

CF and parenting



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Introduction

Increasing number of CF patients becoming parents

Literature mainly concerns fertility and pregnancy issues

Literature on chronically ill parents is sparse. No published studies are found on CF and parenting

Aims

Raising children is a demanding job, as it is also for healthy parents

The aim of this study was to explore :

- the perceptions and experiences of CF adults who are parents
- how they balance daily family life and their CF care

Methods

Participants

21 /152 patients have children

They were all invited to take part in the study

Procedure

Initial contact was made by phone

At the next clinic visit the interviews were undertaken

All interviews were audio taped with consent

Interviews

Interviews were semi – structured and lasted about 45 minutes to one hour

One researcher conducted all the interviews

Questions in the interview were based on

- Literature on chronically ill parents
- Experiences of the psychologist and nurse specialised in CF care

Interview topics

Time to study , work , leisure – activities

Self care (time for treatment, hospital appointments)

Desire to have children (fertility and pregnancy issues, communication with partner)

Experience of pregnancy

Experience of *being a parent*

Data analyses

- Interview transcripts were analysed thematically
- Line by line coding of the transcripts was undertaken to generate common concepts (specific words, phrases, or sentences)
- Concepts were then grouped into themes
- This was done independently by two researchers
- Inter-rater agreement was 72 % at this stage
- Following discussions the coding of concepts and themes were all agreed

Results

- 18 of 21 patients were interviewed.

	Age	Child age (n = 22)
Fathers (n = 8)	36 Y (30 – 42)	5Y (n = 10) (4m – 12y)
Mothers (n = 10)	34 Y (22 – 55)	9 Y (n= 12) (10m – 26y)

Clinical characteristics

- 2 mothers have received a second transplant

FEV₁ % predicted	Up to 3 months before pregnancy	At birth	At interview
CF mothers	72 (65 – 81)	74 (68 – 83)	67 (49 – 82)
Transplanted mothers (n = 4)	92	92	87 (49 – 120)
CF fathers	43 (37 – 44)	42 (35 – 48)	61 (34 – 110)
Transplanted fathers (n = 4)	105 (82 – 128)	103 (79 – 127)	79 (48 – 124)

Results

Four overarching themes emerged from the analysis:

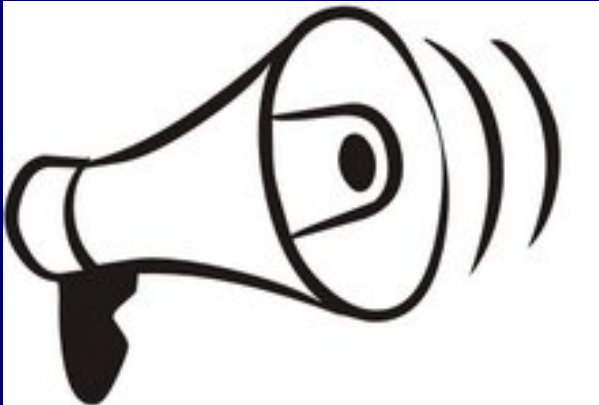
Communication / lack of communication

Fertility and pregnancy

Being a parent

CF care and impact on family

Communication



Carrier status

Household

Treatment

Job

Fertility

Future and CF

Support

Communication - Quotes

About household tasks

“My partner is not aware of the burden of these tasks” (M)

“Not talking was one of the reasons for our divorce I think” (M)

About job

“I want to work and have time for my child” (F)

*“There is an big financial pressure to stay to work”
(M)*

Communication - Quotes

About Fertility

“My partner was first against pregnancy “(F)

“We chose for adoption because of CF “(F)

About future and CF

“No, we do not talk about it, it is too difficult “(M)

“It was hard to think and talk about death, but we did it “(F)

Communication - Quotes

About carrier status

“We used a sperm donor and we agreed not to talk about being a carrier to the child “ (M)

