



Quality of life and patient functioning in clinical guidelines: a statement of G-I-N's Allied Health Community

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Members Allied Health committee

- **Sarah Bazin**, Heart of England NHS Foundation Trust, England
- **Dorien van Benthem**, Comprehensive Cancer Centre (IKNL), the Netherlands
- **Dunja Dreesens**, Dutch Council for the Quality of Healthcare, the Netherlands
- **Simone van Dulmen**, Radboud University Nijmegen Medical Centre
- **Jenny Gordon**, Royal college of Nursing, England
- **Sue Lukersmith**, Independent guideline developer, Australia
- **Josephine Muxlow**, Health Canada First Nations & Inuit Health
- **Elaine Santa Mina**, Ryerson University Toronto, Canada
- **Philip van der Wees**, Royal Dutch Society for Physical Therapy (KNGF), the Netherlands

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Objective

Objective of this project

To develop a position paper to promote patient functioning and Health Related Quality of Life (HRQoL) in guideline development and implementation

Objective of this session

- To discuss our vision about the concepts related to HRQoL in guidelines
- To identify barriers and facilitators for implementation

Funding

Royal Dutch Society for Physical Therapy (KNGF)
Dutch Counsel of Quality of Healthcare (Regieraad)

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Method

- Three discussion rounds with AHC
- Literature search
- Open access wiki discussion board
- Email to all G-I-N members, experts and stakeholders

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Allied Health Community Allied Health Community G-I-N

Introduction
Background and method
Definition Quality Of Life
ICF
Shared Decision-Making
Outcome measurements
What's next?
Who are we
Call us on

Definition Quality Of Life

Definition

Although QOL and HRQOL are often used interchangeably, they are in fact different constructs. **[i]** *Quality of life* or the difference, at a particular point in time, between the hopes and expectations of an individual and the various domains. **[ii]** A general accepted definition of *Health Related Quality of Life (HRQOL)* is the patient's physical, psychological, social functioning and well-being. **[iii]** HRQOL concerns those domains that are broader holistic perspective. It refers to a concept of health in terms of a set of health domains ('under the hood' as a biological but also as a social entity. **[iv]** Multiple health care providers use the construct of QOL in terms of a person's satisfaction with his or her life situation (even during serious or chronic illness), and (3) as an outcome measure.

Why in guidelines

The increasing prevalence of chronic disease in developed countries has led to an increased focus on the impact of disease on quality of life. However, as it has become an important goal of treatment and marker of success in health care interventions. **[v]** Patient's perspective and expectations can be identified by using quality of life measurements, as they can be considered valid indicators of service needs and intervention outcomes. Self-assessed health status also provides information on health. **[vi]**

Question (please motivate your answer):

1. Should the concept of Health Related Quality of Life be used in all guidelines?

[i] Davis E, Waters, E. Correspondence Re: Studies on Health-Related Quality of Life and Economic Evaluation. *Medical Care*. 1997;35(12):1211-1212.


[ii] Bjornson KF, McLaughlin JF. The measurement of health-related quality of life (HRQOL) in children with chronic illness. *Journal of Clinical Pharmacy and Therapeutics*. 1998;23(1):1-10.

[iii] Committee for Medicinal Products for Human Use. Reflection Paper on the Regulatory Guidance for the Assessment of Health-Related Quality of Life in Clinical Trials. London, UK; European Medicines Agency, 2005.

[iv] Cleza A, Bickenbach J, Chatterji S. The ICF as a conceptual platform to specify and discuss health and disability. *International Journal of Rehabilitation Research*. 2001;25(1):1-10.

[v] Gutteling JJ, Man RA de, Busschbach JJV, Darlington A-SE. Overview of research on health-related quality of life. *Quality of Life Research*. 2001;10(1):1-10.

