

Prof. Dr. Andreas Zieger, Oldenburg (D)

Rehabilitation and Quality Management¹

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Wellcome and acknowledgement

Good morning, ladies and gentlemen,

It is a great honour for me to chair this panel session 5 “Rehabilitation and Quality Management”.

Let me first thank my colleague Doctor Steinhoff for his kind invitation.

I wish to welcome all participants of this session, especially our lectures from France and Ireland.

Thank you very much for your participation and for your interest.

We have got 90 minutes. Let’s first listen to all presentations and then have the discussion afterward.

I Introduction

2 Quote from VvW

In the early 1950^{ies} of the last century Viktor von Weizsäcker, a German physician and philosopher, and the founder of medical anthropology, said, quote, “medicine is a manner how people treat each other.”

Interacting in medicine like in other areas of human society often creates conflicts due to different wishes, interests and attitudes.

In order to co-operate people need social competences, and they have to balance their interests among each other. Balancing interests is an everyday process and a part of the human culture.

3 Rehabilitation and QM – terms of contradiction?

More than one century ago quality management originally was developed for the needs of industrial production to correct errors, to steer ongoing improvement of structures, to steer processes, and outcomes as well as customers’ satisfaction.

For many physicians rehabilitation medicine and quality management are not free of contradictions. Physicians commonly want to make decisions freely and independently because of their professional obligations and ethical attitudes with regard to the patient-physician-relationship. This relationship can be disturbed. Patients’ rights to

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information and participation, doctors' freedom to practice their profession, and increasing legal and economic restrictions do not always go together well.

Two questions arise:

- 1.) Can patients in rehabilitation be calculated like objects or things, particularly by use of the custom tailored approach?
- 2.) Can principles and targets of Total Quality Management be transferred to rehabilitation, particularly to rehabilitation of TBI-Patients?

About 100 years ago quality management has been developed for industrial enterprises to improve the cost-benefit relation. Quality management was necessary for benchmarking, competition, and successful development. Since the 1960^{ies} and 1970^{ies} a development boom of medical knowledge and medical industry can be observed.

Economic conditions strongly affect social systems and health-care services. However, in contrast to the custom-oriented free market rehabilitation can not act freely in this market, due to legal restrictions. Rehabilitation patients cannot choose their pension insurance. They cannot decide which rehab centre they wish to enter.

Therefore the principles and targets of quality management in total cannot be transferred to rehabilitation services.

II Paradigm-shifts

4 Paradigm-shifts - until 1980

Let me outline shortly how quality management has been established in health-care and rehabilitation taking into account the different perspectives of the main participants of the health-care market.

Until the 1980^{ies} the industrial quality management has changed its focus from error control to steering control of total structures, processes and outcomes of the enterprise. The Deming Plan-Do-Check-Act cycle was applied.

In those times the World Health Organization developed the International Classification of Impairment, Disability and Handicap. This was a deficit-oriented understanding of health and disability according to the medical model: Impairment of body structure or mental function cause disabilities, and disabilities cause social handicaps. The result was a negative image of disabled people.

Health insurances had another perspective on quality. In Germany they paid hospitals for each day of stay for each patient.

In hospitals quality thinking focused on the patient's survival and the reduction of disability. In those times rehabilitation often was not offered.

Patients were understood to be passive partners, dependent on the doctor's advice.

5 1980-2000

Within the period 1980 to 2000 the paradigm shifted once more.

In industrial consumer production steering control changed to comprehensive quality assurance and quality management.

In 1980 the WHO published the ICIDH-2. This classification focused on the level of activity and participation in the context of everyday life and community. It did not look at any handicap. The terms activity and participation change the understanding of a person's health-problem in a positive way according to the social model of disability.

In Germany, the "Movement for the Rehabilitation of Brain Injured People" developed. It was supported by politicians, health-authorities, health-insurances, some scientific neurological and neurosurgical societies, and the Federal Association for Rehabilitation. All over the country, early rehabilitation wards were built in acute hospitals with ICU wards or in traditional rehabilitation centres.

For the first time the Phase Model of Neurological Rehabilitation was developed by the Federal Association of Rehabilitation with the help of scientific societies and self-help organizations. For the first time the Association of Neurological-Neurosurgical Early Rehabilitation developed guidelines for the treatment of brain-injured people.

6 Phase Model of Neurologic Rehabilitation

Some specific characteristics of rehabilitation can be marked as a standard of quality: Rehabilitation is holistic, comprehensive, single patient-oriented, multi-, inter- and transdisciplinary, multiperspective, integrative, and participative.

This phase model demonstrates several steps or "milestones" forming a dynamic process of remission and recovery.

The rehabilitation process follows a time axis beginning with the impact of the lesion, the emergency and acute management with resuscitation procedures (Phase A), the early and post-acute rehabilitation (Phases B to D), the vocational and social reintegration (Phase E) and the long-term care after the patient's return to the family or his or her discharge to a nursing home (Phase F).