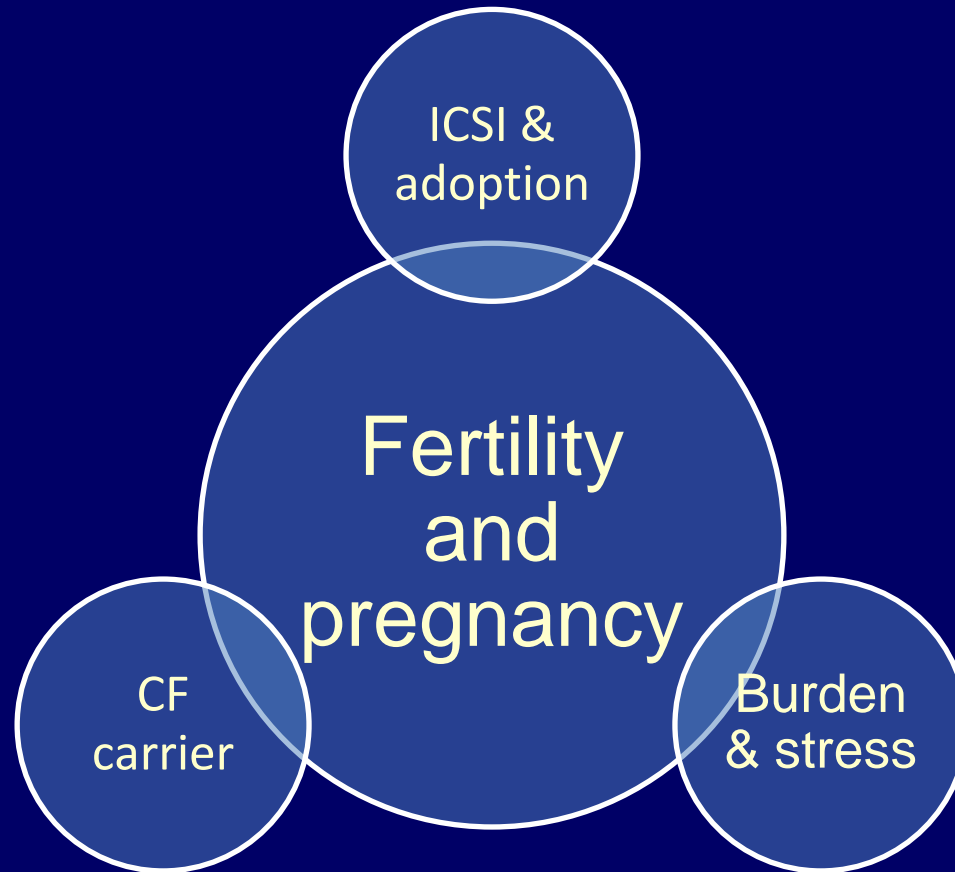
“We will talk to our child about being a carrier at the appropriate time” (F)

About treatment

“I try to answer when my child asks questions “ (M)

“We talk very little about it, because we do not want to worry our child “ (M)

