PRISM-Manual ©

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1 Introduction

"It is the aim of medicine to heal and – where this is no longer possible – to relieve suffering." (Cassel 1982)

In future medicine will be involved with the dimension of suffering even more than before: The morbidity structure of the developing industrial society is changing while chronical diseases are noticeably on the increase at the same time. Since the early sixties epidemicological statistics have shown that previously prevailing infectious diseases have lost significance and that chronic diseases of the cardiovascular and musculoskeletal system, as well as cancer and mental health problems, have taken their place as most frequent impairment to health. The prevalence and incidence of chronic diseases will also further increase in future. This is contributed to by the demographic development, with a growing number of old people leading to an increase of chronic degenerative diseases. The progress of acute medicine paradoxically also leads to an increase of chronic disabilities: Although survival is made possible, this is often at the cost of permanent disabilities. Living with chronic diseases and functional limitations, or psychosocial handicaps connected therewith, has long become health problem no. 1 in industrial society (Gerdes & Weis 2000).

If healing is, however, not possible for an ever increasing number of patients, the subject of suffering i.e. the therapy of suffering have to play an important role in medicine.

Suffering is a central human experience, which medicine has intensively occupied itself with since Descartes. Since a split into a body-orientated medicine and a spirit-orientated religion took place in the 16th century, science has turned its back on this subject. It is only in the last 20 years that a paradigm shift has taken place, in that the individual has increasingly moved into focus. In this context quality of life has become a central subject of medicine. At the same time this has caused a reassessment of the subjective experience of the patient. His individuality was approached by taking his day- to-day life and the adverse effects of his disease into consideration. Suffering is connected to a person's experience of his physical-psychological-spiritual entity. Focussing on causes and treatment of suffering therefore contributes to overcoming the body-spirit split in medicine.

The present script deals with the question concerning detection and therapy of suffering in the case of physical diseases. With PRISM we have developed an instrument that offers insight into the adverse effects experienced by the patient. PRISM is an extraordinary instrument: It comprises visual and tactile characteristics and makes the pictorial

representation of subjective, cognitive and emotional experiences possible. In addition language is used to better understand the self-image portrayed by the patient. Here it is not a word that comes first, but an image.

Images are symbolic portrayals. They can express experiences, which are difficult to only communicate by language. In this sense PRISM confirms an old proverb: "A picture is worth a thousand words."

2 Basic Principles

2.1 Ethical background

The dignity of a human being is inviolable and undetachable. This means, that every human being is indisposible and may not be instrumentalized by anyone for any purpose. Every human being has a self purpose at heart and is not a means to an end. In the knowledge of our biological and biographical conditionality and self-construction we act on the assumption of an **ultimately unfathomable mystery that intrinsically constitutes a human being** – **his self**. PRISM represents this self with an unchangeable yellow circle. This is introduced to the patient as "you yourself in your life".

Birth and death are border points of human existence. The individual development is based on **relationship** ("The human being emerges as an I in the interaction with a you" (after Buber 1983). It takes place as a process, which also **encompasses conflicts**; conflicts that accompany the loss of something previously present and the potential of something new. **The human being is a being, that is continuously born anew** (Hannah Arendt).

The human being is born as a self-organized system with the capacity of renewal and transcendence. Healing can be understood as an example of renewal of parts with the overall structure remaining intact at the same time. This system complexity is commensurate with a **systemic circular process thinking** rather than a causal linear approach.

2.2 Therapy Concept

As basis for a relationship between therapist and client we refer to the discourse and communication ethics respectively. These assume an ideal communication situation in which all participants in the discourse have the same rights and obligations. What finds general consensus in the mutual deliberation of sensible people, who are open to discussion, is considered as ethically binding. Instead of existing norms or virtues serving as points of orientation, the process of a rational and consensus-orientated problem-solving is moved into focus.

Basically every therapy is based on cooperative partnership in trying to solve the problem. The client's concrete capacity for **autonomy** must however be reflected and examined thoroughly, as it is the basis of therapeutic collaboration. This appraisal serves as orientation for the way in which PRISM is put into practice: If the capacity for autonomy is impaired, the

therapist has a supporting "auxilliary-I" function. In this specific case the appraisal is communicated to the client in a transparent way.

The **search for meaning** is a human need, finding a meaning is a self-healing power (Frankl 1981). Therapeutic work therefore has to get involved with the why-question and the search for meaning, especially in a value-pluralistic society. However it is essential that the therapist deals respectfully with culturally and individually shaped values or value differences, this being an indispensable prerequisite of an ethical capacity for judgement. The Swiss philosopher Hans Saner calls it "**tolerance of differences**" (Saner 2002). We are convinced that it forms the basis for carefully dealing with our clients' **value systems** and therefore regard the continual reflection of our own attitudes and values as indispensable.

PRISM a tertium is added. The person is a subject having a unique biography, physical prerequisites, dispositions, qualities and values. PRISM offers a playing surface, on which the client grasps his problem in a tactile-visual way, externalizes it and places it in relation to the self at the same time. The therapist guides the exploration process with cues, asking socratic questions about the meaning of the illustration. While the therapeutic relationship plays a role as stable basis for the client to deal with his reality, it is, however, not regarded as therapy content as such. Since the individually defined meaning of a problem moulds the suffering, the relationship of the person to the problem, but not the problem itself, is in the focus of a PRISM-based therapy.

2.3 Suffering and growth

With reference to Eriksson (Eriksson 1966) we understand the development of human identity as a phase-like process within an arc of life. To express it schematically simplified, the task of a human being in his first half of life consists of developing an "I-strength" in terms of an individuality, which distinguishes itself from a you. In the second half of life the individual faces the task of "watering down" or relinquishing the previously created self-concepts. Particularly in view of dying and death the relinquishing of previously developed concepts is an inevitable process. Suffering arises at that point in the life cycle, where relinquishment has been rejected and an attempt is made to maintain the old self-image under all circumstances. According to Kleinmann the cause for suffering as a result of life cycle changes lies in the inner resistance against the flow of life (Kleinmann 1989).

For roughly 10 years empirical research has dealt with **posttraumatic growth** (Tedeschi & Calhoun 1996). Traumatic experiences are defined as those experiences which endanger

the physical or psychological integrity of a person. The dimension of growth is not uniformly defined, but usually the following central aspects are considered:

- Setting new life priorities
- Stronger relatedness to other persons
- Intensified contact with the living
- New self-assuredness in the sense of knowing that much can be overcome

Growth therefore encompasses a dimension of being reconnected with life. A prerequisite for this is the previously described ability to also discover positive aspects in a traumatic loss, an expression of successfully finding meaning.

The results of empirical studies partially showed surprising findings that are briefly summarized here:

- The stronger the trauma the more pronounced the growth
- Women, who usually show more pronounced symptoms of a posttraumatic stress disorder usually have significantly higher growth-values than men.
- Growth appears as dimension that is surprisingly independent of personality factors (e.g. the salutogenetic sense for coherence), but also of mental symptoms (e.g. depression and fear)

In an own study we examined 54 parents 3-6 years after the death of their premature infants. It was shown that the grief over the lost child was the specific suffering of these parents. Parents that were still strongly grieving, were mentally in a worse condition, but also simultaneously declared to have matured.

Empirical studies therefore indicate, that even **very painful traumatic injuries can be beneficial.** One of the most well known researchers in the area of posttraumatic stress disorders, Prof. Berthold Gersons from Amsterdam, coined a phrase which summarizes his experiences with traumatized people: **"sadder, but wiser"**

What does the aspect of growth through suffering mean for the therapeutic contact with suffering people? The relief of suffering is the noblest and most important task of therapeutic action. A pre-condition for beneficially dealing with suffering is to accept it as conditio humanis. Knowing about the growth processes, which can be initiated through suffering, it is of central importance to keep this in mind.

2.4 Narrative based medicine

Man differentiates himself from other living creatures by the **significance of language**. He has the capabilty to create himself through the linguistic construction of his narratives. The **processes of falling ill, being ill, regaining health and coping with the disease can** also **be understood as individual narratives**. In the medical context of a hospital or a doctor's practice there is not much room for such narratives. An analysis of communication in the medical context shows that a medical requirement for definition, which tries to classify disease according to a diagnostic context, usually prevails – the **case history becomes a medical record**. The results thereof are obvious: The medical system has power over the medical record, the patient risks losing his autonomy to act.

The *narrative based medicine (NBM)* (Greehalgh & Hurwit 2004) gives a central meaning to the individual experience of *being* ill and therewith sets a contrast to the scientific-epidemiologically oriented *evidence based medicine* (Sackett 1997) according to Anton Tschechov:

"With the methods of science you can find out what is generally true about human beings. But it is the art of narratives that captures the unique truth"

NBM sees the narratives of disease as a phenomenological form, in which patients experience their being ill. The narratives are regarded as foundation for understanding the problems of the patient in the context of his values and life. They include existential qualities such as hopelessness, loneliness, abandonment, guilt or shame that often accompany diseases or are even the core of actually being ill. Suffering, in the context of threatened integrity of a person, can only be understood from the perspective of the patient, never, however, in the category system of the medical record. Similarly the dimension of the individual meaning of a situation can only be comprehended from an individual perspective, never in a predetermined system of diagnosis. Patient narratives are very personal narratives that are only told by the persons concerned under certain favourable conditions (a trusted person, enough time, favourable spatial conditions). The narrative is rarely known in the medical system for these reasons in particular.

The medical sociologist Arthur Frank (Frank 1995) describes three different forms of patient narratives that he distinguishes between according to content and form of experience:

1. Restitution narrative

The content of the narrative is simple: The **narrator was ill and recovered completely**. The more dramatic the conquered disease, the more powerful the narrative. Often medicine plays

a central role through drugs and surgical operation. It is the narrative that is understood and loved by medics and that forms the central myth of hospital medicine and medical training. An example is the biography of cycling star Lance Armstrong, in which his victory over testicular cancer up to his victory in the Tour de France is described.