ENTER YOUR COMMENT HERE



A framework to inform clinical guidelines

the International Classification of Functioning Disability and Health

Sue Lukersmith

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Conceptual frameworks for health

- Medical – pre 1976
- Social – 1976 -1990's

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The Issues

- Simplified view of health
- Focus on singular elements
 - Body and physical
 - Social domain
- Imbalance between individual and environment/context
- No acknowledgement of the interaction of elements

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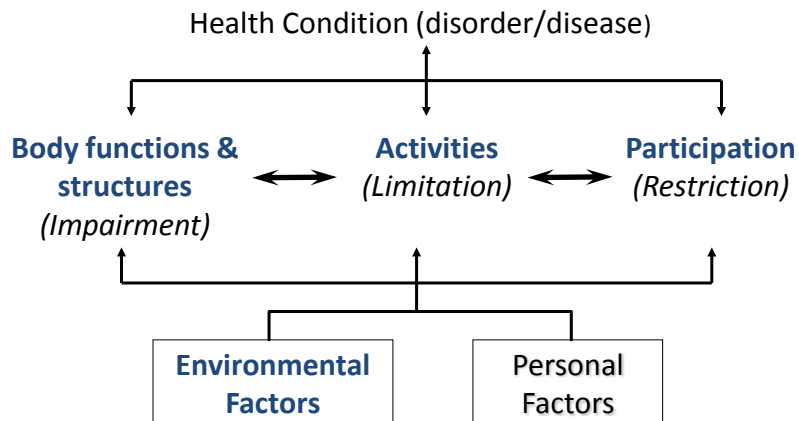
The solution in understanding

- Neither medical nor social
- Role of barriers and disability
- Complex, dynamic and multidimensional
- Bio-psychosocial 

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International Classification of Functioning (ICF) 2001 World Health Organization (WHO)

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Definitions (1)

- **Body functions** are the physiological functions of body systems (including psychological functions)
- **Body structures** are anatomical parts of the body such as organs, limbs and their components
- **Impairments** are problems in body function and structure such as significant deviation or loss

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Definitions (2)

- **Activity** is the execution of a task or action by an individual
- **Participation** is involvement in a life situation
- **Activity limitations** are difficulties an individual may have in executing activities
- **Participation restrictions** are problems an individual may experience in involvement in life situations

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Definitions (3)

- **Environmental factors** make up the physical, social and attitudinal environment in which people live and conduct their lives.

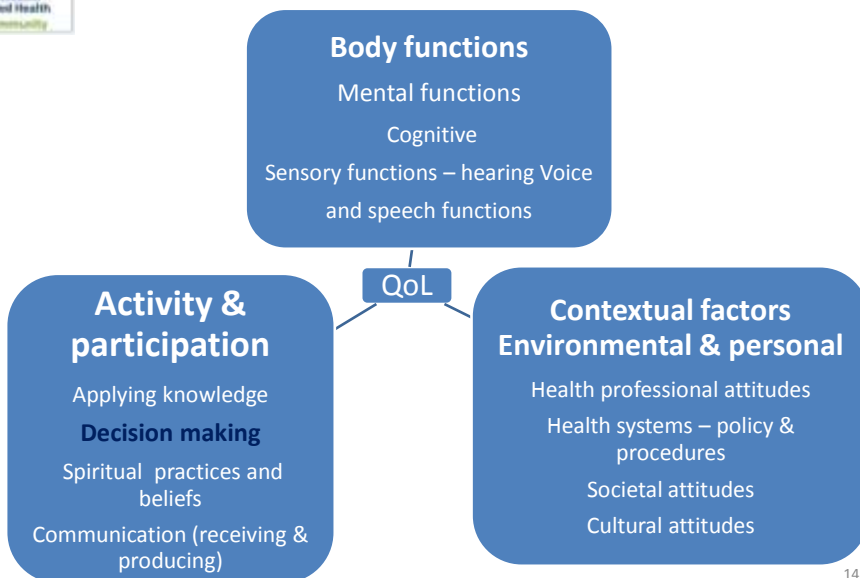
These are either barriers to or facilitators of the person's functioning.

