INTERNATIONAL STUDY DAY

Quality of life issues / Thomas Rating / Barcelona Oct. 4, 2013
What is quality of life? It’s the well being of an individual.

Influenced by: income, employment, family, physical and mental health, etc.

Therefor: quality of life is something very subjective / changes during process

For this reason I will only talk about my own personal experience.

Situation: married, two children aged 10 and 6 at point of diagnosis.

What do you expect? Be able to get same quality of life as before leukemia, but knowing that it will not be possible for a certain time.
CHAMBER

Long period of time (40 days)

No natural light / no feeling of day and night

Can not be with family BUT electronic devices allow contact via Skype, e-mail, Face Time, etc.

Food: could not eat / loss of weight / memory / nurses: cheering up!

Example: my son did not want to visit me!
POST CHAMBER

Food restriction: at the beginning very restrictive / cooking for family and separately for patient BUT family adopts new habits (peeling of tomato) and quality of life is not so bad

You stay at home / no restaurants / don’t go out with friends

Bathing / sun: living near Mediterranean Sea is a problem / can not play with kids at pool / always at the shadow – long sleeves
POST CHAMBER

Catheter: uncomfortable for sleeping and shower / high risk of infection

Where do I see improvement?

1.) Cleaning of catheter: following of procedures

2.) Helios / Dermatology

VERY POSITIVE!!!!!!!: Home care
POST CHAMBER

Physical changes: use of cortisone / got very fat / dislike physical aspect / reduced mobility / had to cut socks / shoes without laces

Result: feel depressed and useless / can not help anybody (specially the family)
BUT you know it is temporarily and medical staff optimistic because of good clinical evolution

Can I as a patient decide? Mesenchymal cells
POST CHAMBER

Oral GvHD: during 10 months / not many solutions and difficult area / only issue that really reduced my quality of life / could not talk during a couple of weeks / only liquid / sushi or yoghurt would have been perfect

Improvement: would have been good to get some advice on what to do during this critical period

Mask: inconvenient for breathing / at the very beginning at school, park (spring), home (family members when they caught a cold)
IMPORTANT FACTOR

Teamwork, confidence level between patient – medical staff (mutual). I have trusted all instructions and followed them and they trust me. As a result: I’ve been allowed certain ‘forbidden’ things but doing it with common sense. As a result: that improved my quality of life.
THANK YOU

FOR YOUR

ATTENTION!