

From Child to Adult with Cystic Fibrosis - a PhD study



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How do we prepare adolescents with
cystic fibrosis (CF) for adult life ?

- the adolescents' and parents'
perspectives

Outline

- Background
- Aim
- Qualitative study:
 - Parenting adolescents with cystic fibrosis
- Questionnaire survey:
 - Barriers to adherence in CF
 - Support from the CF centre
- Conclusions
- Implications

Adolescents with CF

- Reduction in lung function
- Psychosocial and psychiatric problems
 - Depression
 - Anxiety
 - Eating disturbances/eating disorders
- Risky behaviour
- Quality of life

Chronic diseases in general:

Parenting adolescents

- Parents are the best allies (Taylor 2008)
- Support ➡ good adherence (Kyngäs 2001)
- Supervision ➡ good adherence (Wysocki 2006)
- Premature withdrawal ➡ low adherence (Wysocki 2006)
- Support ➡ good quality of life (Botello-Harbaum 2008)

Cystic fibrosis:

Parenting adolescents

- Little supervision ➡ low adherence (Modi 2008)
- Families with only little support, warmth and openness ➡ low adherence (DeLambo 2004)
- Better family functioning ➡ better quality of life (Szyndler 2005)
- Non-supportive behaviour ➡ psychological maladjustment (Graetz 2000)

Adherence in adolescents with cystic fibrosis

- Low adherence **➡** reduction in lung function
- Adherence vary depending on:
 - Kind of treatment
 - Age
 - Gender
 - Method of assessment
 - Family functioning

Barriers to adherence

Adolescents with CF:

- Treatment burden
- Lack of time
- Forgetfulness



Adolescents' preferences for health care

- Physicians should be honest with them
- Participation in own care
- Their viewpoints and concerns should be taken seriously
- Information should be communicated directly to them

Summary of the background

- Reduction in lung function
- Low adherence
- Risk of psycho-social problems
- Supervision and family function influences adherence
 - The adolescents' wishes for parental support is not yet investigated
- Only few studies about barriers to adherence
 - The parents' perspective is not yet investigated
- Only few studies about the adolescents' and parents' requests for support from the CF centre

