ORIGINAL ARTICLE

Mental Disorders in People Affected by Thalidomide

A Cross-Sectional Study of Prevalence and Psychosocial Needs

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SUMMARY

Background: More than 50 years after the withdrawal of thalidomide from the market, subsequent orthopedic damages and psychosocial impairments dominate the complaints of thalidomide-affected individuals. The aim of the study was to determine the prevalence of mental disorders in this group.

Methods: A total of 193 thalidomide-affected individuals from North Rhine–Westphalia (mean age 50.5 years, 56.5% women) underwent personal and comprehensive psychodiagnostic testing, which was based on the Structured Clinical Interview for DSM-IV disorders (SCID-I & SCID-II) and self-reporting questionnaires.

Results: Overall, the four-week prevalence of mental disorders was 47.2%. Multiple mental disorders were present in 45.1% among the 91 participants with diagnosed mental disorders. The most frequent diagnoses were unipolar depressive disorders (16.5%), somatoform disorders (14.0%), phobic disorders (12.4%), and alcohol-related disorders (6.2%). Immediate mental health care was indicated in 80.2% of participants with current mental disorders, but only 29.7% had used some form of psychosocial treatment in the 12 months preceding the study.

Conclusions: Mental disorders occur approximately twice as often (relative risk [RR]: 1.77; 95% confidence interval [1.49; 2.10]) in thalidomide-affected individuals as in the age-matched German population. Together with a very low rate of utilization of mental health care, this finding implies an underuse of psychosocial healthcare. The development of specialized psychosocial treatment services may remove barriers that impede access to the healthcare system.

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The introduction of thalidomide on 1 October 1957 led to “the drug disaster with the most serious repercussions in the 20th century” (1). The substance, synthesized by the company Chemie Grunenthal, was first approved in Germany under the trade name Contergan, and sold as an over-the-counter sedative, and went on to be marketed in 46 countries around the world. It took all of four years for the devastating embryotoxicity of thalidomide to come to light, leading to the drug being withdrawn from market on 27 November 1961.

In the years between 1957 and 1962, an estimated 5000 “thalidomide children” were born in West Germany and more than 10 000 worldwide. The numbers of unreported spontaneous abortions and stillbirths remain unknown (1–8). The first publications appeared shortly thereafter, strongly suggesting the use of thalidomide by pregnant women to be the cause for a huge increase of infant malformations (9, 10).

Following the devastating consequences for damaged individuals and their families, the thalidomide case had a major impact on modern medicine. In Germany, for example, it led to the establishment of a State Department of Health. Today, the medical and ethical aspects of the situation still need to be debated in light of the resumption of thalidomide use i.e. in leprosy and multiple myeloma, and cases of thalidomide embryopathy in low income countries (11–17).

There are some 2400 thalidomide-impaired individuals currently living in Germany (18), 804 of them in North Rhine–Westphalia (49.8% women; written communication from “Conterganstiftung für behinderte Menschen e.V.” of 27 April 2016). They are increasingly suffering from the consequences of their disability, manifesting in particular as chronic pain and functional limitations and movement impairments of the skeletal system (19). The original and the consequent damage have led to far-reaching psychosocial consequences, so that their way of life is often characterized by reduced working and earning capacity, dependence on assistive equipment (e.g. wheelchair), personal assistance and care, and the threat of social isolation (20).

Several studies on the quality of life of thalidomide-affected subjects were carried out in the past, describing reduced satisfaction with their life. However, apart

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from one Japanese interview study ($n = 22$), which estimates a prevalence of 40.9% for a possible mental disorder, the literature contains little evidence on mental health in this group (21–28). Even though increased mental stress was measured in the most extensive study to date, using a depression inventory and aimed at the special needs and care shortcomings of 870 German thalidomide-impaired individuals, no psychodiagnostic interviews were carried out (20).

The aim of this study was to systematically determine the prevalence of mental disorders among subjects with prenatal thalidomide embryopathy by a methodologically high-quality structured interview, as well as to assess the rate of utilization of mental health care and of psychosocial health care needs.

