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The operative group as a care learning tool for mothers of children with disabilities

O grupo operativo como instrumento de aprendizagem do cuidado por mães de filhos com deficiência El grupo operativo como instrumento de aprendizaje del cuidado por madres de hijos con deficiencia

ABSTRACT

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Objective: To understand the meaning attached to the operative group technique by mothers that take care of children with disabilities. **Methods:** Qualitative research with eight mothers who participate in operative groups, whose children are treated at a specialized program in Minas Gerais. Data were collected through interviews with discursive questions, in 2013, and analyzed using content analysis, interpreted in light of Pichon-Rivière. **Results:** The study led to the creation of the categories "Embracement space, exchanges and new meanings" and "Inducing strategy for caring for yourself and your child". The results reveal the importance of the operative group in the daily life of the participants, which highlights the contributions that such educational practice brings to the care experience of these mothers. **Conclusion:** The operative group was a care learning tool, which suggests the need for health services to invest in offering group activities for caregivers of people with disabilities.

Keywords: Nursing; Disabled Persons; Group Processes; Mother-Child Relations; Qualitative Research.

RESUMO

Objetivo: Compreender os significados atribuídos ao grupo operativo por mães que cuidam do filho com deficiência. Métodos: Pesquisa de abordagem qualitativa, com oito mães participantes de grupos operativos, cujos filhos são acompanhados em um programa especializado, de Minas Gerais. Os dados foram coletados, em 2013, por meio de entrevista com questões abertas, e submetidos à análise de conteúdo, sendo interpretados à luz de Pichon-Rivière. **Resultados:** Da análise, emergiram as categorias "Espaço de acolhimento, trocas e ressignificações" e "Estratégia indutora do cuidado de si e do filho". Os resultados trazem à tona a importância do grupo operativo no cotidiano das participantes, o que evidencia o valor que esta atividade educativa agrega à experiência de cuidado dessas mães. **Conclusão:** O grupo operativo constituiu um instrumento de aprendizagem de cuidado, o que sinaliza a necessidade de os serviços de saúde investirem na oferta de atividades grupais destinadas aos cuidadores de pessoas com deficiência.

Palavras-chave: Enfermagem; Pessoas com Deficiência; Processos Grupais; Relações Mãe-Filho; Pesquisa Qualitativa.

RESUMEN

Objetivo: Comprender los significados atribuidos al grupo operativo por madres que cuidan de hijos con deficiencia. Métodos: Estudio de abordaje cualitativo, con ocho madres participantes de grupos operativos, cuyos hijos son acompañados en un programa especializado, de Minas Gerais. Los datos fueron recolectados en 2013, en entrevistas con cuestiones abiertas y presentadas al análisis de contenido, siendo interpretados a la luz de Pichon-Rivière. **Resultados:** Del análisis emergieron las categorías "Espacio de acogida, intercambio y resignificaciones" y "Estrategia inductora del cuidado de sí misma y del hijo". Los resultados demuestran la importancia del grupo en el cotidiano de las participantes, lo que evidencia el valor que esta actividad educativa agrega a la experiencia de cuidado de estas madres. **Conclusión:** El grupo operativo constituye un instrumento de aprendizaje de cuidado, lo que muestra la necesidad de que los servicios de salud inviertan en actividades grupales para cuidadores de personas con deficiencia.

Palabras clave: Enfermería; Personas con Discapacidad; Procesos de Grupo; Relaciones Madre-Hijo; Investigación Cualitativa.

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INTRODUCTION

In the current society, unlike in other historical moments, there is a movement in favor of social inclusion for people with disabilities. This may be associated with the expansion of the democratic vision for the rights of all citizens, including individuals with disabilities¹.

From the perspective of the social microstructure, the birth of a disabled child predicts a complex and unpredictable event in the family context. The impact of such news can leave deep marks on the family, especially on the mother and father, significant others directly related to the child^{2,3}.

The fact of having a disability makes this child need a differentiated aid for carrying out activities of daily living, being such a commonly transferred task for their family caregivers, who go through a process of reconfiguration of their lives as a result of the child's care needs. It is known that the function of caring for people with disabilities is significantly performed by a family member, who assumes the primary caregiver role, a responsibility that implies dedication of more time to the child⁴.