Eksplorative study

Interviews parents

Focus group: n=5

Individual: n=2

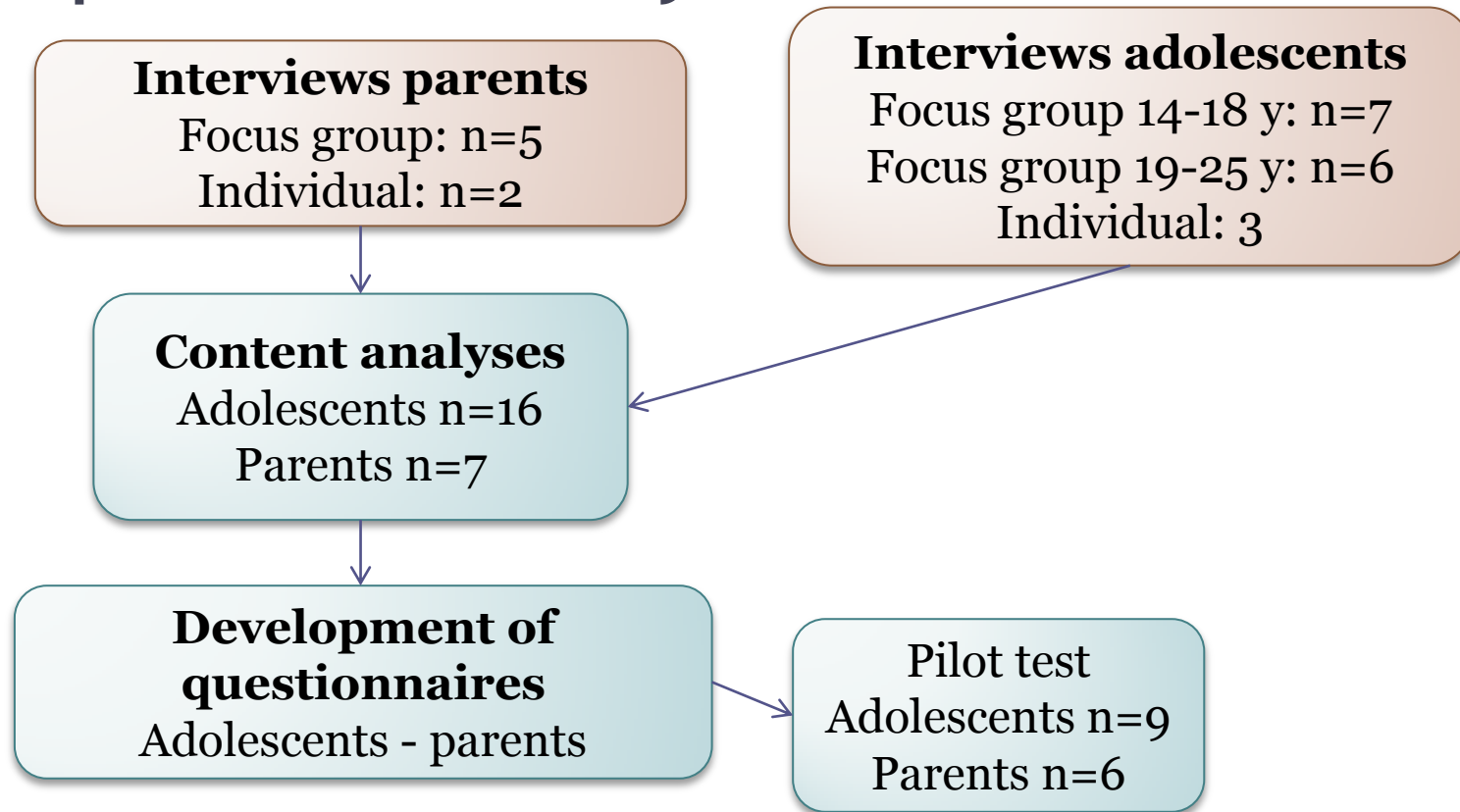
Interviews adolescents

Focus group 14-18 y: n=7

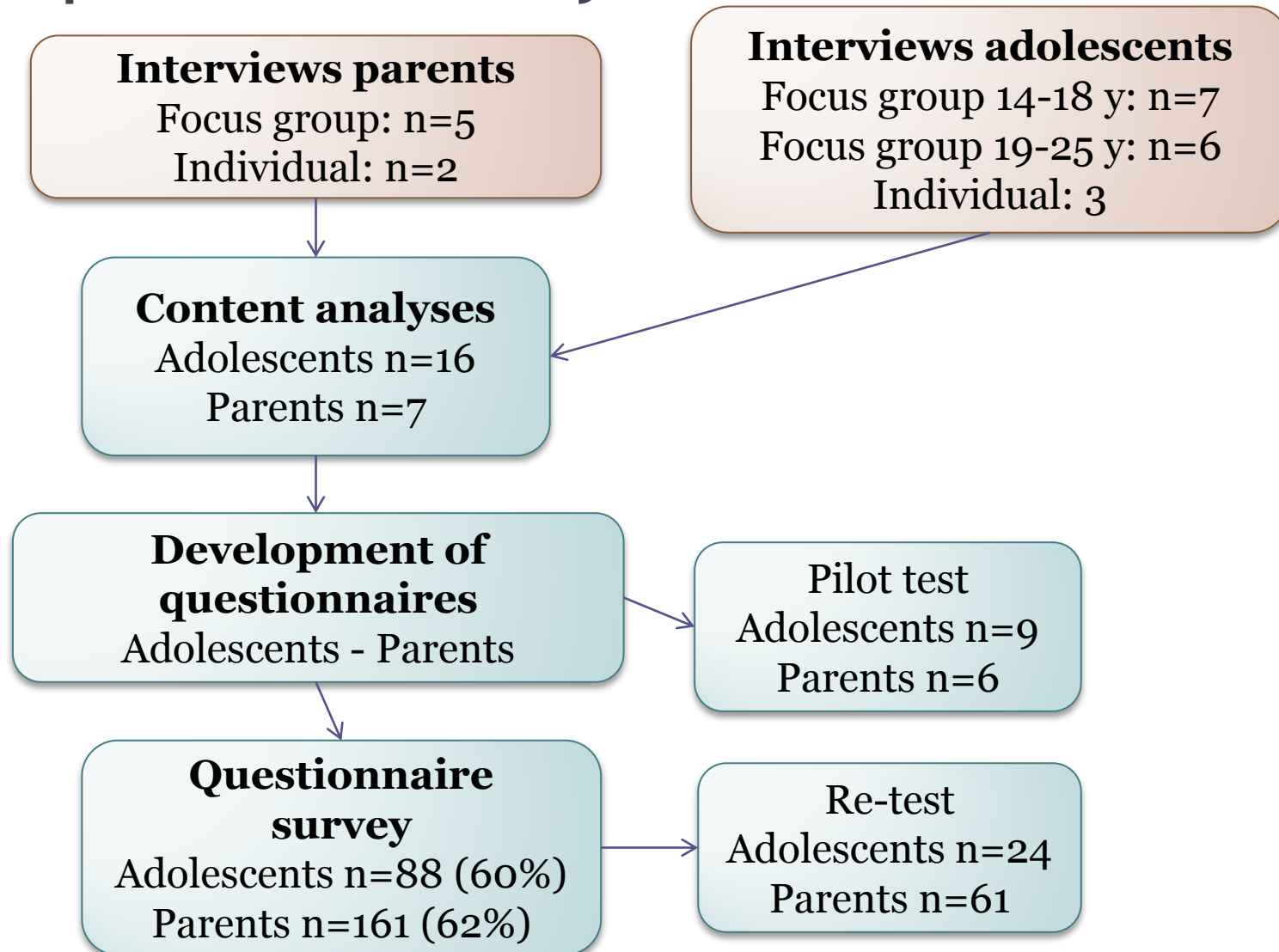
Focus group 19-25 y: n=6

Individual: 3

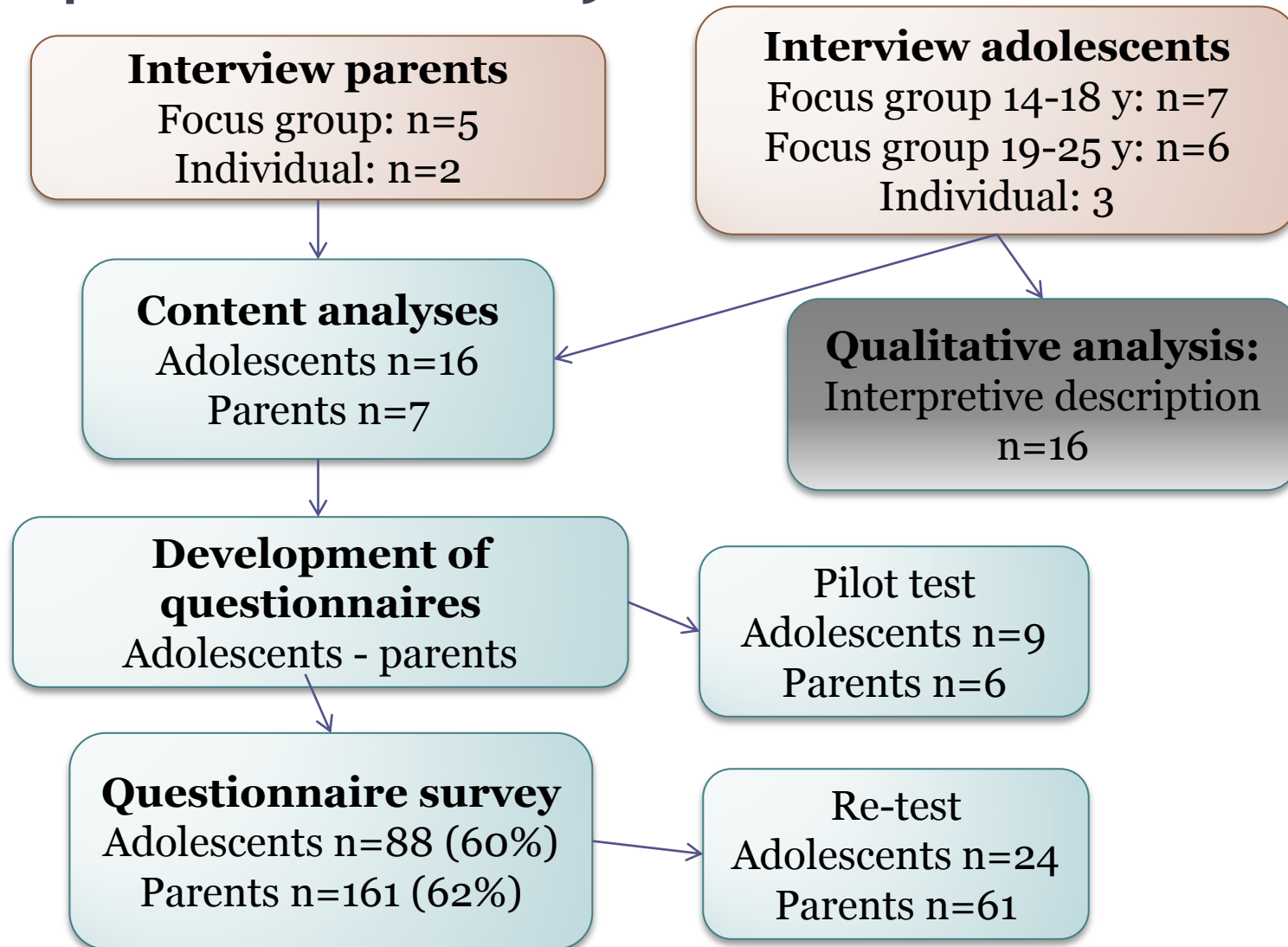
Eksplorative study



Eksplorative study



Eksplorative study



Aim

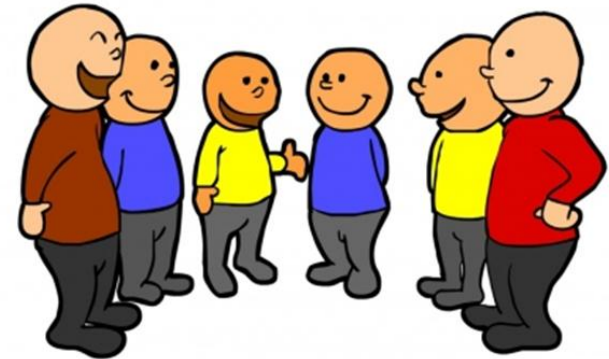
1. What kind of support do the adolescents want
- from their parents?
2. Barriers to adherence?
- the adolescents' and parents' perspectives
3. What kind of support do the adolescents and their parents want
- from the health care system?

Qualitative part - interview

1. What kind of support do the adolescents want
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Method (1)

- Interviews of adolescents with CF
 - Focus groups
 - Individual interviews
- Qualitative analysis
 - Of selected topic
 - Secondary analysis
 - Interpretive description



Interview guide

Support from the CF centre in the transition to adult life:

- Handling the disease in everyday life
- Balance between autonomy and adherence
- Risky behaviour
- The parents

Results


Adolescents with CF:

Parents need support in handling adolescents with CF – they need to learn:

- A pedagogical parenting style
- To trust the adolescents
- To gradually hand over the responsibility for the treatment

A pedagogical parenting style

- Parents should have a dialogue with the adolescents about the treatment
- Parents should give reasons and explanations for the treatments
- Adolescents wished their parents would forget about the disease now and then and treat them as any other adolescent




