-related values. If one compares the derived values with those documented with regard to cases in the general population suffering from severe ailments like osteoarthritis or heart diseases, one finds that both values coincide to a large extent. This also matches the symptomatology of thalidomide victims, who for the most part suffer from pain and reduced ability to cope with stress.

## 3.17.2 QUALITY OF LIFE AND PHYSICAL CONDITION

Pain significantly deteriorates quality of life. 84.6% of the surveyed individuals complain of pain, of which 35.8% alone complain of severe to extremely severe pain. Because of this, 99% of cases in this severely affected group are particularly restricted in performing their everyday activities, and 90.5% of cases are unable to form social relationships. Muscle tension also causes pain and has an influence on the physical well-being. 76.7% of the respondents suffer from muscle tension in the spinal region; 52.2% in fact suffer from considerable and severe muscle tension. 98% of these cases suffer from chronic complaints, which permanently restrict efficiency and ability to work and require huge treatment costs. The information given by these individuals to assess the quality of life is significantly more negative than the average values determined in the case of thalidomide victims.

Another cause of the significantly reduced quality of life in these individuals as compared to the general population is the impairment of physical capacity and fitness. This is applicable to 80.7% of all respondents, 64.4% have been observing this for more than 5 years. Indicators are that individuals tire easily and need longer relaxation time after physical activities. Wherever physical activity is a prerequisite for professional work, maintaining social relationships, personal care and social participation, reduced ability to cope with stress or strain can have an effect on the quality of life. In at least 43.8% of thalidomide victims physical capacity and fitness is impaired to a considerable or large extent.

#### 3.17.3 QUALITY OF LIFE BY NUMBER OF DAMAGE AREAS

The risk of losing independence, developing secondary damages and pain increases with the number of damage areas that have cumulated in an individual. As expected, this has an effect on the quality of life. The higher the number of simultaneously affected areas, the poorer is the quality of life. In particular, the values defining physical health become poor with an increasing number of damage areas. In contrast, however, the relatively good values for items pertaining to environment and social relationships are worthy of notice. Perhaps this is an expression of the fact that thalidomide victims give particularly high value to a functioning social network and assistance in the living and surrounding environment. The quality of life that is only below-average for the total sample is reached by individuals exhibiting 5 or more damage areas; this corresponds to one-third of the total sample.

#### 3.17.4 QUALITY OF LIFE IN FOCUS GROUPS

Statements on quality of life were also recorded for individual focus groups. The values of the total sample and the group of individuals with most severe functional impairments were taken as a reference.

The group comprising 25% of thalidomide victims with least functional ability exhibits values most deviant from the average result of the total sample on the question of quality of life. The impairments recorded there are in terms of everyday functions as well as mobility and participation. Almost all these individuals need long-term nursing care. Values in terms of quality of life are extremely poor in the physical domain and in the overall value strongly related to physical health and fitness. This is indicative of the fact that the concept of health is defined to an exceptionally crucial degree by the ability to function in the case of thalidomide victims. The results of this group in terms of physical ability, social relationships and environmental aspects is likewise significantly worse; however, they do not deviate much from the average value except in the area of physical ability. The relative satisfaction with social relationships corresponds to the life-long efforts by thalidomide victims necessary to build a stable network based on sustainable and strong relationships.

#### 3.17.5 QUALITY OF LIFE AND FULFILLMENT OF NEEDS

There is a distinct correlation between quality of life and the existence or fulfillment of the need for assistance. Reference groups are individuals without the need for assistance, who are capable of achieving the best values in all domains defining the quality of life. Where the need for assistance is covered, the quality of life in all observed areas is significantly better as compared to uncovered need for assistance. It is particularly evident in the level of satisfaction with environmental conditions. Negotiating barriers is often possible only with assistance. However, if this assistance is available, it is likely to result in a positive appreciation of environmental circumstances. In the social domain it is possible to understand the negative assessment in the case of uncovered need for assistance: Assistance is defined by the existing social relationships. Individuals who are not alone have the possibility of receiving assistive support, even if it is required only for a short time.

Even the fulfillment of the need for long-term nursing care shows a clear correlation with quality of life. Where this need is not fulfilled, all the values are significantly poorer – like in the case of 29.8% of the respondents – as compared to cases where the need is fulfilled (20.0%). The level of satisfaction with social relationships forms an exception.

The quality of life is considered poorer if there is an urgent requirement for house reconstruction or modification, as reported by one-third of the respondents. This is also true if there is no health insurance available.

### 3.17.6 Relative Importance of Characteristics Defining Quality of Life

Highly significant regression models emerged for each domain and for the overall quality of life. In the process, the highest variance was explained in the case of physical well-being with an R<sup>2</sup> of 0.64. The most important parametric features here are the markedness of pain, functional ability, depressiveness, social network and income. Psychological well-being is primarily dependent upon the existence of depression and the quality of social relationships. The satisfaction with environmental conditions, which also involves medical care, shows close connections with all incorporated characteristics. On the whole, the results highlight the importance of the social network. A close correlation between depression and quality of life was found throughout; this corresponds to the results obtained in other studies during the WHOQUOL analyses.

## 3.18 RESULTS OF INTERVIEWS AND FOCUS GROUPS

#### 3.18.1 THE HETEROGENEITY OF THE GROUP OF THALIDOMIDE-AFFECTED WOMEN AND MEN

The specific damages, with which the thalidomide-affected women and men are confronted from birth, prove to be extremely diverse. Above all, however, huge differences can be seen in the manner in which the thalidomide-affected women and men have attempted to compensate for the functional damages in their lives so far, as well as the kind and scope of help and assistance they have received in their attempts.

The major differences are found (a) in the support given or not given by family members in childhood and at school age, (b) in the way one's own parents – in the experience of the child – dealt with the thalidomide damage and the attitude of the family, neighbours, acquaintances and friends, (c) in the extent of emotional support provided to the daughter or son affected by thalidomide and (d) in the way they themselves dealt with the thalidomide damage in their child – in terms of self-reproach, reproach against the partner, blaming fate, dejection, in the sense of focussing more on the child and its promotion or in the sense of denial. And this very heterogeneity seems to explain to a great extent the distinctness with which these people have gone about their lives.

#### 3.18.2 EXPECTATIONS OF THALIDOMIDE-AFFECTED WOMEN AND MEN AS REASONABLE CLAIMS

The findings from the interviews and focus groups shed light on the fact that a vast majority of thalidomide-affected women and men were able to stand up to the social environment, to develop a high degree of independence and take initiatives quite early on in life. Against the backdrop of these creative and inventive achievements there is also the need to understand and appreciate the currently described apprehensions and fears about being able to retain the physiological compensation, as well as the expectations in terms of medical and rehabilitative care, availability of resources and guarantee of assistance as an expression of expertise apropos living one's own life. This also predicates that the expectations in terms of the facilities and provisions that need to be made available in the future are reasonable and justified claims and not merely "subjective ideas of covetousness and desire".