In this context falls the mother, who usually takes care of the child. The impact of disability is experienced as a painful process and one of many conflicts for this mother, who initially feels unprepared in the face of new requirements of care. Having a child with disabilities represents the breakdown of expectations as to what was intended^{5,6}. Having overcome the early stage, the mother commonly transposes the first disability-related obstacles, seeking to restore the emotional balance that allows that child to be raised in society⁷.

The challenges will arise over the years for the family, especially for this mother. National and international studies show that the network of support to the mother who lives through the experience of having a child with disabilities is restricted, often added to the absence of policies that prioritize approaches to these families, requiring that they cope with the daily task of caring for the child alone^{6.8}. A study conducted in Australia revealed that the families of disabled children present complex needs, making it essential to develop strategies to help them in this context, such as operative groups⁹.

The operative group is considered an intervention technique that places the person as the protagonist of their learning process, making them active in the production of their health, in building their knowledge and senses that give meaning to their human experience¹⁰.

This group technique was theorized by Pichon-Rivière. His ideological matrix transcends gathering individuals around a common goal, with the aim of forming a group centered in an explicit task - such as learning, diagnosis or treatment - and implicitly guided by the subjective experience of the explicit task that is, how each member experiences the group. It also involves

a frame, consisting of fixed elements involved in the group process - time, duration, frequency, function of the coordinator and the observer¹¹.

The aim of the operative group technique is to enhance the operational capacity that a group has, centering its members in the recognition of their needs in preparation of a project and task performance¹¹. As a group intervention tool, it promotes interaction between people and their environment, enhancing the learning experience that is built on this interaction. In this sense, group participants tend to learn to organize and reframe their experiences, feelings, perceptions, emotions and thoughts¹¹.

This group technique has been used by health professionals, with the purpose of learning and coping with challenging situations such groups can give to people who participate in them¹²⁻¹⁴. In this perspective is the nurse who, among health professionals, by virtue of their training guided by the development of educational competence, is presented as the one who is usually involved in coordinating operative groups, performed with different audiences in different health care scenarios¹³.

One of the contexts in which the group educational modality has been held concerns those who register people with disabilities, still experiencing many challenges to be faced in the fields of health, education, professional training and insertion in the labor market. To help overcome this reality it is necessary that the professionals who care for these patients know the experience of these people and their families, finding strategies that enable them to face daily challenges¹⁵.

Starting from the assumption that the operative group assists participants in facing these challenges, it is necessary to investigate whether this attempt is identified in the experience of mothers who care for children with disabilities and that are supported by this group technique.

Studies commonly found in literature involving the relatives of those with disabilities have addressed the health needs especially the psychic order - of families and caregivers^{3,4} and the importance of support networks in the care of people with disabilities^{5,7,9}. Regarding mothers, evidence can be found on their work on the care of disabled children⁵, but not linked to their participation in operative groups.

A shortage of research findings that reveal the impact of group interventions on the experience of family members of persons with disabilities is evident¹⁶, therefore, making this gap even greater with regard to the evidence that is brought by mothers who take care of children with this condition and are assisted through operative groups.

Given the above, and considering the purpose of the operative group, the following questions emerge: Does the operative group create a learning context for mothers who care for children with disabilities? What is the support provided by the operative group to the daily care routine of these mothers? In this perspective, the study aimed to understand the meanings attributed to the operative group for mothers who care for disabled children.

METHODS

This is a qualitative descriptive study with the perspective of analyzing the experience of mothers participating in an operative group. This is considered an intervention technique that places the person as protagonist of their learning process, making them active in the production of their health, and in the building of their knowledge and senses that give meaning to their human experience¹⁰.

As an analytical perspective for the experience described in this study, the theoretical assumptions of the operative group proposed by Pichon-Rivière¹¹ were used, which were found in the experience of mothers who take care of children with disabilities assisted by this group technique.

The study was conducted in the Adapted Physical Activity Program (PROAFA, as per its acronym in Portuguese), at the Federal University of Viçosa (UFV, as per its acronym in Portuguese). This program assists individuals with disabilities, drug addicts and institutionalized elderly people, who are assisted in the logic of rehabilitation and socialization, with actions aimed at increasing their independence and autonomy. The PROAFA works with a multidisciplinary team, involving undergraduate students and professionals in the field of Physical Education, Nursing, Dancing and Medicine from UFV.

