

Family Centered Care: the “Accoglienza” therapy

Cura centrata sulla famiglia: la “Terapia dell’accoglienza”

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Being sick is tough. It gets even tougher when a child is sick, because there are not only his own needs, but also the ones of his family. Even harder is the moment when the young patient and his family have to move to another city, because of the rarity and complexity of the sickness. Besides the continuity of clinical treatment for the young patient, a continuity in the family's care is also needed. Family Services are specifically meant to take care of the child and his family for all the non-clinical aspects of assistance, whatever fundamental: a real “therapy of care”. For a parent, the possibility of focusing all his attention only on the child's disease means that he can give the highest level of collaboration with the hospital team; the sick child is not only able to rely on the course of treatment in the strict sense, but also on the strength that the psychological and emotional relationship with the family is able to provide him with. In Italy the number of structures organized to support family needs considering the global care of the family, from the first contact with the hospital, as a critical factor for therapy is almost non-existent. In this regard, through the constant analysis of the needs of families, Bambino Gesù Children's Hospital in the last few years has emphasized the importance of building a Family Service organization that is careful to protect the patient and his family from the traumatic effects of hospital admission. A warm welcome is an introduction to a positive treatment: this is our philosophy, and our slogan, with whom we receive our families: “all you need to do is care for your child, we'll take care of the rest”.

Key words: Therapy of care

Il momento della malattia è un momento difficile. Lo è ancora di più quando riguarda un bambino perché alle necessità di assistenza del piccolo somma i bisogni diversi della sua famiglia. Ancora più arduo è il momento in cui il piccolo paziente e la sua famiglia sono costretti a spostarsi in un'altra città e, accanto alla continuità di cura clinica del piccolo paziente, è necessaria la continuità di “care” della sua famiglia. È con questi fini che la “Terapia dell'accoglienza” si sviluppa in una serie di servizi che hanno l'obiettivo di rispondere ai bisogni di salute dei piccoli pazienti anche attraverso la cura delle famiglie, con l'aiuto di personale dedicato, considerando l'accoglienza della famiglia, fin dal primo contatto con l'ospedale, un fattore fondamentale della cura. Per un genitore, poter concentrare l'attenzione sulla malattia – e sulle potenzialità di guarigione e cura del proprio figlio – significa garantire il massimo livello di collaborazione alla squadra terapeutica e convogliare tutte le proprie forze in modo appropriato; per il bambino malato significa poter contare non solo sul percorso terapeutico in senso stretto ma anche sulla forza che il rapporto psico-affettivo con la propria famiglia è in grado di garantirgli. Molto scarse però, se non quasi inesistenti, sono in Italia le strutture ospedaliere organizzate con strutture di accoglienza e che, parallelamente alle strutture di clinica e ricerca, considerano l'accoglienza della famiglia, fin dal primo contatto con l'ospedale, come un fattore fondamentale della cura. Al riguardo, attraverso la costante analisi delle esigenze delle famiglie, l'Ospedale Pediatrico Bambino Gesù ha negli anni viceversa rilevato l'importanza di costruire un servizio di accoglienza massimamente attento ad ammortizzare gli effetti traumatici su paziente e suoi familiari dell'ingresso in Ospedale. Accogliere bene è già curare: questa è la nostra filosofia, ed il nostro motto, col quale ci rivolgiamo alle nostre famiglie, è: “Pensate solo a vostro figlio, al resto pensiamo noi”.

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Introduction

Bewilderment. That’s the dominant sensation for those who have to face with an admission to a hospital, especially if that hospital is far away from home, even worse if the patient is your child and you, the parent, relative, or just an adult helper, should be a landmark for him. Instead, you don’t know what to do, who you can talk to or where to go. You just feel lost among the information, wards, comings and goings of patients and white coats.

However, everything can be different if the hospital, together with treatment in the strict sense, invests in family care. For instance, before reaching the hospital, the family is contacted to make an appointment and subsequently received by a team of “Guardian Angels” from Family Services, who are trained to care for the whole family, for as long as required, until the discharge and even after.

My professional experience as a doctor has increasingly convinced me that family care is a necessary part of treatment. Giving the sensation of being cared for enables the family to focus on the only thing that matters: their child’s health. When I graduated, there was a real dichotomy between healthcare providers, or rather doctors and nurses, and parents. I am sure, instead, that this separation is senseless, and that the parents’ presence in helping and aiding their child’s therapeutic path must be integrated. My great-grandfather, a pediatrician, used to assert that the main doctor is the mother: I believe he was right.