## 3.18.3 Self-image and Self-dependence as a Central Theme in Life

Going by the descriptions of subjectively important events and experiences it can be concluded that the many problems occurring in life have been dealt with objectively and realistically.

The sources of the internal control patterns can more or less be traced back to childhood or school age: On the one hand, they seem to have developed under the effect of the parents being cautious and concerned about self-dependence and self-image quite early on. On the other hand, they had to be conceptualised and developed by the children themselves with extreme self-reliance because the parents as well as the attending family physicians and orthopaedists were unable to convey or facilitate physiological compensation strategies. This is coupled with the fact that many children lived in a boarding school or rehabilitation institution for long durations, where they had to largely fend for themselves and, thus, had to become self-reliant quite early.

Self-dependence and personal responsibility is also evident in the comparatively high psychological ability to adjust, which is mainly reflected in the ability to accept the life that has passed so far as well as the damages that exist. As per the interviewer's evaluation, individual indications of depression symptoms were observed in around one-third of the participants of the interview. In certain discussions a marked tendency to not accept fate combined with suicidal intentions and considerable loss of motivation was observed, which is indicative of symptoms of depression that require treatment.

Going by the biographical statements made in the interviews it appears that already as children or adolescents, thalidomide-affected women and men learned to deal with the physical and social limitations created by the disability in a mature way. Furthermore, they developed creative adjustment strategies keeping in view the spatial and environmental requirements. Even if practically all thalidomide-affected women and men spoke of specific instances of discrimination, the perception that personal development was negatively affected by discriminative experiences was present only in a few cases comparatively.

#### 3.18.4 NECESSITY OF DIFFERENTIATION BETWEEN ACCEPTANCE AND SATISFACTION

The comparatively high percentage of thalidomide-affected women and men indicating an acceptance of their life, the disability and the current situation should, however, not be equated with an equally high percentage of women and men who could have been satisfied with their life situation. In fact, the majority of women and men in the interviews were convinced that they would not be able to retain the present physiological compensation in the future. Moreover, they feared being confronted with increasing health and functional impairments, as well as with episodes of pain and, correspondingly, exhibiting an increased need for assistance. The statements recorded in the interviews, that one could compare one's health situation as well as functional ability with that of much older people, are an indicator of this rather pessimistic anticipation of the future.

## 3.18.5 INCREASING THREAT TO COMPENSATORY ABILITIES

A major section of the interviewees and participants expressed spontaneously or upon enquiry the apprehension that the current support arrangement (network, assistance, freedom from barriers, technical support) for compensating the functional impairments would not be enough, perhaps not even sustainable, in the future. Most of the participants of the interviews described a gradual decline in physical ability and strength as shown primarily by significantly increased fatiguability, considerably quicker onset of tiredness and exhaustion and significantly decreasing pace while performing everyday tasks.

A section of the interview participants have reduced their occupational hours or even quit their jobs. All participants of the interviews intensively dealt with the question as to how they would react to the already present or feared deterioration of their health situation. The outlook was dominated by apprehensions and worries: a few of these include in particular further development in terms of self-dependence, financial autonomy, continued mobility, maintenance of sustainable social networks, as well as independent, socially integrated living. Alternative models were suggested with regard to living, such as several generations living together or living in local residential communities. As was to be expected, retirement or old-age homes were not considered a realistic option at all. Making alterations and modifications to the house constituted a central purport of the future personal enterprise; expectations of receiving appropriate financing for these modifications are very strong.

## 3.18.6 Dealing with Pains that may Occur or Intensify in Future

The apprehensions reported by the interview participants about episodes of pain occurring in the future or else intensifying further is important also from the point of view of the thoughts and reflections about (a) future in the job, (b) future activities in personal routine and (c) future health care requirements.

Regarding (a): Thoughts and reflections about jobs concentrated, on the one hand, on the speculation as to how long one could even remain employed if pains arise or existing pains intensify in future. On the other hand, many reflections were made as to how the working conditions should be designed to be able to at least work part-time even in the case of severe pain. These ideas mainly included: (I) modified ergonomic conditions in the work place, combined with a discernibly developed technology to support the physiological compensation of functional impairments and reduced physical performance levels; (II) increased integration of periods of rest and relaxation, combined with relaxation training incorporated into the work routine to mitigate episodes of pain as well as ease tensions; the currently available options were unanimously rated as insufficient; (III) switching to another work place, at which the required pace of work processes is considerably reduced and expertise is given more importance instead.

Regarding (b): Episodes of pain were considered as an important cause for problems while carrying out activities of everyday life. The reason given for declining self-dependence and reduced social participation was mainly the fact that episodes of pain often lead to adaptive postures and a lot of time and energy needs to be spent on treatment and prevention of pain, which brings about more stress and also adversely affects the quality of life. An optimised pain therapy according to them included within the context of discussion topics like "self-dependence", "coping with stress", "demands on the medical and nursing care system" significant protection against detriments to self-dependence and social participation.

Regarding (c): Finally, in the interviews, particularly in the appropriate focus groups, requirements for future medical care, which result from the specific role of pain in the lives of thalidomide-affected women and men, were formulated. Utmost importance was assigned to the need for highly differentiated and more in-depth pain diagnostics, as well as considerably better physical and pharmacological therapy – and at the same time complaints were made that physical therapy is too rarely prescribed and if prescribed, it is not for a sufficient amount of time and the pharmacological therapy is not sufficiently funded. Almost all participants of the interviews as well as the focus groups expressed this criticism of the current medicinal and rehabilitative care. It was repeatedly expressed that the personal need is not covered by what the physician deems normal.

All individuals who complained of chronic or repeatedly occurring acute episodes of pain, highlighted the outstanding importance pain and the successful control of pain play in defining the quality of life. The high psychological adjustment abilities required during episodes of pain were spoken of in the focus groups in particular – though even with successful psychological adjustment there are frequent occasions, when there is a loss of motivation and feeling of resignation. The result of this is often that

the will to live is considerably diminished for some time and there are episodes of depression. This is observed mainly in cases when after a period of considerably reduced pain or even no pain, episodes of pain reoccur and persist for long periods. It is in these cases that psychotherapeutic support is expected.

## 3.18.7 PROFESSIONAL OCCUPATION AS AN IMPORTANT FORM OF SOCIAL PARTICIPATION

For a majority of thalidomide victims professional occupation formed or forms a significant opportunity for social participation, feeling competent and experiencing autonomy. A section of the interviewees described thalidomide damage as a reason for not being able to realise the professional goal, for which appropriate qualification was acquired. Nevertheless, it was established for a majority of even these women and men that they identify with their professional occupation and find meaning and a sense of fulfillment in it. Against the backdrop of these statements, the impending giving-up of employment due to functional impairments and chronic pain is not only associated with huge financial risks, but also with the risk of significantly impeding social participation.

