

TRANSLATED FOR THE THALIDOMIDE TRUST

Institute of
Gerontology
of the University of Heidelberg

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THALIDOMIDE

**Enquiries to be carried out repeatedly with regard to problems,
specific needs and support deficits of thalidomide
victims**

Summarising report of the first survey results
and derivation of first action recommendations

Presented by the
Institute of Gerontology
of Ruprecht Karls Universität Heidelberg

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Inquiries to be carried out repeatedly with regard to problems, specific needs and support deficits of thalidomide victims

Summarising report of the first survey results and derivation of first action recommendations

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1 INTRODUCTION: REPORT ON A WOMAN WITH THALIDOMIDE DAMAGE

The summarising inquiry report begins with an account of the life situation of a woman with thalidomide damage, who was prepared to report in detail about her daily life and her current state of health. Because of the thalidomide damage, this woman is confronted with numerous demands and stresses in her daily life; coping with them presents not only high demands on physical fitness, but also on psychological processing capacity. In recent years marked limitations of mobility have occurred; in addition, the experience of this woman is more and more determined by pains. In the interview we also asked the question, how, in her opinion, will this process develop in the coming years. To this question she gave a very clear answer, which is representative of the answers of many thalidomide victims,¹ whom we interviewed.

The following text was inserted here with the consent of the woman concerned. The example is representative of the very successful way of coping with everyday life over many years achieved by this woman with severe damage, at the same time it shows new problem areas, which in her description will clearly emerge in the near future and it will become necessary to develop new strategies for coping with them. The constellation of problems opening up here affects not only this woman, but the majority of thalidomide victims; for this reason this biographical extract has been placed at the beginning of this report. It should make political decision makers, who were still not able to obtain a differentiated insight into the daily life of thalidomide victims, sensitive to the demands and stresses, with which women and men damaged by thalidomide are faced in daily life.

The damage with this woman comprises phocomelia in the region of the upper extremities: there is a severe shortening of both arms with malformation of the hands and absence of the thumb, there is shoulder damage on both sides, no elbows have developed, there is dislocation of the hip on both sides, scoliosis and development of vertebral block and spondylolisthesis in the region of the lumbar spine. This woman belongs to the group of victims with severe damage.

This woman lives together with her husband and is employed full-time, she works 41 hours per week. She is employed in a position with mainly administrative duties. She had wanted to become a doctor, although had had to realise very soon that she was not suitable for this because of her short arms and the limited mobility of her arms. She went to university, although after successful completion of the course, a doctorate was not possible due to the disability, she also followed training at a university of applied sciences. She says: "As a disabled woman who was "slightly" overqualified I reckoned I had more chances on the job market". After several attempts with discrimination on two

¹ In this report people who are victims of thalidomide are also called thalidomide victims for reasons of linguistic simplification.

occasions she found a job which appealed to her. Because a doctorate stimulated her, she did her doctorate alongside her professional occupation. Neither the studying nor the doctorate awarded with the second highest level of distinction (magna cum laude) has paid off professionally.

The day begins in the morning at 06:00. Showering and going to the toilet are carried out independently in the shower/WC equipped with dressing hook. In the summer, when it is hot or muggy, she needs help with putting on pants and bra as her skin does not dry properly. She also needs help during the day outside of the house on normal toilets. At times she can dress independently, loops are attached to clothes to pull them up. She can only put on socks. She does not put on nylon stockings because she cannot do that alone. For slightly more representative clothing she needs help from her husband or from female colleagues. At events outside of the house in the summer, with the exception of bra and pants, she sometimes has to be dressed and undressed again by female colleagues.

She makes breakfast herself with one limitation: she cannot peel any fruit. She leaves the house at approximately 07:30 and drives to work with the car that has been adapted to her needs.

Her working day begins at approximately 08:00. She works between 6 and 6½ hours per day. During the lunch break she goes to manual therapy and fango once weekly, or alternatively she does exercises on site or goes walking. If she has evening appointments (approximately 1 every 2 weeks), she extends her lunch break and lies down for 30 minutes so that her back does not hurt. After a normal working day she goes swimming twice weekly. In order to avoid the dependence on a person accompanying her, she has overcome her shame and on the spot lets strangers, to whom she talks, help her to put on and take off her swimsuit as well as her pants, bra and vest. She needs regular intensive physical exercise daily in order to avoid back and arm pains.

She returns home at approximately 17:30, is tired from her long working day. For this reason she cannot maintain all her personal contacts as she needs time for recovery. Her husband cooks. She sets the table independently and works the washing machine – she wants to relieve her husband by doing this, She has a home help, who comes regularly, and takes the washing to the laundry and irons. She says: “Household activities ruin the health of every thalidomide victim with phocomelia. Carrying out these activities is again the basis for not neglecting oneself and the family and for being able to eat sensibly. As I still work full-time, I have received no classification in the first class of nursing care; given my employment and the fact that I need a great deal of help with housekeeping, a classification barely pays. I have to work in order to be able to pay for the housekeeping support on the scale which I need.”

Her mother is over 80 years old and alters her clothes. Buying an anorak or a coat is extremely protracted and exhausting. She has to devote 4–5 complete shopping days on the search. If she does not find anything, the tour starts again in the following winter. She

has not yet found a solution for everything. People with disability of the arms, for example, for the most part cannot wear gloves. They carry keys, handbags etc. between their fingers and in the winter the skin between the fingers breaks open in cold, damp weather – the open skin heals up badly in the winter and hurts for days on end. In addition, the increasing cold leads to longer lasting pains in the shoulder joint and in the arms.

Pains occur on exertion, working is exertion. For approximately 10 to 12 years increasing symptoms have occurred in the region of the shoulders and the arms/hands: slowly at first, although in recent years they have increased rapidly. The limit of fitness has been rapidly reached in the meantime. She tires quickly and tries to remain fit through sport, although also through phases of rest. She tries to cure tension in the shoulder region by lying on a bobble massage ball until the pains ease. Her doctor cannot prescribe her massage, she already receives 10 x manual therapy and fango per quarter. As a health insurance policy holder she is not entitled to more.

The woman hopes that she can still work for a few more years; however, she will no longer manage the remaining 13 years until her retirement pension. As a civil servant she cannot reduce her working hours as she will otherwise receive deductions from her pension.

If she was not able to do any exercises during the day, exercises are carried out two to three times weekly in the evening. The physiotherapist shows her the exercises, they change depending on requirement. In the meantime severe arthrosis in the left hip joint and moderate arthrosis in the right hip joint have been established.

How will her state of health possibly develop in the next five years?

It is to be assumed that physical fitness will decrease further with a simultaneous increase in the symptoms. The need for periods of rest will increase; however, the woman will not be able to rest sufficiently. Daily routine is strictly regulated today. If there is a further decrease in capacity for exertion, the daily therapies are no longer compatible with the current scale of employment. She will have to make a decision whether she reduces her working hours or alternatively starts to treat the increasing pains with medication as well, which she has so far largely been able to avoid.

In the next 3 years she will have to prepare for an artificial hip on the left with a time-consuming search for a doctor, who has the appropriate knowledge and is prepared to operate on her deformed joint. She is afraid of the time after the operation. Which rehabilitation facility has experience with postoperative care with people with severe disability of the arm following hip replacement? Can she pursue her employment again after the operation? Because of the advanced pain symptoms and the severe damage in the region of the arms and the vertebral column, the distance she can walk and her independence at home and at work will possibly decrease in the coming years also

regardless of the operation. She cannot use a walking aid because of her short arms and damaged shoulders. Even with non-damaged legs, she is at risk of ultimately sooner or later requiring a wheelchair due to the dysplasia of the hips and its sequelae and the emerging muscle weakness. As a result a difficult turning point in the sequence of her life so far would occur, mobility outside of the house and also in the house as well as independence are at acute risk. The professional and voluntary occupations, the great number of contacts and leisure activities at work and at the weekend could no longer be maintained on the scale to date, which can lead to isolation and possible depressive moods. Under these circumstances how long will she still be able to find the discipline and energy for the regular physiotherapy at home or for swimming? So far she has been able to cope with her situation with all hurdles and obstacles; will she manage this with this additional and severe stress?

2 THE PROJECT “ENQUIRIES TO BE CARRIED OUT REPEATEDLY WITH REGARD TO PROBLEMS, SPECIFIC NEEDS AND SUPPORT DEFICITS OF THALIDOMIDE VICTIMS”

The Contergan Foundation has commissioned the University of Heidelberg, through systematic recording of sociodemographic, physical and psychological features with the help of questionnaires, focus groups and interviews, to record the existing needs and support deficits of men and women who are the victims of thalidomide and to develop action recommendations for the future; the latter with the objective of initiating preventative and rehabilitative measures on the basis of the results in order to ensure independence and involvement for as long as possible.

2.1 NUMBER OF SURVEY PARTICIPANTS

2,380 thalidomide victims entitled to benefits in the German-speaking world were written to by the Contergan Foundation. Of these 900 have completed the questionnaire sent and returned it; 870 questionnaires could be accepted completely in the analysis, with the remaining 30 questionnaires only answers to individual areas could be used for assessment. 338 people agreed to participate in an interview, 184 people expressed readiness or a desire to participate in a group discussion, and 239 people consented to the doctor providing treatment also being included in the survey.

2.2 THE QUESTIONNAIRE

Data on the following content was recorded: (a) physical prenatal damage, secondary diseases, pain development and its progress. (b) Functional limitations in daily activities. (c) Subjective health and state of mind. (d) Quality of life. (e) Medical treatment, nursing care, assistance, aids and the needs not covered from the perspective of men and women who are thalidomide victims. (e) Social networks. (f) Barriers to autonomous way of life and social joint responsibility. (g) Sociodemographic data.

All quantitative calculations were carried out with the statistical program SPSS,

Version 19.1. The verification of the data is completed, the primary data set created. The descriptive portrayal of individual questionnaire sections is completed, data transformation was commenced.

First calculations for this report were carried out; the data and action recommendations found here are based on these calculations.

2.3 THE SHORT QUESTIONNAIRE

Sociodemographic data as well as type and extent of the prenatal thalidomide damage was recorded.

2.4 THE GUIDED INTERVIEWS

The performance of the total of 338 interviews is oriented towards a main thread developed by the Institute of Gerontology. Through the interviews the quantitative results are deepened and differentiated. The following complexes of question were discussed: (a) Daily routine from getting up to going to bed: extent of independence in daily activities such as hygiene, dressing, preparation of meals, mobility on the way to work and professional occupation. (b) Freedom from barriers. (c) Social contacts and leisure activities. Life story, development of strengths and observation of losses. Rejection and heteronomy. (d) Evaluation of the disability. Health development, secondary sequelae, late sequelae and pains. Measures to boost health. (e) Medical care, dealing with health insurance companies and offices. Situation of the thalidomide victims in the last ten years and in the coming years: what will be needed? (f) Notions of growing old and the future, plans, unfulfilled desires.

The interviews substantially supplement and deepen the quantitatively recorded statements of the questionnaire. Up to the present time 220 interviews have been carried out. It is anticipated that all the thalidomide victims, who have expressed willingness to participate in an interview, had received an appointment for an interview by October 2012.

The transcription of the conducted interviews as well as the focus groups is carried out by means of the freely obtainable program f4, Version 4.2. This program tool supports the transcription of interviews, i.e. the typing up of discussion situations onto audio recordings. Following completion of the transcription the completed text files are transferred to the program MAXQDA, Version 10. A category system allows access to the entire data material, without pre-empting the interpretation of the contents by the researchers.

2.5 FOCUS GROUPS

There are 183 acceptances for a focus group. Up to the present time 18 focus groups have been offered in different towns; costly journeys by the participants should thus be avoided. A further six focus groups are still planned, in this approximately 50 participants are to be taken into account.

Focus groups deal with thematically defined contents, the discussion of which was and is suggested by the thalidomide victims. To date the following subject areas have been worked on together: (a) Living in old age. (b) Coping with old age and independence in old age. (c) Secondary sequelae and medical care, independence in daily life, provision of aids, medical care. (d) Secondary sequelae, late sequelae and psychological problems. (c) Employment history, professional situation and security in old age.

The study is not yet concluded at the present time, the results presented here are therefore to be regarded as *interim*. However, our first results give us significant indications of the direction in which the survey results point: therefore these results have also already been presented at the current time. Further interviews and focus groups are still outstanding, as is the questioning of 239 doctors, who were released from their obligations of medical confidentiality by the thalidomide victims. Contact has already been established with those doctors, who have knowledge about specific risks of thalidomide damage as well as secondary sequelae and late sequelae. A co-operation develops here, which also has the objective of developing curricula for doctors interested in continuing education and further education.

2.6 METHODOLOGICAL COMMENT WITH REGARD TO REPRESENTATIVENESS AND SIGNIFICANCE TEST CARRIED OUT

The question regarding the representativeness of the random samples from the questionnaires, interviews and focus groups has already occupied us since the beginning of the thalidomide study. The methodological basic problems lies in the fact that the basic population of thalidomide victims is not known to us. In order to ensure the anonymity of the interviewees, the dispatch of the questionnaires and the declarations of consent was carried out by the Contergan Foundation for Disabled People itself. There is no certain knowledge available about composition of the basic population according to different damage patterns and socially relevant criteria.

The representativeness of the results according to probability theoretical criteria can therefore only be strived for. What is possible (and are endeavours are directed towards this): avoid systematically distorting errors in the extraction of test subjects for the random sample. Through the great variety of access routes to the interviewees as well as through the mix of method we took care to reduce or at least compensate possibly selection effects and systematic distortions of the individual access route; in addition, the results were and are repeatedly validated by means of triangulation.

The response rate achieved is just 37% with 870 questionnaires entered into the assessment. Therefore a high power is given for significance tests to be performed.

With the question of non-response bias, i.e. subjects choosing not to respond to certain

questions, we can fall back on knowledge from consensual, communicative expert validation. This confirms our impression that in recording the questionnaires we have reached a sufficient illustration of the target population and with the interviews and focus groups there is a slight “covering effect”. That means: the results described are in reality shown to be factually slightly worse, which with the qualitative interpretation corresponds figuratively to a “type 2 error”, although in this case only underlines the necessity of the action recommendations.

With knowledge of the research status it is to be assumed that this examination represents the most up-to-date and comprehensive recording of the researched subject areas and also, because of the high acceptance with the interviewees, offers a relatively reliable data quality, this also in view of the capacity for generalisation of the results. The scientific theoretical explanation about research without random samples is to be proved to be right in this case, if it is postulated that internal validity and causal interpretation capacity take precedence and testing and falsification of theories and hypotheses underlie empirical research as the main objective.

2 STUDY RESULTS

Results from the questionnaires, the focus groups and the interviews are collated and presented below.

The thalidomide victims, who participated in the study, were born between 1957 and 1966, although mainly (93.8%) between 1960 and 1962. Analysis of the questionnaires shows a percentage of 51.7% women and 48.3% men who participated in the survey. Of these 62% (according to the statements of the interviews) participated in the study not only out of interest and curiosity, but also because they assume that in an independent study it can be established which problems and uncovered needs exist. They assume that the participation of as many as possible of those affected and the sharing of their experiences – how their life has run with damage caused by thalidomide, with which personal problems they are confronted, which barriers make their daily life more difficult – will help improve the level of knowledge of the decision makers, so that sound decisions can be reached with regard to an improvement in their situation.

In the analysis of the data three groups were identified, which carry an additionally high risk. It is on the one hand the group of the victims with quadruple limb damage, which in the study are represented at 18.7% (n=163). It comprises all persons, with whom there is basically a malformation and/or shortening of arms and hands as well as legs to a variable extent. Their problems lie both in the reduced functionality as well as in the markedly more severely pronounced pain symptoms. On the other hand the group of people with hearing damage was noticed, which constitutes a percentage of 40.3% (n=354) in the total group; this includes people with reduced hearing (34.6%, n=305) and

the deaf (5.5%, n=49). The reduced communication or lack of communication with the hearing population forms the main problem here with the deaf particularly disadvantaged. In the 1960s the use of sign language was prohibited; the parents were also urged to communicate with their children in the language of the hearing population. Later they learned sign language, which they use amongst themselves today and which, however, only a few of the hearing population master, so that within the family communication is also limited. Severe additional limitations emerge with those deaf people, who show damage in the region of the locomotor system as not only is physical fitness limited, but possibly also the capacity to communicate by sign language. The group of thalidomide victims with low income was considered as the third group.

