OI & HEARING LOSS
HOW DOES IT AFFECT QUALITY OF LIFE

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Hello!
We are Tamara and Neus
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OSTEOGENESIS IMPERFECTA

- Most common heritable disorder of connective tissue
- Associated with fractures following relatively minor injury, blue sclerae, dentinogenesis imperfecta, increased joint mobility, short stature, pain, hearing loss
Progressive hearing loss is one of the main symptoms of OI. It affects about 50% of adult patients, it may occur in childhood, and it can be accompanied by hearing loss, pain, reduced mobility, and other symptoms.
How did you notice your hearing difficulties?
I couldn't get a word

I didn't hear/understand the teacher questions

Watching TV

I turned on the radio but I couldn't listen to the music

When someone was ringing the bell

I had tinnitus

Alarm clock

I've been one hour, ringing the door bell!!! I was thinking that something happened with you!!!

I do listen nothing.

What's she saying... I don't understand her... I will act dumb...

I'll pretend a cough... hope she stop asking me, now!!!

Don't tattle me, can't hear you!!

At classroom the teacher ask me a straight question... and it was eternal

Xiu Xiu Xiu...

XIU XIU XIU...
While talking on the phone

Labels: Lost in thoughts
Distracted
Abstent-minded
Live in another world

NEUS... NEEEUUUSSS, HEAR!!

SUCH A PEACEFUL...

THERE SHE'S AGAIN, DAYDREAMER...
IN A WORD OR A SENTENCE, WHAT DOES HEARING LOSS MEAN FOR YOU?
Communication problems
A nightmare
I feel disconnected with the world
Misunderstanding
Overexertion
Cannot understand others
Exclusion
Weakness
Uncertain future (progression)
I’ve lost my self-esteem. I’m not the one who I want to be
xxxxx luck
POTENTIAL CONSEQUENCES OF HEARING LOSS

PHYSICAL  PSYCHOLOGICAL  SOCIAL

INVISIBLE DISABILITY
**Physical Consequences of Hearing Loss**

- Using hearing aids
- Fatigue, tiredness
- Tinnitus
- Headache
- Concentration problems
- Balance problems
- Vertigo
- Pain
I listen to myself breathing, swallowing, eating... It’s ANNOYING!
PSYCHOLOGICAL CONSEQUENCES OF HEARING LOSS

× Range of emotions

- Embarrassment
- Guilt
- Rejection
- Insecurity
- Isolation
- Anger
- Frustration
- Worry
- Sadness
- Guilt
- Fear
- Rejection

SOMETIMES I THINK HOW HARDLY I’LL MISS HEARING

THE WAY HOW MY FATHER LAUGHS

THE SOUND OF WAVES... THAT RELAX ME LOTS

SO MANY, MANY AND MANY FAVORITE SONGS...

HIS VOICE

MY MOTHER SAYING TO ME "I LOVE YOU"

AND SUCH A LONG LIST...
PSYCHOLOGICAL CONSEQUENCES OF HEARING LOSS

- Communication problems: to participate fully in conversations at work, home and in social situations
- Anxiety

Situational factors
- Background noise
- Room acoustics
- Familiarity

I only spend a few time with my nephews because communication is so hard

Hearing but not understanding

Slow to catch on
Psychological consequences of hearing loss:

- Low self-confidence and self-esteem
- Sadness or depression
- Talking about it
SOCIAL CONSEQUENCES OF HEARING LOSS

- Social withdrawal

I avoid meetings in noisy places or with many people attending.

I go to concerts less than I used to.
SOCIAL CONSEQUENCES OF HEARING LOSS

× Recreation: swimming, yoga, playing music, theatre, cinema, going to the beach, guided visits, etc
SOCIAL CONSEQUENCES OF HEARING LOSS

- Employment:
  - Choice of vocation
  - Discrimination
  - Negative attitudes
  - Obtain and retain employment

- Economy

I wasn’t able to do my job properly
SOCIAL CONSEQUENCES OF HEARING LOSS

× Education

I would love to learn English but the speaking is impossible with hearing loss
HELP!

- Hearing aids, cochlear implant, surgery
- Meet people with hearing loss
- Family support
- Focus on the strengths and abilities
- Hearing loss organizations
- Psychology service
HELP!

- Sign language
- Lip movement
- Subtitles
- Learn to focus the attention, only listen what you want
- Physiotherapist → Vertigo
- Acceptance
THANKS!

Any questions?
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