## 3.18.8 SOCIAL PARTICIPATION AS A CENTRAL NECESSITY

A review of the lives and biographies during the interviews already provided an insight into the wide spectrum of reasons for social participation: Participation in social network, intensive contact with individual people of this network, the necessity to also do something for others, the give and take of help and assistance, as well as a sense of shared responsibility experienced and practised for other people form the central reasons for social participation.

Relationships with other people were rated positively in most cases.

Serious discriminations were reported only rarely. Rather, a comparatively higher sense of satisfaction with the type, extent and quality of social contacts emerges in thalidomide-affected women and men in the interviews and the focus groups. There were only very few indications of experiences of stressful isolation.

Maintaining social integration and participation – also in terms of commitments to other people – was indicated by a majority of interview participants as the key prerequisite for good quality of life and well-being. This explains, too, why maintaining mobility was interpreted by all interview participants as another central requirement for the quality of life and well-being.

Adequate mobility alone ensures integration and participation in society. The subsequent question dealt with in the interviews and focus groups was: what happens to an individual when one loses one's job and with that the relations with colleagues decline, when children leave the parents' home and town, when one's own parents become dependent and are then unable to support the child any longer, when parents pass away. These possible developments were seen as threatening also because they have a direct impact on social integration and participation. This indeed helped to derive the overriding significance of continuation of personal assistance for thalidomide-affected women and men so that they have a sense of

being alive: In the absence of any surety of being able to socially integrate and participate the importance of professionally and personally significant assistance becomes all the more important than it already is. For in this case assistance also ensures interaction, which becomes more and more difficult to have with declining social integration and participation.

## 3.18.9 GUARANTEE OF PERSONAL ASSISTANCE IN THE FUTURE OUTLOOK

The fact that the physiological compensation strategies once successfully implemented are now being increasingly challenged by the increasing physical vulnerability and must be redesigned again and again – together with the changes in the social network that have already happened or else are apprehended in the near future - makes it extremely important for thalidomide-affected women and men to have a guarantee of personal assistance in their lives. The guarantee of personal assistance - and one that has been selected by the victim himself/herself - was considered as an important component even of future health care and maintenance by the women and men surveyed in the interviews and the focus groups. In this regard, almost all women and men expressly emphasised that thalidomide damage should not be equated with need for care. Instead, even if it entails receiving nursing insurance benefits now or in future, it should mainly be understood as an umbrella term for a broad spectrum of disabilities that varies from individual to individual. And this very understanding should form the basis of all decisions with respect to the type and scope of personal assistance – a decision, that in principle can be made only by a thalidomide victim. Owing to the gaps in the existing social network of thalidomideaffected women and men definitive decisions with regard to a person capable of undertaking this personal assistance will become necessary to some extent in the near future itself.

## 3.18.10 CONTINUED MOBILITY

Ensuring mobility emerged as the most important topic in all interviews and focus groups. Opinions gathered on this topic were mainly related to modification of personal cars. In this context it should be noted that an increasing number of thalidomide-affected women and men live alone and, therefore, have to use the personal car on their own. This for instance is possible for individuals with phocomelia if a foot control is integrated in the vehicle. Vehicles with provision to take wheelchairs along as well as absorption of modification costs were demanded as part of unfulfilled requirements in the interviews and formed a repeatedly raised demand in the focus groups as well. A personal car equipped as per requirement and also financed was considered as a crucial characteristic of good quality of life by almost all participants of the interviews.

### 3.18.11 CONTACT WITH PUBLIC AUTHORITIES, HEALTH INSURANCE COMPANIES AND PHYSICIANS

Contacts with public authorities and health insurance companies were described as riddled with conflict by a majority of thalidomide-affected women and men. As shown by the interviews and discussions, this mainly had to do with an extremely low, to some extent entirely absent, perceived level of information of the administrative authorities; it was unanimously complained that the administration had no idea about the physiological compensation strategies adopted by thalidomide-affected women and men, as well as of the possible threat to the successful continuation of these physiological compensations. Physically disabled people are often treated as people with mental handicaps. Against the backdrop of such stereotypes and distorted perceptions a more discerning and precise understanding of the need for aid and support is likely to be quite low and is likely to question the expertise of thalidomide victims regarding the necessary health care facilities. For these reasons it is important that employees in public administration radically amend their attitude and mindset as well as their methods vis-à-vis thalidomide victims.

Contact with physicians was characterised as problematic in the sense that they did not really know about the given complications, or treated them either incorrectly or not at all. There are, as was revealed in the interviews, huge differences between physicians with respect to appropriate and individually-suited prescription of therapies, rehabilitation programmes and aids. A few people reported on a physician, who acknowledges a thalidomide victim exclusively as an expert in his or her own matters and complies with his or her prescription preferences – and the interviews showed that thalidomide victims know a lot about the disability and are able to demonstrate this knowledge of their specific condition.

#### 3.18.12 FINANCIAL DIFFERENCES AND BOTTLENECKS

The amount of financial resources available has a particularly great impact especially in the case of disabled people with physiological compensation. Sufficient financial resources are important not only from the point of view of financial security, but also with regard to financing personal assistance services and ensuring reciprocity in social relations.

Regarding statements on the financial situation it should also be taken into consideration that thalidomide victims often finance particular rehabilitation programmes on their own, which yet again clarifies how important adequate financial resources are for maintaining self-dependence. All thalidomide-affected women and men emphasised that they should be provided with a definite financial sum and the decision on how to use this amount should be with the individual. For the individual is in the best position to judge what he or she needs; the individual possesses the knowledge that a public administration employee does not have. A catalogue of non-cash benefits was unanimously considered extremely problematic, as thalidomide victims differ greatly in their specific needs and requirements. All thalidomide-affected women and men exclusively expressed the need for assistance – financial benefits significantly higher than those provided currently are required to be able to regulate this need individually.

#### 3.19 DEAF AND HEARING-IMPAIRED VICTIMS

In comparison with hearing-impaired victims or with the group of thalidomide victims without hearing impairment deaf victims exhibit a very high percentage of severe damages in the head region and the sense organs; the musculoskeletal system, however, is affected to a much lesser extent. The severe secondary damages involving severe pain and limitation of movement and mobility are, therefore, less pronounced in deaf victims than in hearing-impaired victims and those without hearing impairment, and the degree of pain is also less.

47% and 37% of the deaf victims exhibit damage in arms or hands respectively; damage in lower extremities is found in 33% of cases. Instances of malformations in the vertebral column are also found more often (63%).

