

Psychotherapeutic Experiences with Chronically Ill Children and Their Parents

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Abstract

Objectives: By establishing parent's groups we could reduce social exclusion of people taking care of children and young adults with special needs and their feeling of being emotionally abandoned, so as they could find support to manage their unresolved tenseness.

Methods: The group could serve as a basis for comparison in which anyone and everyone can compare his own decision with others' experience, reactions and expectations. It will result in strengthening their ability to fight for their children's interest after a while. Content of psychotherapy teams were analyzed.

We need to learn how to encourage parent being alone with their sorrow and discomfort, and how to make them more active.

Results: In order to achieve the above developing, treatment and training team must develop its approach.

Parents should be accepted as partner, not only some "accessory" and in the interest of the child's development we must collaborate with them.

Integrated service of children with special needs must be established at all levels of institutional education, and we should support similar initiatives with care providers, professionals and developmental tools.

Conclusion: To summarize the above we could say that parents' groups of mutually collaborating, self-supporting members are extraordinarily useful and effective in helping parents in their everyday lives. It serves as an emotional and practical support, safety; friends in joy and companion in trouble. Its training and forming power is enormous, its impact is far over the individual level, personal life, as it could grow into a power of social reform in acceptance, tolerance. We really in need of this so as we could dose up to Europe in the field of caring and education of children with special needs.

Keywords: Parent's group; Children with special needs; Exclusion; Integrated care

Introduction

One of the most common challenges parents face when managing the care of their chronically ill children is that they may not have the ability to cope [1]. According to Carnevale et al. [2] families with children with special needs (ventilator-assisted children) report a deep sense of isolation and live with daily distress. Besides, caregivers of children with disabilities describe negative physical, emotional and functional health consequences of long-term, informal caregiving [3]. Health and well-being of caregivers of children with cerebral palsy are negatively affected by these conditions [4]. Stauffer [5] has found that long-term psychotherapy groups for children with chronic medical illness can have a positive influence on children's psychological adjustment, well-being and health status.

To belong to a group and experience of belonging there is basically important for a child, especially for those who live with special needs, as well as for the family.

The most significant contribution of a group experience to the development of a personality is the modification or total clean-up of the self-focusing attitude and isolation. It strengthens the individual's ability to feel sympathy towards others and to establish a positive self-identification [6-8].

The group - be it either a family or a therapy group - should not be considered to be the sum of individuals, but as an unique, dynamic unit with its own special rules from which individuals separate out based on differentiation during development.

In group therapies an attitude should be established which perceps and understands individual manifestations within and together with the group's own order and system of correlations [9].

During meetings of the parents' group we take care of the children in our nursery centre. For siblings of normal development we have established a creative therapy group under the supervision of psychologists and special teachers [10,11].

A joyful therapy using artistic techniques developed by Elaine Polcz [12] improves and motivates creativity. It supports development of communication, pulls out from passivity and helps socialization through creative activities.

When feeling how great it is to create something, their relations were fonning and their siblings' personality changed, as well. So their feeling lonely reduced, they were not eliminated from common family experience, travels to our institution [13,14].

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The Establishment of the Parents' Group

Group development process improves the acceptance of a child with special needs, as we as undertaking that would come, and supports psychodynamic processes [15].

- Considering *mothers'* post-delivery and failure-caused depression we can state that these lessen their basically reduced self-consciousness and could cause emotional refusal towards the child. Due to their strong anxiety they are not able to focus on the child's signs and they have less unconscious, positive reactions than mothers in general.
- *Fathers'* acceptance is quite different. They feel ashamed, unsuccessful, stigmatized. Their anxiety becomes stronger and stronger and in many cases they become workaholic or alcoholic.
- Regarding the *couple* we can observe that acceptance causes tension, and many times they blame or accuse each other. This process often results in divorce.

The only way out of this is strengthening their parental self-consciousness, getting stronger in their struggle and in collaboration. Familiar coping mechanisms have significant role in this process on the parents' part. Birth of a child with special needs enforces the family to change and to adapt itself to the new situation.

