1 Introduction

Cystic fibrosis is a chronic rare organic disorder, which burdens everyday life and makes quality of life difficult.

Cognitive behavioral psychotherapy is an evidence-based psychotherapy for all mental disorders (Hofmann et al., 2012; Rakitzi, 2023), but also for the burden of cystic fibrosis. This burden can be expressed with anxiety disorders, depression and of course with fear of death (Quittner et al., 2016; Verkleij et al., 2021).

Cognitive-behavioral psychotherapy always sets specific goals by relieving present and past problems. This psychotherapy offers full understanding and transparency about how the problems are described and how they can be treated.

Dr. Stavroula Rakitzi collaborates with the Hellenic Cystic Fibrosis Association, offering her services voluntarily once a year with the implementation of an online cognitive behavioral psychotherapy group program. This program was created by Dr. S. Rakitzi, consists of 13 weekly sessions, takes place once a year and is aimed at people suffering from cystic fibrosis as well as caregivers of people suffering from the disease. Everyone must be a member of the Hellenic Cystic Fibrosis Association. The main focus of this group is stress and anger management, improving mood, strengthening assertiveness and an introduction to Grief management.

The group is characterized by rules of conduct, such as that we respect each other, bullying is prohibited, everyone will express their own opinion and that there must be a written notification in case of absence before the session. Up to 3 absences are allowed.

The main goal of this group is the relief of individuals and better management of everyday life with a better quality of life. The main research hypothesis is whether the program is effective for the group members. The first pilot application of the program in 2022 (Rakitzi, 2022) showed the first positive results.

A democratic society is called upon to protect vulnerable people and ensure they have access to effective treatments, within which it is understood how problems can be addressed and resolved.

2. Methods

The following reliable and valide psychometric tests were administered before and after the intervention: Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), SCL-90-R, FAF (Fehlerschlagangstfragebögen) and U (Unsicherheitsfragebögen) (Antoniou et al., 2015; Beck et al., 1988, 1988a; Donias et al., 1991), Symptoms Rating Scale for depression and Anxiety (SRSDA) (Fountoulakis et al., 2003), WHODAS 2.0 Greek version (Koumpouros et al., 2018), which assesses the overall degree of disability and functional outcome as well as individual categories: 1 cognitive function-understanding and communication, 2 mobility-movement and ease of movement, 3 Self-care-care for personal hygiene, dressing, eating, and living independently, 4 social contacts, 5 life activities: domestic, leisure, work, school and 6 : participation, inclusion in community and society activities and finally the Recovery Assessment Scale (RAS-DS), which assesses a total score as well as individual categories: 1. doing things I value, 2. looking forward to the future, 3. controlling my disorder and 4. connection and belonging (Hancock et al., 2019).

3. Statistical analysis

SPSS version 13 was used to perform the statistical analysis. T-paired test and effect sizes (Bortz, 2002; Cohen, 1988) were used for statistical analysis. The results will be presented below.

The cystic fibrosis patient group initially had 13 members. 4 interrupted. Reasons for discontinuation: 3 became distressed by the treatment and one person declared participation but did not come at all. 10 (71.42%) participated and completed the treatment without exceeding the allowable limit of 3 absences and sent the pre- and post-treatment questionnaires. I recommended 2 members to continue their treatment by a psychologist and a psychiatrist.

The cystic fibrosis caregiver group initially had 16 members. 10 interrupted. Reasons for discontinuation: 3 did not participate at all in the first session and 7 exceeded the limit of 3 absences and did not enter the notification process. The 10 people who dropped out showed great difficulty in adapting to the group rules and empathizing with the other members. Of the 6 members (37.5%) who completed the group, one member did not return the questionnaires after treatment. I recommended one member to continue the treatment by a psychologist and a psychiatrist.

4. Results

The results of the teams will be presented below

Table 1. Characteristics of patients with Cystic Fibrosis

	N=10		
	M(SD)	t/Chi.Sq.	*p*
Age	37.50(7.84)	15.10	.00
Sex (F 90%, M 10%)	1.10(0.31)	10. 00	.35
Family Status (married 30% divorced 30% unmarried 40%)	2.10(0.87)	20. 00	.33
Employment Status (employee 40% retired 30% unemployed 30%)	1.90(0.87)	20. 00	.33

Table 2. T-paired Test patients with Cystic Fibrosis

N=10			
	M(SD)	t(df)	*p*
Anxiety before	8.10(4.65)		
Anxiety after	4.50(2.32)	2.60(9)	**.02**
Obsession before	18.80(13.79)		
Obsession after	14.40(14.15)	2.59(9)	**.02**
Assertiveness (DiffNo) before	29.50(8.68)		
Assertiveness (DiffNo) after	22.30(10.66)	2.87(9)	**.01**
Recovery 1 before	82.70(16.52)		
Recovery 1 after	94.16(5.97)	2.60(9)	**.02**

WHODAStotal before	29.66 (16.13)		
WHODAStotal after	20.83 (13.02)	2.46(8)	**.03**
WHODAS 6 before	44.57(24.45)		
WHODAS 6 after	27.08(19.77)	2.27(9)	**.04**

DiffNo: Difficulty of saying No, Recovery 1: Doing things i value, WHODAS 6: participation on society

effect sizes patient group (Cohen: 0, 2 small, 0, 4 medium, 0, 8 large)