According to Lurija's culture-historical theory each "milestone" on the way of recovery can be understood as the "next zone" of the patient's development. This development is empowered by other people's assistance, living together in a social context.

These changes in rehabilitation have occurred also due to the rising amount of knowledge about the great potentials of plasticity and learning of the human brain.

Rehabilitation now aims at social inclusion and participation in social life for everybody, independently of the state of consciousness or the kind or level of disability.

Health-insurances established comprehensive quality assurance systems in order to increase the efficiency of rehabilitation structures, processes, outcomes, and patient's satisfaction, and to reduce expenses.

More and more, the patient has become an active partner.

7 Since 2000

Since 2000 industry and other services now have established total quality management systems. I wish to quote the director of the University of Medicine of Heidelberg

“The quality of hospitals requires: a vision uniting all contributing agents, measurable aims, the mobilisation of all staff, a carefully co-ordinated plan of action for the hospital as a whole, perspective planning in accordance with the hospital's aims, documentation of such planning, and a target-oriented evaluation of results.”

Total quality management comprehensively takes into account products and customers, employees, environmental conditions, and bench-marking.

In 2001, the International Classification of Functioning, Disability and Health of the WHO shifted the target of rehabilitation at strict social reintegration and participation. Following this purpose in 2001 the German Federal Government legalized the right of entire social integration, participation and inclusion for everybody, independent of the kind and level of disability.

Research on neuroplasticity and recovery of function have shown that there is a potential of the social brain for life-long improvement and life-long learning.

Within the last two decades like in Germany in several European countries networks of long-term nursing homes have been established for people with severest brain injuries, living with unresponsive wakefulness syndrome or minimally responsive states.

Patients and their families have been discovered as competent partners for shared decision making.

In 2007 for the first time guidelines for quality management of apallic syndrome / vegetative state patients were published by an EFNS subgroup. The management aimed at the social reintegration of patients or has to guarantee humanistic active nursing if treatment fails.

8 UN-Convention

In 2008 the Convention on the Rights of Persons with Disabilities of the United Nations declared in article 26 that nations have, quote,

“to enable persons with disabilities to full inclusion and participation in all aspects of life.”

II Teamwork – core process in rehabilitation

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Crosby (1979), one of the pioneers of total quality management reminds us, quote, “Quality starts with human beings, not with things. Who wants to change quality at first has to target at the inner attitudes of the employees.”

Teamwork is the core process of rehabilitation and it is crucial for quality development. Its manner of organization is flat hierarchy.

10 ICF-oriented rehab planning

The quality of rehabilitation team-work depends on the team’s capabilities and resources. Team quality and good team practice require continuous assessments, team conferences, individualized treatment planning, and a weekly goal-setting.

This dynamic process enables the team-conference to adapt their goals to the patient’s wishes and needs, and this enables the patients to improve their level of daily activities and to learn how to participate in family and social life step by step.

11 Participation from the very beginning

Participation starts at the very beginning of in-patient rehabilitation. The team has to look at the patient’s next zone of development. The mobilization from bed to wheelchair or joining the breakfast-group in the day room are first steps to improve the patients’ capabilities of participation.

Further, participation is an important method to re-orientate a patient’s wishes and interests to his or her real life-situation. Extending activities like visits to the hospital’s cafeteria and garden, therapeutic visits at home, and home-oriented training can help the patients and their families to learn how to handle barriers and resources within typical social areas.

The results of such treatment and training techniques have to be fed back into the team conference. They must be evaluated carefully for further treatment planning and the development of social perspectives for the single patient.

In contrast to this positive experience, today, rehabilitation services are forced to work more and more efficiently to cut down expenses.

In 2007 the Federal Government of Germany legalized quality assurance systems as obligatory for every hospital.

III QM in Rehabilitation

12 QM in Rehabilitation

In order to evaluate the quality of rehabilitation several assessment tools have been developed to measure the functional outcome of individual patients or of all patients in total. These outcome measures are a good basis for the evaluation of the effectiveness and quality of rehabilitation treatment.

With regard to the quality of integration, several measures have been developed like the health-related Quality of Life in Traumatic Brain Injury (QUOLIBRI) (Steinbüchel et al 2005), the Quality of Community Integration (QoCI) (Truelle et al 2010), Quality of Life Satisfaction (QoLS) (Oswald et al 2009), and also the Questionnaire Sense of Coherence (Q-SOC) (Antonovsky 1997). We will hear about some of this research during this session later on.

13 Evidence Based Medicine in neurological rehabilitation

In the past 10 to 20 years, the amount of studies dealing with evidenced based medicine in rehabilitation and neurorehabilitation has increased. This method can create well organized knowledge in order to evaluate the effectiveness of treatment and to shape physicians' decision making.

The critical question is: can evidence based medicine help the physician to improve his decision making for a particular patient ?

In 1996 Sackett stated, quote,

“Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of *individual* patients. The practice of evidence based medicine means *integrating individual clinical expertise with the best available external clinical evidence from systematic research.*“

The principle for evidence based medicine is based on the results of the quality of studies which try to collect certain information about possible treatments. The critical question is how far can principles of evidence based practice be applied in rehabilitation training techniques within clinical everyday rehabilitation?

