# Support as a source of meanings: report of an intervention with a parents' association

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In this paper we report on the first stage of an intervention, implemented after a request came to our team from the management of an association of parents with children affected by rare genetic and genetic-metabolic syndromes, concerning the provision of psychological support for the parents in the association.

The report was used by us and it is presented here as a cognitive process useful in identifying the criteria guiding the construction of the intervention. We will therefore spend some time explaining the connections between theory and practice which, in the context established by the intervention request, oriented our professional action (Carli & Paniccia, 2005). Specifically, we will offer a reflection on the setting-up phase of the intervention, seen as a phase aimed at analysing the demand, defining the growth objectives and constructing the setting (Carli & Paniccia, 2003). This phase used some operative actions (conducted in different times and places, and with different interlocutors) connected to each other by the aim of constructing the setting of the intervention and exploring the symbolic matrix underlying it (Carli, 1987; Carli & Paniccia, 2003; Salvatore & Scotto di Carlo, 2005; Grasso, Cordella & Pennella, 2004). The actions referred to in the report concern: 1) the initial interviews conducted with the client constituted by the management of the association; 2) some group interviews with the members belonging to the enlarged management committee, open to the public 3) some joint meetings with the management committee, the medical team and psychologists; and lastly, 4) study and research activity aimed to understand, in a broader context, the models of meaning that organize the support processes typical of the context of the association of parents with children affected by chronic pathologies and/or disabilities.

This report is the final outcome of a series of accounts, which followed and anticipated the meetings in this phase of the intervention; we adopted reporting as a reflexive methodology designed to understand and control the dynamics of the intervention (Salvatore & Scotto di Carlo, op.cit.), and therefore as a recursive trigger for sense-construction operations which served to identify trajectories of development and to outline the purpose of the process.

## *A glance at the associations*

The request for intervention arose in the "third sector", a term used to refer to forms of association, linked to the crisis of the welfare state in western countries, for the autonomous management of economic and social services starting from goals and tools marked by social solidarity (Donati & Colozzi, 1998).

In Italy, as in other European countries, since the 1980s there has been a considerable increase in the number of associations, created due to the pathologies of the members themselves or of their children or family members. This growth has implied an increase in associations both in number and in structure, giving rise to a combination of different types of association connected to a variety of problems and goals[1].

The development of associationism in response to the evolution of the idea of the right to well-being, as well as the State's difficulty in satisfying the population's demand for quality of life, has gradually marked the transition from informal, spontaneous forms of solidarity towards more structured modes of participation defining the typical forms of associationism (Bassi, 2000).

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[1] Associative contexts take forms starting from small groups, but there are more and more forms of union between groups, aimed at facilitating the implementation of available resources and possible contacts with services and institutions at a national, and still rarely, international level. Some groups are linked to various local socio-health services and to their operators, or form proper "alliances" with such services (Silverman, 1980).

Research[2] carried out by our group (Oberti, A., Gleijeses, M.G., &. al., 2006) on the web sites of national associations of parents with children affected by chronic pathologies and/or disabilities, aimed at exploring the support functions proposed and activated in these associative contexts enabled us to show some basic categories of purposes of the association process connected to this type of problem: a) to activate links in the fragmentary health and assistance services in order to provide parents with guidance in contacts with specialized operators; b) to promote information campaigns aimed at the community in order to defend and promote the rights of families and of sick/disabled children; c) to build bonds so as to reduce experiences of impotence and isolation. The modes of associative support therefore describe the main functions of social support: concrete functional support to supply resources and services; information support to transmit information and practical skills; emotional support and control consisting of sharing and establishing a relationship of trust and affection as well as implementing gratifying modes of social interaction and interaction aimed at promoting the members' rights in the social context.

The forms of solidarity characterizing the associations in question seem to have their cultural roots, on the one hand, in the type of support offered by the 19th century "mutual aid societies"[3], and on the other, in the support roles activated by "self-help groups"[4]. In this sense, one can talk about an association of people made up of a more "militant" component that wants to defend the rights of its members, symbolically categorized as an oppressed minority seeking to change the power balance in relations with the wider society, and by a more "affective" dimension related to the creation of bonds of mutual recognition, in which the change concerns the members themselves, categorized precisely due to their similarity as a single group.

In this sense the associations can be represented as a mode of transformational support both for the families and for the community (Laville, 1998), re-activating and multiplying the relationships and conveying a new culture for the community, serving to prevent the risk of falling back on the private sphere, and to promote the well-being of the individual and the group (Tognetti Bordogna, 2005). Participating in an association can play an important role for the parents as regards the possibility of providing one's children with skilled assistance, and thus offering support for the parental role of caring, placed under great pressure by their children's pathological condition (Goldfarb, Brotherson, Summers & Turnbull, 1986; Senatore Pilleri & Oliverio Ferraris, 1989). The task of putting pressure on the institutions, as well as the participation in an active community, might give the impression of the family's competence in dealing with the illness and therefore with their child. The associations, in fact, in sharing the same problem, seem to offer the possibility of

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[2] The web sites of 20 national associations of parents with children affected by chronic pathologies or disabilities were explored in order to identify and classify the support roles proposed and implemented by the associations. To this end, the study considered the weight of the individual roles in the associations as a whole, their different organizational modalities and whether they were oriented internally within the same association context, or externally.