Methods

The study was targeted at all thalidomide-impaired individuals either currently resident or born in North Rhine–Westphalia, Germany, and recognized by the foundation that manages the compensation pensions (“Conterganstiftung für behinderte Menschen e.V.”). The recruitment process was supported by a patient support group (“Interessenverband Congergeschädigter Nordrhein-Westfalen e.V.”). Main outcome measures were the nature and extent of mental disorders according to the International Classification of Diseases (30) by testing with the Structured Clinical Interview for DSM-IV disorders (SCID-I & SCID-II) (29). Further methodological information pertaining to patient involvement, recruitment, study instruments, statistical analysis, and ethical approval is published in the *eBox*.

Results

Of the 453 letters mailed to individuals with a known postal address by the patient support group, 67 could not be delivered and were returned, while 192 individuals responded and were willing to participate. Additionally, 13 individuals responded to alternative recruitment methods. Three of these 205 participants had no recognized thalidomide impairment and were subsequently excluded. For the overall study, 202 thalidomide-impaired participants were recruited (response rate 44.6%). Among these, a psychological examination could not be conducted in 9 cases ($n = 8$ on account of refusal, $n = 1$ for logistical reasons). Results on mental disorders were therefore available for 193 participants, which is about a quarter of the total affected population in North Rhine–Westphalia. Results will be reported only for this part of the sample. In 6 cases, where a SCID interview was not feasible due to substantial mental impairment, the diagnosis was based on a clinical assessment ($n = 4$ intellectual disability, $n = 1$ dementia, $n = 1$ paranoid schizophrenia).

Sociodemographic and somatic characteristics

The average age of all study participants who underwent the psychological examination ($n = 193$) was

TABLE 1

Sociodemographic and somatic characteristics of study participants ($n = 193$ thalidomide-impaired individuals)

	Total	Women	Men
	193 (100.0%)	109 (56.5%)	84 (43.5%)
Age (mean value in years)	50.5	50.5	50.6
Damage pattern			
Twofold damage* ¹	154 (79.3%)	87 (79.8%)	67 (79.8%)
Fourfold damage* ²	18 (9.8%)	10 (9.2%)	8 (9.5%)
Damage without dysmelia	21 (10.9%)	12 (11.0%)	9 (10.7%)
Housing situation			
Living alone	52 (26.9%)	25 (22.9%)	27 (32.1%)
Living together* ³	141 (73.1%)	84 (77.1%)	57 (67.9%)
– with partner	120 (62.2%)	71 (65.1%)	49 (58.3%)
– with children	49 (25.4%)	30 (27.5%)	19 (22.6%)
– with parents	11 (5.7%)	7 (6.4%)	4 (4.8%)
– other form of housing	14 (7.3%)	8 (7.3%)	6 (7.1%)
Educational status			
University/college degree	66 (34.2%)	37 (33.9%)	29 (34.5%)
Apprenticeship	58 (30.1%)	33 (30.3%)	25 (29.8%)
High school degree (<i>Abitur</i>)	26 (13.5%)	17 (15.6%)	9 (10.7%)
Year 10 lower secondary school certificate (<i>Realschulabschluss</i>)	18 (9.3%)	12 (11.0%)	6 (7.1%)
Year 9 lower secondary school certificate (<i>Hauptschulabschluss</i>)	17 (8.8%)	8 (7.3%)	9 (10.7%)
Schooling incomplete	8 (4.1%)	2 (1.8%)	6 (7.1%)
Employment status			
Employed	138 (71.5%)	71 (65.1%)	67 (79.8%)
Unemployed	14 (7.3%)	9 (8.3%)	5 (6.0%)
Inactive	41 (21.2%)	29 (26.6%)	12 (14.3%)
Disability status			
Degree of disability ≥ 50	187 (96.9%)	105 (96.3%)	82 (97.6%)

*¹ Twofold damage = dysmelia of the upper extremities

*² Fourfold damage = dysmelia of both upper and lower extremities

*³ Multiple answers were possible, so the percentages in the subcategories should not be added together, since this would give a distorted picture

