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Umanizzazione della gestione integrata del bambino in ospedale: studio di valutazione dell'esistente e del percepito

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Al mio amato papà

Abstract

Umanizzazione della gestione integrata del bambino in ospedale: studio di valutazione dell'esistente e del percepito

Introduzione: l'umanizzazione delle cure pediatriche (UCP) prevede un'assistenza incentrata non solo sul bambino-paziente ma sull'intera famiglia. La letteratura è carente di studi inerenti i benefici ottenuti da pazienti e operatori in seguito a interventi strutturati di UCP, mirati soprattutto alle fasce più fragili e/o affette da patologia cronica.

Obiettivi:

1. revisione dei dati della letteratura
2. analizzare mediante tool appropriati le differenze tra il grado di UCP esistente e percepito in sette strutture pediatriche ospedaliere della regione Campania, esaminando se esiste una differenza tra il grado di umanizzazione percepito (GUP) dagli utenti (genitori/visitatori) - rispetto ai membri del personale - con l'obiettivo di:

A. individuare aree implementabili nell'ambito dell'accoglienza, ricovero e dimissione del paziente pediatrico;

B. programmare ed attuare strategie misurabili d'intervento.

Metodi: il progetto è stato condotto nei reparti pediatrici di sette ospedali della regione Campania, classificati come ospedali generali (n=4), pediatrici (n=1) e universitari (n=2). Il grado di umanizzazione esistente (GUE) è stato valutato da un focus group multidisciplinare per ciascun ospedale attraverso la checklist AGENAS, validata e orientata all'assistenza pediatrica nonché specificatamente sviluppata per individuare le aree più critiche (ovvero quelle con punteggio <2.5). Il GUP è stato valutato attraverso il questionario LpCp–Tool mediante l'utilizzo di quattro indicatori: benessere, aspetti sociali, sicurezza e protezione e promozione della salute valutati.

Risultati:

A. Revisione della letteratura internazionale: seppur siano necessari RCT più ampi, l'UCP si dimostra efficace nel migliorare la qualità dell'assistenza, il livello di soddisfazione dei genitori e i costi della spesa sanitaria, anche se può essere percepita in modo diverso dagli utenti e dagli operatori sanitari.

B. Analisi del GUE:
    1. l'area dell'accessibilità fisica, vivibilità e comfort ha manifestato carenze nel confort delle sale di attesa, della segnaletica e dell'orientamento negli ospedali;
    2. l'area dei percorsi di benessere e processi organizzativi orientati al rispetto e alla specificità della persona, è risultata deficitaria nella funzione di supporto psicologico, ospedale senza dolore, continuità delle cure/transizione, rispetto della privacy;
    3. dall'area del rapporto con il paziente e con il cittadino sono emerse difficoltà nella preparazione e formazione del personale e nella cura della comunicazione;
    4. l'area dedicata all'accesso alle informazioni, semplificazione e trasparenza è risultata, infine, globalmente deficitaria.
C. Analisi del GUP: insufficiente il confort delle stanza di degenza, l'organizzazione delle attività ricreative, le aree verdi, le occasioni di sport e svago (area benessere); scarsa presenza di mediazione, traduzione, interpretazione dei servizi (aspetti sociali), carenze di strategie atte alla sicurezza e alla protezione, sorveglianza a rischio di infezioni ospedaliere (sicurezza e protezione). Infine, fra i tecnici valutatori, si è evinto un deficit di attività di promozione alla salute.
D. Per ogni area implementabile sono state individuate delle strategie misurabili d'intervento, alcune delle quali avviate discusse nella tesi.

Conclusioni: gli interventi di UCP atti a garantire cure ospedaliere a misura di bambino e famiglia richiedono attente valutazioni preliminari, adattate a ciascuna categoria di reparto pediatrico, e dovrebbero considerare sempre le possibili differenze tra il GUE e il GUP. In generale, la qualità percepita dei servizi, la lunghezza eccessiva delle liste di attesa, e la competenza del medico sembrano rappresentare aspetti importanti per le famiglie dei pazienti campani che spesso ricorrono alla migrazione sanitaria extraregionale. Sono auspicabili nuove e consistenti strategie di UCP per limitare questo vasto fenomeno che ancora oggi interessa diffusamente la nostra Regione.

Abstract

Humanization of integrated pediatric care:
evaluation study of the existing and perceived degree of assistance

Introduction: humanization of pediatric care (HC) provides for assistance centered not only on the child-patient but also on the whole family. The literature lacks of studies concerning the benefits obtained by patients and operators after structured UCP interventions, above all the ones devoted to the most fragile and/or chronic children.