However, in Italy very few hospitals are organized with Family Services. Few professionals consider that the care of the family is as an essential factor in treatment along with Clinical and Research units.

Therefore, by considering a constant analysis of family needs, Bambino Gesù Children’s Hospital has understood the importance of building a Family Service department highly dedicated to softening the traumatic experience on the patient and his relatives after their entrance in the hospital. The goal is to recreate an environment as close to home as possible, inside the hospital. Experiencing a disease is indeed sad and hard, even more so when it involves a trip to another city or region because of the rarity or complexity of that disease. The trauma of the patient and family being away from home and losing their natural support structures can have a great impact emotionally. This is a strong case for properly supporting the patient and his relatives during their stay in addition to the normal clinical treatments.

Since ancient times, hospitality has involved the capacity to interact with the “customer”, and to treat him as a guest: there are many examples of care, such as greetings, offers of food and drink, activities to help pass the time, safety, transport, kindness and consideration in both personal and impersonal interactions. The employees have a key role in that they must be kind, available, and disposed to personal relations. The quality of the service becomes central, especially for those services closely linked to patients and families with a long stay (Fig. 1).

Contribution

It’s with these purposes in mind that the Family Services department of Bambino Gesù Children’s Hospital offers diverse services that answer all the health needs of our

Hospital Professionals

Medical Doctors/Surgeons

Nurses
Technicians

Psychologists
Counselors

Social workers

Professional Educators and
Play workers

Administrative personnel



Additional Support Staff

Volunteers

Clowns

Art Therapist, other
therapeutic staff

Parents associations

Parents and families

Figure 1. *The world around the Child.*

young patients; this goal is also pursued by taking care of the families, with the help of a dedicated staff who ensure a supporting environment for the family from the first moment they arrive at the hospital. A warm hospitable welcome is the beginning of the healing process: this is our philosophy. And our slogan, with whom we receive our families, is: “all you need to do is care for your child, we’ll take care of the rest”.

For a parent, being able to focus on the disease – and on the healing and/or treatment options – means that he can guarantee the maximum level of collaboration to the therapeutic team, and direct all his energies in an appropriate way; for the sick child it means that he can count not only on treatment in the strict sense, but also on the emotional bond with his family.

Since 2008, this process has been implemented with various services specifically dedicated to families, whose very positive results have encouraged me to describe the model.

Family services: organization model

The patient and his family are constantly at the center of the treatment system, which rotates around them, through various services that integrate with each other (Fig. 2).

The model we’ve structured during the last few years starts with the Front Line System.

Front line

For starters, it is necessary to praise the all too often burdened front line service. The “simple” Care and Information desks have a role that is rarely recognized for its importance in systems that generally staff them with lower quality employees. The philosophy that should animate the front line staff, which are selected and trained, is to be proactive. Whether our staff is just standing in the hall and available for giving information or orientation, the most important thing is taking charge of possible problems. Our staff can be easily recognized not only by their smile, but also because of their uniform; the schedule is as broad as possible including weekends and holidays. In addition at the call-centers, the answer is never “it’s not my responsibility”, but instead: “I’ll deal with this”. Answer times are never beyond 24 hours, and the same applies for the email service. Timely and competent replies are directly proportionate to the feeling of protection and help for those who seek it. It’s not unknown for a cus-