79% of hearing-impaired victims exhibit malformation of the arms, 73% of fingers and thumb. They suffer from damages in these areas to a lesser extent as compared to victims without hearing impairment, but almost twice as often as the deaf victims. At 60% the number of hearing-impaired victims suffering from damages in the leg region is almost double that of deaf victims. Damages in the vertebral column are found in over 90% of hearing-impaired victims and thalidomide victims without hearing impairment and, thus, significantly more often than in the case of deaf victims.

In the sense organ area deaf victims are affected more often than the other two groups. With regard to relative prevalence of damages in internal organs deaf victims are affected most severely at 75%, followed by hearing-impaired victims at 68% and thalidomide victims without hearing impairment at 55%. Abnormal developments in internal organs take on greater significance with increasing age; ageing processes build on existing abnormal developments and limitations of the organ function and lead to further loss of health.

Facioplegia, or paralysis of the facial muscles, occurs in 64.6% of deaf victims, which is two and a half times more often than in hearing-impaired victims. The situation in the case of deaf victims is more aggravated because the malformation occurs on both sides in more than one-quarter of the cases. Owing to the paralysis of the facial muscles the faculty of facial expression, which plays an extremely significant role in interpersonal communication, is largely destroyed or else deformed.

Vision damage was found in all three groups. The deaf victims exhibit the highest overall percentage of 69.3%; in 55.1% of the cases the vision damage is in both eyes. This group also showed the highest number of blind cases, the relative percentage is 8.7%.

Vision damage also occurred in half the hearing-impaired victims and 43.8% of individuals with no hearing impairment. More than one-third of the deaf victims exhibit malformation of the jaw and teeth; cleft palate with speech disability is found in 18.8% of cases; the values of both reference groups are in single digits.

The percentage of prenatal damage in the musculoskeletal system is low in the case of deaf victims; it is outweighed by internal damages and damages in the head region. 10% of the deaf victims report severe pain episodes in the auricular region, auditory canals and head. Due to ophthalmoplegia or eye-muscle paralysis pain is

experienced in the neck, as while reading the head has to follow the lines or the book has to be passed in front of the eyes.

The problems faced by hearing-impaired victims are quite different from those encountered by deaf victims, as they are able to hear and, therefore, learn the language of hearing people. With age, the deficit or impairment of hearing is perceived as loss of hearing by many victims; although the hearing capacity does not reduce in all cases, the acoustic perception decreases. Hearing aids are of no use in the case of hearing impairment on one side, as here one ear listens via aerotympanal conduction while the other via bone conduction.

82% of the deaf victims need spectacles, 42% a hearing aid. 70% of hearingimpaired victims require spectacles. Wearing spectacles can have a negative effect on lip-reading, as sometimes presbyopia can cause problems. In comparison, very few (42%) require a hearing aid.

In comparison with hearing people hearing-impaired victims exhibit varying results when it comes to education and professional occupation. The extent to which hearing-impaired victims are able to communicate with hearing people decides what school-leaving qualification they achieve.

13% of the deaf victims have no school-leaving qualification and almost half have a certificate of secondary education. All three groups are equally represented (25%) in the Realschule [~secondary school]. One-third of individuals with no hearing impairment and one-quarter of hearing-impaired victims complete abitur [secondary school leaving certificate], and only 2.2% of deaf victims complete abitur. Acquiring higher education is very strenuous for the victims and requires an intensive school support to balance the deficits in language and communication skills with hearing people.

27% of the deaf victims with thalidomide damage have no vocational and occupational certificate and almost 50% of cases have only one certificate. These people are rarely represented among academics in contrast to both reference groups. Hearing-impaired victims have problems with the spoken language as well; however, they are familiar with the language of hearing people. They have acquired a university degree in 14% of cases just like the thalidomide victims without hearing impairment.

The number of deaf victims with complete earning disability is 44.2%, and at 36.6% the hearing-impaired victims are considerably above the average value of the total sample. The number of individuals with partial earning disability is at 11.0% and corresponds approximately to the percentage of deaf victims and hearing-impaired victims. It is not only pain and discomfort that leads to quitting of jobs, but also the lack of communication in the work place that invariably has the result that important information does not reach the victims, that there is an increasing sense of isolation in the work place and no interpersonal contacts are maintained.

## 3.20 LONG-TERM SEQUELAE

During pregnancy thalidomide causes prenatal damages in the musculoskeletal system and the internal organs. The type and degree of damage are determined by the timing of drug administration. Thalidomide damages all the growing blood vessels. Long-term sequelae should be classified as prenatal damages, which due to various reasons have been diagnosed only at a later point in time.

Based on a systematic survey and clinical reports there was evidence to anticipate long-term sequelae in three areas:

1. Prenatal damage of the vascular system

There is evidence that blood vessels are often narrow, thin-walled and fragile. The vessel density can also be low causing decreased blood circulation. The course of the blood vessels is not always proper, because of which atypical blood vessel courses can be expected during surgical procedures. Taking a blood sample is complicated in many victims; it is not always possible to take the pulse or check the blood pressure, or else these can be measured at atypical locations.

Malformation of the lymphatic system is also possible, which causes painful oedemas that are successfully handled therapeutically by the victims everyday by means of a lymph drainage.

- 2. Prenatal damages of the nervous system The victims report on an atypical course and inappropriate positioning of the peripheral nerves, and, corresponding to this finding, an atypical supply to the periphery, with development of sensory and motor disorders.
- 3. Prenatal damage of the musculature

An increasing weakness of the muscles and decrease in the ability to cope with stress is reported by a high percentage of victims; the situation has become significantly aggravated in the last three to five years. After undertaking a physical activity that is strenuous for the victims they do not need the usual couple of hours of rest or relaxation. Instead, they often require one or more days in between activities. During muscular strain, victims describe muscular cramps of varying degrees even in the extremities not visually affected. Also mentioned are subtle, rhythmically longer lasting spasms, which do not allow normal movement, to painful muscle contractions, tremor-like episodes, also tensions of long durations that cause pain, or muscular pain during strain or stress.

On the basis of a focussed and specific survey of thalidomide victims, as well as a look into the medical records, it can be assumed that the vascular system – arteries, veins and lymphatic vessels – and/or the nervous system and/or the musculature have been prenatally damaged in varying degrees in at least a part of the victims. These damages are usually termed as long-term sequelae, which however is misleading, as it involves prenatal, structural damages.

Because this type of damage involves prenatal damage, there is no primary prophylaxis or cause-related therapy. The direct and indirect consequences of these damages can, however, be assessed on closer examination and diagnosis, and can be avoided or alleviated by means of appropriate measures. A systematic and scientific examination is recommended to determine the type and extent of these prenatal damages and to avert possible dangers faced by thalidomide victims.

