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Humanization of Care and Culture of Welcome. The Bambino Gesù Children Hospital: a Case of Study

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Humanization of Care and Culture of Welcome. The Bambino Gesù Children Hospital: a Case of Study

Andrea Casavecchia

Abstract: The article shows the development and diffusion of a "culture of welcome", a secondary concept in the health system, compared to care and research. After identifying some points of contact between the humanization process and the evidence-based medicine method, a case study is analysed through biographical interviews with key informants and secondary data, provided by the hospital. The main phases of a process of cultural change, which took place in the Bambino Gesù Pediatric Hospital, one of the Italian and international excellences, are shown. The culture of welcome, born from the humanization process, is transformed from an individual commitment to a shared goal. As long as the activities put in place lead to the conscious construction of a system that integrates and supports the health care system.

Keywords: Culture of welcome, Humanization of cure, family-centered approach, cultural change

"What is essential is invisible to the eye": this statement accompanied by its illustration is written on one of the walls of the canteen of Bambino Gesù Children Hospital on the Gianicolo hill in Rome. Some of the quotes, here, were chosen from The Little prince – the famous work by Antoine de Saint-Exupery – to enrich the restored dining area. Furniture and colours are designed to make the environment less harsh for younger patients.

The drawings are everywhere, on the walls of the ward, of the waiting rooms, of the surgical or medical examination rooms. As an ensemble, they announce the wish to pay attention to patients and their families. The aim is to mitigate the totalizing impact of hospital experience on people, to become child and family-friendly.

Meticulous attention to hospital space design (Surrenti, 2008) is not just a marketing need for customer and citizen satisfaction. Above all, it affects the progressive rooting of the process of humanization of care. It invites the healthcare system to overcome the attitude that led to seeing people only as patients and acknowledging only their therapeutic pathways. It has asked to broaden the horizon and to see sick people in the frame of their history, life complexity, and relationships (Cersosimo, 2019).

The aim of this article is to highlight some results of the humanization process, which can promote over time a "culture of welcome" to be integrated with therapeutic protocols of the healthcare organizations. It proposes to achieve this through a case study[1] that observes the activities put in place at the Bambino Gesù Children Hospital. First of all, the humanization concept will be described in relation to the evidence-based medicine method. Then some significant episodes for the hospital history will be shown, which mark the path of cultural change that led to moving from a disease-centered approach to a person-centered approach. Subsequently, the initiatives that are gradually addressed to patients and their families will be explained. In this way, it will be possible to observe how a "culture of welcome" emerges by stemming from the awareness of single persons and becoming a real integrated system that supports the therapeutic pathway.

Humanization of care, when the invisible appears

The process of humanization of care and the evidence-based medicine approach are affirmed almost at the same time. On the one hand, there is an openness to the relationship with the patient and their involvement as pro-

[1] The needful information was collected through documentary sources to portrait the hospital and its history, through focused interview to 20 key informants (physicians, nurses, hospitality managers who work or have worked at least 20 years in the hospital) to understand the attention payed to the humanization process and through specific data on the hospitality activities – granted by the hospital – to explore what has built about it.

tagonists of the therapeutic pathway, on the other hand, there is a rationalization approach through the application of the scientific method translated into guidelines and protocols for health assistance.

The humanization of care was acknowledged in the Italian legal system between 1992 and 1999 with a reform process[2], in which the principle of regular and continuous monitoring of structures and services to citizens' needs was introduced. In order to assess the qualitative dimensions of the service, a set of indicators was developed, including the personalization and humanization of assistance. The new legislation certifies the change of the health model. It goes from a disease-centered approach to a person-centered approach. In the field of health, humanization means improving the quality and safety of places of care and medical practices. It means reconciling reception actions with the therapies, and it means informing the patients and supporting them in the care pathways. Not only does the patient have a disease, but they are also people with their cultural background and skills (Cilona, 2017).

The illness does not compromise only health, but the whole vital world of the person is affected. The humanization process[3] takes the vision of the entire health system beyond its borders. It took time until it's important was accepted: the dimensions of health emerge from the perception of its absence. Health is noticed when it is lacking (Gadamer, 1994). From its absence, awareness of the plurality of its meanings slowly arises: to the *disease*, which circumscribes the attention to the medical-biological field, are added the *illness*, which widens the set to the subjective dimension of the patient, and the *sickness*, which opens the field to the social and cultural context (Maturo, 2007).

