

Pain and Mobility in People with Thalidomide Embryopathy

3. Academic meeting on Thalidomide Embryopathy

Tokyo - February 9th 2019

こんにちは - *KONNICHI WA*



AGENDA

- 1. What is Pain?**
- 2. The Biopsychosocial Approach to Chronic Pain**
- 3. Pain and Mobility**
- 4. Pain in People with Thalidomide Embryopathy**
- 5. What helps from the patients view**
- 6. Pain Control**

WHAT IS PAIN?

- Pain accompanies us since the beginning of evolution.
- Pain is a complex survival super sense.
- Pain protects us from hazards.
- Pain influences our behavior.



NOCICEPTION & PAIN

- 1. Detection of a Pain stimulus**
 - Specific free nerve endings as receptor
- 2. Forwarding of nociceptive information**
 - Peripheral nerve -> spinal cord -> brain
- 3. Signal processing**
 - Amplifying and filter function
- 4. Realization of Pain**

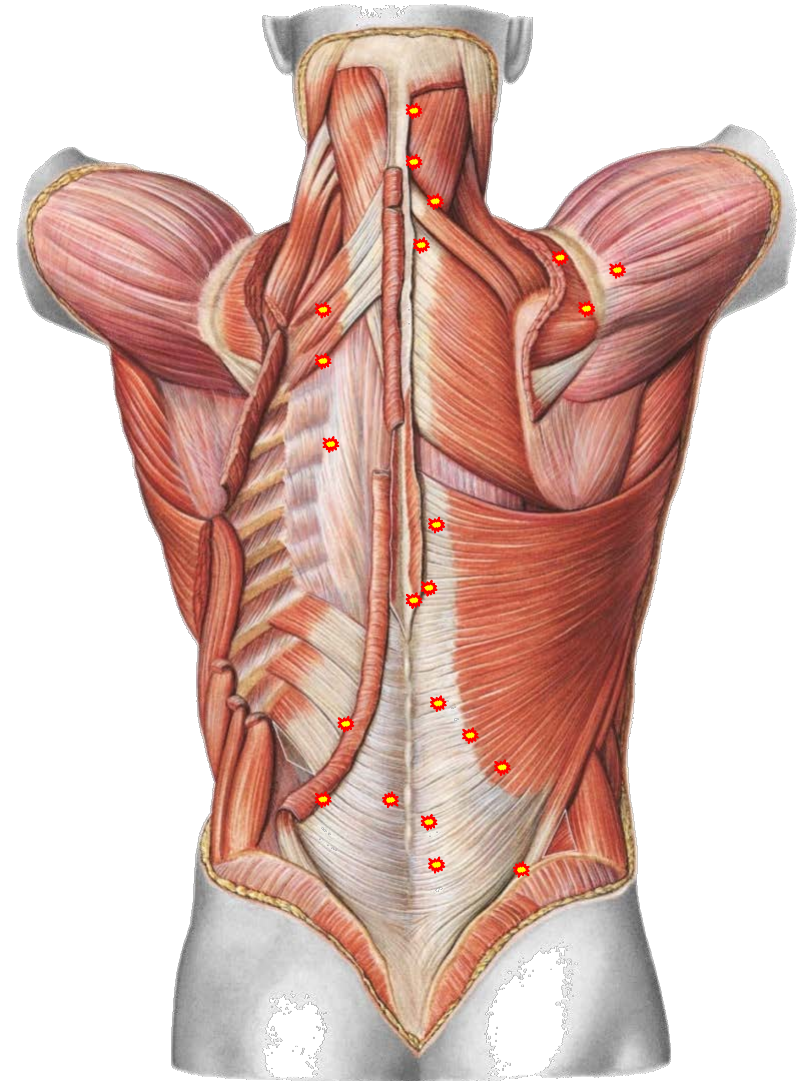


COMPONENTS OF PAIN

- **Sensory:** localize & estimate the damage
- **Motoric:** get out of the danger zone
- **Vegetative:** prepare the body for fight or flight
- **Affective:** personal emotional component
- **Cognitive:** analyzing, comparing with experience

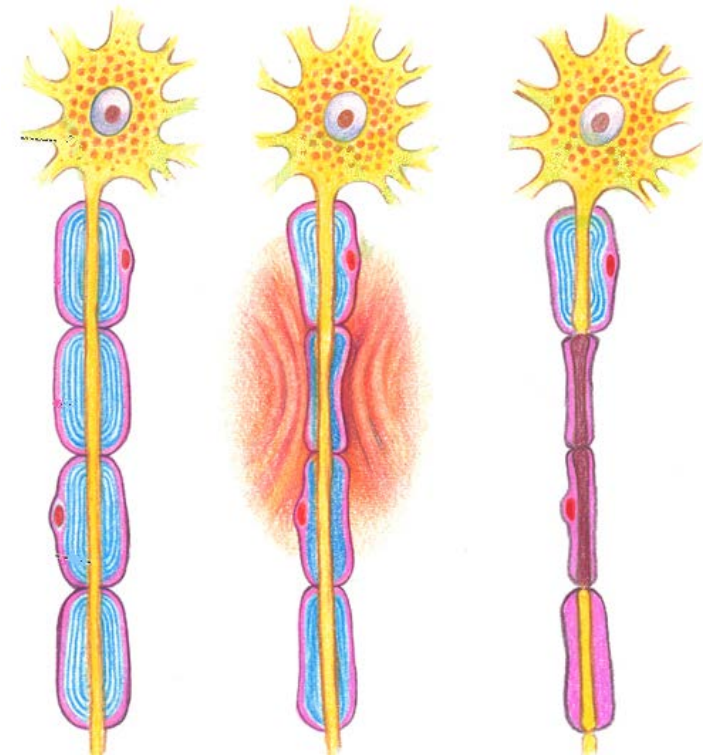
MUSCULOSKELETAL PAIN

- **Mechanical receptors**
 - Polymodal nociceptive properties
- **Free nerve endings**
 - Respond to products of the muscle metabolism (ATP, pH)
- **Pain receptors are widespread**
 - Muscle
 - Fascia
 - Bone and joints

