Caregiver burden and quality of life of parents of young children with cystic fibrosis

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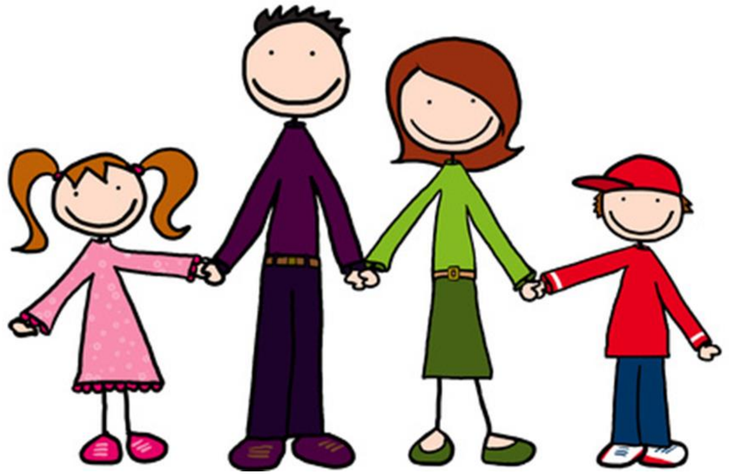
Introduction

Growing interest in measuring quality of life (QOL)

Numerous studies have measured QOL of cystic fibrosis (CF) patients

Paucity of research on impact of informal caregiving on parents of children with cystic fibrosis

Ireland has highest incidence rate of CF worldwide

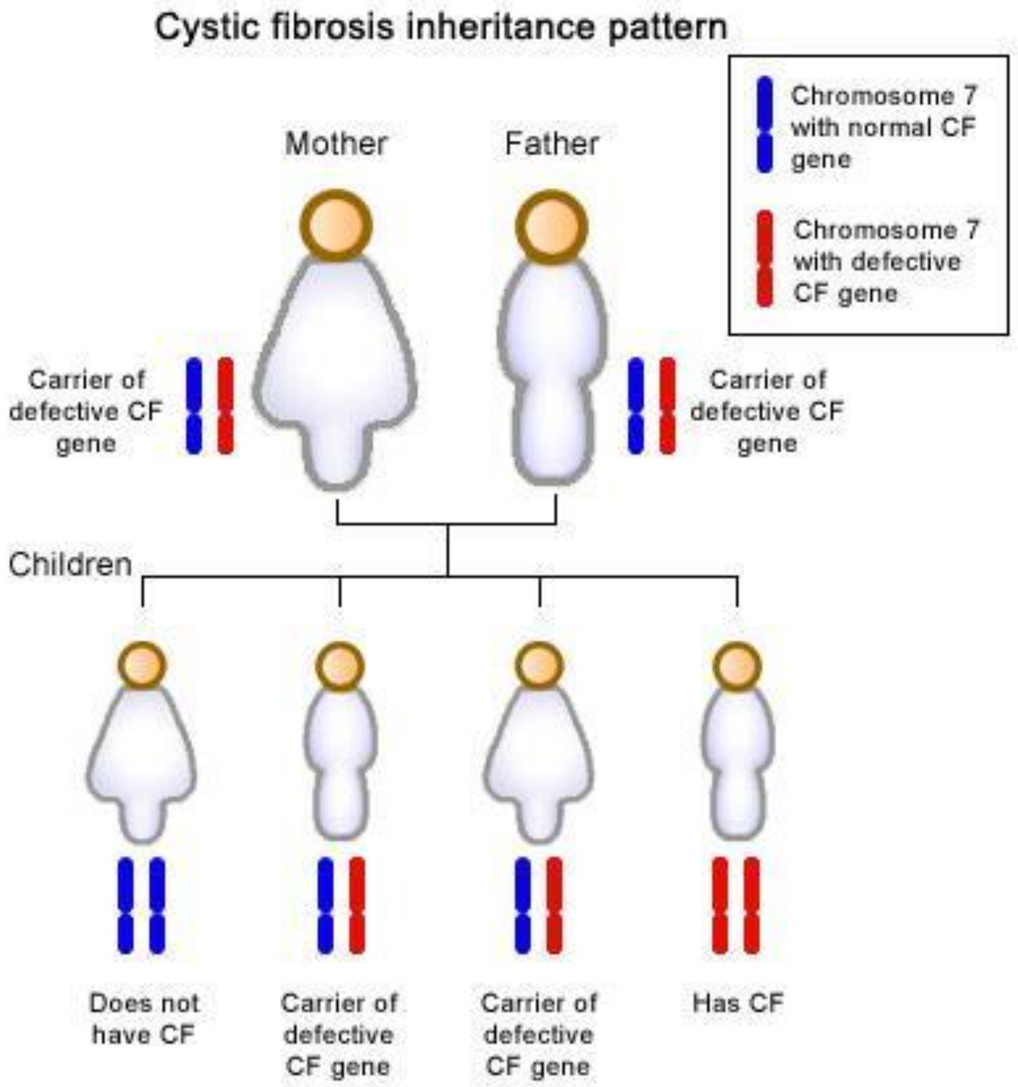


What is Cystic Fibrosis?