Objective:

1. semi-systematic review of most recents HC available literature data;
2. analysis - using appropriate tools – of the differences between existing and perceived UCP in 7 Campanian pediatric hospitals, together with the examination of the existing difference between the degree of humanization perceived (PH) by users (parents / visitors) and the one perceived by the members of the personnel, with the aim of:

A. identify areas of implementation of the context of reception, hospitalization and discharge of the pediatric patient;

B. plan and improve measurable intervention strategies.

Methods: this project was conducted in the pediatric wards of 7 Campanian hospitals, classified as general (n = 4), pediatric (n = 1) and university (n = 2) hospitals. The existing degree of humanization (EH) was assessed by a multidisciplinary focus group for each hospital through the AGENAS checklist, validated and oriented towards pediatric care and specifically developed to identify the most critical areas. PH was assessed through the LpCp – Tool questionnaire using four indicators: well-being, social aspects, safety, protection and health promotion.

Results:

A. Semi-systematic review of the international literature confirm the need for larger RCTs and demonstrates that HC is effective in improving the quality of care, in enhancing the response of parental satisfaction and in managing the costs of health care , although these factors can be perceived differently both by users and healthcare professionals.

B. Analysis of the EH:
1. area of *physical accessibility, livability and comfort* showed critical issues in the comfort of waiting rooms, signage and orientation;
2. area of *well-being paths and organizational processes oriented toward the respect and the specificity of the person*, was deficient in the psychological support, pain-free policy, continuity of care/transition, respect for privacy;
3. difficulties in the preparation and training of the staff and in the care of communication emerged from analysis of the area of *relationship with the patient and the citizen*;
4. area of *access to information, simplification and transparency* was globally deficient.
C. Analysis of the PH: hospital room comfort, recreational activities, green areas, sports opportunities (*wellness area*) were insufficient; mediation, translation, interpretation of services (*social aspects*), safety and security strategies, surveillance at risk of hospital infections (*safety and protection*) were severely lacking. Finally, among the evaluating technicians, a deficit in health promotion activities emerged.
D. For each implementable area, measurable intervention strategies have been identified, some of which were started and discussed in the thesis.
Conclusions: HC interventions require careful preliminary assessments, adapted to each category of pediatric ward, and should always consider the possible differences between EH/PH. In general, the perceived quality of services, the very long waiting lists, and the doctor's competence seem to represent important aspects for Campanian families to often decide for extra-regional health migration. New and consistent HC strategies are desirable to limit this wide phenomenon which still today largely affects our Region.

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Summary

Chapter 1

Background and objectives

1.1 HUMANIZATION OF CARE

The humanization of care (HOC) is a multidimensional process that places the patient at the center of health care with a complete cure, respecting his state of mind and health. In practice, the patient becomes a subject who participates and shares the therapeutic program. In pediatrics, HOC intends to provide a service centered not only on the child as a patient, but necessarily on the whole family, which is involved in the phases of reception, diagnosis and hospital care, as well as in the physical and psychosocial growth process of the child. Knowledge in this field is constantly evolving [1, 2]. The approach of HOC varies in different cultures and is based on historical, ethical, religious and economic aspects. In particular, while the basic principles of HOC are transversal, humanization interventions often arise from specific needs of a country. The American Academy of Pediatrics - for exemple - provides the definition of patient-centered and family-centered care (FCC) as an innovative approach built on a mutually beneficial partnership

between patients, families and healthcare professionals, recognizing the importance of family in the life of the patient. [3]. Models of HOC differ substantially on the basis of geo-social factors, and the main programs have been elaborated and developed in the Americas - particularly in the USA [3] and Brazil [4] - and in Europe [5,6]. There is still little information on the overall results obtained from projects aimed to improving the care of adult [7] and pediatric patients in various hospitals or other medical facilities. In the pediatric field, family-centered care (FCC) and shared decision-making (SDM) are the main components of humanization programs, even if the different models proposed rarely have been experimentally verified through randomized controlled trials (RCT) and a specific evidence regarding the benefits of FCC/SDM was limited and of moderate quality [8]. A study has showed that, in the US healthcare system, the annual prevalence of FCC/SDM varies from 38.6 to 93.7% [9]. This wide range may depend (in part) on the selected assessment strategy, which could lead to different interpretations of the quality of health care even when the same data are used.