Disability - arises from the negative interaction between health conditions, environmental and personal factors

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Functioning, disability & health



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Evolution of evidence based medicine (EBM) – clinical guidelines

“The explicit and judicious use of the best available evidence”
(Sackett 1996)

From : the expertise of the clinician and dominance of their view
(entirely clinicians making decisions about care)

- Excludes other forms of knowledge
- = ??? Wise use of best evidence

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Evolution of evidence based medicine (EBM) – clinical guidelines

TOWARDS (last 10 years)

- Recognition of the influence of preferences (personal) and contextual factors e.g values of the patient
 - Patient preferences
 - Patient’s context
 - Barriers and facilitators that contribute to treatment compliance and outcomes
- These are increasingly been recognized in the move from evidence to recommendations e.g GRADE

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Interface of CPG & the ICF

ICF	Guidelines
Body function and structure	Capacity for patient's decision making – cognitive, communication (avoid assumptions)
Activity and participation	Decision making = making a choice among options, implementing the choice and evaluating the effects of the choice(d150) Shared decision making Better outcomes from treatment Enhanced quality of life

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Interface of CPG & the ICF cont'd

ICF	Guidelines
Environmental barriers or facilitators (e310 to e599)	Opportunity - Guideline can facilitate - system and policy recognition of patient's right for choice – shared decision making Attitude of clinician Attitude of society Cultural considerations Education & information on options Opportunity Support and relationship –shared decision making, supported decision making
Personal factors (barriers or facilitators) not coded	Personal attitude Adjustment to health condition

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The ICF.....

- Informs guidelines
- Provides a common language
- Helps to understand a person's functioning and health
- Recognizes the complex interaction of components, barriers and facilitators
- Reinforces the need for consideration of patient preferences and shared decisions
- Can be used with outcome measures