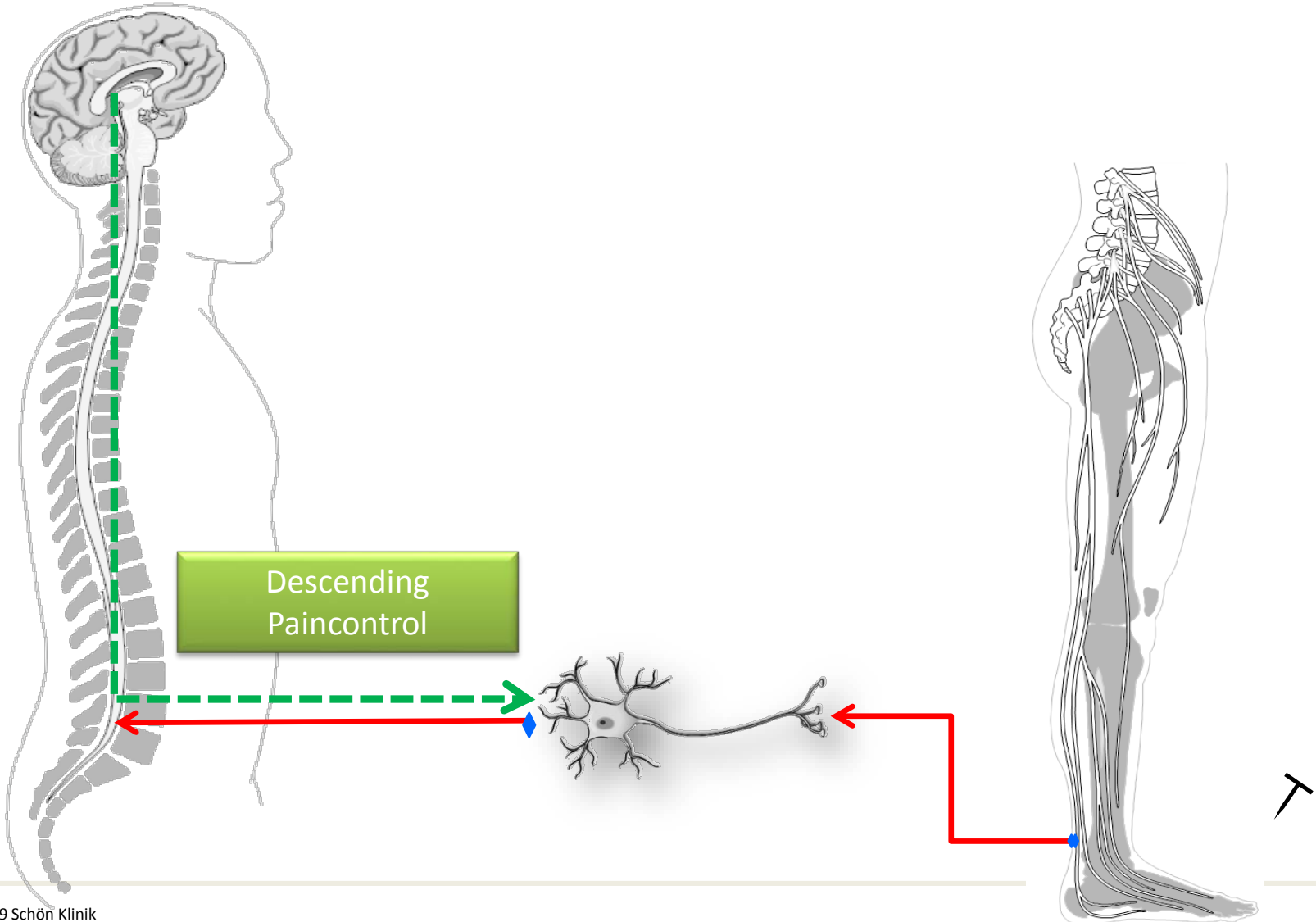


NEUROPATHIC PAIN

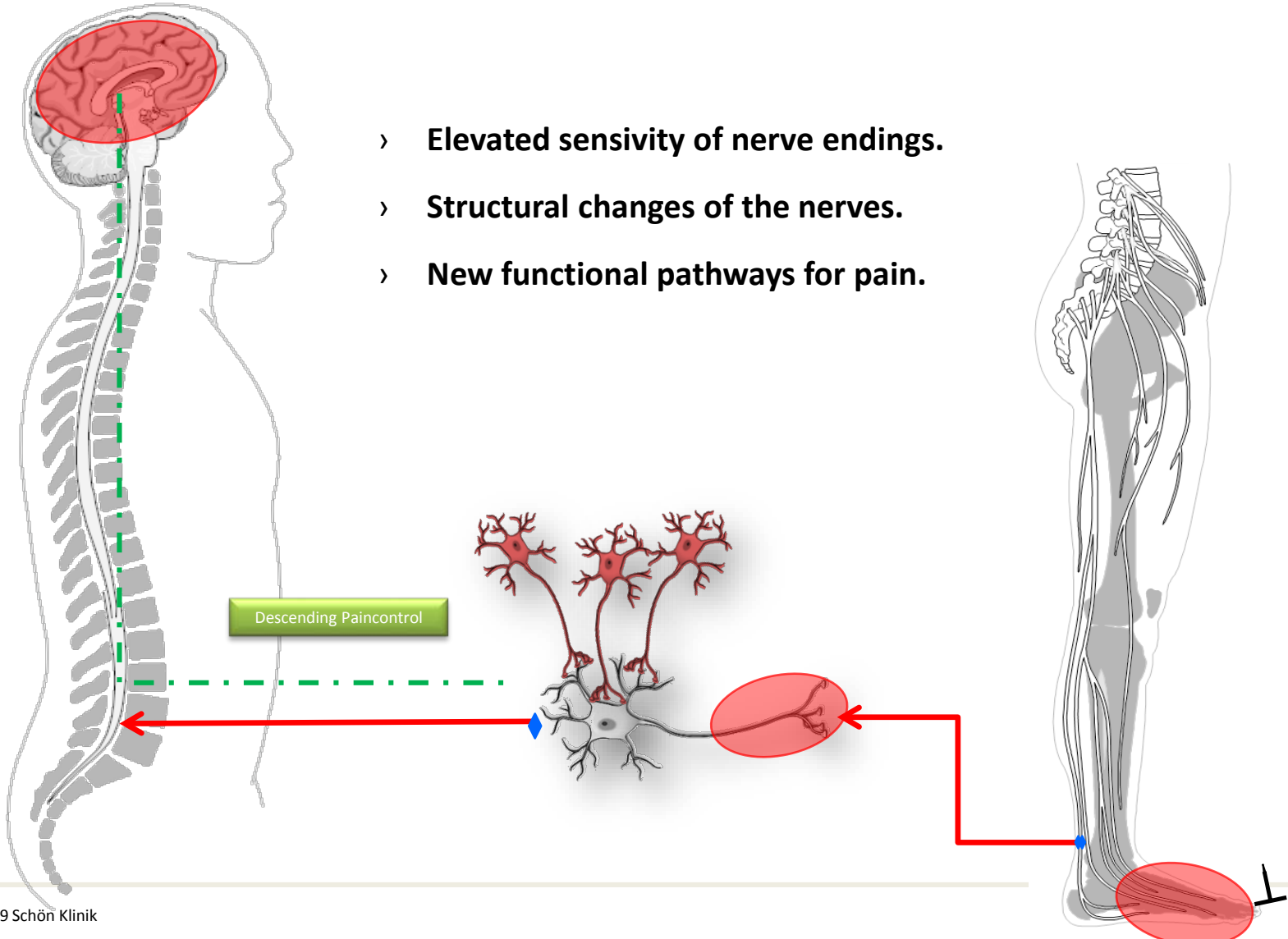
- **Damage or disturbance of the nerves**
 - Missing information is replaced by “wrong” information (pain)
 - Uncontrolled “neuronal fire”
- **Symptoms**
 - Pins & needles, burning or shooting pain
 - Numbness, weakness
 - Disturbance of heat / cold sense
- **Causes for neuropathy**
 - Nerve compression
 - Diabetes, Alcohol, Low vitamin B



SENSITIZATION AND CHRONIFICATION



SENSITIZATION AND CHRONIFICATION



- › Elevated sensitivity of nerve endings.
- › Structural changes of the nerves.
- › New functional pathways for pain.

SENSITIZATION AND CHRONIFICATION

1. Step: Elevated sensibility of nerve endings.

2. Step: Structural changes of the nerves.

Result: New functional pathways for pain.

SENSITIZATION AND CHRONIFICATION

Chronic pain may result in structural remodeling of the peripheral and central nerve system that lead to new pathways for pain stimuli.

BIOPSYCHOSOCIAL APPROACH



THALIDOMIDE DAMAGE - LIVE LONG BURDEN



MOBILITY

„Mobility is the
key to self
determined life
and social
participation.

Mobility it self is
fun



Gernot Stracke, President of the Thalidomide Association Hamburg
Ducati Multistrada 1000 ds: 84hp

MOBILITY

- **Mobility is the most relevant ability for quality of life.**
- **Barriers to regular physical activity have a significant impact on health and prevention.**
- **Limiting factors for mobility:**
 - Malformation of extremities
 - Limited function of sensory organs
 - Aging
 - Pain

MOBILITY



PAIN & MOBILITY

- **Pain is a major factor in restricting mobility.**
- **Physical activity and exercise can have a positive impact on the intensity of pain.**
- **Pain and movement influence each other.**
- **Both aspects should be considered equally when implementing appropriate therapy concepts.**

PAIN SITUATION OF THALIDOMIDE VICTIMS

Kruse, Ding-Greiner 2012

- **Pain occurred in 84.3% of 870 Thalidomidiers.**
- **50% reported daily pain, 39% continuous pain.**
- **Pain intensity is proportional to the damage.**
- **Incorrect posture cause mainly as muscular tension in:**
 - The back (78.6%)
 - The arms (43.0%)
 - The legs (19.5%)

Kruse A, Ding-Greiner C, Becker G et al. Contergan - Endbericht an die Conterganstiftung für behinderte Menschen: Wiederholt durchzuführende Befragungen zu Problemen, speziellen Bedarfen und Versorgungsdefiziten von contergangeschädigten Menschen. Institut für Gerontologie der Universität Heidelberg 2012: 1–297