“If I had got a coin every time my mum or dad said, “Did you remember to take your treatment?” I would be a millionaire today”

Man 15 years

Trust

- Parents should trust the adolescent and not always check whether the adolescents had taken their medication




“My father wanted to control, to control things. So when I was going to take over, we had many discussions because he would not let me, yes, he wanted to, but then he got anxious, if I could, if I was mature enough”

Woman 22 years

Responsibility

- The parents should involve the adolescents at an early age in making decisions about treatment and healthcare
- The CF centre should guide parents in handing over responsibility



Tell them [the parents] that they should try for just one week and then see how it is. To ignore the disease for a week and then see if you [the adolescent] can handle it. And if you cannot, then they can interfere

Woman 22 years

Conclusion

The adolescents:

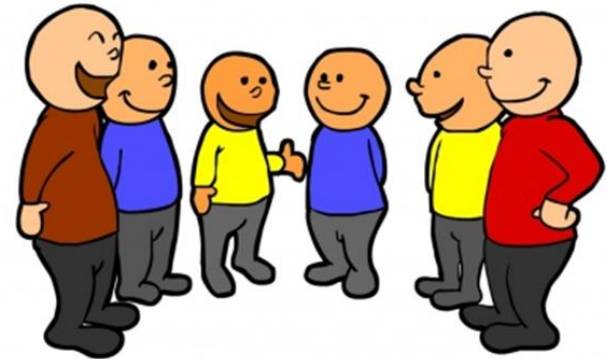
Parents need to learn skills
to help the adolescents better
manage their disease

Quantitative part - questionnaires

1. What kind of support do the adolescents want
- from their parents?
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3. What kind of support do the adolescents and their parents want
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Method (2)

- Interviews of adolescents with CF and their parents
 - Focus groups
 - Individual interviews
- Content analysis
 - Questionnaire for the adolescents
 - Questionnaire for the parents



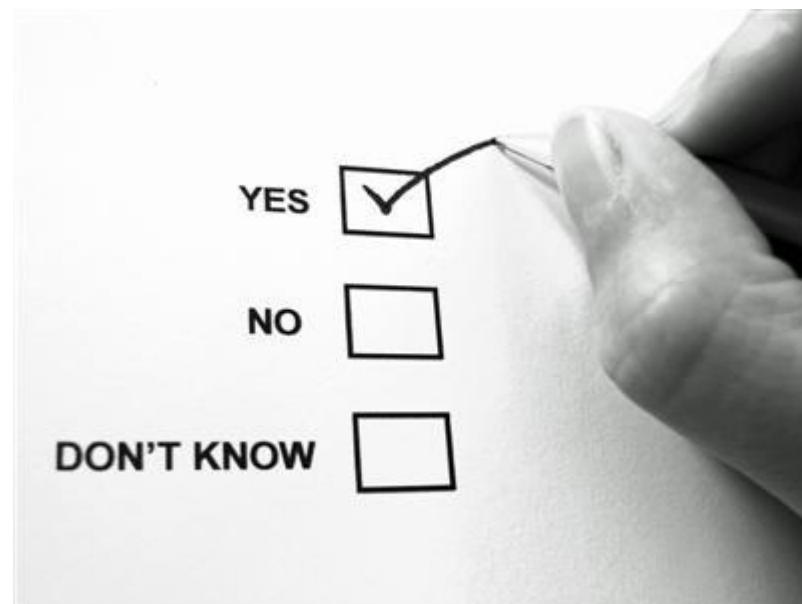
Questionnaires

1. Barriers to adherence
2. Adherence
3. Reactions from mother - father – the adolescent
4. Communication about CF in the family
5. Support from the CF centre