Humanization requires that therapeutic and clinical aspects are not divided by communication, by empathy, by the relational context by the person's vital worlds marked by an event that brings a *biographical break* (Ingros-

[2] The series of reforms began in 1992 with the Delegated Law 421 which concerns many areas of the Italian welfare system, and with the subsequent De Lorenzo reform (Legislative Decree 502 of 1992) which has the aim of reorganizing the National Health System. The last stage is reached in the nineties with the Bindi reform (Law 229 of 1999). In the various steps, some common criteria are applied: the progressive administrative decentralization of the management and coordination functions; the search for greater efficiency in containing costs; the reduction of waste; and the appropriateness of the services for an adequate satisfaction of the right to health of the citizens.

[3] The first works on humanization in Italy (Ranci Ortigosa, 1991, Cipolla, 1989) underlined the multidimensionality of the concept which, in addition to medical know-how, puts the person at the center, with the quality of their psychic and social life as well as biological (Ranci Ortigosa & Rotondo, 1997). However the first document on humanization was written in 1981 by Fra' Pierluigi Marchesi (1929-2002), religious of the Hospital Order of San Giovanni di Dio. He underlined: "Do not look at the sick as a carrier of illness. You look at the disease brought by man, by a person who often loads his psychic damage and, sometimes, the pathology of the spirit on an organ" (Angelucci, 2006).

so, 1999). The disease affects not only the body, but it also affects the person and involves all the people close to them in a dramatic[4] and totalizing experience (Nigris, 2008). Humanization also leads to a personalization of care[5] which considers the patient's identity and interpersonal relationships (Cipolla & Porcu, 1997) and which considers hospitality, reliability of the service, quality of interaction with operators, the presence of voluntary associations and procedures for the verification of therapeutic paths (Agnoletti, 2012). Therefore, humanization and personalization allow us to respond to the citizen-user who aspires to be considered and involved in the treatment path and connected to the healthcare institutions (Ardigò, 1997).

In the beginning, humanization of care has activated - and activates - an action to contrast the process of moving the disease away from society and segregating the patient from his daily life (Giddens, 1991). Thus, society leads to the stigmatization of the patient, to exorcise the diseases and existential questions that this implies (Raffa, 2017). Today, neglecting the humanization process can lead to the bureaucratization and depersonalization of the paths (Giarelli, 2007) and the spreading of a *culture of medicalization*[6], in which all the attention is directed to the pharmacological care and entrusted exclusively to medical technology (Conrad, 2007).

The goal of humanizing care is not to contrast with the clinical path[7] but to enrich its perspectives (Cardano, 2015). Healing requires the awareness that the patient's health depends on the management and execution of the therapeutic pathway. They are, in turn, influenced by many factors: their level of education, their individual and family income, their social background[8], their lifestyle, and eating habits are important because they create the conditions for understanding and following the way to recovery (Sarti et al., 2015).

[4] In the Anglo-Saxon environment, we can find the first studies open to a complex idea of disease. They stress the importance of biographies of sick people and point out the poor knowledge of the *tolerance limits* of the disease for the family and the workplace (Bury, 1982). In addition, they will develop attention to studies on narrative medicine (Kelly 1992, Bury, 2001).

[5] Personalization of care should not be confused with personalization of treatment (which should be called individualization of treatment). With the latter, in the medical environment, we mean the specificity of therapeutic paths tailored to the genetic characteristics of individual patients.

[6] The medicalization process of society - in the writer's opinion - with its consumerist ideology of well-being appears as a new way of exorcising the ideas of death and human frailty and a new way of bringing attention back exclusively to the "disease".

[7] Instead, treatments that do not adopt evidence-based medicine should be reported. They can run counter to the therapeutic pathways and sometimes damage the results.

[8] The relationship between obesity and social distress is an example. A study highlights the relationship between adolescence and obesity. It shows that the effects of the 2008 economic crisis caused a deterioration in eating habits and a decrease in investment in healthcare, and consequently, childhood and youth obesity increased (Cersosimo & Merico, 2017).

Evidence-based medicine has spread in the healthcare system since the early 1990s, as well. Its implementation is required on a formal level by the same reform process of the nineties, described above. The transition from the empirical method to the scientific method was accomplished. The new approach offers the structuring of a clinical practice based on the application of research results, on the production of therapeutic protocols relating to different pathologies, on the development of guidelines and procedures updated consistently. Thus, starting from the diagnosis, the doctors insert the patient into a standardized path that offers the highest guarantees of success (Timmermans & Berg, 2002). The method provides a fundamental contribution to guide and verify the patient's therapeutic pathway. These standards, however, are calibrated on the realities of the subjects and the system involved: patients, nurses, doctors, healthcare facilities, hospital technologies (Mozzana, 2015).