PAIN SITUATION OF THALIDOMIDE VICTIMS

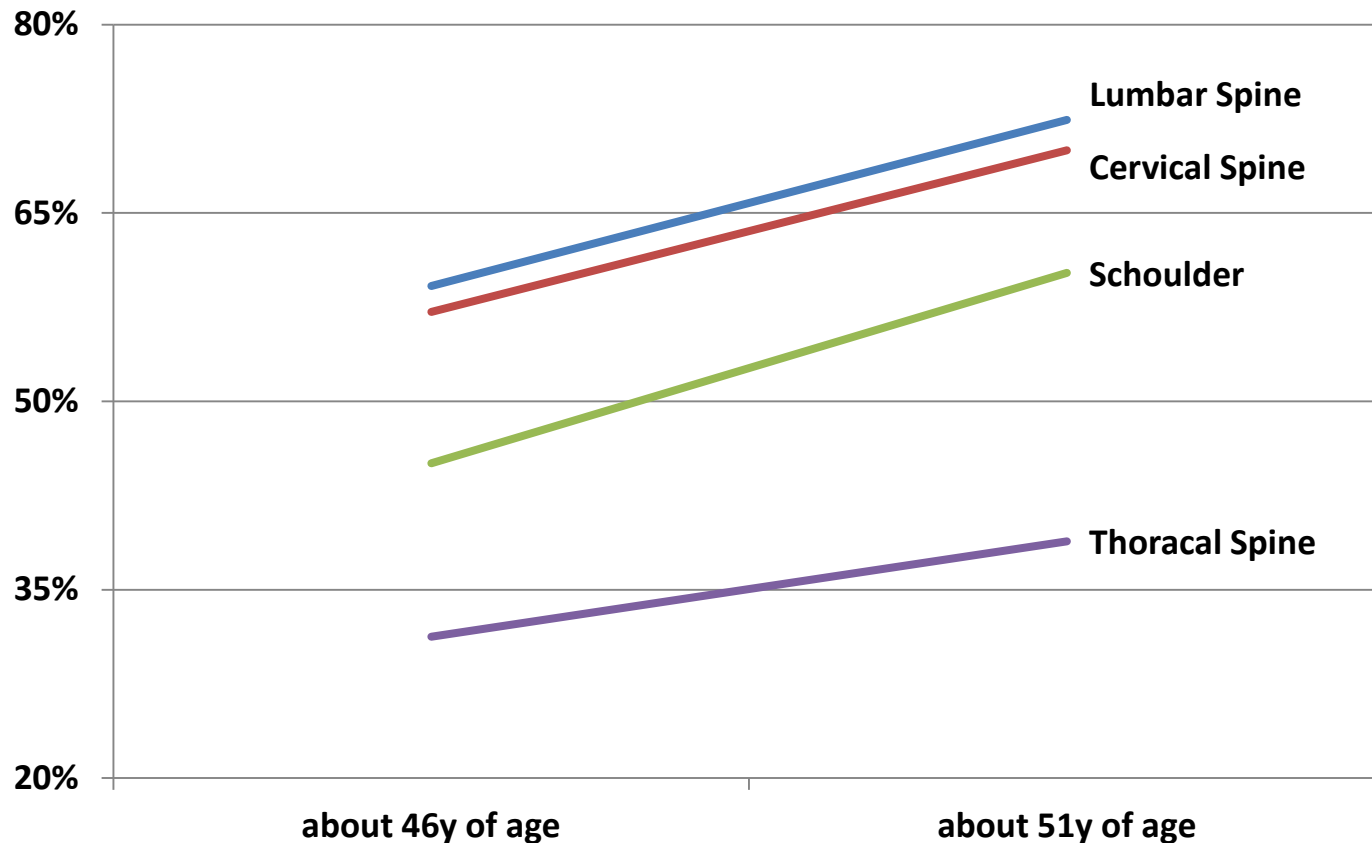
Kruse, Ding-Greiner 2012

- **The extent of stress or lack of rest periods and protection plays an important role.**
- **Those who have the opportunity to determine for themselves how intensive daily stress is, who can use therapies and who are supported in everyday life, have a good chance of developing less pain.**

Kruse A, Ding-Greiner C, Becker G et al. Contergan - Endbericht an die Conterganstiftung für behinderte Menschen: Wiederholt durchzuführende Befragungen zu Problemen, speziellen Bedarfen und Versorgungsdefiziten von contergangeschädigten Menschen. Institut für Gerontologie der Universität Heidelberg 2012: 1–297

INCREASING PAIN WITHIN 5 YEARS*

According to Kruse, Ding-Greiner 2012



*Diagram according to data from Kruse and Ding-Greiner 2012.

N = 870. comparison of how many people already suffered from pain 5 years ago and how many at the time of the study.

PAIN SITUATION OF THALIDOMIDE VICTIMS

Peters, Albus, Lungen 2014

- **62% of 202 had a high level of pain chronification.**
- **Half of Thalidomiders had a neuropathic component.**
- **Pain was reported as:**
 - neck pain (80.7%)
 - back pain (78.2%)
 - shoulder pain (64.5%)
 - knee pain (54.3%)
 - hip pain (54.3%)

Peters KM, Albus C, Lungen M et al. Gesundheitsschäden, psychosoziale Beeinträchtigungen und Versorgungsbedarf von contergangeschädigten Menschen aus Nordrhein-Westfalen in der Langzeitperspektive: Gutachten im Auftrag des LZG.NRW. Landeszentrum Gesundheit Nordrhein-Westfalen 2014: 1–207

PAIN SITUATION OF THALIDOMIDE VICTIMS

Thalidomide Trust 2016

- **A study with 20 participants showed that nerve compression frequently occur in Thalidomiders:**
 - 90% had evidence of nerve compression.
 - 15% had compression of the spinal cord (myelopathy)
 - 5% had compression of the spinal nerves (radiculopathy)
- **The validity of this study is limited by the small number of cases.**

Nicotra A, Newman C, Johnson M et al. Peripheral Nerve Dysfunction in Middle-Aged Subjects Born with Thalidomide Embryopathy. PloS one 2016; 11(4): e0152902

GERMAN PAIN QUESTIONNAIRE

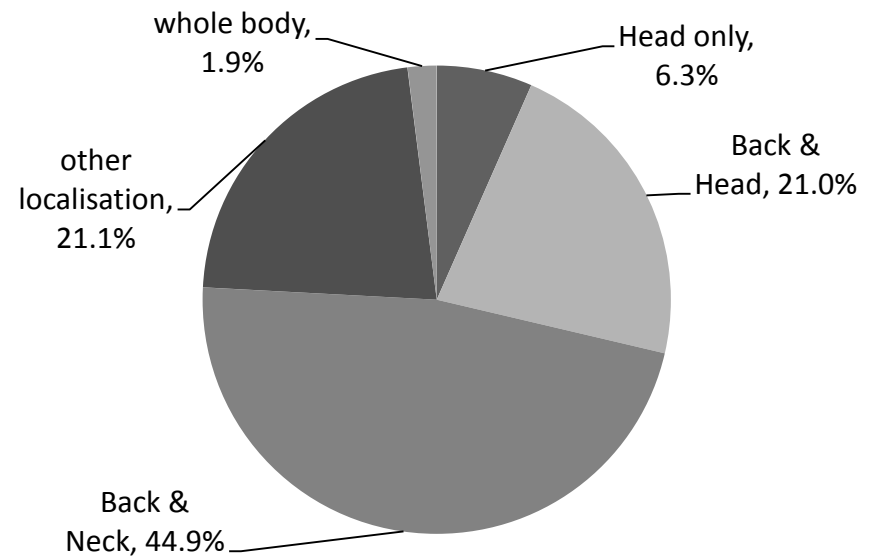
Validation Study* of the German Pain Society 2006

N = 1086 non TE patients with chronic Pain

Average age: 54 years



Locations of principal pain

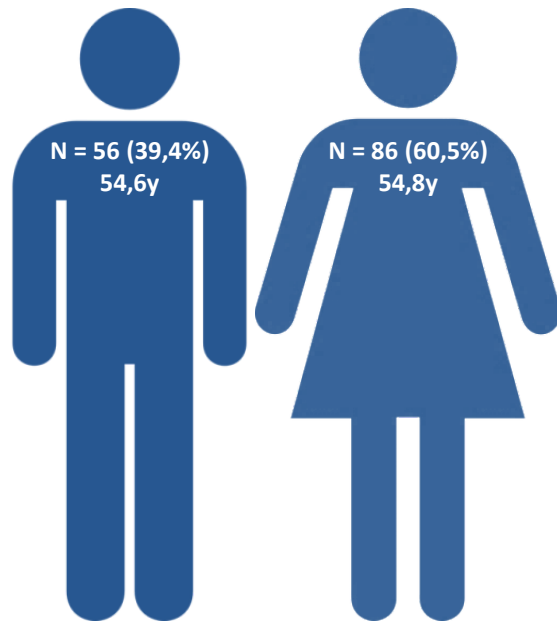


*B. Nagel, M. Pfingsten, G. Lindena, Th. Kohlmann. Handbuch DSF Deutscher Schmerz-Fragebogen. Deutsche Schmerzgesellschaft 2015.