All groups were considered separately: this is also referred to subsequently.

3.1 SOCIODEMOGRAPHIC DATA

- ❖ 48.5% of the women and 47.7% of the men are married. The percentage of men and women who are married or living in a relationship is 70.3% in the corresponding age cohort.
- ❖ 10% of the men and 20.1% of the women are divorced. In the age group of the 50 to 54-year-olds in the total population 14.8% of men compared to 16.4% of women are divorced.
- ❖ 29.1% of the women and 39.9% of the men are single, in the total population the percentage of single men and women is 11.4%.
- ❖ 53.2% of the women and 48.2% of the men have children. The comparative figure for the total population in the corresponding female age cohort is 76.7%. 66.7% of the children of the male thalidomide victims are minors, the percentage with women is 45.5%.
- ❖ 28.7% of the men and 26.7% of the women receive support from the parents.
- ❖ With 21.6% of the men and 36.4% of the women the children take on tasks.
- ❖ With 21.6% of the men and 36.4% of the women the children take on tasks, which are to be classified as assistance.

Approximately half of the men and women with thalidomide damage are married; by comparison, in the corresponding age cohort of the general population it is 70%. The percentage of divorces in both groups lies at 15%, i.e. considerably more marriages with one or two partners with thalidomide damage are dissolved. According to statements of those affected marriages break up or alternatively marriage partners decide to live separately because the stresses, which develop due to the great and continuous hard work of the healthy partner for the partner with thalidomide damage, lead to physical and psychological exhaustion and excessive strain. With the loss of a spouse or partner, gaps

in care emerge as the assistance by the partner, who has more or less made possible a normal life, is suddenly lacking. Thus, those affected are increasingly dependent on their relatives, friends and work colleagues and their support.

9.8% of the interviewees report that their parents live in the same household. However, irrespective of the parents' place of residence, in each case approximately one quarter of the men and women receive support from their parents. The parents are well advanced in years, many have already died, others are in need of nursing care. Therefore with many of those affected there is a lack of the support, which they have received for decades, for example alteration of clothes, support in the preparation of meals, help with personal hygiene and in the household. One quarter of those affected are still supported by their parents. To a lesser extent the sons and daughters with thalidomide damage are today involved in the care and nursing of their parents.

Approximately one third of the men and women are single, according to their own statements most of them not by their own choosing, the choice of partner is difficult with existing visible disability: a relationship is only entered into late. This possibly explains the high percentage of children who are minors, which is to be interpreted as the result of a late marriage. Approximately half of the interviewees have children who are minors, who still go to school and live at home. Thus as the parents, due to age, are in the long term no longer able to carry out the tasks, which they have taken over, after completing school-leaving qualifications the children will leave their parents' house. In the event of given need for assistance neighbours and friends take over helping out with 55% of those affected, which makes the normal daily routine easier. Nevertheless, in the near future professional assistance by the hour up to all day will increasingly become necessary. The deficits caused by the damage can at least be compensated in part by an assistant.

3.2 SCHOOL EDUCATION

TABLE 1: DATA ON THE GENERAL SCHOOL EDUCATION OF MALE AND FEMALE THALIDOMIDE VICTIMS (N=870) AND IN THE 50–55 YEAR-OLD AGE GROUP IN THE TOTAL POPULATION

School leaving qualification	Thalidomide		Total population	
	Men	Women	Men	Women
Secondary school	26%	23.7%	35.8%	32.2%
Middle school	21%	29.2%	17.5%	24.7%
Applied sciences university entry diploma/A levels	44.8%	41.6%	27.2%	23.3%

*Source: Federal Statistical Office on the Education Level of the Population, 2011

Thalidomide victims (78%), according to their statements, were urged an early stage and for a long time by their parents or legal guardians to be independent and autonomous in all things; in this they recognised at an early stage that education represents an opportunity for them, also with severe physical impairments, to attain autonomy professionally. Age-correlating data from the total population was drawn on for

comparison with the data recorded by us on general school education. The total group of thalidomide victims shows a markedly higher percentage of higher school leaving qualifications.

With reference to school education there now follows a further differentiation of the data for the totality of thalidomide victims, for deaf people and people with impaired hearing as well as persons with low income and victims with quadruple limb damage.

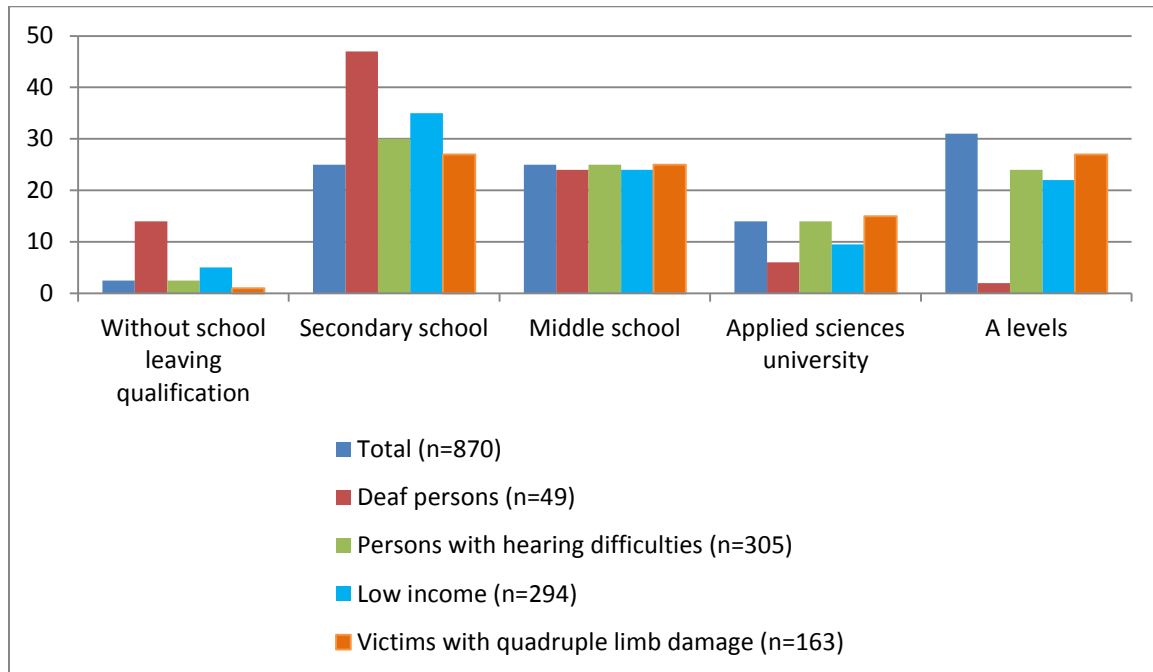


FIGURE 1: GENERAL SCHOOL LEAVING QUALIFICATION PROPORTIONATELY WITH THALIDOMIDE VICTIMS IN TOTAL, DEAF PERSONS, PERSONS WITH HEARING DIFFICULTIES, THALIDOMIDE VICTIMS WITH LOW INCOME, AS WELL AS VICTIMS WITH QUADRUPLE LIMB DAMAGE

The data on the school education of the victims with quadruple limb damage largely corresponds to that of the total group; the percentage of persons concerned with quadruple limb damage, who have gained the applied sciences university entry diploma is 14.8%, 27.2% have gained A levels. The persons with hearing damage show results deviating from this; the extent of the capacity for communication with the hearing population is mainly determined by which school leaving qualification they achieved. With them the persons with middle school leaving qualifications predominate, a higher educational leaving qualification is found less commonly with them than in the other groups. The highest percentage of those thalidomide victims, who have no school leaving qualifications or alternatively have a middle school leaving qualification, occurs with the deaf persons at 13.3%/46.7%. Whilst 30.7% of the total group and one quarter of the persons with impaired hearing and victims with quadruple limb damage pass A levels, it is only 22.7% of the thalidomide victims with low income and only 2.2% of the deaf persons.

3.3 VOCATIONAL TRAINING

The percentage of thalidomide victims without professional qualifications lies at 2.9% in the total group. In the comparable age group of the total population this percentage amounts to 3.9%.

The tendency, which is shown in school education, continues in vocational training. The following figure shows the training qualifications of the thalidomide victims.

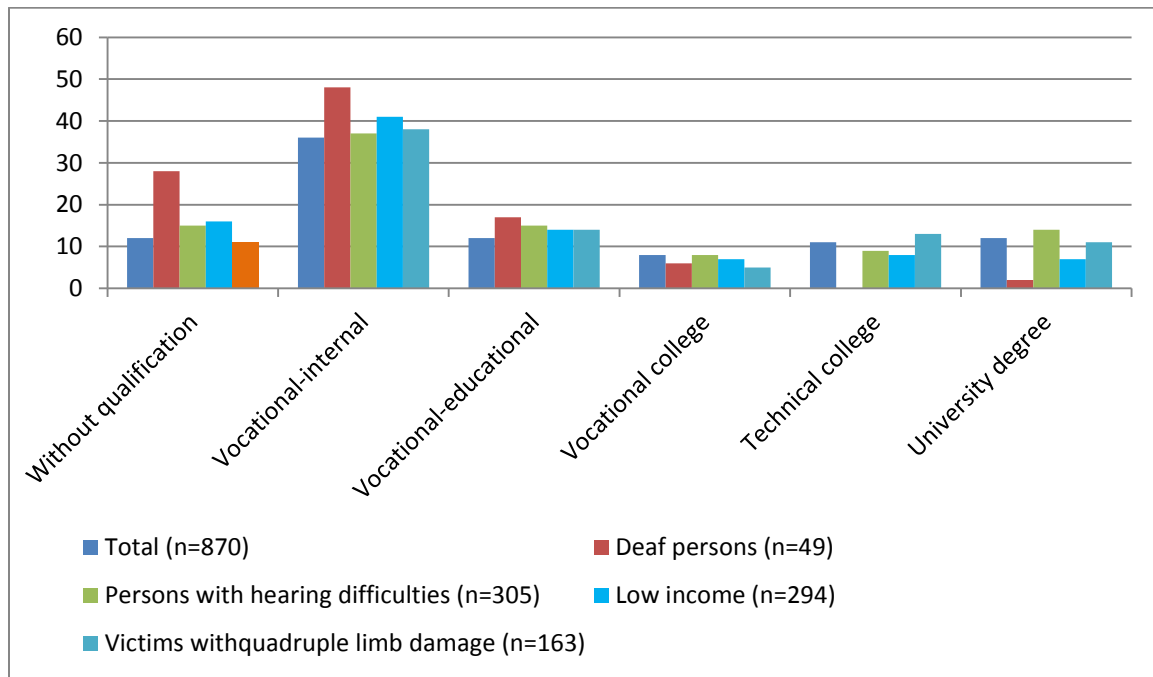


FIGURE 2: VOCATIONAL TRAINING PROPORTIONATELY WITH THALIDOMIDE VICTIMS IN TOTAL, DEAF PERSONS, PERSONS WITH HEARING DIFFICULTIES, THALIDOMIDE VICTIMS WITH LOW INCOME, AS WELL AS VICTIMS WITH QUADRUPLE LIMB DAMAGE

In the total group of thalidomide victims the percentage of persons without vocational qualifications lies slightly below the total population. The data for deaf thalidomide victims shows that they often have only have no qualifications or alternatively a vocational-internal qualification and that they are barely represented amongst academics, in contrast to the comparable groups. Only with very high financial and personal expenditure on the part of those affected and their families can, for example, a course of study with the help of an assistant, who accompanies the person concerned at the university also during the lectures, be completed.

3.4 EMPLOYMENT ACTIVITY

- ❖ The percentage of employed thalidomide victims is 61.3%, the average in the corresponding age cohort of the total population is 77.1%.
- ❖ There is a reduction of full time employment capacity of 32.8% of the thalidomide victims questioned. Comparable figures in the total population lie at approximately 3%.
- ❖ There is a reduction of part time employment capacity of 11% of the interviewees.
- ❖ 36.6% of persons with hearing difficulties and 44.2% of deaf persons are reduced in full time employment capacity. The percentage of victims with quadruple limb damage who are not employed is 43.7%.
- ❖ 34.6% of women are employed full time, 82.4% of men.
- ❖ 65.4% of women are employed part time, 17.6% of men.
- ❖ Number of working hours per week with employed thalidomide victims
 - 40-45 working hours: 23.2%
 - 30 up to less than 40 working hours: 37.5%
 - 20 up to less than 30 working hours: 16.6%
 - Less than 20 working hours: 14.5%

Although the percentage without vocational qualifications is lower with thalidomide victims than in the comparable age group of the total population, and male and female thalidomide victims also show a better education or university degree, the percentage of employed persons amongst thalidomide victims clearly lies below the average of the total population. Female and male thalidomide victims are employed in approximately the same proportions. Women are more frequently employed part time than men; this is demonstrated in the following figure.

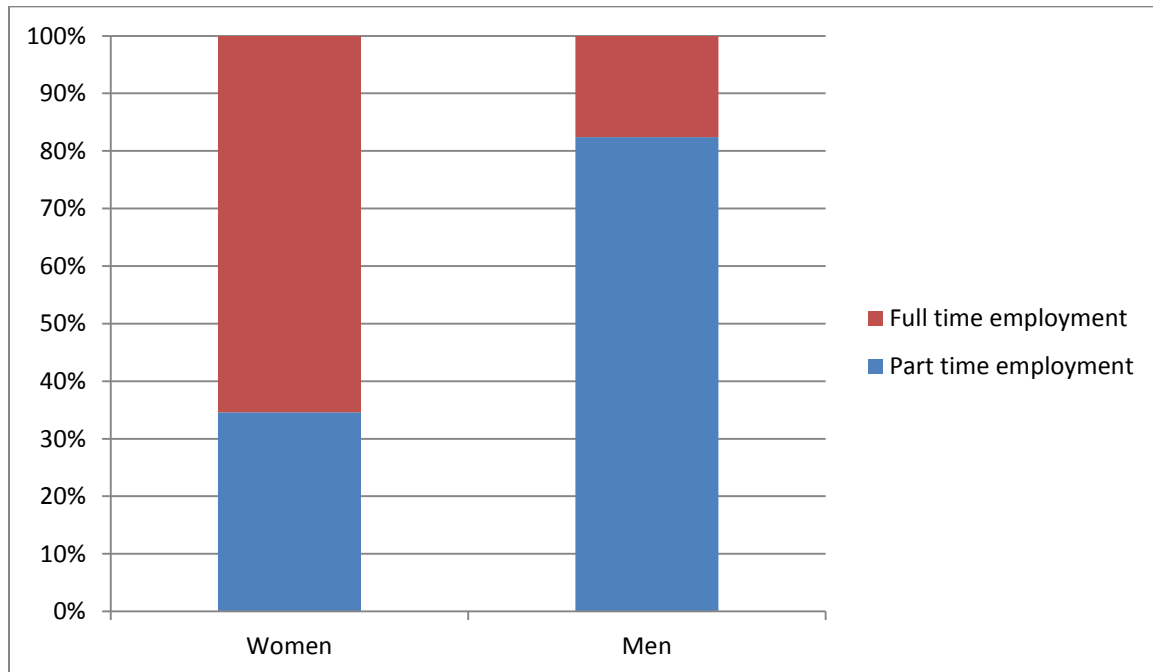


FIGURE 3: PART TIME EMPLOYMENT AND FULL TIME EMPLOYMENT ACCORDING TO GENDER WITH THALIDOMIDE VICTIMS (N=534)

The analysis of the working hours managed shows that 60.7% of employed thalidomide victims work between 30 and 45 hours per week. Victims with quadruple limb damage in the number of weekly working hours managed by them show only slight deviations from the figures cited above, despite severe physical impairment and despite a higher pronouncement of pains, they manage a comparable employment performance.

There is a reduction of part time work at 11% in the total group of thalidomide victims, of 32.8% (n=285) of the interviewees, a reduction of full time employment was reported. According to our research, the comparable figures from the total population for example lie at 3% in this age group.