## 4 STUDY RESULTS OF THE PHYSICIANS' SURVEY

Letters were sent to registered physicians, whose patients had released them from their confidentiality obligation. 69.4% male and 30.6% female physicians took part in the survey, and 87.1% of the participants indicated their field of specialisation as general medicine or internal medicine. Representation of orthopaedic specialists was at 6.5%. Medical practitioners of all age groups from 35 to 84 years took part in the survey.

The question as to whether the physician had special knowledge of thalidomide damage was answered in affirmative by one-third of the physicians. Apart from newspapers and lectures, the most important source of information is getting acquainted with thalidomide-affected patients themselves. The surveyed physicians reported to have acquired specific knowledge on thalidomide damages from their acquaintance with thalidomide victims. From the physicians' point of view, 82% of the victims seek medical help regularly.

# 4.1 THALIDOMIDE DAMAGES: AFFECTED ORGAN SYSTEMS AND COURSES

Over 90% of the complaints and problems communicated to the attending physicians relate to the musculoskeletal system; one-third of the problems concern cardiovascular organs, and almost half of the victims seek a physician because of psychological problems. These results more or less correspond to the results of the victims' survey.

Two-thirds of the attending physicians have observed changes leading to deterioration of health for the last five years or more; around one-third indicate this period to be between two and below five years.

Two-thirds of the medical practitioners observed the preliminary instances of secondary damages for the first time five or more years ago; a further one-third observed these in a period between two to below five years. 70.7% considered the progression of the deterioration as being slow; one-quarter considered it as being rapid. These results confirm the statements of those thalidomide victims who participated in the study.

## 4.2 PAIN

83.3% of attending physicians observed pain in thalidomide-affected patients. The percentage corresponds to the results of the victims' survey. More than half the respondents state that pain has been observed for a long time, ten years or more. 22.9% have observed pain for the last 5 years or more, 16.7% only for the last 2 to less than 5 years.

An increase in episodes of pain has been observed for the last two to less than five years by almost half the physicians. One-third of the physicians have been observing the increase in pain for a longer period, for the last five years or more.

A little more than half of the attending physicians report that thalidomide victims take pain-killers, and are prescribed non-opioid analgesics in 77.8% of cases, light opioid analgesics in 14.8% of cases and strong opioid analgesics in 7.4% of cases. This result confirms the statements of the thalidomide victims that they are very reluctant to take medications.

91.8% of the physicians confirmed the need for physiotherapy for alleviating pain and discomfort. Out of the 46 physicians who answered the question as to whether they could provide adequate physiotherapy treatment, only 27 physicians responded in affirmative.

Almost two-thirds of the surveyed physicians confirmed in accordance with the results of the study that there is an increase in the episodes of pain and the need for assistance, and that in the coming years the functionality will reduce.

#### 4.3 LONG-TERM SEQUELAE

38 physicians reported long-term sequelae, out of which 42.1% reported long-term sequelae in the blood vessels, 21.1% in the nervous system area and 57.9% in the musculature. An atypical course of blood vessels was reported by 10% of the physicians. 5 out of 40 physicians observed an atypical course of nerves in the peripheral nervous system, an equal number documented evidence for an atypical structuring of the PNS / CNS using imaging techniques.

39 physicians answered questions about long-term sequelae in the musculature. Half of them mentioned a non-age-appropriate weakness of muscles, 69.2% mentioned reduced trainability, 28.2% mentioned atypical muscular structure.

### 4.4 PATIENT-CENTRED CARE OF THALIDOMIDE-AFFECTED PATIENTS

75.4% of the physicians confirmed spending added time towards patient-centred care of thalidomide victims, as they often require forms of therapy other than those required by the general population.

To the question as to whether thalidomide victims received all required therapies/aids from the statutory health insurance the response 'yes' was given by 70.2% of physicians. The following question as to whether patients are in a position to pay themselves for the services and benefits not covered was answered 'no' by 61.5% of physicians. The physicians, thus, confirm that the amount of required therapeutic services and benefits is not optimal for a majority of their patients.

Half of the surveyed physicians state that the health care provisions for thalidomideaffected patients are not sufficient. Medical care services are described as 'very good' only by 3.2% of the respondents. Owing to the inadequate health care provisions, as well as the increasing complaints, 24 out 27 physicians anticipate that thalidomide victims will retire earlier from their professional lives.

An extremely low budget earmarked for thalidomide victims with most severe and multiple damages was predominantly stated as the reason for the inadequate quality of health care provisions, and 96.7% spoke out in favour of withdrawing thalidomide victims from the budgeting regulations.

Specific knowledge about the damage and the measures that lead to optimal therapy are required for appropriate health care provision. 67.2% of the attending physicians are interested in specialised and advanced training, and 80% would also like to use a Contergan (thalidomide) database with information on thalidomide, the damages and their consequences on an interactive platform.

## 5 COLLATION OF DAMAGE POINTS, PRENATAL DAMAGE AND CURRENT SITUATION

#### 5.1 DAMAGE POINTS

Damage points depict the location and the nature of prenatal damage, and form the basis for the financial benefits provided to the recipient.

With an increasing number of damage points the number of prenatally damaged organ systems also cumulates, as well as the degree of individual damage. The Medical Points Table can be viewed on the Contergan Foundation homepage. The damages are subdivided into orthopaedic, internal, eyes and ENT damages, which are evaluated with a point system that assigns a maximum of 100 points for each area mentioned. The total value is calculated using a formula, which determines the amount of monthly benefit, capital compensation and special payments. It is not possible to reach more than the maximum 100 points.

Prenatal damages are very diverse and occur in very different combinations. They are attributed to the day or days of taking Contergan (thalidomide) during pregnancy and to the development stage of the unborn child. The developmental stage of the embryo is the determining factor for the sensitivity towards damaging substances.

Thalidomide has a negative effect on growing blood vessels; the substance impedes their development. This effect is particularly noteworthy in the case of rapidly developing organ systems. However, the fact should not be ignored that in the prenatal stage the entire organism is in a state of growth and development in varying degrees.

Every victim is affected differently in terms of the type and extent of prenatal damage. The size of the total damage score is not indicative of which organ systems are affected and to what extent. Extremely diverse damages could arrive at the same damage score in terms of numbers. Thus, for instance, loss of hearing or vision on both sides or complete paraplegia receive 60 damage points each. An inoperable cardiac anomaly with insufficiency is evaluated at 50 points, amelia (abrachia) of upper or lower extremities is evaluated at 44 and 40 damage points respectively. Thus, damages with the same or similar score could be very different from each other.

Case studies were designed to convey the range of prenatal damages and their consequences in the context of the assigned damage points. The prenatal stage is compared with the current situation in order to illustrate the progress of the damage in the past 50 years and its consequences, and to shed some light on individual

needs. The gender selection is random. The examples are available for review in the final report.