Inherited chronic disease - primarily affects respiratory & gastrointestinal system

Autosomal recessive disorder (two copies of abnormal (CFTR) gene present for disease to develop)

Predominantly affects Caucasians



Detection of cystic fibrosis

Clinically

Family history

Signs and symptoms

Newborn Bloodspot screening

Clinical diagnosis – signs and symptoms

- **Meconium ileus**: a thick and sticky first bowel movement of a baby that can block the bowel
- **Respiratory symptoms** - cough, wheezing, or breathing difficulty
- **Failure to thrive** - not gaining weight normally after birth

Symptoms and signs of CF

- Thick, heavy, sticky mucus; can clog the lungs, making a child with CF very prone to breathing difficulties & lung infections

- Thickened digestive juices; failure to break down and absorb nutrients from food causing digestive and growth problems

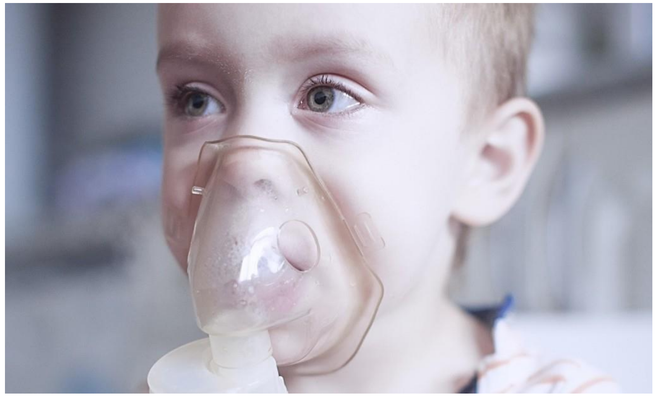
Pseudomonas aeruginosa

- *Pseudomonas aeruginosa* is a major pathogen in CF lung infections, and the most important pathogen in progressive and severe CF lung disease
- Can become chronic
- Difficult to eradicate
- Focus on prevention

Caring for a young child with CF

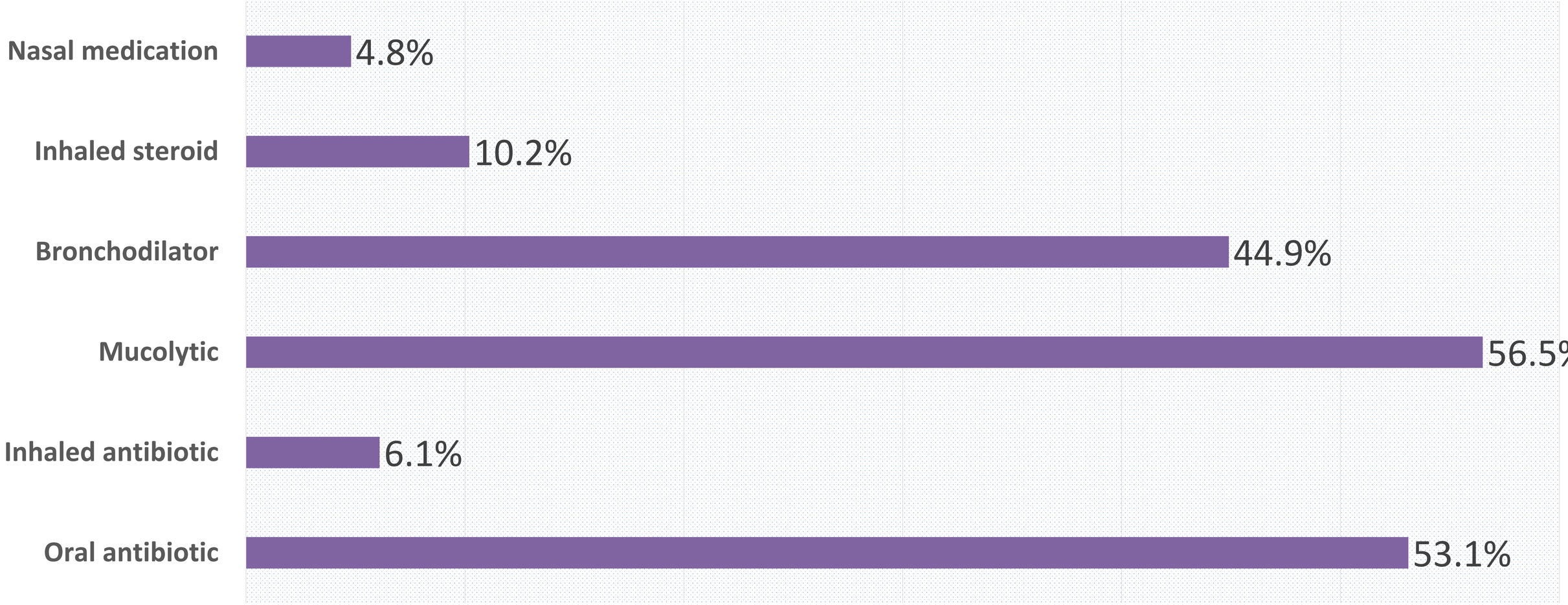
- **Daily**
  - Airway clearance / physiotherapy
  - Pancreatic enzyme supplements
  - Dietary requirements
  - Infection control

- **Routine**
  - CF Clinic visits every 2-3 months
  - Annual assessment at specialist CF centre
  - Education



- **Other**
  - Maintenance treatments
  - Hospital admission
  - Home IV therapy
  - Home nebulisers

Cystic Fibrosis Registry of Ireland, Annual Report: Children < 6 years Long-term maintenance treatments (for period of 3 months minimum)



Caring for child with long term disease

- Diagnosis of long-term illness in a child causes major upheaval in the lives of both the child and family.
- Stressful
- Daily workload
- Child in hospital
- Concern about future