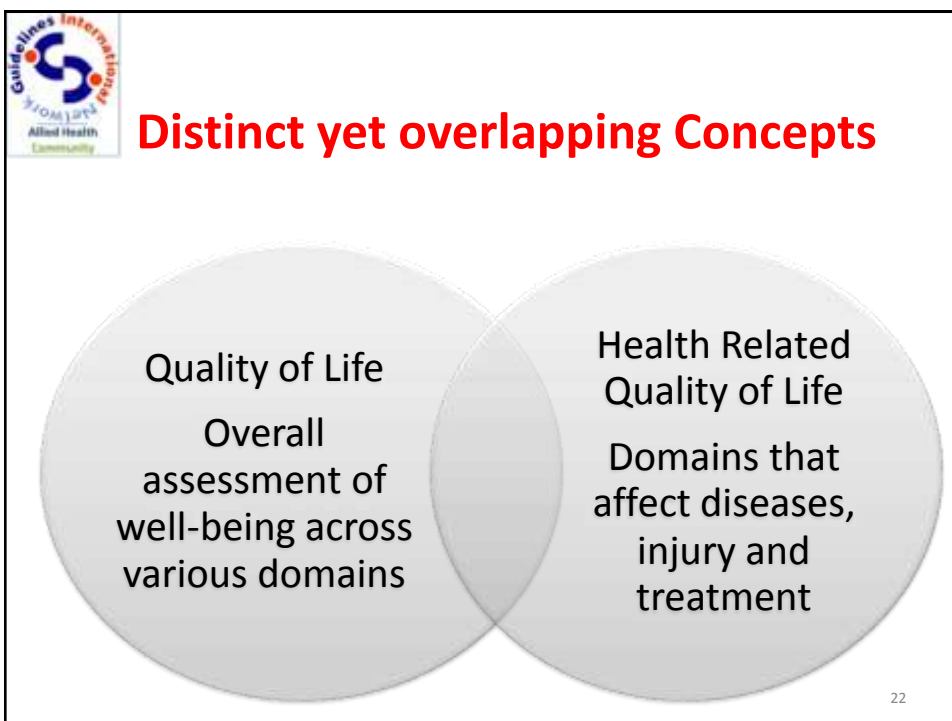
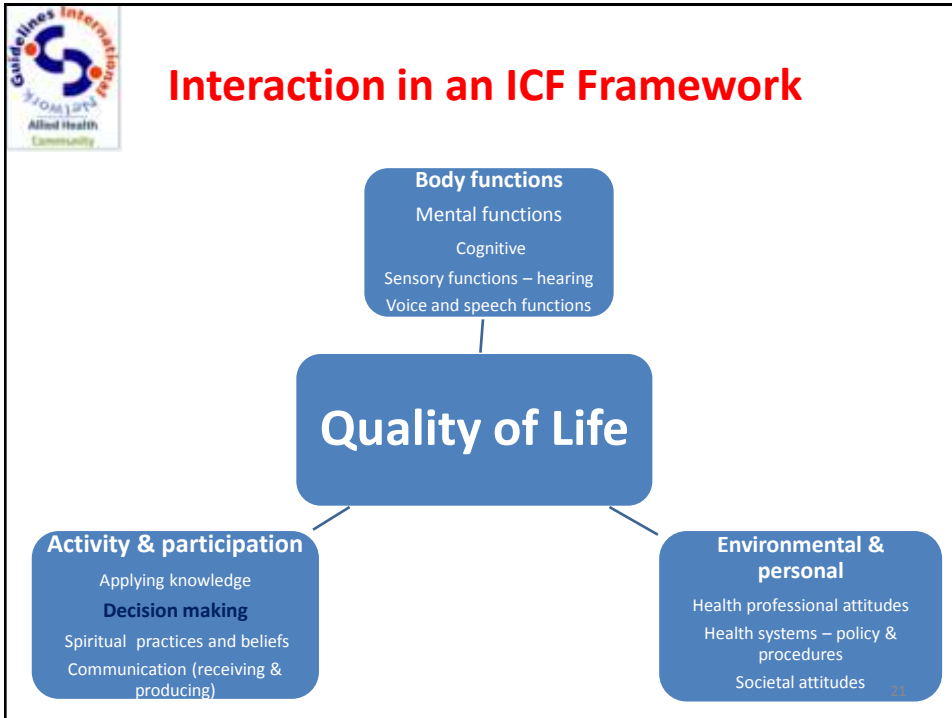
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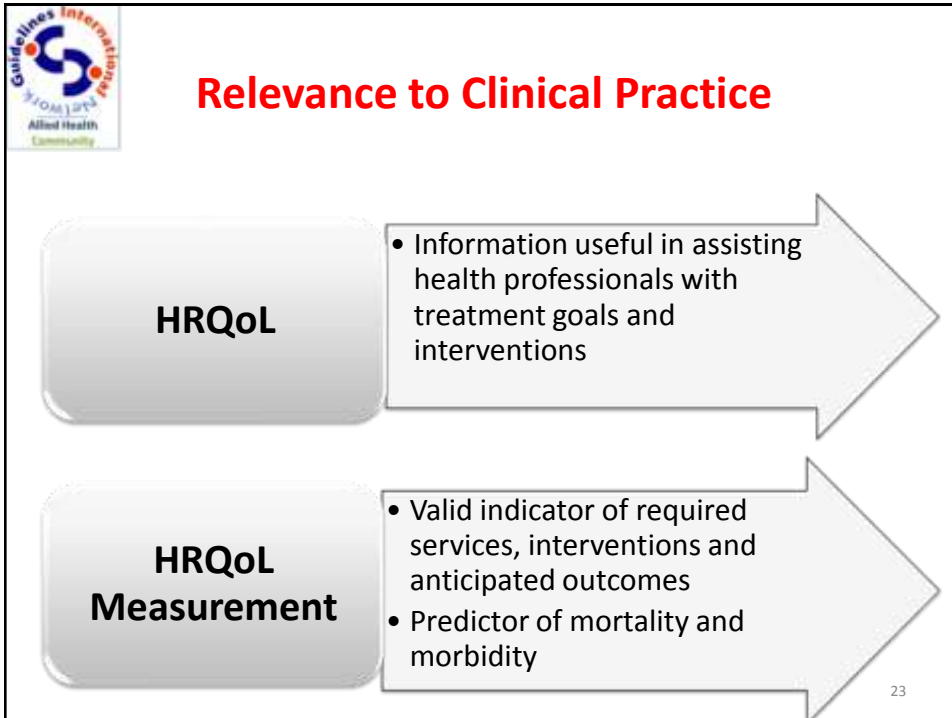