Family Services organization model

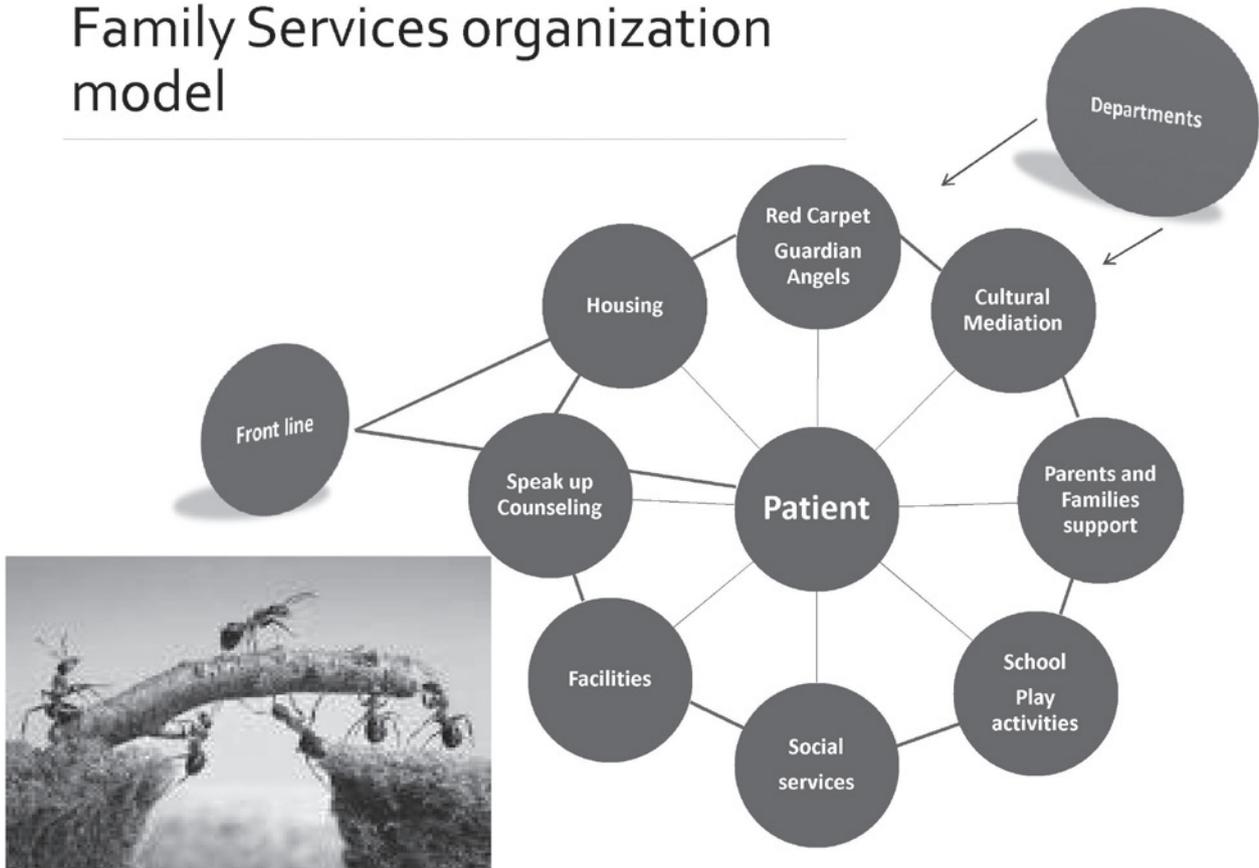


Figure 2.

tomers to react positively to an answer that doesn't coincide with his first expectations, as long as it's prompt, kind and well explained. A considered reply can increase the customer's faith in the system, and therefore turn him from a potential critic to a sympathetic ally.

Accommodation care

The first, basic problem with accommodation for those who come from far away, is having a roof over their head. Home is home, the place where we cry, laugh, sleep and live in. Without a home there's no care. Even if one of the two parents can stay for 24 hours with the recovering child, the need for a personal space out of the hospital is paramount: for the other parent or for a supporting relative, and sometimes for the whole family.

The principal network is the one dedicated to needy families: the hospital offers them free accommodation in structures linked to the hospital. For access they might follow a path from a triage, made by Social Services on the base of clear criteria such as: distance of their residence from the hospital, disease of the child, duration of recovery, family composition, so that we can guarantee those with greater need get the most help. Along with family care accommodations provided by nonprofit organizations and a network of hotels, today the hospital counts on almost 200 rooms to accommodate families for free: in 2014 more than 4,500 families were accommodated (about 13,500 people, for more than 100,000 nights per year) (Fig. 3).

Red carpet

Being sick is tough. It gets even tougher when a child is sick, because there are not only his own needs, but also the ones of his family. Even harder is the moment when the young patient and his family have to move to another city, because of the rarity and complexity of the sickness. Besides the continuity of clinical treatment for the young patient, a continuity in the family's care is also needed. Project “Red Carpet” was created for these families: the Family Services of Bambino Gesù Children's Hospital contact the family before they leave in order to introduce themselves and to verify any potential needs (accommodation, social assistance, etc). From the moment of admission at one of the locations of Bambino Gesù Children's Hospital, the family will find a Family Service Tutor waiting for them, who has knowledge about the clinical case and the information collected from clinicians and family. The Tutor will take care of the patient and family, welcoming the child by calling him by his first name. The family will receive all the information about the hospital's structure and facilities (summarized in a guide), a small kit/diary for the child and indications about possible available accommodation. The Family Services Tutor will lead the family to the ward and introduce them to the staff.