As several analyses emphasize, the humanization process and evidence-based medicine are intertwined; hence, they are not alternatives to one another. In fact, seeking collaboration and dialogue between doctor and patient is important in order to start a course of treatment and create successful conditions (Lutfey 2005). Listening and collecting biographies of patients gain value because they offer more opportunities to establish the best relationship between health professionals and citizens that can also be supported by technological innovations in communication (Cersosimo, 2017). Long therapeutic protocols require the active involvement of patients and their families. This involvement is especially needed when complex diseases are present. People need to become experts to monitor their health conditions (Oudshoon, 2008). The tasks and responsibilities of the patient and their family members are recognized in managing the care pathway (May et al. 2014). It should also be underlined that there is no longer only a patient-doctor relationship. Many other professional figures are included in the care process (Tousjin, 2012). The spaces of collaboration are open to other relationship opportunities and, at the same time, they complicate it: from a doctor-patient interaction to a health worker-patient interaction. It can be deduced that the quality of the interaction is not only the task of the individual subjects. It must become a system action because "having care means participating in the care itself. As a consequence, social and political health engagement should be modulated accordingly. Thus, health professionals can adapt their way of interacting in order to meet patients' needs and inclinations better. Therefore, a shared symbolisms and meanings in daily life are required towards the full integration of patients and care professionals in a conjunct framework where they are even more compatible." (Cersosimo, 2019, p. 313).

We can say that the effectiveness of the treatment is an indispensable element for health, but the humanization process is an essential factor in the therapeutic pathway for the patient's quality of life.

In this framework, the process of humanization of care, integrated with evidence-based medicine, has to take into consideration three points. *The first is the centrality of the person*: we have seen that evidence-based medicine requires interaction between healthcare professionals and the patient who needs to be trained and enabled. *The second is the attention to personal biography*, to the social network, to the lifestyle, that become a piece for treatments. *The third emerges from the influence of the context*: the management and the good progress of the therapeutic pathway are also influenced by the social and economic conditions and by the habitus of the patients and their families, who often become caregivers.

It follows from this that the implementation of humanization should not be entrusted to the will of individuals, but it must be recognized and encouraged in hospital structures.

The humanization of care appears together with the identification of the different dimensions of health and does not require the renunciation of evidence based medicine. As shown in the article, humanization as an invisible ingredient of care becomes increasingly tangible both in the awareness of health workers and in the structuring of a specific reception system for the sick person and his family.

Therefore, the proposed case study shows, on the one hand, the cultural change that has occurred with the slow rootedness of the humanization process. On the other hand, it is highlighted how the culture of hospitality promotes the construction of a welcome system that integrates the assistance system in a hospital focused on evidence-based medicine and considered an Italian and international institution of excellence in care and research pediatric. We want to show that the generally "invisible" culture emerges as a qualifying resource of the therapeutic pathway to the side of the hospital care system.

The case study analysis consists of three steps. First of all, we will observe the development of the humanization process, underlining the attention for the hospitality of children and their families. In the beginning, being welcoming to the child is delegated to the individual duty of every nurse. Later on, it becomes a goal of the entire hospital system to improve the quality of service for families and their children. In this process, the hospital constitutes a "welcome culture." After that, through the interviews with key informants, the diffusion and some dimensions of this hospitality culture are identified. Finally, the interventions carried out to build an integrated system for care services are described.

About "Bambino Gesù": cure (and care for) the sick children

The Bambino Gesù Children Hospital was founded in 1869 when an equipped room was opened to accept four little sick girls. After 150 years, it became one of the most prominent pediatric hospitals in the world. Over time, the hospital was accompanied by the development of pediatric medicine. In 2019, the hospital provided over 2 million outpatients service and over 28 thousand of ordinary acute hospitalizations[9] in its four centers, two in Rome and two in the hinterland of the city[10].

These results have been achieved, over the years, due the continuous attention to innovation and scientific discoveries. Thus, it was able to widen the complexity of the cases treated and to have all the pediatric specializations. In 1985, the hospital was acknowledged as Institute for Research Hospitalization and Health Care (IRHHC). Since 2009 it has been accredited by the Joint Commission International[11] and since 2015 it was acknowledged by the Academic Medical Center[12].

A culture of hospitality emerges in a hospital strongly oriented towards improving the quality of care through research and technology. Its roots are found at the origins of Bambino Gesù and its shape changes along the time.

