



Growing up with Cystic Fibrosis

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Who are we?



Resea rch

This presentation represents only a part of my PhD work Doutoramento em Ciências de Enfermagem do Instituto Ciências Biomédicas Abel Salazar da Universidade do Porto





Why did I choose this theme?

I worked in a pediatrics unit at St John's Hospital – Porto where these children were hospitalized

When I started working at Nursing School I lost their contact

In Nursing School I'm part of the Quality of Life research unit and my curiosity grew.

And this is an unknow disease for most people.

A vertical strip on the left side of the slide shows a nighttime view of a city skyline, likely Lisbon, with numerous buildings illuminated and their lights reflected in the water. The scene is dark, with the city lights providing the primary illumination.

Activities

Bibliography research

APFQ volunteering

Contact with INSG

Contact with nurses from Lisboa,
Coimbra and Porto hospitals

Research bibliography

To study this theme I divided it in:

- Growing up and living with CF
- Adolescents with CF and their family
- The quality of life that adolescents with CF have
- The nursing team
- Transition to adults unit





Volunteering in APFQ

During my research I found the
APFQ

Then I offered my help to do the
needfull.

Contacts with INGS



During my research in the internet I found INGS and I sent many emails to all names in the list

I had responses and a friendly nurse invited me to present my work in this conference



Contacts with other colleagues

To increase my knowledge about this theme I contacted several nurses who work in Pediatric Hospitals in Porto, Lisboa and Coimbra



Goal:

Contribute to the excellence of nursing care provided to adolescents with CF, with a view to optimize their entry into adulthood.

Aims:

Explore the concepts of adolescents, parents and nurses involved in their illness and their life experience about how to grow up with CF;

Understanding the role of the nurse, behold the prevention, care to adolescents with CF at various levels.



Main question:

How is growing up with CF in the perspective of adolescents, parents and nurses.

Methods

An exploratory, qualitative study with tenets from grounded theory was used to elicit detailed descriptions of adolescent's, parent's and nurse's cystic fibrosis life experiences.

We will record the interviews of the participants.





Participants

Adolescents aged 11 to 21 years old

Adolescent's parents

Nurses who work with these children



Adolescents interview script

What do you remember about the diagnosis?

What difficulties have you got in your day?

How is the relationship with your parents and friends?

Do you talk about your disease with your friends?

Who health professionals give you support?

What do you want to do in the future?

An aerial photograph of a large, dark steel arch bridge spanning a wide river. The bridge has a prominent arch structure and is surrounded by a cityscape with various buildings and greenery. The sky is clear and blue.

Parents interview script

Can you describe your day as mother/father of an adolescent with CF?

Where do you go when your child is sick?

Do you know the difficulties of your son?

What is your concern about your child's future?



Nurses interview script

Describe your role in work team

What health needs have the child in the unit hospital?

Do you need guidelines to work with this patients?

How do you see the future of these patients?

Some adolescentes' concernes

They are protected by siblings, parents and colleagues

They know their limits

If they can't run, because they are tired, they do another thing, but they keep playing.

They don't like cough near the friends

Only talk about to their disease if necessary






Some parents' concerns

They don't want to think about the future

They need a lot of information at the beginning

One of the parents can't work

They need a big family support



Some nurses concerns

They worry about:

poor economics conditions

lack of informations at schools

dysfuntionals families

the adolescent's behavior

the adaptations that people have to make



I like to think that the sun will shine for these families and his children one day and I believe that nurses will have a positive role in the work team to improve the quality of life of these patients.

Thank you