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## Tortured refugees' expectations of a multidisciplinary pain rehabilitation programme: An explorative qualitative study

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## ORIGINAL REPORT

# TORTURED REFUGEES' EXPECTATIONS OF A MULTIDISCIPLINARY PAIN REHABILITATION PROGRAMME: AN EXPLORATIVE QUALITATIVE STUDY

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**Background:** Refugees have often been exposed to torture in their countries of origin. Rehabilitation of tortured refugees living in Denmark is offered by the specialized Rehabilitation and Research Centre for Torture Victims in Copenhagen. After an interdisciplinary assessment eligible patients are recommended rehabilitation.

**Objective:** To explore tortured refugees' expectations of the multidisciplinary pain rehabilitation programme offered at our centre.

**Design:** Explorative qualitative interview study.

**Patients:** Fifteen consecutive Arabic-speaking men, waiting for rehabilitation after having been assessed by a physician, a psychologist, a physiotherapist and a social worker, were interviewed.

**Methods:** Individual qualitative interviews were performed by an Arabic-speaking psychologist, and analysed with content analyses.

**Results:** One theme: different expectations of multidisciplinary pain rehabilitation and 4 categories emerged: general expectations of the rehabilitation programme; specific expectations of professional treatment; expectations of mutual participation and communication; and expected rehabilitation outcomes.

**Conclusion:** The tortured refugees had different, mostly positive, expectations of the multidisciplinary pain rehabilitation programme. General expectations of the rehabilitation content, as well as specific expectations of the professionals' treatment, were expressed. Mutual and active participation and communication between patients and therapists were important expectations. In addition, positive outcomes, such as improved health, improved coping ability and decreased pain, were expected.

**Key words:** communication; content analysis; health; participation; torture victims; treatment.

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## INTRODUCTION

Refugees have often been exposed to torture in their countries of origin. A recent study in Denmark (1) among asylum-seeking immigrants indicates that 45% have been subjected to torture. A central issue for these persons is the multifaceted somatic, psychological and social problem-set affecting participation and activities of daily life. Pain is one of the most frequent complaints of torture survivors (2). The patients have multiple problems: post-traumatic stress disorder (PTSD), depression, anxiety, chronic pain, poverty, isolation, inactivity, unemployment, and various other social distress factors.

Rehabilitation of tortured refugees living in Denmark is offered by the Rehabilitation and Research Centre for Torture Victims (3) in Copenhagen, a specialized rehabilitation clinic and a global knowledge and research centre with government support. To be admitted to this centre, people who have been exposed to torture or organized violence must have a residence permit in Denmark and a referral from a physician. All patients undergo an interdisciplinary assessment, which includes medical, physiotherapeutic, psychological and social examinations, followed by a team conference where a rehabilitation plan is discussed with the patient who, if eligible, is offered rehabilitation. Specific pre-treatment assessment has been shown to improve quality of life and satisfaction among patients with mixed chronic muscular pain (4). Interdisciplinary and bio-psycho-social rehabilitation are the guiding principles at the centre (5, 6).

Patients' pre-treatment beliefs about recovery after rehabilitation have been found to influence rehabilitation outcomes. Patients with a positive outlook showed long-lasting significant increases in life satisfaction and decreases in pain intensity (7). Increasing the motivation for active participation in rehabilitation programmes also has positive impact on outcome. Formulated goals and positive self-efficacy beliefs are also important for positive rehabilitation outcomes. Self-efficacy, the belief in one's own ability to meet situational demands, is concerned with what a person believes he/she can do with his/her capabilities, and is important for high goal commitment and goal attainment in rehabilitation and for overall health (8, 9). The stronger the self-efficacy beliefs the patient has, the stronger the motivation to participate in rehabilitation, and the more positive outcomes. Expectations can be defined as: (i) patient-related expectations, for example expectations of increased self-efficacy; (ii) process-related expectations; and/or (iii) treatment-related expectations

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This article has been fully handled by one of the Associate Editors, who has made the decision for acceptance.

of the rehabilitation programme (10). Positive expectations of treatment outcomes are important predictors for recovery from illness in rehabilitation (11, 12).

In a study about expectations in patients with low-back pain, the results showed that it is important through dialogue to help the patients to adjust their expectations. It is also important that rehabilitation professionals promote the patients in their self-management activities in daily life (13). Interaction and communication processes have been an area of increased research in recent years (14–16).