The hospital history shows, on the one hand, the attention to the person, on the other hand, the transition from the *disease-oriented approach* to a *patient-centered approach*. The Bambino Gesù Children Hospital was created to cure the sick little children. It is the first "real pediatric hospital in Italy" (Burgio, 2011). Before it, children were treated as little adults, and they stayed in the same rooms. Thus, its foundation derives from the need to give specific attention to patients with unique characteristics, different from others. However, in the first *Internal regulation*, it is specified that the nuns and the nurses should always observe an attitude of delicacy and kindness towards hospitalized children[13]. Furthermore, the words contained in the doctors' reports show the attention paid to the child as a new type of patient.

[9] In 2010, the outpatient services were almost 1 million and 300 thousand and the ordinary acute hospitalizations were 23 thousand (OPBG 2020).

[10] Two centers are in Rome (Gianicolo and San Paolo) and other two are in the hinterland of the city (Santa Marinella e Palidoro).

[11] It is an international organization "that certifies excellence in hospitalization and in the quality of care. It is an extremely complex process that places Bambino Gesù in an exclusive network along with the highest qualified pediatric centres in the world" (www.ospedalebambinogesu.net, site visited on 9th April 2020).

[12] For a deeper understanding of the growth related to research, care and mercy in the history of the Bambino Gesù children hospital, see Casavecchia, 2020.

[13] In the hospital regulations, art. 24, we can read: "It will be the duty of every nurse not only take care of children, but also to treat them with kindness and keep them happy. Any intolerance and anger will be severely punished with dismissal" (Rendiconto 1870-1872, p. 13).

"The hospital of sick children for the man of art is worth the meaning of an exercise that implies supreme difficulties. In fact, the diseases of poor children take place in infirm bodies, given the prolonged action of unsanitary conditions; they are often overlooked in the early days of the invasion of evil when this is most recognizable and tameable; not infrequently they are treated in the domestic hovel under the prejudices of ignorance with Cerretano or with the mores of the elderly, and often under the vague surveillance of people who therefore cannot account for the course of the disease. […] If we add to this the oppositive attitude of the children to an exact exploration and practice of treatment, we will have a very rough idea of the nature of the subjects on which my investigations and treatments are dedicated. Really very emaciated subjects, impoverished organisms, acute or almost chronic diseases." (De Blasi, 1873, pp.36-37).[14]

Two attitudes become clear from the excerpt extracted from the first medical report of the hospital: firstly, the interest in fighting the disease leads to neglecting the peculiarities of being a "child", and fails to highlight the child as a sick person. Secondly, the family and social context of hospitalized children are considered as an obstacle to the treatments. When pediatrics originated in Italy, the path taken, on the one hand, intended to alleviate the conditions of hospitalization with a welcoming style - and this was delegated to the nuns and the nurses. On the other hand, it raised a wall of separation between the healthcare space and the daily-life space, as to family relationships. These attitudes persisted for a long time. A song written in 1933 testifies to this. It tells of the hope of a father waiting in front of the hospital gates. He looks inside for signs, but cannot enter. He waits for news of his sick son.

Exceptional visits were allowed only to the mothers of patients near death. The first changes were introduced in the early 1980s, but are not initially accepted willingly. An episode told by the former hospital president explains the impact of the change:

> I authorized the presence of the mothers 24 hours a day. It was a revolution, which created real dramas in the nuns. Poor women! They came from the tradition where the child was swaddled in bed. I remember a nun who had put beautiful plants in the corridors. One day, passing, I said to the head nurse: "Beautiful plants. So, how do the kids run here?". The nun took offense. Afterward, I went to the convent asking to change the mentality because the children had to have the possibility to move.[15]

The change was initially traumatic for all the hospital staff. Extremely remarkable is the testimony of Franco Martinelli, the doctor who tells the first documented history of the hospital:

[14] Translated by the author.
[15] Interview to former President of Bambino Gesù children Hospital (1978-1992).

> "The first decision, perhaps the most important, was to open the doors to parents of hospitalized children. This decision, however legitimate and human, faced up to many obstacles. The strongest disapproval came from us doctors, who suddenly realized we were being watched and checked by parents. Until then, physician and senior nurses had managed their departments unquestionably. Many points of friction arose when the mothers began to meddle. Then, we understood that no one observes a child better than his/her mother, and we realized that the negative sides of hospitalization were reduced. We understood that the humanization of the hospital was the most crucial step to development."[16] (Martinelli 1990,p. 232).

His words show, on the one hand, the instinctive reaction of the health workers who considered the presence of family members an intrusion. On the other hand, Martinelli wrote that humanization was the "most important" decision for the time[17]. The subsequent acknowledgment derives from the contribution to the care of people who know the patient well, even if totally unprepared in the field of health.