- Considering the socialization of the child with special needs we could observe that either overprotecting, or hidden or real refusing care attitude of the parents could have negative impact on the development of the child's selfnotion.

Our parents' group - after a period of time - was called "Flower in the desert - a child with special needs in the family".

The program was supported by "Save Our Future and Talent" Foundation Family Support Service and "For Our Children" Parental Organization.

The aims of the parents' group

1. Identification, coping with losses after the birth of the child with special needs in collaboration with professionals.
2. Sharing anxiety and fear with other parents in similar situation.
3. Introduction of interventional solutions for the second and third crisis.
4. Effective troubleshooting and problem solving instead of suppressing, neglecting them.
5. Mutual load-bearing, sharing in a marriage.
6. Introduction of solutions of marriage crises.
7. Identification and avoidance of special problems, care mistakes and "matches" linked to the care for a child with special needs.
8. Difficulties and solution regarding the relationship between the child with special needs and siblings of normal development.

Cases and Methods

Duration: We had meetings once in 3 weeks in the Children's Rehabilitation Centre for 2,5-3 hours for 10 years.

The group was moderated by clinical psychologist, psycho-therapist and psychologist.

Method: Free interaction developed by verbal content analysis. The aim of content analysis was to identify and collect those main issues that arose during the therapy period and which the group was willing to analyze.

We have provided open questionnaires to different categories of the content analysis. Responds strengthened the effectivity and significance of treatment of the special topic. Issues appeared after content analyses were the followings:

1. Introduction, problem identification (questionnaire, talking)
2. Pregnancy, delivery, birth of a child with special needs. First crisis.
3. The nature of disability and its impact on family members. Accusation, self-accusation.
4. What would happen with the marriage?
5. Motherhood - a different view. Fathers in a different role. Compunction. Division of tasks. How to help?
6. Neglected siblings of normal development.
7. Reactions of the wider family environment. Second crisis. Shame and compassion.
8. The nature of crises. Denial and isolation.
9. Living with problems - acceptance. Strategies to struggle.
10. Daily routine, division of tasks between parents.
11. Isolation or integrated care.
12. Special problems of child care.
13. Present and future. Desires and reality.
14. Mental hygiene of the parents. Self-value, self-consciousness.

In the followings we will present relevant questions and answers for unfinished sentences in the questionnaire. We developed a questionnaire for parents to ease tuning to the specific issue and to start talking. The first composed of unfinished sentences. The most important and interesting questions were the followings:

The nicest moment in my life...

Most mothers denoted the birth of her child.

Several respondents denoted change in the status of the child with special needs: "When my daughter started to walk at her age of 4."

The most horrible moments in my life...

Most of the respondents denoted facing the disability.

Fear of losing the child.

Separation from the child (day-nursery, kindergarten, or residential school education)

My most difficult decision...

- "Shall I give birth to my child or not?"
- "Shall I put up my child with special needs in an institution or not?"
- "I should have given my work up to be able to stay at home with him / her."

- “Moving from P to D, and to give my work up.”
- “Who should be in the first place: my child with disability or the other three with normal development?”

I'm afraid...

Parents described their uncertainties about the future as third crisis in their responds: “My child would not reach adulthood.”

“I would get ill, because there is nobody in the world that could take care of my child...”

“My child's situation will get worse. I am not be able to take care of him / her.”

The first crisis for the parents of a child with disability is to face with the disability of the baby. Mothers have dramatic memories about what happened in the delivery room: “Everyone was happy there except me as they did not give my baby to me...it was horrible (she's crying)”

“I wanted to die!”

“I closed myself.”

“There was no reason to live for.”

Acceptance of the disability is even more difficult as physicians do not describe the situation precisely, consciously, there is no sympathy, they do not try to be intimate when telling the diagnosis, even correct information is missing. Parents tell the followings about it:

“It was in the corridor when they told me that my child has Down syndrome. I did not even understand what I was told...”

“The child cannot be blinder. There would be problems with his motion, too.” “He will not survive, he is not viable.”