To improve rehabilitation of tortured refugees more knowledge is needed regarding expectations of treatments and rehabilitation programmes offered. To our knowledge this has not been studied. Thus, the aim of this study was to explore tortured refugees' expectations of the multidisciplinary pain rehabilitation programme offered at a specialized rehabilitation centre for torture victims.

## METHODS

### Recruitment

The participants recruited were tortured refugees from the Middle East, who had asylum and lived in Denmark. They were referred to our centre from their general practitioner, because of their long-term sequelae from various types of torture that they had been subjected to several years earlier in their homeland.

A multidisciplinary approach is the key to the rehabilitation of torture victims. Here the patients are screened by a multidisciplinary assessment team composed of a physiotherapist, a physician, a psychologist and a social worker supported by an interpreter. The centre's admission criteria are: (i) torture victim with asylum in Denmark; (ii) physical, psychological and social needs; (iii) no overt psychosis; (iv) no drug or alcohol abuse; and (v) available treatment capacity. If the patient was judged eligible after the team assessments, they were offered either individual or group rehabilitation. The overall rehabilitation goals are to reduce the severity of the pain condition; to teach and train effective stress management tools; to restore overall movement and health; and to encourage cooperation in group activities, e.g. to provide encouragement and support self-help.

### Informants

The 15 participants had a mean age of 47 years; 13 were originally from Iraq and 2 were from Lebanon. They had been living in Denmark for between 8 and 30 years (Table I). Their background education/work varied widely, and was largely within professional and academic areas (accountant, teacher, university student, lawyer, engineer), and service (taxi driver, truck driver, hairdresser, greengrocer, and one had been a soldier). The 3 patients who were working, all part-time, worked as a teacher, a hairdresser and a greengrocer. Of the remaining 12 patients, 1 was retired, 3 were on sick-leave, and 8 were receiving social welfare.

Data retrieved from the medical records showed that 13 of the patients had been diagnosed with the mental diagnosis PTSD, and many with anxiety and depression (Table I). All but 1 had chronic pain (mean pain duration 21 years), and, in addition, one or more physical diagnoses; for example, diabetes, heart disease, hypertension, respiratory disease, osteoarthritis and/or abdominal pains. The most common medications were analgesics (paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs)) and antidepressants.

Pre-interview assessment outcomes (mean, median and range) are presented in Table I. At the time of the assessments 14 of the informants reported a mean pain intensity of 60 mm on the visual analogue scale (VAS 0–100 mm (17)). Eleven informants had severe pain (VAS, 50–100 mm) and only 3 informants had a pain intensity below 49 mm, displaying the symptom severity in most of them. According

Table I. Demographic data and pre-interview assessment outcomes

	<i>n</i>
Country of origin, <i>n</i>	
Iraq	13
Lebanon	2
Living with an adult, <i>n</i>	10
Living alone, <i>n</i>	5
Working, <i>n</i>	3
Non-working, <i>n</i>	12
Pension	1
Social well-fare	8
Sick-leave	3
Sleep disorders, <i>n</i>	15
Years living in Denmark, mean (median) [range]	17 (19) [8–30]
Pain duration, years, mean (median) [range]	21 (20) [11–29]
Mean pain intensity (VAS; 0–100 mm), mean (median) [range]	60 (65) [24–85]
Disability Rating Index (sum score of 12 items; 0–100 mm VAS), mean (median) [range]	55 (54) [4–85]
HADS (max score 21), mean (median) [range]	
Anxiety	18 (19) [14–21]
Depression	15 (15) [9–21]
General Self-Efficacy Scale (sum score; range 10–40; Arabic version), mean (median) [range], IQR	18 (16) [10–28], 7

VAS: visual analogue score; HADS: Hospital Anxiety and Depression Scale; IQR: interquartile range.

to the Disability Rating Index (DRI) (18) a decreased level of daily activity functioning was reported (mean 55 mm;  $n=13$ ), indicating perceived disability. Seven of the informants reported a DRI sum score between 50 and 85. The mean of the 10 Hospital Anxiety and Depression Scale (HADS) (19) scores, possible to retrieve, was high for both anxiety and depression. Scores in the range 15–21 indicate severe anxiety and/or depression. Eight of these 10 had high HADS anxiety scores (scores 18–21) and 5 had high depression scores, but somewhat less prominent (scores 15–21) at the time of assessment. At the time of the interview they also completed the Arabic version of the General Self-Efficacy Scale (21) and the median score was 16 and the interquartile range 7 (Table I).