After this first step toward humanization, the attention is paid to the organization of recreational activities for patients who have to stay in the hospital for a long time. Towards the nineties, structures dedicated to reception were created, also under the pressure of the reform process of the National Health Service. In 1999, the "Charter of the rights of children in hospital" had been drawn up together with other pediatric institutes: some commitments were formalized, for example: "the right to receive comprehensive information on diagnosis, therapy and prognosis in accessible and understandable terms"; the commitment to "build friendly relationships with the family and the child, thanks to the work of the volunteers". Two years later, the Public Relations Office - in compliance with the law - and the first hospital playroom are inaugurated. Pedagogists and educators are hired. The game begins to be considered an activity where it is possible to get information on the person's state of well-being and his health condition.

The culture of welcome

The development of humanization of care leads the hospital to foster a "culture of welcome" within its organization. The information obtained from some biographical interviews[18] (Bichi, 2011), collected for a research project

[16] Translated by the author.

[17] The affirmation is strong because – in the same period – the hospital becomes IRHHC (1986) and introduces – for the first time in Italy - the organizational structure of the departments (1982), which today is the rule in hospitals.

[18] The track of the interview is structured in such a way as to stimulate key informants to tell about their experience in the hospital, the changes caused by discoveries and innova-

dedicated to the 150-year celebration of the Bambino Gesù hospital, is used to identify the dimensions of this 'welcome culture.' There are four of them: the attention to the whole person, the centrality of the family, the importance of parents training for health issues, the attempts to offer a support network to the child's family.

Attention to the person emerges from several interviews. Here, a doctor underlines the changes experienced during his work life. His professional growth is not single-handed. Collaboration with other professional figures allows him to see different points of view:

> We have grown up with the staff, and the ongoing comparison with them. We start our mornings with a coffee with the staff while we discuss all the cases. There are nurses near us. We don't just discuss the clinical aspects, but we discuss the human, existential aspects of the problems that parents might have and their feelings.
>
> (Doctor, 39 years in the hospital)

Human aspects and clinical aspects go hand in hand. Another respondent talks about a "multidisciplinary approach"[19] for analysing cases. The interviewees pay close attention to the patients' psychological and emotional dimensions, their motivations, and their expectations. An interviewee proudly states: "my department was the first to introduce psychologists to help patients and parents" [20]. Even the importance of playing, for the little patients, is highlighted: "I remember thirty years ago when the first play assistants entered with the task of going to the children's rooms and organizing activities. For long-term patients, it is an essential service"[21].

The interviewees also speak of the need for caution during interviews with parents and children: "We must be able to adapt to the people we deal with because everyone has their own culture. Not only are people from Northern and Southern Italy different, but we also have people from other countries"[22].

Moreover, the attention to the person as a whole is stimulated and also facilitated by the new technologies. Another interviewee clarifies:

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tions that have taken place in their profession, the change in relations with patients and their families, their prospects for future compared to the mission of the hospital. The Bambino Gesù Children Hospital has indicated 20 health workers among doctors and nurses with more than twenty-year service. The interviews were conducted for a study commissioned by the hospital to mark its 150th anniversary. Although the sample number of respondents was limited, it was possible to reach the saturation of information. Their interviews allowed a reconstruction of the changing process that the hospital has gone through, described in "L'ospedale dei bambini" (Casavecchia, 2020). Some parts of the biographical interviews allow to develop the theme of hospitality in relation to the processes of humanization of care.

[19] Doctor 40 years in the hospital.

[20] Retired doctor, 38 years in the hospital.

[21] Doctor, 40 years in the hospital.

[22] Doctor, 27 years in the hospital.

> […] because the child has a playful approach to technological tools and doesn't need any specific purpose to use them. Nobody can force others to learn. Technology is particularly important for a child who may be suffering from a birth injury. We get to see them when they are 4 or even 8 years old. Therefore, they are tired of going through rehabilitation treatments, and therefore motivating them to go to the gym and to accept the treatment becomes difficult; with these systems, however, we have them "on our side"
>
> (Doctor, 20 years in the hospital).

The centrality of the family is the second topic. The acknowledgment of the role of the parents, of their children, of the relatives emerges in its centrality. A doctor says:

> When I arrived at the hospital, there were dormitories with ten beds. Relatives and mothers were not allowed to stay with their children. […] Now, however, everyone is in the departments. It was a different way of welcoming. In pediatrics, we do not only treat the child. When the child gets sick, the family gets sick, and sometimes there are tragedies inside the family. Be aware that when a child is seriously ill, the episode reinforces family ties or causes the family to break out.
>
> (Retired doctor, over 40 years of work in the hospital).

