Health-related QoL in chronic neuroendocrine diseases: Qualitative research



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discussion

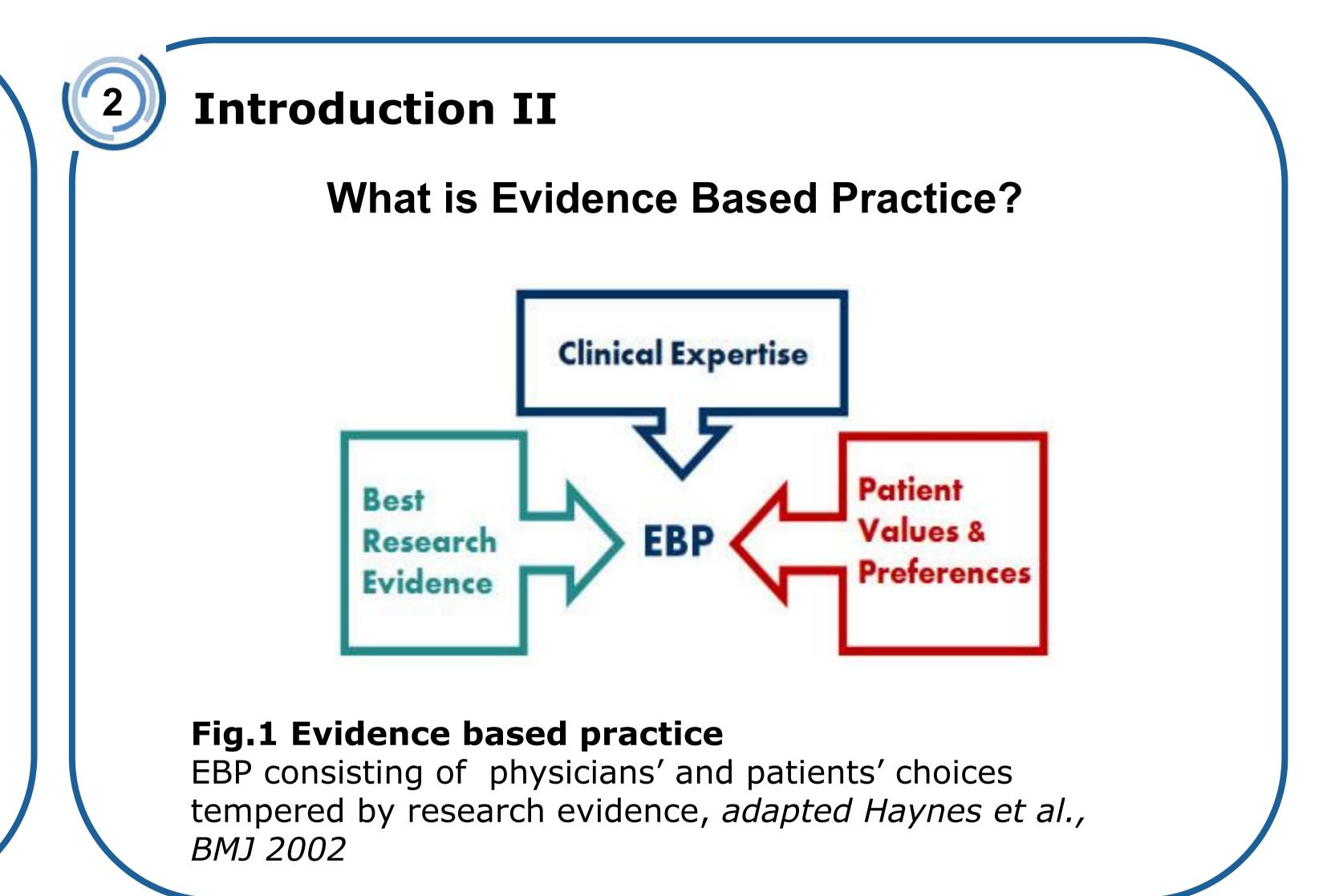
Results

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Introduction I Patient relevant health outcomes (WHO report 2002) **Mortality Morbidity Quality of life (QoL) Quantitative & Qualitative** Research e.g. Focus group



Methods

Qualitative Research: Exploring patient needs in two focus group discussions

e.g. Randomized

clinical trial

- 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 analysed according to the principles of Grounded Theory Methodology by Anselm Strauss using the software MAXQDA.

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.

Health burden Uncertainty (concerning the illness) Stress due to stigmatization Stress regarding the future personal development ✓ Therapeutic aspects perceived to be effective ✓ Support of social network QoL ✓ Participation in social life ✓ Personal development of coping strategies Critical importance of providing information, especially in the context of a complex disease Comprehensive treatment approaches Need for patients' own initiative to search for information and gain certainty

Factors influencing QoL

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