People with disabilities are regularly assisted in the Psychomotor Stimulation Laboratory (PSL) of PROAFA. They are taken to the PSL by their caregivers who wait for them at the site while the activities are carried out by the program team. The idle presence of these caregivers encouraged the team - in which the researchers of this study work or have worked - to establish operative groups focused on this audience, in order to provide a space for listening, dialogue and care while waiting for their children.

The study included mothers who care for children with disabilities assisted in the PSL and who participated in at least three operative groups. The approach to them occurred when they were taking their children to this laboratory, when the researchers explained the purpose of the research. Those who agreed to participate signed a free and informed consent form. The interviews took place on the premises of the PSL - venue of choice of the participants - on agreed dates and times according to their availability, with an average duration of 40 minutes each.

The testimonies were collected from August to October 2013, through an interview script with the following open-ended

questions: What is it like for you to participate in the operative group with caregivers of people with disabilities? As a caregiver of a child with disability, how do you believe the group helps you to face this reality?

The interviews were finished when the study questions were answered and their purpose achieved in accordance with the theoretical saturation method¹⁷. The convergence of the meanings attributed to the operative group occurred in the seventh interview. In order to confirm theoretical saturation, another interview was held totaling eight participants.

To preserve their anonymity, the interviewees were identified with the initial letter M, as in mother, followed by the number corresponding to the order of the interviews, namely: M1 to M8.

After authorization by the participants, the interviews were recorded and fully transcribed. Data were organized into study categories, based on the main ideas contained in the statements, and analyzed from the perspective of Lawrence Bardin's content analysis technique¹⁸.

Data analysis was conducted according to the following steps: pre-analysis, material exploration, and processing and interpretation of results. These steps were initiated by a repetitive and attentive reading of the transcripts of the interviews. In accordance with the objectives of the study, significant sections were defined for further elaboration of the categories, which revealed the convergence of the senses that emerged from the participants' testimonies¹⁸. Interpretation of the results was based on conceptual assumptions of the theory of the operative group by Pichon-Rivière and the literature on the theme.

In line with the ethical standards set by the Brazilian National Health Council resolution 466/2012, the research proposal was approved by the Human Research Ethics Committee of UFV, registered under n° 300584/2013.

RESULTS

The study participants were aged between 35 and 59 years, six were housewives, one was a nursing technician and one was a school service technician. With respect to education, three reported having incomplete primary education and one complete; three had finished high school and one had not. The study group had an average income of two minimum wages. Regarding the number of children, three had two children, four women had three children and one was the mother of four children. All women had a child with disabilities.

The statements of the study participants led to the construction of two categories, which allowed the identification of the meanings attributed to the operative group by the mothers who take care of disabled children, "Embracement space, exchanges and new meanings" and "Inducing strategy for caring for yourself and your child".

Embracement space, exchanges and new meanings

The participants' statements made it possible to understand that the operative group is configured as a place where mothers feel embraced in the reality they experience. In this space, they perceive being seen by the team beyond social labels - as mothers of a child with a disability - which makes them feel like equals, not as different mothers. Embracement is also perceived by participants as something present among other people who make up the group, creating a sense of security and comfort, which they associate with the representation of a family:

I like the group because it embraces us a lot. We feel at ease and it is very good (M4).

In the group we have the feeling of family warmth, everyone comes together [...] (M5).

People here in the group treat you as we are not treated elsewhere. They treat people equally, not differently [...] sometimes we're down, but when we see that the PSL team treats us as equals, we are lifted [...] (M6).

Anchored in the interaction with other family members who make up the group and the horizontality of the relationship with the team that leads it, the embracement expressed by mothers allows participants to feel open to sharing experiences. This is guided in the dialogue they can establish with the team that coordinates the group and the people who live the experience of being caregivers for children with disabilities, creating a mutual understanding of the universe:

> [...] They always ask for our opinion. [...] They don't take things ready and just show them to us. [...] It really is a group. The team and us working together (M1).

> [...] Everyone will be talking, then one will be talking about their life, we will be talking about ours and everyone will be identified. We will give some advice to others [...], because everyone understands (M2).

> We have to talk to people who belong with us, who understand us. I have to talk to people who live with us, living the same reality, who know our problems and who can help (M7).