This project is integrated with the Guardian Angel's (Tutor or Navigator) program: the family is followed by the same person during the entire process, who gives information and logistical support. They can also offer counseling services through counselors specialized in listening and support-

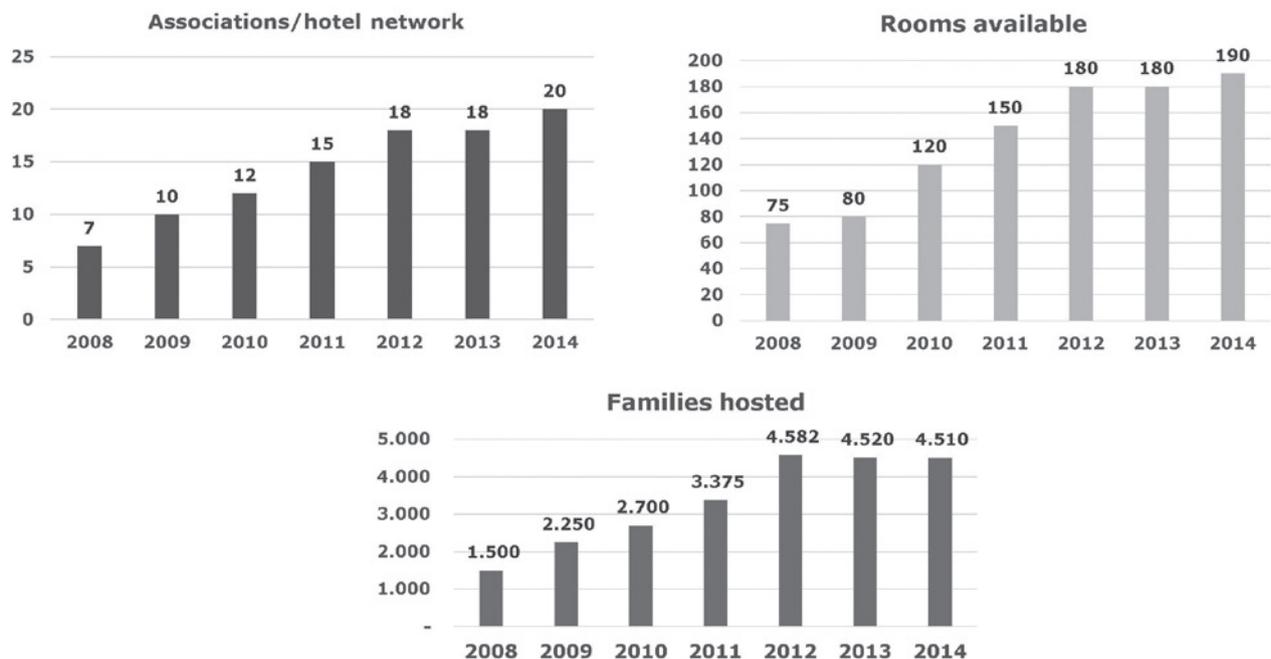


Figure 3. Accommodation care.

ing the family members traveling with the patient until they get back home. In 2014, Bambino Gesù Children's Hospital hosted 104 families in "Red Carpet". At the same time the Family Services staff were "Guardian Angels" for 472 families.

International Patient Service

Another cause that has led to diversifying family care strategies is the massive increase of foreigners, who have increasingly turned to our hospital for treatment over the years. From a small number of 113 foreign customers charged by our service in 2001, we reached 1,108 families in 2014.

The cultural mediation service has a double system: one in outsourcing, that guarantees the presence of interpreters for more than 30 languages within two hours from the request; and one for immediate translation through a free phone number, that can be activated from the telephones of all the hospital's locations and from all of the accommodation houses, active for 101 languages within only two minutes.

In 2014 there were more than 2,000 mediations, for 47 different languages: Albanian, Afghan, Amharic, Arabic, Armenian, Bengali, Bulgarian, Czech, Chinese, Ceylonese, Korean, Kurdish, Dari, Danish, Edo, Ethiopian, Farsi, Filipino, French, Greek, Indian, English, Khmer, sign language, Macedonian, Nigerian, Pakistani, Polish, Portuguese, Punjabi, Romanian, Russian, Serbo-Croatian, Somali, Spanish, Swedish, Swahili, Tamil, German; Tigrinya, Turkish, Urdu, Ukrainian, Hungarian and Vietnamese.

For foreign citizens there is a call center with a specific phone number, and it is possible to refer to a dedicated Family Service staff for recovery files and for administrative and social counseling. More than 570 patients each year are helped and supported in their various needs.

Child life services

Playing is serious business. Nowadays it has been proven that the psychosocial treatment of the child and his family is not an optional measure in the treatment of a hospitalized child, but it's indeed a primary part of the treatment process: creative activities and games are means through which it is possible to create a connection with the outside world, and express and communicate feelings, control situations, exchanging roles, express aggressiveness. During hospitalization, the help we give the child to cope with their fears and needs, also means supporting the family and the health operators.