TABLE 2

Prevalences of mental disorders*1

Disorder or group of disorders (ICD-10-GM code)	4-week prevalence (total, n = 193)	4-week prevalence (women, n = 109)	4-week prevalence (men, n = 84)	Lifetime prevalence (total, n = 193)	Lifetime prevalence (women, n = 109)	Lifetime prevalence (men, n = 84)
Neurocognitive disorder (F0x)*2	1 (0.5%)	1 (0.9%)	0 (0.0%)	1 (0.5%)	1 (0.9%)	0 (0.0%)
Substance-related disorder (F1x)*3	16 (8.3%)	3 (2.8%)	13 (15.5%)	29 (15.0%)	4 (3.7%)	25 (29.8%)
– Alcohol-related disorder	12 (6.2%)	2 (1.8%)	10 (11.9%)	26 (13.5%)	3 (2.8%)	23 (27.4%)
– Medicine/drug-related disorder	6 (3.1%)	1 (0.9%)	5 (6.0%)	9 (4.7%)	2 (1.8%)	7 (8.3%)
Psychotic disorder (F2x)*2	1 (0.5%)	1 (0.9%)	0 (0.0%)	1 (0.5%)	1 (0.9%)	0 (0.0%)
Affective disorders (F3x)	44 (22.8%)	25 (22.9%)	19 (22.6%)	76 (39.4%)	42 (38.5%)	34 (40.5%)
– Unipolar depression	32 (16.5%)	18 (16.5%)	14 (16.7%)	64 (33.2%)	35 (32.1%)	29 (34.5%)
– Dysthymic disorder	3 (1.6%)	1 (0.9%)	2 (2.4%)	3 (1.6%)	1 (0.9%)	2 (2.4%)
– Minor depression	10 (5.2%)	6 (5.5%)	4 (4.8%)	11 (5.7%)	6 (5.5%)	5 (6.0%)
Neurotic, stress, and somatoform disorders (F4x)	52 (26.9%)	33 (30.3%)	19 (22.6%)	59 (30.6%)	37 (33.9%)	22 (26.2%)
– Phobic disorder	24 (12.4%)	14 (12.8%)	10 (11.9%)	27 (14.0%)	16 (14.7%)	11 (13.1%)
– Anxiety disorder	5 (2.6%)	4 (3.7%)	1 (1.2%)	10 (5.2%)	7 (6.4%)	3 (3.6%)
– Panic disorder	4 (2.1%)	3 (2.8%)	1 (1.2%)	9 (4.7%)	6 (5.5%)	3 (3.6%)
– Generalized anxiety disorder	1 (0.5%)	1 (0.9%)	0 (0.0%)	1 (0.5%)	1 (0.9%)	0 (0.0%)
– Obsessive-compulsive disorder	2 (1.0%)	1 (0.9%)	1 (1.2%)	3 (1.6%)	2 (1.8%)	1 (1.2%)
– Post-traumatic stress disorder	6 (3.1%)	5 (4.6%)	1 (1.2%)	8 (4.1%)	7 (6.4%)	1 (1.2%)
– Dissociative disorder	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.5%)	1 (0.5%)	0 (0.0%)
– Somatoform disorder	27 (14.0%)	18 (16.5%)	9 (10.7%)	27 (14.0%)	18 (16.5%)	9 (10.7%)
– Pain disorder	24 (12.4%)	17 (15.6%)	7 (8.3%)	25 (13.0%)	18 (16.5%)	7 (8.3%)
– Other somatoform disorders	4 (2.1%)	2 (1.8%)	2 (2.4%)	4 (2.1%)	2 (2.8%)	2 (2.4%)
Eating disorder (F50.x)	5 (2.6%)	5 (4.6%)	0 (0.0%)	7 (3.6%)	6 (5.5%)	1 (1.2%)
– Anorexia nervosa	3 (1.6%)	3 (2.8%)	0 (0.0%)	3 (1.6%)	3 (2.8%)	0 (0.0%)
– Other eating disorder	2 (1.0%)	2 (1.8%)	0 (0.0%)	4 (2.1%)	3 (2.8%)	1 (1.2%)

