



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 All	1 93	1,5 Y					



<u>Information</u>

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

UZ LEUVEN Culture



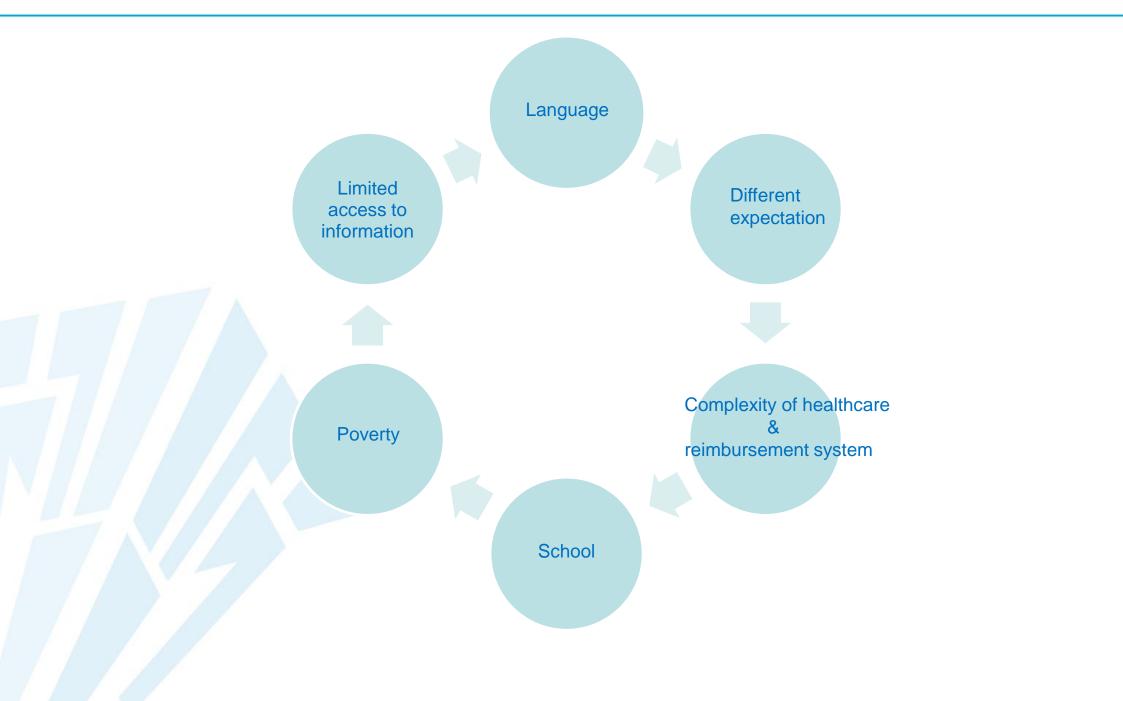
Missing <u>appointments</u>: Mother involved in care but depends on others for transport to the hospital

<u>Hospitalization</u>: 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

UZ LEUVEN Society related difficulties





Thank you







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