[3] The "mutual aid societies", which appeared in the 1800s, mainly involved the largely unprotected working class, and were marked by widespread solidaristic practices in a period when trade unions were still illegal. The associative nature of the mutual aid societies embodied the belief that the workers can improve their material and moral conditions by banding together and helping each other; the elements of cohesion in such associations were the members' shared condition, the common internal rules and goals, as well as the idea of helping each other in order to bring about change (Amerio, 1996; Gattino, 2006).

[4] Self-help is a phenomenon that started to develop in the mid-1900s, with the first organization founded in the United States in 1935 being Alcoholics Anonymous; at present the self-help situation is very complex, with a varied typology of groups spread over many parts of the world. This movement is part of the informal help system and it is made up of people who share a problem situation which affects the sense of belonging to the group, favoring the exchange of emotions and experiences. The groups are usually self-run, organized around concrete issues, serve as an emotional container for their members, and the group experience is a tool for personal change (Amerio, Gattino, 2000). In Italy self-help groups developed in the 1970s in relation to the crisis in the Welfare State, and in particular due to the lack of personalized services that could respond to the users' specific needs, as well as to the emergence of new values expressing the need for more intimate human relationships and for daily solidarity.

constituting a context of membership based on the aspects of reciprocal trust that favour experiences of recognition, of external visibility and of status support (Wills, 1985). In this sense, for the families they can be a reassuring context that can serve as protection against experiences of isolation and of “diversity”, and provide a space where they can talk freely without fear of “being judged by society” (Zanobini, Manetti & Usai, 2002) which increases the feelings of guilt and persecution.

The associative context can therefore be interpreted as a form of participation that involves interrelated practical and symbolic aspects linked to the area of solidarity among peers, to health promotion, the defence of rights and to the relationship with the dimension of caring and of the child’s illness. It can also be read transversally as a form of affective process linked to the painstaking elaboration of mourning (Freud, 1915) related to the loss of their ideal, imagined child.

In the study of symbolic and institutional processes underlying the creation of parents’ associations, a significant contribution was made in 1980 by the pioneering work of Di Cagno and Ravetto on psychological intervention in conditions of chronic and mortal childhood illnesses. Starting from the socioanalytic model of Jaques (1966), the Authors analyse the structure and the associative processes, using two interdependent aspects that link up, on the one hand, with the “explicit” characteristics (organization, concrete aims, roles, rules, rituals etc.) and on the other hand, with the “unconscious” functions of defence against persecutory and depressive anxieties; “The two levels of functioning interact and intersect constantly, although it is only of the first that the members of the association are aware” (Di Cagno & Ravetto op. cit., p. 93).

Chronic and mortal illness, continue the Authors, enters the plot of these families’ lives as a traumatic event, increasing each of the members’ anxiety about death and the need to set up defensive measures and reparatory processes (Klein, 1948) concerning the difficult elaboration of the guilt for having produced a sick child with no possibility of being cured. Setting up an association would then, at an unconscious level, perform a fundamental function of socializing the anxiety about death and as soon as it was implemented, would itself become a catalyst for the defensive measures and reparatory processes. The intertwining of conscious and unconscious expectations and needs shared by its protagonists accompanies and guides the founding of the association, defines its structure, its prevalent relational modes, and last but not least, its purposes. Elaborating mourning by participating, feeling part of a new identity that helps to fill the gaps produced by illness, being able to act instead of suffering, to claim and obtain what one believes right, are some of the primary functions that are performed by associations, according to the Authors. The association is therefore an establishment of bonds, positioned on the intersection between inside and outside, between intrapersonal and interpersonal dynamics, with processes built and affected by conscious, operative ways of categorizing reality and the mind’s unconscious ways of operating, based on processes of affective symbolization (Fornari, 1976). The urgency of sharing the “weight” and of being recognised for one’s own pain, but also the possibility of participating in the community and feeling a correspondence or a resonance in the other person, seem to will (Kaes, 1996) the formation of the associative bond, laying the foundations of every association but also of its constraints and its possibilities of growth, tied to the vicissitudes of these emotional dynamics. Associationism is a mode of social relating which takes a specific form due to the meeting and the intertwining of symbolic processes of a cultural and affective kind (Gleijeses, M.G., Oberti, A., & al., 2006). In this sense, from the interpretative standpoint we are proposing, the association takes shape due to specific symbolic configurations of a basically affective type designed to establish a collusion according to the instructions indicated above[5]. Symbolic configurations traverse and underlie the processes of operative categorization of the association in terms of its roles, its tasks and its actions. The request for psychological intervention by an association is always positioned within these models, starting from a crisis or from the need for growth, and will tend to reproduce in the consultation relationship the cultural models acting in the context of influence (Carli & Paniccia, 2003).

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[5] Collusion is understood as a shared affective symbolization of the context by those who are part of that context (Carli & Paniccia, 2003)

### *What it is about: the first interviews with the association management committee*

A few months ago, our research and working team received a consultation request for the implementation of a project of parenting support from a newly-formed association of parents with children affected by rare genetic-metabolic syndromes. The association has existed for about six months in close collaboration with a prestigious university medical team which plays the roles of case acceptance and research in the field of genetic illnesses, and which looks after all the children of the association members. The association was set up in a situation of a shortage of funds in the Region's health sector, and of cuts to the funds allocated to medical research. The association supports a new alliance between parents and doctors to cope with the situation of precariousness blamed on the health system and on lack of interest on the part of politicians. This precariousness is felt to be particularly dangerous for the operative unit that deals with rare genetic pathologies, which by definition are not very visible or numerous. The number of people affected by metabolic diseases on the whole is certainly not negligible, but if taken singly, most of the illnesses are rare.