### Qualitative interviews

An interview study with a qualitative approach was performed to cover the informants' subjective expectations of the rehabilitation programme offered. Data collection was performed individually according to a semi-structured interview guide (Table II).

Table II. Interview guide

What are your expectations concerning your rehabilitation programme?
Please tell me about them. Describe your expectations of the rehabilitation programme you have been offered.
What do you expect from the programme regarding the medical treatment, physical treatment, psychological treatment, and social counselling? Is there anything more you want to tell? What is most important?
You will need to set off time for the programme. How do you plan to handle this and the time scheduling?
Which factors in your life situation will influence your participation in the programme?
What do you think about your own possibilities of influencing the treatment programme?
Are there situations that you would rather not participate in?
What do you think is expected of you?
Do you expect that you have to contribute with anything to the programme?
What would you like to contribute with?
Do you think that these expectations can influence your treatment?

*Procedure*

All 25 Arabic-speaking men on the waiting list for rehabilitation at our centre at the time of the study were invited to participate. The interviewer, an Arabic-speaking psychologist (who was not involved in the research), informed the patients about the study at individual meetings. Ten of the men did not want to participate. The study was part of the clinics quality assurance, and the World Medical Association Declaration of Helsinki ethical principles for medical research (22) was applied. Verbal and written informed consent was obtained from all participants before the interviews. The patients were interviewed in their native language after the screening by the multidisciplinary team. The interviews were based on voluntary participation, took place at the centre, and lasted 30–90 min. The interviews were taped in Arabic, thereafter translated and transcribed into Danish by the bilingual interviewer.

*Analyses of data*

The interviews were analysed using qualitative content analysis (23, 24). The unit of analysis was the text transcribed from the interviews. Content analysis was performed in the following steps. First, the interviews were read separately by the two researchers to gain an understanding of the whole content. An inductive approach was taken in the analysis. Thereafter, meaning units, i.e. all citations answering the research aim were identified. The meaning units were condensed, abstracted and labelled with codes in consensus by the two researchers. The codes were compared and sorted into categories (see example Table III). The analysis moved back and forth until agreement was reached. Citations to illuminate the categories were selected. Co-operation between the two researchers was assumed to increase the credibility of the analysis.

RESULTS

One theme, different expectations of the multidisciplinary pain rehabilitation programme, emerged, together with 4 categories: general expectations of the rehabilitation programme; specific expectations of the professional treatment; expectations of mutual participation; and communication and expected rehabilitation outcomes.

*General expectations of the rehabilitation programme*

The expectations of the rehabilitation programme were mostly positive and expressed in terms of trust and/or hope in the professionals as rehabilitation experts.

*“Here at this centre all professionals are gathered: physician, psychologist, social worker. If you have a problem it is easy to solve the problem because everything is there. As long as all specialists are here there is a possibility to help.”* (informat (inf) 5).

*“If I believe that something will help me, I will accept it... something that gives me peace.”* (inf 13).

*“I don’t have physical problems...only psychological. I expect them to give me treatment.”* (inf 14).

Other general expectations were to learn new things about themselves, to receive and accept advice, to find solutions to problems and to learn how to cope with them. Some expected that the professionals would share their knowledge with them and follow-up treatment effects. Not all informants had any expectations.

*“Do the professionals expect anything from me? I am the one that has expectations on them.”* (inf 10).

*“They cannot expect anything from me... I have nothing to offer...my will has been taken away from me.”* (inf 9).

The informants expected themselves to become aware of their personal characteristics and to accept and/or question offered treatments and suggestions.

*“To be honest, to be open, and to practice given advice... to keep appointments and to be on time.”* (inf 15).

On the other hand, they expected the professionals to take responsibility to improve their health conditions.

*Specific expectations of professional treatment*

Physiotherapeutic, medical, and psychological treatments, as well as social counselling, were expected. The physiotherapeutic treatments expected were pain treatment, massage, hydrotherapy and physical exercise to improve their physical condition.