2. Chaos narrative

The patient experiences more than he can cope with through the disease. He is in a state of being ill and not of having an illness. This condition is accompanied by a speechlessness and lack of communication of the concerned person. This experience is suffered in extreme pain but also in a state of shock., e.g. after hearing a carcinoma diagnosis. The medical system often deals with such situations in a helpless and surprisingly uncritical way.

3. Quest narrative

Chronic and incurable diseases, but also disorders with an unpredictable progression lastingly change the self-image and the life-perspectives of the person concerned This constellation challenges the individual to adapt his life-concept and self-image. The question of meaning emerges as a central issue. Empirical research has shown that this question comprises two mutually independent dimensions: The capacity to understand the loss of health in a greater context on the one hand and to define the new situation as opportunity for something new on the other hand.

Although chronic illnesses and disorders are on the increase because of sociodemographical as well as medicaltechnological developments, the medical system has shown little interest in this question up to now.

PRISM offers itself as appropriate auxilliary tool for a narrative based medicine. It focusses on the person, not the disease, and makes it possible (through PRISM+) to construct changes in the progression of the disease as personal history.

Experience with PRISM in hospitals and by general practitioners indicates that PRISM makes it possible to address the individual experience of the disease, even in cases of limited time ressources, which are otherwise insufficient for recording patient narratives. PRISM is particularly suitable for quest narratives, but also for chaos narratives, i.e. especially for those narrative types, for which the medical system often proves to be incompetent.

3 PRISM- Development and Validation

3.1 Health related quality of life

3.1.1 Historical development

The expression "quality of life" was first used primarily in **politics**; in the American constitution it was defined as indispensable component of a free democratic constitution under the slogan "pursuit of happiness". In the German language area the introduction of the term is ascribed to Willi Brandt, who, in a speech held in 1967, spoke about the citizens' quality of life as fundamental goal of a social state (Glatzer & Zapf 1994).

In the **literature of social sciences** the term "quality of life" had already played an important role in the forties and fifties. In the sixties, first large-scale cross-culturally applied studies were undertaken to investigate the quality of life in different countries. Quality of life was here primarily defined via socio-economic resources and the public health care and was measured e.g. by means of the gross national product or the neonatal mortality rate (Bullinger et al. 2000).

The term "quality of life" was introduced into medicine at a relatively late stage, even though the WHO had already defined health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity in 1947 (Constitution of the World Health Organisation 1952). This definition meant turning away from a focus on somatic aspects of health and disease to a comprehensive bio-psycho-social model of health and disease, which also included mental and social dimensions. A new subject, intensively to be discussed in a medical context only 20 years later, however, was addressed herewith: The question concerning the aim of medical treatment as well as the criteria for the assessment of treatment results. The backdrop for this was formed by developments in health care policies: The proportion of the elderly, potentially chronically ill population needing long-term treatment, increased. At the same time fiscal decisions forced health care systems worldwide to critically assess medical care and its quality criteria (Bullinger 1997).

In the last years a paradigm shift has taken place: Not only the change of clinical symptoms or the prolongation of life alone, but the question as to how ill people experience their state of health, is gaining significance as evaluation criterion of therapy (Anderson et al. 1993).

The measurement of quality of life was first introduced to medicine in the area of oncology (Katz 1987). The benefit of life-prolonging measures in relation to a reduced quality of life through side effects of the therapy was discussed in particular. Later, therapy goal criteria, which focus more on the subjectively experienced state of health of the patient, were also stipulated in other disciplines. These were recorded with so-called health-related quality of life instruments. Furthermore, the concept of quality of life also gained significance in the areas of health economy and public health research (Bullinger et al. 2000).

3.1.2 Definitions and Concepts

It is hardly possible to clearly define quality of life linguistically. Therefore there is also no satisfying "nominal" definition of quality of life or health-related quality of life, (Bullinger 2000). Up to now, research attempts pertaining to quality of life have mainly concentrated on "operationally" defining the complex content by taking the determining parts of the phenomenon and their correlation into consideration. In the meantime, an international consensus exists in terms of the operational definition that physical, mental and social dimensions of health must be taken into account when recording the construct of "health-related quality of life". An attempt at defining health-related quality of life in the **operational model** could possibly be "the subjective and objective well-being with unrestricted potential for mental, physical and social activity" (BSV 2000).

This operational definition is contrasted by socio-scientific and philosophical considerations, which deal with an individual evaluation and experience of quality of life. They include social comparison processes and value system theories, but also take considerations pertaining to the utility theory into account.

Representatives of an **individualized definition of quality of life** name the following points of reference as determinants (Carr & Higginson 2001):

- Extent of conformity between wishes or expectations and the experienced reality
- Individual perception of the personal circumstances in the context of culture and value system of the person concerned as well as his aims, expectations, measures of value and fears
- Comparison of the current condition with an ideal condition
- Things that people consider to be important

A general consensus exists that the evaluation of quality of life should be done by the affected person himself whenever possible. In the research concerning quality of life, self-evaluation of the affected person is therefore preferred to the evaluation done by others, such as the physician (Bullinger et al. 2000).

Based on these different theoretical basic assumptions, three models, which are used for quality of life research, can be differentiated (Bullinger 1997):

A.Operational Model

<u>General</u>: the operational model is by far the most significant for clinical research. Most results and findings pertaining to QOL refer to the operational model. Until recently, research referred to "quality of life" mainly in the context of health so that "quality of life" and "health related quality of life" are often used synonymously.

Theoretical basis: The assumption that quality of life is describable supra-individually by a limited number of dimensions forms the basis of the operational model. With respect to the area of health, many authors and research groups agree that physical, mental as well as social aspects have to be taken into account. In part, the physical functionality is explicitly incorporated as additional fourth dimension. Internationally there are a number of medically comprehensive measuring instruments, which have been translated into different languages, tested psychometrically in the respective languages and can be used in clinical studies. In the last years, WHO, in particular, endeavoured to more comprehensively operationalize quality of life.

In addition to the above-named areas, the current concepts also take economic and spiritual dimensions into account (WHOQOL Group 1994).

Measuring instruments: On the basis of operationalization, different questionnaire instruments were developed to record health-related quality of life. The most important medically comprehensive instruments (e.g. the *SF-36* (Ware & Sherbourne 1992), the *Nottingham Health Scale* (Hunt et al. 1980) or the *Sicknesss Impact Profile* (Bergner et al. 1981) are based on the already mentioned 3- and 4-dimensionality. The more comprehensive *WHOQOL-100*, which is not limited to physical health and which was developed by the WHO (WHOQOL Group 1994), takes 6 dimensions into account. Range of use: Clinical and epidemiological studies

B. Individualized Model

General: It was rightly argued that the conventional quality of life instruments, derived from the operational model, reflect the individual perspective of the concerned person only incompletely and in individual cases, highly varying relevance assessments of health problems must be taken into account. As alternative to the dominant instruments with fixed specifications for the problem areas to be assessed, other methods were therefore suggested. These all have in common that they attempt measuring health relevant impairments on an "individualized" basis by allowing an individual assessment of the

impaired areas of life as well as a weighting of the mentioned dimensions (Böhmer & Kohlmann 2000).

Theoretical Basis: Quality of life is understood to be an individual factor, which does not allow for a comparison between different persons, as, per definition, it varies from person to person in its dimensions. Representatives of this approach assume that quality of life can only be described intra-individually. An abstraction involving several persons is only possible on the basis of a definition of quality of life, which not only records the difference of the targeted individual goals as point of reference but also the way in which their realization was experienced. For quantitative studies, the difference in value between the targeted and actual state of the individual health condition should be recorded according to this definition (Carr et al. 2001).

Measuring instruments: Measuring instruments were developed, which allow the patients to define their problem areas and record changes in these areas themselves. The procedures are based on approaches that have been derived from the Repertory Grid Method developed by G.A.Kelly (Thunedborg et al. 1993) as well as the Goal Attainment Scaling (Kiresuk & Sherman 1969) respectively. The two most well known instruments are:

- <u>SEIQoL</u> [Schedule for Evaluation of Individual Quality of Life (O'Boyle et al. 1992)]: The
 patient selects the most important five areas of his life and assesses his corresponding
 satisfaction. He then assesses the relative importance of the five areas by means of a
 360° sectogram.
- <u>DRP</u> [Disease Repercussion Profile (DRP, (Carr 1996)]: The patient determines his subjective impairment, the resulting personal problems as well as the relevance of these problems for six predetermined areas (physical activity, social activity and contacts, relationships, finances/work, mental well-being, body image, feeling of self-esteem).

Range of use: The SEIQoL was used for clinical research projects with an individual orientation (O'Boyle et al. 1992; Hickey et al. 1996; Smith et al. 2000), the DRP was developed as an instrument for clinical practice, is, however, also partly used for clinical studies (Carr et al. 1996).

C. Utility theory model

<u>General</u>: Approaches of the utility theory model to measure health-related quality of life were developed primarily for health-economic reasons. For this purpose quality of life had to be reduced to one single parameter. This is done by using cost-ultility approaches on the one hand and the assessment of so-called indices (aggregated indices from questionnaires in connection with health-related quality of life) on the other hand.

<u>Theoretical Basis</u>: When using cost-utility approaches¹, it is assumed that quality of life must implicitly be assessed by patient preferences and that it is not accessible by direct questioning. Specific scenarios of states of health or approaches from the games theory are used to assess the respective health results of the affected persons.

Measuring methods:

- <u>Time-Trade-Off</u>: The test persons compare a residual life spent in a restricted state of health with a corresponding time spent in perfect health (Torrance 1976). In this way, a time of 5 years spent in optimal quality of life, for example, is seen to be equivalent to 10 years of residual life with a restricted quality of life due to illness. Put in relation with each other, a value of 0.5 QALYs is obtained for one year of life spent with restricted health.
- <u>Standard Gamble</u>: The test persons have the choice, to remain in a certain state of health on the one hand or to obtain a state of complete health on the other hand, this, however, being connected to a certain risk of not surviving the operation. If the test person now judges the time of restricted life quality to be equal to e.g. a 50% chance of survival with curative measures, this corresponds to a year of 0.5 QALYs.
- Rating Scale, Magnitude Estimate as well as Person-Trade-Off are three other health economic measuring methods, which are, however, rarely used and which will therefore not be elaborated on.
- <u>Utility theory measurements of life quality with QOL-questionnaires</u>: Different one-dimensional, medically-comprehensive quality of life measuring instruments can be used for cost-utility calculations. They enable the development of health indices, which can be utilized for health economic problems. The three most important instruments are the *Quality of Well-Being Scale (QWB)*, *Health Utility Index (HUI)* (Feeny et al. 1995) as well as the *EuroQol (EQ-ED)* (EuroQol Group 1990).
- Range of use: health economic evaluations.