In the following figure the development of the reduction of full time employment is shown in our random sample. 264 persons have provided information about the respective start of the reduction of full time employment. In Figure 4 the percentage of persons with reduction of full time employment for the period up to 1985 was summarised, the respective percentages for the following years are shown in 5-year stages. The last column shows the percentage for the period from 2006 up to March 2011. On the basis of the so far exponential development of the reduction of full time employment with the thalidomide victims examined by us it is to be expected that in a few years the main percentage will be reduced in full time employment.

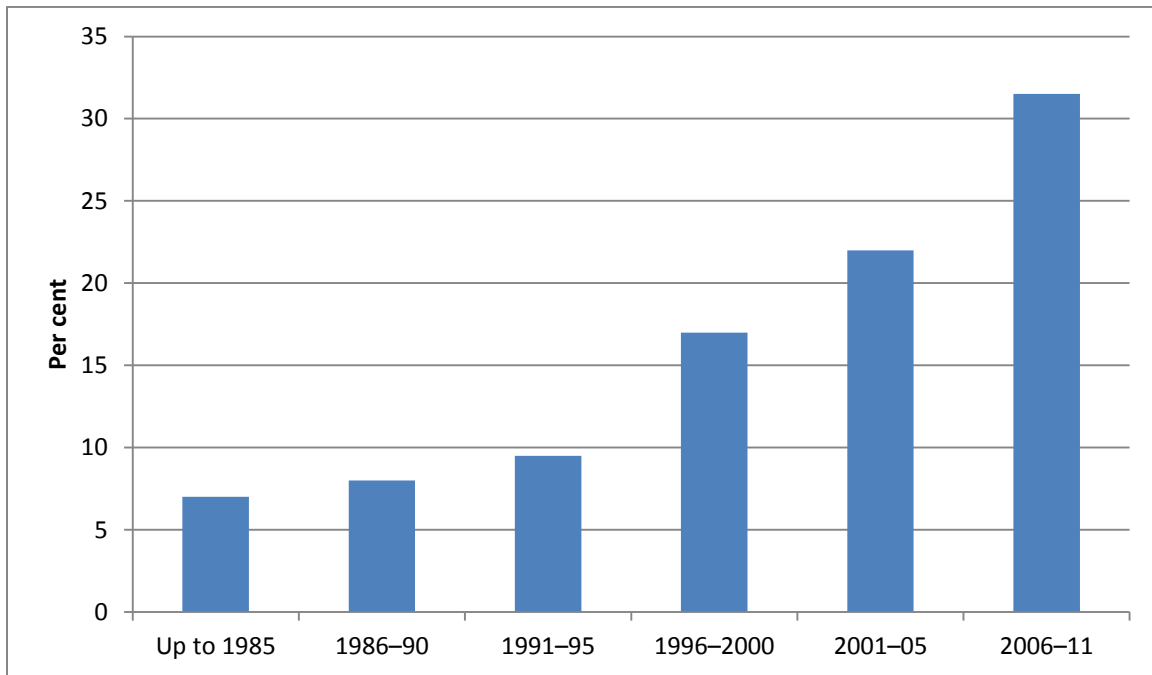


FIGURE 4: PERCENTAGE OF FULL TIME EMPLOYMENT REDUCTION WITH THALIDOMIDE VICTIMS IN EACH CASE RELATED TO THE REPORTED TIME SECTIONS

In the area of the employment persons with hearing difficulties are also disadvantaged due to the limited communication; they are reduced in full time employment to a markedly higher percentage. The percentage of victims with quadruple limb damage who are not employed is very high; compared with the other groups, this shows markedly more severe pain symptoms and a reduced capacity for exertion, which has led to a regular professional activity no longer being able to be pursued.

95% of early retirements are caused by the thalidomide damage and its sequelae. In this women are more often affected than men. The employment biographies, which were documented in interviews and focus groups, show that they have often learned several trades. The first training was in an occupation, which long-term was too strenuous physically, so that often after further training office work is commenced in the hope of being able to remain in working life longer due to lower physical exertion. The interviewees still employed expressed the fear of not being able to work until they reached retirement age for health reasons, which is followed by financial losses. If the tendency of the past years continues, a very high percentage of those affected will leave working life. In the event of premature departure from working life or reduction in employment due to pains and/or functional limitations, because of the short time span of the employment the standard of living often cannot be maintained, the support of the family and in particular the education of the children who are minors are jeopardized.

Today a high percentage of women and men already have problems with the financing

of monthly expenditures. To the question "Can you support yourself though your monthly income?", of the 870 interviewees 72% of the men and 58.5% of the women answered with "Yes"; that means that a quarter of the men and slightly less than half of the women are not able to earn their living independently. In this the necessary living covers food, accommodation, clothes, personal hygiene, household effects, heating and personal needs of daily life.

Following differentiated questioning in the interviews and focus groups as well as data recording with questionnaires on the causes for the limited employment activity, the following central reasons can be established:

1. Premature ageing of the thalidomide victims due to secondary and late sequelae. Increasingly limitations of movement occur due to tension, muscle weakness and arthrosis. The general capacity for exertion has markedly reduced in recent years.
2. Severe states of pain, which increasingly limit participation in working life or alternatively lead to a premature departure from working life.
3. Severe congenital physical limitations as well as the development of secondary sequelae, which for many of those affected does not permit participation in working life or only permits participation with limitations.
4. Underrating of the thalidomide victims and their performance at work by the employers. Often there was no offer of employment at all, although those affected could show the required qualifications for the job.
5. With women who are victims of thalidomide, as a result of physical damage and limitations, for example due to short arms and missing fingers and/or hip damage, a pregnancy and the care of the neonates and infants are a very great stress, which often permanently worsens the physical condition, so that they can no longer pursue a professional occupation.
6. Limited or unsatisfactory communication in the field of work, caused by a hearing impediment or deafness.

In the interview questions were not asked with regard to the level of the income, instead only with regard to the earning situation and income sources and afterwards whether the living could be earned without consideration of the thalidomide pension. A differentiation of these results will be carried out at a later time. Possibly it is the thalidomide pension which makes possible household security with a percentage of those affected, although with others the thalidomide pension cannot prevent considerable

disadvantages.² *These results form the empirical basis for Recommendation No. 2.*³

3.5 PRENATAL DAMAGE

TABLE 2: PRENATAL DAMAGE IN DIFFERENT REGIONS OF THE BODY. TOTAL GROUP OF THE VICTIMS OF THALIDOMIDE

Prenatal damage	Heidelberg 2011 (n=870)
Upper extremity	88.8%
Phocomelia* upper extremity	10.6%
Amelia** upper extremity	4.9%
Lower extremity	30.5%
Phocomelia/amelia** lower extremity	1.8%
Vertebral column and pelvis	93%
Damage to vision and blindness	40.3%
Impediment of speech and swallowing	18.2%
Hearing loss	34.7%
Deafness	5.6%
Internal organs (amongst others heart, kidneys, gastrointestinal tract)	60.6%
Sexual organs	11.1%

*Arms/legs are not developed, the hands have grown on the shoulders, feet have grown on the hips

** Arms/legs are not developed, hands/feet are missing

² This precarious financial situation can also have health consequences with thalidomide victims. Connections between income and growth are known and frequently described in the literature. In financially weak population groups health-related limitations in daily life are found more frequently, symptoms and pains are more frequently reported, behaviour hazardous to health is more frequently observed, increased alcohol and nicotine lead to diseases of the cardiovascular system, liver diseases, carcinomas. Less attention is paid to diet and exercise. The quality of life is lower, the risk of suffering psychological illness is markedly increased, the risk of dying is also increased.

³ The recommendations are cited in their entirety at *the end of the report*; each recommendation, which is produced as a result of the study, is already cited in a footnote in order to make clear the connections between the empirical basis on the one hand and this recommendation on the other hand.

Recommendation no. 2. Disadvantages caused by the thalidomide damage and its sequelae are emerging with regard to employment not only with the victims themselves, but also with their relatives, who provide assistance and for this reason have to limit their employment. One third of the thalidomide victims already no longer works now, according to our assessment in face-to-face interviews it is to be expected that the majority of thalidomide victims will not reach the statutory pension age due to reduction of full time employment. For these reasons financial compensation of these disadvantages is imperative.

Due to the prenatal damage of the locomotor system and the malformations in the region of the skeletal system, the joints and the postural apparatus as well as the musculature, those affected compensate for the lacking functions by a movement pattern learned at an early stage and trained for a long time. The independence in daily life acquired in this way is today jeopardized, with many of those affected it is even already limited due to reduced general capacity for exertion and reduction of physical fitness, i.e. due to losses of mobility in the physical region, which can mainly be attributed to tension, muscle weakness and arthritic changes of the joints, changes to tendons and ligaments as well as severe pain symptoms in the region of the prenatal damage and/or also in other areas not originally damaged (secondary sequelae).

Self-determination and responsibility for oneself are rated by those affected as very important for their lives. 99% of the interviewees described it as important to be able to keep daily routine self-determined. At the age of 50 years they regard themselves as too young to add the loss of independence, which is observed in a similar form in the total population only from the age of 70 to 80 years. Deficits are observed in the physical area, although not in the area of cognition.

3.6 SECONDARY SEQUELAE

- ❖ 71.7% of those affected report secondary sequelae in the upper extremities, 73.4% in the lower extremities and 72.6% in the region of the vertebral column and/or the pelvis.
- ❖ The analysis of the results shows a clear increase in the pronouncement of the secondary sequelae in all regions of the body in the periods of five years ago and two years ago up to today.

Secondary sequelae have their origin in that movement pattern practised at an early stage, with which missing functions are compensated. Abnormal exertion and overexertion of originally healthy joints and limbs, with whose help mobility could be improved, is the cause of severe arthrosis and wear and tear occurring today, which lead to tension and pains as well as an additional considerable limitation of mobility also in these areas originally not affected.

The questioning differentiates three points in time: the condition today, the condition two years ago and the condition five years ago - in each case with reference to the upper and the lower extremities as well as vertebral column and pelvis. In addition, pain, arthrosis, muscle weakness as well as muscle tension and their pronouncement (slight – moderate – considerable – severe) were recorded.

The following three tables show the respective number of persons, who have reported suffering from secondary sequelae, and the average degree of pronouncement of what they cited today and five years ago. The figures for the upper extremities (Table 3) and the lower extremities (Table 4) as well as for the vertebral column and pelvis (Table 5) are shown; in addition, once for the total group as well as for persons with low incomes and for victims with quadruple limb damage.

With the total values reported it is to be noted that for the understanding of the group increase within the last five years *the figures of those persons are cited, who assessed the symptoms on a rating scale*. In the calculation of the arithmetical mean for the “value 5 years ago” the victims are also entered, who *only today* report symptoms, and namely the value 0 for “no pains”. Thus a systematic distortion by persons, who have only recently had pains and also often only slight ones, is counteracted.

TABLE 3: NUMBER OF PERSONS WITH SECONDARY SEQUELAE AND THEIR AVERAGE DEGREE OF PRONOUNCEMENT 5 YEARS AGO AND TODAY, UPPER EXTREMITIES

NUMBER OF PERSONS WITH SECONDARY SEQUELAE AND THEIR AVERAGE DEGREE OF PRONOUNCEMENT 5 YEARS AGO AND TODAY, UPPER EXTREMITIES						
	N total	SD	N low income	SD	N quadruple limb damage	SD
Arthrosis, shoulder joints, today	312	2.65***	141	2.81***	76	2.93***
Arthrosis, shoulder joints, 5 years ago	245	1.59	119	1.92	61	1.84
Pains, shoulder joints, today	524	2.74***	203	3.01***	116	2.87***
Pains, shoulder joints, 5 years ago	392	1.71	162	2.01	89	1.90
Arthrosis, elbow joints, today	116	2.59***	51	2.88***	32	2.94***
Arthrosis, elbow joints, 5 years ago	87	1.72	43	2.15	22	1.84
Pains, elbow joints, today	242	2.26***	105	2.53***	53	2.40***
Pains, elbow joints, 5 years ago	157	1.44***	70	1.63	37	1.68
Arthrosis, wrists, today	242	2.68***	100	2.91***	61	2.79***
Arthrosis, wrists, 5 years ago	188	1.69	81	1.89	50	1.85
Pains, wrists, today	461	2.51	168	2.79***	102	2.56***
Pains, wrists, 5 years ago	315	1.48	116	1.66	74	1.54
Muscle weakness, arms, today	358	2.66***	137	2.89***	69	2.71***
Muscle weakness, arms, 5 years ago	203	1.39	81	1.54	48	1.72
Muscle tension, arms, today	373	2.88***	138	3.09***	76	2.91***
Muscle tension, arms, 5 years ago	280	1.89	111	2.23	54	1.92

+ on a scale: 0=none, 1=slight, 2=moderate, 3=considerable, 4=severe

Significance levels: *p<05; **p<01; ***p<001; Wilcoxon Test with the pairs today's value with the pronouncement of 5 years ago

TABLE 4: NUMBER OF PERSONS WITH SECONDARY SEQUELAE AND THEIR AVERAGE DEGREE OF PRONOUNCEMENT 5 YEARS AGO AND TODAY, LOWER EXTREMITIES

NUMBER OF PERSONS WITH SECONDARY SEQUELAE AND THEIR AVERAGE DEGREE OF PRONOUNCEMENT 5 YEARS AGO AND TODAY, LOWER EXTREMITIES						
	N total	SD	N low income	SD	N quadruple limb damage	SD
Arthrosis, hip joints, today	222	2.83***	92	3.61***	79	3.25***
Arthrosis, hip joints, 5 years ago	182	2.00	78	2.28	74	2.47
Pains, hip joints, today	369	2.64***	142	2.90***	119	2.90***
Pains, hip joints, 5 years ago	272	1.81	113	2.17	97	2.11
Arthrosis, knee joints, today	203	2.67***	94	2.85***	54	3.00***
Arthrosis, knee joints, 5 years ago	164	1.92	76	2.14	43	2.19
Pains, knee joints, today	346	2.45***	142	2.73***	85	2.73***
Pains, knee joints, 5 years ago	241	1.63	108	1.99	69	1.97
Arthrosis, foot and ankle joints, today	90	2.76***	47	3.11**	40	2.63***
Arthrosis, foot and ankle joints, 5 years ago	71	1.97	42	2.46	29	1.73
Pains, foot and ankle joints, today	192	2.35***	82	2.66***	66	2.39***
Pains, foot and ankle joints, 5 years ago	135	1.56	66	1.97	44	1.48
Muscle weakness, legs, today	118	2.70***	58	2.81***	61	2.98***
Muscle weakness, legs, 5 years ago	95	2.13	51	2.42	52	2.43
Muscle tension, legs, today	170	2.63**	84	2.73***	63	2.95***
Muscle tension, legs, 5 years ago	137	1.88	72	2.08	56	2.27

+ on a scale: 0=none, 1=slight, 2=moderate, 3=considerable, 4=severe

Significance levels: *p<05; **p<01; ***p<001; Wilcoxon Test with the pairs today's value with the pronouncement of 5 years ago

TABLE 5: NUMBER OF PERSONS WITH SECONDARY SEQUELAE AND THEIR AVERAGE DEGREE OF PRONOUNCEMENT 5 YEARS AGO AND TODAY, VERTEBRAL COLUMN AND PELVIS

NUMBER OF PERSONS WITH SECONDARY SEQUELAE AND THEIR AVERAGE DEGREE OF PRONOUNCEMENT 5 YEARS AGO AND TODAY, VERTEBRAL COLUMN AND PELVIS						
	N total	SD	N low income	SD	N quadruple limb damage	SD
Muscle tension, back, today	684	2.94***	239	3.22***	143	3.06***
Muscle tension, back, 5 years ago	600	2.32	212	2.58	130	2.43
Muscle weakness, back, today	272	2.52***	117	2.73***	64	2.75***
Muscle weakness, back, 5 years ago	226	2.01	96	2.20	58	2.21
Pains, cervical spine, today	609	2.75***	224	2.98***	121	2.82***
Pains, cervical spine, 5 years ago	497	2.10	188	2.34	97	2.22
Arthrosis, thoracic spine, today	338	2.57***	133	2.80**	69	2.75***
Arthrosis, thoracic spine, 5 years ago	272	1.97	109	2.23	54	2.01
Pains, lumbar spine, today	630	2.70***	222	2.97***	129	2.86***
Pains, lumbar spine, 5 years ago	515	2.08	186	2.34	107	2.24

+ on a scale: 0=none, 1=slight, 2=moderate, 3=considerable, 4=severe

Significance levels: *p<05; **p<01; ***p<001; Wilcoxon Test with the pairs today's value with the pronouncement of 5 years ago

The values show a considerable deterioration from five years ago to today. Virtually every secondary sequela in this area shows highly significant differences in the course of time. It is still to be observed that the group of those persons, who cannot support themselves with their income, is almost always worse positioned than the group of victims with quadruple limb damage, especially in the region of the upper extremities and the vertebral column.