Disorder or group of disorders (ICD-10-GM code)	4-week prevalence (total, n = 193)	4-week prevalence (women, n = 109)	4-week prevalence (men, n = 84)	Lifetime prevalence (total, n = 193)	Lifetime prevalence (women, n = 109)	Lifetime prevalence (men, n = 84)
Personality disorder (F6x)	15 (7.8%)	6 (5.5%)	9 (10.7%)	15 (7.8%)	6 (5.5%)	9 (10.7%)
– Cluster A personality disorder	4 (2.1%)	2 (1.8%)	2 (2.4%)	4 (2.1%)	2 (1.8%)	2 (2.4%)
– Cluster B personality disorder	4 (2.1%)	2 (1.8%)	2 (2.4%)	4 (2.1%)	2 (1.8%)	2 (2.4%)
– Cluster C personality disorder	3 (1.6%)	2 (1.8%)	1 (1.2%)	3 (1.6%)	2 (1.8%)	1 (1.2%)
– mixed-type personality disorder	4 (2.1%)	0 (0.0%)	4 (4.8%)	4 (2.1%)	0 (0.0%)	4 (4.8%)
Intellectual disability (F7x) ²	4 (2.1%)	1 (0.9%)	3 (3.6%)	4 (2.1%)	1 (0.9%)	3 (3.6%)
At least one mental disorder	91 (47.2%)	51 (46.8%)	40 (47.6%)	115 (59.6%)	62 (56.9%)	53 (63.1%)
– One diagnosis	50 (25.9%)	29 (26.6%)	21 (25.0%)	51 (26.4%)	30 (27.5%)	21 (25.0%)
– Two diagnoses ²	25 (13.0%)	14 (12.8%)	11 (13.1%)	36 (18.7%)	17 (15.6%)	19 (22.6%)
– Three or more diagnoses ²	16 (8.3%)	8 (7.3%)	8 (9.5%)	28 (14.5%)	15 (13.8%)	13 (15.5%)

¹ Comorbidity of the disorders diagnosed renders any addition of the individual prevalence rates (overall and in the subcategories) invalid, since this would give a figure higher than the total prevalence reported.
² Neurocognitive disorders, intellectual disability, and psychotic disorders were diagnosed clinically (n = 6). In these cases no further disorder was diagnosed which may lead to a slight underestimate of the degree of comorbidity
³ Including abuse and dependence, excluding nicotine dependence

50.5, with a range of 48 to 54 years. Most of the participants were born in 1961. There were more women (56.5%) than men (43.5%). The original damage caused by thalidomide consisted of dysmelia of the upper extremities in 154 cases (79.3% “twofold damage”) and dysmelia of both upper and lower extremities in 18 cases (9.8% “fourfold damage”). In 21 cases there was no dysmelia, but instead damage in the facial region (10.9% “damage without dysmelia”), most of which were associated with deafness or pronounced loss of hearing (n=13). More of the subjects lived with their relatives (73.1%) than independently in single households (26.9%). More than a third had received higher education (34.2%) and only a small proportion (4.1%) had not completed their schooling. At the time of the study, most of the subjects (71.5%) were in paid employment, but the percentage in full-time employment was low (18.8%). The disability was classified as severe by the pension offices in nearly all cases (*Table 1*).

Prevalence of mental disorders

In a total of 91 participants, at least one mental disorder was present within the four weeks preceding the examination (four-week prevalence [FWP] 47.2%, 95% CI [40.2; 54.2]). The occurrence of a mental disorder during the entire lifespan was documented for 115 participants (lifetime prevalence [LTP] 59.6%). In a sex comparison, mental disorders were found more often among men than among women, which particularly became evident on comparison of the LTP rates (63.1% vs 56.9%, $p = 0.383$). The simultaneous presence of more than one mental disorder in one and the same individual in the group of thalidomide-impaired subjects with current mental disorders was found in 45.1% (*Table 2*).