It is here pointed out once again that the operational model is the most relevant in medicine and that it is generally considered to be equivalent to quality of life.

¹ In the cost-utility analysis the patient's quality of life is connected to the generally valid epidemiological value of residual life or residual life expectancy. The most common concept in this context uses QALYs, so-called quality adjusted life years. In this way a one-dimensional index for quality of life is determined. By accounting for years of life, "utility values" or preference assessments of health paths, like e.g. QALYs, are formed, which, after relating them with the corresponding costs, can be used to compare fundamentally different technologies with one another.

Table 1: Summary: Models of research concerning quality of life

	Operational model	Individualized model	Utility theory model
Theoretical approach	heuristic multi- dimensional construct	individual difference target/actual	preferences conclusion w.r.t. QOL
Measuring instruments/ - methods	questionnaires	qualitative methods	Time-trade off Standard Gamble LQ-Index
Range of use	clinical and epidemiological studies	clinical practice	health economy
Advantages	comparability	individual relevance	comparability
Disadvantages	no choice of relevant areas, no subjective weighting	group comparisons not possible	low qualitative validity

3.1.3 Open questions in the research of quality of life

In reference to Higginson and Carr (Higginson & Carr 2001), who list the most relevant open questions of research concerning quality of life, the following three central questions of quality of life research will be discussed in the following paragraph:

1. Do changes of scores for health-related QOL really imply changes of the subjective state of health?

Empirical research in the area of health related QOL has established itself well in the last five to ten years. The scores of HRQOL-instruments are well recognized outcome parameters in clinical research. Implicitly it is assumed that changed scores following a therapy are directly due to the effects of the treatment, as the evaluation criteria of the patient are assumed to be stable.

Own experience with chronically ill or critically ill carcinoma patients in a palliative ward indicate that evaluation processes of patients, concerning their illness or quality of life respectively, can change drastically. For example, a patient, who only a few months before considered his life not worth living without being able to practice his hobbies or travel into foreign countries, can be happy about returning home, to be cared for there by his wife. Similar phenomena are recorded in QOL research under the term "paradox of illness". Time and again, it is shown that patients with a pronounced functional impairment due to illness can have a better subjective quality of life than less ill or healthy persons respectively. Apparently an adaptation process therefore takes place in the physically severely ill, which leads to a changed evaluation of quality of life.

It is only since a few years that QOL research has occupied itself more intensively with the changes of the evaluation process under the keyword of "response shift"(Sprangers & Schwartz 1999). With **response shift** the change of self-evaluation with respect to health is understood, which results from changes in the areas of

- 1. an inner scaling for the evaluation of specific health aspects
- 2. a change of dimensions considered to be relevant for QOL as well as
- 3. a redefinition of the life aspect considered to be central.

It is assumed that changes in illness trigger dynamic processes, which can lead to a response shift and thereby changes in subjective quality of life by individual processes of adaptation. With the term "response shift", it becomes comprehensible that objectively worse conditions can correspond with higher QOL-values. If these dynamic inner-psychological evaluation processes of response shift are taken into account, it becomes evident how difficult it is to interpret values of health related QOL.

In summary it can be said that values of health-related quality of life can only partly be explained by a change in the state of health. For the interpretation of the data the dynamic subjective evaluation processes of response shift must be taken into account.

2. Does the use of common QOL-questionnaire instruments lead to an improved clinical treatment quality?

Currently particularly the standardized QOL instruments, derived from the operationalized model, are being used for clinical studies. Often they are used as outcome parameters in intervention studies, next to other, rather subjective measures of the state of health (Büchi et al. 2000a). At the same time they can also be used as record of the outcome-quality of institutions for health care insurance providers. It is generally accepted that the use of these instruments has no direct effect on the treatment of patients. Individualized QOL instruments are less frequently used and have hardly been tested with respect to their clinical application.

<u>In summary</u> it can be said that quality of life instruments have so far hardly had an effect on the quality of clinical treatment.

3. Do the existing instruments used to record quality of life comply with requirements for an efficient use in the daily clinical routine or must new instruments be developed?

According to Higginson (Higginson & Carr 2001) the use of QOL-instruments should influence the following aspects of clinical practice and thereby improve the process quality of medical care:

• Identification of problems and setting priorities when facing different problems

Problems should be identified more precisely by using QOL instruments. When dealing
with patients with complex, multiple problems (e.g. palliative medicine), the instruments
should allow the setting of priorities for the treatment of the problems.

Improvement of communication

The instruments should help the patient describe his problems and should facilitate the analysis of the problem. Medical care can be adapted better to the requirements of the patient.

• Screening for hidden problems

Certain problems of the patient are often submerged in the normal daily clinical routine. With the help of QOL-instruments, which question a wide range of problems (e.g. also psychological symptoms) in a standardized way, previously undetected problems can be discovered.

• Relief of "shared clinical decision making"

With the help of the instruments, the expectations of the patients with respect to the therapy should be identified. Unrealistic expectations can be clarified in conversations,

thereby positively influencing treatment satisfaction. Goals, which have been jointly developed, make it possible to consistently adapt the therapy according to the needs of the patient.

- Monitoring of changes or therapy effects
- At present, changes during therapy are usually only registered via laboratory values or clinical investigations. The changes perceived by the patient during therapy can be of significance for therapy adherence.

<u>In summary</u> it can be said that the most frequently used instruments to record health related quality of life are used mainly in the area of clinical research as well as increasingly for the institutional evaluation of outcome quality. So far, there is a lack of **QOL-instruments**, which prioritize and improve the process quality of medical and therapeutic services

Health-related quality of life and the disease consequence-model of the WHO In 1980 the WHO reacted to the increasing significance of chronic illness by developing a classification schema (International Classification of Impairments, Disabilities and Handicaps; ICIDH), which must be credited for systematically focussing on the **consequences of** (terminal) illnesses and health impairment – and not only the illness itself - for the first time.

The original model was revised under the title "ICIDH2" (WHO 2000) in the last years. Thereby the previously chosen negative terms were positively redefined. In addition to the basic categories of disability, the so-called environmental and **context factors** were newly introduced, which are subdivided into personal and environmental factors (cp. Fig. 1)

The following three levels of disability or consequences of illness are differentiated:

- **Impairment:** Level of the <u>organs</u> and their physiological and/or psychological structure and function
- Activity: Level of the person and goal-oriented actions
- Participation: Level of social roles

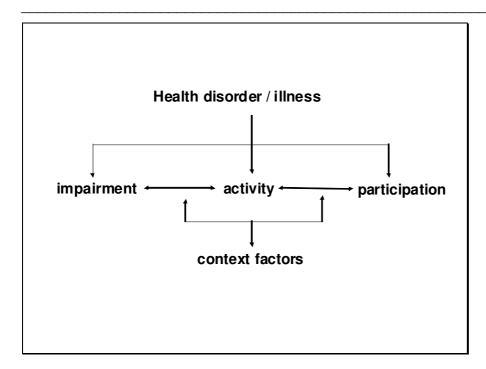


Figure 1: WHO-model of illness consequences (ICIDH-2-diagnostics)

The model met the broad approval of rehabilitation medicine in particular, and there formed the generally accepted theoretical basis for treatment (Gerdes & Weis 2000). That the affected persons manage to largely cope with the demands of daily life and comply with their obligations in family, occupation and society to a large extent in spite of their health impairment and its consequences can be defined as generally valid therapy goal here. The level of participation therefore moves into the focus of diagnostic and therapeutic interest of rehabilitation medicine.

It is not possible to determine participation by conventional diagnostic procedures. Only methods, which determine individual impairment, can be of help. HRQOL-instruments, which primarily record the level of participation and - to a lesser extent - also the level of activity referred to by ICIDH-diagnostics, are applied here.

3.2 PRISM-development

To gain a clinical impression of the subjectively relevant impairments of patients, we conducted explorative interviews with patients, who were suffering from chronic polyarthritis. In the process, a previously hardly noticed dimension of the illness came to the fore: The patients described their **suffering** from the illness as central factor of experience. The subjective suffering described in conversations could be felt and experienced, but was very difficult to express in words. It became clear that patients suffered differently and to a varying extent.

The intuitive assessment was essentially based on the perception of their affective condition and the described effects of the illness. But who could know how badly the patients really suffered? The extent of suffering, understood to be the physically, affectively and cognitively experienced overall impairment of the patient by the illness, was defined by us as **psychological strain**.

Further efforts undertaken by us aimed at changing this construct of high subjectivity into an objective one, which is inter-individually comparable. In searching for a method for this purpose, we bore the following four premises in mind:

1. Linguistic methods unsuitable

Suffering, understood as physical-affective experience, is a primary experience close to the self. Language related questionnaire-instruments work with knowledge, which is remote from the self, and are therefore unsuitable for registering psychological strain from a methodical point of view. Knowledge, which is close to the self, reveals itself as personal knowledge, either acting implicitly or in a pictorial form.

2. Individual assessment

The impairment, which is individually relevant for the patient, should be assessed. With respect to dimensions, there are no specifications to be considered.

3. Measurabillity

Psychological strain, understood as subjectively experienced psychological quantity, should be measurable. The method to be developed should sensitively record relevant changes of suffering.

4. Practicability

Evaluating the psychological strain should be simple, so that it can be applied during the daily clinical routine.