Such pathologies, also defined as congenital metabolism defects, are a group of genetic illnesses caused by the partial or total deficit of a specific enzymatic activity or of a protein with the function of carrying specific compounds through the cell walls.

In most metabolic illnesses, the damage can therefore be due to the fact that the child's body lacks an important substance that is no longer synthesized; in others, however, the damage is caused by both the processes. The kind of symptoms and the organs affected vary according to the type of damage: every illness therefore has different clinical characteristics. For many metabolic illnesses there is no definitive cure, but for some there are support treatments available that are effective especially if begun early. Consequently a correct diagnosis of the metabolic illness, based on laboratory tests, is essential both for the possible therapeutic approaches and for a proper genetic consultation for the family at risk.

We are talking about a situation of chronic pathologies, the worst of which can have a fatal outcome during childhood, a condition where the only prospects of a cure lie in research advances in genetic medicine. This is a research field that has been in extreme ferment in recent years and is at the centre of a complex debate on bioethics. In this field, despite the great advances in diagnosis and aetiology, there has not yet been the expected improvement in identifying therapies. At the moment the only possible therapies are called "support therapies" and concern the management of sophisticated diets and/or the administration of dietary supplements and enzymes.

The presence of a genetic-metabolic pathology in a child, which today can be recognised and diagnosed, while respecting the differences connected to differing levels of seriousness, generates decidedly critical responses. It is a type of pathology that annuls the original function of the parental role tied to the transmission of a genetic patrimony that can guarantee survival; it also annuls the function of medical assistance anchored to its role of care and healing and today poses a significant challenge to research and to society, which is forced to question its own limits and its duties.

After providing the indications given above, during the first meeting, the management committee specified the activities that it had planned, already printed in a brochure, the first of which to become operative was the parental support project. The intervention was represented as support addressed to individuals; however this representation was put forward as an "ideal", since the lack of funds made it necessary right from the start for the management committee to fall back on a form of support organized for the group. The need for psychological support was assumed in the discourse due to the intensity of the trauma experienced with the diagnosis of the children's rare genetic pathology, which was presented as a fracture in the continuity of existence *("Nothing is the same as it was before")* accompanied by feelings of profound solitude and impotence. It is this experience and its strongly destabilizing effect that the management committee referred to in identifying an urgent need for parental psychological support to provide for its members, a not well-defined or organized group of parents who, on medical advice, had joined the association. The

group of members were described as being in dire need, *"hungry*" for care, *"a hundred mouths to feed" (*there are a hundred parent-members), but at the same time ironically defined by the management committee as *"the silent mass"*, incapable of expressing their need and becoming an active resource for the association, and being such a passive interlocutor that they risked making the management committee's initiatives fruitless.
Alongside this "certainty" of need, there was the anxiety about the members not using the service; this emerges from the image of the space dedicated to this work as an "empty" space and due to this fantasy, various strategies were formulated on how the psychological intervention should deal firstly with convincing the members to "use the service".

*What to do*

The team was faced immediately with the strategic choice of a paradigm to guide the construction of the setting for the intervention. The need for support could in fact be taken as given, perfectly acceptable in many respects, and therefore it could be hypothesised that the setting for the intervention of individual or group support would be the health service, in view of the strategy used to co-opt members, with doctors given the task of motivating and sustaining the referral[6]. In this strategy the difference between individual and group intervention was only numerical and technical, since in both situations the assumed setting would split the client, in our case the association, into a sender and a receiver, and direct the operator's action towards the receiver. From this point of view, the pain, the anger and the impotence that traverse the experience of one's child having an illness are considered phenomena endowed with objective characteristics, connoting the parent's inner world and requiring case-acceptance and support. In this perspective the psychologist takes the other as the object of his intervention, either alone or part of a group, and the other's inner characteristics, which though not pathological, have to be resolved and and oriented since they are anchored in a painful reality. In other words, the diagnosis offered by those commissioning the intervention is taken for granted, and it is used in operating regardless of the system of relations in which the request is positioned. The second path, instead, involves challenging the need, and challenging the common sense view that whoever goes through a traumatic experience necessarily needs psychological support; in taking this path, the setting of the intervention is based on the suspension of action (Carli, 1987) in the sense of a methodological device aimed at 'conceiving of' the emotional dynamics at work in the relationship set up by the request for intervention. This perspective envisages a methodological assumption designed to consider the request for intervention within the structure of interdependence generated between those commissioning the intervention, the beneficiaries and the technical side, the psychologist. In this case the hypothesis orienting the work concerns the analysis of the request, treated in terms of demand, in the sense of a semiotic device that translates and reproposes, in the client-consultant relationship, the models of affective symbolization of the context (Carli & Paniccia, 2003). Regarding the case we are talking about, analysis of the demand concerns the possibility of making hypotheses about the connection between different elements: the processes of categorizing psychological support, as they were proposed and delegated to the psychologist, the processes of categorization underlying the complex relationship with their children, and therefore with the doctors, and lastly the role of associative processes. The analysis of emotional symbolizations proposed by the association in the relationship established with the demand, tended not only to make a conjectural reconstruction of the collusive processes underlying the relationships in the organizational context, but also to attribute to them some functional problems, seen as difficulties of the commissioning party, the management committee, to keep its development goals in sight. The premise of this type of setting is the hypothesis that it is the possibility of conceiving the categorial models orienting their development that enables them to