Fertility & pregnancy



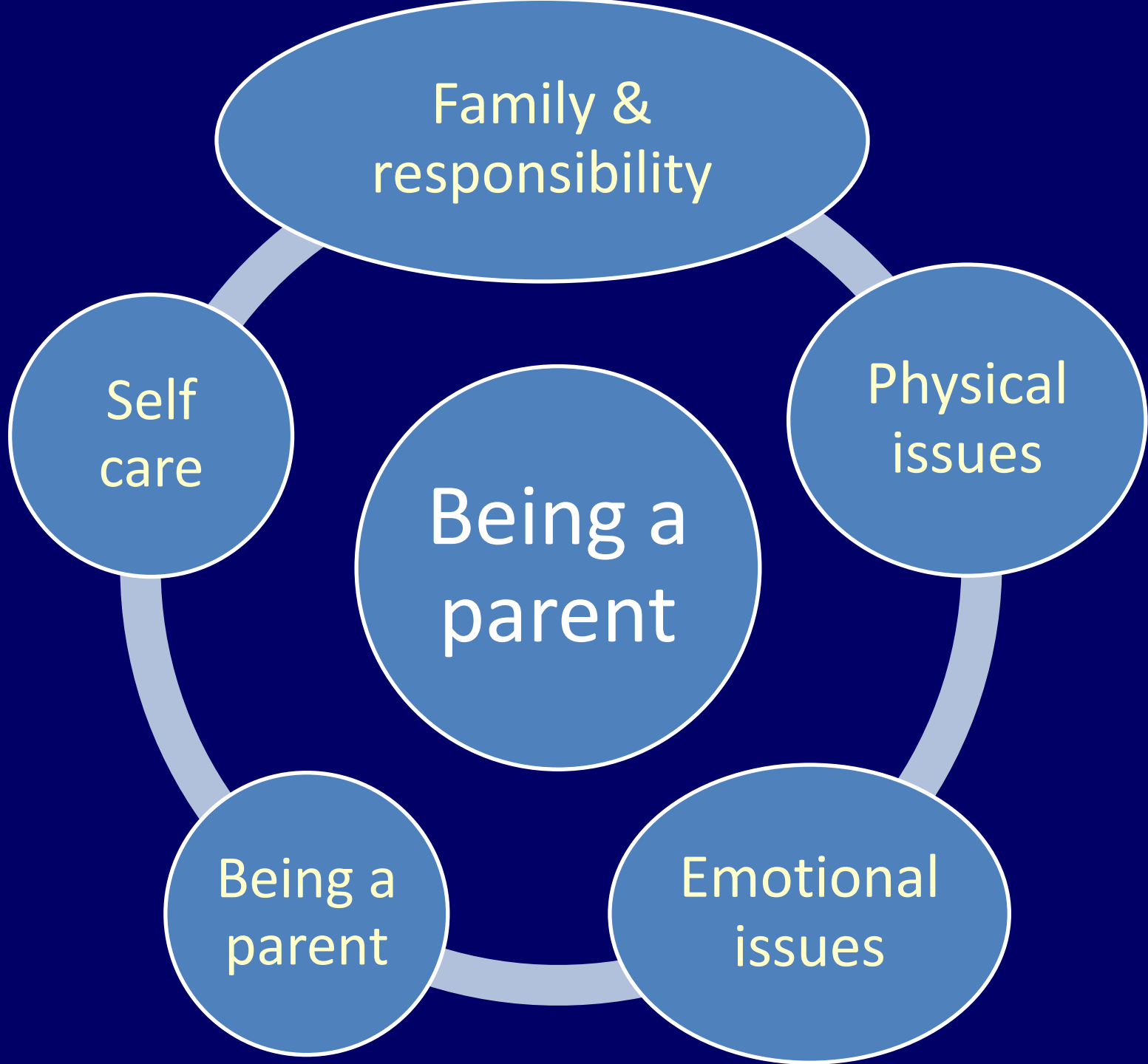
Fertility & pregnancy quotes

“I felt guilty that my partner had to go through all this” (M)

“The disappointment was very difficult, especially not knowing if it would ever work out” (F)

“The doctor said : you should not become pregnant if you want to live” (F)

“I didn't want my child to be a CF carrier” (M)