In 2014 the hospital's playgrounds saw more than 30,000 children and teenagers among the ones recovered in the different wards or aided in the day-hospital, including their brothers

and sisters. The service has two main targets: to offer children and parents care and games for entertainment and relaxation and, at the same time, a way to express and elaborate fears, doubts, worries and negative emotions linked with hospitalization. For this purpose, there is a plan of activities, diversified in relation with different ages and contents: spontaneous and guided games, laboratory activities (such as graphical-pictorial activities, marionettes construction and dramatization, role games, manipulation and making of clay, toys and musical instruments construction, movement activities also with music or with stimulation of the imagination, reading and creation of tales and stories about peculiar themes), creative use and familiarization with therapeutic procedures and potentially disquieting objects used in the hospital, more specific activities of art-therapy, thematic laboratories and guided imagination laboratories. There is also a video archive, a library and a Toy Bank for loans or offers.

Individual interventions are also done at the bedside in Intensive Care Units (Fig. 4).

For parents, who can entrust their children to qualified staff, there are meeting and shared areas or manual activities that can help them to find emotional resources and playful support to relate themselves with their child even in the hardest times.

Following an invitation from the Child Life Council (USA) to its International Congress in New Orleans, a project to increase training for Professional Educators has been carried out. The Child Life Specialist/Professional Educator is an expert, qualified to help children facing the stress and fear of sickness and hospitalization. Training for Professional Educators is essential to ensure the cure and rehabilitation process; Regione Lazio has recognized the key role that these educators play in rehabilitation teams.

School

Continuity of the scholastic itinerary must be guaranteed, especially to those children who spend long periods



Figure 4. *Blowing the Pain Away.*

at the hospital or who often go there. Inside Bambino Gesù Children’s Hospital primary and secondary school lessons of every grade are provided. A school course, in a peculiar environment such as a hospital specialized in pediatrics, involves a complete change of mind on a curricular, educational and methodological level. At the hospital there can’t be a physical classroom, as long as most of the kids are bedridden, especially in the intensive wards. School is built around individual students or small groups (often from different classes) in the rooms of the different wards or, when possible, held around the bed of a patient who can’t move. The teacher is therefore always moving. In “normal” schools the teacher is the main protagonist of those training and orientation processes that are the basic purposes of instruction. At school in the hospital, instead, the teacher becomes a cooperater at the side of other experts working all around the child-patient-student. Our pupils are kids that for different diseases arrive at the hospital from all the regions of center and south Italy, and, in an increasing amount, from non-EU countries. In 2014 there were more than 2,800 patients in primary or secondary school: Bambino Gesù Children’s Hospital can be considered as a real academic institution, where recovering children can sit their final examinations.

Volunteers

Volunteers are at the hospital every day, and they serve as unique channels among the patient, family and health operators. Due to their focused training they offer their assistance with respect, accessibility and professionalism.

The volunteers tasks are various: requested by doctors, they are in almost all of the wards, they dedicate assistance to children during treatment and leisure. They assist families, with particular attention to mothers: they help them with the bureaucratic activities necessary for recovery; they substitute them when they need some rest; they involve them in manual and laboratory activities to distract them from their daily life; they show them how to get around easily at the hospital; they’re also beside the parents of children undergoing surgery till the end of the procedure.

Parents associations

Parents associations are a precious resource, both because of their direct knowledge of the assistance and psychological problems of the patients, and because of their capability to find empathetic and trusted links with customers. The venture is integrated in the project of Family Centered Care, which includes the creation of structured paths to involve the families directly in the family care process.

The associations active at the hospital have a reserved placement inside the Family Services: at the desk they can

both inform and listen to the families of children with specific illnesses, and they represent a channel between the family’s requests and the hospital’s operators. In particular, they direct and ease the access of patients and their families to Bambino Gesù Children’s Hospital’s facilities through agreed paths and help them when it’s time to return home, by creating a protective net.

In 2014 the opinion of patients and families, which were already participating in the different committees of the hospital, was taken into greater consideration thanks to the councils composed of both relatives and teenagers.

The teenagers committee gathers monthly at Family Services. Patients are identified at all the hospital’s departments, with the contribution of Chaplains, nurses and doctors, hospital teachers and volunteers. The targets are:

- creation of a direct channel to communicate with young patients;
- listen to the adolescents point of view in relation to the strengths and weaknesses of care and assistance;
- improve the quality of recovery.