The experiences shared in the operative group produce new meanings to individual experiences, enabling mutual learning that extends into the daily lives of mothers who care for disabled children:

[...] We participate, gather, talk, share the problems [...] can learn more from each other. [...] feel close to one

another, feel safe [...]. As we talk in the group, new ideas emerge and we learn together. Formulating an idea alone is difficult, but with the group it is easier (M7).

You learn that you can live better with the problem we have [...] sometimes I am very stressed and I remember the group, where I learn many things that help me in the day to day (M6).

In the learning universe that supports mothers in their everyday, another important representation of the operative group in their lives emerges, in which it is understood as a space that helps in the care for themselves and their child.

Inducing strategy for caring for yourself and your child

The operative group is seen by mothers as a care storehouse. One perspective brought in their speeches concerns the dimension of care itself. In this sense, the group allows to see themselves as beings that need to be looked after by encouraging self-care:

> I started to become more attentive to myself [...] how am I going to take care of the children if I get sick? The group was a warning to me. Then I try to do, if only a little, what they guide us to [...] (M1).

> The group helped me to see many things in my life, that once I left aside [...] for example, think of me, have some time just for myself [...] (M5).

What is good in the group is that it addresses the selfesteem of people, they are not only concerned about health but also about physical appearance, which we forget a little [...] it shakes people in order not to forget [...] that it is important we take care of ourselves (M8).

On the other hand, the operative group is also evidenced by the participants as an important support in the direction of care for the disabled children. In this perspective, it is understood by the mothers as a mediating space for care, in which the overprotection and victimization generated by the deficiency gives rise to looking out for the child's potential in order to lead to a greater degree of autonomy and independence:

> I used to treat him differently. I felt sorrier for him. Now I don't feel sorry any more. I think this is good for him. [...] I can't treat him as fully equal to my other son, but I do not do whatever he wants me to as I did before (M2).

> My daughter had some crazes, but for me they were just crazes. Through the group, it was said that they may cause harm in her life.So today when she does these

things and hides them, it's because I call her attention and before I did not (M1).

In the group I learned a lot, gained more strength [...] learned to understand better and cope better with it [...] cope better with the situation [...] things that I helped him in day-to-day tasks, today I do not help (M6).

DISCUSSION

By bringing to light the meaning of the operative group for mothers who care for disabled children this study made it possible to identify this important therapeutic tool and learn the experience of mothers who participated in groups in the study setting.

It was possible to understand the emergence of an explicit task - the implied learning in the care of a child with disability and herself - and an implied task, with respect to how each parent is internally organized to carry out this care dimension, enabling, through this process, successive resignifications of their care experience.

These tasks, together with the embracement from the group members and the link established between the participants, are principles that support the ideology of the operative group. The bond is expressed in the interaction among the group members and between them and the group coordinator, setting up twodimensional and three-dimensional mechanisms, respectively¹¹.

The results of this research show that these principles of the operative group made their presence felt in the experience of the participating mothers. The group context was expressed as a mediating space for embracement practices, bonding and listening, by giving priority in their approach to sharing among members who live similar experiences and the team that coordinates the group.

Thus, the operative group helps everyone to organize themselves internally and to mobilize themselves through group interaction, which enables learning and dialogue about the experienced and shared challenges, favoring the process of coping with the situations experienced by its members¹².

The task forms the path taken by the group to achieve its objectives and relates to how each participant interacts, based on their own needs. The sharing of these, around the group's common goals, forms a common thread for flexibility, decentralization and the possibility of openness to what is new¹⁹.

The group participants interact through feelings of belonging and relevance, which unites them around a task and a common goal. The relevance, regarding the perception of the members as to centering tasks¹¹ could be identified in the daily life of mothers who, even absent from the group context had remained focused on care that creates new meanings, supported by cooperation built in the operative group.

The relevance was also present in the statements of participants by expressing the feeling of identification with the experiences of other mothers in the group, who played an important role of mutual support to reframe the experience of caring for a child with disabilities.

Learning in a group means that, in the educational activity, concern is not given only to the product of learning, but to the process that enabled the reinterpretation of experiences¹¹. This process is guided in the dialogue between scientific knowledge and experiences of the participants, valuing each as a way of teaching and learning, resulting in a collective construction²⁰.