Family & Responsibility



Sole

- CF women & female partner

Sharing

- Depends on illness severity

F / M
difference

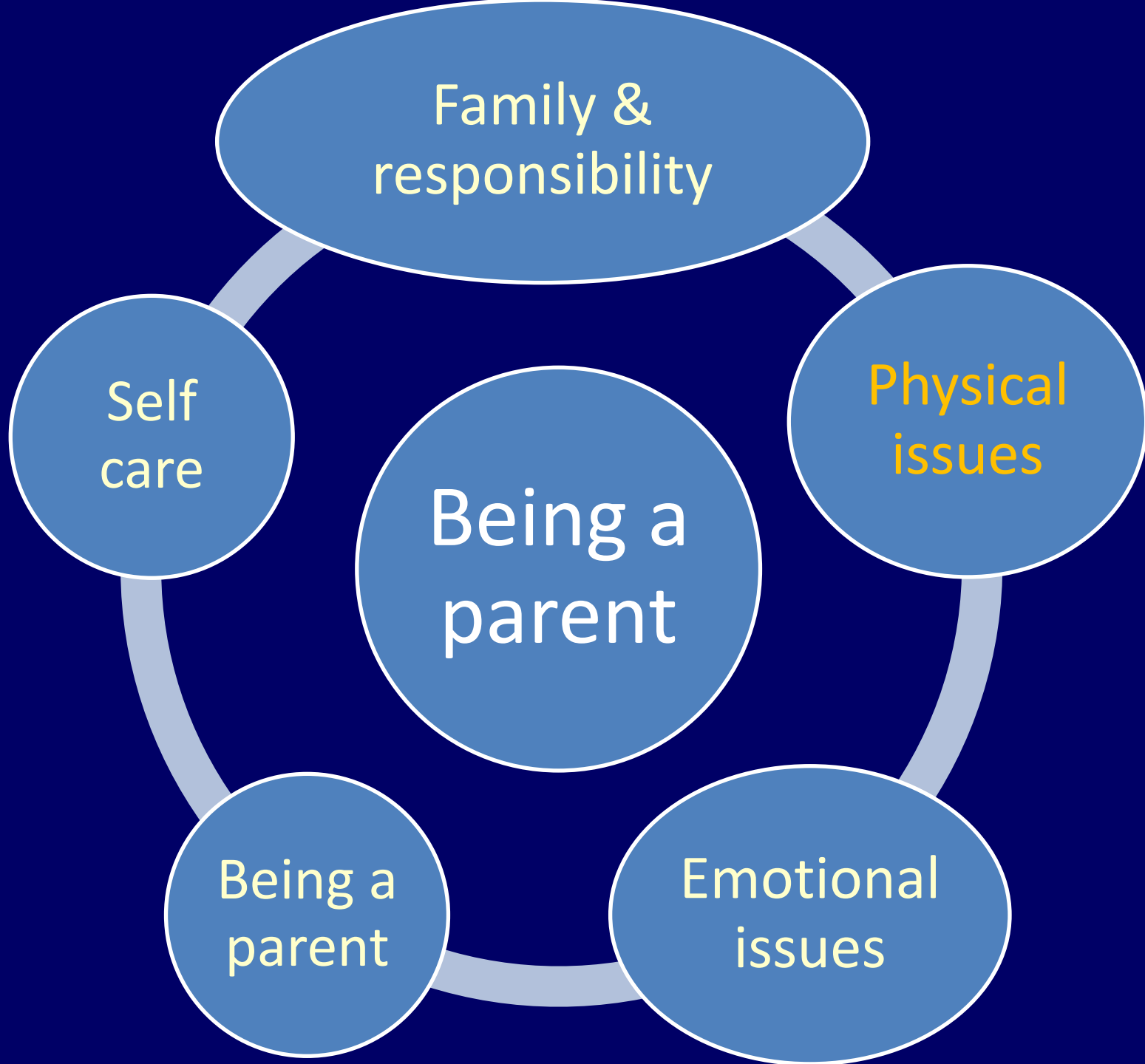
- Men work more outdoor
- More burden for partner of CF man

Family & responsibility quotes

“My partner is the most important carer, I help her in the evening and in the weekends” (M)

“Months before transplantation were very difficult. My partner worked FT and I had to do the household, even when I was very ill” (M)

“Before transplantation my responsibilities shifted depending on how ill I was” (F)



