

SPIRITUALITY FOR A COMMUNITY CARE. THE EXPERIENCE OF BAMBINO GESÙ CHILDREN’S HOSPITAL

Andrea CASAVECCHIA ¹

Abstract: *The healthcare system becomes a field of investigation in the search for spirituality, when the human weakness encountered in illness questions nurses and doctors, children and their families about the meaning of life. The paper aims to analyse a case study of Bambino Gesù Children's Hospital. This holistic method allows to interpret statistical data, narrative methods, and participants' perspectives. The findings underline an original interaction between evidence-based medicine methods, the humanisation of care and the role of spirituality.*

Key words: *spirituality, welcome therapy, children, community care.*

1. Introduction

Care is not only an action. It is a peculiar relationship in situations of vulnerability and fragility that can open questions about the meaning of life. The paper addresses the topic of individual and communitarian spirituality in a paediatric health care system.

The impact of spirituality emerges in different areas of interest (Balboni et al., 2022): some studies emphasise the usefulness of meditation or relaxation practices to reduce stress in patients, especially children, with chronic diseases (Darvishi et al. 2020), other studies underline the importance of acquiring skills in spiritual care for nurses and midwives (Attard et. al. 2014), and others show the impact of the spirituality on professional commitment and caring (Chiang et al. 2016). As others have noted (Sloan, 2006), attention to spirituality does not replace the scientific medical approach, but it can support the care relationship that encounters painful paths and possible fragilities. This research observes the emergence of spirituality in the life of “little patients” and healthcare workers, and how it can become a resource for dealing with the pain. The relationship between evidence-based medicine methods, humanisation of care and emerging spirituality is analysed through the case study (Harrison et al. 2017) of the Bambino Gesù Children’s Hospital (BGCH). The data collected shows the role of the humanization of care approach to build community care that becomes a generative field for spirituality.

¹ *University of Roma Tre*, andrea.casavecchia@uniroma3.it

2. Spirituality and its effects in the Health system

The attention to spirituality in the healthcare system (Timmins et al., 2022) grows in Western society, where secularism (Davie 2023) encounters new and traditional forms of spiritualities (Palmisano, 2017). In this cultural contest, if the bonds of institutionalised religions tie people less, spirituality becomes a central ingredient for life since it can include the dimensions of experience, community, and transcendence.

This form of spirituality can also take an individualised form. Personal experience is the field of understanding the truth and the criteria to address the search for self-realisation, which shapes a religion of heart (Watts 2020), where feelings and sensations are the basis for verifying one's authenticity and guarantee the attainment of individual freedom in the balance between mind, spirit, and body.

The close link between well-being and the search for meaning in life opens a space to develop the care for spirituality and health to achieve harmony between mind, body, and soul (Lalani, 2021). Studies show that concern for patients' spiritual needs and lives improves treatment. This attention is an aspect of holistic care (McSherry et al., 2021). Patients' well-being increases when spiritual-care-sensitive healthcare workers are present (Karaman, 2021 et al.): significant effects are found in good quality of care (Kudubes, et al. 2021) and in the creation of community care (Lalani et al. 2021). Although doctors, nurses and health workers try to improvise due to the lack of specific preparation, for example, during the Covid-19 pandemic emergency (Carry, 2021), the need to intervene in spiritual and pastoral care became increasingly widespread (Chirico & Nucero, 2020).

3. The case study

This research aims to observe the relationship between illness, spirituality, and well-being in the therapeutic path by collecting data from the experiences of healthcare workers, children, and their families in a specific healthcare system – the BGHC.

The research path was directed towards a case study (Harrison et al. 2017: 4) “as a valid form of inquiry to explore a broad scope of complex issues, particularly when human behaviour and social interactions are central” to understanding the research questions and findings (Merriam, 2009).

The hospital can be considered a social field (Bourdieu, 1979), where multiple dynamic energies converge that arise from little patients and their families, from health workers and researchers, from the administrative structure and stakeholders, from volunteers and pastoral workers, but also from the rules and norms of the national and supranational legislative systems, and from health system protocols to nutritional standards. We can interpret statistical data, narrative methods, and participants' perspectives to understand practices, processes, and relations with the case study (Harrison et al. 2017).