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[6] Repeating, in this case, the cultural model of health contexts which says that the primary responsibility for managing a case is that of the doctor who is the only one that can establish what to do with the patient in the hospital context, including the management of access to psychological intervention (Guerra, 1992).

develop (Carli & Paniccia, 2003; Salvatore & Scotto di Carlo 2005; Grasso, Cordella & Pennella, 2004; Cordella & Pennella, 2007). In line with this theoretical and methodological viewpoint, the first stage of the intervention explored the configurations of sense guiding the role of the commissioning party (the management committee and, in the background, the medical team) in its relationship with the beneficiary (the group of parent-members) and in understanding what kind of collusive dynamic existed between the two. It seemed clear that the beneficiary was not considered problematic or particularly needy, but that the intervention aimed at exploring how it was viewed as such due to the commissioning party’s models of meaning. The methodological hypothesis adopted was that the commissioning party would designate as beneficiary the element that showed the problematic nature of the collusion adopted and delegated this discordant element to the psychologist so as to recover or support the collusive models underlying his own relationship with reality: that is, “the confirmation of his own symbolization of the context and of his own emotional positioning in it” (Cordella & Pennella 2007, p. 44).

In the request for intervention made by the association, the existence of a clear separation between those who planned the action and its beneficiaries, served as a significant sign that the association was repeating some basic aspects of the medical model of providing assistance. In this model the relationship is based on the dependence of one side on the other: one component of the relationship is strong and competent, opposed to a weak, needy component. Consistent with this symbolization of the intervention, the technical side, the psychologist, was given the task of convincing the potential beneficiaries of the necessity of the intervention; equally consistent with this model is delegating to the psychologist the emotional behaviors of the associative experience and of being together.

The delegated emotions of anger and impotence, although even in this perspective they can be interpreted with reference to the painstaking work of grief required by the traumatic experience, and to the elaboration of the sense of guilt and anxiety about death, are read as emotive dynamics underlying the association context, its defensive aspects collusively shared by the members, the construction of relationships within it, the identification of its aims and the capacity to support them. Due to this, the emotions in the traumatic experience were interpreted as generating models of representation of reality which, in the relationship with the consultant, needed to be supported.

In this rationale, the reference to the psychological support group was not made only as a cheaper solution than the idea of an intervention addressed to individuals, but also referred to a group dimension of being together, typical of an association context, and essential to the sharing of the affective and painful aspects of the experience. The group aspect acted as a critical event compared to the adoption and maintaining of a medical model, oriented to “doing”; it challenged the identification with the model of care aimed at guaranteeing dual relationships based on control, in which there is one side with knowledge and tools and another side that uses such tools in a dependent way. At the same time, referring to the group aspect reminds us of the need to elaborate strategies for being together, for dialogue and integration between the group members, for the opening of spaces where experiences are shared and essentially of the need for the construction of an association fabric that can connect the members. It can be hypothesised that in the setting-up stages of this association, the group represented a problematic aspect, linked to the anxieties generated by coming into contact with needs and anxieties that were impossible to placate (the members as mouths to feed), but also a line of development or possibility of constructing an association in the sense of a place of bonding and exchanges (the members were the strategic lever of growth: the urgency of creating a cohesive group to guarantee the survival of the association, willing to shoulder the burden and to share the numerous tasks involved in the life of an association).

There emerged, in this phase, a context of intervention in which the demand was brought to the consultant by a group of parents who in theory shared the same problems and the same difficulties as the beneficiaries of the intervention; the difference seems to lie in the sense of urgency in acting on the part of the former and the tendency to passivity, and a reduced ability to control the drift of emotions on the part of the latter. For this reason the psychologist was asked to take on a role of shoring up the overflow of emotions so as to enable the association to take the first steps in setting-up the group on a less slippery terrain and to try to motivate the other members to action, all in conformity with the wishes of the doctors who were asked to cope with the "enemy health system". The need to explore the form of the request for support in the processes of group construction, as well as the dynamics between members seen as active and members seen as passive, led to the consultants proposing an enlargement of the number of interlocutors of the planned intervention. This led to a series of 4 meetings open to different members, and later to two meetings with  the health team.

### *Topics and issues*

#### *The meetings with the parents in the association*

The very first meetings dealt only with topics specifically concerning the organizational aspects of the association. As has already been mentioned, the first organizing nucleus of the discourse concerned the relationship between the association management committee and the group of members. The management committee reported the difficulties it had in reaching the extended group of parent-members who were described as distant and uninterested in the decisions and commitments involved in the group's growth process. The group was presented as absent, but at the same time, insistent in asking for help of a practical and bureaucratic kind about managing the pathology. The management committee was "weighed down", "fatigued" "frightened" and perhaps "overcome" by such a load of urgent, heartfelt requests, so demanding from both the operative and the emotive points of view. In the discourse, the relationship between management committee and members was revealed also in another thematic nucleus represented by "diversity". This diversity was expressed not only in the many different forms of rare syndromes found in the association, but also in the socio-cultural differences between the members, which it is presumed led both to a greater difficulty for the extended group to take responsibility for operative and management issues, and to its greater difficulty in containing and controlling the emotive component of the experience, and therefore in modulating the communication and sharing of pain, anger and frustration connected  to the illness. The internal diversity of the group seemed to play the role in the discourse of regulating the associative functions both as regards the creation of external bonds, and as regards the management of internal ties.  In relating to society, diversity is a limit since it reminds one of the isolation generated by the rarity of the illnesses and therefore of the association's scarce possibilities of becoming socially important; in internal relationships, while on the one hand diversity represents a constraint for the construction of shared tools and goals, on the other it works like an opaque screen reducing the risk/opportunity of being reflected in the relationship with the other and of being contaminated by his pain which echoes one's own.  From the first meeting, the group of doctors was presented as the families' main interlocutor in the difficult task of managing the pathology as well as the association itself in its task of constructing a dialogue with its members  and with a network of external bodies and interlocutors. It was reported during the meetings that the relationship between the association and the group of paediatricians seemed to repropose an adolescent dynamic in which pushes for autonomy and differentiation went alongside and followed the intense need to recover a relationship of dependence that could guarantee security and objects of identification. In this sense, the health service, and more exactly the medical team, was symbolically described as at times a benevolent "mother" responsible for accepting the cases of children affected by these pathologies, but also for their families, as well as for the birth and growth of the association itself, and at times as an authoritarian "father" who decides what is acceptable or unacceptable in the construction of the future of the "child", parent and association, or otherwise "*throws his child into the sea and says: go on, swim!!*".