3.3 Instrument

A variety of experiments with new media have finally led to the development of a visual method, which we called PRISM (Pictorial Representation of Illness and Self Measure)

PRISM-Instrument

The examiner presents a white, A-4 sized metal plate with a fixed yellow circle in the lower right corner, measuring 7cm in diameter. He explains to the patient that the plate represents his life and that the yellow circle represents the centre of his life, his "self". Then he introduces a red magnetic disc having a diameter of 5cm as "illness"

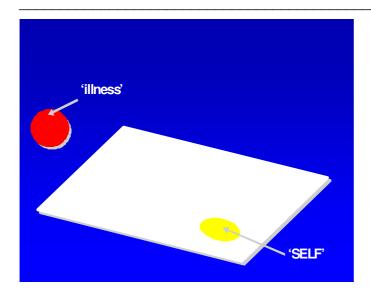


Figure 2: PRISM-instrument

Conducting the PRISM-test and measurement of self-illness-separation (SIS)

The examiner asks the patient to place the red disc on the plate in such a way that it shows which place the illness currently occupies in his life. The distance between the centre of the "self" and the illness disc is called "self illness separation" SIS and is measured in cm. The minimum amounts to 0cm, the maximum to 27cm (range is 0-27)

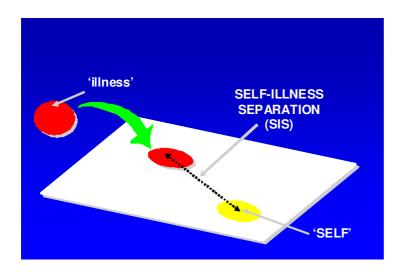


Figure 3: Self-Illness-Separation (SIS)

3.4 Standardized introduction of PRISM

"We now want to ask you to show us with the help of a test, which place your illness occupies in your life at the moment.

This white (A-4 sized) surface represents your life, the yellow circle in the lower right corner represents you in your life and this red disc represents your illness. Please now place the illness disc on your white "life area" in such a way that you illustrate which space is currently taken up by your illness."

(Measure the distance between the centres of the red disc and the yellow circle in cm with a ruler)

Thank you for your willingness to participate in this investigation!"

If a patient does not understand the task, an intermediate step will be conducted for clarification purposes.

"This is a visual and therefore unaccustomed way to understand, which place the illness takes up in your life. We therefore want to give you an example from another area of life: The blue disc means "work": For some, work is a very central aspect of life and a very important part of their personality. These people would place this disc completely onto the yellow circle that represents themselves".

(Place the blue disc onto the yellow circle as illustration)

For others again, work is rather unimportant, they work to earn money for their life. These people would not see the blue disc as part of themselves and would rather see it as a peripheral aspect of their lives.

(Now place the blue disc in the left upper corner)

Please could you now place the red "illness disc" on the white surface in such a way that it represents the space, which your illness currently takes up in your life?"

(Measure the distance between the centres of the red disc and yellow circle in cm with a ruler)

"Thank you for your willingness to participate in this test!"

3.5 Definition of terms

As has already become clear from the linguistic introduction of the method (... their "self" in their "lives" ...), PRISM is a method for visualizing self image changes due to disease. It is essential that the instrument can be introduced in an as simple and easily understandable form as possible. The used terms "life" and "self" proved to be generally well understood. The question now poses itself, how these terms can be understood within the framework of a theoretical self-model.

Gergen describes three central psychological trends in his comprehensive work on understanding the self (Gergen 1984):

- James' (James 1910) examinations of different aspects of identity and self-value lead to the experimental research of the construction of the self. His work had a decisive influence on the Gestalt psychology.
- The **psycho-analysis** founded by Sigmund Freud understood the "self" to be a dynamic construct consisting of three interacting aspects, the "super-ego", "ego", and "id" (Freud 1923).
- The symbolic interactionism (Mead 1934) had a decisive influence on sociological and psychological research. In this approach it is assumed that our environment consists of objects, which represent or symbolize individual social meaning. The interaction between the self and others is central here.⁴

With respect to the terminology of relevant terms such as "I" and "self" there is no consensus either within or between the three trends. Simple definitions of the terms "self" and "life", largely corresponding to the understanding of patients, were taken from the psychoanalytical model. In accordance with Rudolf (Rudolf 1996) we define the terms used for the introduction of PRISM in the following way (table 1):

PRISM-term	Term in the self-model	Definition
"Self"	"Self"	Central organisation unit of the psyche
"Life"	,,["	Entirety of what a person thinks of himself

Table 1: Definitions of the terms "Self" und "Life"

3.6 PRISM and health-related quality of life – a comparison

The results of the pilot study showed qualitatively (verbal explanations of the patients concerning SIS) that PRISM records significant aspects of suffering, lost social roles or control over life as it is perceived. The quantitative results with correlating interrelationships of SIS for depression, pain and control over illness also confirm that PRISM measures relevant aspects of suffering (Büchi et al. 1998b).

PRISM versus HRQOL-instruments (operationalized model)

The relationship of PRISM to the established HRQOL-instruments of the operationalized model can be characterized as follows (table 3):

- PRISM and HRQOL-instruments orientate themselves on subjectively relevant impairment caused by illness.
- There is an inverse relationship between psychological strain and quality of life: The greater the psychological strain, the more reduced the quality of life.
- With PRISM, the relationship between the illness and the "self" or person is measured.
 - Conversely, the conventional HRQOL-instruments focus primarily on the impairment of social roles such as in family, work and leisure time.
- Because of the pictorial medium, the assessment processes with PRISM are intuitive and global. By means of the HRQOL-questionnaire instruments, however, linguistic information is registered in digital form.
- With PRISM a global measure (SIS) is recorded. Conversely, the information derived from the HRQOL-instruments is more differentiated. Different charts can be shown, which demonstrate physical, mental and social problems of the patient quantitatively.
- Because it is simple to conduct with the recording of a standardized, objective
 measurement parameter (SIS), PRISM can, in principle, be used for clinical research
 just as well as the HRQOL-instruments.

PRISM versus QOL-instruments of the individualized model

By means of PRISM a global measure (SIS) is recorded, which, as such, does not supply any information about individually relevant impairment and which fundamentally differs from the aims of individualized QOL-instruments

As can be seen from the tables 2 and 3, the individual strain exerted on the patient by the illness can be recorded by talking about the SIS. PRISM can therefore be understood as instrument that records relevant patient-related strain similar to the QOL-instruments of the individualized model.

Tabelle 2: Comparison of PRISM versus HRQOL-instruments (operational model)

	PRISM	HRQOL-instruments
Measured variables	psychological strain	quality of life
Reference level	Person close to the "self"	Social roles remote from the "self"
assessment - medium - process	image Global, intuitive	language partial, digital
Information gain	global – a value	differentiated – different charts
Use in empirical research	possible	possible

3.7 What PRISM measures – a model

For the empirical assessment of PRISM a model was developed, which places PRISM into a relationship with HRQOL-instruments in the context of the disease consequence model of the WHO (see fig 4). The construct² "psychological strain", recorded by means of PRISM, differs from HRQOL-instruments in its level of assessment and mode of impairment assessment. The model assumes that the impairment is initially assessed intuitively in the context of a threat to the **intactness of the person**. This first global assessment has a direct

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² A psychological construct is defined as: a psychological attribute, which can be assumed to feature individually different characteristics. A construct cannot be observed directly; rather it presents a theoretical construct, which has been derived from research and other experience to explain observed phenomena.

effect on the **affective condition of the person**. The second, linguistic assessment process to determine the HRQOL registers the loss of **social roles** in a partially digital way.

As is shown in fig. 4, the assessment process is understood to be dependent on the affected person, who again is characterized by stable personality traits. The personality trait of stress resistance, which is relevant for coping with illness, can, as own previous studies substantiate, be recorded with the so-called Sense of Coherence (Büchi et al. 1998a; Schnyder et al. 1999; Schnyder et al. 2000). This will be dealt with in more detail at a later stage.

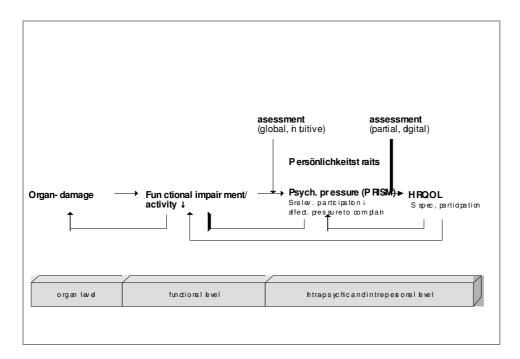


Figure 4: PRISM-model

The model comprises three relevant aspects of psychological pressure:

- **Person**, i.e. the person's assessment of stress-resistance
- Social roles, i.e. participation by means of HRQOL
- Emotional condition, i.e. affective pressure

It is obvious that the complex concept of "suffering" cannot be comprehensively covered by these three aspects. Other dimensions, also significant in the context of suffering, as e.g. the social context or religious-spiritual beliefs, were not considered because of their complexity or the impossibility of an empirical measurement.

4 PRISM as therapeutic instrument – theoretical bases

As described in the previous chapter the SIS (Self-Illness-Separation) was measured for empirical trials of PRISM and compared to other measurable variables. As the **individual meaning** of this distance is important in clinical use, it is - in addition - also **verbalized** and recorded. Furthermore PRISM can easily be expanded for therapeutic purposes, so that other individually relevant life aspects can be depicted in addition to the disease. With the enhanced instrument, **PRISM+**, the patient can name the aspects relevant to him and can assign them to coloured discs (Büchi & Sensky 1999).

PRISM can be used therapeutically to **help cope with the disease**. The theoretical framework for this is formed by the **stress-model**. One of the most important models defines stress as person-stressor-relationship. Disease is understood as being a stressor that puts a strain on or threatens a person. PRISM can depict this intrapsychic person-disease-relationship symbolically. Current stress research points out the central importance of available personal and social **resources** as well as the perceived controllability of the individual. The reactivation of ressources by means of an **improved internal control** is central to the therapeutic use of PRISM+.