Participants

Adolescents 88 (60 %)

Parents 161 (62 %)

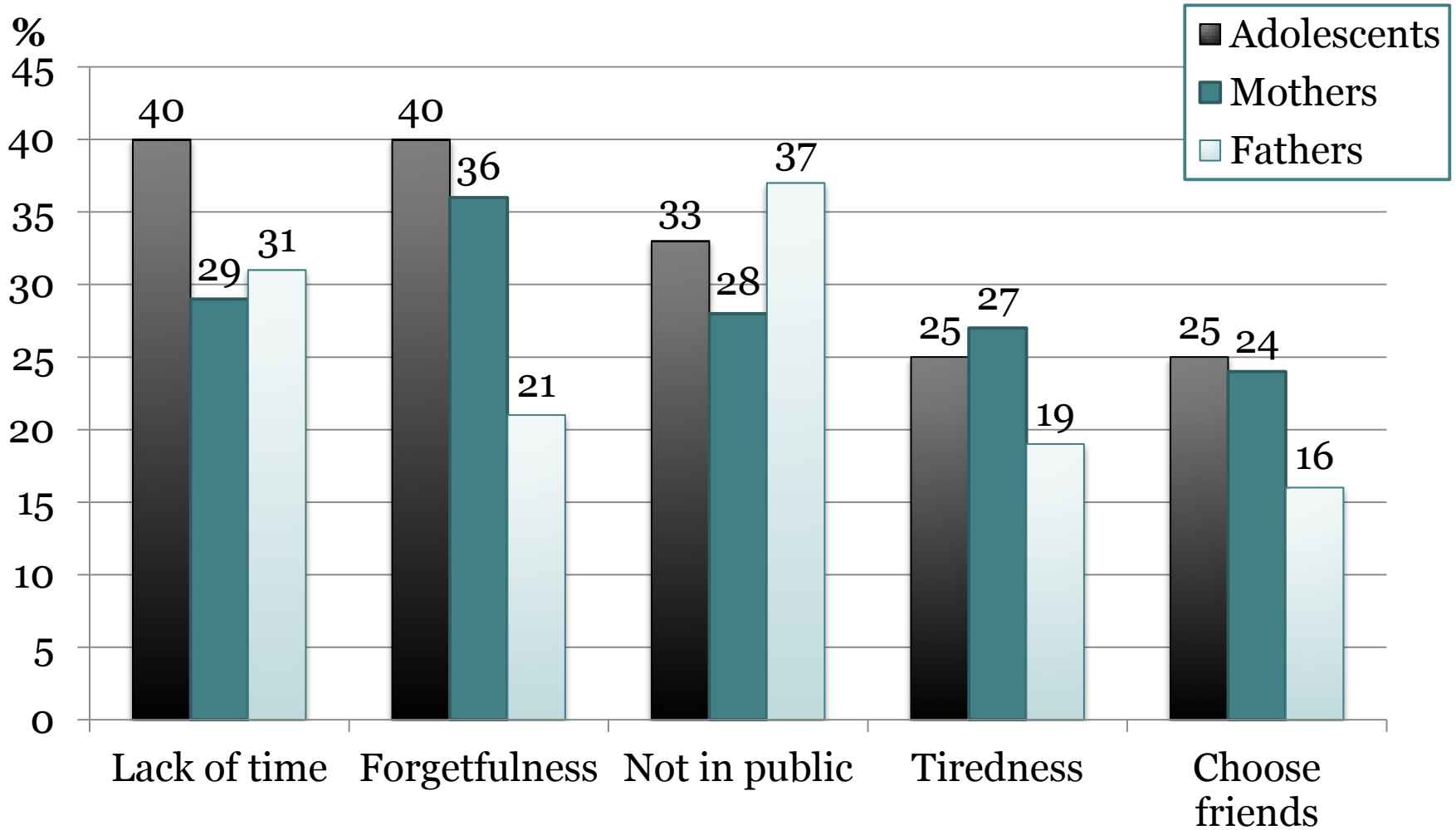


Barriers to adherence?