*“Firstly I expect, to get rid of chronic pain, and if this is not possible, to learn to live with the least possible pain.”* (inf 6).

Advice and supervision; for example, ergonomic advice, was also asked for.

*“The physiotherapist will teach exercises and give ergonomic advice on how to sit and how to reduce physical strain when lifting.”* (inf 15).

Concerning medical treatments the informants expressed expectations of a thorough clinical examination, a correct diagnosis, and to understand their condition through dialogue with the physician.

*“It is important to be clinically examined by a doctor.”* (inf 15).

*“I want to understand the cause of my condition through dialogue with the doctor.”* (inf 13).

They wanted to get advice about anxiety, depression, pain and sleep and also to be prescribed, adjust or get rid of medication.

*“I want to get rid of sleep medication because it influences my head and my thinking the following day.”* (inf 5).

Most informants expressed positive expectations and trust in psychological treatment. They wanted to have consultations with the psychologist through dialogue and help to change their thought patterns, get rid of flashbacks, get proper advice and

Table III. A practical example of the categorization process

Meaning unit (citation)	Condensed meaning unit	Code	Category
<i>“As far as there are specialists here at this centre, there is the possibility to help us patients. The physiotherapist alone cannot help, neither can the psychologist...”</i>	The centre’s professional staff together provide opportunities for helping	Multidisciplinary help	Expectations about the multidisciplinary team treatment

guidance, reduce anxiety and learn how to cope with complex situations and to reach psychological insight.

*"About flashbacks... I don't think that you can forget your past... but I would like that the impact of these terrible pictures disappear."* (inf 11).

*"I expect psychological advice to cope with complex situations, depression and negative thoughts."* (inf 5).

*"If you have a problem that you are not aware of, the psychologist will help you to become conscious of it."* (inf 3).

*"I expect a treatment that will help me with my depression."* (inf 7).

Expectations of social interventions, such as assistance with private economy and personal needs, help with family matters and help in participating in social life outside the home, were also mentioned.

*"Help from social worker to be active outside home."* (inf 1).

Economic expectancies included assistance with household costs, costs for medication and other treatments and practical help with private economy.

*"I expect economic advice and assistance to my family and I also hope that the social worker is merciful and helps me to come out of this situation."* (inf 8).

Expectations of help with family matters included explanation of social laws and family rights and, for example, help in finding an apartment.

*"Explain social laws and rights, things that I do not know about... my rights and obligations."* (inf 6).

#### *Expectations of mutual participation and communication*

Mutual participation and communication between patients and therapists were expected. It was expected to actively participate in the rehabilitation programme, to share experiences, and to contribute by listening and expressing thoughts. The informants wanted to decide by themselves when and how to participate.

*"I can participate by telling about what I have gone through and been exposed to."* (inf 2).

*"In a specific situation I will decide if I want to participate or not."* (inf 11).

*"I am a good listener. I can express my thoughts in words, and contribute by collaborating as well as with respect if I have trust in the rehabilitation group."* (inf 12).

Some informants could not participate in group treatment because of their psychological condition.

*"I expect professional confidentiality... if someone will use violence, verbally or physically, I will leave."* (inf 3).

*"I find it difficult to listen to others talking about torture. I try to avoid it, and I also avoid talking about politics or fanaticism."* (inf 4).

#### *Expected rehabilitation outcomes*

Rehabilitation outcomes expected were improved physical and psychological health; for example, to recover, to achieve mental peace, to decrease pain, to improve sleep and to obtain

help to open up psychologically to be able to live a normal daily life. The informants also expressed that they wanted to get rid of tiring thoughts and break their isolation, to get rid of nightmares and thoughts that upset them.

*"I wish I could go on with my life and leave behind the things that are impairing me."* (inf 5).

*"I wish help to come out of my isolation. I have no one to talk to. I am all alone, also with my thoughts. I wish for a better life, psychological peace, and to live a normal life, like other people."* (inf 2).

*"I expect to recover... I want to get better."* (inf 10).

*"To come out of my vicious circle and be like in former days."* (inf 8).

Some informants expected to improve their coping ability to be able to cope with problems in daily life; for example, aggressive behaviour and how to handle stress and personal crisis.

*"I want advice about how to cope with situations in my family life. If I understand a problem it is possible to solve it."* (inf 3).