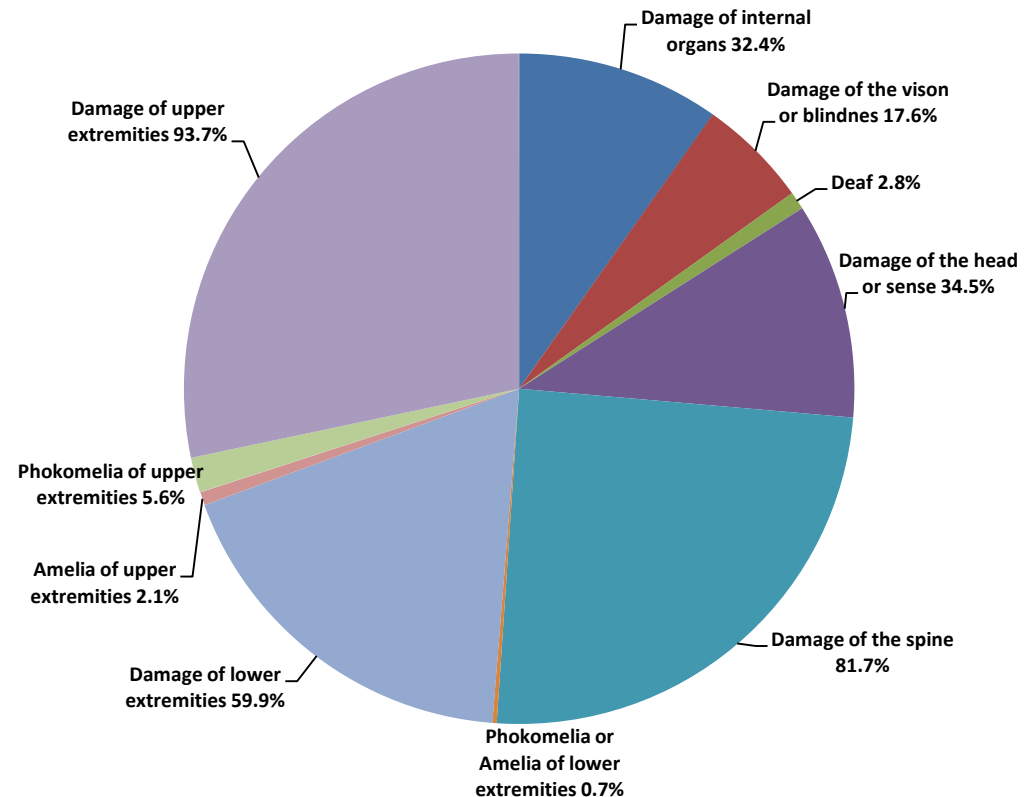
GERMAN PAIN QUESTIONNAIRE

Patient Survey of the Thalidomide Clinic Hamburg

N = 142 TE patients

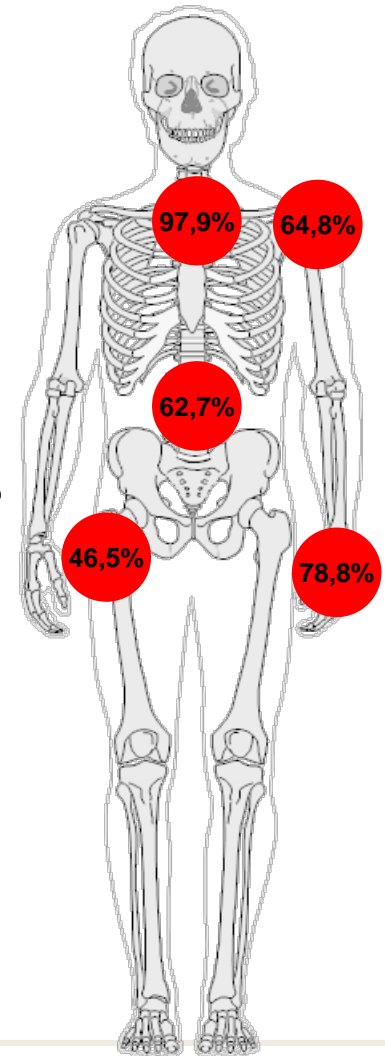
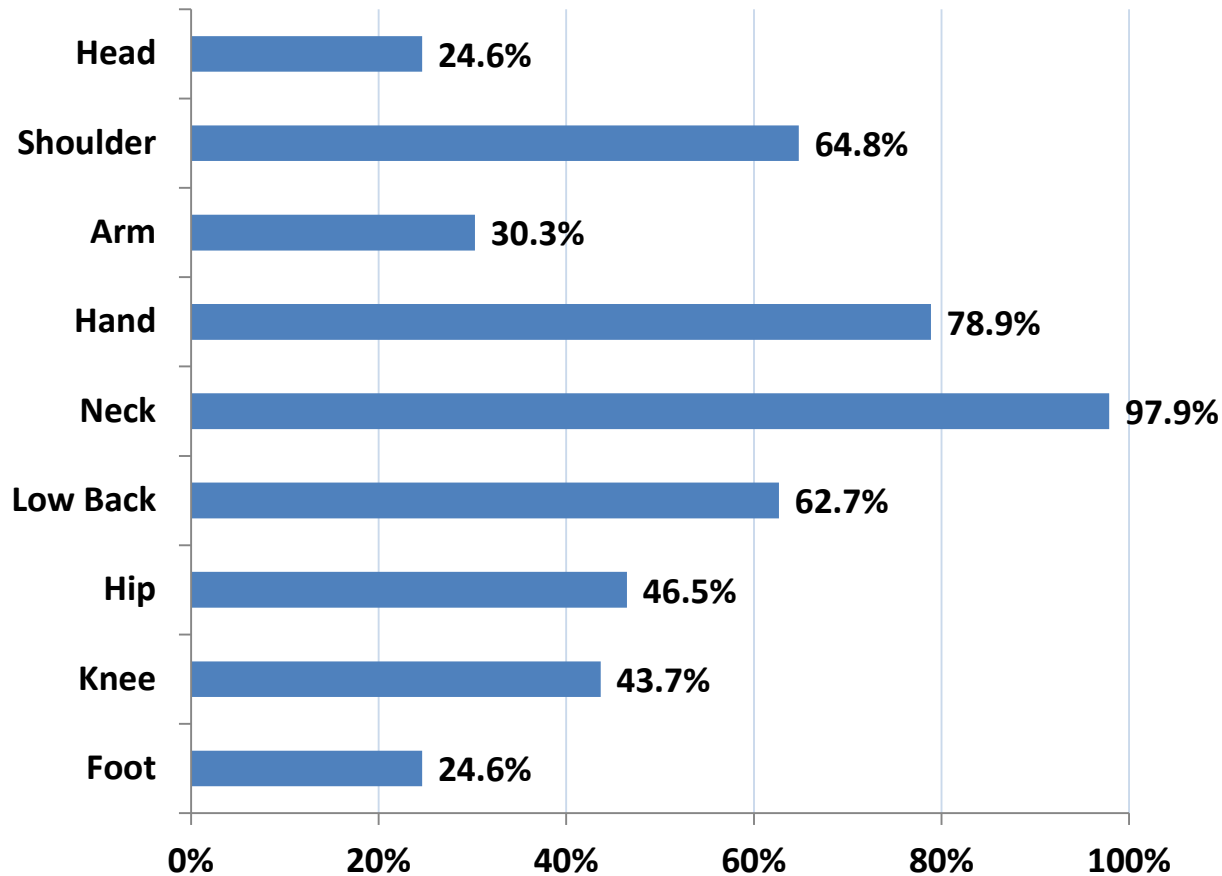


Damage Groups*



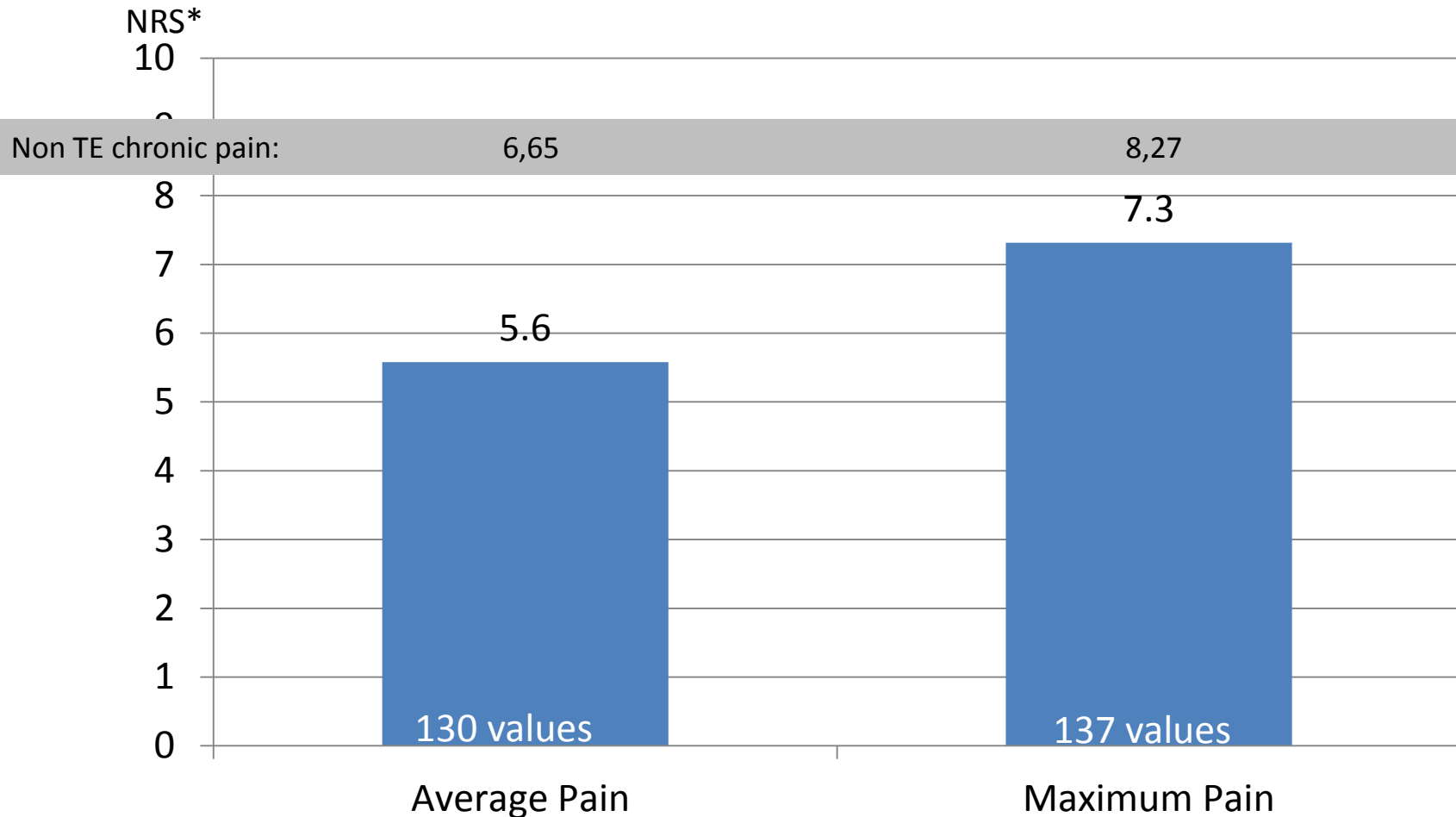
*patients distributed in more than one damage group