While explaining that many complex cases are being treated in the hospital, a doctor says, "Parents need to understand what is happening to their child"[23]. In the relationship, there is collaborative research. A nurse says: "We need to listen, to stay close because the relationship between parents and children is special. It becomes part of the care"[24]. Another nurse explains: "There are particular moments, where there is a need for a hug, a caress, a smile. Even a smile is therapeutic, even for ourselves"[25]. The learning path that led to knowing the role of the family has not been forgotten:

> We no longer take care of the child, but take care of the whole family: child and family. […] Training, self-conviction work was done, and a great benefit came from it because it was possible to accompany the parents even in moments of pain. Besides, parents give a hand in identifying the needs of their child because they know them very well.
>
> (Sister, 30 years in the hospital).

The contribution of parents is also visible in the monitoring of children's health. They provide feedback to understand the reactions of their children to the treatments. A nurse explains:

[23] Doctor, 20 years in the hospital.
[24] Nurse, 32 years in the hospital.
[25] Nurse, 25 years in the hospital.

> For the effectiveness of the treatment, for us, the presence of the mother in some way helps us. Also, in the symptomatology: a mother describes a change of attitude of her child better than we strangers could. The presence of the parent is constant. This allows a more relaxed relationship with family members, because parents know us and trust all the procedures more
>
> (Nurse, 39 years in the hospital).

Then the study highlights the importance of the space that has been obtained for the parents within the departments:

> My department was one of the first, if not the first, to have a bed for mother or father. We even went to choose this bed because it had to be a comfortable bed. […] Clearly, because the family is in the hospital, they must be welcomed in the hospital.
>
> (Doctor 25 years in the hospital).

The third topic dealt with is the importance of parents training for health issues. Parents need to enter a new social space. From the interviews, the attention to guide them emerges. Sister[26] says: "There are parents, especially those who come from the emergency room, that must be taken by the hand." During an interview, a nurse tells us: "We happen to meet scared dads and mums. When we start giving them small tasks, they focus on what they have to do and calm down a little"[27] Another asserts: "We often explain therapies to mothers and teach them how to do it"[28].

The family must also be accompanied in the process of getting familiar with the "hospital system" and in the acquisition of the critical ability concerning information opportunities on the treatment. In this case, healthcare professionals have an orientation function:

> A crucial moment was the transition from a doctor-patient relationship to a team relationship. The first was a situation in which everything was resolved within the doctor-patient relationship, i.e., between the pediatrician and the child and his/her family. This change, of course, has important consequences. […] Everything becomes more complicated when you have to take care of a team. Sometimes the parent begins to struggle to understand "who" has to take care of the child. So, someone who has the ultimate responsibility of the child care (care manager or caregiver) is always needed, because otherwise the parent is lost.
>
> (Doctor 30 years in the hospital).

[26] Sister, 40 years in the hospital.
[27] Nurse, 32 years in the hospital.
[28] Nurse, 28 years in the hospital.

An example of accompanying families in the process is the momentous change occurred in the nurse figure, which parents must acknowledge:

> A fundamental aspect is the radical change in the role of the nurse: in the past, they were simple performers; today, they are no longer that. Now, they are the ones closest to the child. The nurse is an active protagonist of pediatric care, guarantees appropriateness and quality of care, and continuity of care, from the care point of view.
>
> (Doctor 30 years in the hospital).

In addition, healthcare professionals take on a family empowerment task, because the possibility of curing complex diseases requires long times, during which the children will not be in hospital:

> The so-called complex diseases require constant and continuous care, both in the hospital and at home, and hence the engagement is necessary. The patient must be adequately prepared and informed - the patient and, of course, those around him. Some children are, in fact, partly informed about their needs, but above all, it is parents who carry out the fundamental task. This aspect is unavoidable in the case of chronic diseases because neither the doctor nor the nurse can always be present.
>
> (Doctor 30 years in the hospital).

The attempt to offer a support network to the child's family is the last topic. On the one hand, spontaneous support actions are carried out. A nurse tells us about her colleague, who accompanied a little girl for walks when her parents were unable to come to the hospital[29]. In another interview, it is noted that some nurses were concerned about bringing "something to eat"[30] to a mother who did not move from her child's side, and one of them recalls: "We once heated some food here in the ward for that mother"[31].

