



UZ
LEUVEN



Cultural differences –nurse experience

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| | Number | Mean age at diagnosis | Pancreatic insufficiency | Mean FEV ₁ % | Mutation DF508 Homozygous | Mutation DF508 Heterozygous | Other mutation |
|-----------------------|-----------------|------------------------------|--------------------------|-------------------------|---------------------------|-----------------------------|----------------|
| Children All | 7 (2 M) 103 | 1,0 Y (0,1 – 2,7) 1,1 Y | 7 | 84% / 94,4% | 3 | / | 4 |
| Adults All | 10 (4 M) 154 | 12,5 Y (0,1 – 65,2) 7,7 Y | 9 | 48,3% / 67,1% | 2 | 1 | 7 |
| Transplant Patient | 1 | 1,5 Y | | | | | |
| All | 93 | | | | | | |

Information

Given by patient not well understood by nurse

Older child / patient translates for parents (... sometimes only what he/she likes to translate)

Qualified interpreter not for “urgent” talks available

Complexity of therapy

Performing new treatments: not well understood by patient / parents

Difficult to explain necessity of treatment to patient / parents

Missing appointments: Mother involved in care but depends on others for transport to the hospital

Hospitalization: boyfriend staying overnight, concerns for food (mealtimes/ meat)

Pregnancy: important for partner, despite low FEV₁

Medication: pork-gelatin capsules

Motivation for compliance / religious belief

Pain experience



