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# SELF-HELP GROUP OF MOTHERS CARING FOR DISABLED CHILDREN

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## Abstract

The paper aims to discuss an experiment to improve the quality of life of mothers caring for their mentally challenged children (now adults) through a self-help (encounter) group. The experimental group involved 10 mothers attending the Čmeláček day care centre in Ostrava (Czech Republic with their children). The sub-objectives in the presented paper were to investigate changes in the ways that participants coped with stress, and secondly to detect their life traumas. The Stress Coping Style questionnaire developed by Wilhelm Janke and Gisela Erdmann (SVF 78) was used. The diaries of participants and the choice of topics by group members in the implementation of the Balint groups were used as an instrument to help resolve difficulties in the interpersonal relationships of the group members. The main findings are statistically significant shifts in dealing with stress and opening of difficult topics with which mothers are forced to deal. One of the most serious topics is the aggression of participants as a response to their feelings of powerlessness.

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# 1. Introduction

Raising a child is a challenging task. We aim to develop the child's physical and mental health, intellectual, emotional and social development. We strive for the child's various competences in order to as an adult, has integrated into society and been successful in it, which is usually one of the fundamentals prerequisites for a satisfied personal, professional and social life. Parenting is a difficult process, even more difficult when a child is born with a disability. Time, attention, development of specific abilities and skills enabling the necessary care to be handled and education requires unprecedented effort and energy.

The purpose of our project is an attempt to shift the personality development of reference persons (specifically mothers) in their roles as caregivers of mentally disabled children, namely through so-called meeting groups (see below). We understand the caregiver as a person, (Pörtner, 2009, p. 11), who cares for someone else, "... to have everything necessary he needs to be well".

# 2. Purpose of the Study

The main objective of the experiment, which was carried out from January 2022 to June 2022, was to test the possibilities of improving the quality of life of mothers caring for disabled children through participation in an encounter (self-help) group. The group consisted of 10 women interested in this experiment aged between 45 and 69 years, who attended with their children the Čmeláček day care centre in Ostrava (Czech Republic). The experiment followed the group for the first 12 sessions, which we refer to in this paper. Each session lasted approximately 3.5 hours. The group sessions were facilitated by a group therapist (Julius Sekera, hereinafter "Facilitator"). There was no control group. The main objective was saturated by sub-objectives listed below:

a) Identify stage of group development in terms of the positions of individual members and the building of emotional connection (cohesion) of the group in the birth of a permissive environment among people in a similar life situation.

b) Analyse the ways of coping with stress by mothers who provide daily care of their disabled children, and the influence of the self-help group on this process.

c) Detect the main life traumas and possibly the undermining behaviours of mothers in overcoming hardships in their lives.

d) Evaluate the content and course of the encounter group sessions by the participants

# 3. Research Questions

Research design was guided by the questions below:

- i. What is the effect of the therapist's intervention within the encounter group on the mothers' stress management strategies?
- ii. What strategy do group members choose to manage the stresses that arise in connection with everyday tasks in caring for disabled children?

# 4. Methodology

To determine the emotional cohesion of the group, we used a sociometry method in its simple version focused on the authority of individual group members among themselves. The measurements were taken at the beginning and at the end of the experiment. In order to observe the relationships and communication between group members, we also used a video recording. The results are not presented in this paper. Instead, they will be part of our final report.

We tried to monitor the possible influence of encounter groups on stress coping strategies by application of the standardised Stress Coping Style questionnaire developed by Wilhelm Janke and Gisela Erdmann (SVF 78).

The most important life traumas related to the care of disabled children from the perspective of the group members were explored through the diaries that the participants wrote during the group's existence. Another method we used to reach this objective was the Balint groups. The topics in the Balint groups were opened based on the wishes and needs of the group members to help them deal with difficult situations in their interpersonal relationships.

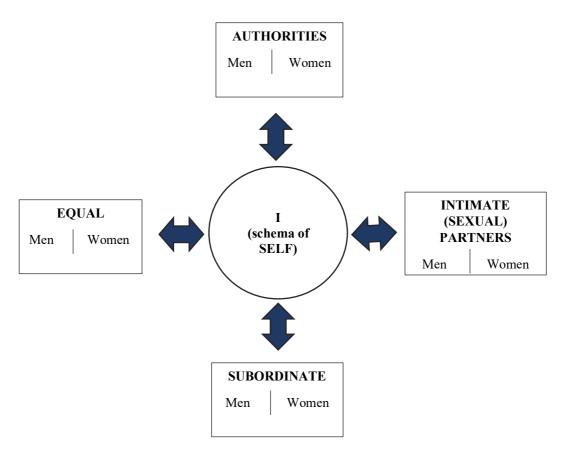
The course of the twelve sessions was evaluated through Interpretative Phenomenological Analysis (hereinafter "IPA") developed by Jonathan A. Smith et al. (2009).

We declare that all diagnostic procedures (including video) were approved by the respondents and applicable ethical standards were met.