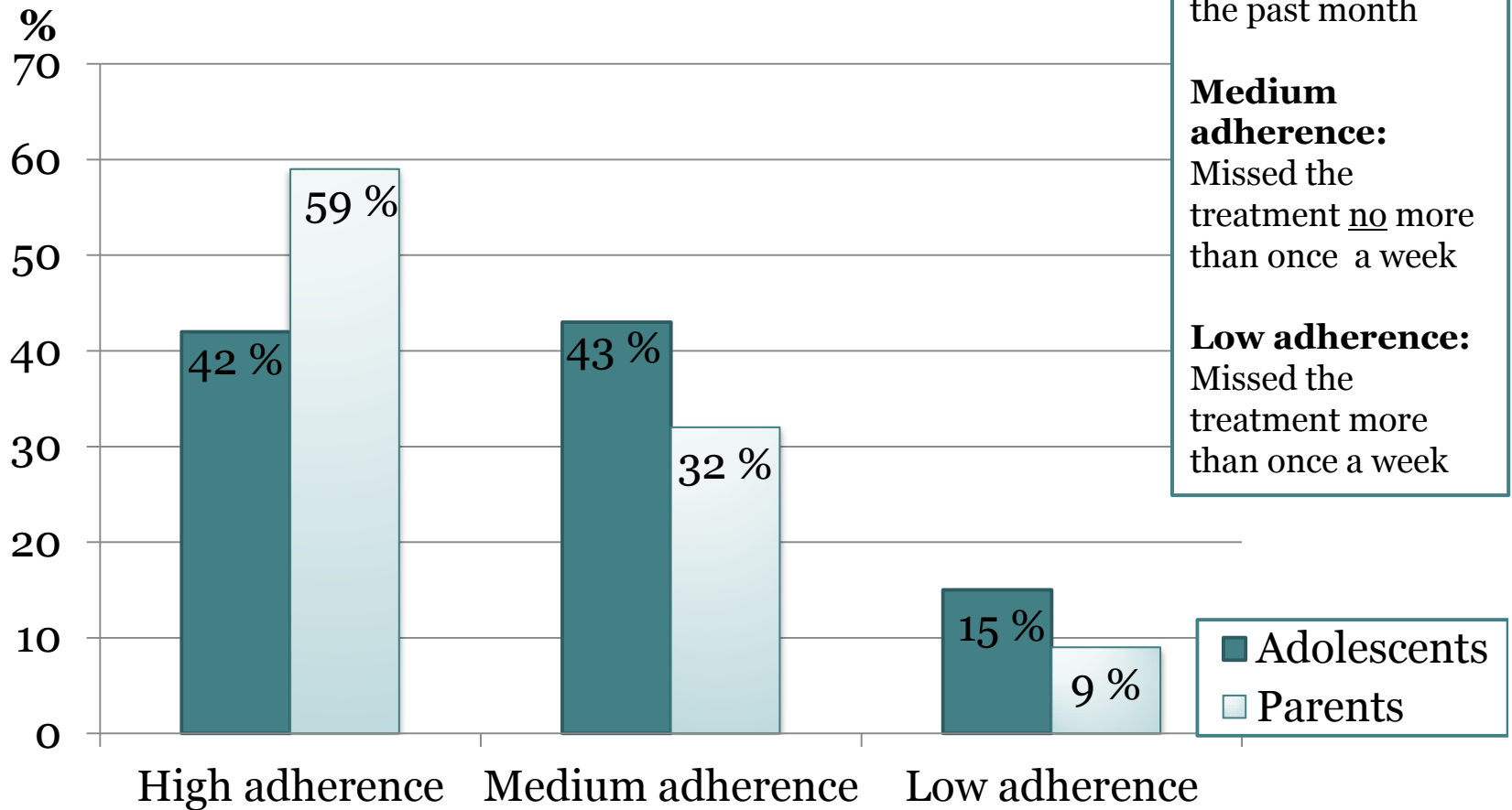
1. It is difficult for me to find time to take CF treatment
2. I often forget to take CF treatment
3. I often choose to be with friends instead of taking CF treatment
4. I am often too tired to take CF treatment
5. I will not take CF treatment in public

- absolutely right
- mostly right
- mostly wrong
- absolutely wrong
- do not know

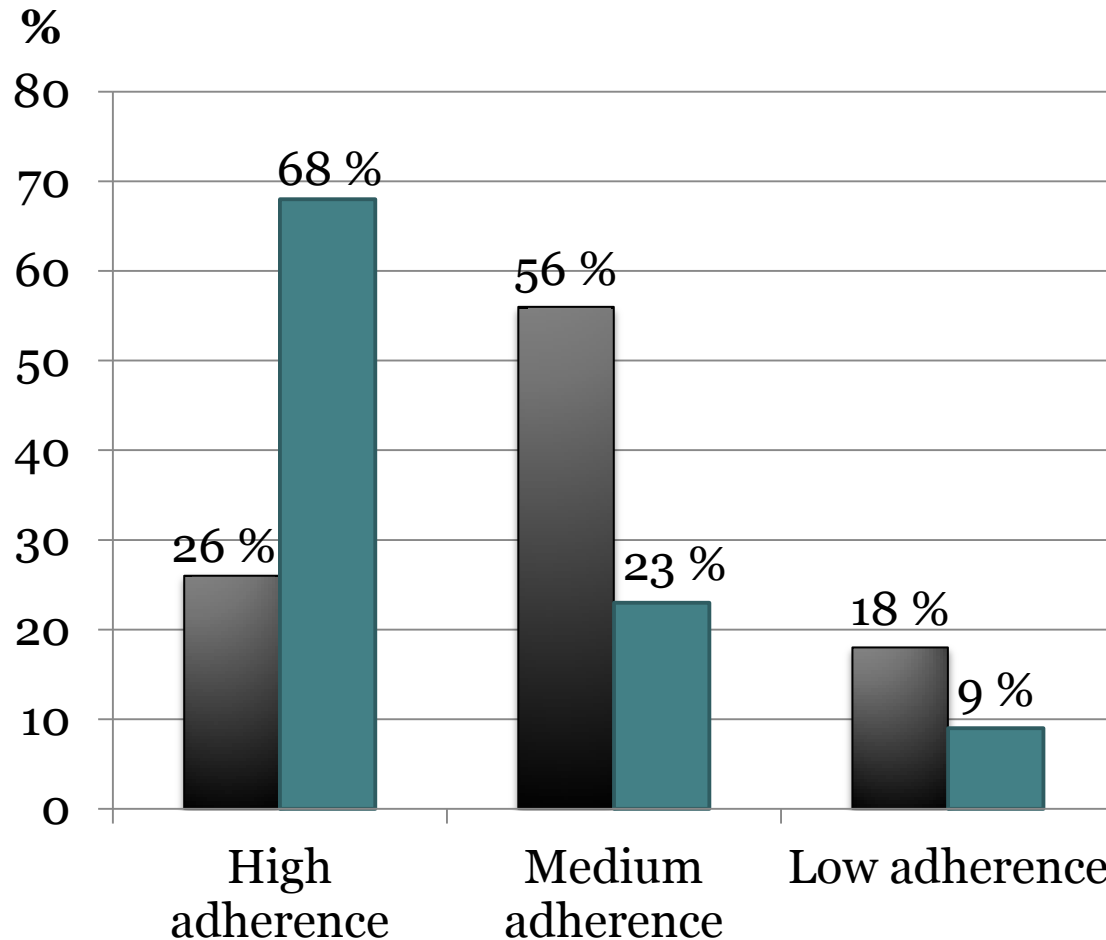
Barriers to adherence



Adherence



Adherence



High adherence:

Missed the treatment no more than once during the past month

Medium adherence:

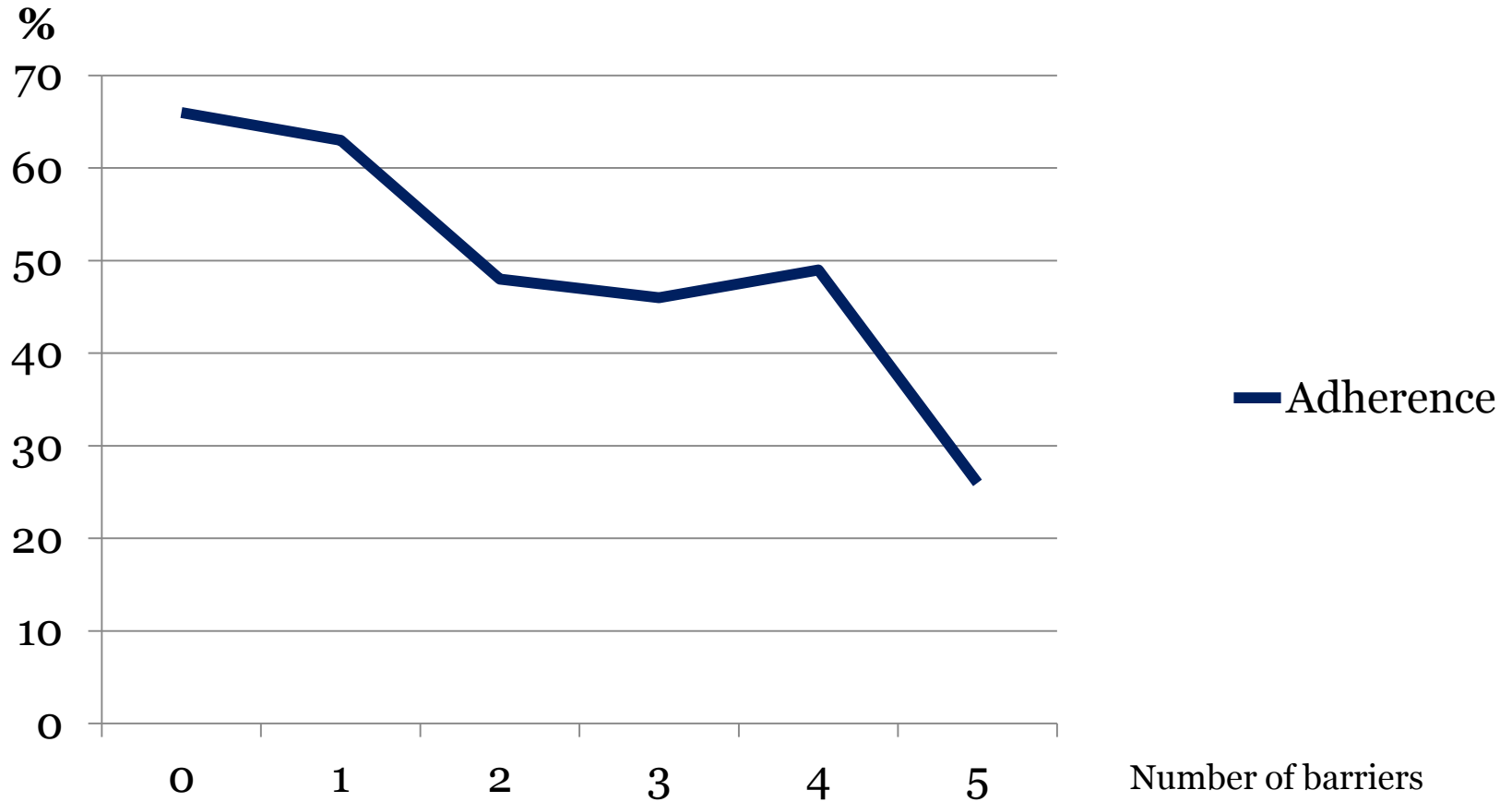
Missed the treatment no more than once a week

Low adherence:

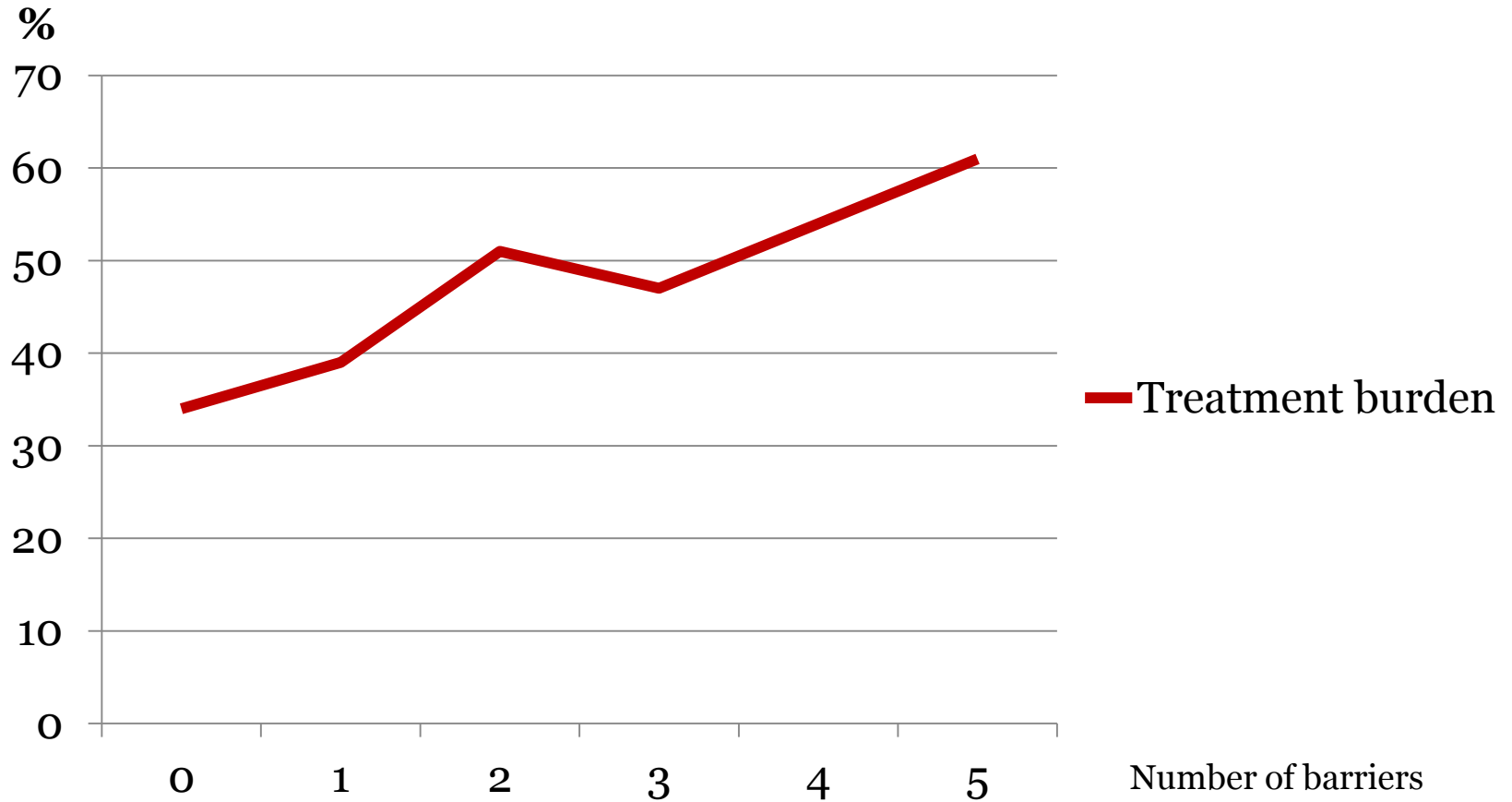
Missed the treatment more than once a week