Intimacy is important in protecting rights of the personality. Humane and objective information makes it easy to face the terrible reality.

It is important on the physician's side to give time to compass the information as for the first hearing parents could get into a kind of shock. It must be assured that parents could articulate their concerns, questions.

It was in France where they introduced “Parents' Solidarity Program”. The essence of the program is that parents facing with similar problems support each other. Exchange of experience, emotional support is important, more over indispensable. No one else could understand a family caring for a child with special needs as another family in the same situation. There were true friendships born within the parents' group. They have continuously been organizing common programs, like celebrations, holidays. They keep contact outside the group. They inform each other about new opportunities.

During the first crisis they sometimes find support, someone to lean on. A grandma told her daughter the followings:

“Try to be glad to what you have.”

It has become a sort of proverb among parents since then.

Many times it is even more difficult for the father to cope and struggle with the crisis. A man cannot give it up. Many of them escaped, divorced, left the mother alone with their disabled child.

Those who did not leave the family had terribly hard fights (alcoholism), then recovered and became a real partner for the mother

and careful “male-nurse”, protecting father of the child. They are the ones who attend the group. When development is visible, one of hem told:

“We managed to cope with the disability itself.” “I accepted his state as it is.”

The questionnaire was based on this latter statement and relevant literature. Faith in positive thinking, hope and possible advantages are behind our questions - beyond losses families had to face with. Let me review some important topics based on the parents' responds.

1. What sort of desires, fantasies did you have of your child?

“His eyesight could be improved by operation.”

“I will be able to raise his maximum abilities.”

“I will show what others couldn't.”

2. What has your child lost due to the disability??

“Beauties of adulthood - he will always remain a child...”

“Normal, everyday life and his father.”

“Conscious life.”

“Valuable life.”

“Real cooperation with his peers.”

3. What have you lost due to your child's disability??

“There is no any area of my life where I could come up as I want to.”

“Really nothing. This is an extra.. Now I know what it means to grow a child with special needs.”

“I have become rather better, more interesting as I should cope with a different, not usual role as a mother.”

4. Are you able to see your child, not just the diagnosis??

Most of the parents simply answered ‘yes’.

“He is a beautiful personality.”

“We see of child, not his disability.”

How does the family become richer through caring for a child with special needs?

“A parent of a child with special needs is not less, but more.”

“He enriches our world of emotions.”

“Siblings learn to see the world in a different way.”

“We become richer by his life.”

One of the fathers said:

“Do I have the right to decide about a life? Do I have the right to let him live? Or not to?”

Later the same father encouraged his wife:

“It is a real record what you do. You recover from time to time.”

One of the most significant developments was that of a mother of a boy with special needs whose husband immediately left them when the disability turned out.

The child's mental development was highlighted during Christmas time.

“He was anxious that Santa Claus didn’t come to him. It was great as he realized...” - anxiety was well understood and the child’s different behaviour turned to a positive notion.

He articulated the second crisis as follows:

“I have never been walking with my son in the High street. Now we go to see the Christmas tree!”

6. Motherhood, fatherhood - in a different way

Parents could easily fall into the “matchplay of the sick child” and tend to overprotect their children with special needs. Some of them admit that they were wrong.

“I worried, protected him too much.”

“I’m sorry.

“I leave too much to him.”

“I was an unconditional mother - now I require.” A father said:

“I am stricter than my wife. He can extort from his mother what he wants.”

With regard to rewarding and punishment opinions and views differ.

“Think about it! - I make him stand in the corner. Say sorry!”

“He cannot be punished until compunction does not develop in his personality, as he is not able to make difference between good and bad.”

“Wooden spoon - he ran to the TV and pushed it down. It was dangerous what he has done. Later it was enough to mention ‘wooden spoon’ and he stopped destruction.”

“I leave him alone and go out of the room - this is the most serious punishment (the child lives with physical disability). I do not say a word.”