LOCATIONS OF PRINCIPAL PAIN*



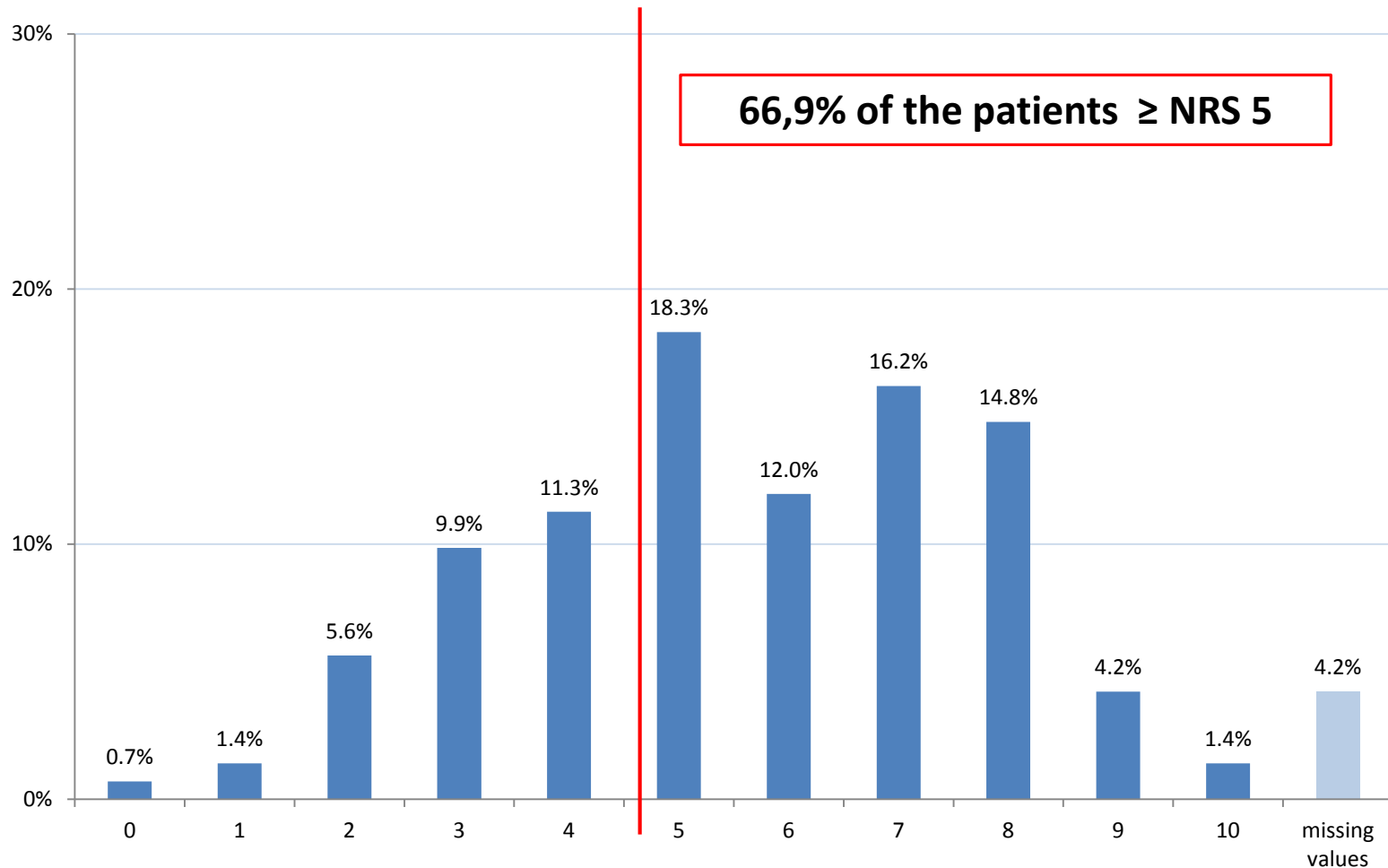
*total of 952 statements from 142 patients