Further analyses will clarify how far the assumption, which is based on reports from focus groups and interviews, applies, namely that there are intersections between both observed groups and that in the group with low incomes two risk factors accumulate, which can exert a negative effect on the progress of the secondary sequelae.

The following figures show the development of arthrosis, pains, muscle weakness and tensions in the last five or in the last two years, with the upper and lower extremities and vertebral column and pelvis shown separately. The further development to be expected on this basis is shown by linear trend lines. The arithmetical mean values of this data were first established over the person, then over the totality of the persons, who reported secondary sequelae.

The analysis of the results shows an increase in the pronouncement of all mean values in all three regions of the body in the periods of five years ago, two years ago and today. These results tally with the statements of those affected in interviews and in focus groups, namely that secondary sequelae have been increasing slowly for approximately 5–10 years, that changes in the joints are occurring, which together with the tension and pains and because of the muscle weakness are leading to an increasing limitation of fitness. This development has accelerated markedly in the last two to three years.

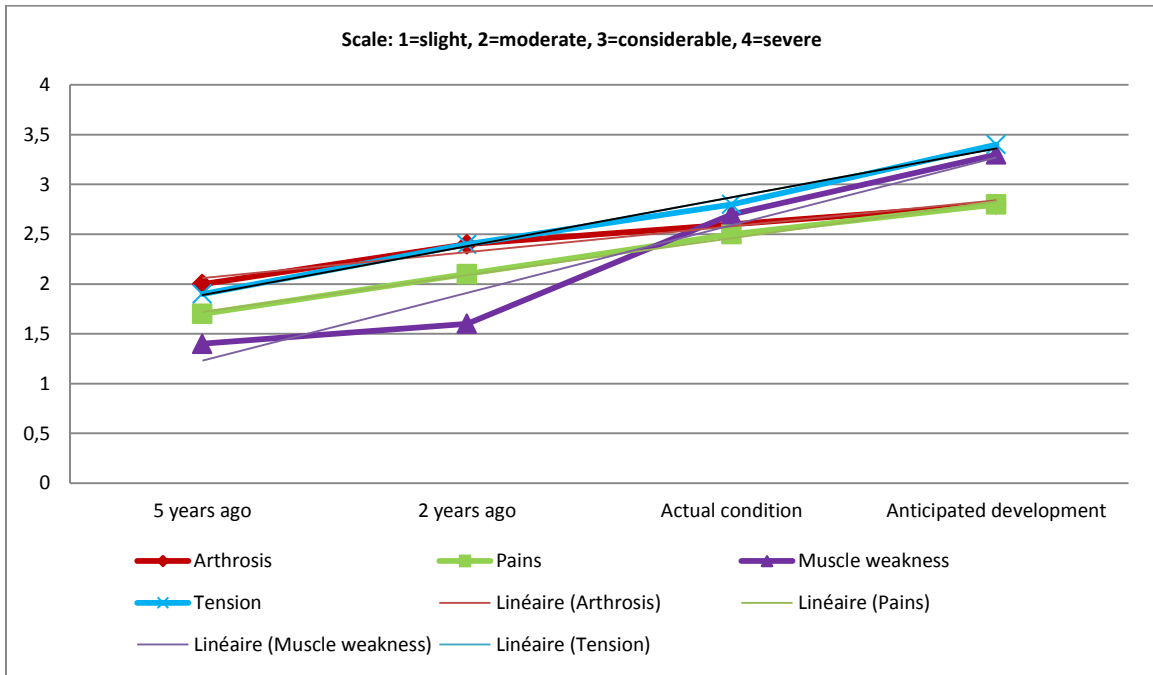


FIGURE 5: DEVELOPMENT AND PROGRESS OF SECONDARY SEQUELAE IN THE REGION OF THE UPPER EXTREMITIES OVER 5 YEARS AND ANTICIPATED DEVELOPMENT IN THE FUTURE

MEAN VALUES OF THE REPORTS OF ARTHROSIS (N=319), PAINS (N=529), MUSCLE WEAKNESS (N=368) AND TENSION (N=378) ARE SHOWN



FIGURE 6: DEVELOPMENT AND PROGRESS OF SECONDARY SEQUELAE IN THE REGION OF THE UPPER EXTREMITIES OVER 5 YEARS AND ANTICIPATED DEVELOPMENT IN THE FUTURE

MEAN VALUES OF THE REPORTS OF ARTHROSIS (N=230), PAINS (N=376), MUSCLE WEAKNESS (N=119) AND TENSION (N=172) ARE SHOWN

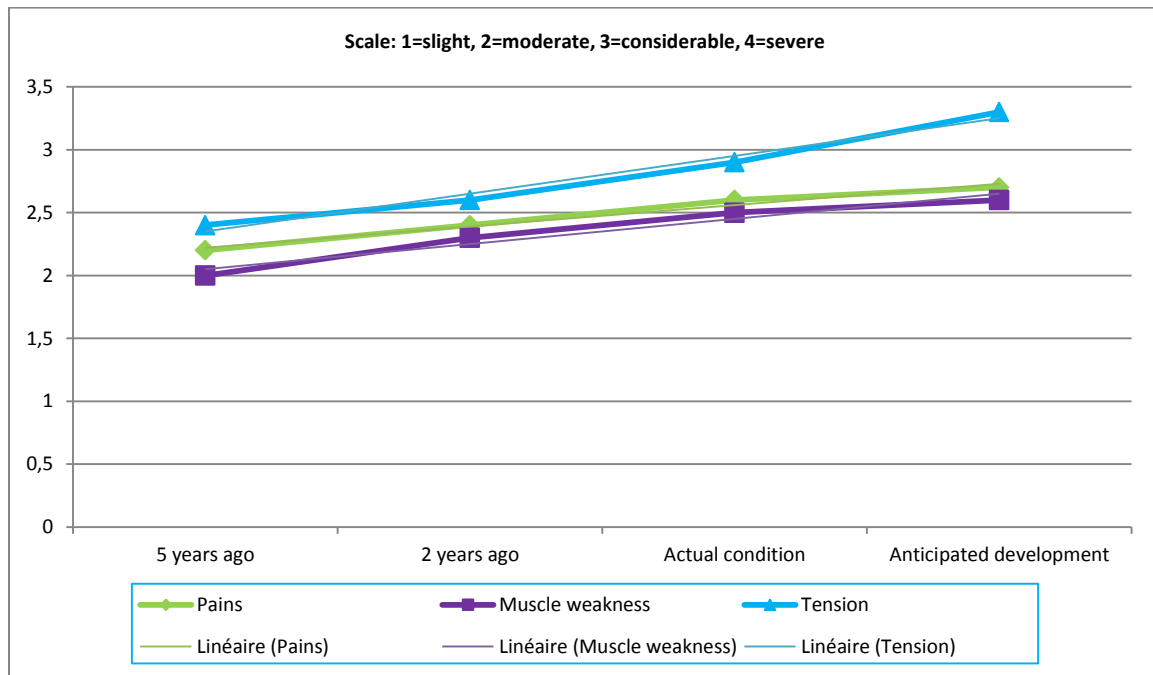


FIGURE 7: DEVELOPMENT AND PROGRESS OF SECONDARY SEQUELAE IN THE REGION OF THE VERTEBRAL COLUMN AND PELVIS OVER 5 YEARS AND ANTICIPATED DEVELOPMENT IN THE FUTURE
MEAN VALUES OF THE REPORTS OF PAINS (N=640) AND MUSCLE WEAKNESS (N=279) AND TENSION (N=693) ARE SHOWN

The development and effects of secondary sequelae should be illustrated with two examples.

Example 1: A man who is a thalidomide victim with shortened arms and malformed hands, although normally developed shoulder joints and a normally developed vertebral column in the course of the years can develop arthritic changes in the shoulders with corresponding pain symptoms as the activities which he carries out with the upper extremities take place out of the shoulders. This increased strain and abnormal exertion in the shoulder girdle, in the cervical spine, also the altered interplay of the musculature in this region can additionally lead to deformation of the vertebral column, for example in the form of scoliosis. Both the scoliosis of the vertebral column as well as the wear and tear in the region of the shoulder joints would be to be described as secondary sequelae in this case. This acquired damage occurs additionally to that which over time develops in the regions damaged before birth, in our example the arms and hands.

Example 2: A woman who is a thalidomide victim with missing arms and malformed hands will carry out the majority of daily activities with the feet, she learnt this as a child, and this training forms the basis for independence in her daily life. She compensates for the missing functions of the arms and hands by increased use of the legs and feet, for example in operating the PC or with writing and eating. Due to the persistent abnormal strain of the joints in the region of the lower extremities and the hips over years,

symptoms/pains and effects of arthrosis in the hip and knee joints not originally malformed as well as in the overstrained joints, in tendons and muscles of the foot are increasingly observed. In this way she suffers not only in the area of the arms and shoulders, but also increasingly in the region of the lower extremities not actually damaged.

The prenatal damage and the secondary sequelae were recorded differentiated in the questionnaire, beyond that in the interviews, which were carried out face-to-face, *the damage and its effects in daily situations could be observed*. The fact that thalidomide victims with similar damage can differ very markedly in their mobility and physical fitness formed a further finding for the examination team. Individual severely damaged persons with phocomelia of the arms can for example within limits lead an independent life, although the expenditure of time and energy for all activities is markedly higher without support. Due to the increasing muscle weakness, the arthrosis, the states of severe pain as well as the secondary sequelae, which occur in very many of those affected, support can be dispensed with less and less, mobility and thus independence reduce.

Losses of abilities and skills have been emerging in those affected for approximately 5 to 10 years, the increase tends to take place slowly in the first years; however, in the last 2 to 3 years this process has perceptibly accelerated. In the sequence of movement a proportionate difference between a reduction in fitness, which is to be attributed to prenatal damage or secondary sequelae, is not to be found without prior knowledge of the prenatal damage pattern. The process is no longer found to be a linear increase by those affected, instead it is found rather to be exponential. An only slight reduction in mobility can for example with a shortening of the arms have significant effects in daily life: the hair can currently still be washed independently, if there is a slight reduction in strength and mobility this no longer works, those affected will then require help in performing this activity. This development has consequences for the daily life of all affected thalidomide victims: personal hygiene, for example cutting toenails, cooking, making beds or manual jobs, such as for example minor repairs to the house, gardening or alternatively hobbies, handicrafts or artistic activities, are no longer possible, shirt buttons can no longer be fastened independently, fastening shoes is difficult. The distance that can be walked becomes shorter, sitting for a long period can become difficult, therefore social involvement or a professional occupation are also jeopardized. The need for assistance in performing these helping hands, which are small, although necessary in daily life, is increasing.

In interviews and focus groups 67% of those affected see that the extent of the secondary damage depends on the extent of the life-long physical stress, which is to be attributed to stresses in the family area and/or at work. Those who have the opportunity to rest, for example because the partner earns enough, compared with those who work in full time employment, are affected to a clearly lesser extent.

In the following figures the mean values of the pronouncement (scaling 1–4) over

three points in time for pains in the lower extremities and pains in the back are shown for the group of victims with quadruple limb damage compared with the group of victims without quadruple limb damage.

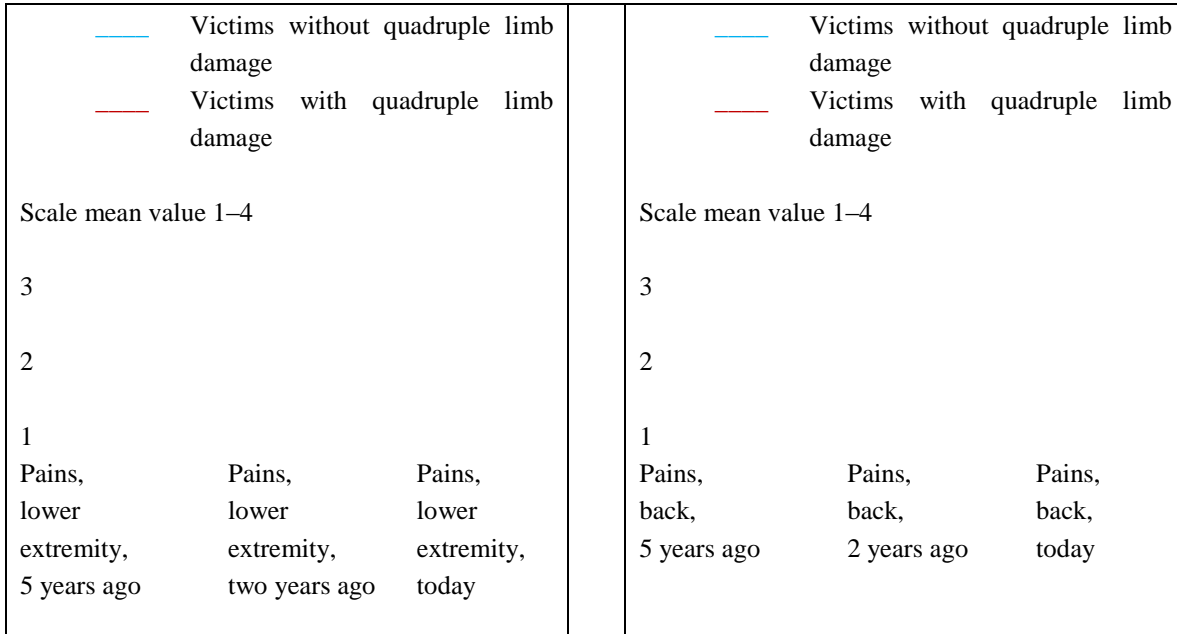


FIGURE 8: DEVELOPMENT AND PROGRESS OF SECONDARY SEQUELAE IN THE REGION OF THE LOWER EXTREMITIES OVER 5 YEARS

FIGURE 8: DEVELOPMENT AND PROGRESS OF SECONDARY SEQUELAE IN THE REGION OF THE BACK OVER 5 YEARS

In these figures it is clearly manifest that the mean values for the pronouncement of the pains due to secondary sequelae in these regions of the body at all times with victims with quadruple limb damage are higher than with victims without quadruple limb damage. Functionality is not only reduced by the extent of the severe damage, which affects the four extremities, but additionally by the occurrence of severe states of pain. *These results form the empirical basis for Recommendation No. 1.*⁴

3.7 LATE SEQUELAE

Late sequelae constitute the results of pathological changes in the course and in the structure of nerves and vessels, in part also in the cellular structure of the musculature, which possibly developed prior to birth under the influence of thalidomide. Thalidomide damages all vessels which are growing; as all organ systems of the unborn child are in the process of growing, even if in differing intensity, the assumption that damage has

⁴ **Recommendation No. 1:** Because of the great significance of secondary sequelae for the current and future situation and independence, re-evaluation and recognition of the secondary sequelae are imperative.

developed in the entire vascular system, appears entirely logical. The malformation of the organ systems also includes the peripheral nervous system, so that dysfunction can also occur there; likewise the course of the nerves in thalidomide victims often does not correspond to the norm. Through systematic questioning with a section of those affected a reduced capacity for exertion of the musculature could also be established, which could represent an indication of a defective structure of the musculature.

Late sequelae have not been examined systematically to date as their existence had largely been unknown to date and furthermore the diagnostic methods were not available at the time of the discovery of the prenatal damage. Anomalies of the vascular system can be assumed, if taking blood samples is difficult or not possible, if the pulse is not palpable in typical location or is not palpable at all, if the pain symptoms suggest an altered course of a peripheral nerve. In interviews it could be documented that taking a blood sample on extremities apparently not affected was only possible with great difficulty. The vessels lie deep and not in typical location. One interviewee confided that because of incomplete vascular development and thus under-perfusion of the joints, the heads of both femurs are becoming broken down.