From a therapeutic point of view the clinical use of PRISM should improve the **process quality** of treatment. In the foreground of this are the mutual development of therapy aims, the improvement of doctor-patient communication, as well as the monitoring of therapy effects. This is also illustrated and discussed with **case studies**.

PRISM has been used in **different medical areas** for some years. Its use in consultation-liaison psychiatry, psychotherapy, palliative medicine and in the practice of the general practitioner will be discussed hereafter. Questions of **indication and contra-indication** of PRISM will also be dealt with briefly.

4.1 PRISM and coping

On the background of rising life expectancy and an age pattern shift towards higher years of life, the subject of "coping with disease" has increasingly gained importance in the past decades. Chronic illness and morbidity are becoming a problem for an increasing number of especially older people in our society and dealing with disease is becoming a long-term daily task. Accordingly, the interest in research of determinants of successful coping with disease is rising. In the last years the influence of protective personality factors as well as social ressources were examined in particular. (Schröder 1997).

The transactional approach of Lazarus (Lazarus & Folkman 1984; Lazarus 1993) assumes a reciprocal person-environment interaction, in which the person not only actively has an impact on the environment, but the environment also influences the behaviour of the person. The person himself actively contributes to the stress and coping process as the case may be. This is in clear contrast to the stimulus-oriented stress conceptions, in which the person is seen as the "passive victim" of environmental influences. Beyond that, Lazarus postulates that interaction has a process-like character, since the stress of dealing with the subject corresponds to a dynamic adaptation process. Lazarus calls this "transactional"

Lazarus defines stress as following (Lazarus & Folkman 1986): "Psychological stress refers to a relationship with the environment, which the individual assesses as being significant with respect to his well-being, but which simultaneously places demands on the individual which either strain or overstrain his coping abilities."

The following appraisal processes are therefore central to this definition of stress:

- With respect to well-being: Primary appraisal
- With respect to available ressources: Secondary appraisal

In **primary appraisals** the person assesses the demands as irrelevant, positive or stressful, whereby three stressful transactions can be differentiated:

- Threat (with anticipated damage) and
- Challenge (coping with a difficult situation seems possible)
- Harm (with incurred impairment)

The three stress related transactions lead to the mobilization of coping measures. In the **secondary appraisal** the individual assesses his resources and possibilities in terms of a successful conclusion of dealing with the stress related situation. According to Lazarus (Lazarus 1993) the assessment of personal ressources is of utmost importance with regard to whether a stress situation is experienced as threat or as challenge.

Coping is defined by Lazarus and Folkman (Lazarus & Folkman 1984) as management of those external or internal challenges which the individual views as straining or overstraining his personal ressources. The coping strategies used to fullfill this task can be assigned to two functions: **Emotion - and problem-focussed coping**. Problem-focussed coping occurs, if the person directly occupies himself with the conditions from which an impairment, threat or

challenge arises. Under emotion-focussed ("palliative") coping of stress Lazarus understands those endeavours that are primarily aimed at the regulation of emotions. Particularly in his newer publications Lazarus emphasizes that the same type of coping can have both functions.

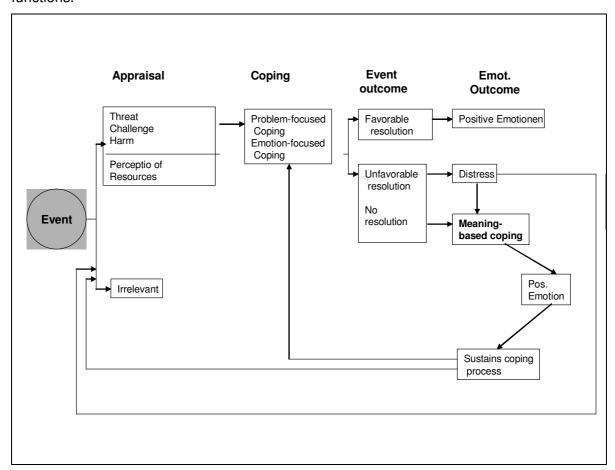


Figure 5: The transactional stress-model of Lazarus [modified according to Folkman (Folkman 1997)]

Successfully coping with the stressor is experienced as emotionally positive. A failure in coping expresses itself emotionally as fear or depression and is called **distress**. It is a strain on the person and also challenges him to a **reappraisal** of his environment-person relationship. The reappraisal, which is also called "reframing", includes the renewed assessment of the strain, the resources, as well as the individual objectives. The level of the objectives is of particular importance, especially in complex problems as for example the occurrence of a chronic disease (Richards & Folkman 2000). According to Stein (Stein et al. 1994) objectives can be assessed on two levels: **Superior and situational goals**. While situational goals usually apply to circumscribed situations, superior goals are deeply connected to the identity of the person. The clarification and modification of superior goals is of utmost importance in coping with chronic disease, which upsets the life-perspectives of patients. Working on and clarifying superior goals in the therapy of the chronically ill with PRISM therefore plays an important role.

4.1.1 PRISM and the transactional stress-model (Lazarus)

Within the transactional stress model of Lazarus PRISM can be understood as instrument of visualization for the individual person-disease relationship. In terms of the above mentioned secondary appraisal the overlapping of "disease" and "self" (SIS<4cm) can be seen as expression of an assessment of overstrain. As empirical results of the PRISM validation and those of pilot studies with patients having chronic polyarthritis show, patients with a shorter distance assess their controllability as being distinctively reduced, are more occupied with coping with their disease and show more depressive symptoms. We therefore suspect a tendency to emotion-focussed coping in this group. This pattern of dealing with the problem primarily aims at influencing unpleasant affects, but less at dealing concretely with the disease.

Irrespective of the severity of the disease, patients with a greater PRISM-distance, i.e. a more distinct spatial separation of "disease" and "self", have an assessment of greater control over the disease, spend less time occupying themselves with the disease and are less depressive. With these affectively less burdened patients we suspect a stronger problem-focussed coping.

On the basis of the transactional stress model of Lazarus, we have developed a simplified PRISM-stress model, which has proved itself in clinical operation (compare fig. 6). In this model the appraisal of the patient is of central significance: In the primary appraisal of the disease it is decided, whether the patient perceives the disease as loss or as threat to his identity. Of particular importance is the appraisal of the coping possibilities (secondary appraisal according to Lazarus). If the available resources are considered too meagre to be able to cope with the threatening disease, the disease is experienced as threat to the identity of the person. This leads to a reaction to overstrain, which may be expressed cognitively in terms of catastrophisation, emotionally as fear and depression, as well as behaviourally, eg. as impaired cooperation or adherence. It is important to note that the therapeutic focus of working with PRISM is not on the cognitive-affective-behavioural overstrain symptoms, but on the cognitive appraisal of the disease burden in relation to own resources. If the modification of this appraisal is successful in psychotherapeutic work, this corresponds to a **reappraisal** of the situation: The disease is now no longer primarily perceived as overstrain. but as burden, to which a response of problem-focussed coping is more easily possible. In the following therapeutic work it is attempted to increase the SIS still further in order to thereby reduce the subjective pressure of suffering.

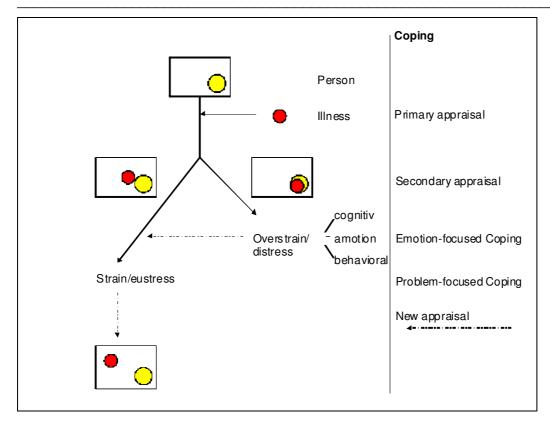


Figure 6: PRISM-Stress-model

To reduce the pressure of suffering with the help of PRISM, two techniques are employed which influence the balance of person-disease-interaction:

- Improvement of controllability in dealing with the disease
- Reactivation of personal resources

The next two chapters 4.1.2 and 4.1.3 deal with the theoretical background, as well as the practical implementation of these two aspects.

4.1.2 PRISM and subjective controllability

The significance of controllability, i.e. the control of the stress experience by the person, was examined on the basis of strain in the work environment in particular. The American sociologist Karasek phrased the so-called "job-strain-model", which was later further developed by the Swedish physician Theorell. The basic idea consists of deriving strain experience from a combination of two central dimensions of work – workload and controllability of the work task respectively. Chronic distress results from a work situation, in which continuously high demands are placed on the employees while they simultaneously have little scope for decision-taking in the working process. Investigations of both authors in the motor car industry confirmed that there is a high correlation between high distress and illness accumulation (Karasek & Theorell 1990).

What can be deduced from these studies for dealing with chronic disease? As the quantity of the stressor chronic disease cannot be substantially changed, the only factor that can be influenced is the **perceived controllability of the disease**.

Chronic disease, understood as biological progression of disease, is by definition, not curable and is only controllable to a very limited extent. The external scope of action of the patient is limited. With optimal self-therapy and adherence respectively, he can, at best slow down the progression of the disease, but he cannot stop or even reverse it. In other words this "external" controllability is limited to the biological stressor "chronic disease". This low controllability represents a fundamental source of strain in coping with the disease.

Does this low controllability in the physical sphere mean that the patient is at the mercy of his disease? With the help of PRISM the patient's attention is drawn to an area of the disease, in which there is theoretically a high degree of controllability – **dealing with the disease using internal coping strategies**.

With the therapeutic use of PRISM, the internal coping with disease is visualized and depicted symbolically by means of a microanalysis of a successful "internal" control.³ With the help of this **sequence analysis of a process of distraction** from the disease, the patient discovers his own internal controllabilities. This knowledge can be concretely used in future to enable the conscious development of those activities, which bring about the increased alienation from the disease desired by the patient. The experience of an inner controllability of dealing with the disease should awaken the hope of increased realization of own wishes and objectives.