INTENSITY OF PAIN

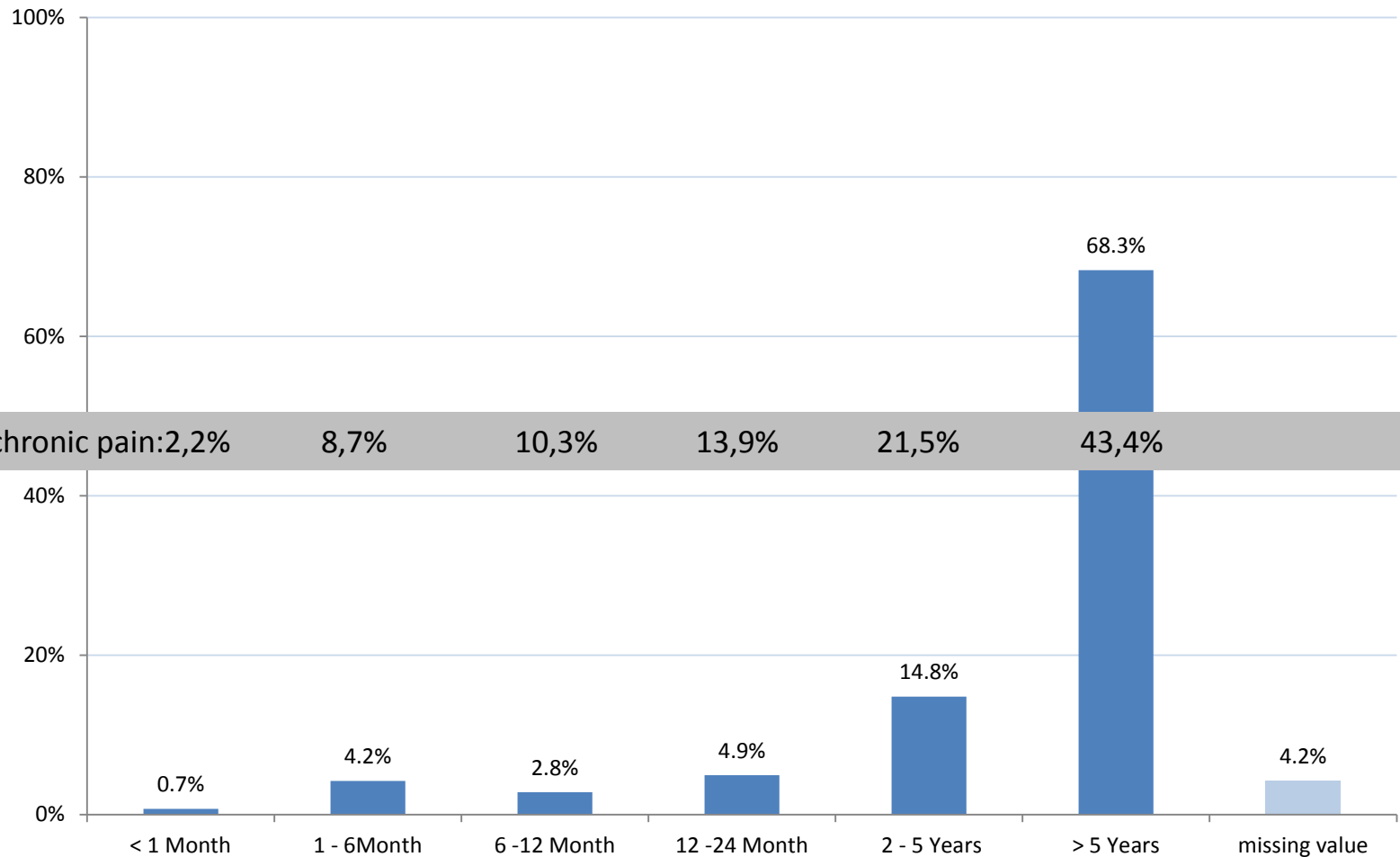


*NRS = Numeric Rating Scale: 0 = No pain, 10 = Maximum pain imaginable

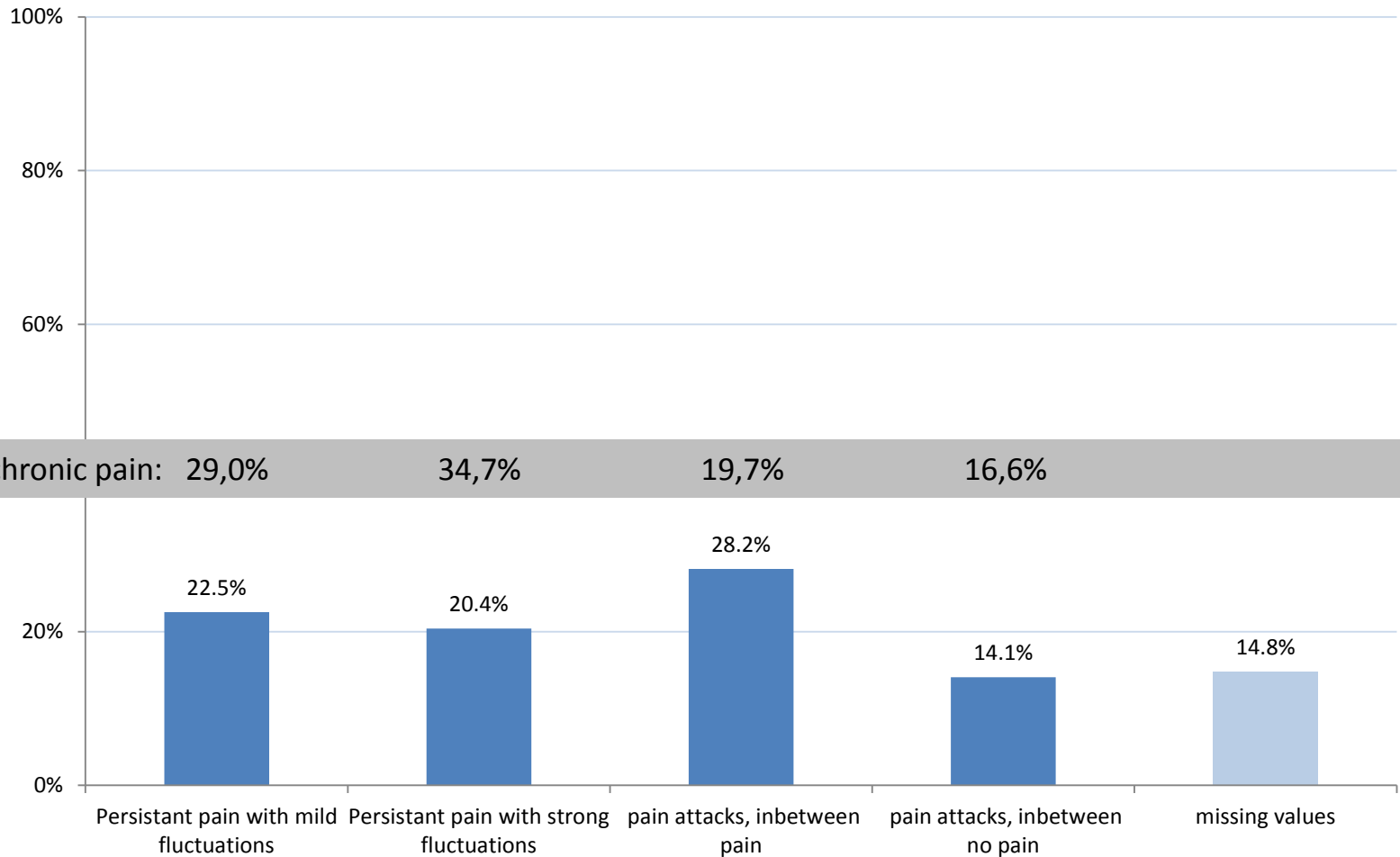
FREQUENCY DISTRIBUTION OF AVERAGE PAIN



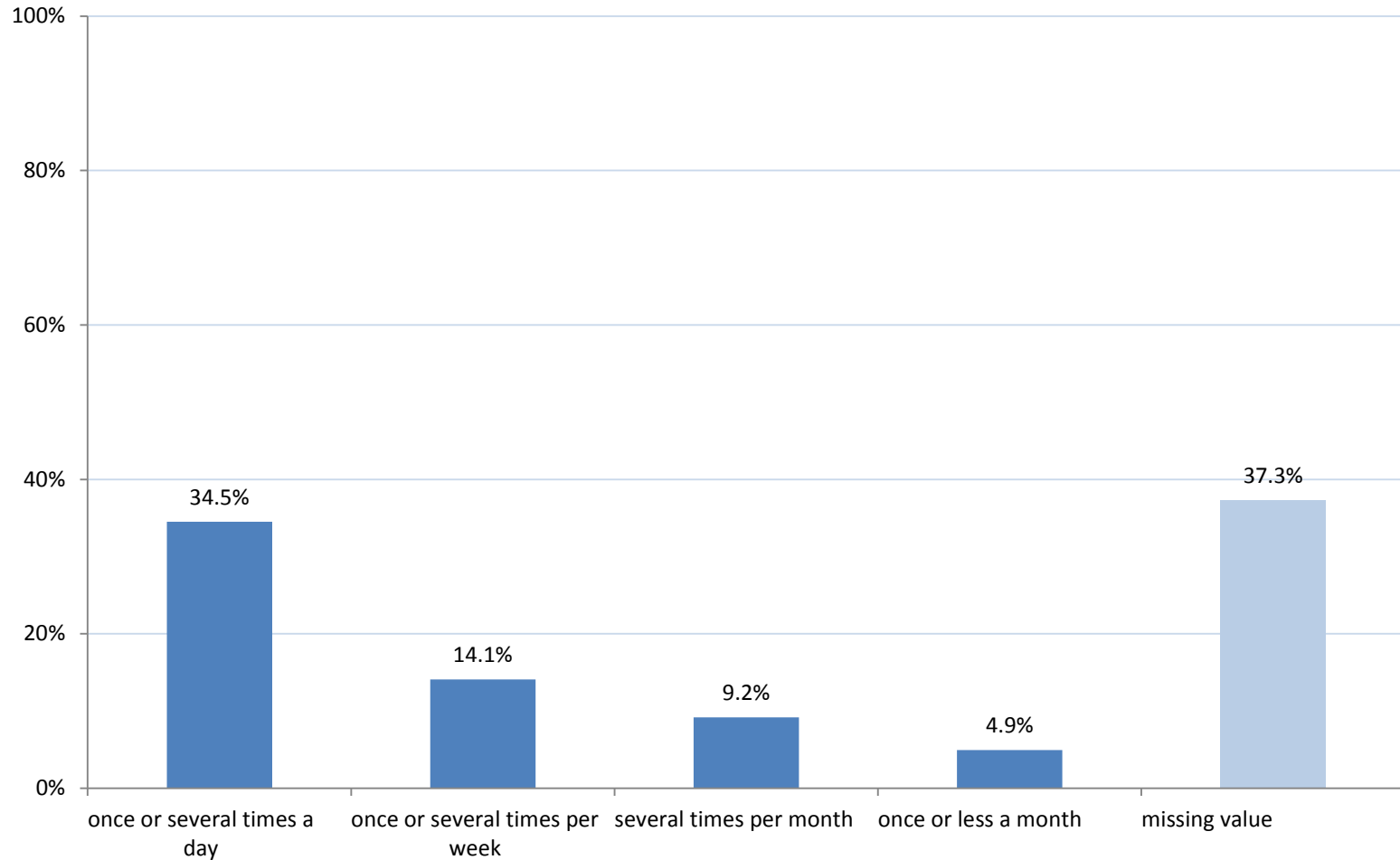
ONSET AND DURATION OF PAIN



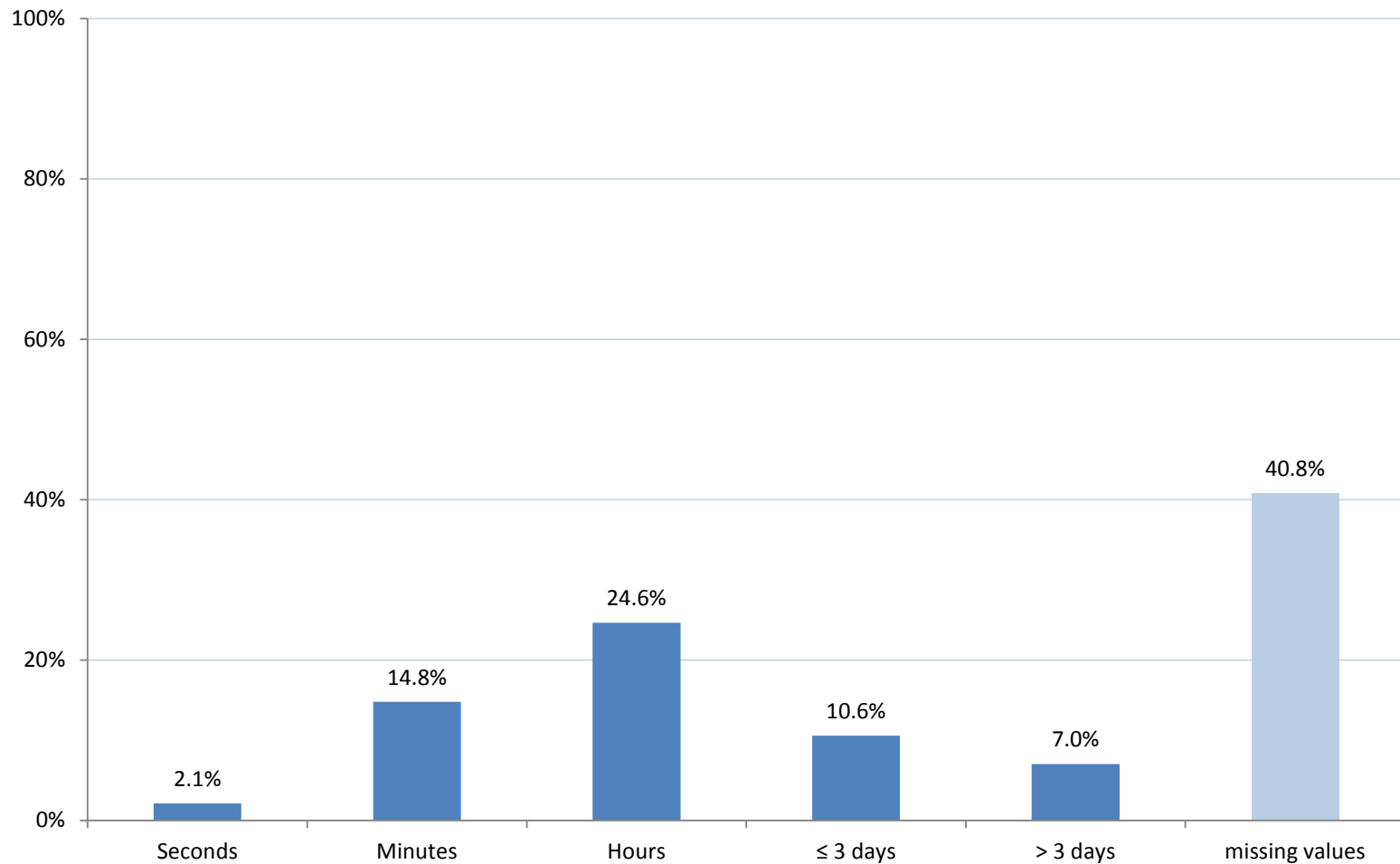
FREQUENCY OF PAIN



FREQUENCY OF PAIN ATTACKS

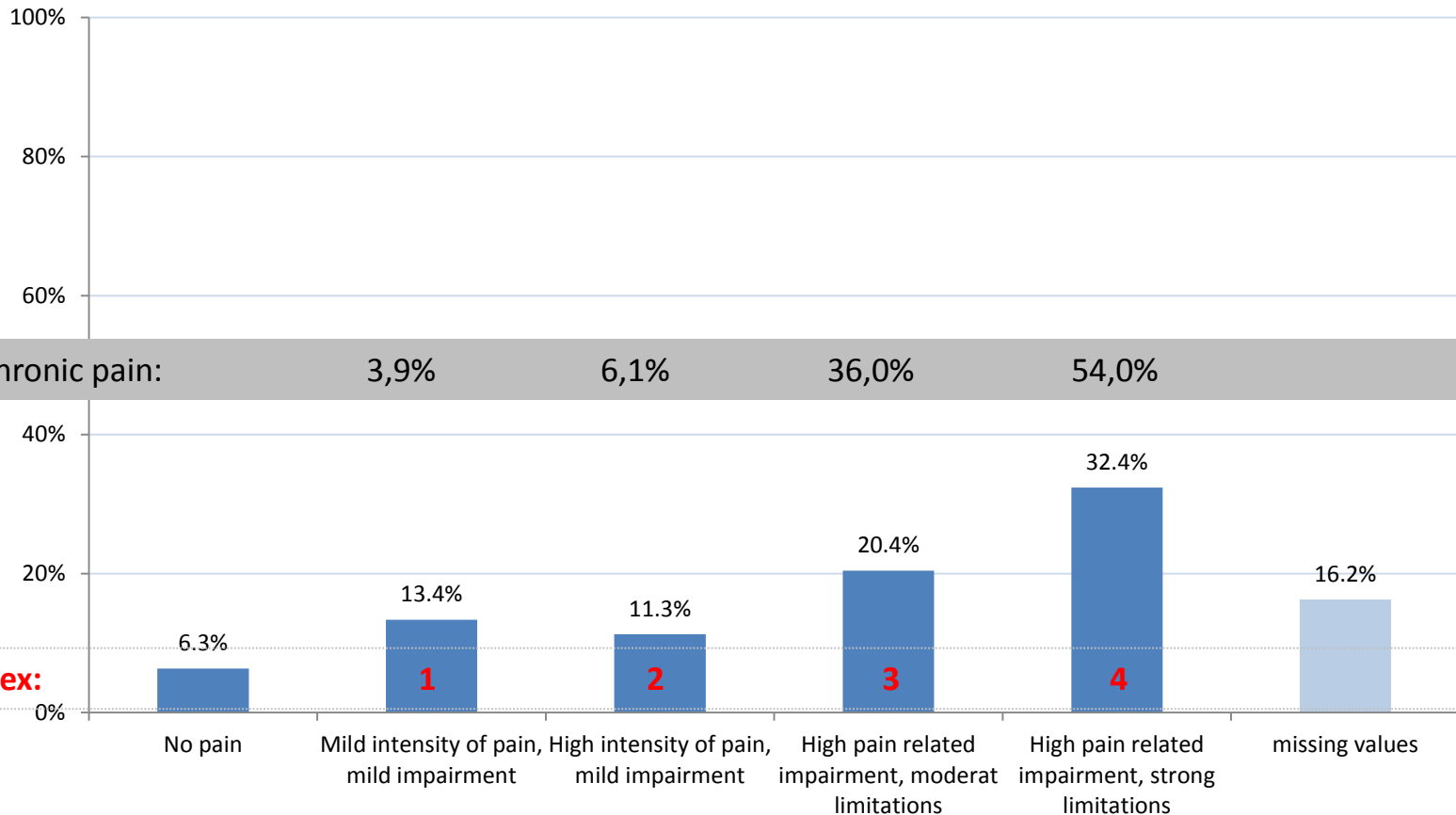


DURATION OF PAIN ATTACKS

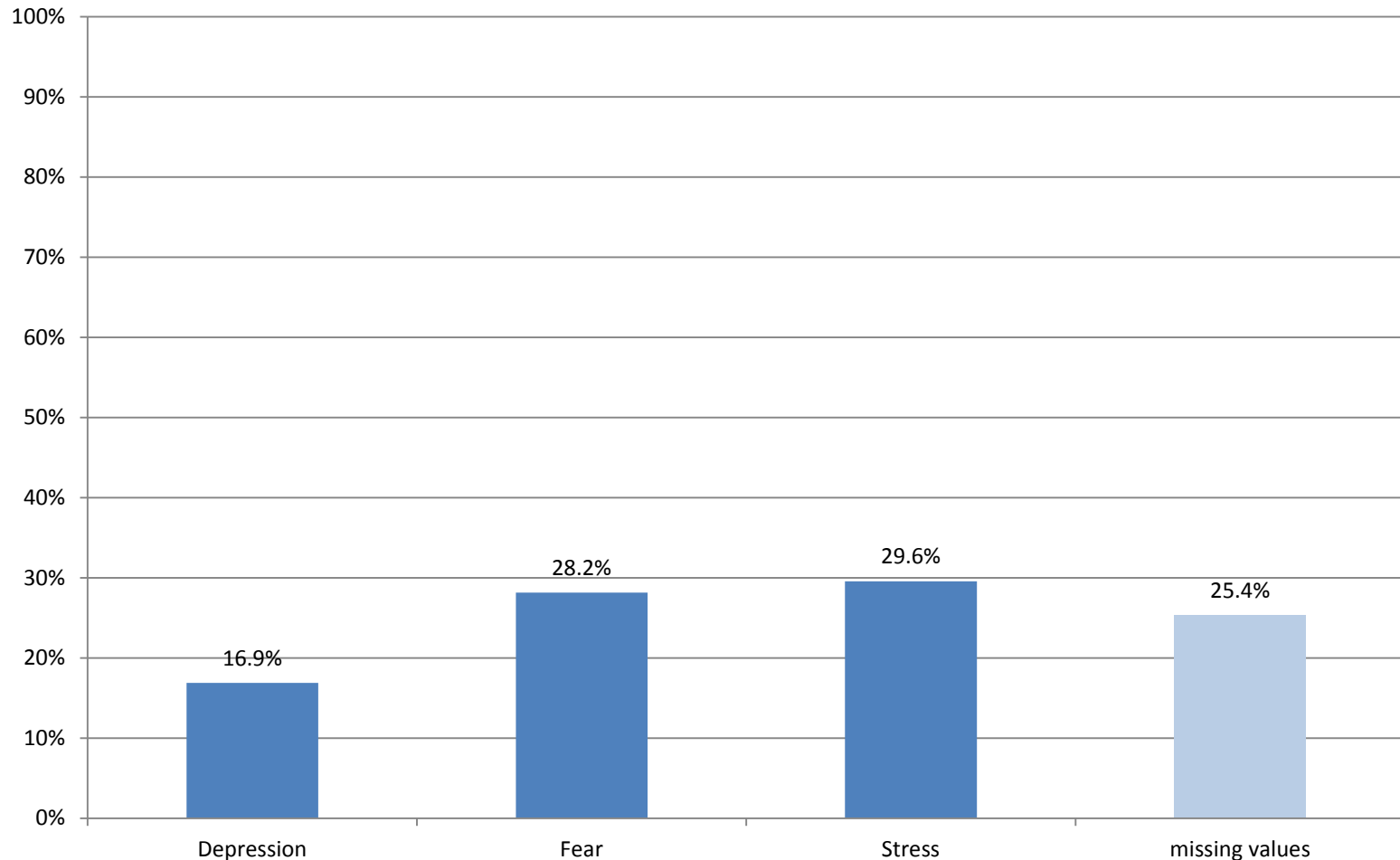


DEGREE OF PAIN SEVERITY

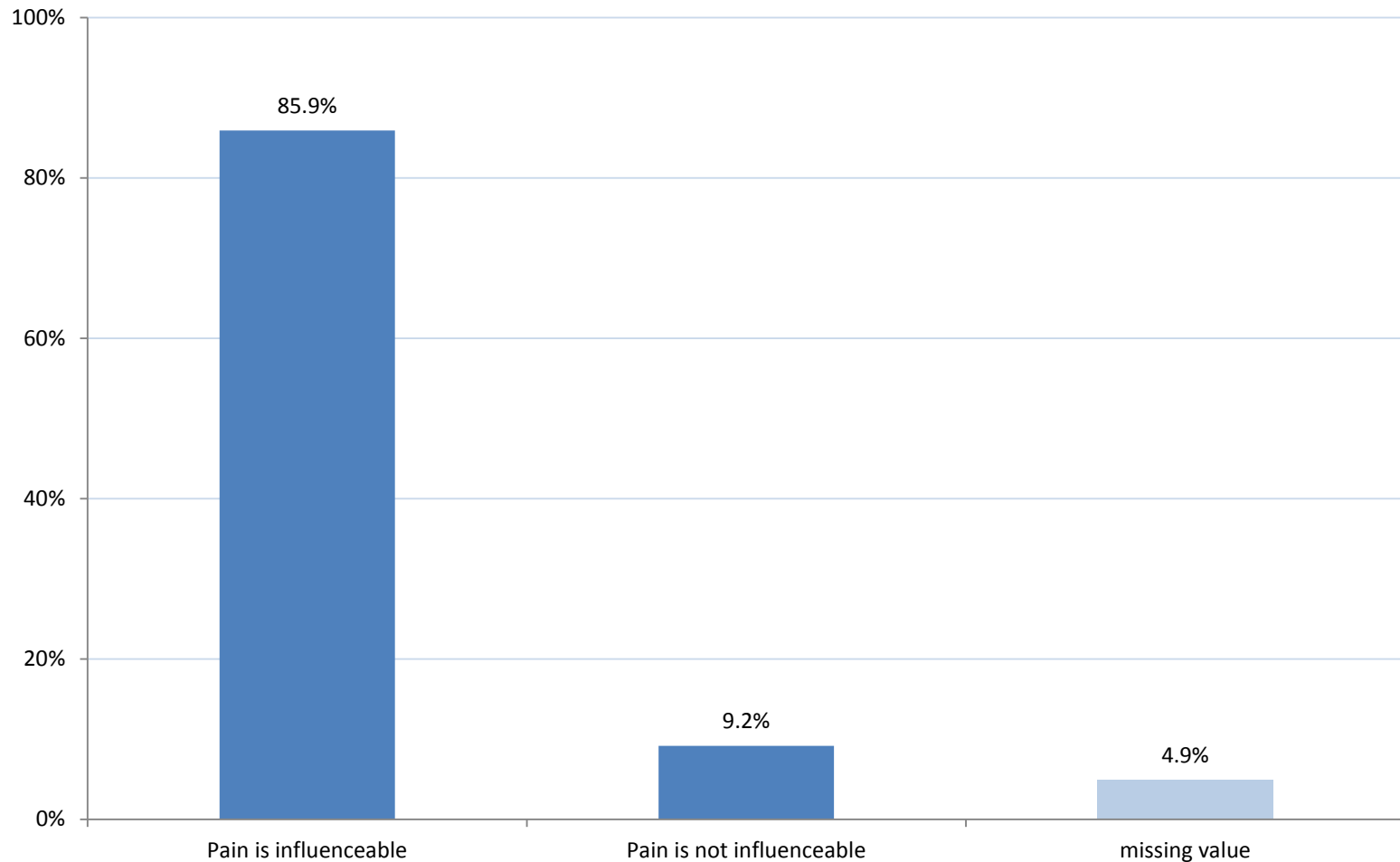
KORFF-Index: intensity of pain, pain related impairment, days with disturbance of ADLs



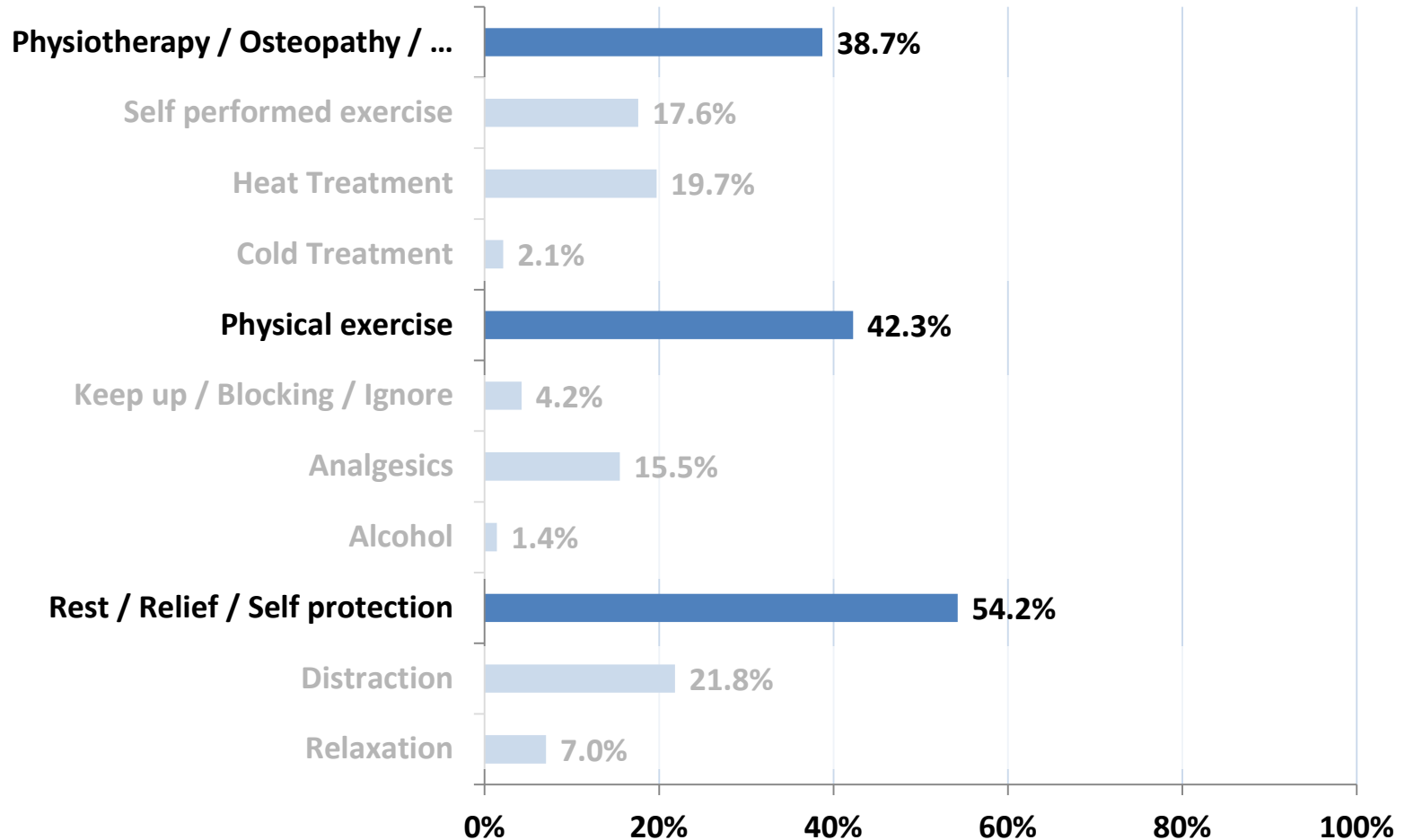
SCREENING FOR PSYCHOLOGICAL DISORDERS



SUGGESTIBILITY OF PAIN



WHAT HELPS FROM THE PATIENTS VIEW*



*total of 458 statements from 142 patients

PAIN CONTROL

1. Refer the patient to a Pain Specialist?
2. Prescribe a stronger painkiller?
3. Escalate therapy by invasive procedures & surgery?

CRAP!

APPROACH TO PEOPLE WITH CHRONIC PAIN

Are there any new treatments for pain?



No, but if we could develop a new pill, that ...

... taken by the doctor, makes him feel exactly the same as the patient feels, this would improve the treatment.

APPROACH TO PEOPLE WITH CHRONIC PAIN

Understanding of the patients problem is based on the individual...

- **Biological conditions:**
 - Nociceptiv vs. neuropathic pain, medical disturbance
- **Psychological effects due to pain and vice versa:**