As other members took part in the interviews, the discourse of the group developed and was extended to include new thematic nuclei organizing new ways of understanding the group and the role of the psychologist's intervention. To the organizational topics were added topics more closely connected to the parent-child relationship, to the children, their stories and their difficulties. The entry into the interviews of some mother-members, particularly keen on helping the association develop, enabled the context of meetings and intervention to be read in a new light, as a possible space for telling one’s own story, for sharing painful periods and for exploring open questions as well as the personal and group resources in accepting diversity and the weight of pain. The discourses during meetings were animated by various protagonists, such as the association itself, the paediatricians, the dieticians, the children affected by genetic and genetic-metabolic pathologies, and the mothers and fathers, who had an both important place in the discourse field and a place in the background, alternating their roles and enabling some of the emotions in the field to be recognised and conceived.

The interviews began to proceed through stories, which dwelled on and repeated many times the traumatic phase of the diagnosis, called the *“abyss”* that annulled all reference points of known meaning in favour of a state of total impotence and confusion and saw the parents endlessly “running round in circles” in search of hope in order to deny the illness. The diagnosis re-connected the components of the intervention context, re-proposed to the group the aspect of pain as the object of psychological intervention, led the discourse to an encounter between pathology, child, parenthood and relationship with the doctors. The discourses in the group became sad, pained, and at the same time, angry, in recounting the different and yet similar stories of diagnosis, the confused, paralysing feelings on coming face to face with the pathology and with the doctors, at times hated for having given a name to the possible which in that way became a stringent certainty; at times considered champions of the cause for ending the disorder and enabling the “enemy” to be confronted, no longer unknown but known at least by the specialists; for responding to anxiety with a therapy, albeit of ‘support’, with their presence and when possible with a gleam of hope linked to the research activity.

For the parents, talking about the diagnosis of a rare pathology also meant considering the medical team’s “specialization”, described, in the lives of these families, as a reference point compared to the local paediatric network which was totally unprepared for the management of these syndromes and which therefore reminded the families of the image of “diversity”, of total incommunicability due to lack of a shared language code.

The diagnosis recalled the account of the urgent need not to feel alone, to react to the experience of isolation, which from the start seemed to accompany the awareness of the child’s pathology, seeking understanding in those who were believed capable of understanding: in the medical specialists, or even more, in other parents, often hard to find, who had been through or were going through a similar experience. The parents’ stories revealed relational dynamics with their children centred on control, in a painstaking process of acceptance of the pathology which in many cases took the concrete form of a very strict, endless diet, and of the constant swinging between “saying and not saying”, between recognising the pathology and denying it with “white lies” to give the relationship an image as close as possible to “normality”.

The parents recounted the passages typical of growing up as danger-points in view of the child’s possible rejection of the conditions and practices necessary for his survival, with crises in the child’s relationship of dependence connected to the parents’ responsibility for guaranteeing that the therapies of dietary supplements, diet and regular medical visits were followed. They felt that they could not leave anything to chance, and at the same time, expressed their pain at not being able to do so, and at transmitting to their child the same sense of overwhelming responsibility. The parents compared experiences, sharing past and present anxieties and fears. They posed questions to the group and the consultants about what it was right to do, how to guarantee the child not only survival but also the chance to feel free and to have wishes. They suggested possible psychological support interventions for the children affected by these pathologies to help face the phases of change in their own growth, to accompany them in their development, as well as joint interventions at significant moments in their development such as weaning or treatment during the teenage years, but they also expressed concern for the doctors with the excessive load of emotions and pain that they had to deal with. They made requests about our intervention with the medical staff, rather than with the parents, in the most stressful steps of the process, like the initial diagnosis, in the phases when the pathology becomes acute again, and in the possible terminal stages.

In this way the parents revealed the areas it would be interesting for them to work in although they were almost always cautious about taking on a personal involvement in the need for support, attributing a role of testimony to their own participation in the group, and denoting the needs they expressed as a contribution to the development of the “Support Project” and ending their comments with an expression that over time seemed to become a slogan: “ *let’s hope it’s useful to someone*” where this someone was always external, a member imagined as particularly in need and not participating in the meetings.

### *The meetings with the doctors*

During the whole series of open meetings, the medical team of paediatricians and specialist figures were, as we have said, an important protagonist in the discourses and stories of all the participants, until they became protagonists “in the flesh” during the following phase of joint meetings between the association management committee, the psychologists and the health group.