On the other hand, cases emerge that show the importance of an organized network: "when the animator arrives he is very happy"[32], says a nurse referring to a child who cannot get out of bed. In another interview, it is stated: "For patients who are staying with us for some time, school time and play activities are strong stimuli"[33]. Furthermore, a doctor adds: "Offering complex patients the possibility of being hosted in a family home near us helps them get away for a moment"[34]. For the interviewees, the task of treatment does not end within the boundaries of the hospital: two interviews indicate this attention. Great importance is given to the organization of a territorial network that allows

[29] Nurse 30 years in the hospital.
[30] Nurse 27 years in the hospital.
[31] Nurse 25 years in the hospital.
[32] Nurse 27 years in the hospital.
[33] Doctor 35 years in the hospital.
[34] Doctor 20 years in the hospital.

the family to assist the child both during the hospital phase and in the second phase, when services will be needed near the child's home.

> The center is designed as a "second home" for users. You have your own room, and the kitchen is shared. So, there is an opportunity to socialize. People come from all over the world but also from different Italian cities, from North to South. There is a diversity of cultures. You can watch them cook together, using the same kitchen. In each room, they find their own dishes, their own things, but in the evening, they come together to cook - obviously, for those who want. Some patients stay for 3-4 months, sometimes even longer, so they don't want to leave anymore!
>
> (Office worker[35], 20 years in the hospital).

> The link with the territory is essential because it is a team effort: we do the specialist-hospital part, limited in time, but the cares on the territory are the most extensive part. In Italy, rehabilitation is divided into the intensive phase, the hospital one that we do, and the extensive one, on projects of 1-2 even 5 years, which carries out the territory with services near the home of the child.
>
> (Doctor, 20 years in the hospital).

In the interviews, different meanings are attributed to being welcoming: it means considering the different dimensions of a person, enhancing the centrality of the family and the importance of strengthening skills to improve the quality of care, and finally offering the conditions so that parents can be close to their children. The awareness of the full meaning of being welcoming encourages the growth of a "culture of welcome" and allows the development of a system to achieve it.

The Welcome Therapy

Fragility, fear, and loss are the feelings perceived when you get in a hospital. People with green, white, and blue coats move resolutely and quickly, while you repeat the instructions you have received in your mind, so as not to get lost. You are a foreigner in a structure that should host you, and you are in front of people who should help you to heal. These are the feelings that little patients and their families experience when faced with hospitalization.

[35] In the wider study (Casavecchia, 2020) carried out for the celebrations of the 150th anniversary of the hospital, it was also possible to meet some employees. It seems significant to insert a sentence from one of them, which shows attention to being welcoming even when it is not directly the topic of the interview. It is an indicator of the widespread culture of the humanization process of care in the different members of the hospital community.

The goal of a welcoming system is to try to decrease this sense of vulnerability. The head of the reception of the Bambino Gesù Children Hospital states:

> "My professional experience as a doctor has increasingly convinced me that family care is a necessary part of treatment. Conveying a feeling of being cared for enables a 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 meaningless, and that the parents' presence in helping and aiding their child's therapeutic pathway must be integrated. [...] 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 high impact emotionally. All these factors are sound reasons why one should adequately support the patient and his relatives during their stay, in addition to their standard clinical treatments." (Celesti, 2015, p.25).

The "welcome therapy" is illustrated with three main elements: the importance of supporting the critical issues of families, the value of playing to activate the resources of children and teenagers, the family-centered care. To describe the philosophy, Celesti and Raponi (2017: 30) write: "Welcoming is already curing." Welcome Therapy becomes a parallel path to assistance. Based on the actions implemented by the hospital, we can highlight the peculiarities of the system. The data relating to hospitality show the dimensions of this system that ranges from playrooms to schools, from family homes to cultural mediations. They can be described by placing them within three different stages (tab. 1).

Table 1 - Welcome system main activities

Stage	Activity	Starting year	Users	Frequency in 2019	% increase or decrease over the past 5 years
1	Freecharge accommodation	2008	Families	5569	58,5%
	Cultural mediation service	2008	Children / families	8700	115,5%
2	Playroom	2000	Children / teenager	26045	-12,5%
	School	1978	Children / teenager	3569	80%
3	Social service	2000	Families	1926	1,5%
	Social service (Hard-discharge)	2010	Families	31[36]	10,7%

Data provided by the Health Department and Communication Department of the hospital

[36] The data refers to 2018.

The data in tab. 1 shows the increase in the number of patients and families who use different services. In addition, the different years in which the activities started indicate the commitment to vary the offer of initiatives to cover different dimensions of reception. There are three stages regulate Welcome Therapy:

Going to meet: it collects direct actions to create the conditions for good hospitality - cultural and linguistic understanding, personal knowledge, accommodation

Hospitality: it offers services to improve the quality of the daily routine.

Supporting: it provides service to attend in the presence of social or psychological problems.