 - Depression, Fear, Stress
- **Social impairment in terms of social participation:**
 - Grade of self determined life

PRACTICAL RECOMMENDATION

Step 1: Diagnosis is the basic of therapy planning

- **Diagnosis of Pain: acute vs. chronic, nociceptive vs. neuropathic.**
- **Further diagnostic measures necessary to confirm diagnosis?**
 - Key question: is there a possible reason for specific pain?
- **A Pain Questioner is a good tool for the consultation hour.**
 - What are special needs and worries
 - What are the resources of patient

PRACTICAL RECOMMENDATION

Step 2: If there is a specific reason, consider causal therapy options

- Utilize causal therapy options (e.g. optimize diabetes therapy, operative decompression in nerve compression, etc.).
- Combine with general therapy options (-> Step 3).

PRACTICAL RECOMMENDATION

Step 3: If the pain is chronic, consider general therapy options

- **Physiotherapy and physical exercise.**
 - all kinds of professional guided active and passive therapy
- **Personal physical activity and exercise.**
- **Cognitive behavioural treatment.**
- **Relaxation and protection from physical overuse.**
 - Support by personal assistance
- **Drug therapy planning.**
 - A therapy with analgesic medication is one part of pain therapy

PRACTICAL RECOMMENDATION

Step 4: Drug therapy planning

Evaluate previous pain therapy:

- Take comorbidities into account, including the possible side effects.
- Take co-medications into account, including their possible interactions.