Study Introduction

The Cystic Fibrosis Irish Comparative Outcome Study (ICOS study) - longitudinal cohort study comparing children with CF

Clinical	Newborn bloodspot screening

Provided opportunity to measure impact of informal caregiving on parents of children with CF

Methods

Two cohorts recruited by year of birth

July 1st 2008
Birth Cohort A

Birth Cohort A (clinically diagnosed) are children with CF **BORN** between 1st July 2008 - 30th June 2011

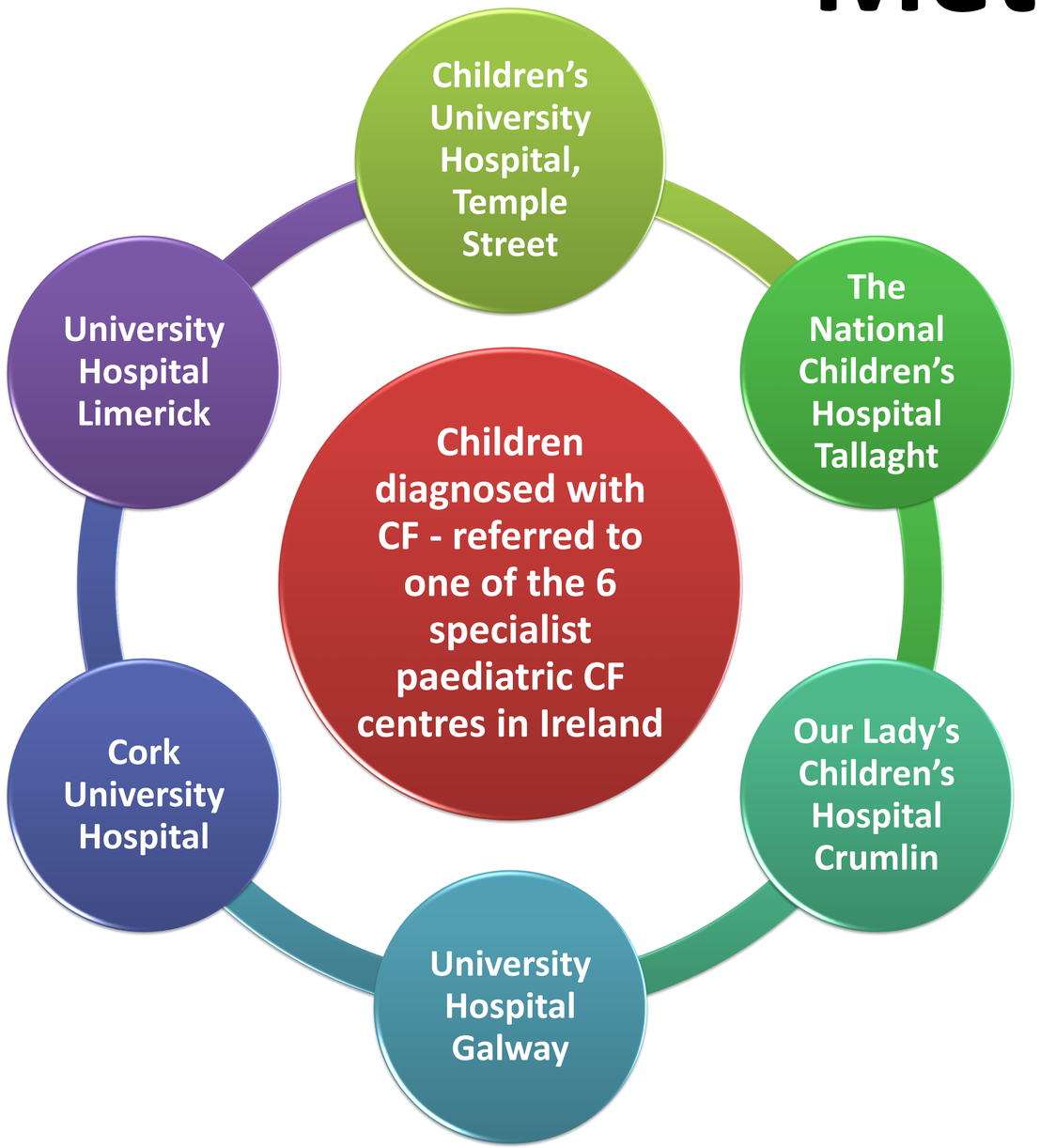
Finish Recruitment
June 30th 2016

July 1st 2011
Birth Cohort B

Birth Cohort B (screen diagnosed) are children with CF **BORN** between 1st July 2011 - 30th June 2016