Going to meet is the first stage. A sequence of actions is carried out to accompany the admission of children and their families into the hospital. *A reception service* contacts the family before a planned hospitalization and checks their needs (accommodation, social assistance, cultural mediation, e.g.). When the family reaches the hospital, they find a tutor who is informed about their needs and the clinical case. The tutor describes the hospital's facilities and services, then accompanies the new arrivals to the ward and presents them to the healthcare personnel. During the period spent in the hospital, the family is supported by a volunteer who provides information and logistical support if necessary. The project has been active since 2012 and involves 2211 volunteer tutors (an increase of 98% in the past 5 years).

Another service has started to help *search for accommodation* when a family has to move to Rome to take care of the child. The hospital promotes a network of family homes and hotel beds. Freecharge housing provided by non-profit institutions and hotels is offered for families in need. «The Hospital evaluates access to these services based upon specific criteria, with an eye to giving greater help to those who most need it, both due to distance from their place of residence and family income, the pathology of the child, the length of hospitalization, family composition» (Social report, 2016: 31). Finally, *a cultural mediation service* is offered for foreign children and their parents. The cultural-linguistic interpreting service is active for over 100 languages. Telephone and on-site mediation are possible. Cultural mediators help families integrate into a new context and help health professionals to understand cultural habits and to evaluate needs expressed.

Hospitality is the second stage. The goal of Welcome Therapy is to provide, as far as possible, place time and rhythms of a normal life.

Playing is a right. Also, it is considered an integral element of the therapeutic pathway: «Creativity and play are tools through which it is possible to structure a relationship with the outside world, express and communicate feelings, control situations, reverse roles, express aggression, actively re-enact what had to be experienced passively» (Bilancio sociale, 2018: 46).

Playrooms welcome children with their sisters and brothers; moreover, a "Space time out" is dedicated to teenagers. There they can meet, read and watch movies together. In the hospital, there are professional educators who participate in the design of rehabilitation plans and who provide advice in the wards.

Studying is a right too. The continuity of the school path must be guaranteed to children and adolescents who are hospitalized for a long time and who need constant care. The hospital environment requires a specific curricular, didactic, and methodological plan. There are many single students and some small groups made up of boys and girls of different ages. The teacher is itinerant and must coordinate with the professional figures who work in the hospital. *Some facilities have been dedicated to parents*. A comfort area for breastfeeding mothers; a "parents' room" to offer a relaxing environment in which to read, use the PC, participate in recreational activities; a room to welcome the parents of emergency hospitalized children, at night. A laundrette for washing and drying the clothes of the child and the parent who sleeps in the hospital is available.

Supporting is the third stage. In the reception system, there are some services for social and psychological help. There is a *Counseling* to support parents and relatives. Some counselors activate help relationships through the interview method. The receptive ear of the counselor promotes the externalization of emotions and a better awareness of one's resources. There is also a group of mutual help led by moderators to encourage the narration of biographical experiences and the gathering of people who face similar problems and can compare how they manage them. All these activities promote people's empowerment. The service started in 2011. The meetings organized with parents were 179 in 2019 (an increase of 358% in the last 5 years).

The social service has set up various interventions to alleviate the socio-economic difficulties of some families, from the activation of the housing network to the advice for the search of financial support (through patronage), to the guarantee of rights of parents and family members during the hospitalization their children. Furthermore, social service plays a role in the connection between the resources of the territory and the needs of the family. Finally, help is offered in the delicate moment of the discharge of children suffering from serious or chronic diseases. In these cases, an integrated health care service is activated, so that parents are not left alone to face the fatigue of treatment.

Conclusions

The Welcome Therapy becomes a metaphor (Lusardi & Tomelleri, 2016) that communicates the image of a system that integrates the medical assis-

tance dimension with the social-psychological assistance dimension. This metaphor allows conveying the image that "care" goes hand in hand with "cure" inside and outside the hospital community.

The three illustrated phases highlight a path leading to being closer to the patients and their families. They are designed to accompany them from the moment of planning the hospitalization to their discharge. Welcome Therapy is supported by a culture widespread among healthcare professionals. It has taken root over time through the process of humanizing care. This culture facilitates healthcare professionals to understand the importance of a relationship with patients and their families and makes them available to share their ways of interacting (Cersosimo, 2019).

Thus an "invisible" structure emerges, which fosters attention to the centrality of the person and their family through individual behavior and through the offer of specific services. Welcome Therapy becomes a factor that contributes to applying the evidence-based medicine therapy pathway, which addresses increasingly complex cases and requires children and their families to become active protagonists.

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