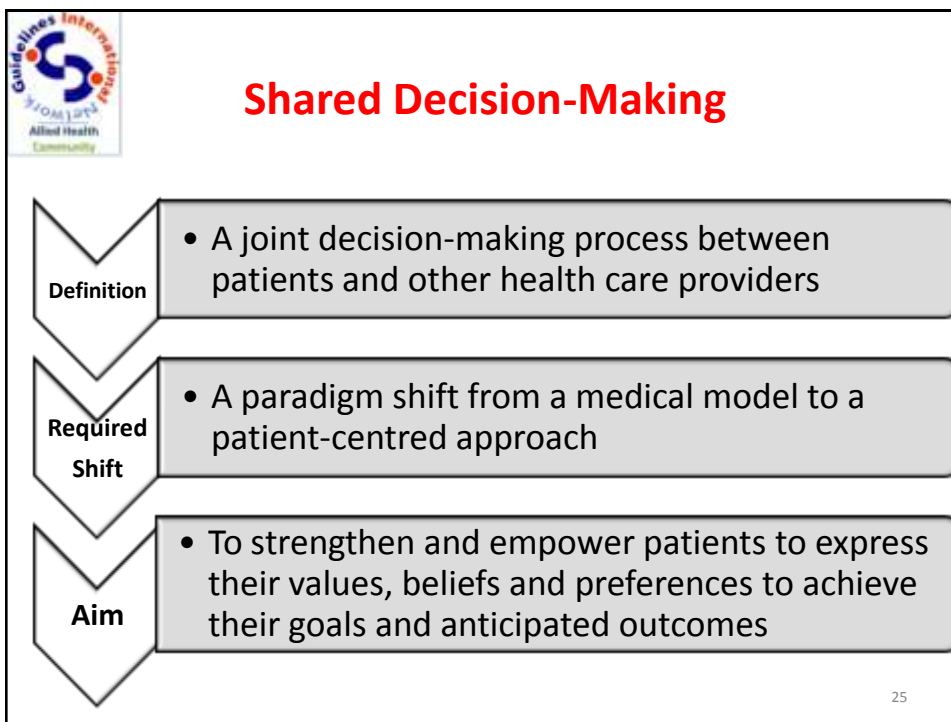
Health Related Quality of Life Concept Within Clinical Guidelines