*"I want to learn to cope with my daily life. There are some obstacles in my life and I have come here to reduce them."* (inf 4).

*"I expect to get some information that will help me to see if I can manage or not. For example examine if I am able to work or not."* (inf 15).

*"I would like to have tools to overcome my psychological crisis or to learn to live with them."* (inf 12).

A few informants could not contribute with any expectations or ideas about outcomes.

## DISCUSSION

The theme different expectations of the multidisciplinary pain rehabilitation programme covered both the content and the outcomes of the programme. The tortured refugees had general expectations of the rehabilitation content as well as specific expectations of the professionals' treatment regarding medical, physiotherapeutic, psychological and social interventions. They also expected mutual participation and communication between patients and therapists and had expectations of active participation. Positive rehabilitation outcomes, such as decreased pain and improved health and coping ability, were also expected.

#### *General expectations of the rehabilitation programme*

The positive general expectations of trust and hope in the rehabilitation professionals are promising news, as tortured refugees' expectations of multiprofessional rehabilitation have not been studied previously. Research from other areas of healthcare confirm that being trustful, emphatic, open, and having an ability to listen are important for good interaction in rehabilitation in general (13, 16). Professional competence and support, language factors, framing and time scheduling are important prerequisites for good interaction with traumatized patients. Furthermore, for good interaction it is important to

consider cultural factors, to tailor the treatment according to the patient's needs and to have the capacity to handle negative emotions (16).

In addition, the tortured refugees expected to learn new things about themselves and how to cope with problems, and to accept and/or question the treatments offered. It is interesting that the refugees so clearly expressed what they thought they were able to contribute, such as practice the given advice, keep appointments and take part in the rehabilitation. To learn new things from the professionals and to learn how to cope with problems were also expected. It has been confirmed previously that it is important to share knowledge with the patients (14, 15). Other important issues to consider in the communication with traumatized patients are language factors, framing and time scheduling (16). These aspects need further study.

The informants expected, not only to accept, but also to question, the professionals' suggestions, to practice given advice, to keep planned meetings, and to take part in the rehabilitation. Regarding the professionals, they expected them to take responsibility to improve the patients' health. Interestingly, the tortured refugees had the opinion that the professionals would develop their competence by communicating with them. This new knowledge can be used to develop the centres' overall rehabilitation approach.

#### *Specific expectations of professional treatment*

Some of the tortured refugees expected different treatments from the respective team professionals, e.g. the physiotherapist, the physician, the psychologist and the social worker.

Regarding physiotherapy, a need for active and passive treatments and personal advice was experienced. Research from a professional perspective supports that various physiotherapeutic treatments, tailored to the patient's needs, are important and should be included in the rehabilitation of this patient group (16). Specific patient expectations of physiotherapy treatment for this group have not, to our knowledge, been published before.

Regarding the informants medical treatment, a thorough clinical examination and a dialogue with the physician, including advice about their medical condition and medication, were expected. These findings deepen the knowledge about medical treatment expectations within this area (25). Pain relief, and to be able to control pain, were also important expected treatment outcomes. Recently published research in a group of traumatized migrants reported not only positive, but also negative, expectations about medical treatment (26).

The informants expressed positive expectations and trust that the psychological treatment could result in changing their patterns of thinking, getting rid of flashbacks, reducing anxiety, and learning how to cope with complex situations. Illness among traumatized migrants can be characterized as a multifactorial and psychosocial process with corresponding expectations about treatment (26). Consequently, the rehabilitation should be both multifactorial and psychosocial. Our findings clarify patient expectations of the psychosocial rehabilitation

content. Maier & Straub (26) found that traumatized migrants hoped to receive help and reduce suffering, but that they also may express passivity and resignation.

Regarding social interventions, the informants expected among other things assistance with private economy and personal needs, help with family matters and help to increase their participation in social life outside home. Clinical experience indicates that social aspects are important to consider early in the rehabilitation process. Social aspects also influence participation in rehabilitation and this has, only to some extent, been published recently (27–30). Such research is warranted.

