

A Coaching Program for Parents with a Child, Diagnosed with CF after NBS, Feasibility and Possible Effects



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Abstract

Newborn Screening for Cystic Fibrosis was introduced in The Netherlands in 2011. Parents, who have a child diagnosed with Cystic Fibrosis, are faced with a sudden and impactful life event that evokes anxiety and stress. A parental coaching program was set up by the Dutch Cystic Fibrosis Foundation in order to support the parents. Feasibility and possible effects of the program were studied in a pilot. The program seems to have positive effects on the psychological wellbeing of the parents. After the intervention, levels of anxiety and distress of the parents significantly decreased, compared to the start of the program. Overall, the program was rated very positively by the participants and 90% stated they reached their personal predefined goals. Both the structure and content of the program are feasible for them. They would highly advise the program to future parents with a child diagnosed with CF.

Keywords: Early intervention; Parental support; Rare Diseases.

Abbreviations: NBS: Newborn Screening; CF: Cystic Fibrosis; ECFS: European Cystic Fibrosis Society.

Introduction

Newborn Screening (NBS) for Cystic Fibrosis (CF) has positive effects on nutritional, respiratory and survival outcomes [1] and is expanding across Europe. In countries where CF is implemented in NBS programs, this is done according to the standards of the European Cystic Fibrosis Society (ECFS), although techniques and procedures are variable [2]. In the Netherlands NBS for CF was implemented in May 2011. Parents are predominantly in favour of NBS, being aware of the advances when treatment starts as early as possible. At the same time the diagnosis has a huge impact on them and interferes with the bonding between parents and child [3]. Coaching of individuals and groups has been developed during recent years as an addition to psychological interventions to promote coping with life events and resilience [4].

The Dutch Cystic Fibrosis Foundation (NCFS) wanted to reach out to parents and help them to overcome or even prevent stress and anxiety and to increase their resilience. A coaching program was developed and offered to parents. The purpose of

the program was to enable parents to cope with the diagnosis of CF in their child; to optimize the mental health status of the parents; to enable them to take care of their child, each other and their family; to optimize social and work-related functioning; to empower them in their relationship with the clinical healthcare system if needed. The aim of this pilot study was to explore the feasibility and possible effects of the program. The perception of the parents towards the coaching program was evaluated.

Methods

Participants

Parents of children diagnosed with CF after NBS were offered the coaching program via the CF centres and via the information for parents of newly diagnosed children at the NCFS website. They could apply for participation within two years after the diagnosis. NCFS supported the project financially and parents were not charged when participating.

Intervention

Qualified and registered mental health coaches, with knowledge and experience in guiding parents with regard to chronically ill children and parenting, formed a team. The coaches worked along the lines of family therapy with a systemic approach. The coaching team was educated about the many different aspects of CF, like its clinical symptoms and the care system that the parents became acquainted with. The program was announced by NCFS and supported by all Dutch CF centers, that perceived the program as additional to their own mental health care routine. The coaching program consisted of four sessions at home (individually or with both parents) with the coach. In the first session parents defined their personal goals and subsequently worked on these goals with the coach in an individualized, tailor made program. Parents were in control of the period of time in which the four sessions took place. Finally, after their individual program, they were offered one group session with other parents, under the guidance of a coach.

Measurements

A pre post study design was used. At start of the program (T = 0) and after finishing the program, usually around 12 months after the start (T=1), participating parents filled in standardized questionnaires, developed by the NCFS, concerning:

i. Goals: the personal goals of the parents and the level of achievement of these goals using a 5-point scale

ii. Distress: to assess the level of tension, concern and anxiety, three questions from the HADS [5] were used on a five-point scale.

iii. Satisfaction: about the information, content and organization of the program, using a 5-point scale. All 5-point scales had the same structure: 5=very good, 4=good, 3=sufficient, 2=not sufficient, 1=bad. For a complete list of the questions see addendum.

Statistical analysis

Descriptive analysis consisted of frequency analysis of the HADS scores and 5-point scales. Differences between T0 and T1 on the level of distress were analyzed using a Wilcoxon Signed Rank Test.

Results

Participants

One third of the parents (n=76), confronted with the diagnosis CF after NBS, participated in the program, according to data from the Dutch CF Registry 2011-2016. 67 of them (31 males and 36 females) filled in the questionnaires at T0 and T1.

Outcomes

i. **Goals:** personal predefined goals were reached by 93.6% of the parents, ranging from sufficient to very good (Figure 1).