The researcher was able to visit and spend time in the hospital for two years; during this time, he got to know the healthcare workers, the organisation, and the structures, guided by the BGHC Communication Office. Various sources were used to intercept the complexity of data: the institutional page on Facebook; publications relating to healthcare and scientific activities and the hospital's social budget from 2018 to 2023;

participants' observation between 2018 and 2019 on the initiatives organised to celebrate the 150th anniversary of the foundation of the hospital; semi-structured interviews with 20 healthcare workers to intercept the transformations in their professional biography in the hospital and an analysis of documentaries made by Rai and Stand by Me between 2017 and 2023.

4. Results: became a community care

The BGCH is the social field in which it is possible to match the humanisation of care, the evidence-based medicine approach, and the relationship between religious practice and spirituality. The hospital is included in the Italian Health System (L.502/1990), but it is a property of the Vatican City State, recognised by the 1929 Lateran Treaty between Italy and the Holy See State. Since 1995, BGCH has been accredited as an Institute for the Care of Research and Health Treatment; since it has been acknowledged as an Academic Hospital by the Joint Commission Academy, the leading international certification institution in the international context, since 2006 (Casavecchia, 2020b).

Every year, the BGCH system, which has six different locations in Rome and its hinterland, carries out over two and a half million outpatient services, more than 32 thousand surgical operations and over 300 transplants. It stands out as a national and international centre of excellence: its healthcare system includes all medical specialties. It is the only European centre that can respond to all paediatric transplant needs and is a full member of the 15 European References Network of the EU. Its scientific research activity is relevant both for clinical studies where new prevention, therapy and diagnosis approaches are promoted and for the Pharmaceutical Workshop (the largest, good manufacturing practice facility in Italy) where medicines for therapies are generated advanced on gene-therapy (OPBG, 2023). This hospital is analysed as a community care through two dimensions: the application of the humanisation approach in the organisation of health structures, and the presence of the spiritual dimension inside a caring relationship.

4.1. Humanisation of the care toward the community care

A post on the Facebook BGHC page notes the words of a mother:

A sound healthcare system can be seen not only from the professionalism and innovative tools but also depends on the humanity of the operator and the serenity of the patient [...] kindness, patience, sensitivity, attention are difficult to measure, but they make a difference» (parent, f, BGCH fb page).

This parent shows the need to keep together the effectiveness of care and the attention to people. The process of humanisation of care and the institution of evidence-based medicine intertwined between the 1980s and 1990s of the twentieth century. Both changes affect the assistance system's processes, leading the hospital institution and operators who perceive themselves as a community of care (Casavecchia, 2020a). The evidence-based medicine method links the high professionalism professionalism of workers, the excellence of research and innovation accredited by the international

scientific community, and the therapeutic pathway certified by medical organisations (i.e. WHO), as proved by the international awards received by the hospital. The humanisation process requires the healthcare system to see patients as people in the complexity of their lives and relationships (Cersosimo, 2019). A person's health conditions involve the biological-medical field, the subjective-psychological dimension, and the socio-cultural context in which they are included (Maturo, 2007). At the same time, the institution of the evidence-based medicine approach leads to the production of increasingly personalised therapeutic protocols. The physicians propose standardised paths calibrated to every single patient (Timmermans & Berg, 2002). In different ways, the humanisation process and the evidence method place the person at the centre of care and direct the hospital to take on the appearance of community care. The statements in the interviews of hospital workers who have lived these changes describe the effects of the transformations. A doctor explains how introducing evidence-based medicine helps direct the diagnosis without tiring young patients with unnecessary therapies.

Some time ago, our attempts were based on experience, based on trial and error [...] Now we know what we need exactly, what is instead useless, and what is potentially useful, although we do not have scientific evidence yet. There is a "scientific rationale", and we base our rehabilitative intervention on that. (Doctor, m., 20 years in BGCH).

Another doctor highlights how the introduction of integrated analysis in complex diseases leads to care based on the intensity of the health assistance:

It was a small revolution: it meant that children were not hospitalised based on the type of illness they suffered from, but on the intensity of the required health assistance; [...] This change implies "breaking down the walls" between the specialised units, which no longer exist and are transformed into teams (Doctor, 30 years in BGHC).