To deepen the full spectrum of pediatric HOC, we preliminarily performed a systematic review of the literature with the objective of identify relevant studies previously published in the area of HOC,

analyzing and comparing different intervention strategies [10]. Although there is an absence of robust trials, this review found that these measures are generally considered effective and likely to have beneficial effects on several aspects of pediatric hospitalization and confirmed that despite the persistent differences in the approach to pediatric care, there is a common need to improve the quality of the interventions offered [11]. To meet this need, each hospital seeks to individually implement its own humanization measures of care even if patient and health care practitioners' assessments of the quality and quantity of humanization/person-centered care interventions may differ between independent observers [12,13]. To answer the question regarding whether/ to what extent there is a difference between the degree of HOC existing and perceived in pediatric structures, this study has also esamined - by validated tools for HOC assessment - the evaluation differences relating to the HOC, acquired by focuses groups in 7 pediatric campanian wards [14], as perceived by staff vs parents [15] and according to the category of the pediatric settings.

Simultaneously, in line with WHO adopted strategies, a set of existing tools for the assessment and improvement of child rights in hospital and the further analysis of quality of hospital care for children is still being in progress. The adopted set of tools - the Manual and Tools for

the assessment and improvement of children's rights in hospital - was prepared by the Task Force on Health Promotion for Children and Adolescents in and by Hospitals, a working group of the International Network of Health Promoting Hospitals and Health Services, in collaboration with hospitals and international partners, including WHO [16].

The aim of this analysis is to identify areas that can be implemented in the context of the reception, hospitalization and discharge of the pediatric patient and to plan and implement measurable intervention strategies of HOC.

1.2 MODELS OF HUMANIZATION OF CARE

The main Humanization of Care programs have been elaborated and developed in the Americas, particularly in Brazil, the USA, and Europe, with seemingly different ways from one another but ultimately with the same aim (Table 1).

Table 1. Comparison of the main characteristics of the Brazilian (NHP) , the North American (PFCC) and the European (CFHC) models of humanization

NATIONAL HUMANIZATION POLICY (NHP)	PATIENT AND FAMILY CENTERED CARE (PFCC)	CHILD-FRIENDLY HEALTH CARE (CFHC)
BRASIL[4]	*USA[30,33,83,91]*	*EUROPE[50]*
	Aims	
Enable, promote and consolidate in hospitals accredited by SUS (Sistema Único de Saúde) the creation of a humanization culture that is democratic, compassionate and critical.	• Respect and dignity. • Information Sharing. • Participation. • Partnership and Collaboration. • Negotiation	• To improve the quality of health care in term of effectiveness, efficiency and equity with attention to patient safety and his satisfaction. • Services designed for the child and his family. • Interventions focus not only on managing the child's health condition, but also on their physical or social environment • To encourage children to exercise their right to participate.
	Methods	
• To sensitize the hospital management • Census of the hospital situation in terms of humanized services • Development and implementation of the operational plan of humanization • Evaluation of the results of the implementation of the process of humanization	• Step 1: select a care experience • Step 2: establish the "Care Experience GuidingCouncil" • Step 3: evaluate the current state using shadowing • Step 4: expand GuidingCouncil into working group and care team • Step 5: write the history of "ideal experience" • Step 6: identify projects and form project improvement teams	• Interventions in five areas: participation, promotion, protection, prevention and provision. • Training for staff. • To assist children to become "knowledgeable patients". • To achieve synergy between: policy makers from different sectors; commissioners, providers and regulators of services; health, education and social-care organizations. • "Child-friendly" healthcare environment. • Age-appropriate interventions to reduce fear, discomfort and pain.
	Instruments	
1. National Network for the Humanization 2. Working groups	• Family Centered Rounds (FCR) • Interdisciplinary care	• Practical model of policy based on children's rights. • Applying evidence-based and user-friendly guidelines for health professionals and families.
	Result indicators	
1. Welcome and user support 2. Work professionals' work 3. Logic of management	1. Staff satisfaction 2. Parents satisfaction 3. Level of anxiety in parents and patients 4. Timing of discharge	1. Improved health 2. Reducing inequalities 3. Creating a sustainable system within the limits of available resources.

1.2.1 Brazil: The National Humanization Policy (NHP)

In Brazil, large social disparities and the difference between types of hospitals (including their setting in large cities and suburbs) have determined the need to create a government task force to make Humanization programs that were aimed at ensuring equal reception opportunities and care for all citizens. The Brazilian Federal Constitution of 1988 established a new legal basis for health policy, defining health as a right of every citizen and, therefore, an obligation of the State. In that Country, the belief began to spread that health is a concept much wider than the mere disease's absence, and it must include a complete physical, mental and social well-being as, indeed, had already established the WHO (World Health Organization) in 1946. Hence, given the State obligation to provide health protection, the need to establish equitable social policies was born. This led, in 2001, to the birth of the "National Program of Humanization of the Hospital" (PNHAH) [17]. The PNHAH aimed to improve the hospital care quality for all age groups, focusing primarily on the relationship between users and health professionals, among the professionals themselves, and between the hospital and the community, to ensure the best possible functioning of their Unique Health System (SUS). Since then, the Humanization of care has been the subject of other