Anxiety 0, 67 medium

Obsession 0, 82 large

Anger 1, 06 large

Assertiveness variables

Fear of criticism 0, 37 medium

Fear of contact 0, 29 small

Assertiveness 0, 47 medium

Difficulty of saying No 0, 91 large

Guilt 0, 34 small

Recovery

RAStotal 0, 53 medium

R1 (Doing things i value) 0, 82 large

R2 (Looking forward) 0,42 medium

R4 (connection and belonging) 0, 52 medium

Functional outcome

WHODAStotal 0, 82 large

W1 (cognitive function, communication) 0, 23 medium

W3 (self-care) 0, 58 large

W4 (social contacts) 0, 29 small

W5.1 (activities at home) 0, 30 small

W5. 2. (school, studies, work 1, 16 large

W6 (participation on society) 0, 71 large

Total therapy effect size 0, 57 medium

Table 3. Characteristics of caregivers of patients with Cystic Fibrosis

	N=5		
	M(SD)	t/Chi.Sq.	*p*
Age	46.20(10.01)	10.32	.00
Sex (F 80%, M 20%)	1.20(0.44)	5.00	.28
Family Status (married 80% divorced 20%)	1.20(0.44)	5.00	.28
Employment Status (employee 80% retired 20%	1.20(0.44)	5.00	.28

Table 4. T-paired Test caregivers of patients with Cystic Fibrosis

	N=5		
	M(SD)	t(df)	*p*
Depression before	10.20(4.65)		
Depression after	7.40(5.94)	4.22(4)	**.01**
Assertiveness (DiffNo) before	25.80(7.79)		
Assertiveness (DiffNo) after	13.20(14.82)	2.87(9)	**.03**

DiffNo: Difficulty of saying No.

Effect sizes

Depression 1, 67 large

Anxiety 1, 08 large

Obsession 0, 53 medium

Anger 0, 31 small

Assertiveness

Fear of criticism 0, 49 medium

Fear of contact 0, 79 large

Assertiveness 0, 42 medium

Diffficulty of saying No 1, 35

Guilt 0, 72 large

Recovery

RAS Total 0, 46 medium

R1 (doing things I value) 1, 05 large

R2 (looking forward) 0, 11 very small

R3 (control my disorder) 0, 60 medium

Functional outcome

W1 (cognitive function, communication) 0, 67 medium

W3 (self-care) 0, 44 medium

W4 (social contacts) 0, 61 medium

W51 (activities at home) 0, 44 medium

W52 (school, studies, work) 0, 57 medium

W6 (participation on society) 0, 25 small

Total therapy effect 0, 48 medium

5. Discussion

This research protocol is in progress. For 2023 we have the following results. The group of patients with cystic fibrosis showed statistically significant results in regarding improvement in anxiety, obsessive-compulsiveness, difficulty saying no (assertiveness), improvement in disability and functioning (total score and community participation) and regarding recovery and reintegration into the society (doing things I value); Effect sizes, which shows impact the treatment effect, showed improvement in anxiety, obsessive-compulsiveness, and anger, assertiveness variables, and variables associated with functioning and recovery. The overall treatment effect size is 0.57, satisfactory for an intervention.

The 2023 cystic fibrosis caregiver group showed statistically significant results in terms of improvement in depression, and difficulty saying no (assertiveness). Effect sizes, which indicate the size of the treatment effect, showed improvement in depression, anxiety, obsessive-compulsiveness, and anger, assertiveness variables, and variables associated with functioning and recovery. The overall treatment effect size is 0.48, satisfactory for an intervention.

The above results highlighted the positive effect of this online group cognitive behavioral psychotherapy, which are in accordance with the results of other studies (Quittner et al., 2016; Speed et al., 2017; Verkleij et al., 2021) as well as with the pilot application of the program in 2022 (Ρακιτζή, 2022). Improving assertiveness can lead to improved anxiety, depression and self-confidence (Speed et al., 2018).

This group intervention lasts 13 sessions. The continuation of the therapy of some members of the groups was considered necessary and therefore the appropriate referrals were made to the multidisciplinary team of the cystic fibrosis units. The cooperation with cystic fibrosis units in the National Health System is essential.

The main goal of this group intervention is the psycho-education and psychotherapy training in a mechanism for dealing with everyday life and reframing life based on the new data. At the same time, individual responsibility towards problems is strengthened. Thus this group therapy is applied through the perspective of recovery and redefinition of life (Rakitzi, 2023), which improves individual responsibility and adaptability in life.

The drop out in the caregiver group is high, which is related to the difficulty of commitment to the group for 3 months as well as to the lack of empathy towards the other members.

The samples of the 2 groups are small, which always negatively affects the statistical analysis. There is no comparison with a control group, something that was not feasible, because more volunteer psychotherapists are needed.

In conclusion, psychotherapy is an integral part of cystic fibrosis management. Investigating the effectiveness and efficacy of this group therapy in a larger sample is our future goal.

Members self-reported the following impressions from therapy: I learned from others to think differently, improved negative thinking management, improved self-confidence, improved stress management, we are not alone, improved anger management, learned to say no, I learned to share things with others and so now I feel stronger to be actively involved with the club, I learned new things, group psychotherapy is more interesting than individual psychotherapy, my empathy increased I manage the fear of death better, we are one family, increased the acceptance.

A democratic society must provide evidence-based treatments to vulnerable people!

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