- Adolescents with barriers
- Adolescents without barriers

Number of barriers in correlation to adherence



Number of barriers in correlation to treatment burden



Reactions from the adolescent?

1. Get annoyed when my parents ask me to take treatment
2. Tell my parents that I appreciate their help
3. Get sullen when my parents ask me to take treatment
4. Ask my parents to mind their own business
5. Quarrel with my parents about treatment

- never
- monthly
- weekly
- daily
- not relevant

Reactions from mother/father?

1. Say you are good at remembering treatment
2. Scold you for forgetting treatment
3. Ask you to take your treatment although you are doing something else
4. Quarrel with you about treatment
5. Praise your effort to take treatment
6. Help you only when you ask for help
7. Check that you have taken your treatment
8. Trust that you have taken your treatment

- never
- monthly
- weekly
- daily
- not relevant

Communication in the family about CF

1. We communicate openly about CF
2. We are good at supporting each other when CF takes up all the time
3. We can express our feelings towards each other regarding CF
4. We can talk about everything concerning CF
5. We can talk about our anxiety concerning CF
6. We can communicate about CF although we are depressed

- strongly agree
- agree
- disagree
- strongly disagree

Reactions from the adolescents, mothers and fathers

Quarrels and negative reactions were significantly more often reported by the adolescents reporting adherence barriers than by adolescents reporting no barriers

Communication about CF in the family

Support and positive communication about CF in the family were significantly more infrequently reported by adolescents with adherence barriers than by those reporting no barriers

Quantitative part - questionnaires

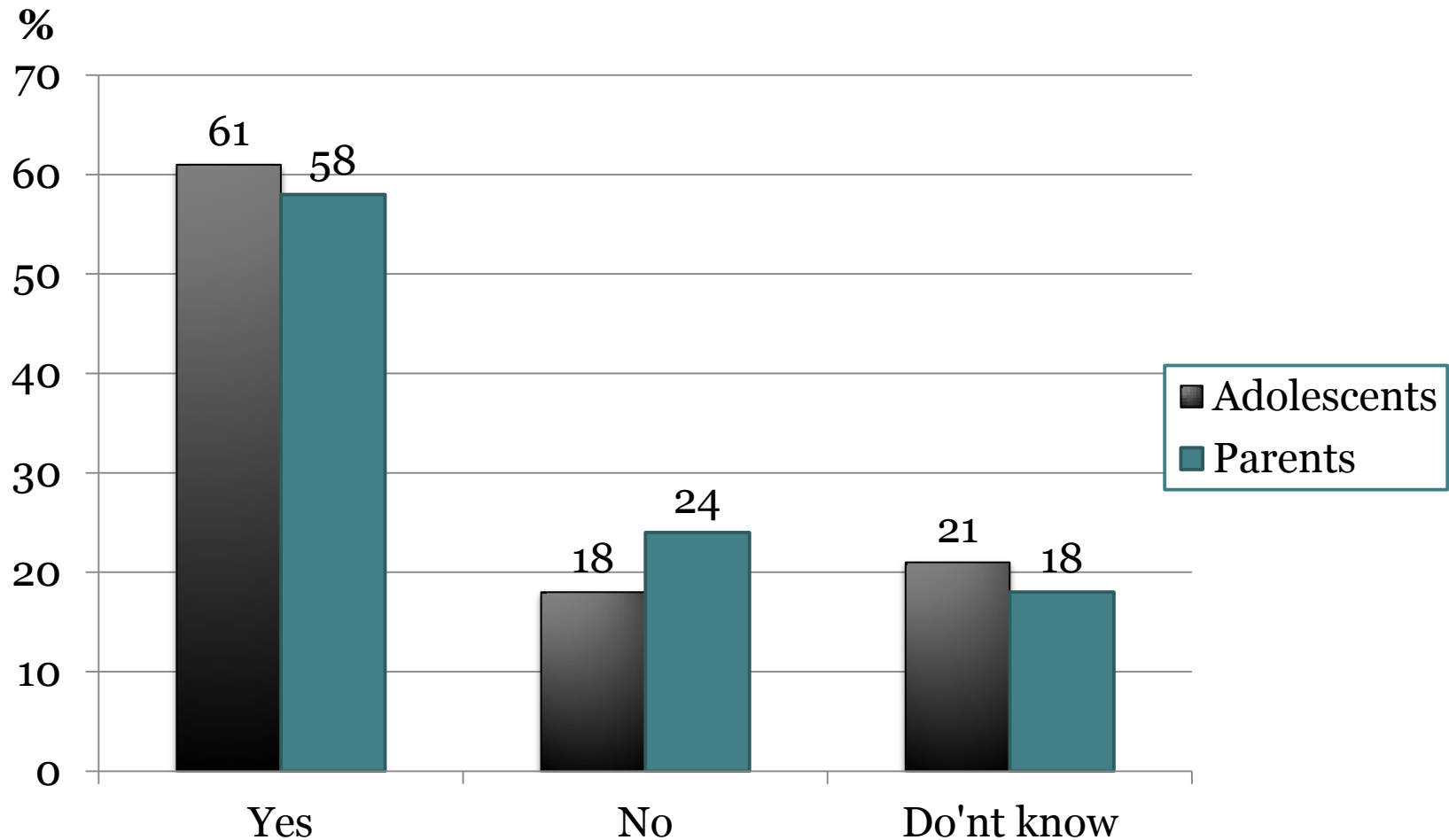
1. What kind of support do the adolescents want
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Requests for support from the CF centre