6 months | 12 months | 18 months | 2 years | 3 years | 4 years | 5 years

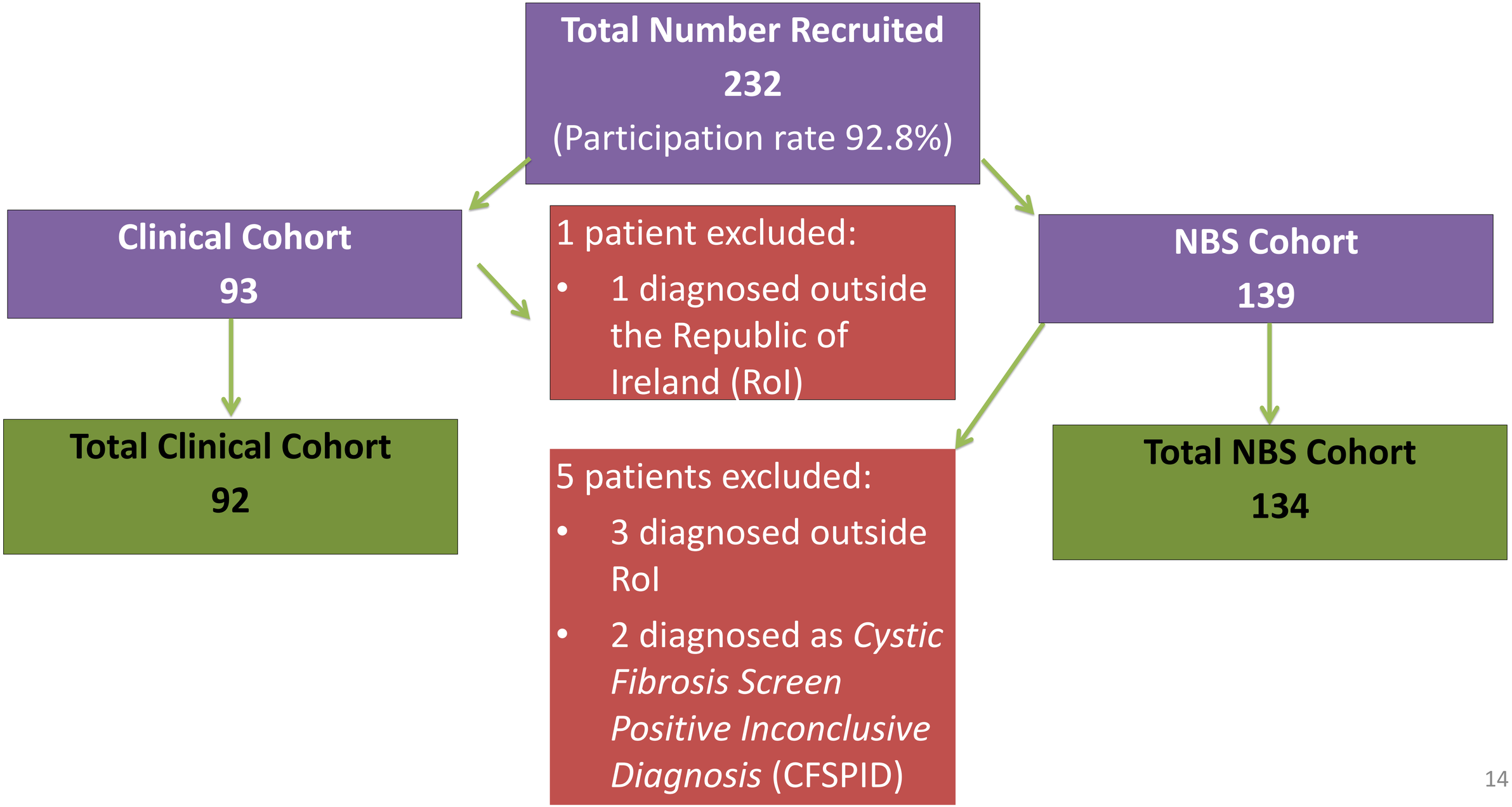
Methods



Informed consent:

- Clinicians and CF Nurses obtain informed consent from parents to participate in the study

Recruitment



Methods

Cross-sectional study of 213 families recruited to the ICOS study

Parents consented - CarerQol questionnaire completed via telephone consultation

Questionnaire was completed by both parents separately

CarerQol-7D

Parents indicate whether an item applies to them

3 possible answers

None

Some

A lot of

CarerQoL Questionnaire

CarerQol measures caregiver burden

Based on the EuroQol

Parents of children with:

-Haemophilia

-Craniofacial malformations

-Autism spectrum disorder

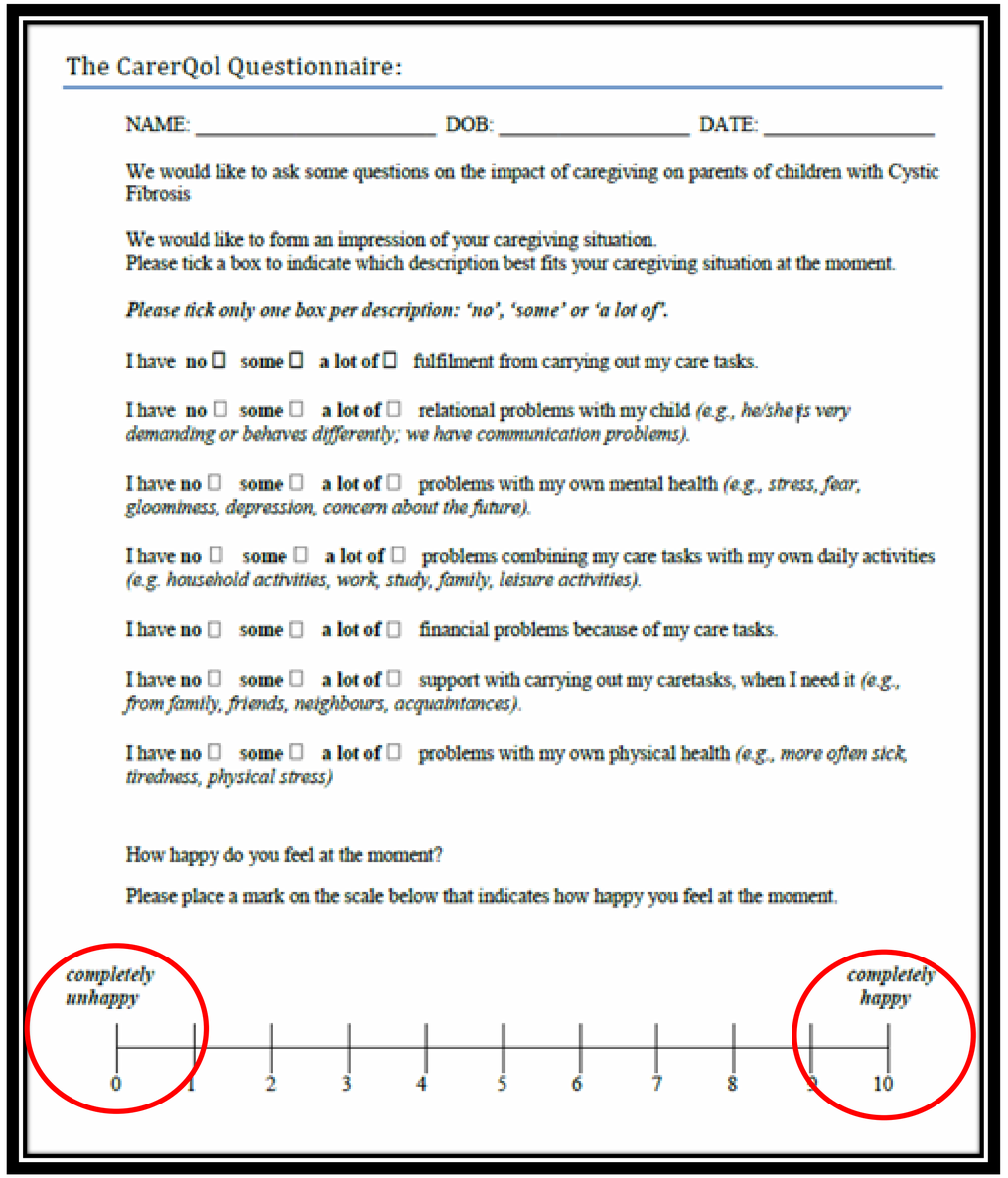
Five validation studies conducted previously - showed favourable results re psychometric properties

Methods

The CarerQol - two components

A visual analogue scale (VAS) measures happiness

scale 0 to 10



The CarerQol Questionnaire:

NAME: _____ DOB: _____ DATE: _____

We would like to ask some questions on the impact of caregiving on parents of children with Cystic Fibrosis

We would like to form an impression of your caregiving situation.
Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of'.

I have **no** ☐ **some** ☐ **a lot of** ☐ fulfilment from carrying out my care tasks.

I have **no** ☐ **some** ☐ **a lot of** ☐ relational problems with my child *(e.g., he/she is very demanding or behaves differently; we have communication problems).*

I have **no** ☐ **some** ☐ **a lot of** ☐ problems with my own mental health *(e.g., stress, fear, gloominess, depression, concern about the future).*

I have **no** ☐ **some** ☐ **a lot of** ☐ problems combining my care tasks with my own daily activities *(e.g. household activities, work, study, family, leisure activities).*

I have **no** ☐ **some** ☐ **a lot of** ☐ financial problems because of my care tasks.

I have **no** ☐ **some** ☐ **a lot of** ☐ support with carrying out my caretasks, when I need it *(e.g., from family, friends, neighbours, acquaintances).*

I have **no** ☐ **some** ☐ **a lot of** ☐ problems with my own physical health *(e.g., more often sick, tiredness, physical stress)*

How happy do you feel at the moment?

Please place a mark on the scale below that indicates how happy you feel at the moment.

completely unhappy — *completely happy*

0 1 2 3 4 5 6 7 8 9 10

(Brouwer et al., 2006)