Physical Issues



Baby &
toddler

School
age

Puberty

Adult
child

Infection &
hygiene

Physical issues Quotes

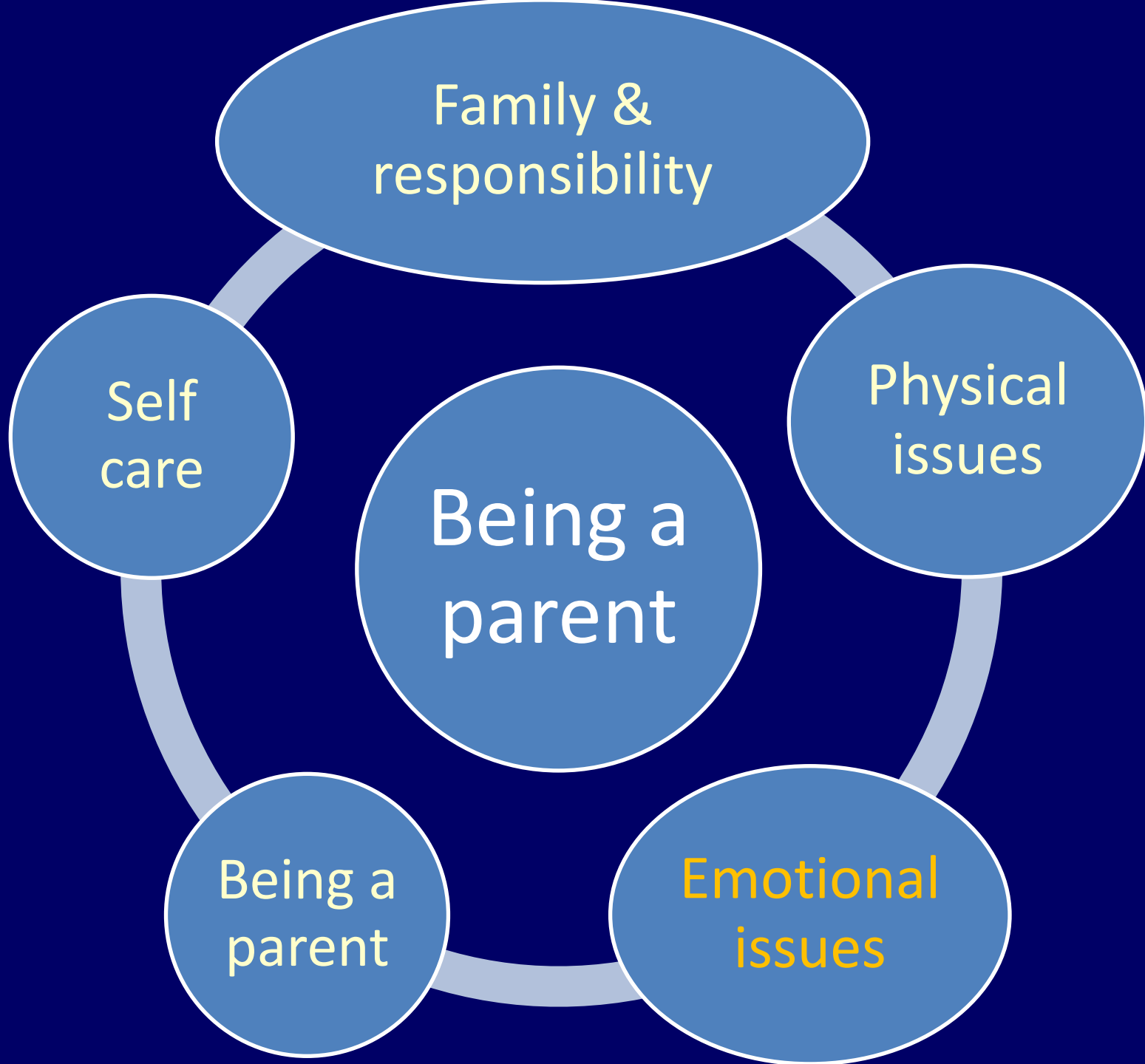
“The days I am well we colour plates, look at videos” (4y)

“It becomes harder to keep up with my son when playing football” (8y)

“My son laughs at me when I ask him to wash his hands” (14y)

“My daughter vacuums before going to work” (21y)

“There is hand alcohol at the frond door for everyone who comes in”(6y & 8y)