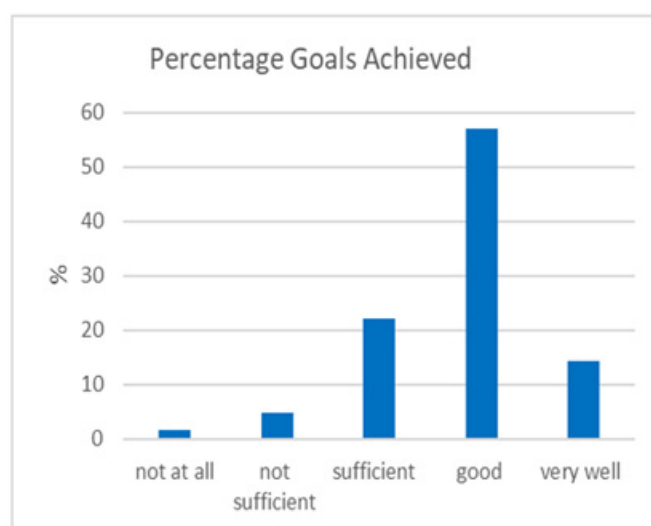


Figure 1: Perceived achievement of predefined goals.

ii. **Distress:** the percentage of parents that felt 'very concerned' or 'concerned' decreased from 52,2% at the beginning of the program to 35,7% at the end of the program ($p < 0.001$). The percentage of parents feeling 'mostly distressed' and 'often distressed' decreased from 48,2% at the start of the program

to 31,2% at the end ($p < 0.04$). The percentage of parents who experienced feelings of anxiety 'very often' and 'often' decreased from 51,8% to 39,6%, compared to the end of the program ($p < 0.018$) (Figure 2).

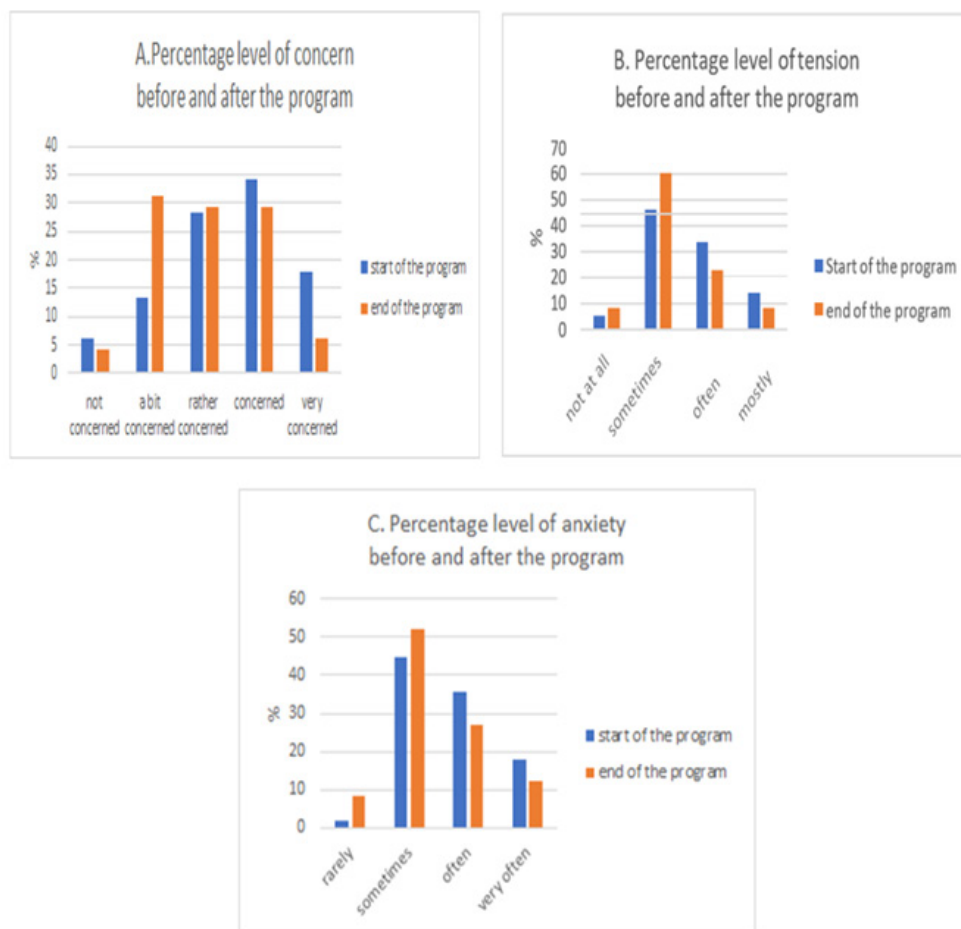


Figure 2: Perceived distress (concern (A), tension (B) and anxiety (C)) at start and end of the program.

iii. **Satisfaction:** at the start of the program over 80% of the participants rated the information about the program ‘good’ or ‘very good’, in relation to their expectations, the methods being used (approach), the definition of the goals, and the organization of the program. According to 96.9% of the parents, the coaching program contributed to their personal development. The implementation of the content of the coaching program into their daily lives on a practical basis was doable for 88.9% of the parents. The program gave 88.9% of the parents greater insight into their functioning. The program fitted into the family circumstances for 95.3% of the respondents and 88.9% described the program as fitting to their personal situation. The content of the program was considered as relevant by 87.3% of the respondents. The number of sessions offered in the program was rated as ‘good’ or ‘very good’ by 71.5% of the participants. The other 28.5% stated to be in favor of more sessions. The distribution of time in between the total amount of sessions was rated as ‘good’ or ‘very good’ by 88.8% of the responders. Of all respondents, 92.4% stated they would recommend the coaching program to other parents with a child, diagnosed with CF (Figure 3).