In four-fifths at least one diagnosis fell into one of the following three diagnostic ICD-10-clusters:

- Neurotic, stress, and somatoform disorders with the highest FWP (26.9%)
- Affective disorders with the highest LTP (39.4%)
- Substance-related disorders.

In women, neurotic, stress, and somatoform disorders occurred more commonly than in men (FWP: 30.3% vs 22.6%, $p = 0.234$), in whom the percentage of substance-related disorders was significantly higher (LTP: 29.8% vs 3.7%, $p < 0.001$), whereas in affective disorders there was no relevant difference between the sexes (FWP: 22.6% vs 22.9%, $p = 0.958$).

Looking at individual diagnoses, unipolar depression was equally present in both sexes and was the most commonly diagnosed condition in both time intervals. One-third of subjects had gone through a phase of major depression at least once in their lives (LTP 33.2%). Including dysthymic disorders and minor depressive syndromes, the frequency was 39.4%. Besides unipolar depressive disorders, the most commonly diagnosed individual conditions were somatoform disorders (FWP 14.0%, LTP 14.0%), phobic disorders (FWP 12.4%, LTP 14.0%), and alcohol-related disorders (FWP 6.2%, LTP 13.0%). In women, somatoform disorders had a FWP as high as that for unipolar

depression, and at the time of this study they had in all cases become chronic (FWP 16.5%, LTP 16.5%) and were almost without exception of the pain-dominant type. Over a quarter of male participants had at least once had an alcohol-related disorder in the past (LTP 27.4%). Phobic disorders often manifested themselves as specific phobias relating to the healthcare system, for example as phobias relating to doctors, injections, or drugs with corresponding avoidance behavior or adherence problems (*Table 2*).

As far as the utilization of psychosocial treatment services is concerned, in total 32 participants of the whole sample reported that they had accessed some form of professional help in the preceding 12 months (16.6% [12.0; 22.5]). Of these, 27 participants currently had a mental disorder and 5 had none. On the other hand, the researchers identified 73 cases in immediate need for psychosocial treatment services (80.2% of the participants with current mental disorders). Based on a clinical judgment, the most commonly recommended treatments were psychotherapy (54 cases) and psychiatric treatment (24 cases).

Discussion

Strengths and limitations of the study

The original damage and its consequential effects, including comorbid mental disorders, were determined systematically for the first time in 202 thalidomide-damaged individuals—so far the largest such population of patients with thalidomide syndrome worldwide. Nearly a quarter of the total affected population of North Rhine–Westphalia was included. This study has shown the high degree of mental comorbidity in people with thalidomide-related, prenatal physical disabilities by using the methodological gold standard.

This study has certain limitations. The lack of basic data on the affected population as a whole does not allow providing robust information on the representativeness of the data. Most thalidomide-impaired subjects have been recruited as members of a patient support group, which might induce a self-selection bias into the sample. Since a classical epidemiological approach was not feasible, our results have to be interpreted with caution. Although sex ratios for thalidomide embryopathy are essentially evenly distributed, slightly more women than men took part in the study. However, at least as far as age is concerned, a distribution pattern typical of the thalidomide epidemic between the years 1957 and 1962 is observed (4).

Comparison with other studies

Comparing this study with the numerically largest thalidomide study by Kruse et al. (20), both show corresponding sociodemographic characteristics and a predominance of women in the studied sample. Similar to the data presented here, Kruse et al. found that thalidomide-impaired people are far below average in terms of full earning capacity, although they are highly educated. Furthermore, a high proportion of them are on a pension. Moreover, in the general population, it is

known that professional exclusion/marginalization is associated with an increased rate of mental disorders (31).

Another finding of our study is that among people affected by thalidomide, both men and women live by themselves in single households much more frequently compared with the German population as a whole (26.9% vs 18.2%); this is an indicator of social isolation (32). On the other hand Kruse et al. reported that thalidomide-affected subjects often rely on parents, partners, or children to cover their needs for personal assistance and care. With the passage of time, however, the parents' generation is increasingly dying out while the children of the impaired grow up and leave home, so that the familial helper system is currently at risk of falling apart (20).