CarerQol-7D

Five negative dimensions of providing informal care

Two positive dimensions of providing informal care

Relational problems

Mental health problems

Problems combining daily activities with care

Financial problems

Physical health problems

Fulfilment from caregiving

Social and family support when needed

Utility Score(US) – weighted average of subjective burden

0 – 100 Higher score indicates a reduced burden

Reliability & Validity

Pilot study → *Face validity* → *CarerQol-7D; Cronbach's alpha 0.60*

Methods

CarerQol7D: Differences between mother-father dyads

Analysed matched pairs – McNemar-Bowker test

Utility Score: Differences in median US/VAS mother-father dyads

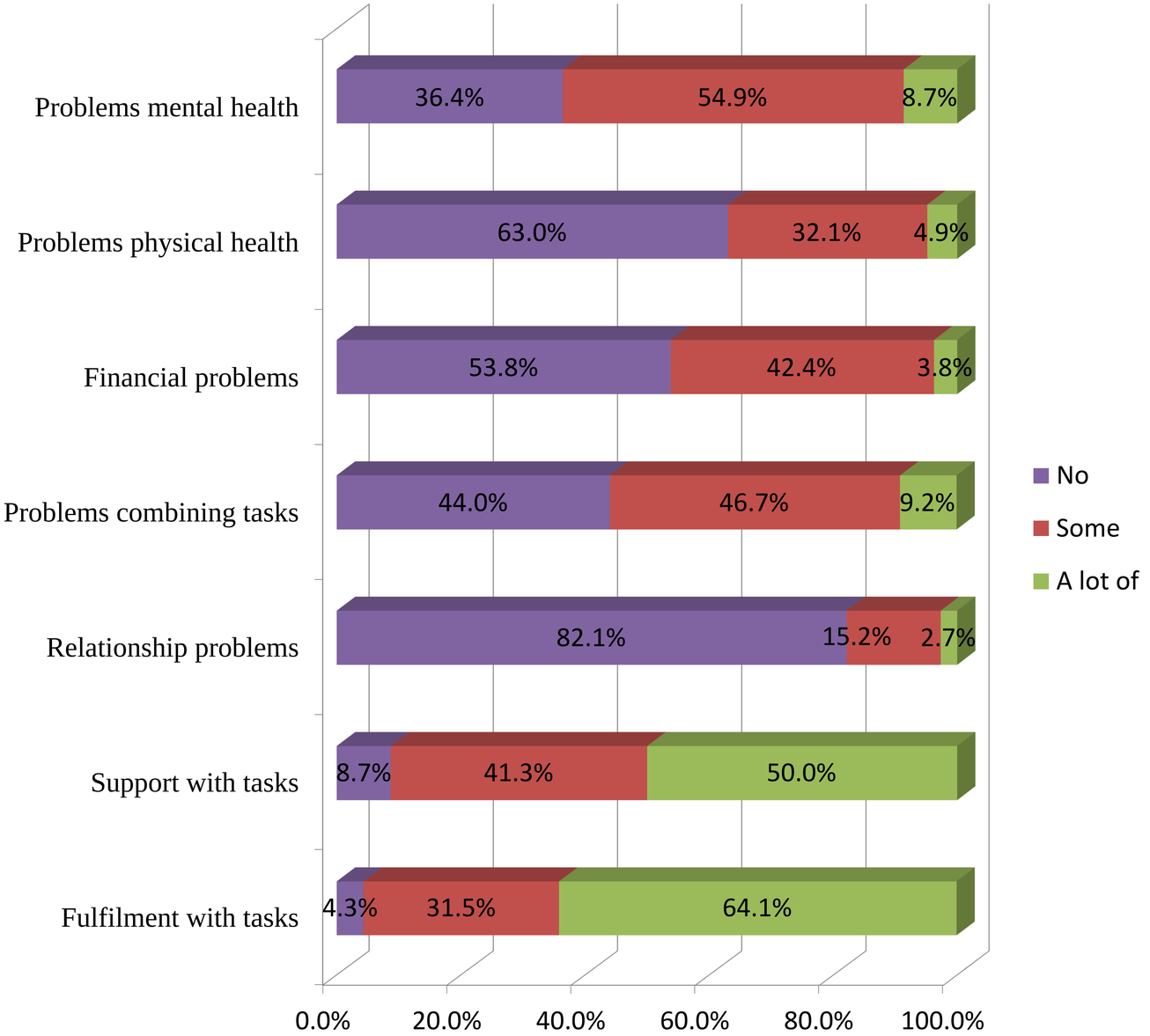
Results: Caregiver quality of life

Of the 213 families recruited to the ICOS study

- At least one parent from 195 families completed the questionnaire
- 130 mother-father dyads (189 mothers and 137 fathers)

Results

- A total of 189 mothers - response rate 88.7% (of which 55 were mothers of preschool children age 3 to 5 years) completed the questionnaire.
- 64% of mothers reported some/ a lot of problems with their mental health
- Most mothers (91.3%) reported some or a lot of support with tasks
- 95.7% reported some or a lot of fulfilment with tasks