#### 5.2 PRENATAL DAMAGE

Damage points have not been taken into consideration in the study. Prenatal damage was taken as basis for the analyses. The aim was to determine the actual health situation; this includes the progress of the prenatal damage and of the secondary damages that have developed over five decades, the occurrence and extent of discomfort and pain and the resultant functional impairments.

Almost 90% of all thalidomide victims who took part in the survey exhibit damages in varying degrees in the areas of the arms and/or the hands. Around half of them reported prenatal damages in the area of lower extremities and the vertebral column. Between 35% and 40% mentioned damages in the head region – hearing impairment, facioplegia, deformation of the jaw and nose, the auricles, cleft palate – apart from vision damages or blindness and damages of the internal organs. The latter damages are not visible on the outside; they often occur in conjunction with severe damages of the musculoskeletal system and are partly responsible for the decrease in functionality, expressed in the form of reduced ability to cope with strain and stress.

## 5.3 CURRENT SITUATION

The aim of the study is to present the current situation in terms of health in order to derive from the data the needs and requirements. Two different processes determine the situation as of today:

- 1. Prenatal damages and particularly those in the area of the musculoskeletal system have considerably worsened over the course of 50 years in the form of development of severe osteoarthritis or joint destruction due to overstressing or improper biomechanical stress. These grave changes are mostly accompanied by one or more less pronounced symptoms of pain, as the sinews and the musculature are also affected. Due to improper biomechanical stress prenatal damages of the vertebral column lead to serious changes, which in turn cause pain due to compression of nerve roots as a result of scoliosis and kyphosis or of a prenatally existing stiffening of the vertebral column. The pain symptoms, functional damage of the joints and the tensions, as well as the weakness of the musculature lead to significant decrease in performance and functionality in the area of prenatal damages.
- 2. The limitation of movement due to prenatal damages, for instance due to extremely small arms, is compensated for by increased utilisation of organ systems that are not affected, e.g. by using the feet more, so that one may gain more self-dependence. Overstraining and improper biomechanical stressing of prenatally unaffected organ systems also leads to joint and muscle damage, pain and consequently loss of functionality in the long run. These acquired damages in originally unaffected organ systems are called secondary damages.

An increase in damages is seen in the various damage areas. The difference in the area of lower extremities is just below 7%; this involves secondary damages that have come about due to compensatory movement in the hips-legs-feet area owing to short arms. A 36% increase is observed in the vertebral column areas, which is ascribed to the fact that chronic overstraining and improper biomechanical stress owing to damaged extremities and compensatory movement patterns led to malformation of the vertebral column. The increase in the number of damage instances in the internal organs area is around 24%. This increase is to some extent attributed to the fact that prenatal damages were not identified in early childhood. However, it could also be attributed to the fact that the prenatally damaged functions can no longer be compensated, like for example cardiac anomalies, or that a reduced fluid intake over decades has damaged the healthy kidneys. Vision damages and damages in the head region (e.g. hearing impairment) increase by almost 5-7%. In this case, it does not always involve the normal age-related reduction in vision or hearing capacity; the loss of vision for instance often cannot be compensated with wearing spectacles.

## 5.4 DAMAGE GROUPS AND SEVERITY OF DAMAGE

Contrary to the classification of medical damage points, which takes into account the individual body areas and the severity of prenatal damage in each area, in this study ten prenatal damage areas were specified that form the basis for further analysis. The classification is based on the current situation; the severity of the total damage is defined by the number of cumulated damage areas per person.

In another step the relative frequency of occurrence of the ten damage areas was determined in individual damage groups. Almost 90% of the respondents reported a damage in the area of the arms. Legs and hips were affected in about 60% of the cases, and the vertebral column in over 90% of cases. The higher the number of simultaneously occurring damages, the higher the degree of damage severity. The damage groups show severity of damage increasing from group to group.

The first two damage groups exhibit comparatively less damage severity; the arms and the vertebral columns are predominantly affected here. The groups mainly include individuals with double limb damage with relatively long arms, who are more or less independent in their everyday routine. Damages of the vertebral column mostly involve secondary damages.

The third and fourth damage groups exhibit a very steep rise in the damage severity and the extent of the damages in comparison with both groups. Half to two-thirds of the victims suffer from damages in the area of legs and hips; damages of the internal organs are found in the fourth damage group in almost three-quarters of the victims. One-quarter of the victims suffer from vision damages; around one-third suffers from damages in the head region, which also includes hearing impairment.

The fifth and sixth damage groups comprise thalidomide victims with severe damages in various areas; they predominantly include individuals with quadruple limb damage – a group of individuals who are seriously impaired owing to the shortening of arms and legs, as well as additional damages of the internal organs or sense organs.

The seventh damage group comprises victims with 100% instances of damage in arms, legs, vertebral column and head region. Almost half the victims exhibit phocomelia, while one-fifth shows amelia of upper extremities. One-third of the victims are deaf; malformation of internal organs and vision damages shows further increase to over 90%.

The eighth damage group is very small. Phocomelia is seen in all cases and onefifth of the group exhibits amelia; lower extremities are affected in almost half the group. In this group half the victims are deaf. All other areas are 100% affected.

As per our experience these severely affected thalidomide victims are equivalent to the group of severely affected victims with quadruple limb damage or else the deaf victims. They exhibit damages not only in the area of musculoskeletal system, but also in the sense organs or the internal organs. In their entirety, these cumulated damages lead to serious loss of functionality, self-dependence, the victims suffer from chronic pain that opens the door to psychological disorders.

#### 5.5 FUNCTIONALITY

Activities of daily living (ADLs) are relevant from the perspective of nursing care; these include food intake, personal hygiene and dressing, as well as mobility. Instrumental activities of daily living (IADLs) are relevant from the assistance point of view; these include preparing meals, cleaning the house and washing clothes, running small errands, completing administrative procedures and visiting the physician, using one's own personal car or public transport, using a PC or telephone.

#### 5.6 ACTIVITIES OF DAILY LIVING

In damage groups one and two the relative percentage of victims exhibiting varying degrees of difficulty in performing activities of daily living increases to more than one-third. Problems during intake of food is seen only to some extent in approximately 10% of victims.

In damage groups three and four more than half the victims already have problems in varying degrees with personal care and dressing; around one-third have difficulties eating food. The increase in difficulty in eating food is not primarily attributed to problems in the oral region, the masticatory muscles or the jaw. Instead, it is attributed to the shortening and malformation of arms and hands that gets more pronounced with each damage group, which makes eating difficult, particularly if there is a condition of painful osteoarthritis and if fine motor skills are limited. Many victims with considerably short arms eat with the help of feet; this process becomes more and more difficult with increasing osteoarthritis in the hip joints and the knees.