#### *Expectations about mutual participation and communication*

Mutual and active participation and communication between patient and therapist were expected during the upcoming rehabilitation. It is promising that the informants were willing to share their experiences, and that they wanted to decide independently how and when to participate. It is also interesting that they considered that their participation could contribute to a competence development for the professionals. We consider it always important to meet the patient where she/he is and to respond to emerging issues of mutual interest, hence sharing our knowledge, which is also supported by research (14, 15). Due to their mental state some tortured refugees expressed inability to participate in group treatment sessions; for example, by a risk of being provoked into aggressive behaviour. It is internationally agreed that the participation level is influenced by both personal and environmental factors, for example psychological and emotional factors (31). However, deeper knowledge on how to obtain optimal participation for traumatized patients is needed.

#### *Expected rehabilitation outcomes*

The men in our study had, to a great extent, expectations about a thorough clinical examination and wanted a correct diagnosis. An earlier study has shown that, compared with women, men with chronic musculoskeletal pain were more likely to expect that the cause of their pain would be found (32).

Eleven patients reported a high level of pain intensity displaying the symptom severity in most of them. Concerning the HADS scores (20) at the time of assessment more patients had higher anxiety than depression scores, perhaps due to the fact that this is a traumatized patient group, and that the reported use of antidepressants had positive effects. Regarding perceived function, the mean DRI sum score was 55, indicating extensive limitations to daily activities. Seven of the informants reported a sum score between 50 and 85, whereas in a group of patients with chronic low-back pain, the mean DRI sum score was 48–49 mm (19). The severity of patients' disability and psychological state has influence on the shaping of expectations (25). In addition, these patients are vulnerable and severely traumatized, often living with a high level of stress, which may originate from negative memories and/or emotions, such as anger, fear and anxiety. During the rehabilitation process it is important to address this and to let

the patient express all kinds of emotions (33). Our informants had expectations to achieve mental peace and improve sleep, and through psychological treatment regain health in order to live a normal everyday life. Some wanted to learn how to handle stress and personal crisis and how to cope with stressful situations, results that are clearly formulated outcomes.

Earlier research about expectations about rehabilitation outcomes have been formulated in more general terms without specifying such clear goals (26). In the goal-setting rehabilitation planning at our rehabilitation centre we commonly balance patients' expectations with their reality. Our centre has a client-centred perspective whereby we try to fulfil each patient's expectations, and it seems that at least some of the informants have taken in the information given at the time of the assessments, possibly indicating that the rehabilitation process had already started at that time. The results of this study could thus be used to develop an overall rehabilitation approach towards tortured and traumatized patients.

#### *Methodological considerations*

All our patients were men from Arabic-speaking countries in the Middle East. The reason we chose men for this study was that approximately 80% of the patients referred to our centre are males with heterogeneous educational and socio-economic backgrounds. They were interviewed by a psychologist in their native language, and this person also translated and transcribed the interviews into Danish, a methodological advantage. Thereby an interpreter did not have to be present, thus avoiding the risk of misunderstandings when communicating through a third person. This interview situation may have increased the informants' confidence during the interview and consequently also increased the trustworthiness of the results.

The fact that the analysis was based on continuous discussion between the authors throughout the process may have increased the trustworthiness of the analysis. At the planning stage of this study, the questions in the interview guide were discussed between the researchers until consensus was reached, which may have increased the reasonableness of the questions. The semi-structured interview gave the informants the opportunity to describe their expectations freely, and additional questions could be asked.

Both authors analysed the interviews in cooperation, performed the categorization together, and obtained consensus, according to Graneheim & Lundman (23). They also translated the citations into English together, before performing the categorization. The analysis was based on continuous discussions between the researchers. In addition, the researchers had a physiotherapeutic and a psychological rehabilitation perspective, respectively. All these factors may have increased the credibility of the content analysis. All participants came from the Middle East, but they had different backgrounds and life experiences, which also may strengthen the credibility of our study. Concerning transferability, we consider our results relevant and applicable for rehabilitation professionals when planning treatments for tortured refugees. In this explorative study our aim was to cover all possible expectations. Therefore we used an interview

guide with open questions about expectations as well as questions about the multi-disciplinary rehabilitation.

In conclusion, the tortured refugees had different, mostly positive, expectations of the multidisciplinary pain rehabilitation programme. General expectations of the rehabilitation content, as well as specific expectations of the professionals' treatment, were expressed. Mutual and active participation and communication between patients and therapists were important expectations. In addition, positive rehabilitation outcomes, such as improved health, improved coping ability and decreased pain, were expected.

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