The subjects analyzed are the following: general care, cleanliness, facilities, daily organization, food, information received and relationships with the health operators. At the end we ask for feedback about what they’ve liked most and the least, and about their needs, advice or suggestions.

The most critical aspects in 2014 were about food and play areas for the adolescents, whereas relationships with health operators was great.

In anticipation for the accreditation survey of the Joint Commission International, 23 associations (of the approximately 100 associations qualified at the hospital) actively participated in preparation with our health professionals by adapting their files to the required standards.

A training course on research was provided for parents and teenagers inside participating associations that was a successful first step in a possible continuation of this offering.

Social services

In the last few years the number of families supported by Social Services has enormously increased: from 200 families in 2001, to more than 2,500 families of 2014. They are families for whom Social Services has activated structured support processes (hotel accommodation based on a “social triage” on the criteria of need, psychological counseling and tutoring by the Family Service’s staff). The primary goal at Bambino Gesù Children’s Hospital during recovery is to help families when they need it most – in the period of loneliness and desperation for their child’s sickness – and to make them feel loved and respected, as a part of a great family. But the most critical moment often comes with the discharge, when the family goes back home from the hospital: the lack of any social facility supporting the family is often a serious prob-

lem, especially in the cases, more and more frequent each year, of children with acute or chronic diseases, which makes it difficult to provide an at home management of the illness.

A particularly serious phenomenon is the underground abuse, negligence and mistreatment of children. Social Services are part of the hospital network for protection of children's rights, paying particular attention to child abuse, for prevention and immediate intervention. In addition, at Bambino Gesù Children's Hospital there is a procedure of early screening for abuse and mistreatment (Fig. 5).

In 2014 Social Services aided more than 2,500 needy families, in particular for abuse and mistreatment (54 cases referred to judicial authorities) and for facilitating the discharge of children with chronic diseases or social-health problems (more than 100 difficult discharges, made possible by the task force of Social Workers). In 2013 a project of collaboration between the hospital and parishes, through Rome's Vicariato, was established to create another protective net around those families who need it. Needy families who live in different municipalities – and parishes – are placed in a virtuous net, in which the Unitalsi Association also participates: volunteer teams aid children and families after their discharge for both practical needs and emotional and social support.

A close network among the different services and social operators is fundamental in order to provide support to the child and family.

Bambino Gesù Children's Hospital, in cooperation with other pediatric hospitals, promoted the first research project on accreditation on children's rights in Italy and the first Accreditation Manual on Children's Rights in Italian Hospitals, and participated in the work of the National Institute for Children's Rights (INDIMI) on a new children's rights code.

Counseling

The hospital counselors, specialized in supporting and listening to the family during difficult times, build relationships to help them, in which they attentively listen and offer sympathetic understanding, all the while withholding judgment. Conversation is the foundation of this work method: the counseling process helps developing awareness, opinions and abilities useful for problem management and for personal growth, thanks to the improvement of self-confidence and personal resources. The objective is to offer guide, support and to encourage development of relationships and building potential. Counseling activity is strictly confidential. It is not psychotherapy, therefore it can't be used for psychological or psychiatric diseases, as they require a different approach. In 2014 this kind of support was given to 108 people.

The hospital counselors have activated a self-help group which gathers periodically in the Parents Room; more than 100 meetings took place last year. The WHO defines mutual self-help as “the combination of measures adopted by non-professional people to promote, maintain or recover health, meant as complete physical, psychological and social wellness of a community”. The goal of mutual self-help is to “transform those who ask for help into people who can give help”.

The purpose of the group is to exchange experiences, relating and listening; meeting people that are facing the same problems and who have found optimal ways to overcome and manage those problems, giving them hope and optimism.

Participation of parents who have had their children recovered or recently discharged from the wards is voluntary and the number of participants in the group can reach up to around 10 people. If there's a foreign parent participating, a cultural mediator is activated.