14 Level of evidence

A hierarchical cascade of levels of evidence, which runs from top-level I down to level IV has been established. Level Ia means that there exists a meta-analysis summarizing several randomised controlled clinical trials. According to evidence based thinking, level Ia-studies have the highest quality. Quantitative statistics can produce reliable knowledge as a basis of certain recommendations for special guidelines in order to improve quality of decision making.

Case reports, narratives, expert opinions and patient's experience have the lowest level of evidence and quality. The reason for this may be found in “insufficient” methods. The therapeutic effects in a single case only are described or reported. Thus, the results could not be reliable for certain decision making.

According to this thinking the quality of the method applied in the study determines the level of evidence.

Today studies most frequently apply biometrical methods and group-statistic calculations, which are derived from mathematical logic. This mathematical logic calculates patients and their subjective sensations or behaviours like objects. The critical question is how far can patients be calculated like objects?

15 Reasons for a critical debate

Ranking levels of evidence to demonstrate quality in rehabilitation is under ongoing critical debate for several reasons:

- Complexity of life of human beings cannot be reduced to calculations and simple costs.
- Patients cannot be reduced to objects or customs.
- Case reports and patients' narratives always have been a vital part of medicine.
- Severest brain injured patients who cannot respond or show hidden or minimal behaviour only cannot be applied to regular testing.
- Research method and design must be adapted to the capacities of low-level patients by use of quality research.
- Low-level evidence is an integral part of evidence based thinking and quality research! Remember Sackett!

16 Integration of narrative and empirical quality of medicine

The holistic philosophy of rehabilitation considers the quality-oriented approach of *narrative* based medicine to be complementary to the quantity-oriented approach of *empirical* based medicine.

In the past decades, narrative medicine studies on particular patients have shown a growing amount of low- and mid-level therapeutic effects. The research design of these studies often bases on qualitative intersubjective methods which are controlled by supervision and reflection, like in music therapy or in other recreational therapies.

These studies are based on a sophisticated multiperspective analysis of the person-environment relation in order to understand the patient's complex biopsychosocial situation.

To improve rehabilitation, scientific research must be translated into practical applications, and vice versa. That means a translational research paradigm. Empirical based knowledge can be transferred from "bench" to "bedside" as well as narrative based knowledge can transferred from "bedside" to "bench".

Thus, research integrates subjective, intersubjective and objective perspectives as well as qualitative and quantitative methods. Research integrates different kinds of scientific knowledge approaches, i.e. empirical-statistics, phenomenology, and hermeneutic.

17 Patients' expertise for rehabilitation research

Patients and families in rehabilitation programmes often develop cognitive concepts of good quality in health care for them. Until now there is little systematic knowledge about the role of patients' views on quality in rehabilitation and how to participate patients into research.

A recent study at the University of Leipzig demonstrated that patients report ideas about indicators and preconditions of good quality in rehabilitation care. However, patients' quality concepts differ in some aspects from the quality definition of health-care professionals.

Research gives some evidence that perspectives of the patients and their families on quality definitions are useful. Patients' views have an impact on how rehabilitation facilities are selected and used. They also influence programme elements, patients' satisfaction, and long-term outcome. Their ideas can help to gain a deeper understanding of patients' and families' needs. Patients are experts of their own life, particularly with regard to barriers, resources and support of special needs.

They can point out specific problems to the researchers with regard to their specific experiences and views on life-satisfaction, quality of life and quality of community integration.

At last, patients' views are necessary for extension and completion of community integration and participation evaluation.

Thus, research should be driven by both the normative empirical needs of health insurances and health-care politics and the factual patients' narrative expertise.

18 NIH Consensus report

This does not seem to be fantastic. Recently, the Consensus Conference of the National Institutes of Health on the project "The customer perspective on existing models of rehabilitation for traumatic brain injury" reported about three patient-driven research projects: The Clubhouse project, the Learning in Natural Community project LINCS, and the Life after Brain-Injury: Office of Special Education & Rehab Services project OSERS.

IV Conclusion

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Finally, I will try to give an answer to the question how the quality of rehabilitation research could be managed and improved without contradictions:

First, patients' wishes for life-quality and life-satisfaction should be assessed.
Second, patients' experiences, visions and recommendations should be integrated into research design.

Third, the results of studies should be discussed in public meetings among patients, researchers, clinicians, health insurances, and health authorities.

Forth, rehabilitation research should be translated into clinical practice and quality management programmes.

Fifth, research should be extended to disability studies and participative evaluation.

Sixth: Decision making on quality in rehabilitation and research should be organized on both regional and federal level.

20 QM in neurorehabilitation - an overall integrating and developing process

Thus, quality management in rehabilitation may have the power of an overall integrating and developing process to improve outcome, participation, and life satisfaction, as a benefit for the whole society.

Thank you very much for your attention!