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1 Introduction I

Patient relevant health outcomes (WHO report 2002)

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    graph TD
      A["Mortality  
Morbidity  
Quality of life (QoL)"] --> B["Quantitative & Qualitative  
Research"]
      B --> C["e.g. Randomized  
clinical trial"]
      B --> D["e.g. Focus group  
discussion"]
    
```

2 Introduction II

What is Evidence Based Practice?

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    graph TD
      A["Clinical Expertise"] --> EBP
      B["Best Research Evidence"] --> EBP
      C["Patient Values & Preferences"] --> EBP
    
```

Fig.1 Evidence based practice
EBP consisting of physicians' and patients' choices tempered by research evidence, adapted Haynes et al., BMJ 2002

3 Methods

Qualitative Research: Exploring patient needs in two focus group discussions

- N= 25 patients (aged 24-82 yrs., 18 f.) with **chronic endocrine diseases** were invited through a local support group.
- Qualitative social research analysis based on two **focus group discussions** according to a **predefined protocol** which had been reviewed by an endocrinologist, a sociologist and an epidemiologist.
- Audio-recordings were transcribed and analysed according to the principles of Grounded Theory Methodology by Anselm Strauss using the software MAXQDA.

4 Results

Factors influencing QoL

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    graph TD
      subgraph NegativeFactors [ ]
        direction TB
        N1[Health burden]
        N2[Uncertainty (concerning the illness)]
        N3[Stress due to stigmatization]
        N4[Stress regarding the future personal development]
      end
      subgraph PositiveFactors [ ]
        direction TB
        P1[Therapeutic aspects perceived to be effective]
        P2[Support of social network]
        P3[Participation in social life]
        P4[Personal development of coping strategies]
      end
      N1 --> QoL[QoL]
      N2 --> QoL
      N3 --> QoL
      N4 --> QoL
      P1 --> QoL
      P2 --> QoL
      P3 --> QoL
      P4 --> QoL
      I1["Critical importance of providing information, especially in the context of a complex disease"]
      I2["Comprehensive treatment approaches"]
      I3["Need for patients' own initiative to search for information and gain certainty"]
      I1 --> QoL
      I2 --> QoL
      I3 --> QoL
    
```

5 Conclusion

Through this quantitative study, in contrast to results of qualitative studies, we identified **feelings of uncertainty and insecurity** regarding both the illness itself and the treatment as one the main obstacles for a good coping strategy.

Patients emphasized the **pivotal role of health care professionals in providing information and guidance** – a role that is underestimated by physicians according to patients' opinion.

The role of structured patient management programs targeting these topics should be evaluated.