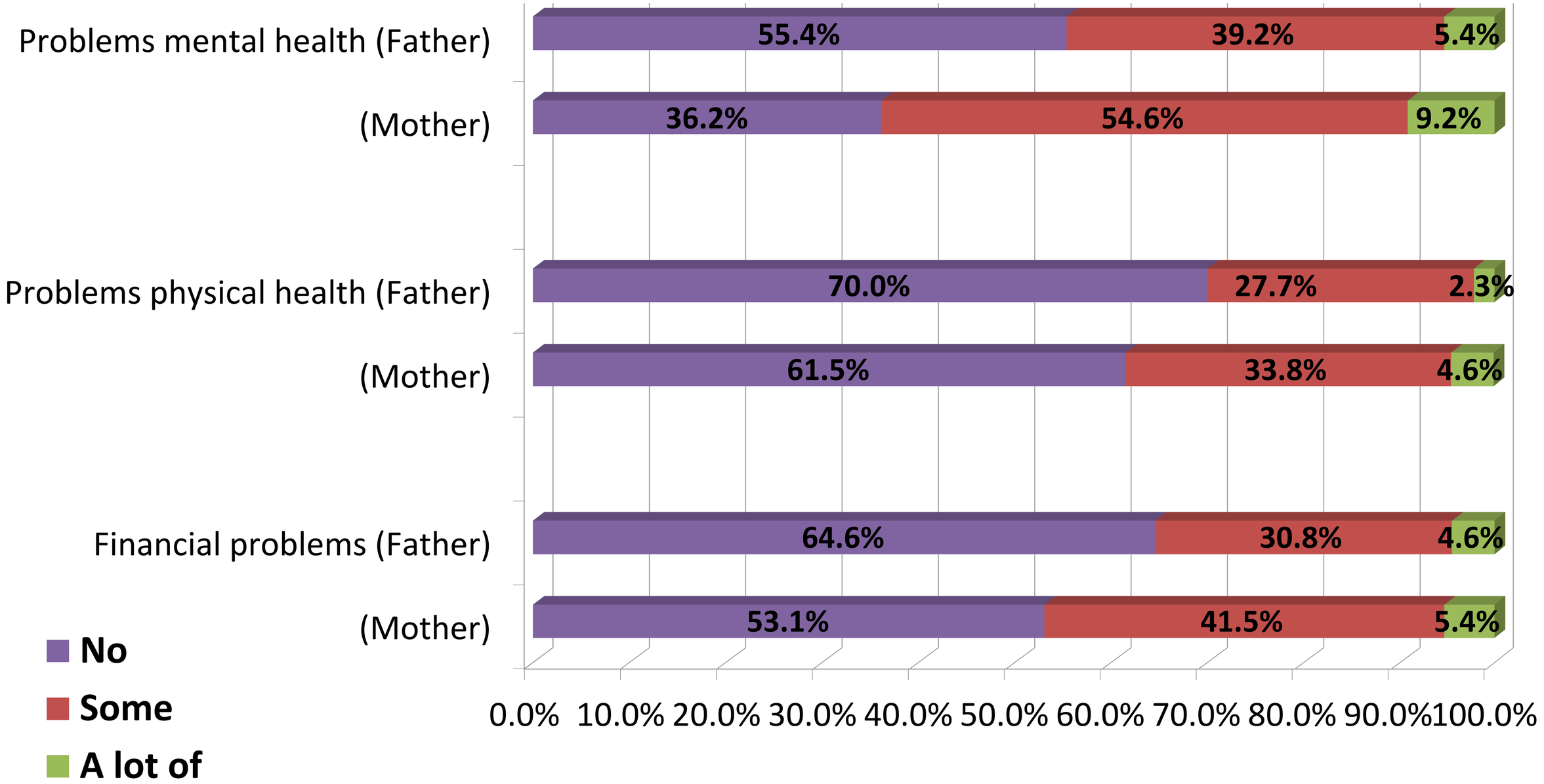


Distribution of responses to CarerQoL-7D dimensions in mothers of children with CF (n=189)

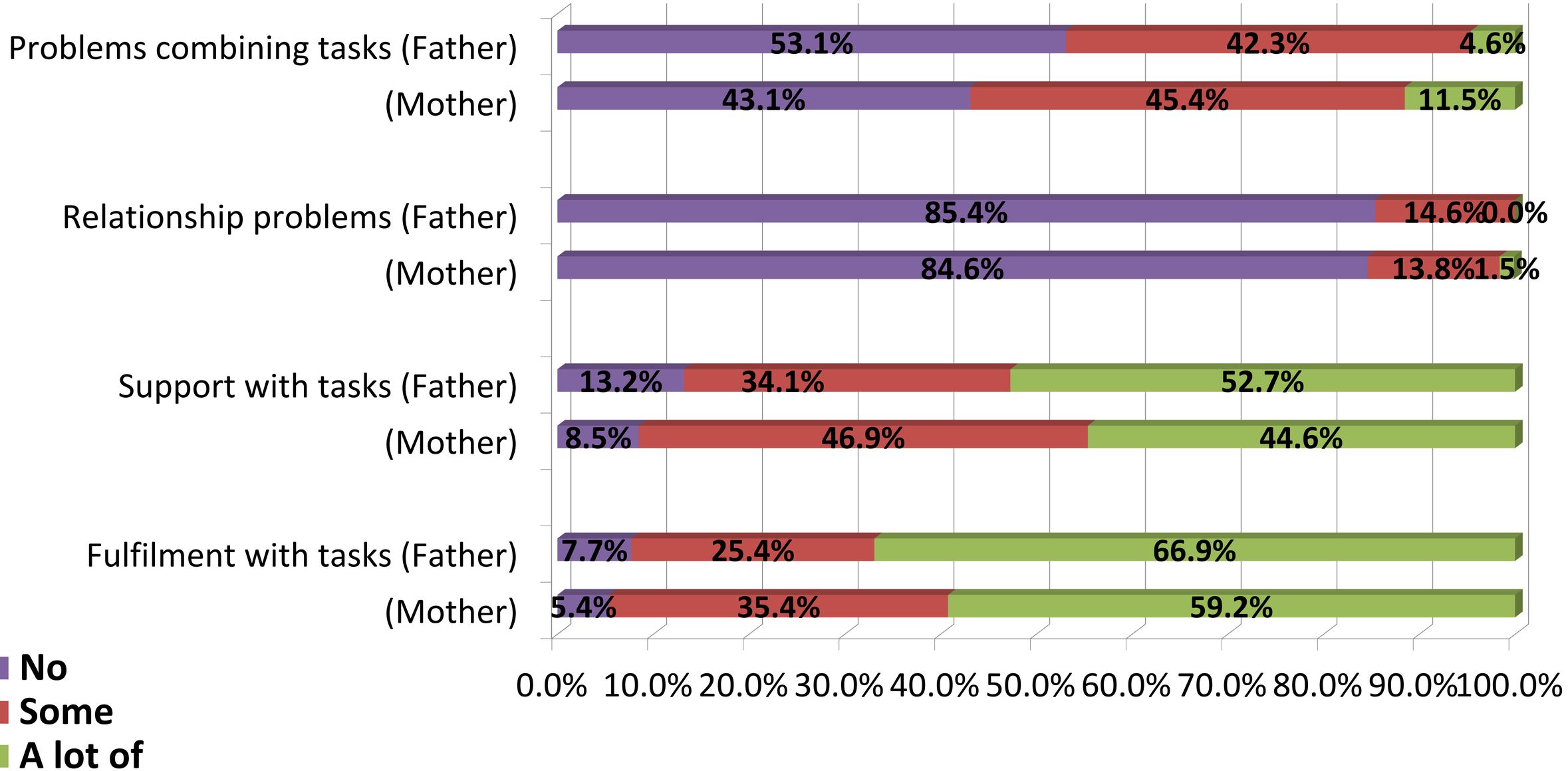
Results: Mothers - Preschool group

- Median US for mothers was 82.6 (IQR 75.8-88.7) median VAS was 7.00 (IQR 6-8)
- When stratified by diagnosis method of child (Clinical or Screen-detected) median US was a little higher (better) in newborn screening cohort but this was not significant
- There was no difference in median VAS (measuring happiness)