Large-scale representative population studies, such as the German Federal Health Survey—Mental Health Module (DEGS-MH) have shown that mental disorders occur in a substantial section of the general population (33, 34). Thus, in the German age cohort of 50 to 64-year-olds, the 12-month prevalence of mental disorders of 27.1% is slightly below the value for the age-averaged German population as a whole, with these conditions being diagnosed more often in women than in men (31.9% vs 22.4%). Compared with this reference data our findings show some striking differences: The FWP of comorbid mental disorders in individuals with thalidomide embryopathy is almost twice as high than the 12-month prevalence found in DEGS-MH (47.2% vs 27.1%, $p < 0.001$; relative risk [RR]: 1.77 [1.49; 2.10]). In comparison with same-sex reference data, the prevalence of mental disorders in men with thalidomide damage is even more than twice as high than that in thalidomide-affected women (RR: 2.25 [1.74; 2.96]), which might indicate that men have more difficulties coping with congenital physical impairment than women.

A limitation in the comparison with reference data for the general German population is that, whereas both studies were based on methodologically high-quality structured interviews, a different psychodiagnostic interview (M-CIDI) was used in the Federal Health Survey. The prevalence figures given in the two studies also referred to different time intervals (4 weeks vs 12 months). The M-CIDI covered a slightly narrower spectrum of diagnoses than the SCID. Nevertheless, only by looking at the SCID-I and after removing “minor depression” and “drug dependence” from the data set in order to make the data comparable between the two studies, the four-week prevalence of mental disorders in the group of people impaired by thalidomide remains significantly higher than the twelve-month prevalence in the age-matched general population ($p < 0.001$).

Conclusion

The results regarding prevalence of psychological comorbidity in thalidomide-affected people indicate that this is at least as high as reported for chronic physical

diseases (35, 36) or physical disabilities (37). In people affected by thalidomide, the prevalence of a single diagnosis of unipolar depression—the most commonly established mental health diagnosis in both sexes in this group (33.2%)—is nearly twice as high as that reported in the German National Care Guideline for unipolar depression (33.2% vs ~18% LTP; RR: 2.31[1.61; 3.33]) (38). The high proportion of multiple mental disorders in one and the same person in thalidomide-affected people is, moreover, associated with an increased tendency towards chronification and an unfavorable prognosis (39). The high prevalence of mental disorders in thalidomide-impaired individuals may be explained by biological factors (i.e. neurotoxicity) as well as by psychological factors (i.e. stress arising from restrictions of physical function and restricted social participation), social mortification and the specific historic context (i.e. stigmatization, “thalidomide scandal”).

In our study, the percentage of thalidomide-impaired individuals receiving treatment for mental disorders was much lower than that for the general German population, with both analyses using the same methodological criteria (16.6% vs 36.4%, $p < 0.001$ [12.0; 22.5]) (40). This finding, which is in contrast with the increased prevalence of mental disorders compared to the reference population, suggests that mental health-care is insufficient or, in many cases, lacking. In people seriously damaged by a pharmaceutical agent, this may be due to skepticism towards healthcare and medication as such. In addition, thalidomide-impaired individuals might fear stigmatization not only as physically impaired, but also as mentally ill. Developing specialized health care services might reduce these barriers.

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Conflict of interest statement

Prof. Peters has received lecture honoraria from Amgen, Alexion, and Pfizer, reimbursement of travel and accommodation costs from UCB Pharma and Amgen, and a consulting fee from Gedeon Richter Pharma.

The remaining authors declare that no conflicts of interest exists.

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KEY MESSAGES

- 50 years after their prenatal damage, a sample of 193 individuals with thalidomide embryopathy was investigated for the first time by comprehensive psychodiagnostic interviewing.
- Thalidomide-affected individuals exhibit rates of mental disorder that are approximately twice as high compared to the general population.
- The utilization of mental health services is approximately half as high compared to the general population.
- Because of a large amount of unmet needs the development of specialized psychosocial treatment services is essential.