³ First the current location of the disease in the life of the patient is registered (standardized introduction). Then the content-related meaning of the SIS is asked for: "What does it mean, that the disease takes up this space?""What would the difference be, if the SIS were larger or smaller?" If the patient names a symptom (e.g. more pain) the following question is asked: "Was there a shorter or longer episode in the last two (24, 48 or 72 hours respectively), in which the problem took up a different location as that currently indicated?" Many patients can spontaneously affirm this question. They mention the card-game with friends yesterday or talk of the satisfying garden work on the last sunny day. The patient is now asked to determine the location of the disease at that enjoyable moment of time. He now places the disease at a greater distance away from the "self". To enable him to understand this change, the following question is then posed: "How do you explain this difference in comparison to the previously described current location of the disease?" Some patients now mention, that it was probably the "distraction" from the disease by a valued activity which caused the difference. The question, as to how they explain the difference with the help of the PRISM-board, usually leads to a discussion about the inner effects of activity with variable contents. In addition the patient can assign a coloured PRISM+-disc to the positively described activity (at the favourable point in time) and place it in relation to the disease.

4.1.3 PRISM and Resources

The analysis of **personal and social resources** has come into focus in current research of stress. *Ressources are defined as protective or aiding factors, that are available to a person when burdens arise.* "Internal" or "personal" resources are understood as being helpful characteristics of a person. "External" or "social" resources are supportive offers of the environment. In the last years there has been an increasing interest in the dynamic relationship between personal and social resources.

The discussion concerning **personal ressources** was initiated primarily by Antonovsky, who occupied himself with individual resilience. Antonovsky's resilience-concept of **salutogenesis** (Antonovsky 1987) and related concepts such as **hardiness** or **self-efficacy** were already dealt with in chapter 5.3.1.1 (page 4). The different concepts of determining personal resources are related to each other and comprise the subjectively estimated self-efficiency beliefs. A further well examined personal resource to be mentioned is the so-called **dispositional optimism** (Scheier et al. 1989), defined as relatively stable and generalized expectation of positive events.

Research as to the influence of social resources has been carried out frequently in recent times. Different studies support the stress-cushioning effect of social backing. Social backing consists of the two dimensions of **social integration** and **social support**. Social integration refers to whether and to which extent social relationships exist and is the prerequisite for social support. This again can be divided into **expected** and **received social support**: It either is a matter of the person expecting to receive support and help through the social network in a problematic situation or of effectively receiving support.

Experimental findings prove that the expected social support in particular stabilizes the psychic well-being. In an overview assignment about research results for coping with chronic disease it was shown that social resources can be implemented together with internal resources, whereby the internal resources (including the expected social support) are of greater importance in predicting effective coping of disease (Schröder 1997). The coherences of personal and social resources are depicted in fig. 7.

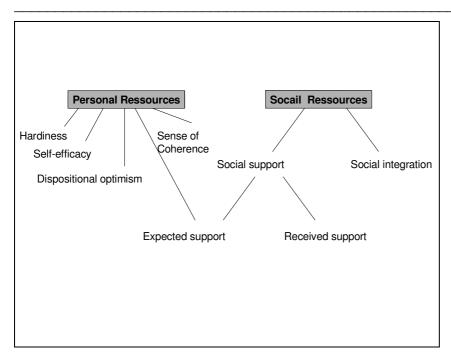


Figure 7: Personal and social resources

Conservation of resources theory (COR) by Hobfoll

For the work with PRISM a second stress concept is worth mentioning besides Lazarus' transactional model. This derives from Hobfoll and is called **conservation of resources theory** (Hobfoll 1989). Based on Lazarus' cognitive-transactional model, Hobfoll defines **stress as loss of resources**.

Stress occurs in three situative conditions, if:

- There is a loss of resources
- Resources are threatened by loss
- People have invested in resources without subsequent gain of fully-fledged resources.

The less the possibility of regaining or replacing resources and the bigger the subjective significance of the resources, the more stressful the situation will be experienced as.

Therefore the assessment of the threat and the importance of the resources determine the intensity of the stress reaction. The following categories of resources were suggested by Hobfoll:

- Object resources (e.g. home, material possessions)
- Conditional resources (living conditions and social roles that are highly valued and aspired to, such as partnership, marriage, social relationships and occupational status)
- Energy resources (knowledge, money, time) and
- **Personal resources** (e.g., belief in self-effectiveness)

In case of chronic disease all these resources can become a matter of stress if they are threatened in a specific way by the disease and functional impairments connected therewith. Personal resources can have a stress cushioning effect, in that they positively influence the appraisal of stress and support active efforts to preserve, regain or substitute the affected object, conditional and energy resources. They can, however, also turn into a loss as such and augment the experience of stress.

Hobfoll postulated that the person plays an active role in gaining resources. The use of resources should help to maintain other resources. By having many resources at his disposal, a person should have a low vulnerability towards stressful events. **According to this theory the stress event can be analyzed and described** by **compiling the resources**. How this can be implemented in a visual way with the help of PRISM+, is shown as follows:

4.1.2 PRISM+ and the Visualization of Resources

PRISM, which helps to visualize the person-disease relationship, can be expanded for therapeutic use with further coloured discs of the same size. It is then called **PRISM+**. The additional discs help to detect relevant life aspects of the patient. They are understood to be individual ressources of the patient and correspond to the object, condition and energy ressources of Hobfolls. Clinical experience shows that the following aspects are mentioned most often in sequence of declining order: Marriage/family/children, profession, hobby, finances, pets, God/spirituality, more rarely also freedom/autonomy/independence. In a second step the patient places his individually specified disc on the PRISM board in such a way that he thereby captures its individual significance. By analogy with the experience with SIS, it is also shown here that more important aspects are placed closer to the yellow "self-disc" than the subjectively less significant ones.

The **personal resource** of self-effectiveness according to the models of Lazarus as well as Hobfoll can only be elicited indirectly by means of PRISM / PRISM+:

In the PRISM-model belief in self-efficiency or stress resilience can most likely be represented by an (invisible) repellent energy of the "self"-area for the "disease-disc". In the PRISM+-model, personal resources can be understood as the power which makes it possible to preserve relevant aspects of life despite disease or to replace a lost aspect in an adequate way, as the case may be.

The effects of chronic disease on the state of ressources can be detected in a simple way. ⁵ Clinically it can be shown that a small SIS in PRISM usually accompanies a complete or threatened loss of a previously crucially important life aspect in PRISM+. In contrast, a large SIS corresponds to only slight disease-related changes of relevant life aspects. This reveals, that the two stress concepts of Lazarus and Hobfell can be combined and put to use therapeutically by means of PRISM:

- PRISM depicts the disease-person interaction (Lazarus-model)
- PRISM+ additionally depicts the effects of the disease on individual resources (Hobfoll-model)

Before going into the practical use of PRISM in the evaluation of therapy goals and monitorization of therapeutic effects in the next chapters, the **different clinical uses of PRISM and PRISM+** will be pointed out briefly:

- PRISM is an easily applicable diagnostic and therapeutic instrument that can give an
 indication of the stress experienced by a chronically ill individual within a short time (4-8
 minutes). With PRISM, therapy goals can be captured visually and linguistically and
 therapeutic changes can be monitorized easily. The range of use is therefore broad: The
 use of PRISM can be recommended not only for hospitals but also for private practice.
- The use of PRISM+ is much more complex and usually only possible at the end of a longer conversation about stress and coping with disease, as well as other life aspects. Since conducting the PRISM+ procedure requires 20-30 minutes, the use of PRISM+ is particularly indicated within the framework of a psychotherapeutic treatment. The information of the resource analysis can be used in different ways in psychotherapeutic work: In addition to the problem analysis the resource profile completes the overall picture of the patient in a salutogenetic way. Furthermore, the individual resources present the potential solution for the coping process. A further field of application is palliative medicine. Here PRISM+ is used in complex patient situations for a differentiated analysis of resources and problems as well as the improvement of interdisciplinary communication.

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⁵ This takes place with the following questions: "Where is the present location of the disease in your life" (PRISM; only one disease-disc) "Who were you before the onset of the disease?" What was important in your life at the time?" (PRISM+ with different individually specified discs). "Which aspects are important to you today and which space do they occupy?" (PRISM+ including the disease-disc)

4.2 PRISM and process quality

quality and satisfaction of patients.

The therapeutic work with chronically ill people is an **individual-related service** with the aim of maintaining and/ or promoting optimal quality of life for the patient. Instruments, which capture the quality of the therapy should depict the corresponding relevant changes.

For the classification of quality the tripartition created by Donabedian into *structure*, *process* and *result* has stood the test (Donabedian 1966). In the health sector area of individual-related services these terms can be defined in the following way (Herzog & Stein 2000):

- Structural quality includes the qualification of medical and non-medical staff, the
 infrastructure, administrative facilities or the standardized operational procedures, which
 have been predetermined by medical and administrative sides respectively.

 Measurement: The most comprehensively established approach to measure the
 structural quality is the accreditation of hospitals, especially in the USA by the Joint
 Commission for Accreditation of Health Care Organizations (JCAHO).
- Process quality describes the medical care as such, i.e. how diagnoses are made, interventions are conducted or drugs are administered.⁶
 Measurement: Important quality measures for process quality are the satisfaction of the patient and his relatives as well as the so-called personal costs of the patient and his relatives, such as, for instance pain, fear or loss of dignity.
- Result quality captures effects which result from the previously mentioned processes. The result constitutes the decisive reference basis for a quality appraisal. In the medical field five forms of result criteria, known as the "5Ds", have been established: Death, disease, disability, discomfort and dissatisfaction.
 Measurement: Important parameters of the result quality are, for example, relief of pain, prologation of life, a reduced duration of stay in hospital, as well as particularly the life

The three dimensions of registering quality represent a helpful classification even if a clear allocation is not always possible in the daily routine.

It is decisive that not only the result (result quality) but also the process (**process quality**) is taken into consideration. This applies especially to medical-therapeutic services which can be of a very long duration as, for example, the therapy of chronic disease.