- Take intolerances into account.
- Patient wishes with regard to avoidable side effects should be taken into account.

PRACTICAL RECOMMENDATION

Step 5: Patient information

- **Formulate and coordinate therapy goals together:**
 - Pain reduction by 30-50%
 - Improving sleep quality and quality of life
 - Preservation of social activity
 - Recovering and maintaining work/daily competences
- **Specify the drugs used and explain their use as analgesics to the patient (support medication adherence).**
- **Explain possible side effects and avoid interactions.**

PRACTICAL RECOMMENDATION

Step 6: Re-evaluation - control efficiency and side effects

- Is there an improvement in terms of the goals?
- Are there side effects?
- Is the therapy appropriate for long term use?

MULTIMODAL & INTERDISCIPLINARY



FUTURE TASK

- **The problems of Thalidomiders are expected to worsen in the future as a result of the natural ageing.**
- **A particular challenge in developing suitable treatment strategies is the enormous range of deformities.**
- **There is no "patent solution" that can apply equally to all patients.**

FUTURE NEEDS

It seems to be reasonable to try out many different forms of treatment and bring them to the attention of the Thalidomiders.

Therapeutically decision making should involve the patients experience and feedback in a particular way.

In order to preserve the skills of everyday activities, we should test all therapy forms individually.