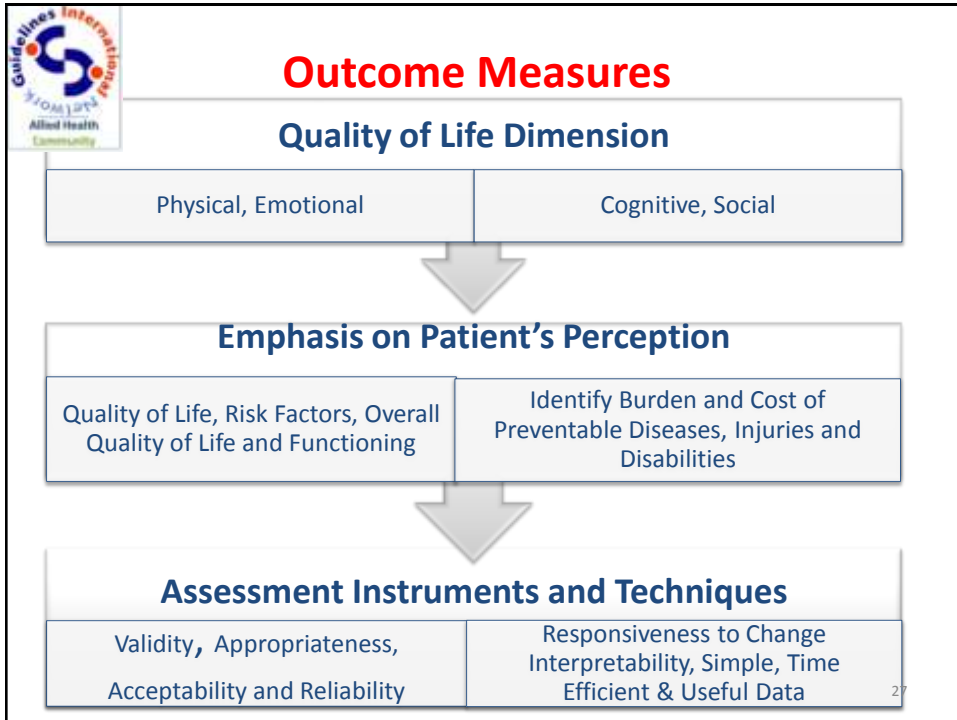
Josephine Muxlow

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Facilitated Discussion

Elaine Santa Mina

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Response on wiki discussion board

Total 38 comments

14 responders

- General comments (5)
- Definition of quality of life (10)
- ICF as a conceptual framework (5)
- Shared Decision Making (10)
- Outcome measures (8)

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General Comments

1. Do you think that it is on the **important to develop a position paper** inclusion of HRQoL, ICF and SDM as recommendations within guideline development?

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2. Should the concept:
***Health Related Quality of Life
(HRQoL)***
be used in all guidelines?

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3. Is the concept:
***International Classification of
Functioning (ICF)***
generally accepted by guideline
developers, implementers and health
care providers?

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4. Is **ICF**
a good construct
to promote
HRQoL?

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5. Is the concept
Shared Decision Making (SDM)
generally accepted by guideline
developers, implementers and
health care providers?

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6. Should **decision making aides** be recommended in guidelines?

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7. What **dissemination strategies** for this position paper would you recommend to our allied health committee?

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8. What **barriers to dissemination and/or implementation** of HRQoL, ICF, and SDM recommendations within guideline development would you anticipate?

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9. Do you have any suggestions on what level we should start the implementation?

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Thank You!

Guideline Osteoarthritis of the National Institute for Health and Clinical Excellence (NICE)

- Why: This guideline provides an excellent example of how a patient centered approach is used in a guideline.
- The holistic assessment includes the following topics: social, existing thoughts, occupational, mood, quality of sleep, support network, other musculoskeletal pain, attitudes to exercise, co morbidity, pain assessment and points the relevant treatment options

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Case example

Man, 40 years, knee problems since ½ year: starting problems, especially in the morning, pain in the knee during and sitting > 1hour and after playing tennis.

Intermittent: swelling in the joint and back pain.

Pain, stiffness and swelling increased since 4 weeks. Patient started to move less and stopped playing tennis. Patient feels depressed and isolated because tennis is an important social activity and physical activity in general is important for his emotional wellbeing.

Work: administrative

Sport: tennis, 2/3 times a week, (except for the last 4 weeks because of pain and anxiousness about the cause of the pain)

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Managementplan:

Patient information:

- information about the disease
- provocation of tennis (not most favorable activity)
- function of cold packs
- explanation of back pain (compensation)

Treatment options:

- exercise therapy and postural correction: physical therapy or fitness
- Medication: paracetamol, NSAID's (risks and benefits)

Self management: behavioral changes: losing weight

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Informed and shared decision

- Treatment: start with physical therapy because patient has had bad experience with self-training in a fitness school.
- Tennis: start quietly, not playing tennis two days in a row, use of cold pack
- Medication: paracetamol on a regular base
- Work: more frequently moving during work time
- dietitian for losing weight, additional activity

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