

Challenges facing different cultures

Patients experiences

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First patient:

- ➔ **Girl, H., 13 years old**
- ➔ **Maroccan, born in Belgium**
- ➔ **Parents immigrated**
- ➔ **Has 2 healthy, younger sisters**
- ➔ **Muslim family**

- ➔ **Mother and H. say there are not many cultural differences about illness and treatment**
- ➔ **H. does not get a lot of questions or annoying comments about illness, treatment**
- ➔ **Family accepts the therapy, because the doctor says it's necessary**

- **It is primarily the mother who takes care of her daughter. Father is not really involved**
- **Mom can't read nor write. Help from home-physiotherapist and neighbour for administration needed**
- **Language problem: interpreter**
- **H. needed to be in charge of her therapy at early age**

- **H. feels better in Marocco because of the milder climate, not that often sick**
- **Ramadan: H. wants to participate, but not possible due to CF**
- **Wearing a veil: H. is not willing now, mother prefers she would, but accepts the choice of her daughter**
- **Parents understand H. is growing up in 2 different cultures**

Conclusions:

- ➔ **Although the parents are strict Muslim, they perform and accept all aspects of the treatment**
- ➔ **Parents respect the autonomy of their daughter**
- ➔ **As caregiver: awareness for language barrier and illiteracy**

Second patient:

- ➔ **S. is a Turkish lady of 27 years old**
- ➔ **Had a brother who died from CF 2 years ago, he was then 27.**
- ➔ **Has 2 healthy brothers and 1 healthy sister, all younger**
- ➔ **Has a daughter of 2 years old**
- ➔ **Muslim**

Background

- **S. states there is a difference between culture and religion, are different dimensions in her life**
- **Coping and living with CF is determined by her religion and the culture she lives in**
- **She says her disease is ‘from Allah’, she accepts it and Allah wants her to take good care of herself, so she does**

Background

- ➔ **S. has hope new investigations and new treatments will be available, because Allah will take care of that**
- ➔ **S. says there is a strong connection between Allah and nature**

Background

- ➔ Her brother didn't cope so well with his disease, he was angry for it
- ➔ He was also angry at his parents, he blamed them for the disease he got because they got married
- ➔ The brother also believed in Allah, though was more a rebellion

Background

- ➔ **S. feels culture determines the type of contacts and the network you are in, family is crucial and comforting**
- ➔ **On the other hand: a lot of people want to know a lot about you and there may be gossiping, what burdens the disease**
- ➔ **Having a disease can give the feeling of getting a label**

Family

- **Close family bound: being supported well. Understand it's hard to cope and not possible to live like a non-CF person**
- **Parents arranged marriage: found a husband whom they suspected was going to cope well with the disease of S. CF influenced the choice of husband.**

Treatment

- ➔ **Culture and religion restrict. But for instance: Creon®: necessary!**
- ➔ **Transplantation: necessary!**
- ➔ **Family expects S. to do all the things needed to help her**
- ➔ **Pregnancy: family was very positive. Even if help from lab was needed. Stimulated to take good care of herself**

- ➔ **Having children is having a family, so is essential**
- ➔ **CF was not a problem in her own family**
- ➔ **Her brother was also willing to have a baby with the help of the fertility clinic, parents fully agreed. Sadly it never came to that (he was married)**

- ➔ **S. feels there is more freedom without religion and culture. They call it ‘living like a Belgian’**

Coping

- ➔ **Network is important: family and school help educating you**
- ➔ **Discrimination: difference between Muslim and Western people, but does not feel discriminated in Belgium**
- ➔ **When comparison Belgium – Turkey: other possibilities and perspectives**

Determinants

- ➔ **Education: lower expectations from her family.**
- ➔ **Gender differences: parents wanted the same for S. as for her brother. Within her culture: men work and women take care of family. Different expectations for men and women. Women are more depending on their men.**

Determinants

- **Parent – child relationship: taking care of each other is central, also when having a disease**
- **Parents take care of their children and vice versa**
- **Freedom: is limited due to illness, but also by culture**

Determinants

- ➔ **Autonomy: is more difficult with CF, because of the continuous support of her family**
- ➔ **But is also attractive to let you be supported continuously**

- ➔ **S. is happy with her life, her husband, her daughter and she is pregnant again!**

➔ **Thank you!**