Records of demonstrations of vessels and operation reports are available to the Institute of Gerontology, which document the presence of atypical changes of this nature.

Those affected are at risk that through possibly reduced density of the vessels and their malposition, circulation is restricted and can lead to severe additional organ damage. In addition, the medical profession is often not aware of these deviating courses and structures in the area of the vascular system and the nervous system, and a danger to the patient quite specifically then emerges, if surgical procedures are necessary. Thus, for example, severing of peripheral nerves or alternatively damage of vessels can occur because their course does not correspond to the norm. More precise knowledge with regard to possible prenatal damage of the musculature is important when initiating rehabilitative measures to build up the musculature. In this respect thalidomide victims differ markedly from people with a physical disability of different origin. *These results form the empirical basis for Recommendation No. 13.*⁵

3.8 PAINS

3.8.1 PRONOUNCEMENT OF PAINS

- ❖ 733 interviewees or 84.7% reported suffering from pains.

⁵ **Recommendation No. 13:** A scientific study of late sequelae is to be carried out concerning a malposition of vessels, nerves and muscles; recognition of them as prenatal damage is to be ensured.

- ❖ 89.4% of women are affected
- ❖ 79.4% of men are affected
- ❖ The impairment at work (to a variable extent) due to pains is shown to be at n=671 or 77%.
- ❖ Complete impairment at work due to pain (n=671) is shown to be at 22.7% of the men and 25.7% of the women.

Thalidomide victims, who report suffering from pains, were questioned about the pronouncement of their pains during the last two weeks. The following figure provides information about the extent of pains.

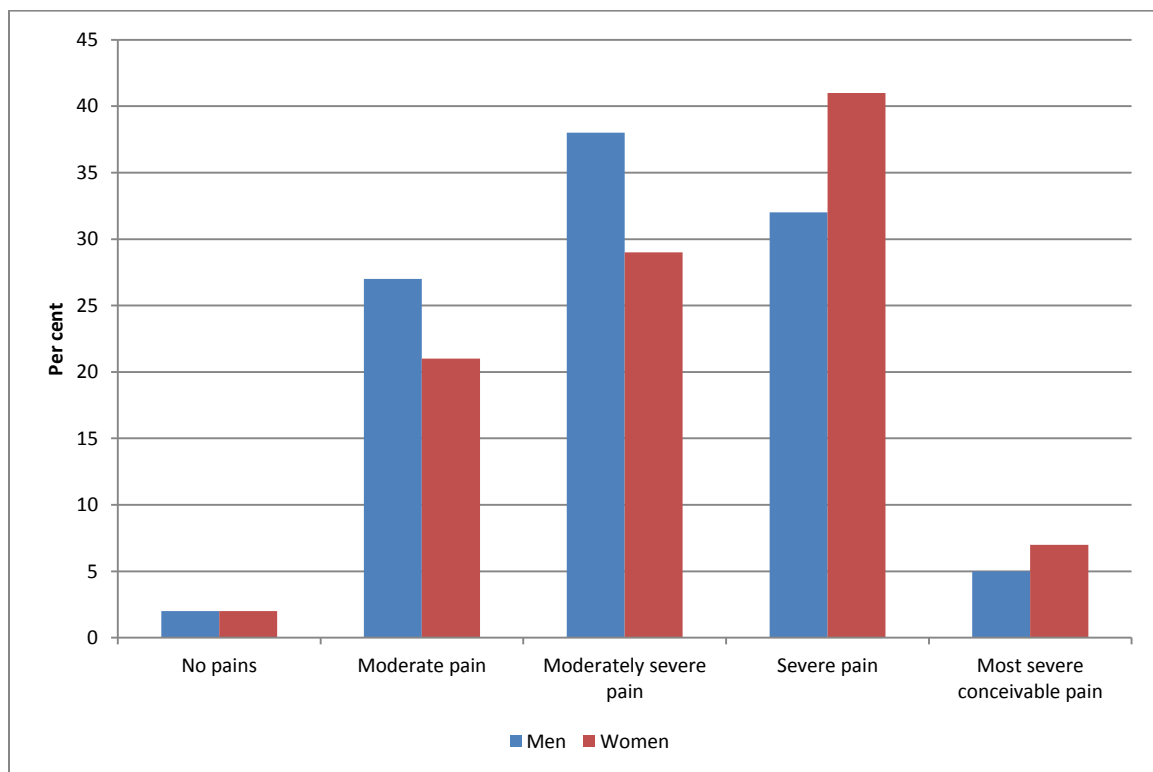


FIGURE 10: PRONOUNCEMENT OF PAINS DURING THE LAST TWO WEEKS (N=733)

The figure shows that women report a stronger pronouncement of pain. This finding tallies with the results reported in the pain literature. Deaf persons show damage in the region of the locomotor system only approximately half as often as persons with hearing loss or persons without damaged hearing. In contrast with this, damage in the region of the internal organs and the head occur more frequently. For this reason pains in the region of the locomotor system are cited less commonly, for this deaf persons complain of pains in the region of the ears, the auditory canal or the auditory nerves. Victims with quadruple limb damage report in all regions more frequent pains than the comparable group of victims without quadruple limb damage

3.8.2 TREATMENT OF PAINS

In the following table the proportion of those pain therapy measures are cited, which, according to their statements, those affected need and which, however, are not available.

TABLE 6: PAIN THERAPIES NEEDED AND THEIR AVAILABILITY (N=733)

Type of treatment	Treatment necessary (%)	Treatment is <u>not</u> available (%)
Medication		
Men	57.0	8.0
Women	68.8	4.9
Outpatient medical treatment		
Men	47.8	18.5
Women	57.4	14.5
Physiotherapy		
Men	73.5	35.2
Women	83.7	29.8
Massage		
Men	77.8	44.3
Women	83.1	46.1

Pains are only treated with medication by those affected if there are severe symptoms as with thalidomide victims there are clear reservations about medication. Instead they try to alleviate the pains with conventional physical methods, with massages, physiotherapy, lymph drainage, or alternatively with alternative methods as these methods are more tolerable for them.⁶ In their experience, through regular weekly or daily applications, medication, which always shows unwanted side-effects, can largely be avoided. However, services of this type are as a rule not financed to the necessary extent by the statutory health insurance schemes. The result is not only a reduced quality of life as a result of pains and medication-induced side-effects, but also an increasing reduction in fitness up to the point of giving up work as the pains are frequently not compatible with a professional occupation.

⁶ Further literature:

1. Bennell, K. & Hinman, R. (2011). A review of the clinical evidence for exercise in osteoarthritis of the hip and knee. *Journal of Science and Medicine in Sport* 14, 4-9.
2. Ernst, H. (2003). Krankengymnastik und physikalische Therapiemaßnahmen zur konservativen Therapie der Arthrose. *Deutsche Zeitschrift für Sportmedizin [Physiotherapy and Physical Therapy Measures for Conservative Treatment of Arthrosis. German Journal of Sports Medicine]*, 54, 6, 191-195.
3. Madry, H. & Kohn, D. (2004). Konservative Therapie der Kniearthrose. *Der Unfallchirurg [Conservative Treatment of Arthrosis of the Knee. The Trauma Surgeon]*, 107, 8, 689-700.
4. Greß, S., Kiselev, J., Mohokum, M., Kuss, K. & v.Wagensveld, A. (2011). Die Rolle der Physiotherapie bei der Versorgung chronischer Erkrankungen. *Internationale Erfahrungen und nationale Defizite. Sozialer Fortschritt [The Role of Physiotherapy in the Treatment of Chronic Diseases. International Experiences and National Deficits. Social Progress]*, 60, 7, 151-159.
5. Kolster, B.C. (2010). *Massage*. Springer Berlin Heidelberg, 3rd edition

3.9 UNCOVERED COSTS FOR MEDICAL MEASURES AND AIDS

- ❖ Of 65.9% of the interviewees (n=573) uncovered costs for medical services are reported.
- ❖ 50.3% report uncovered costs for aids.
- ❖ 71.8% report uncovered costs for physical therapy.
- ❖ 33.4% of the interviewees (n=578) finance their uncovered costs by themselves

According to the statements of the interviewees, necessary medical services, such as expensive analgesics or physical therapy, aids and technical aids are frequently not met to the necessary extent by the statutory medical insurance schemes and in the framework of budgeting are not prescribed by doctors in a sufficient quantity. The following table shows the respective proportion of the thalidomide victims, who have reported uncovered costs for various medical measures in the questionnaire.

TABLE 7: MEDICAL MEASURES AND AIDS WITH VICTIMS OF THALIDOMIDE (N=573), WHERE COSTS ARISE, WHICH ARE NOT MET BY THE HEALTH INSURANCE SCHEME (N=573)

Uncovered costs for	Percentage of persons with uncovered costs (n=573)
Medication	37.8%
Aids, e.g. wheelchairs, hearing aids, their purchase, inspection and servicing. Electric shutters and garage doors, light/bell systems, high adjustable computer workstations, speech recognition programs	50.3%
Physical therapy, e.g. massage, physiotherapy, manual therapy, lymph drainage, acupuncture, osteopathy	71.8%
Rehabilitative measures: e.g. stays in spas by those affected once per year for four to six weeks, adjustment of the pain therapy	46.2%

A section of the thalidomide victims, with whom a medical need is not met by the insurance schemes, finance their medical treatment by themselves if possible in order to be able to fulfil their familial and professional obligations. In the following table the annual financial burden due to these expenditures is cited and the percentage of those persons, who undertake the financing of the additional costs themselves is cited.

TABLE 8: FINANCIAL BURDEN PER YEAR DUE TO ADDITIONAL NECESSARY MEDICAL SERVICES/AIDS, WHICH ARE NOT MET BY THE HEALTH INSURANCE SCHEMES. FINANCING BY PERSONAL CONTRIBUTION

Annual financial burden due to uncovered need for medical services	Percentage of thalidomide victims with uncovered costs
Up to € 1,500	39.5
€ 1,500 up to under 2,500	19.2
€ 2,500 up to under 5,000	18.8
€ 5,000 up to under 10,000	11.2
€ 10,000 and more	11.3
Financing by personal contribution of	33.4

*Lack of information with 21 persons

Reports of those affected in interviews and focus groups confirm this uncovered need. In the interviews and focus groups it was emphasised that physical therapy in the extent to which it is met by the statutory insurance schemes - 6 or 10 applications in a quarter -, does not suffice by a long way. Massages, lymph drainage and manual therapy in the treatment of states of pain, which are to be traced back to tension, orthopaedic problems or disturbances of circulation are evaluated by those affected as very efficient. However, the applications are needed daily or at least several times weekly in order to alleviate pains long-term; not every one of those affected is able to meet the costs associated with this. Therefore medication is often increasingly prescribed and taken, which can lead to corresponding undesired side-effects, although it is for the most part met by the insurance schemes without problems. *These results form the empirical basis for Recommendation No. 4.*⁷

⁷ **Recommendation No. 4:** The treatment of thalidomide victims with the necessary medical and therapeutic measures in the outpatient and inpatient area is to be ensured without financial expenditure for those affected. The proven thalidomide damage is the justification for the patient not being classed as the norm and not falling into the budgeting regulations for medical service in order to guarantee the best possible treatment. For this reason endeavours should also be made so that a sufficient number of doctors in Germany are available, who have at their disposal a high level of competence with regard to the advising and treatment of thalidomide victims and can also advise medical colleagues, to whom the thalidomide victims turn with requests for rehabilitation. Explanation for thalidomide victims about the options of rehabilitation tailored to their specific situation is to be ensured. The treatment of thalidomide victims with outpatient or inpatient rehabilitation services is to be ensured. It is to be ensured that the rehabilitation need perceived and articulated by thalidomide victims be converted into action without delay.

3.10 ASSISTANCE NEED

- ❖ There is assistance need with 384 persons or 44.9%
- ❖ There is assistance need in the group of victims with quadruple limb damage (n=163) at 66.9%.
- ❖ Victims with quadruple limb damage have an almost double high assistance need in hours per week as victims without quadruple limb damage.
- ❖ 11.1% of the thalidomide victims with assistance need and uncovered costs (n=219) finance their assistance need by themselves.

Assistance is not to be equated with nursing care. A need for assistance develops with thalidomide victims in middle age depending on the extent of the prenatal damage and the secondary sequelae, for example in the area of self-care: the capacity to dress oneself independently, gradually becomes increasingly limited over a longer period of time due to increasing pains in the malformed shoulders, arms and hands. Stressful housekeeping activities, such as making beds or alternatively cleaning vegetables, lifting saucepans, can no longer be carried out without assistance. Walking and cycling become increasingly difficult for many of those affected, if hip joints are malformed and increasingly arthritic changes are shown. In professional life physical activities can frequently no longer be carried out, for example if there is damage in the region of the upper extremities, severe pains in the shoulder often develop and when sitting for longer periods and operating the PC.

In the context of the preliminary discussions, individual interviews and a focus group, which also had personal assistance as the subject, it could be established that the discussions and demands of general disabled associations, such as for example the Independent Living Society (ILS) or the Forum for Self-determined Assistance of Disable People (ForseA), are not accepted by the thalidomide associations or are accepted only on an individual basis.

Many thalidomide victims are not aware of the concept of self-governing assistance on the basis of a personal budget.

The participants in the focus group unanimously stressed that assistance is basically sensible. Individuals explain that with increasing age and increasing limitation the model continues to gain attractiveness for them.

Personal assistance assumes willingness to permit help and moreover organise actively. As independence and personal responsibility – as already presented – are rated very highly by all thalidomide victims, acceptance of support and assistance is difficult and furthermore is regarded as a limitation of their painstakingly attained independence. It was also emphasised that as little help as possible should be called upon “in order not to get out of practice”. However, the reference to old age and the increasing attractiveness

of personal assistance show that there is an awareness that the independence gained in middle age is already reducing due to overstrain and signs of wear and tear.

In our random sample there is an assistance need with 44.9% of the interviewees. The assistance need is particularly high with victims with quadruple limb damage. The need for hours of assistance per week shows clear differences between the two groups. In the following table the assistance need in terms of time of the victims with quadruple limb damage and victims without quadruple limb damage is compared.

TABLE 9: ASSISTANCE NEED IN HOURS PER WEEK FOR VICTIMS WITHOUT QUADRUPLE LIMB DAMAGE AND VICTIMS WITH QUADRUPLE LIMB DAMAGE

Assistance in hours per week	Victims without quadruple limb damage (%) (n=707)*	Victims with quadruple limb damage (%) (n=163)*
No need	59.0	33.1
Under 11 hours	12.8	22.7
11 up to under 21 hours	8.9	12.9
21 up to under 31 hours	4.2	8.0
31 up to under 41 hours	2.8	4.3
41 hours and more	3.7	8.0

* No subsequent information on the level of the number of hours from 8.9 or 11.0%

According to statements of those affected, the need for assistance will increase in the coming years. 65% are of the opinion that the need will increase, according to the estimation of 37% it will remain the same.

It is mainly partners, relatives or alternatively friends, who support those affected in daily life. The latter live either in the same household or alternatively in the neighbourhood and are prepared to take on tasks, such as for example larger shopping or difficult housework as required. In only 13.4% is there support by professional outpatient services. With the majority of those affected it is only about services, which regularly occur spread over the day, although mainly not within a specific period of time. It is about a helping hand with fastening shoes if going out of the house, or help with dressing, combing hair or putting on make-up, with household activities. With the increasing loss of mobility, as is experienced and anticipated by those affected, the need for assistance in daily routine increases.

Financing of assistance is cost-intensive. Assistance on the scale of 24 hours per day on seven days per week is estimated at approximately €12,000 to €15000. In the following table the annual financial burden of those persons is cited, who reported an uncovered need for assistance services (n=146).

