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Key Issues in Paediatric Nutritional Support

Quality of Life Issues

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Quality of Life Issues

Inflammatory bowel disease as an example

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Inflammatory bowel diseases

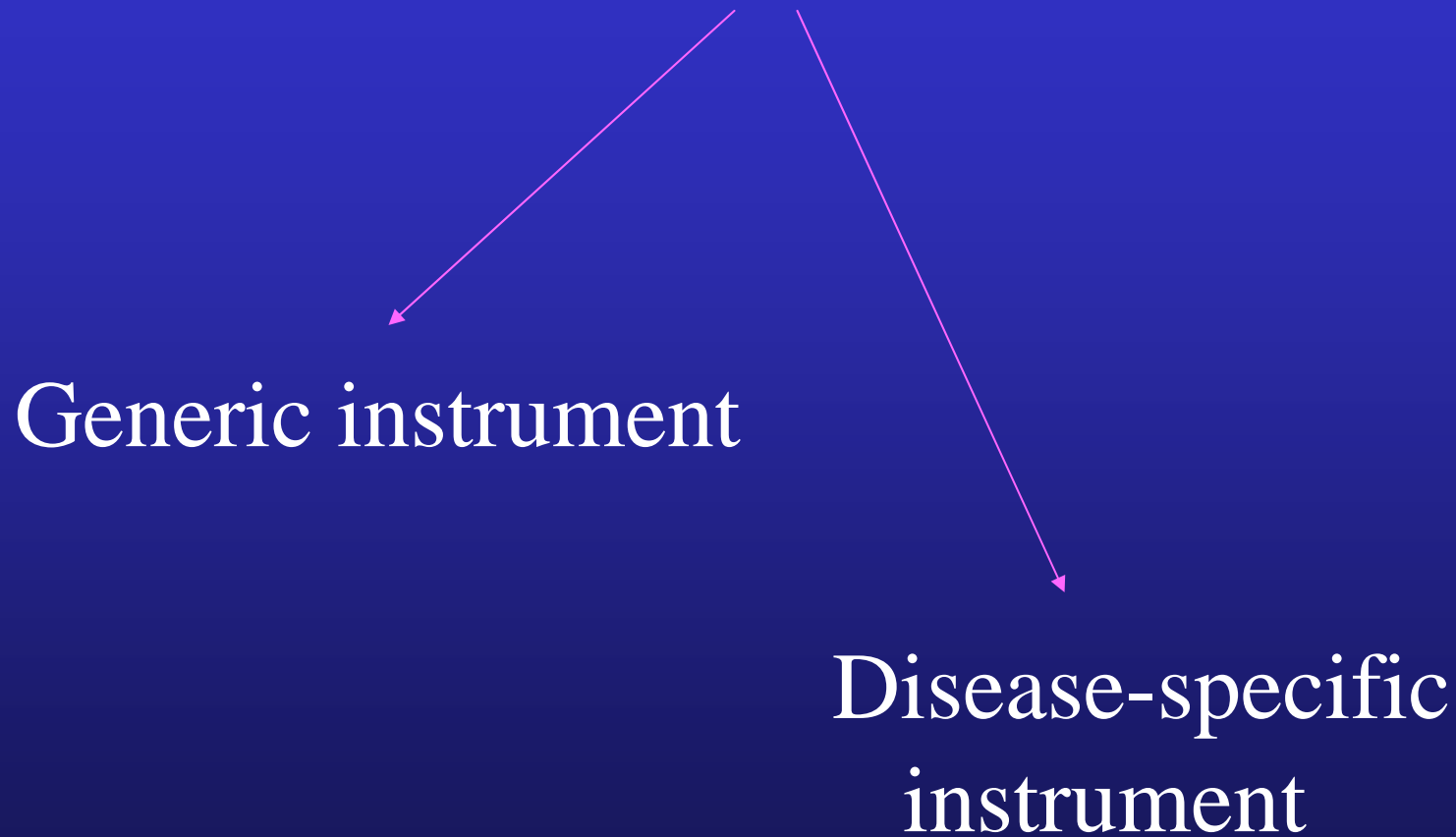
Overview

- What is QoL?
- Why QoL?
- Example of QoL as outcome in a clinical study
- Look at the future

What is QoL

- Patient perception of physical, emotional and social well-being/functioning
- QoL concept is applicable to any disease
- Patient-centred
- Self-completed questionnaire

QoL measurement



Why: we will all be involved

- No large improvements in clinical outcomes
- QoL is considered important outcome
- FDA requires QoL measurements with all new drugs

Why important in nutrition

- In children, nutrition has numerous effects
- Relatively few side effects
- Long term outcome
- Chronic nature

Conclusion

QoL measures something else than
disease activity!

Summary

- QoL needs clear definition by users
- QoL research is important
- Need for QoL research in paediatric nutrition

Key references

- Spilker B. 'Quality of Life and Pharmacoeconomics in Clinical Trials', 2nd ed. Lippincott-Raven Publishers 1996.
- Detsky et al. 'Quality of life of patients on long-term total parenteral nutrition at home', J Gen Intern Med 1986; 1: 26-33.
- Loonen HJ et al. 'Measuring health-related quality of life in pediatric patients', JPGN 2001; 32: 523-526.
- Jeppesen PB et al'. 'Quality of life of patients receiving home parenteral nutrition', Gut 1999; 44: 844-852.