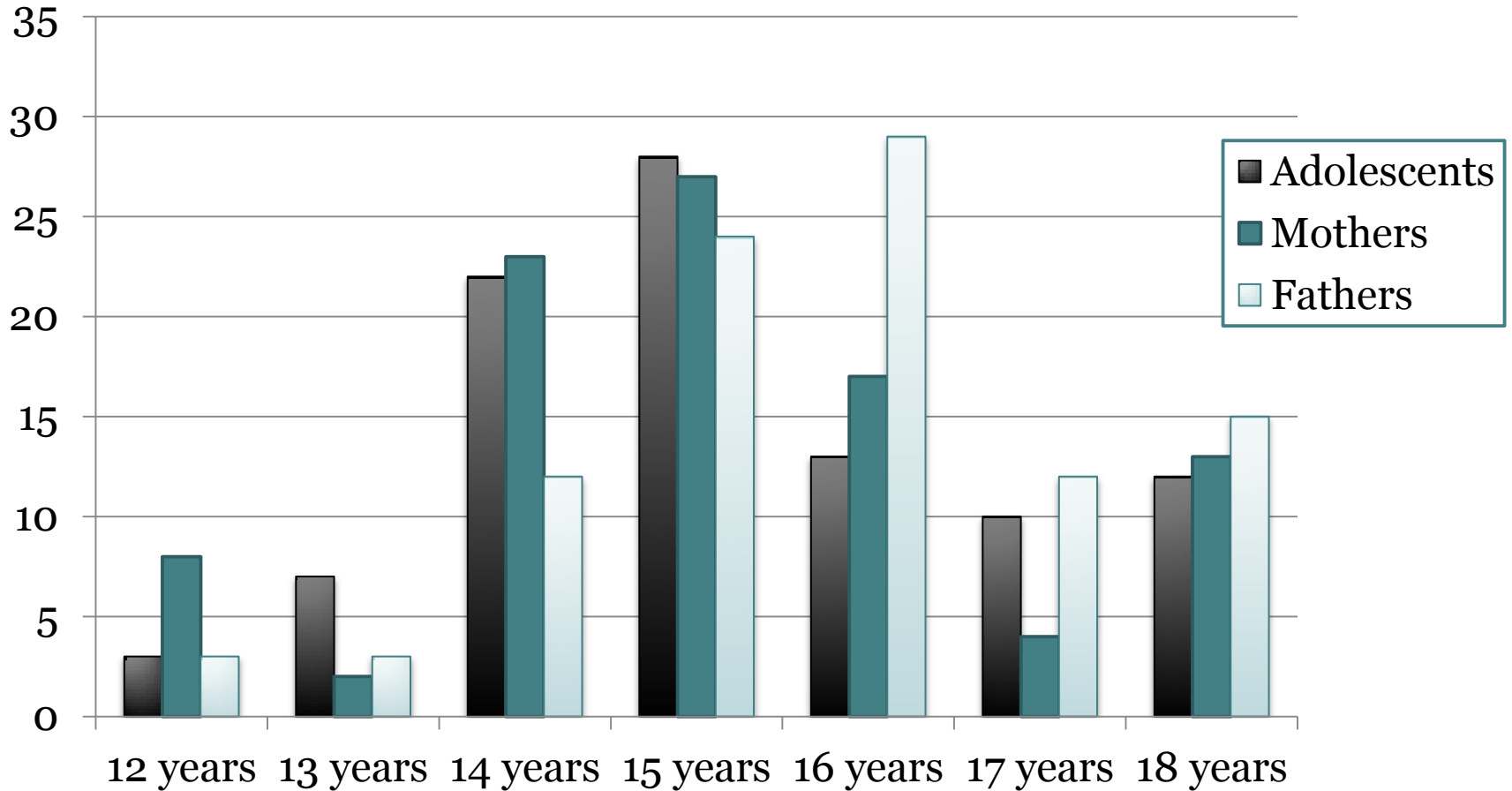
	Adolescents % (n)	Parents % (n)
Ask about adherence	33 (29)	38 (61)
Suggest ideas on how to remember the treatment	33 (29)	30 (48)
Provide information about consequences of low adherence	43 (38)	50 (81)

Those who wanted support had lower adherence than those who did not want support

Adolescent consultations



Adolescents consultations



Conclusion of the whole study

- Guidance to parents on how to parent adolescents with CF
- The majority had barriers to adherence
 - Lack of time, forgetfulness, unwillingness to take treatment in public
 - The parents knew the level and types of barriers
- Correlations:
 - Barriers and adherence
 - Barriers and treatment burden

Conclusion

- Negative reactions and unsupportive communication was more often reported by adolescents with barriers to adherence
- Adolescents and parents wanted more information about potential consequences of low adherence
- Those who wanted support had low adherence
- Individual consultations from the age of 15

Implications for practice

- Guidance on how to parent adolescents with CF
- Focus on barriers to adherence
- Ask about adherence
- Focus on treatment burden
- Individual consultations

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