In this context, it is evident that bonding, relevance and belonging were translated in the discourse of mothers from the dialogic and horizontal relationship between the group's coordinating team and other members, leading to the emergence of a collective sense for the group experience.

The respondents made use of a collective language to refer to learning in the group and contact with other mothers, understanding that these experiences are common among them, since they refer to a shared experience - the care of a child with disabilities. Studies that deal with practical operative groups claim that the appreciation of unique experiences has the potential of reframing collective experiences, while socialized in the group context^{13,14}.

Despite the conflicts and disagreements that may originate from the operative group - because of differences among people that make it up - the exchange of experiences among the participants forms a positive aspect. This is due to the fact that the group enables people to deal with their singularities, building a dynamic collective learning mediated by the group experience²¹.

It was evident in this study that these new meanings are given expressively in the mothers' caregiving dimension, both to them and to their children. Based on the group experiences, the action of taking care of a child was rebuilt in the daily lives of participants who concurrently recovered their self-esteem, giving power to self-care, which was previously in second place due to the care of the child.

Another study on operative groups reported that they help to improve the complexity inscribed on lived experiences, based on a perspective of exploration of emotions, feelings, knowledge and practices at the individual and group level. Moreover, on the premise of a critical reading of the reality, groups enable a process of changes and readjustments by the participants in situations that triggered negative behaviors in them, thus contributing to the improvement of care and self-care^{13,14}.

In this regard, it is worth noting the strategic role of health professionals, including nurses, in order to enable the caregiver dimension present in the operative group. They should act to enhance the group space as a place of openness and dialogue among its members, so that the care experience emanates from the group itself and reverberates in their daily lives, managing changes projects and reinterpretations of living¹⁴. By bringing this discussion to the universe of mothers interviewed in this

study, it appears that this reconfiguration implies a process of transformation, enabled by the adaptation of these mothers to the reality that they find themselves in.

The literature corroborates these findings, stating that having a disabled child brings to mothers a series of demands and daily challenges, making them seek to adapt and reorganize themselves daily to face this reality. In this sense, the operative group in the experience of the participants in this study is configured as a power space to express their experiences and needs related to having a child with disabilities, helping them redesign their care experiences.

Thus, as idealized by Pichon-Rivière, the operative group focused on the audience of this study was an instrument of social transformation, as well as a space for promoting bonding, and sharing common goals and projects¹⁹. This was possible through active, creative and critical participation of its members, explicitly and implicitly involved in the task of learning to care for a child with disabilities.

The findings of this study are in line with those described in an Iranian study developed with relatives of people with disabilities, which also highlighted the strategic role of the groups in providing support to families facing this problem.

The challenge placed in the daily care of the child with disabilities, the importance attached to the operative group in the care experience of the respondents and the fact that nurses commonly coordinate groups in health practices reinforce the need for these professionals to invest in the operative group as a therapeutic and learning tool, focused on assisting these individuals, which should start in their training process.

A study conducted with nursing students from a public university in the state of Goiás reiterated the importance of the practice with operative groups in nursing education. Based on experience with this group technique, participants identified it as a coping tool for overcoming stereotypes, conflicts and difficulties. This experience allowed the students to understand the importance of using operative groups in different contexts and with different audiences in the health field²².

A limitation of this research is that it was held in a specific care scenario, depicting a reality that may differ from other contexts, which prevents generalization of its results. On the other hand, it is of great importance for nurses, since the subjective and intersubjective elements revealed, in the experience of the participants in this study, will help in the care directed to people with disabilities and their families in the routine of healthcare services.

CONCLUSION

The results of this study show that the operative group was a scenario that allowed mothers of children with disabilities to understand, reflect and recreate their care experiences, towards them and their children, leading to the achievement of the operating dimension expressed in the care learning. Since nurses are the professionals who commonly holds group activities in the daily life of health institutions, the findings of this study show the value that these activities add to the experiences of mothers caring for disabled children, whether giving support or new meaning to them.

The need for health services to invest in offering group activities for caregivers of people with disabilities is clear. Therefore, prior to offering these educational practices it is necessary to give them proper value in the context of health education, as well as the various care settings - specialized or not in the care of people with disabilities or their relatives.

In view of the lack of studies regarding the practice of operative groups with the studied public, further research in this area is needed in order to increase knowledge on the use of this educational practice with mothers who care for children with disabilities.

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