The same doctor notes the enhanced role of nurses who have become professional workers responsible for therapeutic paths:

Previously, the nurse was a simple executor; today, it is no longer like that. They (nurses) are the closest people to the children, and they guarantee the appropriateness, quality, and continuity of care. The nurse becomes an active protagonist of paediatric care, and that would have never been imaginable just thirty years ago (Doctor, m. 30 years in BGHC).

A psychiatrist underlines that complex diseases often become chronic, and treatment paths must include the involvement of various professional figures:

The concept of quality of life has entered the evaluations of the results of our treatments in a preponderant way. So, we provide a multidisciplinary approach that was not there before. The figures of the psychologist, the social worker have emerged, and the role of nurses has changed (Doctor, m. 35 years in BGHC).

Medical science shifts attention from the disease to the patient and requires a new engagement from every healthcare worker. A new realisation becomes established: the disease affects the whole person and involves the people close to them. This awareness leads to the humanisation of care. Greater involvement of patients and their families is required for at least two reasons: to make them responsible for following the

therapeutic plan and to encourage their participation in the treatment process.

There are two aspects to consider: to give the patient even greater empowerment and to know how to distinguish between involvement and competence. The health workers have responsibilities for the child's life. [...] there must always be a dialogue, never a monologue, neither on the part of the doctor nor on the part of the patient. (Doctor, m., 20 years in BGHC).

It is understood that when a child is sick, the whole family is sick.

The whole way of caring for children had been reconsidered when the family was admitted to the hospital. Now, we no longer take care of the child, but we take care of the entire family unit: child and family. (Nun, f., 40 years in BGHC).

The humanisation process also changes the relationship between healthcare workers, patients, and families. There is an openness to dialogue and an attitude of listening to the needs of all parties. This attitude improves the quality of care.

The continuous presence of the mother is a way of trying to mitigate the impact of the child's hospitalisation. When I started working, mothers couldn't be there. So, the children were scared and felt alone. [...] The presence of a mother helps [...] She describes better a changed behaviour of the child that we would have never been able to notice. Parents' presence allows a more relaxed relationship. (Nurse, f, 40 years in BGHC).

The BGCH has built a welcome system as it appears in the story of an administration employee who describes the network of the guest families:

The structure is conceived as a "second home" for the users. They can have their room. They can share the kitchen. So, there is the opportunity to socialise. People come from all over the world [...] There is a diversity of cultures that meet and cook together, using the same space. (Worker, f., 33 years in BGHC).

Over time, the hospital has built a welcome system (table 1). It aims to accompany and guide patients and their families throughout the hospitalisation path.

Welcome system in Bambino Gesù Children Hospital

Table 1

Stage	Activity	Users	Frequency in 2022
1	Free of charge accommodation	Families	2705
2	Cultural mediation service	Families	8369
		children	
3	Playroom	children	14997
4	School	children	3624
5	Volunteering	Volunteer	750
		Family association/accredited association	51

¹ Data provided by the sustainability report of OPBG (2023).

The welcome system is organised to support the fragility of children and their families with person-centred assistance. The services aim to create the conditions for quiet access to the hospital, improve the quality of daily hospital care, and support people

through playtime, school, psychological assistance, and social work (Celesti, 2015; Casavecchia, 2020a).

Welcome therapy is a path that patients and their families start in parallel with the clinical path. Its design was conceived, structured and organised to soften the impact of hospitalisation. Within this space, the presence of chaplains or spiritual assistants of different religions, psychologists, music therapists, pedagogues, and counsellors can become strategic to improve relationships.

4.2. Spirituality in a community care

A system based on a person-centred care system creates a positive background for the growth of a spirituality that arises from experience and relationships. We can observe this in the statements of some healthcare workers interviewed and some young patients and their parents, which were detected indirectly through the analysis of Rai documentaries and the posts published on the official social pages of BGHC.