At first, the team took part in the meetings by virtue of the close bond with the history of the association, and therefore as support to the association and to its demand for psychological support; the discourses of the participants went over the history of the association, its difficulties in growing, the position of the health service and of the associative context towards the Institutions and the financial problems that seemed to threaten the survival of the specialist group and their role as a secure reference point for the families. The representatives of the team talked about the relationship binding them to these families, about the need for their continued professional and human presence, about the difficulty of regulating the distances with the parents and children, in a constant oscillation between dynamics of entrapment and the need to set limits: giving them one’s mobile number and extending the space-time limits of one’s assistance beyond the shifts worked and the spaces of the hospital. Soon, from stories of specific, serious or special cases recalled by some member of the team, there emerged the story of pain and emotional shouldering of the burden in the relationship with the family and with one’s own role when faced with the impossibility of accompanying the diagnosis with a definitively successful therapy, or dealing with the death of one’s young patients and with the parents’ personal grief. The team members expressed their suffering at the difficulty of managing the relationships with these families and with the feelings of guilt and impotence concerning their own role in failing to uphold one of the main responsibilities of medical practice, that of guaranteeing the health and well-being of one’s patients, in not being able to offer at least hope as an antidote to the families’ desperation. During the meetings, starting from these themes and from the stories exemplifying them, the health team presented a request for psychological support related to its own role in managing the relationships with the families.

### *The construction of the intervention context: support as a source of meanings*

In the complex system of relations generated between families, paediatric team and children, the rare genetic and genetic-metabolic pathology, in the present state of evolution of medical knowledge, generates a failure of the established relational models to exercise the medical role insofar as, despite sophisticated, innovative diagnostic methods, it does not enable health to be recovered. Doctor and family find themselves involved in a process of caring for the child and his growth which repeatedly confirms the painful idea of failure: the failure of therapeutic practices, which becomes particularly acute in the sudden and at times catastrophic worsening of the symptomatology, and failure of the parental functions which risks recurring at every stage of growth when alongside the developments, new problems appear. Towards rare genetic and genetic-metabolic illnesses, only the most highly specialized paediatricians can successfully develop the intellectual process of diagnosis underlying medical practice, but they find themselves facing the mortification of the therapeutic role that is fundamental in defining their own role and regulating the relationships with the families. The failure of the therapeutic functions creates a crisis, not only concerning the efficacy of the paediatric role closely connected to the possibility of returning a cured child to the family, but also concerning the regulation of the relationship between paediatrician, patient and family in that it threatens the possibility of positioning the health intervention in a definite, transitory space and time. The acceptance of a child's case in these situations is characterised as being a stable factor, cutting across the life cycle of the families, and the doctor's working cycle, interrupted only by the doctor and the child-teenager reaching a certain age, and in more serious cases, by the tragic outcome of the illness. In chronic conditions, like those described, it is the monitoring of diagnostic action as well as the use of a support therapy that performs the task of constructing and preserving the bond. This bond is re-organized around a cultural model of caring, of shouldering the burden of the person and his load of pain. In the health service where the intervention is carried out, faced with the frustration of therapeutic functions, there emerges between doctors and families a different collusive dynamic which, to use a key word recurrent in the interviews, we can call *of reference*, in which the bond of dependence is based on the categorization of the service as a place where one feels welcomed and acknowledged, where everyone is involved above and beyond what is strictly required by their role, through a personal involvement that systematically, sorely tests both the possibility of identifying the confines of the relationship and the definition of rules and limits in the fruition of the service. This dynamic recalls a model of medicine as the response to a request for help, the response to a condition of suffering, with the doctor embracing the suffering due to his competence in illness but also due to the impossibility of definitively implementing a therapy to cure the patient and end the relationship (Guerra, 1992). While this model of relationship in certain respects guarantees the conservation of the relationship of dependence, on the other hand it eliminates the split between person and illness, between clinical practice and research, bringing into play, on all levels, codes linked to fusional affiliative modalities, in which the two fuse with each other, maintaining a pact of hope that looks to future research as the only possibility of resolving the illness and the relationship itself. This model of relationship is challenged by the continual need, in this phase of socio-political life, to control resources and cut funds due to the financial squeeze. The origin of this critical situation can be traced back to the longstanding conflict within the health system, in which when faced with a continual specialization of medical knowledge and of the related operative units, the administrative system is instead oriented to limiting the costs of health care, introducing constraints not based on strategies of integration but on strategies of resource control and economic cuts (Guerra, op. cit.). In this specific case, the situation is even more complex insofar as the illnesses dealt with are not only rare, occurring in small numbers and having little weight on a social level, but also little known and therefore misunderstood by health bodies that do not have specific competences in the area. The referent operative unit is the only place in the south of Italy where the parent feels reassured, since elsewhere in non-specialized places, it is often the parent himself that has to orient the uninformed operator in the complexities of the illness, even in choosing the most suitable medication for a cold.

It was in this context of relationships and conditions that the association was created, to constitute a third party in the conflict between health service and administration, becoming a union of rare illnesses, crossing the boundaries between pathologies in the attempt to establish itself as a numerous enough group to act as a significant interlocutor with society, the referent bodies and institutions. The association presented itself in support of the service and the common need for a specialized pole for the south of Italy to save the families from the risk of having to face difficult, costly journeys, but above all to help them to control the general anxiety created by the risk of losing that *reference* point as a basic support in the arduous process of managing the illness.