TABLE 10: FINANCIAL BURDEN PER YEAR DUE TO UNCOVERED NEED FOR ASSISTANCE

Annual financial burden due to uncovered need for assistance	Percentage of thalidomide victims with assistance need and uncovered costs (%; n=146)
Up to € 1,500	6.3
€ 1,500 up to under 2,500	7.0
€ 2,500 up to under 5,000	19.6
€ 5,000 up to under 10,000	25.9
€ 10,000 and more	33.5
Financing by personal contribution of	7.0

As the expenditure lies clearly higher than the needs for medicine-therapeutic services by way of comparison, only approximately one tenth (7.0%) of thalidomide victims with assistance need and uncovered costs are in a position to finance by personal contribution the costs which are not met by cost-bearers in order to manage in daily life. *These results form the empirical basis for Recommendation No. 8.*⁸

3.11 NURSING CARE NEED

- ❖ 41.7% of the men show a nursing care need to a variable extent
- ❖ 46.6% of the women show a nursing care need to a variable extent
- ❖ The care classes of nursing care are divided as follows:
 - Nursing care class 0: 4.1%
 - Nursing care class I: 33.4%
 - Nursing care class II: 52.8%
 - Nursing care class III: 9.7%
- ❖ With 80% there is a nursing care need over 5 years.
- ❖ The nursing care takes place mainly at home, outpatient services are only called upon in 13% of the cases
- ❖ There is an uncovered nursing care need with 29.1% of the affected men and with 31% of the women.
- ❖ 17.8% of those affected finance the uncovered need by personal contribution.
- ❖ An increase in the nursing care need is anticipated by those affected; 71.8%

⁸ **Recommendation No. 8:** Personal assistance is to be ensured in the form of budget payments; the level of the budget is to be adjusted continuously to the currently reported assistance need and set in a discussion between victim and specialist – supported by peers.

assume that it will become higher in the coming years, 24% are of the opinion that it will stay the same.

The following two tables show to what extent victims are cared for by different groups of persons, such as parents, children, partners etc. (Table 11) and furthermore by how many groups at the time. In order to be able to make a distinction according to degree of severity, a division according to nursing care class 0 and 1 as well as nursing care class 2 and 3 is made. Analogous to the secondary sequelae total group, persons with low income and victims with quadruple limb damage are also placed next to one another here.

The high number of persons, who provide care if there is a higher nursing care class, is noticeable in all groups, people with nursing care class 2 and 3 are cared for by a broad social network. It is precisely with persons with low income and victims with quadruple limb damage that the question arises, who will take over these care services, if the social network should start to crumble in future, e.g. after the children move out or in the event of overload of the partner etc.

TABLE 11: PERCENTAGE OF PERSONS, WHO PROVIDE NURSING CARE FOR VICTIMS

PERCENTAGE OF PERSONS, WHO PROVIDE NURSING CARE FOR VICTIMS DIVIDED ACCORDING TO TOATL RANDOM SAMPLE, PERSONS WITH LOW INCOME AND QUADRUPLE LIMB DAMAGE						
	Total Nursing care class 0 and 1 (N=113)	Total Nursing care class 2 and 3 (N=205)	↓ Income Nursing care class 0 and 1 (N=40)	↓ Income Nursing care class 2 and 3 (N=86)	Quadruple limb damage Nursing care class 0 and 1 (N=22)	Quadruple limb damage Nursing care class 2 and 3 (N=64)
Care by parents	18.0%	25.8%	19.1%	23.6%	22.7%	22.7%
Care by children	20.3%	24.4%	25.5%	32.6%	22.7%	12.1%
Care by siblings	9.4% *	20.7%	8.5%	21.3%	4.5%	21.2%
Care by other relatives	8.6%	12.2%	10.6%	13.5%	9.1%	10.6%
Care by spouse/partner	60.2%	54.2% *	63.8%	56.2%	63.6%	37.9% *
Care by friends/neighbours	21.9% **	38.5%	19.1% **	44.9%	18.2%	34.8%
Care by outpatient care service	7.0% *	16.9%	8.5%	14.6%	9.1%	22.7%
Care by community service	0.8%	2.3%	0%	2.2%	0%	3.0%
Care by other third party	11.7% ***	29.6%	10.6% *	31.5%	13.6% *	42.4%

Significance levels (value lies significantly lower than value of the other nursing care class group):

*p<05;**p<01;***p<.001; Chi² test

TABLE 12: SIZE OF THE GROUPS OF PERSONS, WHO PROVIDE NURSING CARE FOR VICTIMS

SIZE OF THE GROUPS PERSONS, WHO PROVIDE NURSING CARE FOR VICTIMS DIVIDED ACCORDING TO TOATL RANDOM SAMPLE, PERSONS WITH LOW INCOME AND QUADRUPLE LIMB DAMAGE						
	Total Nursing care class 0 and 1 (N=113)	Total Nursing care class 2 and 3 (N=205)	↓ Income Nursing care class 0 and 1 (N=40)	↓ Income Nursing care class 2 and 3 (N=86)	Quadruple limb damage Nursing care class 0 and 1 (N=22)	Quadruple limb damage Nursing care class 2 and 3 (N=64)
Care not provided by anyone	12.4%	3.8%	14.9%	3.4%	9.1%	3.0%
Care by a group of persons	41.4%	31.0%	34.0%	30.3%	36.4%	37.9%
Care by two groups of persons	26.6%	26.3%	27.7%	23.6%	40.9%	28.8%
Care by three groups of persons	15.6%	21.6%	19.1%	16.9%	9.1%	13.6%
Care by four groups of persons	3.1%	12.7%	2.1%	19.1%	4.5%	13.6%
Care by five groups of persons	0.8%	2.8%	2.1%	4.5%	0.0%	1.5%
Care by six groups of persons	0.0%	1.9%	0.0%	2.2%	0.0%	1.5%

There is an uncovered need for nursing care services, which is not met by the health insurance schemes, with approximately one third of the affected men and women according to their own statements. The level of the uncovered need and the percentage of those thalidomide victims, who cover the costs with their own financial means, is reproduced in the following table.

TABLE 13: FINANCIAL BURDEN PER YEAR DUE TO UNCOVERED NEED FOR NURSING CARE

Annual financial burden due to uncovered need for nursing care services	Percentage of thalidomide victims with nursing care need and uncovered costs (%) (n=245)
Up to € 1,500	20.0
€ 1,500 up to under 2,500	21.2
€ 2,500 up to under 5,000	20.0
€ 5,000 up to under 10,000	16.7
€ 10,000 and more	22.0
Financing by personal contribution of	17.8

These results form the empirical basis for Recommendation No. 3.⁹

3.12 DENTAL TREATMENT

- ❖ 18.8% of the totality of thalidomide victims report a malformation of the jaw and/or teeth.
- ❖ With 39.4% of the deaf persons there is a malformation of the jaw.
- ❖ With 36.2% of the deaf persons there is a malformation of the teeth.
- ❖ Thalidomide victims with malformations/shortening of the upper extremities (88.8%) use the teeth in order to compensate for the lack of grasping function of the hands.

Deformities of the jaw and malformations of the teeth mainly occur with persons with damaged hearing. This prenatal damage requires costly dental and/or maxillo-surgical treatment, which are either not met at all or only a small percentage is met by the health insurance schemes. Correction of a malformation or malposition of the jaw is imperative for speech development, communication and for unimpaired eating function.

⁹ **Recommendation No. 3:** In view of the fact that managing with the demands and strains associated with thalidomide damage also means a great challenge for the next of kin, it is to be ensured that the latter are not called upon for financial resources, if a thalidomide victim becomes in need of nursing care and cannot finance the nursing care services extending beyond the legally defined services.

In addition, thalidomide victims with shortened arms and/or malformed hands use the teeth to compensate for the lack of grasping function of the hands. For example they open bottles, carry objects, operate levers with their teeth. However, this damages the teeth.

The prophylaxis in the form of regular professional teeth cleaning is not met by the statutory health insurance schemes, although through this further dental damage could be prevented as thalidomide victims with malformations on arms and/or hands, due to limited functionality, are often not able to carry out daily cleaning of teeth properly. Through tooth loss the grasping function of the teeth is limited, which leads to a further loss of independence as helping hands now become necessary. For this reason dental prosthesis is of central importance.

Dental implants have the advantage that through anchoring in the jaw they lend the teeth stability again. Those thalidomide victims, who have no grasping function or only have it incompletely, cannot handle independently a traditional, removable dental prosthesis.

Aachen Social Security Tribunal, in its decision dated 01.02.2011, rejected an action brought by a thalidomide victim, who had demanded the acceptance of all costs for a treatment with a dental implant beyond the approved fixed allowance by the statutory health insurance scheme. There is therefore not an obligation to perform by the health insurance schemes. Whilst a removable dental prosthesis is financed, this is, however, not fit for the function that it has with many thalidomide victims, and furthermore, cannot be used, removed and cleaned by them independently. *These results form the empirical basis for Recommendation No. 11.*¹⁰

3.13 MEDICAL TREATMENT BY DOCTORS AND PHYSIOTHERAPISTS

In the interviews and focus groups treatment by doctors is regularly discussed. It is fundamentally criticised that a high percentage of the medical profession lacks more precise knowledge about thalidomide damage and its possible sequelae and that adequate treatment options are lacking. In particular, orthopaedic specialists often treat thalidomide victims like physically handicapped with other causes of handicap; however, this with little success. Doctors are not always prepared to prescribe the treatments, which those affected want because the applications in the total population follow other principles. For example, long-term massage or lymph drainage is prescribed only on rare occasions, not only due to reasons of budgeting, but also due to the indications given. According to the

¹⁰ **Recommendation No. 11:** With regard to dental treatment acceptance of all necessary dental and maxillo-surgical measures, which are to be attributed to malformations in the region of the visceral cranium and the jaw, are to be ensured by the statutory health insurance schemes. Professional teeth cleaning for prevention of further damage is to be guaranteed by the cost bearers. In addition, the costs for dental implants are to be met in full for those thalidomide victims, with whom the lack of grasping function of the hands is compensated by the teeth and a removable dental prosthesis cannot be used or removed and cleaned by them independently.

statements of those concerned, regular application of lymph drainage alleviates pains and symptoms, which can be triggered by insufficient circulation and oedema development on the basis of late sequelae. In the total population there are medical indications for lymph drainage if there is interruption of lymph outflow, for example after operative removal of lymph nodes due to carcinoma or alternatively due to condition following severe venous inflammation with venous congestion.

The knowledge and experience, which physiotherapists acquired in the 1960s, have largely been lost. In this area too the successful treatment of thalidomide victims also requires specific knowledge with regard to the nature and extent of the damage. *These results form the empirical basis for Recommendation No. 12.*¹¹

3.14 MOBILITY AND AIDS

- ❖ 20% of all interviewees report problems with walking in the house.
- ❖ 59% of the victims with quadruple damage report problems with walking in the house.
- ❖ 84% of all interviewees have a vehicle, of this 67% cannot finance the adapting of the car themselves.
- ❖ With 50% of the interviewees additional payments or complete financing of aids are necessary. With victims with quadruple damage this percentage lies at 64%.
- ❖ 19% of all interviewees need a hearing aid.
- ❖ With 33% of all interviewees there is an urgent need for adaptation in their home due to the thalidomide damage, of this 92% report having no cost-bearer for the adaptation.
- ❖ With 48% of the victims with quadruple damage there is an urgent need for adaptation, 94% have no cost-bearer.

An important element for quality of life and participation is mobility inside and outside the house. One fifth of all interviewees report problems with walking in the house, 9% in using their wheelchair. With the victims with quadruple damage these percentages are even higher: here 59% report problems with walking in the house, 41% have difficulties in using their wheelchair. With thalidomide victims, who are confined to

¹¹ **Recommendation No. 12:** Multidisciplinary competence centres are to be set up soon, which serve as contact centres for all health issues of the thalidomide victims. A database is to be set up to which those affected, doctors/dentists and specialist nursing care staff have access in order to call up information with regard to the damage and its sequelae, associated risks and best possible treatment, rehabilitation and nursing care and in order to store and share experiences on an interactive basis. Here, for example, information about doctors/dentists in the region should be given, who have experience with the specific health problems of thalidomide victims and with tried and tested treatment, as well as information about qualified inpatient and outpatient rehabilitation offers. In addition, offers for CME-based continuing education and further education with regard to all aspects of thalidomide damage and its treatment should be provided for doctors and dentists who treat thalidomide victims.

a wheelchair, an e-wheelchair with individually adapted steering is necessary since as a rule the upper extremities can only contribute to forward movement to a limited extent. The wheelchairs often additionally require adaptations or alternatively repairs; problems with regard to acceptance of cost are repeatedly reported.

Cars are not only used for transport purposes, but also for maintaining social contacts. Heavy shopping, also over short distances, is only possible independently for severely affected thalidomide victims with a car. 84% interviewees have a vehicle, in 3 out of 4 cases with a new purchase no cost-bearer is available for the adaptation of the car, and two thirds of the interviewees then cannot meet the costs themselves. The refund of costs is basically connected with the working conditions. As a result those thalidomide victims, who are no longer able to work due to increasingly more severe secondary sequelae and at the same time are increasingly limited in their mobility, are particularly affected.

In the group of the victims with quadruple damage (n=163) 82% have a vehicle. Amongst those, who have no vehicle, 45% feel very limited by this with regard to social contacts and participation in society. The feeling of limitation is markedly less pronounced with the victims without quadruple damage at 20%. It is precisely for the victims with quadruple damage that a vehicle is important, although only one quarter of this group is in a position for self-financing if no cost-bearer is available.

Thalidomide victims frequently require special aids, which are often not contained in the aids catalogues of the health insurance schemes. An acceptance of costs by the health insurance scheme is then often refused and makes necessary considerable personal contributions on the part of those affected. With 50% of the interviewees this is shown in additional payments or complete financing, with the victims with quadruple damage this is even 64% the case, although only a percentage of 25% have their own means necessary for this.

Approximately one fifth of all study participants need a hearing aid. Frequently these have to be custom-made as the altered anatomical conditions makes the use of standardised devices impossible.

30% of the study participants are dissatisfied with the fittings of their home. With 33% there is an urgent adaptation need due to the thalidomide damage, 92% report that there is no acceptance of cost by a third party. Only 7% can afford the adaptation themselves, correspondingly a necessary adaptation is frequently not undertaken. The situation of the victims with quadruple damage (n=162) is shown to be even more difficult. 48% of this group urgently need an adaptation of the home and financial support: here too a percentage of 94% has no cost-bearer for this, and only 6% of interviewees are in a position to finance this adaptation themselves. *These results form the empirical basis for Recommendations No. 5¹², 6¹³, 7¹⁴, 9¹⁵, 10¹⁶.*

¹² **Recommendation No. 5:** Thalidomide damage is to be recognised as sufficient justification for the granting of medicines and aids.

3.15 ADMINISTRATIVE PROCEDURES AND APPLICATIONS

Dealing with bureaucracy and negotiations with hospitals on account of application for aids, purchase and adaptation of a car, for purchase or repair of a wheelchair, a special toilet or shower/WC, which is not recognised as an aid, but as an improvement of the building of residence, are time-consuming for thalidomide victims as a large number of supporting documents have to be submitted, the negotiations are often lengthy and laborious, often stretch over years and are often also unsuccessful.

These problems were regularly discussed in the interviews and focus groups. In order to simplify the effort in terms of administration those affected wish for the setting up of a competent contact centre, which in an unbureaucratic manner decides on thalidomide victims' support and aids and makes available the required services. This concerns, for example, the provision of a car and appropriate adaptation for a disabled person, work aids, assistance, medicinal-nursing issues, manufacture and adjustment of wheelchairs to specific needs, aids, repairs, and others besides. *These results form the empirical basis for Recommendation No. 12.*¹⁷

3.16 SOCIAL NETWORK

In the questionnaire as in the interviews and focus groups the social network of

¹³ **Recommendation No. 6:** Full acceptance of additional vehicle costs due to disability, regardless of whether the car is used for work or only privately or in retirement, so that every thalidomide victim has the opportunity to go and see the doctors providing treatment also at greater distances, to participate in treatment, do shopping, participate in public life and maintain social contacts.

¹⁴ **Recommendation No. 7:** Thalidomide victims are entitled to provision of wheelchairs, which are adapted in the best possible way to the existing damage and are equipped in such a way that they provide maximum compliance with the needs for use of thalidomide victims. Acceptance of running and maintenance costs – also in the short-term is to be ensured.