Family &
responsibility

Self
care

Physical
issues

Being a
parent

Being a
parent

Emotional
issues

Emotional Issues

Awareness
of CF by
child

Anxiety

Growing up
fast

Caring for
patient by child



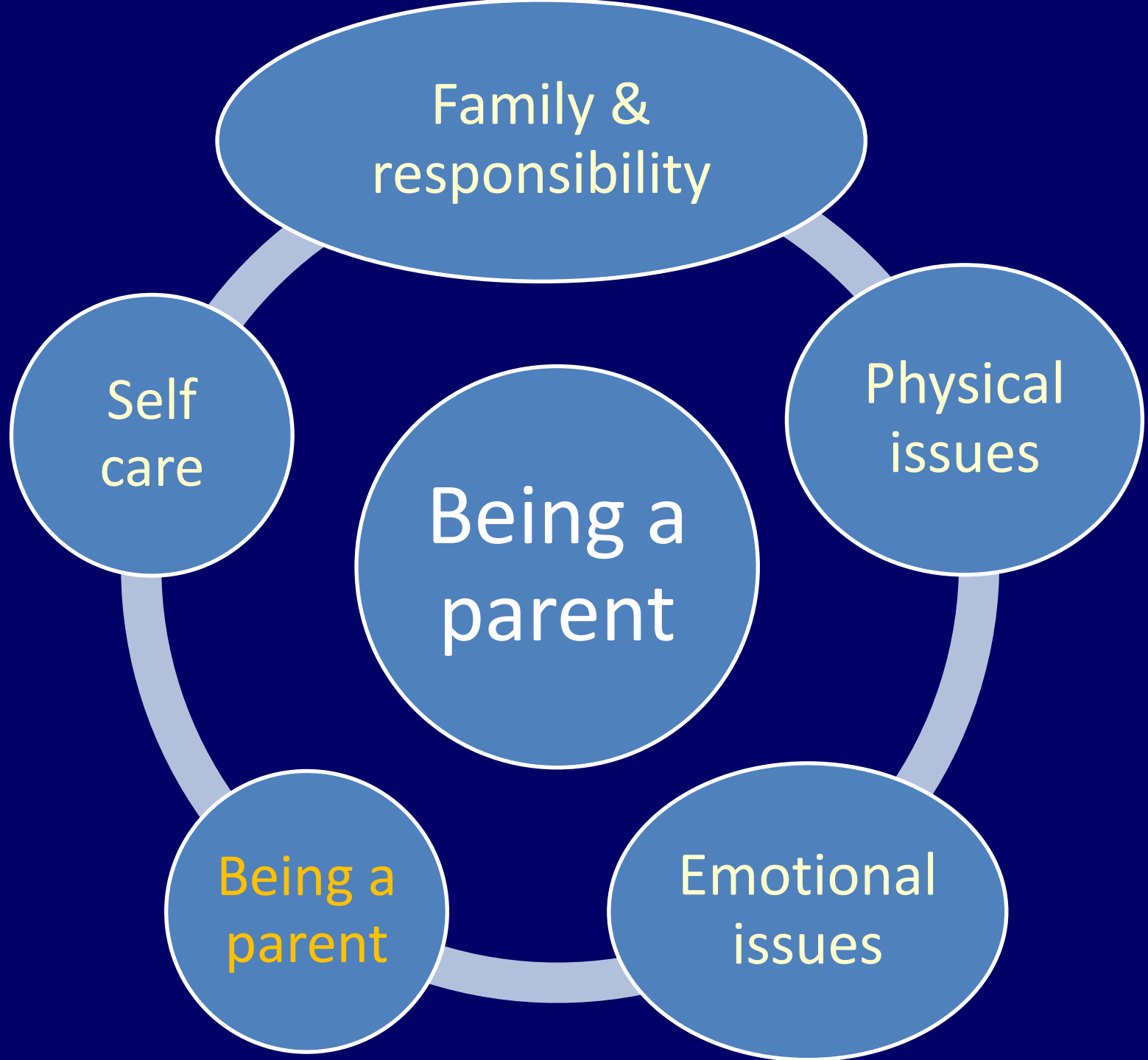
Emotional issues Quotes

“My daughter (4y) asks why I eat all the bad food”(M)

“Where I used to help my son (8y) he now helps me. Transplantation made him more independent”(F)

“My son (12y) sometimes panics when I come to the hospital”(M)

“My child (27y) knows what music to play at my funeral”(F)