The effect of PRISM on three central aspects of the treatment process are analyzed as follows:

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⁶ Note: According to Ovretveit it must be noted that the process incorporating the preparation of a (person-related) service is already a fundamental part of the rendered service and may not be understood as just an instrument of improved quality (Ovretveit 1992).

- Clarification of the therapy goal
- Doctor-patient communication
- Monitorization of the therapy process

Clarification of the therapy goal

Every patient has – usually unvoiced – expectations with respect to the therapy. The clarification of the therapy goals is important for two reasons: Firstly, the goal essentially determines the content of the ensuing therapeutic process. The better the consensus with regard to the goal-setting, the better the cooperation between patient and physician, the satisfaction with the treatment results, as well as the **quality of life** of the patient, which is also significantly affected by the difference between the **target state** and the **current state**.

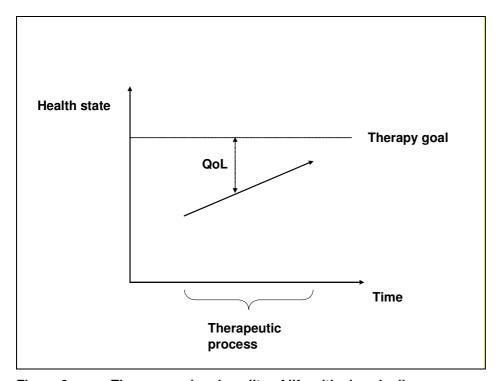


Figure 8: Therapy goal and quality of life with chronic disease

From Figure 8 it becomes apparent that the therapy goal has a significant influence on the patient's quality of life, irrespective of the therapeutic process. In the case of an unrealistic goal expectation, a therapeutic process which would be considered successful, also from a professional point of view, is accompanied by dissatisfaction of the patient. This significant cause of patient dissatisfaction, which only a few therapists are probably aware of, can be assumed to be one of the main causes for breaking off treatment in the therapy of the chronically ill.

In recent times the awareness of the central significance of goal definition in the medical context has increased. Rehabilitation centres, in particular, work with so-called GAS scales (Goal Attainment Scaling; Kiresuk & Sherman 1969). These are used to develop a mutual

"best case scenario" therapy goal together with the patient. This therapy goal is recorded in writing and assigned a nominal value (e.g. 10). Then intermediate steps of success are verbally formulated and recorded on a VAS (Visual Analogue Scale). Experience in clinical practice, however, shows that such a goal formulation is very difficult for patient and therapist alike and requires a lot of practice. PRISM can simplify the goal formulation process in a twofold way:

- Support of goal formulation: When working with the GAS, PRISM can be used instead of a VAS scale⁷. The visual PRISM-access is intuitively close to the patient. With the help of PRISM it is easily possible to formulate a goal within the shortest time. This saving of time is of particular importance in the practice of the general practitioner where only 15 to 20 minutes are usually available for a consultation.
- Expansion of the goal formulation: GAS helps to determine mainly situative goals. With chronic diseases it is, however, often necessary to find new, so-called "superior" life goals (Stein et al. 1994). Within the psychotherapeutic framework a comprehensive new life concept can purposefully be developed with the help of PRISM+.8

Improvement of doctor-patient communication

Apart from the identification of somatic parameters, the appraisal of individual impairments of the patient is important in the treatment of physical diseases. The mutual understanding that doctor and patient have of the physical disorder and subjective psychological strain has a significant influence on patient compliance and therefore is of utmost importance for the course of therapy and disease (Sensky 1990).

In clinical practice a strained doctor-patient communication can arise for a number of reasons: Consultation times are so limited in somatic medicine that medical activity is reduced to diagnostic and therapeutic efforts. The individual significance of syptoms and psychological strain receives too little attention. Many doctors are unaware of the fact that there does not have to be a direct connection between the severity of a disease and the subjective strain. A limited verbalization ability sometimes also contributes to communication

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⁷ With the help of PRISM the following questions can be dealt with. "Where is the present location of the disease?" Where do you hope the location of the disease will be in (e.g.) a year in the case of maximum therapy success?" "How would you notice the difference?" (this is recorded in writing). "If the course of therapy is not optimal, but satisfactory, with which location of the disease in your life would you still be satisfied in (e.g.) a year?" "How would you notice the difference to the present state?" (is recorded in writing).

⁸ Questions for the use of PRISM+: "How would you like to be in (e.g.) a year?" Which life aspects would then take up a bigger, which a smaller space in your life?"

problems: Some patients find it difficult to describe their ailments with any accuracy. They find it even more difficult to express their emotional strain in words.

PRISM can influence the following aspects of doctor-patient communication:

- The visual instrument supports patients in expressing their emotional strain directly as non-verbal, self-related knowledge (Pöppel 2000).
- The introduction of an instrument, which is unfamiliar in appearance will stimulate
 the communication process, opening up new possibilities, particularly with respect
 to interaction patterns which have become deeply entrenched.
- The PRISM-board constitutes an external third aspect, which patient and doctor are busy with while simultaneously focusing on central subjects in their conversation.
- The **patient** "tackles his disease". This is symbolically of great significance and can be expressed by an increase in the patient's activity and self-responsibility.
- The method implicitly develops a connection between the occurrence of the biological disease and the psychic representation. It thereby points out a relevant level of coping with disease.

Monitoring of the course of therapy

In therapeutic processes, especially those of longer duration, it is important to record changes of goal parameters. Corresponding acknowledgements will give the therapist important indications as to the effectiveness of the therapy. In addition he can further reinforce positive changes of the patient in terms of a **feedback**.

Changes of psychological strain are clinically relevant and dependent on different psychic and social factors. Since PRISM (and PRISM+) can capture this information, a simple monitorization of this central factor is possible. The clarification of changes with the help of PRISM+ provides the therapist with a quick **insight into relevant therapeutic effects**. This additionally influences the quality of the therapy positively.

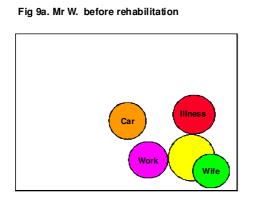
Example: Effects of an ambulatory pulmonary rehabilitation

In the framework of a research project to determine the effects of an ambulatory lung rehabilitation, PRISM+ was employed at the beginning and end of a treatment lasting three months, as well as in the framework of a check-up two years after the termination of treatment. The treatment consisted mainly of physiotherapeutic training, no psychotherapeutic treatment took place.

Representatively for all 24 patients examined, Mr W. is to be mentioned at this point. The patient, born 1923, suffered from a severe tuberculosis infection in his teens which was treated during a 18-month rehabilitation stay in Davos. The left lung was removed in 1955. Throughout his life the patient could not cope well with physical stress and suffered from severe dyspnoea when he exerted himself. He worked as an accountant beyond his retirement, preparing annual statements for smaller businesses.

At the start of treatment his wife and his work were his central ressources. The high significance of the resource "car" is worth mentioning. This vehicle, a white Mercedes 223, to be exact, had always been an expression of upheld autonomy despite physical disability. Whenever possible, he went on excursions over the Swiss mountain passes together with his wife on Sundays. The strain of the disease was severe; the SIS was equal to 4cm at the time (figure 9 a).

The patient was a very committed participant of ambulatory rehabilitation. He belonged to a "core group" which kept training in the fitness centre beyond the actual treatment time and which regularly met with "training partners" for a cup of coffee and some cake after training. Two years after the completion of the official rehabilitation programme, the patient felt much better healthwise. The SIS was equal to 8cm. Due to the regular physical training he felt physically confident as seldom before. The PRISM-disc, designated as "physical confidence" by him, took up a central space. The patient group was of great importance as a new social resource as well. This group helped the patient get over the significant and painful loss of his secondary occupation as accountant. (figure 9b)



Car Patient-Group

Security Wife

Fig 9b. Mr. W. two years after rehabilitation

Figure 9: Mr W. before and after ambulatory pulmonary rehabilitation

Comment

In the example of this case history the complex consequences of a purely physically orientated rehabilitation treatment are depicted with the help of PRISM+. From the view of

the patient the treatment leads to three relevant changes: The impairment through the disease decreases, therefore the SIS increases. At the same time the disease is also represented positively for the first time as "physical confidence". However, it was the patient group which proved to be of particularly significant importance. In this group the elderly man, who had previously lived an isolated life, felt very compfortable and accepted. These fellow sufferers gave him a social backing which helped him get over the loss of his job.

4.2.1 Clinical range of use

Conditions for clinical use

The therapeutic use of PRISM is sophisticated. It has been shown that a thorough theoretical and practical introduction of the method is a prerequisite for effective use. In the process the most relevant theoretical concepts (stress concept, resource model, salutogenesis) are conveyed and practised by using PRISM, first on the basis of patient examples and then in a clinical context. With the help of video recordings, they are then analyzed and reflected upon.

Consultation and Liaison Psychiatry

The development of PRISM is closely connected with the occupational context of the author. He works in the area of consultation and liaison psychiatry (C–L psychiatry) and is confronted with the psychic problems of patients afflicted with physical diseases on a daily basis. The task usually consists of making a psychiatric diagnosis by means of a doctor-patient conversation, as well as getting to know the psychosocial background of the patient in order to deduce possible causes for the present psychic dysfunction, all within the short time of 50 to 70 minutes. At the same time the individual resources should be elicited to such an extent by the end of the conversation, that useful proposals for therapy can be made to the referring physician, as well as the health care team treating the patient.

The following special features are characteristic of the work of a C-L psychiatrist:

- Lack of time
- Resistance of the patient against a "psychiatrization" of his physical suffering, connected with the fear of not being taken seriously.
- Working in a primarily biologically orientated system of a hospital with a bio-psycho-social understanding of disease and communicating this to patients, doctors and health care teams.