The team of psychologists was brought into play in this dynamic and was collusively invited to assume, on the wave of emotional sharing, the absolute necessity for the operative unit to survive, as well as to place the psychological intervention at the service of this function. The psychological intervention was positioned in a system of relationships which in all its forms seemed characterized by the reference to necessary and urgent support functions: the medical therapy was defined 'of support', the association was formed to support the service, just as the relationship hypothesized between the association and its members was of support, and lastly the demand for psychological intervention was aimed at support. The Italian word 's*ostegno'* deriving from the Latin *sustinêre*, composed of the suffix *sub* "so" and of the declension *tenêre "*tenere*",* therefore refers to the capacity to take and hold on oneself, but it also refers, as a noun, "*sostenitore*" to he who sustains, who becomes advocate and defender of a cause. The term ‘sostegno’ (support) is therefore linked to the capacity to shoulder the burden of someone else’s load (*for a while*), and at the same time refers to a hypothesis of alliance, to the capacity and will to assume and promote a cause. Treating support as a semantic category, rather than as an operative practice, enables us to explore the meaning of a demand for intervention designed to delegate to the psychologist (*for a while*) the burden of emotional components from which the association had to be freed if it was to carry out its militant function, and from which also the medical team had to be freed, being weighed down by a burdensome emotive load, and called on to demonstrate its results and intensify its clinical productivity in a period of cuts and shortage. At the same time, it allows us to explore the sense of the demand for support as an action designed to give social visibility to a problem, but also aimed to promote in each other’s estimation, the protagonists of the context; for example, the association in the eyes of the health service and of its own members. Yet again, there was a strategic choice for the intervention, either participating in the complexity of the context, taking a position along a specific trajectory, or suspending this positioning, establishing a process designed to recognise the meaning that support, as a category of affectively based sense, assumed in the organization of relational dynamics. On the other hand, taking one of the components of the context as the sole beneficiary of the intervention risked *supporting* an action that collusively delegated to one specific, distinct component the function of shouldering the burden of the weak, needy parts, in an affective dynamic aimed at controlling the shared, pervasive feelings of anger and impotence. The hypothesis being made is that as an organizer of relations, support is always an organizer of mutual aid. It may be a process that risks supporting a stereotyped and strongly asymmetrical organization of roles, or a process linked to mutual aid as exchange that can therefore support transformational processes based on reciprocal recognition. In this perspective, support is not produced by one individual acting on another, but becomes a process of regulating a relationship that can support power dynamics or that can contribute to the growth of relationships aimed at achieving goals based on the recognition of reciprocity. The psychological support intervention is therefore not connoted, in this initial phase, as an operative action addressed to one category of beneficiaries, but as a process of thinking about the dynamics of “reciprocity” acted out in the context and about their efficacy in promoting the competence to deal with the problems that gradually emerge. It was the client system, which as work went on included members and health staff, that had to be helped to identify its development goals and to recognise the functions and the raison d’être of the various protagonists. We could also say that the intervention set out to recognise and conceive of reciprocity, restoring its exchange value and its transformational potential. The first stage of the intervention concluded with the shared construction of the system of relations organizing the intervention context and with the sharing of a goal: a protocol of understanding was drawn up between the health system, the parents’ association, and the team of psychologists, for the carrying out of an intervention-research project to study the development of support functions in the relationship between association, families and service[7]. The intervention context was more composite than had been envisaged in the initial phases, but this was considered necessary so as to prevent the needs that had emerged for the collaborative support and transformation of the families-service bond, and the feelings of precariousness and threat, from remaining an implicit background to a series of fragmentary actions, and to enable them to become the shared fabric in terms of which to design development goals and possible goal-oriented actions.

### *Models of participation in associations and support functions*

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[7] A protocol of understanding between the Department of Relational Sciences, Department of Paediatrics, School of Specialization in Clinical Psychology of the Neuroscience Department at ‘Federico II’ and ‘Umar’, (Rare Illnesses Union) aimed at carrying out an Intervention Research project entitled: “*Functions and roles of support in the relationship between families and the health system for the case-acceptance of children with genetic-metabolic pathologies”*.