Being a parent

Positive

- motivation,
- compliance

Negative

- future
- frustration

Burden

- partner
- illness



Being a parent Quotes

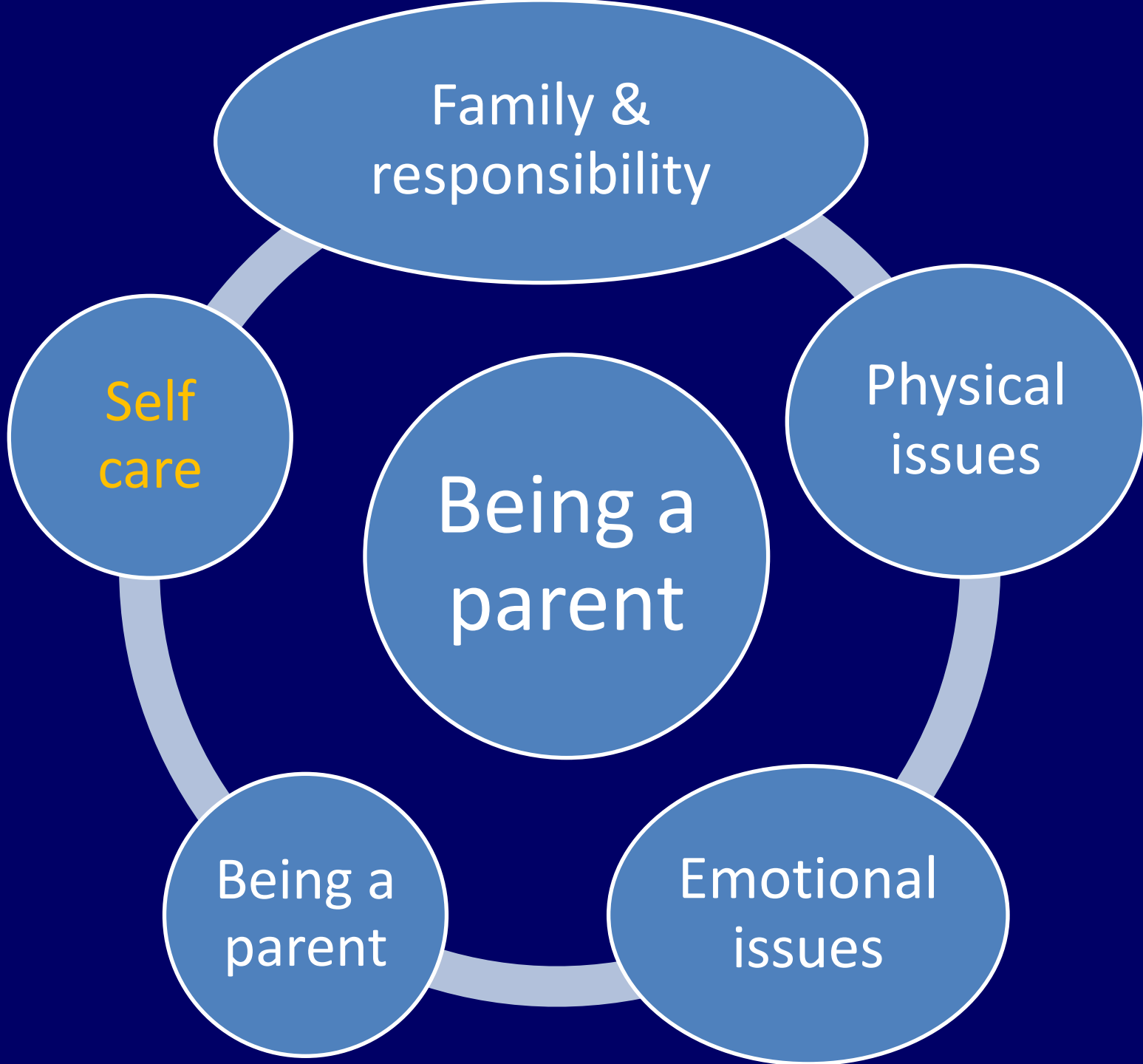
“I now would be more lonely if I didn't had her”(F)

“I feel alive, more complete with children”(M)

“You become more ill having a child, it takes a lot of effort”(F)

“You know that a difficult period is to come, I just hope it's not in her puberty, although I know she is a strong lady”(M)

“It's more difficult for my wife, she has to take care of the children” (M)