In groups five and six around two-thirds of the victims report difficulty with personal care; a little more than half face problems with food intake; in group eight all victims face this problem. Three-quarters of the victims in groups seven and eight have problems dressing. The extent of shortening of the arms and the degree of malformation of the hands, as well as the movement in the shoulders and the elbow

joints are decisive factors for the loss of independence to perform all activities that are carried out with the upper shortened extremities.

## 5.7 MOBILITY INSIDE AND OUTSIDE THE HOUSE

A large section of thalidomide victims is – even if they suffer from phocomelia of the legs – in a position to move about with agility in the house on the floor. However, with increasing arthritic deformation of joints, muscle weakness and symptoms of pain these acquired skills are progressively lost. In instances where the spaces have been optimally customised as per the disability, the victims exhibit independence in doing many things. One-third of the victims in groups seven and eight report problems walking around in the house; even in the case of severe shortening of arms and legs it is by all means possible to move around in the house without aid or support.

The possibilities of leading a partially independent life are lost outside of this optimally adapted environment. For this reason there is a great fear of being admitted to a nursing home, as there the victims live in surroundings that can in no way be spatially modified according to their respective disability.

Mobility outside the house is considerably more difficult than within the house; in particular, it is running small errands that is difficult in the case of individuals with short arms. Feet cannot really be used as aid in this case owing to increasing wear and tear of the joints. Riding on a bus is not easy even with a well-preserved gait, as victims with significantly short arms and/or malformed hands cannot hold on to something to keep themselves steady. Therefore, victims prefer driving their own personal car.

## 5.8 HOUSEHOLD ACTIVITIES

Household activities are strenuous for thalidomide victims even if they suffer from only a few thalidomide damages. Half of the individuals in damage group two have stated facing problems cleaning up the house. Taking care of laundry is found difficult by more than half the individuals in damage group three; in damage group eight this number is at 100%.

Physical stress and intensive and strenuous movements lead to rapid fatigue that meanwhile often requires longer periods of rest extending to a day or two. The same applies to office work requiring utilisation of only one part of the body, for instance using a PC. Owing to limited motility and muscle weakness going through everyday routine is a lot more strenuous in terms of energy and strength than the general population. Chronic overstraining with heavy or one-sided physical work leads to rapid deterioration of the overall physical health and condition. Those who have the means to take proper care of themselves are able to preserve their faculties for a longer period, and the symptoms of pain are also mostly mild.

Preparing meals requires energy on the one hand; on the other hand a minimum degree of fine motor skills is also essential e.g. to prepare vegetables or cut fruits. Around half the victims in damage group three have difficulties preparing the main meals and cutting fruits and vegetables. In damage group eight the number is at 100%.

## 5.9 NEED FOR LONG-TERM NURSING CARE AND ASSISTANCE

An important topic is the need for long-term nursing care, assistance and household help and their financing and organisation in order to cope with everyday life. Thalidomide victims whose family members or partner are increasingly burdened with assistance and nursing care, as well as those who live in restricted financial circumstances are affected the most. The key statements in these interviews and focus groups were systematised and, like the data collected from the questionnaires, form the basis for the tabular representation of the needs and requirements, which can be viewed in the final report.

## **6** RECOMMENDATIONS FOR ACTION

The results of this study form the basis for the recommendations for action provided in the following. As is evident from the data, rapid increase in degenerative and inflammatory changes, as well as severe chronic episodes of pain, loom ahead of a majority of thalidomide victims. One-third of the victims is without gainful occupation, a high percentage will be forced in the coming years to retire early, as the decreasing ability to cope with physical strain, reduced health and fitness as well as chronic episodes of pain will no longer allow them to continue working. The development of thalidomide-affected women and men in terms of health is at a turning point; rapid improvement in nursing care services as well as broadening of the scope of support is required urgently.

#### **6.1 THALIDOMIDE PENSION**

The thalidomide pension should be considerably increased. This would enable an effective compensation for the loss of income. In addition, it is essential for financing higher costs of living in consequence of increasing health and functional impairments.

The thalidomide pension forms a key instrument of financial security. More than half the victims interviewed in the study stated that they would not be in a position to maintain financial independence without the thalidomide pension. One-third of the victims claim that this is not possible even with the thalidomide pension.

## 6.2 ASSISTANCE

The required assistance should be ensured and also continuously adapted in accordance with the current need. Family members and relatives should no longer be called in to provide assistance in future; assistance should be made available regardless of any family and personal financial support.

Thalidomide victims require considerable assistance to be able to participate socially and lead a self-defined life. This is predominantly provided by family members and neighbours. This would not be possible in the future, as parents would not be able to give assistance due to age-related issues and the children would leave home to build their own lives. Furthermore, the need for assistance will increase in future, as the functional state of thalidomide-affected women and men would continue to deteriorate. Presently, professional assistance services are very difficult

to find and are also very expensive. Organising various forms of assistance is extremely cumbersome because of the involvement of different kinds of providers.

### 6.3 MAINTAINING EMPLOYABILITY

It is required to work towards maintaining the employability of thalidomide-affected women and men by significantly broadening the scope of personal assistance, implementing technical assistance systems, operational prevention and rehabilitation services, as well as providing options in terms of number of working hours. In cases where thalidomide-affected women and men are forced to retire from professional life on account of their health a compensation for the loss of earnings that is as comprehensive as possible should be ensured in order to avoid financial bottlenecks.

The present health situation of thalidomide victims presents many of them with the question as to whether it is possible to continue with an occupation and, if yes, then in what form. Many of them aim for a continued employment not only because of the great financial independence that comes with it, but also because of the additional possibility of social participation. There is an increasing threat to employability due to health limitations as well as reduction of functionality. However, there are more and more thalidomide-affected women and men, who are continuing in their jobs despite high levels of strain and stress in terms of health because quitting the work place would entail grave financial losses.

#### 6.4 MOBILITY

Additional refitting and modifications to personal vehicles, which become necessary owing to the disability, should be undertaken irrespective of whether the vehicle is used for work-related or private purposes or upon retirement. As the personal vehicles need to fulfill specific requirements to be able to implement the reconstruction measures, there should be a subsidisation of the costs at the time of car purchase. Thalidomide victims with personal vehicles should be provided with a car park identification for barrier-free usage of disabled parking spaces. If a thalidomide-affected person does not have a driver's licence, he or she should be granted driver's assistance or else the cost of transport services or taxi bills should be absorbed in order to ensure social participation.

The facility of a personal vehicle forms a key prerequisite for thalidomide victims for maintaining mobility and social participation.

#### 6.5 RECONSTRUCTION MEASURES

Thalidomide-affected individuals should be provided financial support towards the reconstruction measures to in turn contribute to their self-dependence and social participation.

The progress of prenatal damages and secondary damages have resulted in additional barriers in the house and the living environment.