#### 5. Brief Description of the Group-Sessions Content to Date

The aim of the first two to three sessions was an intensive process of the creation of a safe environment. The safe environment means creating a permissive environment, which makes it possible to say anything without being exposed to verbal or even physical violence and derogatory comments from other group members. They were characterised by mutual learning and awareness about the application of psychotherapy group methods (mutual messaging "about the other", application of the "Stop!" rule if the participant does not want to talk about the topic for some reason) and other group psychotherapy norms.

The core of our self-help encounter groups was the concept of Integrative Psychotherapy (Knobloch & Knoblochová, 1999). In each participant, we looked for possible self-undermining behaviours and tried to offer a new corrective experience to her that could lead to progressive change in behaviour. The initial thesis of the Knoblochs' conception is based on the idea that the relational/formative figures (forming in principle the most important small social group for an individual) influence the individual's behaviour. They come up with a schema of relational persons. The group of important figures for an individual covers not only the period of childhood, but also extends into his or her adulthood/maturity. The theoretical concept assumes the evolutionary embeddedness of such groups of significant persons in the development of human cultures in general. It is assumed that the group forming a particular individual's "schema" has a considerable influence on socialisation and influences behaviour throughout the individual's life. It significantly influences his or her adaptation or maladaptation to a social system and relational frameworks in which the individual functions throughout life.



Source: Knobloch and Knoblochová, 1999, modified.

#### Figure 1. Schema of significant persons

The topics of the Balint groups, which were brought into the group work session by the participants, are listed below (we present the most frequent ones):

- Partner conflicts
- Lack of understanding by the extended family for the mother's situation
- Masturbating/Sexual practices of their children (now adults)
- Cancer returns...
- I'm tired and nobody understands me...
- I'm all alone buried under a pile of work...

It should be noted that in the 8th session, the diagnostic method of the Tree Puppets was applied (Šauerová, 2018). Approximately 2/3 of the members still felt in the position of lonely person on a social periphery. The remaining members looked resignedly at people striving for a better life situation.

During our group sessions, we applied the Dream Analysis and Saying Goodbye techniques based on the issues brought in by the members. We needed to include the Saying Goodbye technique because there was an actual death of a son of one of the participants. The saying goodbye accompanied with strong emotions was both challenging and essential for the group, because the deceased client of the Čmeláček day care centre had been known to the participants and their children for a long time and was popular there.

## 6. Findings and Discussion

We would like to present two results in this paper. The other results are in progress. The first is the stress coping strategies of our participants. We started with secondary data analysis (desk research). As already mentioned, we used the standardised questionnaire by Janke and Erdmann (Švancara, 2003). The primary research survey was conducted in two rounds. The first round of interviews (pre-test) took place in January 2022 before the group sessions started. The second round of interviews (post-test) was carried out after all group interventions were completed during May 2022.

The test has captured individual tendencies for deploying different ways to manage stress. The subtests have focused on the following 13 strategies:

1) Minimization (attribute less stress to oneself compared to others)

- 2) Guilt denial (acknowledge not to be personally responsible for the situation)
- 3) Distraction from situation (by doing something unrelated to stressor)
- 4) Substitute satisfaction (turn to positive activities or situations)
- 5) Situation control (analyse the situation, plan actions, and act to exert control and solve problems)
- 6) Reaction control (bring or keep one's reactions under control)
- 7) Positive self-instruction (promote self-competence and ability to exert control)
- 8) Need for social support (look for somebody to talk to, for social support and help)
- 9) Avoidance (a resolution to avoid stressors in the future)
- 10) Flight tendency (resigning tendency to escape from stressor)
- 11) Rumination (fail to mentally detach, persistently thinking about stressor)
- 12) Resignation (giving up accompanied with a feeling of helplessness, hopelessness)
- 13) Self-accusation (attribute stress to one's own mistakes)

Authors of the test used these thirteen strategies to construct an overall positive strategy (POSITIVE) and an overall negative strategy (NEGATIVE). We calculated internal consistency of our subtest administration for both the pre-test and the post-test. Internal consistencies appeared satisfactory to very good in both cases.

A paired t-test was used to test the impact of therapeutic intervention on the self-help group. We note that for the positively oriented scales there was an increase in the mean value of the scale due to the therapeutic intervention, and for the negatively oriented scales there was a decrease in the mean value of the scale. Based on the results of the tests performed, the differences between the mean values can be considered statistically significant, meaning that the intervention had a significant impact on stress management within the target group.

However, the correlation analysis of individual subtests within the pre-test and post-test on the scales proved statistically insignificant in most cases.

The design of the SVF 78 Stress Coping Styles questionnaire is very comprehensive. Both its limits and the limits of our relatively small group showed. In the case of our self-help group of mothers, we were confronted with relatively high demands on maintaining attention and understanding certain items. We are also aware of the possibility that factors other than our group interventions may have influenced the results of the survey. Therefore, we supplemented the survey with other methods such as observation (video) and interviews. However, our findings are not yet complete and therefore we do not present them in our paper.