In the previous section we examined the processes of reciprocity organising the intervention context and the complex relationship between association, health service and psychological intervention. During the open-door interviews, conducted in groups with the management committee and members, the exploration of these processes proved to be a useful criterion for reflecting on the categories of symbolization of the association and on the various ways the members positioned themselves within it, as well as on the different ways participating in the association could be used to support one's parental role. The use of an open-door group setting made it possible to gradually construct a discourse around the associative process, to recognise and conceive of the various symbolization models that oriented the participation and that had contributed to its current form. At the time of this phase of the intervention, linked to the first steps in the life of the association, the dominant cultural model seemed to be of an operative type, based on the identification of a medical model, and aimed at a strong positioning of association in the social fabric. The enemy against whom the efforts of the association were focused was not only the illness, but the society classified as indifferent and hostile. This was an affective dynamic in which it could be hypothesised that the feelings of impotence were elaborated by doing; with this model a clear separation was acted out in the association, between those who operate and those who use the services, with the needy state being projected onto a part of the associative fabric represented as passive and absent. Essentially, it was a model that, following a style of medical operating, tended to split the whole association from the fragile/ill part to be looked after, and identified an external enemy to band together against. This model sustained the association in its operative functions of constantly monitoring the association framework, its constraints, its goals and its productivity, and dealt with identifying a place in society for the association. The psychologist was represented as a medical component to be promoted for the beneficiaries, the psychological intervention as the possibility of dealing with one's fragile, needy part, seen as being incongruous and disturbing, and thus maintaining a split based on non-recognition; to the psychologist was delegated the function of caring, and to the beneficiary that of being the receptacle of the fragile parts of the association, of the associative process and of the self. As the discourse about the associative process developed, there also emerged other modalities of symbolizing the context which interact and conflict with the dominant dynamic: the use of the association as a space for participation, where the possibility of playing the role of *helper* was an important support function for the parents. In this model the association was symbolized as a space of participation, where it became possible to come into contact with the emotive components of one's own experience, anchored to a process of sharing designed to strengthen the group project. The painful, affective components of one's experience could be elaborated and shared in the group, if they were recognised as part of a common experience for reflection and exchange in a project in which those who had already been through the experience assumed a competence to use on behalf of others who were taking their first steps in this difficult journey. The psychologist was offered a reversal of the request [8], with the parent participating in the psychological work, being competent in the condition of fragility in which he was immersed, and due to a motivation to understand what can be done for others. The commissioning party and the beneficiaries were still seen as separate, but between these two functions it was possible to acknowledge and develop a bond based on the recognition of shared affects and experience. Breaking the isolation, feeling part of a broader category, mediating the relationship between family, child and society, elaborating the sense of impotence by recognising a useful and visible transformational social role, are some of the functions that this model of participation in the group processes sustains and promotes. Let us think back to the group interviews when a parent-member told of his sense of liberation and satisfaction when, having promoted a fund-drive for the association, he was able to share in public the story of his son in a situation where there were several residents of his neighbourhood present. By means of forming an association, anguish can be shared, feeling part of a category that one identifies with makes it possible to face the sense of diversity linked to the relationship with the

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[8] The reversal of the request, which in this specific case is supported by the relational proposal established by the open-door interview setting.

broader society, and sustains the hope for a chance of understanding and sharing of personal pain.

Another symbolization model constructed from the group discourse, concerns the use of the associative process as a possible source of answers to one's own personal need for support. In this dynamic the needs of the other are identified by starting from the needs recognised as being one's own and for which one tries, in the association, to activate resources to embrace and elaborate them. In this sense the psychological group, as well as the association as a whole, are categorized as places of acceptance of one's inability to cope with problems, where the anxieties and emotions connected to these inabilities can be expressed and shared. There is a process of identification with the other members through which it is possible to take the self as the beneficiary of the association's functions and therefore explicitly conceive of the psychological intervention as a means of personal learning. The latter mode of relating with the association is presented in a similar but not overlapping way to another way of using the associative processes that could be summed up as the model of participating in the role of beneficiary. This is a role of the user of services, to which the members' discourse systematically refers, and which while appearing to be passive and demanding on the one hand, and supposedly reflecting the needy and regressive part of the group, on the other hand  is presented as the outer margin, allowing the group as a whole to elaborate anxiety while maintaining a certain distance from it, splitting the active, propositive component from the demanding, fragile component , which essentially enables boundaries to be constructed between one's own pain and that of others, to filter the contamination of anxieties.

Not having decided, as psychologists, to take this last category of members as the object of the intervention, but having decided to treat the object as the categorial process that had organized the demand and sustained the complex dynamic between commissioners and beneficiaries, enabled us firstly, to open the field and explore the various dynamics of affective symbolization found in the association context; secondly, to set up a destination space, with no specific contents, in which the association could think about itself and recognise the symbolization dynamics affecting it; thirdly, to "see" the prevailing affective symbolization, its dysfunctionality in setting certain goals, and its non-total support which favoured the opening towards the development of support functions innate to the association fabric.  It was not felt in fact that the psychologist had to express a judgement, adopting one of the models as more suitable and advanced that the others, but that the psychological intervention could, in this early phase, help the association to recognise its dominant modes of functioning and the way they sustained certain aims and left others in the shade. In other words, it could help the association in the arduous process of knowing its members, a process based on cutting across codes and points of view, designed to set up a confrontation with the extraneousness of an associative project. This recognition of the other that could transform diversity as a category of juxtaposition into a democratic coexistence and integration of models and affective codes (Fornari, 1978).

The setting, which was achieved thanks to the clinical work conducted so far, envisaged the establishment of a more structured working group with the management committee members and some interested members, designed to develop the association's functions of parental support.  It was a negotiated setting (Salvatore & Scotto di Carlo, op. cit.) in which the suspension of operative action was configured as an opportunity to reveal the various categorial models of interpreting the associative process and its aims. The point was to set up an associative space where it was possible to suspend the action guided by the predominant collusive symbolic model to explore the different points of view involved, which on the one hand would permit the emergence of new configurations of meaning, and on the other enable the different categorial matrixes conveyed by the various protagonists to be conceived and the support functions delegated to the psychologist and addressed to a split-off component of the relational context to be brought back into the context of the association. By establishing a collective fabric based on different models of symbolization, and operative along different trajectories, through exchange this associative function could sustain the processes of elaboration of mourning, the sense of failure and guilt, towards the construction of reparatory processes for mutual aid. This would allow the passage from a condition of impotence to one of openness towards one's own resources and of acknowledgement of one's limits. It seems that this function of group support can be expressed through opening up to the different modes of symbolization and the use of the association by the members, by implementing exchange and sharing within the parent-member group, and with society, and through the possibility of taking part in the group's action in a creative and generative way. All this today, rather than in a hypothetical and more favoured future.

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