### 6.6 REHABILITATION

Thalidomide victims should be provided with outpatient and inpatient rehabilitation services. It should be ensured that rehabilitation needs are determined as per the perception of thalidomide victims and are fulfilled in all respects. Rehabilitative measures should be in accordance with the specific requirements of the thalidomide victim. This also includes the spatial furnishing, as well as provision of appropriate aids and assistance, along with adequate rehabilitation sports equipment. Physicians and professional nursing staff should have specialised qualification and experience so that they are able to take adequate care of thalidomide-affected people. All measures should be aimed at stabilisation of the health condition and the functional state of thalidomide victims.

### 6.7 THERAPY

The substantiated thalidomide damage should suffice as reasonable ground for the argument that the patient is not classified as a normal case and, thus, does not fall under the budgeting system for medical services. This also includes issuing of long-term prescriptions for physiotherapy, massage, lymph drainage, osteopathy, and the like, to ensure optimal health care and maintenance. The recently introduced ICD code for Contergan (thalidomide) should be developed further or made more precise.

#### 6.8 AIDS AND SUPPORTS

Necessary aids and supports should be provided to thalidomide victims without financial expense and, if required, such provision should be ensured for the victims through simplified application processes.

Thalidomide victims often require special aids and supports, which are very often not included in the aid catalogues of statutory health insurance companies. The mobility aids provided should be optimally customised as per the latest and updated technology and the specific kind of damage. A replacement should be provided immediately in the case of any technical defect to ensure the ability to work and move.

High technical quality hearing aids and customised spectacles should be ensured for thalidomide victims with hearing and/or vision damage. In the case of repair an additional set should be made available at short notice so as to ensure the ability to hear and see.

## 6.9 TEETH, IMPLANTS, PROFESSIONAL DENTAL CLEANING, SURGERIES

Implants should be procured for all thalidomide victims in case they need dental prosthesis. As statutory health insurance companies are not obliged to finance dental implants, the costs for these should be reimbursed in some other way. The same is recommended for orthodontic measures. Costs for professional dental cleaning, which are not absorbed by statutory health insurance companies, should be

reimbursed for the required number of sittings per year in order to ensure preservation of teeth through these preventive measures.

## 6.10 HEALTH CARE

Multi-disciplinary competence centres should be set up, where the expertise of existing organisations and institutions should be drawn on in terms of providing medical care to thalidomide-affected people. Specialised outpatient and inpatient health-care centres should be set up. The increase in expenses in terms of the required time and staff, resulting from the type and severity of damage, should be considered in the medical care services financing.

These competence centres should serve as the point of contact for all healthrelated and psycho-social issues of thalidomide victims.

Moreover, physicians, dentists and therapists who attend to thalidomide-affected patients, should be provided the option to do their specialised and advanced training under the CME keeping in view all the aspects of thalidomide damage.

## 6.11 NURSING CARE

The nursing care profile of a thalidomide victim is considerably different from that of a chronically ill, particularly aged person. Nursing care services should be adequately specialised to competently handle the appropriate requirements. Incentives should be put in place to encourage acquiring this kind of specialisation in nursing care services. Family members of thalidomide-affected women and men should be released from financial burdens for any additional or supererogated services provided by them owing to the special nursing care profile of the thalidomide-affected women and men.

Nursing care services can become relevant even when professional care is being provided by assistants if the need for long-term nursing care is not covered for activities of daily living or if there is need for therapeutic care. In this case, both forms of support – assistance on the one hand and nursing care on the other – should be optimally supplemented in order to compensate for the decreased functionality.

While implementing a new concept for the long-term nursing care requirement it should be noted that thalidomide-affected women and men should not have to forego the existing benefits.

## 6.12 SECONDARY DAMAGES

In addition to prenatal damages secondary damages should also be recognised and acknowledged because of their high significance in terms of the health situation and self-dependence of the victims.

As secondary damages have developed in almost all thalidomide victims over the past decades and have, to some extent, also led to severe impairments in the form of pain and limitations in functionality, it is recommended to immediately increase the damage score by 10 to 30 points flat, without changing the already assigned scores.

For instance, damage points up to 39.99 could be increased by 10 damage points, up to 79.99 by 20 damage points and for 80 points onwards by 30 damage points.

Extremely serious secondary damages could occur due to missing or malformed sexual organs (childlessness, problems with partner, psychological stress) or due to malposition of internal organs, e.g. kidneys (renal insufficiency that requires dialysis). It is recommended that these severe secondary damages should be considered separately, without changing the already assigned scores.

#### 6.13 SO-CALLED LONG-TERM SEQUELAE

A systematic and scientific study of damages that are created prenatally but discovered only later (so-called long-term sequelae) should be organised, which focuses on malposition of blood vessels, nerves and muscles. The prerequisite for detecting and recognising a damage is the development of appropriate criteria to determine the existence of such prenatal damage. It should be ensured that the damage is recorded in the medical point system and redressed within a reasonable period of time.

#### 6.14 MEDICAL POINT SYSTEM AND DIAGNOSTIC CODES

Prenatal damages that are not included in the medical point system should be added and assigned appropriate diagnostic codes, e.g. a malformed carpal tunnel or secondary damages. It should be possible to add to the point catalogue at all times in order to be able to include prenatal damages that have been discovered only later, like for instance the so-called long-term sequelae.

#### 6.15 DAMAGE POINTS

The medical damage points assigned for the monthly thalidomide pension should be revised. The need for long-term nursing care, assistance as well as therapies and aids is rising with the increasing damage scope. With the 45 damage point ceiling the respective absolute value of individual damage points sinks to more than half for individuals with most severe damages.

The thalidomide pension increases so far in increments of 5 points up to 44.99 damage points; from 45 points onwards there is no provision for further grading. One option could be to render the grading of damage points void, or extend the ceiling to a maximum reachable score of 100. Damage points could be assigned as per the medical point table, without there being a maximum number. The formula used until now to calculate the score would no longer be applicable, as the damage score could be above 100 points. Retaining the ceiling would be unfair to the most severely affected victims. The value of individual damage points should be the same for all damage cases. The standardisation should be promptly implemented.

Making the grading and the ceiling void as well as standardising the point value require an appropriate revision of the pension amounts.

## 6.16 DATABASE

A database should be set up, to which the victims, physicians/dentists and professional nursing staff have access, so as to be able to obtain information regarding the damage and its consequences, associated risks and optimal therapies, rehabilitation and nursing care, as well as to save and share experiences on an interactive platform. For instance information about registered physicians/dentists in the region should be available, who have experience with the specific health problems of thalidomide victims and with the established and efficient forms of therapy. There should be information available about qualified inpatient and outpatient rehabilitation services as well. This database should ensure improved medical care services by allowing physicians and therapists to acquire specific knowledge.