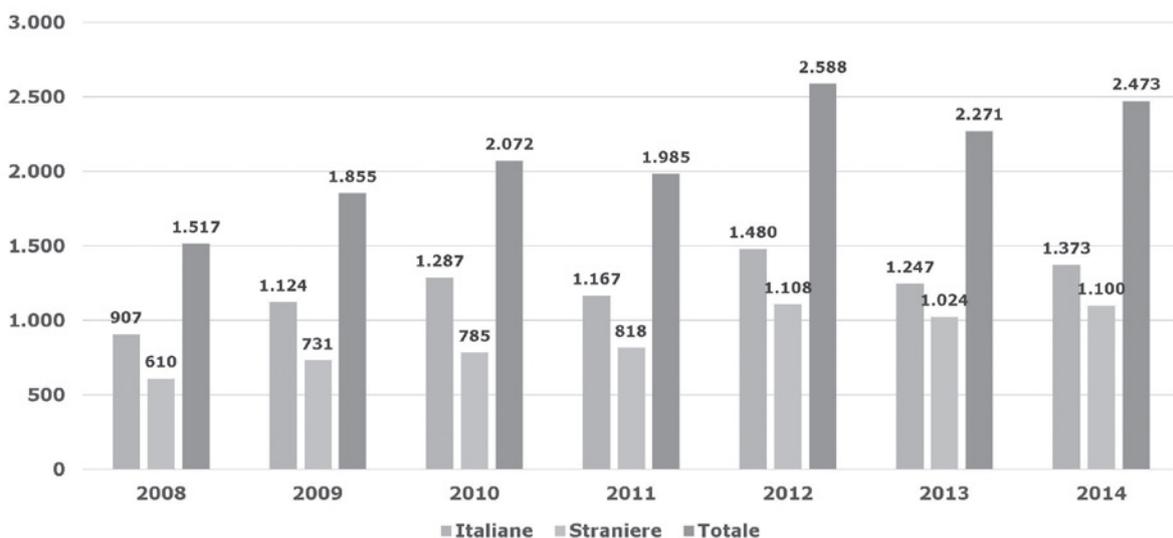


Figure 5. Families followed by the Social Service

Facilities

The hospital’s target is to make parents and young patients feel at home.

That’s why we created: the ‘Stork’s Home’, an area inside the hospital with the comforts of a real apartment for mothers that breastfeed their child, who is being recovered in intense care. It is a comfortable area with up to 9 beds, a kitchen, a living room and bathrooms. Another area is the Parents Room, with a relaxing environment, illuminated by two big ceiling lights that model the constellations of the Boreal and Austral hemispheres, where parents can read, use the computer, listen to music, talk with qualified staff or participate in recreational and training activities (from courses for parents to “burraco” tournaments). The third room is the emergency room, which was created to receive families that arrive to the hospital in an emergency during the night. We also have a Laundrette, a room with washing machines and dryers, where mothers can wash and dry their laundry. Finally there are “milk points” in different areas of the hospital where the mother can breastfeed their child. We also have the possibility for mothers to have gym and yoga lessons while their children play in the playground watched over by our professionals.

For the children there is also the “Ludotac”, a toy TC through which the children are taught to view the TC as a playful adventure rather than a traumatic experience.

In 2013 a specific playground for disabled children was created so that now they can finally go swinging!

Customer satisfaction

The protective circle around the patient and his family concludes with the analysis and verification of the effectiveness of our system.

Customer satisfaction, not only about the hospital in

general, but also about our service, is systematically measured through different tools: satisfaction questionnaires for patients of every kind.

Moreover we send two members of the Family Services staff, every day, to go into the wards to understand what really happens. The goal of this function is to ensure the best customer service by speaking with the families there and asking their opinions on various topics including comfort, cleanliness, food, care and medical and nursing assistance. This project is called “Speak Up”: the information received may be used to solve many problems in a fast way, both for management reasons and to improve the quality of the assistance (Fig. 6).

The observation and the interventions include all the sectors and activities of the hospital and also external contractors and suppliers. In 2014, 2,700 interviews were conducted through Speak Up; 20,000 satisfaction questionnaires and 140 complaints were examined. In 2014 the hospital simplified the feedback loop between family and hospital management by acquiring specific technological devices.

Conclusions

Family Services are meant to take care of the child and his family for all the non-clinical aspects of assistance, whatever fundamental: a real “therapy of care”.

The keyword for all of these services is the humanization of cures. We have tried to create a network, an integrated system for the protection of families and our little patients. Our mission is to assist the patient as best we can without neglecting the family’s needs.

At the beginning of this report I made a reference to the natural knowledge of our grandparents, who recognized the mother’s intuition as a powerful source for diagnosis and therapy.