Problems with mental health, physical health & financial problems: paired comparison of fathers and mothers



Tasks (problems combining, support with & fulfilment with) and relationship problems: comparison of mothers and fathers



CarerQol7D Negative Dimensions

Problems with my own mental health		Father			p value
		None	Some	A lot of	
Mother	None	31 (23.8)	15 (11.5)	1 (0.8)	0.009[b]
	Some	35 (26.9)	32 (24.6)	4 (3.1)	
	A lot of	6 (4.6)	4 (3.1)	2 (1.5)	
Problems combining my care-tasks with my own daily activities		**Father**			
		None	Some	A lot of	
Mother	None	41 (31.5)	15 (11.5)	0 (0.0)	0.046[b]
	Some	23 (17.7)	32 (24.6)	4 (3.1)	
	A lot of	5 (3.8)	8 (6.2)	2 (1.5)	
Relational problems with my child		**Father**			
		None	Some/ A lot of		
Mother	None	100 (76.9)	10 (7.7)		ns[a]
	Some/A lot of	11 (8.5)	9 (6.9)		

[a]McNemar Test, [b]McNemar-Bowker Test

CarerQol7D Negative Dimensions

Financial problems because of my care tasks		Father			p value
		None	Some	A lot of	
Mother	None	60 (46.2)	8 (6.2)	1 (0.8)	ns[b]
	Some	21 (16.2)	29 (22.3)	4 (3.1)	
	A lot of	3 (2.3)	3 (2.3)	1 (0.8)	
Problems with my own physical health		Father			
		None	Some	A lot of	
Mother	None	65 (50.0)	15 (11.5)	0 (0.0)	ns[b]
	Some	22 (16.9)	19 (14.6)	3 (2.3)	
	A lot of	4 (3.1)	2 (1.5)	0 (0.0)	

[b] McNemar-Bowker Test

CarerQol7D Positive Dimensions

Fulfilment from carrying out my care-tasks		Fathers			
		None	Some	A lot of	p value
Mothers	None	2 (1.5)	4 (3.1)	1 (0.8)	ns[b]
	Some	6 (4.6)	22 (16.9)	18 (13.8)	
	A lot of	2 (1.5)	7 (5.4)	68 (52.3)	
Support with carrying out my care-tasks		Father			
		None	Some	A lot of	
Mother	None	7 (5.4)	2 (1.6)	1 (0.8)	0.045[b]
	Some	9 (7.0)	33 (25.6)	19 (14.7)	
	A lot of	1 (0.8)	9 (7.0)	48 (37.2)	

[b] McNemar-Bowker Test

Utility Score/VAS – Total Cohort (n= 130)

		Fathers	Mothers	
		Mean (SD)	Mean (SD)	p value
All (n=130*)	VAS	7.6 (1.69)	7.2 (1.49)	0.003
	US	86.1 (12.9)	82.2 (13.1)	0.048
≥40 Months (n=57)	VAS	7.38 (1.77)	7.0 (6.0-8.0)	0.069
	US	84.3 (13.3)	78.3 (15.4)	0.008
<40 Months (n=69)	VAS	7.72 (1.62)	7.22 (1.49)	0.043
	US	87.5 (12.2)	85.9 (10.04)	NS

*3 pairs excluded from the stratified analysis as sibling in the study; ns = not significant

CarerQol GLMM analysis - predicting high caregiver burden (utility score ≤25 quartile)

Variable	OR	95% CI
Clinically Diagnosed	0.461	0.16, 1.30
Age[a]	1.021	1.00, 1.04*
Mother	1.645	1.02, 2.65*
Meconium Ileus	1.353	0.55, 3.31
Other sibling in the family with CF	1.053	0.45, 2.46
Mothers education Third level	0.790	0.43, 1.46
Pseudomonas aeruginosa (ever positive)	2.481	1.30, 4.73*

GLMM= generalised linear mixed models, OR = Odds Ratio, CI = Confidence Interval, [a] age of child when parent completed CarerQol questionnaire, * p <0 .05.

Conclusions

Mental health issues - mothers & fathers - mothers reported more

High proportions of parents reported good social support & fulfilment with care-tasks

Factors associated with higher caregiver burden:

Increasing age of the child, infection with *Pa* and being a mother

Clinical diagnosis did not predict increased caregiver burden – ICOS study found more hospitalisations and more IV Rx. ?adjustment to diagnosis and to caregiver burden

Conclusions

Overall utility and VAS scores were higher than anticipated. Workload considered challenge rather than burden?

A high proportion of mothers reported mental health issues. This highlights the importance of assessing psychological well-being in mothers of young children with CF

Important to recognise and intervene if mental health issues arise.
Family, Clinicians, Specialist CF Nurses, GP key to identification.
Psychologist part of specialist CF team

Acknowledgements

Parents for participating in the study

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