PRISM has proved to be a very helpful instrument in the C-L-area: To resolve any existing resistance of the patients, the aim and goal of the consultation are usually discussed at the beginning of the conversation. In doing so, the C-L psychiatrist can clarify that he is not looking for the psychic causes of the physical or psychic dysfunction, but that he wants to find ways of optimally dealing with the existing problems together with the patient. This train of thought is taken up again towards the end of the conversation when PRISM⁹ is introduced. As explained in the footnote, PRISM already serves to register and improve the internal controllability at the time of first contact. This aspect is very important because the patient often suffers from a feeling of helplessness on the grounds of his physical condition and the complex, impenetrable structure of a hospital. The use of PRISM aims at increasing the autonomy of the patient and requires between 15 and 25 minutes. This can be briefly illustrated in the following example:

Instituting a psychotropic drug therapy is an important component of C-L activity. For many patients it is difficult to understand why they should take drugs and this can be perceived as loss of autonomy. It is therefore of utmost importance to give an understandable explanation for the prescription of psychotropic drugs and to pay attention to the greatest possible self-determination of the patient with respect to the intake of drugs. With the help of PRISM it can be illustrated that the intake of psychotropic drugs serves the autonomy of the patient and does not lead to an additional dependency. The clear and easily understandable illustration of the effectiveness of a drug reduces fears. Again, the patient should be able to play an active role in the application of the drugs. He can, for example, be given a part of or the whole dosis of the frequently used benzodiazepine-anxiolytica for independent intake.

It is to be particularly emphasized at this point, that PRISM implicates a bio-psycho-social understanding of disease. In reporting back to the referring physician or health care team, PRISM can be used to convey relevant information. With minor time and effort this enables a

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⁹The following questions are dealt with here by means of PRISM and PRISM+ respectively: "Which space does your disease occupy?" "Is this always the same?" "When is the distance bigger, when smaller?" "If the distance is bigger, what occupies a more central space?" "Which space did the disease occupy 3 months ago?" Where do you expect its location to be in 6 or 12 months time?" "Where do you see the location of the different life aspects (mentioned in the conversation)?" Which areas of your life would you like to enhance in the following weeks and months?"

¹⁰ See PRISM-stress model. Currently existing psychic symptoms of overstrain are, for example, fear and depression. The reduction of these symptoms with anxiolytica can – supported by the use of PRISM - contribute towards a change in perception of the situation, in that a previous perception of overstrain changes into one of strain.

comprehensive understanding of the disease and an implementation of a **patient- and not** disease-orientated medical and therapeutic treatment.

Palliative Medicine

PRISM is used in the palliative division of the University Hospital Zürich as central medium of communication. The concept of this palliative ward allows for an intensive interdisciplinary teamwork between specialists (radio-oncologists, medical oncologists, anaesthetists, psychiatrists), the health care team, systemic therapists and social workers. The goal of the treatment, which takes between 4 and 12 weeks, is the improvement of quality of life in cases of advanced terminal cancer. The treatment is strongly geared to the requirements of the patient.

Concretely the physician in charge carries out an analysis of the patient situation together with the responsible member of the health care team. To clarify the individual priorities of the patient, PRISM+ is employed after a thorough case history. The patient himself determines which aspects of treatment, physical (eg. pain, tiredness), psychic (eg. fears, "unfinished affairs") or social (eg. living conditions, health care support), have priority. His problem situation, illustrated by means of PRISM+, is introduced at the interdisciplinary ward round: In a very compact way the specialists caring for the patient thereby gain insight into his life situation. ¹¹

The use of PRISM+ in the palliative ward has had an effect on several levels:

- Improved identification of problems and improved prioritization. The patient names and assesses his central problems himself.
- Improvement of interdisciplinary communication
 Information gained from patient conversations is known to all those involved in an identical way. During the interdisciplinary ward round the specialists can be "put in the picture" with respect to the situation of the patient within a short time.
- Screening for hidden problems

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An example is to illustrate this: A 46-year old woman was referred to the palliative ward because of severe, uncontrollable pain in the hip due to a metastasing mamma-carcinoma. She was the mother of two children of school going age and was in the process of getting divorced. She was worried about her two children and the financial situation (the family had bought their own home three years before). PRISM+ produced the following list of priorities for treatment (the respective therapist consulted is shown in brackets): 1. Pain (anaesthetist), 2. children, divorce (systemic therapist), 3. Finances (social worker).

On bringing the application of PRISM+ to a close, the patients can be asked whether the picture is complete or whether there is an important part missing on the "board". Not rarely some new, not previously mentioned problems, but also resources emerge (eg. my belief in God).

Facilitation of "shared clinical decision making"

At the outset the expectations of the patient with respect to the therapy can be clarified by means of PRISM and a treatment plan be agreed upon by patient and treatment team.

• Monitorization of the therapy effects

Therapeutic effects can continuously be recorded with PRISM+ and potential, newly emerging problems be detected at an early stage.

Therewith all requirements mentioned by Higginson and Carr for the improvement of the process quality of a LQ-Instrument have been met. According to the assessment of persons involved, PRISM has a positive effect on the quality of treatment in the palliative ward of the University Hospital Zürich. Differentiated use is however sophisticated and only possible with repeated training courses and accompanied supervision.

Psychotherapy

As mentioned in the example of a patient suffering from multiple sclerosis under 4.3.1, PRISM can also be used in the psychotherapeutic support of the chronically ill. In this context it becomes particularly apparent that PRISM touches a non-verbal experience level of the patient because of its visual-tactile format. Physical problems affect a person's innermost being. Exclusively verbal methods touching on semantic and thus "self-remote" knowledge (Pöppel 2000) are therefore often insufficient. In a psychotherapeutic setting PRISM can be used besides other non-verbal means such as imagination, katathym imaginative psychotherapy, perception training etc. In contrast to many primarily non-verbal methods, PRISM also makes the monitorization of the procedure possible. As demonstrated in the case study, PRISM can reveal an interrelationship between psychic and physical processes.

General Practice

PRISM finds a high degree of acceptance with general practitioners. Unfortunately it was not yet possible to systematically compile the experience of general practitioners who regularly use PRISM (approx. 150). The present evaluation of the use of PRISM in general practice is based on the following three sources of information: 1. Experience and feedback during PRISM-introductory courses, 2. PRISM-supervision of general practitioners, 3. A detailed,

half-standardized interview with Dr. med Hans Wehrli, general practitioner in Turbenthal, who uses PRISM regularly since 1998.

PRISM is used in general practice in mainly two ways:

A. PRISM as instrument for the monitorization of psychological strain

Various general practitioners use PRISM during their regular consultations, lasting 15 minutes, to briefly examine the prevailing condition of patients suffering from chronic disorders (eg. sleep disorders, fatigue or headaches), psychosomatic disorders, and chronic diseases. The course of the SIS gives indications as to the condition of the patient, the changes, as well as the effects of the therapeutic measures.

B. PRISM as therapeutic instrument

Many general practitioners who regularly use PRISM are interested in psychotherapeutic questions and have gained further commensurate qualifications. Roughly a third has qualifications in psychosomatic and psychosocial medicine. These colleagues work with patients in a more psychotherapeutic setting with consulation times of 30 to 45 minutes. PRISM / PRISM+ is used here in a psychotherapeutic context (see chapter 4.4.4).

The following aspects of using PRISM in general practice are of special significance:

Clarification of therapy expectations

The clarification of patient-expectations is particularly important in prolonged therapies with chronic disorders (compare 4.2.2).

• Time-efficient recording of therapy progression

Therapy effects can be recorded within a short time and can be used to measure the progression.

Improved communication

The visual-tactile method can improve communication about aspects close to the person, such as physical impairment. Patients with chronic disorders, who have been cared for by their general practitioner over a prolonged period of time, experience a rapid change of communication level with PRISM. This can revive the exchange between patient and physician.

Clarification of responsibility

PRISM clarifies that the patient is responsible himself for "internally" dealing with his afflictions. This can be particularly important and helpful with patients, who expect "healing" from their physician in a regressive way.

Conveyance of manageability

PRISM conveys in a vivid manner how patients can actively change and influence their condition.

Playful level

PRISM complements the often serious task of a physician with a playful component.

PRISM as "tertium"

Patient and physician can concentrate on an external medium, which they give shape to during the therapeutic process.

4.3 Indications and contraindications

Indications

Therapists with sufficient theoretical and practical knowledge can use PRISM effectively, particularly with **all chronic ailments and – diseases**, to record and modify the psychological strain.

Contraindications

The experience of the last years has shown only minimal limitations of the use of PRISM:

- No clinical use without previous theoretical and practical introduction:
 If the patient has insufficient knowledge and abilities concerning the use of PRISM,
 additional communication problems can be caused.
- Inadequate verbal communication about the use of PRISM:
 If the patient does not understand the method sufficiently, its use can make the patient feel additionally insecure.
- Very rational digital patients may be irritated by the visual-tactile format of PRISM.
 They prefer clearly structured instruments, as for example the VAS-scales, for the communication of their condition.

5 PRISM as therapeutic instrument – practical instructions

Keep it simple

- The simpler the PRISM-illustration the more effective the intervention
- Work with as few discs as possible
- Deal with a situation at a specific point of time
- Basic rules: simplify/ name/ put in order

Interaction

- Introduce PRISM as clearly and simply as possible. The discs are placed on the white surface and, with PRISM+, not placed on top of each other
- · Record the main rules
- Develop a new understanding with every client/patient; Every client/patient defines the meaning of the discs and the space on the board

Understanding precedes change

- It is your goal to understand the concepts and definitions of the patient through questions, not to change them
- Note: a novel way of seeing and understanding is already effective

The client/patient is the specialist for his problems

- Use the undefined space on the PRISM-board to let the "specialist", i.e. the patient, describe his situation in detail
- Do not let yourself be pushed into the role of a solution-specialist your solutions are not his solutions

"not only ... but also"

- Verbal thinking tends to be a "either ... or"-dichotomy
- PRISM can depict the "not only ... but also" paradox
- Note: bring the missing aspect into the game

Chronicity as illusion - "panta rhei"

- Life is in flux, nothing continues to exist
- Note: look for the flux in the "chronicity"

Crisis as decompensation and transition

- Note: acute overstrain of the psychic system prevents the uptake of verbal information
- Visualisation of the overstrain helps to distance and externalize
- Therapy goal: being a crisis having a crisis
- Introduce new dimensions of time (past and future) as orientation guidea

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