Currently, we are striving to rediscover these ancient values, fundamental for an ethical institution such as ours, in

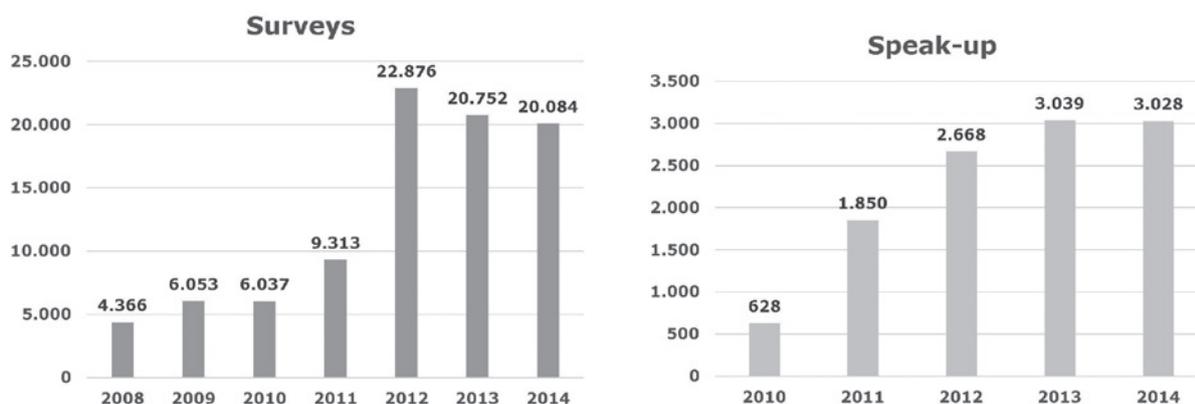


Figure 6. Customer satisfaction: surveys and Speak-Up project

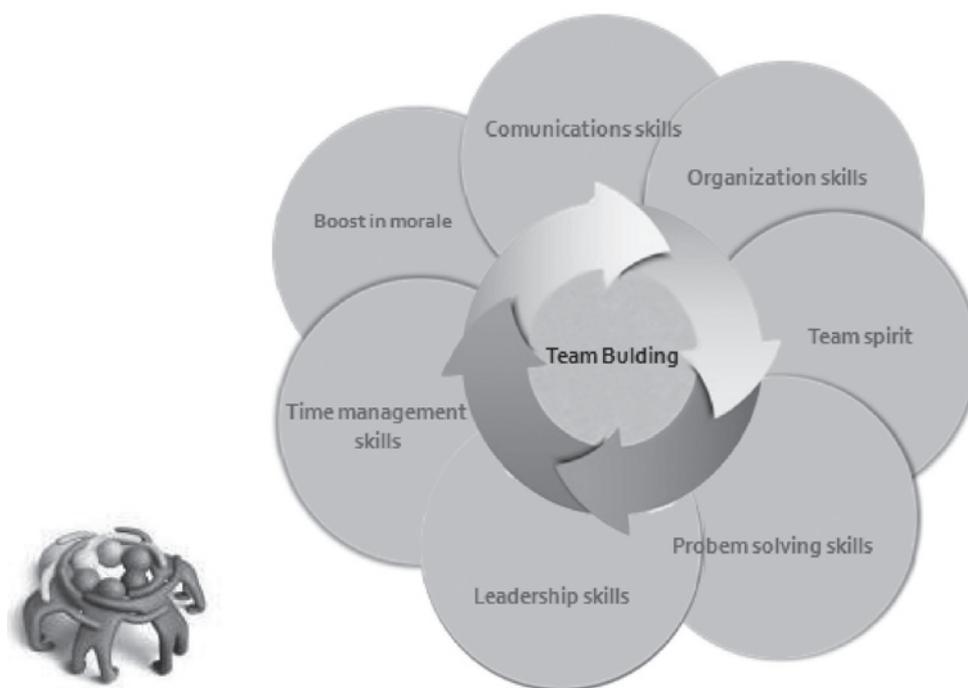


Figure 7. A model for cooperation

order to create a system composed of a plurality of different services committed to curing children and caring for their families.

Bambino Gesù Children's Hospital strives for excellence in health performances through research activities and avant-garde clinical activities performed in accordance with the ethical values and moral principles of the Catholic Church.

In summary, Bambino Gesù Children's Hospital pursues the application of the following values:

Excellence – meant as a continuous struggle to reach the maximum level in every situation and attitude, in which professionalism, research, technology and behavior shall be oriented

Centrality of the Person – meant as the full recognition and respect of human dignity (of a child, a parent, a relative, a health operator).

Competence, Availability, Care and Attention to the needs of the children and families.

All the clinical activities, supported by scientific research, lead to the continuous improvement of diagnostic methods and therapies in compliance with the Christian ethic, to completely realize Christ's commandment: "Cure the sick, serve the invalids".

As a result of these foundational values we have built a strong identity. Today, Family Services is the third pillar, the first two being Clinical and Research activities, aspiring to provide excellence in treatment and care.

Our fundamental belief is that "people heal better with care".

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