The second result of the current survey is the area of detection of major life traumas of members of our encounter group of mothers caring for mentally challenged children (now adults). The instruments we used for their detection were mainly the respondents' diaries. However, we also used Balint groups. A Balint group is a method (procedure) that attempts to take an unbiased view of the difficulties in interpersonal relationships of its group members (protagonists). The Balint groups method follows strictly defined rules. The rule observance is determined by a facilitator with appropriate qualifications. The fixed structure usually provides the protagonist with new perspectives on "his or her" problem other than he or she has had so far.

We have divided the major life trauma and also the sources of vitality of the self-help group members into four basic categories (see Figure 2):

Traumas that are difficult to help with

Traumas that perhaps (under certain circumstances) we can help with

Sources of vitality and optimism beyond the power of encounter group

Sources of vitality and optimism that the group can promote

Figure 2. Traumas and sources of vitality of encounter group members

A. Sources of trauma that we cannot easily help with or cannot at all help within an encounter group

- The material situation of the mother caring for a disabled child
- Severe illness or disability that makes it impossible or difficult for the mother to function as a caregiver. For example, glaucoma and the affected ability to drive a car, which is important in caregiving
- Finding a partner willing to share care, etc.
- B. Sources of trauma where we can perhaps help to some extent within an encounter group
- After learning that a child has been born with a disability, relationships in families are often upended.
- Fathers of disabled children in some cases leave the family after the birth of such a child. This can be accompanied by a tendency to blame the mother for the birth of the disabled child.
- Dismal conditions in the mother's original (biological) family: daughter's resentment toward her own father (later the mother of a disabled child) for his alcoholism, sexual abuse of his underage daughter in the past (now mother), domestic violence; daughter's resentment toward her own mother (later the mother of a disabled child) who neglected or abandoned her children, etc. (see Bowlby's attachment theory).
- The disabled child is aggressive, suffers from mood swings, negatively responds to weather changes, attacks the mother, beats her, shouts at her (at home and in public). People around do not understand what is going on and the mother comes into conflict with the environment.

C. Sources of vitality and optimism where we cannot help and at the same time there is no need to help within an encounter group

- The mother has a stable partner (not always directly the father of disabled children) who functions as a parent and lives in a symbiotic relationship with the mother
- Good material security, garden, hobby courses as sources of relaxation, opportunities for quality leisure time, etc.

D. Sources of vitality and optimism that we can (hopefully) contribute to within an encounter group

- Help in finding friends who might be a support and a "source" of life optimism.
- Help in trying to "get one's head straight", implementing steps of psycho-hygiene.
- Clarify plans for daily tasks and agenda.
- Morning "fights" with the child before going to a facility, and again afternoon and evening "fights" with the child (reality may significantly differ from how it appears, e.g., upon arrival at a day care centre the child is friendly and nice, but this is not the case at home).
- Help in uncovering self-undermining behaviours, providing corrective experience, and making efforts to change behaviour toward the child. An inspiring example can be the Person-Centred Approach (Pörtner, 2009).
- Help in coping with mother's own aggression toward her child and toward the social environment, etc.

We identified two important results in the diaries to date. The first finding is the feeling of the majority of the self-help group that they do not feel as alone as they did before the group was formed. The second finding comes as a certain surprise to us, and it is that the clients have to cope with their aggression, sometimes considerable, often tied to the aggression of their children/relatives. We have found a solution in a potential future training of the mothers to control their own violent behaviours toward their children by using constant techniques. Another and very important option is to change the concept of the relationship with children by applying the "Person-Centred Approach", as e.g., in the Czech context introduced by Pörtner (2009).

## 7. Limits And Conclusions

Although there are several limits to group work, we will mention one of them in our paper. A facilitator is a key factor in self-help group activities. According to a body of research (e.g., Yalom & Leszcz, 2021, p. 632), the psychotherapeutic school to which the encounter group leader belongs plays a rather minor role. What is crucial is the behaviour of the facilitator in actual facilitation of the group. This is difficult to predict solely by his or her affiliation to a psychotherapeutic school (Gestalt therapy, Transactional Analysis, etc.). Whether the facilitator is an expert primarily focused on group work or a psychotherapist who attempts to simply transfer individual psychotherapy into the practice of group facilitation has emerged as more significant. According to Yalom and Leszcz (2021), what is key is the facilitator's ability to cope with four sets of tasks below:

1) Emotional activation (leading group members toward their self-disclosure by being triggered, confronted, etc. by the facilitator)

- 2) Care for group members, i.e., facilitator's ability to provide support to participants, affection, praise, genuineness, concern for the client, etc.
- 3) Meaning attribution, i.e., the ability to explain what is happening in the group and with individual participants, the ability to translate feelings and experiences into ideas
- 4) Performance of facilitator function (setting of boundaries, norms, goals, ability to intervene, etc.). According to Yalom and Leszcz (2021, p. 632), the most important points (tasks) are no. 2 and 3,

i.e., care for group members and being able to explain what is happening in the group and to translate group members' feelings into ideas. The limiting difficulty is that these abilities and skills may vary from facilitator to facilitator, and thus the results of encounter group influence may be tied to the facilitator's personality and his abilities.

We conclude that we are going to continue our experimental work with a self-help group of mothers raising mentally challenged children and monitor opportunities for their further development.

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