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Supplementary material

For eReferences please refer to:
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Supplementary material to:

Mental Disorders in People Affected by Thalidomide

A Cross-Sectional Study of Prevalence and Psychosocial Needs

by Alexander Niecke, Klaus Peters, Christina Samel, Kristin Forster,
Markus Längen, Holger Pfaff, and Christian Albus

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Methodological Details

● Patient involvement

We involved participants at an early stage of study planning, so the object of this research question and the study design were developed in cooperation with the regional patient support group ("Association of thalidomide victims North Rhine–Westphalia"). A peer-to-peer project supported the recruitment process. The study results were disseminated to participants at a public event on 9 April 2016.

● Recruitment

Various recruitment methods were used in order to reach the greatest possible number of subjects with this rare disease. The patient support group mailed information sheets about the study to all of their registered members in September 2011, along with an offer to be accompanied by a peer when taking part. The potential participants were also offered the possibility of receiving a full medical report on all the diagnoses found, as well as individually recommended treatment options after examination. Two reminders were sent, one in May 2012 and one in January 2013. In order to reduce recruitment bias, information about the study was also placed on internet forums and displayed on medical exhibition stands in order to reach thalidomide victims not represented by the patient support group. All examinations were carried out between October 2011 and May 2013 at Dr. Becker Rhein-Sieg Hospital in Nümbrecht, North Rhine–Westphalia.

● Study instruments

The investigation of the presence of mental disorders was based on the Structured Clinical Interview for DSM-IV Disorders (SCID-I & SCID-II). The SCID is a diagnostic exam used to determine major mental disorders (SCID-I) and personality disorders (SCID-II). Due to its high level of reliability and good validity, it is recommended as the gold standard tool for diagnosing mental disorders (29). In the case of deaf subjects, the interviews were carried out with the help of sign language interpreters. If a SCID interview was not feasible, e.g. in cases of pronounced neurocognitive disorders or intellectual disability, the diagnosis were established clinically on the basis of signs already present and on previous medical records. Therefore the study participants were asked to bring all available medical documents for the investigation. The diagnoses were presented in accordance with the 10th edition of the International Classification of Diseases (ICD-10, German version) (30). All SCID interviews were conducted by the same two specially trained researchers, either by a specialist in psychosomatics and psychiatry (AN) or by a qualified psychologist (KF). In the presence of a mental disorder the expert dichotomously rated the indication for various psychosocial treatment services, including psychotherapy, psychopharmacotherapy, addiction treatment, psychosomatic primary care treatment and hospitalization. Sociodemographic characteristics and utilization of psychosocial treatment services were documented using a questionnaire. With regard to utilization, participants were asked whether they had accessed professional help in the 12 months preceding the interview, this being broadly defined such that at least one contact with a psychotherapist or psychiatrist counted as a positive answer (i.e. the same, broad definition as employed by Wittchen and Jacobi [40]). The nature and extent of the original and subsequent physical damage were assessed from previous medical records and a standardized specialized physical examination (KP). The damage patterns were categorized into three disjoint types of damage: "fourfold damage", "twofold damage" and "damage without dysmelia".

● Statistical analysis

The data were analyzed using IBM SPSS Version 21.0 and R Version 2.15.1. Counts and frequencies were used to describe the sample. Contingency tables were created to show associations. To test for differences in proportions, two-sided exact binomial tests were performed. Confidence intervals for proportions were constructed using the Wilson-method (e1). Relative risks are reported with 95% confidence intervals. All test results and confidence intervals are of explorative nature to generate hypotheses for further studies. Therefore no adjustments for multiple testing have been made. The significance level was 5% for all statistical procedures.

● Ethical approval

The study was approved by the ethics committee of the North Rhine–Westphalia State Medical Association (No. 2011286) in accordance with the Declaration of Helsinki. All participants signed an informed consent form.