Disease characterises the biography of people involved in the research. Various experiences indicate the meaning in the face of suffering: a mother who recounted her experience of isolation and uncertainty when she experienced hospitalisation with her daughter positive for COVID-19, says: «For me, it was a walk to hell and not even that fast» (parent, f, Season 3 Episode 5, min: 4' 33"). "Hell" is her vision of the period. When she lived in a hospital room, she only met healthcare workers wearing masks and other protective measures, and she only had one connection to the outside via her cell phone to talk to her husband. The suffering of children and young people who faced the disease is visible in the images of crying, which show fear and raise questions of meaning. They are summarised in the words of a 14-year-old girl awaiting a heart transplant: «I still can't explain what happened to me, and I don't know if I ever will» (patient, f, Season 1, Episode 1, min: 9' 15").

Uncertainty is a constant topic – parents feel powerless since they cannot help and protect their children. It is also present in the risky choice between life and death that they must take. The parents of a child with frequent epileptic seizures who will undergo neurosurgery ask themselves: «What is the right thing to do? » (parent, f, Season 5, Episode 3: min. 9'18"). A 14-year-old boy who will have to undergo surgery to replace a heart valve asks himself: «A surgery will change you, but how will it change you? I'm scared because I think that when we die, we sleep, and we can't wake up for all the years until someone – I don't know who – decides to let us live» (patient, m, Season 1, Episode 3: min. 20'51").

The space of uncertainty and doubt opens to silence, crying, anger, and prayer as it emerges, for example, from the sentences of a grandmother and a mother: «As a grandma, as a religious woman, I started praying intensely: Lord, give me a sign, and I saw a butterfly passing by me. My daughter prayed next to me and said: "Lord, give her back to me, give her back to me» (relative, f, Season 5 Episode 3: min. 28,50"); «I remember, I had a rosary in my hand, and I was praying: Don't take her away! In the end, I broke the rosary with all the strength I had. I doubted: who knows if Jesus exists? And then, that night, he saved her» (parent, f, Season 5 Episode 3: min. 28' 54").

The experience of faith can be reassuring, as one mother declared: «I was terribly afraid, but I have great faith that helps me. I hope my son can face everything» (parent, f, Season 1, Episode 1: min. 3' 30"). Furthermore, parents say they feel an unknown energy never felt before. It emerges when they assist their child. A dad says: «When I go to Bam-bino Gesù and see Laura in the incubator, I feel the strength that she projects on me. It's something that makes me feel privileged» (parent, m, Season 3, Episode 4: min. 10' 50"). All these people live in a state of uncertainty, but, at the same time, they are forced to make a risky decision. In their doubt, hope is born.

Finally, the experience of illness and suffering, which sometimes ends with moments of joy, leads to reconsidering the meaning of life. Two fathers explicitly state this. The first one, who experiences a condition of constant insecurity, says: «I start accepting what happens in my life from the moment I open my eyes in the morning. I live one day at a time, I live the present, and I don't think about the future, too much» (parent, m, Season 5, Episode 2: min. 41'41"). The second one notes that his son's illness was a life lesson: «I imagined I could snorkel, play football with him. I would have liked to do the same things all dads do with their children. Then, when he was born, all my thoughts and all the fantastic castles I had built for myself collapsed. I understood how to live: one step at a time. I think about what must be done every day. It was a painful and good lesson because it took me eight years to reach this conclusion. Today, I can say I'm happy» (parent, m, Season 4, Episode 1: min. 47' 50"). Also, the experience of death becomes transformative: posts on the hospital's FB page are significant. In the first one, a dad notes: «There are no reasons. There is no explanation. There is only a big vacuum. Nothing can take away from us the memories, the happiness, the laughter, the tears, and the hopes that have accompanied us over that month. We have been together and will be together forever» (parent, m. BGCH fb page).

Even healthcare workers reveal acts of faith in moments of uncertainty when faced with decisions about life or death. The words of a cardiac surgeon who is going to engage in a heart transplant are meaningful: «It was a tough choice, and a decision had to be made... and I made it: transplant, and may God deliver us (silence). It is always difficult because you can perform a transplant, but then there's a rejection (silence), and the patient dies (silence). But then, just when she started having complications, the heart arrived (silence). She is very lucky» (doctor, m., Season 1, Episode 2: min. 23'40"). Spirituality also emerges from the interviews of healthcare workers. Another doctor states:

The technical part is undoubtedly essential; otherwise, children do not heal. But the heart is also important. In my opinion, the heart is an essential component. Parents feel that a person should have empathy and the ability to perceive their child's pain and suffering and put himself entirely at service, besides being a professional. (Doctor, m. 20 years in BGCH).