¹⁵ **Recommendation No. 9:** The development of prenatal damage as well as secondary sequelae has already led and will lead to barriers arising in the home and the living environment. From this results the demand to continuously scrutinise the need for adaptation measures and make available the appropriate financial resources, if adaptation measures become necessary.

¹⁶ **Recommendation No. 10:** Based on the high costs in connection with purchases, which are to be attributed to specific needs, the necessity results to guarantee thalidomide victims financial compensation for these costs. This particularly concerns costs for clothes and/or shoes, which it is necessary to alter or have made-to-measure due to physical malformations. Hearing aids and their servicing, speech recognition programs, household and technical aids, which are not met by any cost-bearer.

¹⁷ **Recommendation No. 12:** Multidisciplinary competence centres are to be set up soon, which serve as contact centres for all health issues of the thalidomide victims. A database is to be set up to which those affected, doctors/dentists and specialist nursing care staff have access in order to call up information with regard to the damage and its sequelae, associated risks and best possible treatment, rehabilitation and nursing care and in order to store and share experiences on an interactive basis. Here, for example, information about doctors/dentists in the region should be given, who have experience with the specific health problems of thalidomide victims and with tried and tested treatment, as well as information about qualified inpatient and outpatient rehabilitation offers. In addition, offers for CME-based continuing education and further education with regard to all aspects of thalidomide damage and its treatment should be provided for doctors and dentists who treat thalidomide victims.

thalidomide victims was discussed in detail, whereby not only the question with regard to the degree of subjectively experienced integration was asked, but also the question with regard to the subjectively experienced quality of familial and extra-familial relationships. The 16 items contained in the questionnaire show characteristic features of the social integration and social involvement subjectively experienced. Cronbach's alpha lay at .88 for the 16 items; this value justifies the assumption that the items possibly represent a dimension which could be described by "involvement". This question should be investigated in later analyses; results of an explorative factor analysis can show first indications whether we are actually dealing with characteristic features of a robust dimension here.

In the following table those 16 items on the social network are cited (in an abridged version in each case), which are contained in the questionnaire. In this we compare the mean value of victims with quadruple limb damage with the mean values of people without quadruple limb damage. At a later date of the data evaluation this comparison should be supplemented by comparisons with other specific damage groups.

Initially it emerges from the diagram that subjectively experienced involvement with the thalidomide victims is relatively high; this also applies for victims with quadruple damage. These show items, which discuss how far in the social environment trusted people are to be found, who show willingness to help, with whom something can be done together with them, who are there, if one has difficulties, in whom one can confide in positive as well as stressful situations. In addition, contentment with the contacts as well as the experienced respect, which is shown to one by other people, indicate experienced involvement and social integration. This is matched by the conviction of being able to give other people something.

However, the diagram also shows the differences between the victims with quadruple damage and the victims without quadruple damage. Statistically significant differences between these two groups are shown in the following features: (a) Concern about being a burden on other people (with victims with quadruple damage this concern is more strongly pronounced), (b) frequency with which the relatives are seen (with victims with quadruple damage less), (c) presence of people, in front of whom one can express one's feelings (these type of people are on average cited more occasionally by victims with quadruple damage). The following can be concluded from this: in the current situation the thalidomide victims on average experience a relatively high sense of integration and involvement, although there are specific groups, with whom we observe significant deviations in individual features of social integration and involvement.

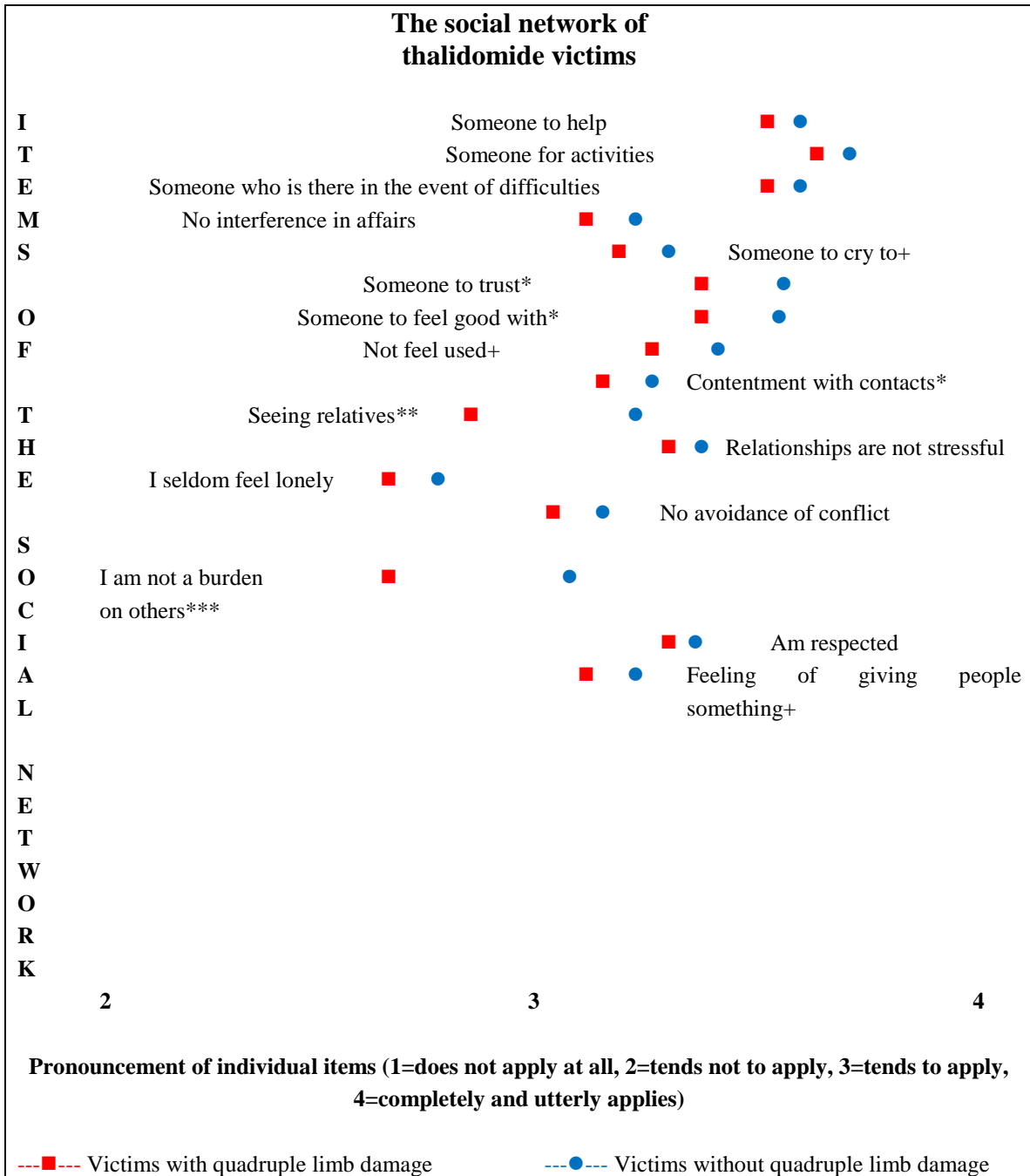


FIGURE 11: 16 ITEMS ON THE SOCIAL NETWORK OF THALIDOMIDE VICTIMS. COMPARISON OF THE AVERAGE VALUES OF VICTIMS WITH QUADRUPLE LIMB DAMAGE WITH THE AVERAGE VALUES OF PEOPLE WITHOUT QUADRUPLE LIMB DAMAGE

Significance levels: *p<.0; **p<.01; ***p<.001; +p<125 (tendency)

In the analysis the questionnaire concentrates on the social network, as this is shown in the experience of thalidomide victims in the current situation. In the interviews questions were not only asked with regard to quantitative and qualitative features of the social

network at the present time, but also with regard to the possible developments of the network in the future. In this it was shown that concerns are articulated precisely with regard to the maintenance of existing social relationships: the concern that contact with the next of kin will be reduced more and more or will be lost through their death, the concern that friends and neighbours will withdraw more and more, if one oneself requires more support than is already the case today. In addition, the concern about increasing loss of mobility – caused by an increase in the symptoms on the basis of the prenatal damage as well as the secondary sequelae – is associated with reducing integration and involvement in the majority of cases. In the interviews numerous examples of this are given, in what measure the integration and involvement are connected with small, but highly effective social networks, whose existence, however, can be completely jeopardized and then integration and involvement put into question. With regard to the future living situation of thalidomide victims attention is to be paid to the question of social integration and involvement.

3.17 PERCEPTION OF DISABILITY

Over the years, due to the at times severe physical limitations, those affected have pursued their work with greater expenditure of physical power and today show severe signs of wear and tear and changes of the damaged locomotor system, which increasingly lead to pains and limitations of mobility and are to be viewed as a result of the severe chronic abnormal strains (compare the chapter Prenatal damage and subsequently).

In the interview the question was basically asked, whether those affected perceived themselves as disabled. 85 answered with “no”. The remaining interviewees agreed that they perceive themselves as disabled, although with the qualification that this has only been the case for a few years. Earlier they would not have perceived themselves as disabled. As long as the daily routine is ensured, as long as the surroundings are adapted to the disability, as long as people are there, who can lend the required helping hand at the right moment, as long as the damage is rather experienced as normality. If there are barriers, if boundaries are encountered, if pains occur and limitations make themselves increasingly noticeable, then the damage is perceived as disability.

3.18 PSYCHOLOGICAL FEATURES

It is basically not to be expected that in the pronouncement of psychological features or the occurrence of psychological illnesses men and women who are thalidomide victims differ from the general population. Nevertheless, there are phenomena, which have particularly developed in this group and were discussed in detail in the interviews of the interviewees. The results from the interviews are described and supplemented with findings from the questionnaires.

- 1) Through acquired strategies and life-long learning processes thalidomide victims are able to master or at endure least difficult situations. The individual questioning in interviews showed that here the ability to communicate is of central importance. As is reported in the interviews, thalidomide victims have learned to cope with and often also to come to terms with their situation. In 76% of the interviews it is emphasised that the thalidomide victims were brought up to particular self-assurance and self-assertion. They have had the experience that openness, approaching others, listening and empathy smooth a great many ways (reported in 80% of the interviews). In addition, there is the ability to accept disappointments and setbacks and seek new ways in order to achieve the strived for aim; this was discussed in 64% of the interviews. 82% of the interviewees rate themselves as creative people. Thalidomide victims support the people in their social environment by listening to them, advising them, passing on their own experiences of life, this is described in detail in 44% of the interviews. In the questionnaire 82.6% of the participants answered yes to the question: "Have you the feeling of being able to give a lot to other people?"
- 2) Even when lifelong strengths could develop, which have a stabilising effect psychologically, nevertheless precisely because of the particular biography with thalidomide victims there is a high risk of aftereffects of earlier stressful (if not even traumatising) experiences to be observed. Childhood was often marked by separation from one's own family, rejection by the social environment due to disability and particular stresses in the school career. The frequent hospital stays in childhood and the associated procedures, trials with physiotherapy and prostheses, presentations to audiences from the specialist world have often lastingly impaired trust in medical measures. In interviews and focus groups it was shown how these early experiences to this day influence contact with doctors. Of 30% of the interviewees it was discussed in the interviews that in contact sessions with doctors memories of early childhood experiences are awakened and these are also still associated with anxieties about medical measures.
- 3) With many of the interviewees building up psychological strengths and resources had helped to leave as independent a life as possible with the disability and face up to the stresses. However, a change is to be noticed here with many of the interviewees. 92% of the interviewees report a reduction in capacity for physical exertion, especially in recent years, due to secondary sequelae and states of pain and a limitation of mobility and independence associated with this. The psychological resources are often overtaxed due to these losses. Psychological stresses due to reduction of social contacts, reduced involvement and states of anxiety and stress are focussed on in 55% of the interviews. The thalidomide victims' proven strategies for coping and coming to terms with their situation, which have so far stabilised them psychologically, are no longer effective, therefore new strategies have to be developed in order to overcome this crisis.
- 4) According to our findings with thalidomide victims episodes of depression are more common than in the normal population. The criteria for depression

- according to the Major Depression Inventory (MDI) were fulfilled in our random sample in 11.3% of the interviewees, in the comparable age group of the normal population the percentage was 8.1% (source: Robert Koch Institute, Health Monitoring System of the Federal Government).
- 5) Anxiety about the future occurs relatively frequently with thalidomide victims. The statement “I feel anxiety if I think about my future” applies to 62.5%. Anxieties about worsening secondary sequelae, loss of mobility, medical complications and procedures, old age or the nursing home, although also inability to work and social losses are most frequently cited. When asked about further development in future, in many cases concern prevails. In 86% of the interviews negative ideas about the future are discussed. Fears about a living situation are expressed, in which the feeling of being left alone with problems predominates. Those affected find it unfair and unreasonable to burden their children in the near future, some of whom today are still minors, with an increasing need for nursing care, possible nursing home costs or alternatively a subsidy of daily maintenance.

3.19 QUALITY OF LIFE

With the WHO’s questionnaire for recording the quality of life (WHOQOL) an instrument frequently used internationally was absorbed into the study. This distinguishes four areas of quality of life: the physical and psychological area, social relationships and environment. In addition, there is a global value for the quality of life, which assumes a special position and is essentially influenced by the physical and psychological state of mind. Particularly with people suffering from somatic illnesses the global quality of life shows abnormal values. As the scales were standardised for Germany, comprehensive comparable data for specific age groups and groups with specific clinical characteristics is available. The values can lie in a range from 0 to 100, high values indicate a good quality of life.¹⁸

The results in the group of the thalidomide victims were initially compared with the values in the general population aged approximately 50 years. Here significant differences were shown: thalidomide victims show markedly worse values for the subjective assessment of quality of life. In the interviews it was almost continually stated that the thalidomide victims feel older than is appropriate for their age, they speak of a subjectively experienced premature aging of 20–30 years. For this reason the data was compared with the results from high age groups. Here it is shown that the perceived quality of life corresponds to that of an approximately 80-year-old. The data therefore underlines the statements of the interviewees.

¹⁸ Steinbüchel, N., Lischetzke, T. Gurny, M., Ines Winkler & The WHOQUOL-OLD Group (2005). Erfassung gesundheitsbezogener Lebensqualität älterer Menschen mit dem WHOQUOL-BREF-Fragebogen. Zeitschrift für Med. Psychologie [Recording of Health-related Quality of Life of Elderly People with the WHOQUOL-BREF Questionnaire. Journal of Medical Psychology] 14, 1, 13-23.

The results confirm not only the subjective impression of a premature ageing, but are also the expression of an on average worse state of health of men and women who are thalidomide victims. This is indicated in particular by the evaluation of the global quality of life. Here the value significantly deviates from the age-related values. If we compare the values established with those, which are documented in the total population with the existence of severe arthrosis or heart disease, a high level of agreement is found. This is also in keeping with the symptoms of the thalidomide victims, who especially suffer from pains and reduced capacity for exertion.