Self care



Child first

- CF women

Being well

- Compliance

Tiredness

- Limit in care

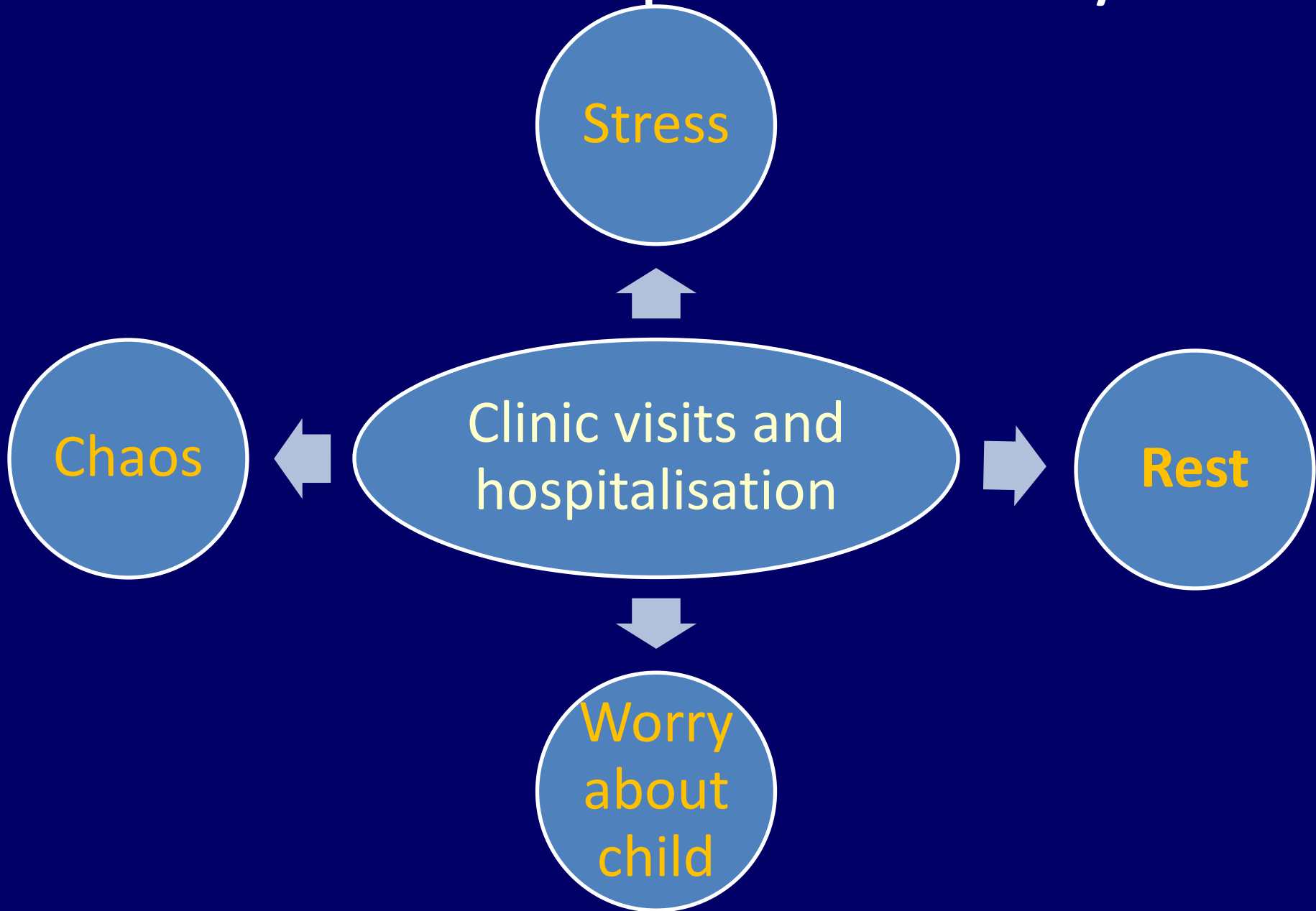
Self care Quotes

“I first take care of my baby, when she sleeps I nebulise”(F)

“My therapy comes for everything, I must stay well for my children”(M)

“I am so tired from her crawling around, I rather go sleeping than nebulising when I can”(F)

CF care and impact on family



CF care and impact on family quotes

“The out patient clinic is always the moment of truth, even when you expect the best”(F)

“It is positive and stimulates me to continue therapy”(M)

“Hospitalisation turns everything upside-down, it means chaos”(M)

“My child worried that I would never come home again”(F)

“For me it means rest, for my wife it is difficult”(M)

Conclusions

These data demonstrate that parents with CF have similar concerns as healthy parents.

But :

There is little communication between partners about how to anticipate with increasing illness and raising children.

Responsibility for child shifts depending on illness severity. Physical limitations in care for young children are important.

Conclusions

There is an emotional impact of CF on the family with fear for the future and anxiety, especially around hospital contacts.

Carrier status of the child is an important concern.

Being a parent is a major motivation for CF therapy.

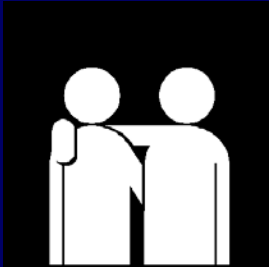
Conclusions

This research is novel and it is exploratory work in progress.

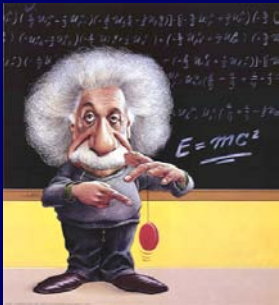
We are aware of the small sample size and heterogeneity of the sample.

There are a limited numbers of parents with CF and we are open to collaboration with other CF centres to produce more robust data.

Many thanks to



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Brainstormer : Janice Abbott



All cooperating patients for the
fascinating interviews