Spirituality emerges from relationships. As highlighted by a nun who reflects on the effects of community care that bring parents and healthcare workers closer together, relationships became a space for spirituality:

There was an exchange, a mutual gift. [...] For us, living in the hospital is a gift because we receive a lot from these mothers who give themselves incessantly. [...] They let us enter a relationship in order to be able to help them, to share the pain they were experiencing until the culminating moment which was the death of their child (nun, f. 30 years in BGCH).

In the world of health workers, it is possible to identify another topic: the role of the ecclesiastical institution within the dynamics of spirituality. We noticed this on several occasions: a doctor highlights the importance of a bishop's visit to a hospital site and clarifies how that event contributed to creating an exceptional climate:

This year, there was a mass celebrated by Mons. Reali who came here for Holy Thursday. He washed the feet of all our twelve hospitalised children (in the hospital premises of Santa Marinella). [...] There was a beautiful atmosphere of love, affection, and tenderness, which I still remember as beautiful, and I believe it has remained in everyone's hearts (Doctor, m. 20 years in BGCH).

Another doctor remembers the visit of Pope Benedict XVI to the hospital and under-lines how his words offered the opportunity to formalise a feeling, to recognise meaning in the actions:

When he came here, he quoted Matthew: "Whatever you did to the little ones, you did it to me" [Mt 25.40], and I believe this is very much felt in the relationships between healthcare workers, doctors, nurses, and children. This concept is behind it even among non-believing professionals (Doctor, 23 years in BGHC).

A final significant moment to highlight spirituality is the meeting with Pope Francis for the hospital's 150th anniversary. During his speech, the Pope asked health workers to raise their hands for blessing; a profound silence fell in the room while all the doctors and nurses – believers or not – kept their hands up. His words became a confirmation of a spiritual feeling for everybody:

You – doctors, surgeons, and nurses – use your hands as a healing instrument. May you always be aware of this blessing of God on your hands... I like to bless the hands of doctors and nurses. Now ... I stop a bit to bless the hands of all the doctors and nurses who are here and all the hands of the doctors and nurses of the Bambino Gesù. (Pope Francesco, Vatican.va, 2019).

6. Conclusion

The case study offers two levels of in-depth analysis. The first level observes the interaction between the scientific method and the humanisation of care. It influences the action of individual operators and directs the organisation of a structure towards improving reception. A community care-based system is formed, favouring an agency attentive to the relational dimension. The second level shows how individuals express their spirituality. It seems to help patients and their parents face the therapeutic path.

The process of humanisation of the cure (Ranci Ortigosa, 1991) becomes a key to the valorisation of spirituality because the therapeutic paths do not focus only on the disease but open up to the totality of the person and their relationships (Maturo, 2007; Cersosimo, 2019). Welcome therapy is not built as an alternative to the evidence-based medicine method but in support of it; as already observed, the presence of chaplains or spiritual assistants of different religions, psychologists, music therapists, etc., can become an asset. In this frame it finds its place. The study confirms that.

A healthcare approach that moves around the person (Lalani, 2021) stimulates the

flourishing of special attention to spirituality. There is a further step that can be considered from the findings. The analysis also returns an institutional dimension that somehow “collects” the experiences of emerging spirituality. The first experience refers to the episode of the washing of the feet celebrated on the Holy Thursday in Santa Marinella; the second experience refers to the blessing of the hands imparted by Pope Francis to healthcare workers during the hospital's 150th anniversary. In both cases, a traditional and communitarian religious practice becomes a moment particularly felt by people during which they remember their experience. Finally, cultivating spirituality does not mean neglecting or replacing medical science but strengthening patients' will and strength. Intensive training of medical and healthcare personnel would, therefore, be desirable to prepare for the reception and relationships always able to consider the whole person, including their spiritual dimension (Timmins et al. 2022).

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