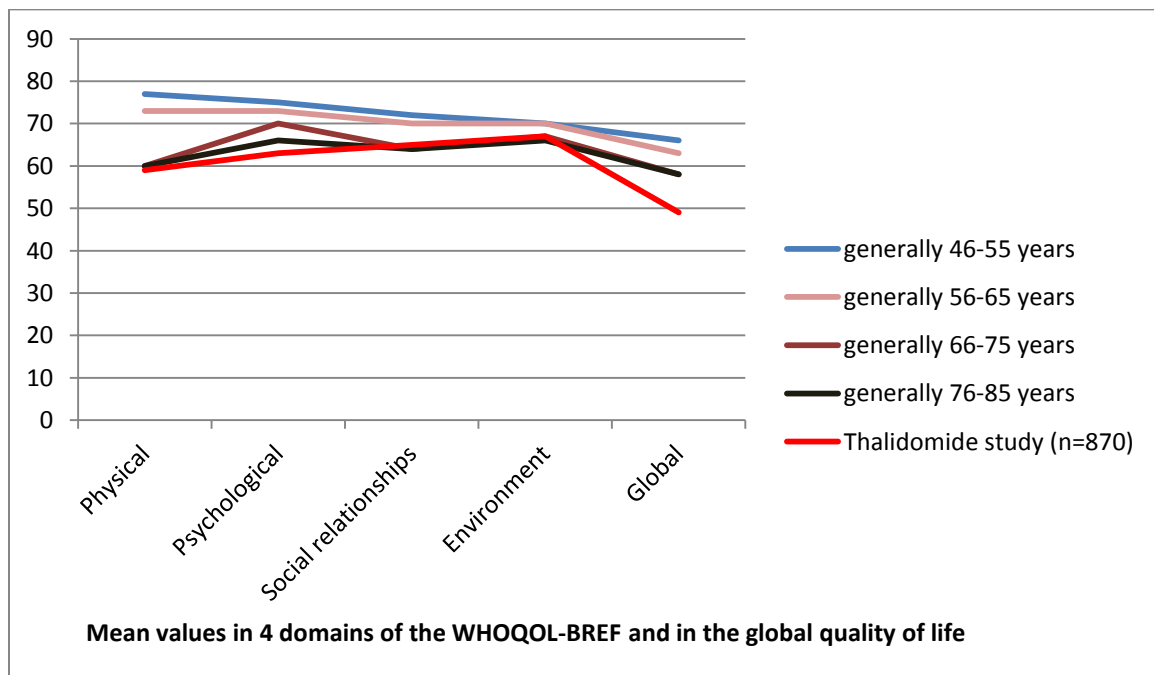


FIGURE 12: AVERAGE VALUES IN 4 DOMAINS OF THE WHOQOL-BREF AND IN THE GLOBAL QUALITY OF LIFE OF THALIDOMIDE VICTIMS AND IN THE GENERAL POPULATION IN DIFFERENT AGE GROUPS

In the interviews dominant themes were formulated, which from the perspective of the thalidomide victims determine the quality of life, results from the questionnaires supplement the statements.

- 1) Self-determination and independence in daily life were most frequently cited. It was emphasised by 99% of the interviewees that the ability to lead life independently and a self-determined life are very important for them. Being able to shape everyday life by themselves has great priority, even if with many interviewees the limit of physical overexertion is reached or exceeded when carrying out daily activities. Therefore freedom from barriers and support in the issues of daily life are of central importance, as is mobility. Having a car is described quite concretely as “a piece of quality of life”, not just as a means of transport, but as an important condition of leading a self-determined life and maintaining social contacts.

- 2) Secondary sequelae and the pains associated with them markedly limited the quality of life of many thalidomide victims; in addition, they often lead to a reduction in independence and are psychologically stressful. 64.6% of all interviewees reported being limited in their self-sufficiency due to pains, 78.8% reported this for familial and household duties.
- 3) From the perspective of the thalidomide victims an important psychological feature for the quality of life is zest for life and optimism. 58% of the interviewees reported not being able to enjoy life or only being able to enjoy it to a moderate extent. 23.1% report they always or at least often notice negative feelings such as sadness, depression, despair or have anxiety. To be needed in the family, to be able to do something for friends, help others, were cited as further elements of the quality of life.
- 4) To pursue a professional occupation and to be socially integrated is rated highly for the quality of life with many interviewees. 60.6% of the thalidomide victims report that accepting an offer of employment is important for them. However, with thalidomide victims maintaining the ability to work is often jeopardized by pains and loss of physical fitness. 69% are limited by this in pursuing a career. Employment will be held onto for as long as possible, even if this means overexertion in order to ensure sufficient provision for old age/access to financing or subsidising of aids. This aim is very frequently jeopardized, and the anticipation of the loss of independence and an early retirement and the financial losses associated with that cause anxiety about the future to develop: For how long will I still be independent, in future will I increasingly suffer from secondary sequelae and pains, can I also look after my family in the future? The uncertainty of the future development markedly reduces the quality of life.
- 5) From the perspective of the thalidomide victims lack of time and stress are gaining higher and higher importance. 74% of the interviewees describe that they need more and more time to cope with daily life, have to start the day earlier and earlier as self-care is becoming more and more time consuming. In addition, there is the high expenditure of time for preventative measures such as treatments, exercises carried out independently, regular exercise.

The weighting of the different influencing factors on the quality of life of thalidomide victims was tested with a linear regression analysis. For the health-related quality of life of thalidomide victims *loss of independence* as a result of the physical damage and the secondary sequelae associated with it is of central importance. In a group of persons, in which pains jeopardise functional competence and involvement, the importance of *pains* as an influencing element of the quality of life must be examined. It is also to be examined how pains and psychological well-being are connected, we frequently find a close correlation between pains and *depression*. Studies prove that depressiveness has an influence on the quality of life. Elements of the *environment* and *treatment* were included in the analysis. With the thalidomide victims these are in particular *rehabilitation measures* to improve health and functional competence, and *adaptation measures*, which produce an adjustment of life experience and freedom from barriers and therefore contribute an improvement in living life independently. The table shows which

scales/variables for the individual domains of the quality of life entered into the analysis.

TABLE 14: VARIABLES ENTERED INTO THE REGRESSION ANALYSIS

Physical well-being	
Pains: Pronouncement of the pains	Intensity scale in 5 categories, value range 1–5 (5=most severe conceivable pain)
Functional competence: Functionality index	Unweighted additive index of 26 activities of daily life and involvement, value range between 0 and 52 (high values with poor functional status)
Psychological well-being	
Depression: Major (ICD 10) Depression Inventory (MDI, Bech P, Rasmussen N-A et al., 2001)	Questionnaire with 10 items, index with value range between 0 and 4 (high values indicate a depressive disorder)
Social relationships	
Social network: Social network index	17 items in a rating scale in four pronouncements, value range between 17 and 68, high value with positive pronouncement
Environment, treatment	
Question with regard to urgent adaptation need	Nominal dichotomous variable (yes=1/no=0)
Question with regard to uncovered rehabilitation need	Nominal dichotomous variable (yes=1/no=0)
Question: “Is your current income enough for you to lead your life?”	Nominal dichotomous variable (yes=1/no=0)

REGRESSION MODEL FOR PREDICTION OF THE IMPROVEMENT IN QUALITY OF LIFE												
	WHO-QOL-BREF GLOBAL N=666				WHO-QOL-BREF PHYSICAL N=660				WHO-QOL-BREF PSYCHOLOGICAL N=657			
	B	SF	β	R ²	B	SF	β	R ²	B	SF	β	R ²
				.46***				.64***				.57***
Pain	-5.37	.72	-.24***		-7.39	.59	-.33***		.30	.60	.02	
Functional competence	-.12	.03	-.16***		-.20	.02	-.26***		-.05	.02	-.07*	
Depressive-ness	-5.20	.64	-.26***		-4.63	.52	-.24***		-8.20	.54	-.45***	
Social network	.54	.09	.21***		.47	.07	.18***		.98	.07	.40***	
Existing adaptation need	-3.94	1.48	-.09**		-2.70	1.21	-.06*		.88	1.24	.02	
Uncovered rehabilitation need	-2.46	1.34	-.06		-4.14	1.09	-.09***		-.46	1.12	-.01	
Income situation	1.63	1.37	.04		4.43	1.11	.10***		2.09	1.14	.05	
	WHO-QOL-BREF SOCIAL N=654				WHO-QOL-BREF ENVIRONMENT N=662							
	B	SF	β	R ²	B	SF	β	R ²				
				.40***				.57***				
Pain	-.68	.079	-.03		-1.24	.53	-.07*					
Functional competence	-.02	.03	-.03		-.12	.02	-.18***					
Depressive-ness	-2.56	.70	-.13***		-2.00	.47	-.12***					
Social network	1.56	.10	.58***		.68	.06	.32***					
Existing adaptation need	-.91	1.61	.02		-8.09	1.08	-.22***					
Uncovered rehabilitation need	1.00	1.46	-.02		-3.13	1.98	-.09**					
Income situation	-3.15	1.49	.07*		7.06	1.0	.w0***					

Significance levels: *p<.05; **p<.01; ***p<.001

For every domain and for every global quality of life there were highly significant regression models; in this with physical well-being with an R^2 of 0.64 the highest declaration of the variance was reached. The most important influence features here are the pronouncement of pains, functional competence, depressiveness, social network and income. Psychological well-being primarily depends on the presence of depression and the quality of social relationships. Contentment with environmental conditions, to which medical care is also added, shows close connections with all features contributed. Overall, with the results the high importance of the social network is noticeable. A close connection with the quality of life is also found throughout for depressiveness, this is in keeping with the results which were obtained in other studies with analyses with the WHOQOL.

These results are of significance for the action recommendations as they express needs, which can be met with support with assistance, with adaptation measures, with rehabilitation measures and financial help. The problem fields of depressiveness and pains indicate a higher need with therapeutic provision.

These results form the empirical basis for Recommendations Nos. 2¹⁹, 4²⁰, 5²¹, 8²², 9²³.

¹⁹ **Recommendation No. 2:** Disadvantages caused by the thalidomide damage and its sequelae are emerging with regard to employment not only with the victims themselves, but also with their relatives, who provide assistance and for this reason have to limit their employment. One third of the thalidomide victims already no longer works now, according to our assessment in face-to-face interviews it is to be expected that the majority of thalidomide victims will not reach the statutory pension age due to reduction of full time employment. For these reasons financial compensation of these disadvantages is imperative.

²⁰ **Recommendation No. 4:** The treatment of thalidomide victims with the necessary medical and therapeutic measures in the outpatient and inpatient area is to be ensured without financial expenditure for those affected. The proven thalidomide damage is the justification for the patient not being classed as the norm and not falling into the budgeting regulations for medical service in order to guarantee the best possible treatment. For this reason endeavours should also be made so that a sufficient number of doctors in Germany are available, who have at their disposal a high level of competence with regard to the advising and treatment of thalidomide victims and can also advise medical colleagues, to whom the thalidomide victims turn with requests for rehabilitation. Explanation for thalidomide victims about the options of rehabilitation tailored to their specific situation is to be ensured. The treatment of thalidomide victims with outpatient or inpatient rehabilitation services is to be ensured. It is to be ensured that the rehabilitation need perceived and articulated by thalidomide victims be converted into action without delay.

²¹ **Recommendation No. 5:** Thalidomide damage is to be recognised as sufficient justification for the granting of medicines and aids.

²² **Recommendation No. 8:** Personal assistance is to be ensured in the form of budget payments; the level of the budget is to be adjusted continuously to the currently reported assistance need and set in a discussion between victim and specialist – supported by peers.

²³ **Recommendation No. 9:** The development of prenatal damage as well as secondary sequelae has already led and will lead to barriers arising in the home and the living environment. From this results the demand to continuously scrutinise the need for adaptation measures and make available the appropriate financial resources, if adaptation measures become necessary.

4 PROVISIONAL ACTION RECOMMENDATIONS

4.1 PRELIMINARY REMARK

The group of thalidomide victims will not change any more in terms of numbers. However, the symptoms, which are caused by prenatal damage, as well as the secondary sequelae are liable to a continuous increase. In the coming years the secondary sequelae, which are already clearly recognisable today, as well as the late sequelae will gain more and more in importance. According to the statements of the thalidomide victims the secondary sequelae have increasingly moved into the central point in the last five to ten years. The deterioration of health and the increasing loss of independence require increased personal assistance, technical assistance and adaptation measures.

From this analysis of the data, which have been recorded in questionnaires, interviews and focus groups and outlined in brief in this report, the Institute of Gerontology has established uncovered needs and on the basis of these has developed provisional action recommendations. These recommendations concern aspects of the guarantee of fundamental independent provision; in addition, the medical, rehabilitative, nursing and medicine-associated services, which are to be reimbursed *separate* from the basic level of insurance. In addition, there is the improvement in medical, nursing care by expanded services and expanded knowledge with regard to the damage and the resulting medical and psychological implications. Thalidomide victims are to be regarded as experts in their own matter, they show and articulate other needs than the physically handicapped with other causes of damage.

The results of the study are discussed in the process of communicative validation with thalidomide victims as are the recommendations directed at the political decision makers.

4.2 PROVISIONAL RECOMMENDATIONS

1. Because of the great significance of secondary sequelae for the current and future situation and independence, re-evaluation and recognition of the secondary sequelae are imperative.
2. Disadvantages caused by the thalidomide damage and its sequelae are emerging with regard to employment not only with the victims themselves, but also with their relatives, who provide assistance and for this reason have to limit their employment. One third of the thalidomide victims already no longer works now, according to our assessment in face-to-face interviews it is to be expected that the majority of thalidomide victims will not reach the statutory pension age due to

- reduction of full time employment. For these reasons financial compensation of these disadvantages is imperative.
3. In view of the fact that the demands and strains of coping with the thalidomide damage also means a great challenge for the next of kin, it is to be ensured that the latter are not called upon for financial resources if a thalidomide victim becomes in need of nursing care and cannot finance the care services extending beyond the legally defined services.
 4. The treatment of thalidomide victims with the necessary medical and therapeutic measures in the outpatient and inpatient area is to be ensured without financial expenditure for those affected. The proven thalidomide damage is the justification for the patient not being classed as the norm and not falling into the budgeting regulations for medical service in order to guarantee the best possible treatment. For this reason endeavours should also be made so that a sufficient number of doctors in Germany are available, who have at their disposal a high level of competence with regard to the advising and treatment of thalidomide victims and can also advise medical colleagues, to whom the thalidomide victims turn with requests for rehabilitation. Explanation for thalidomide victims about the options of rehabilitation tailored to their specific situation is to be ensured. The treatment of thalidomide victims with outpatient or inpatient rehabilitation services is to be ensured. It is to be ensured that the rehabilitation need perceived and articulated by thalidomide victims be converted into action without delay.
 5. Thalidomide damage is to be recognised as sufficient justification for the granting of medicines and aids.
 6. Full acceptance of additional vehicle costs due to disability, regardless of whether the car is used for work or only privately or in retirement, so that every thalidomide victim has the opportunity to go and see the doctors providing treatment also at greater distances, to participate in treatment, do shopping, participate in public life and maintain social contacts.
 7. Thalidomide victims are entitled to provision of wheelchairs, which are adapted in the best possible way to the existing damage and are equipped in such a way that they provide maximum compliance with the needs for use of thalidomide victims. Acceptance of running and maintenance costs – also in the short-term - is to be ensured.
 8. Personal assistance is to be ensured in the form of budget payments; the level of the budget is to be adjusted continuously to the currently reported assistance need and set in a discussion between victim and specialist – supported by peers.

9. The development of prenatal damage as well as secondary sequelae has already led and will lead to barriers arising in the home and the living environment. From this results the demand to continuously scrutinise the need for adaptation measures and make available the appropriate financial resources, if adaptation measures become necessary.
10. Based on the high costs in connection with purchases, which are to be attributed to specific needs, the necessity results to guarantee thalidomide victims financial compensation for these costs. This particularly concerns costs for clothes and/or shoes, which it is necessary to alter or have made-to-measure due to physical malformations. Hearing aids and their servicing, speech recognition programs, household and technical aids, which are not met by any cost-bearer.
11. With regard to dental treatment acceptance of all necessary dental and maxillo-surgical measures, which are to be attributed to malformations in the region of the visceral cranium and the jaw, are to be ensured by the statutory health insurance schemes. Professional teeth cleaning for prevention of further damage is to be guaranteed by the cost bearers. In addition, the costs for dental implants are to be met in full for those thalidomide victims, with whom the lack of grasping function of the hands is compensated by the teeth and a removable dental prosthesis cannot be used or removed and cleaned by them independently.
12. Multidisciplinary competence centres are to be set up soon, which serve as contact centres for all health issues of the thalidomide victims. A database is to be set up to which those affected, doctors/dentists and specialist nursing care staff have access in order to call up information with regard to the damage and its sequelae, associated risks and best possible treatment, rehabilitation and nursing care and in order to store and share experiences on an interactive basis. Here, for example, information about doctors/dentists in the region should be given, who have experience with the specific health problems of thalidomide victims and with tried and tested treatment, as well as information about qualified inpatient and outpatient rehabilitation offers. In addition, offers for CME-based continuing education and further education with regard to all aspects of thalidomide damage and its treatment should be provided for doctors and dentists who treat thalidomide victims.
13. A scientific study of late sequelae is to be carried out concerning a malposition of vessels, nerves and muscles; recognition of them as prenatal damage is to be ensured.