There was a couple that attended a marriage therapy for years, but the father escaped to workaholism, he was neither able to establish contact with his daughter, nor to take care of her. The mother was left alone emotionally, but the marriage was kept alive formally. Years were passing... Years of the parents’ group, too... and one day they accepted their child as she was. After seven years they felt strong enough to have another baby. By that time they refused even the idea. What if the second child were disabled, as well?! The sibling of normal development is now one year old. He is a boy. The father is proud of him very much. “He changes his diaper, feeds his big daughter, the disabled...” - tells the mother with a beaming face. They have broken from their isolation; the family goes together to puppet-show or to the lido.

Discussion

The following section contains the results of the Parents’ Group:

- There are always newcomers in the group. It means 2-3 new families half-yearly, so it did not disturb the development of the group.
- Some of the old members left the group due to moving to another place or illness.
- More and more fathers come with their wives.
- Parents experienced that they are not alone.
- Internal, external and interpersonal relationships improved as long as they learnt to cope with their trauma.

- In some years’ time members of our group became active members of a parents’ association. (e.g. For Our Children, 1991, Support, 1998.)
- They became active in different local and national forums; they participate at conferences, even hold presentations.
- They go to parents’ meetings to school where they share their problems, like a kind of preparation of integrated education, they support integration and acceptance of their children.
- Domestic and foreign - e.g. Transylvanian - institutions are interested in the activity of our parents’ group.
- Isolation of the parents loosened.
- There are more institutions than earlier that are open to integrate children with special needs.

I would summarize the impacts of the parents’ group in the followings:

- Parents’ attitude became more congruent towards their children with special needs
- The extremity - affecting socialization of the child and the family - in their care decreased
- Sooner acceptance of the disability results in a more harmonized development of the personality of the child
- Process of contact development with peers improved, both from the child’s and the family’s aspect
- Their self-notion became more stable
- Maternal acceptance developed faster after the failure which the birth of the child with special needs was
- The collaboration in facing the trauma between the parents improved
- Group experience and process supported coping with the trauma and developed individual models of proper acceptance the child’s disability. Getting to know other families’ solutions helped parents, and plays/played the role of a community support which widens cooperation possibilities outside the group. This way family became less isolated.
- It makes the work of institution professionals more effective as the presence of the familiar balance gave more opportunities for institutionalized integrated education and care. It would make the development of individual care and educational plans much more effective.

Conclusion

In this summary we tried to share experience on the content of group therapy for parents, families of children with special needs. Our aim was to analyse tools, dynamics, and mechanism of the therapy process. Highlighted contents and quotations define the mechanism without / instead of more scientific effect analyses.

Description of rare or less usual therapy events - especially in population chosen and shown in our study - published in psychotherapeutic publications.

Effectivity of psychological and special educational care for children with special needs depend mostly on the parents’ attitude. Therefore therapy involving parents could be determinant in many cases.

Child mental health professionals have important roles to fulfill in helping staff members deal with increased parental participation and directly managing family members with intense distress related to their infants' fragility. It consists of five main tasks according to Mayes [16]: 1. Understanding the nature of the biologic issues facing the child. 2. Understanding the family's relationship with the child and their overall level of functioning. 3. Developing an appreciation of the place of the child in his or her family and how the parents understand the nature of the medical problems. 4. Forming a collaborative relationship with the pediatricians and other subspecialists who care for the child so that behavioral and psychological interventions are integrated with the child's biomedical care. 5. Fostering a brief therapeutic relationship with the family.

Kolarikova [17] has identified four main key factors, which my experiences also confirmed. First of all, health care professionals must be able to sensitively communicate with families in order that the family understands the diagnosis and the consequences of the family member's disability. Besides, partner and family relationships must be based on mutual respect, support, trust and understanding, respecting the needs of individual family members. A functional social support network is also very important. Furthermore, counseling services should respect the needs of families.

Sharing our experience we'd like to encourage colleagues, psychologists and therapists who work in this field. In health care of chronically ill children, participation of the multimodal team and shaping of its attitude are essential. Social approach can also be formed by supporting care of families with disabled children, which can lead to a public health preventive approach.

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