Discussion

As far as we know this is the first description and evaluation of a coaching program for parents after NBS. The coaching program, as developed by the Dutch Cystic Fibrosis Foundation, seems to be feasible and helpful for parents with a recently diagnosed child with CF. It helps parents to achieve the goals they predefined for themselves and they are very enthusiastic about the program. However, this pilot study has its limitations. The lack of a control group makes it difficult to define what caused the changes in the parents’ level of distress, at the start and after the program. Yet, a systematic evaluation of this new intervention took place, to have an overall impression of the feasibility of the program and to explore its effects. The results strongly support continuation of the program and further research, including the use of a control group. The study is also limited by the fact that the HADS questionnaire was not used completely. The researchers wanted to gain experience in this sensitive area, when reaching out to the parents. Thus, the number of topics on the questionnaire was limited, to prevent the parents from withdrawing from this pilot.

In further research it is recommended to use the entire HADS questionnaire.

The pilot focuses on Patients Reported Experience Measures (PREMS), which are becoming more important to include in scientific research [6-8]. We have a clear insight in what parents

go through when confronted with the diagnosis of their new born; it would be possible to implement certain measures to prevent negative impact as a result of the diagnosis. Eventually, we would like to know in what way the diagnosed child is influenced by this program, psychosocially and clinically.

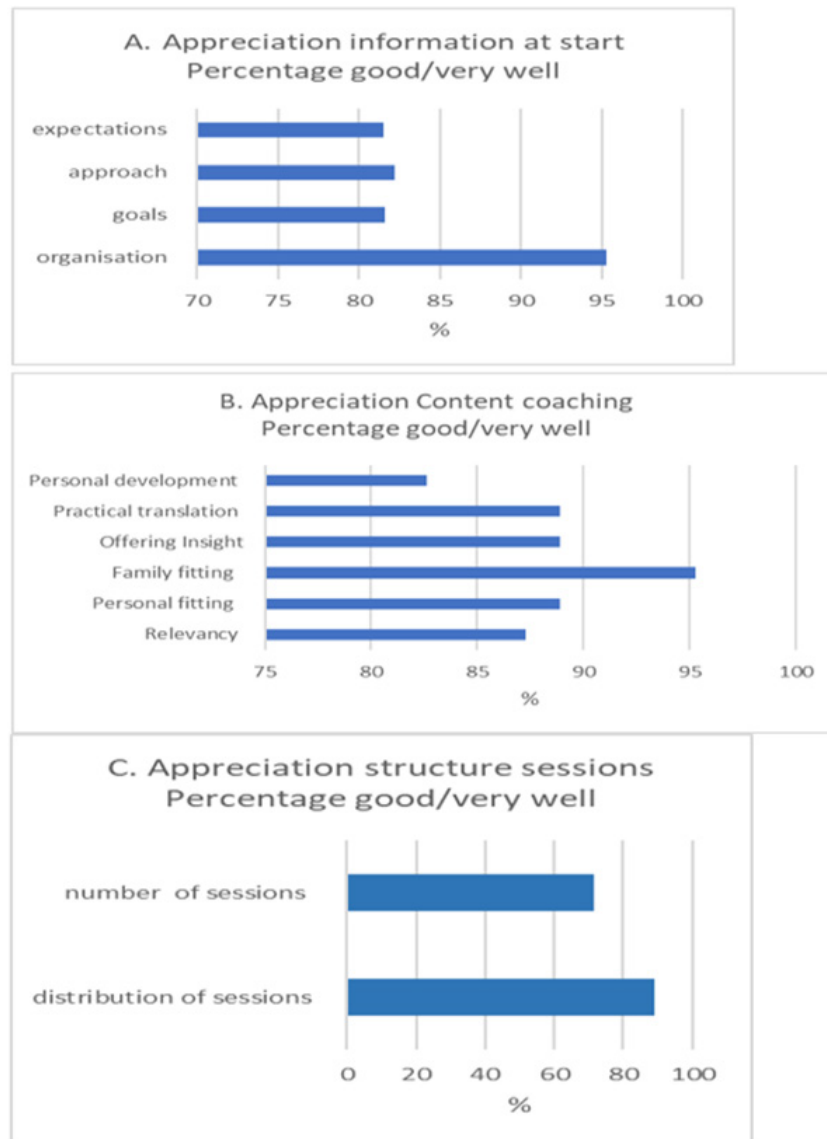


Figure 3: Satisfaction on the information (A), content (B) and structure (C) of the program.

The results of the pilot indicate that this program is manageable and feasible for a patient organization to organize and monitor. Further research is required.

Conclusion

The coaching program, developed by the Dutch Cystic Fibrosis Foundation, seems an effective way of guiding parents through

some common and well-known psychosocial phenomena that occur after a child is diagnosed with CF via NBS. Anxiety and distress of the parents decreased significantly and over all the program was rated very positively by the participants. They highly recommended this program to future parents with a child diagnosed with CF through NBS.

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Conflict of Interest: The authors have no conflict of interest.

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