initiatives and actions of the SUS, and what initially was a program became, in 2003, a policy: the NHP [18,19]. All this was planned in order to create a crosshumanization culture, through the development and implementation of programs in hospitals, that included the awareness of managers and staff training, accrediting the virtuous structures as “Humanized Hospitals” . In summary, the program aims to improve hospital reception and the patient’s care of every age, social class and their families, providing compassionate, democratic and effective cures. The NHP is based on three principles:

- transversality, indicating the expansion of communication between individuals and services;
- inseparability between care and management;
- co-responsibility in the promotion and production of the health of individuals and communities.

In the Brazilian medical literature, there is currently much debate about the concepts and practices of humanization [20,21]. In fact, the studies that brought about the opinions and perceptions concept of humanization [22–26] overcome those which described the humanization interventions carried out. [1, 27, 28].

1.2.2 USA: Patient and family centered care

In the USA, the term humanization refers to specific interventions in the method of delivery care in different age groups. Until the first half of the twentieth century, children were admitted in the hospital without their parents for long periods [29]. Patient- and family-centered care (PFCC) emerged as a concept only during the second half of the twentieth century, at a time of increasing awareness of the importance of meeting the psychosocial and developmental needs of children and the families role in promoting the health and well-being of their children [30]. The concept of Family Centered Care (FCC) in pediatrics is based on the recognition that the family is the primary source of strength and support for the child and that the views of the child and family are important for making decisions about the care program [31].

The concept of PFCC has long been associated with home care: in 1992 it was founded by the “Institute for Family- Centered Care” (now "Institute for Patient- and Family-Centered Care") to encourage the development of partnerships between patients, families and healthcare providers, and to offer leadership to encourage the practice of the PFCC as well [30]. The American Academy of Pediatrics (AAP) recommends pediatric care being “accessible, continuous,

comprehensive, family-centered, coordinated, compassionate and culturally effective." Accordingly, the PFCC is defined as "an innovative approach to the planning, delivery, and evaluation of health care that is grounded on a mutually beneficial partnership among patients, families, and providers that recognize the importance of the family in the patient's life" [30, 32]. The model and the principles of PFCC have been adopted and applied by other associations such as the "Children with Special Health Care Needs" (CSHCN), the "Maternal and Child Health Bureau" (MCHB), and the "Institute for Patient- and Family-Centered Care" (IPFCC), recently compared [33]. The mutually beneficial collaboration between patients, family, and provider during hospitalization is well exemplified by the Family-Centered Rounds (FCR) which consist of an "interdisciplinary work at the bedside in which the patient and his/her family share control of the management plan as well as in the evaluation of the process itself" [34]. The AAP also recommends that conducting attending rounds in patients' rooms in the presence of family members should be a standard hospital practice, and plans on the decision of the patient's care should be made only after such rounds, to incorporate family involvement in decision-making [35]. The FCR have the potential to create a "patient-centered" environment, to improve medical

education and, in parallel, patient care, and outcome [34]. The FCR patient care and the education of students take place simultaneously. For the optimal success of the FCR and in order to let these be benefited both by patients and their families, doctors, and trainees, it is important that the hospital is equipped, also, with wide and large spaces. [36]. There is currently no tool that is universally accepted to "measure" the implementation and results of the PFCC model [37]. However, the family-centered approach appears to significantly increase the degree of the young patients' parents/caregivers satisfaction [38]. Despite the spread of PFCC and the AAP recommendations, the recent study of Azuine et al. noted that, based on what is reported by parents, only 2/3 of American children have received indeed a care according to this model. Notably, exclusion was predominant in underserved and uninsured families [39]. In the 2007 National Survey of Children's Health, conducted in the USA, a considerable part of the parents reported that their child needed a better coordination of care than what they had received. Again, this was mainly reported by blacks and Latino parents and parents of children with special care needs. It follows, therefore, that the improvement and promotion of family-centered care should be implemented to help reduce the racial/ethnic disparities [40]. The

pediatric Hospital for Sick Children (SickKids) in Toronto adopts the Child and Family-Centered Care (C& FCC), an approach similar to PFCC involving all processes of care. The acronym CARE is intended as Clinicalpractice; Administration; Research; and Education, extending beyond the hospital, in the community, and in the health system. SickKids interacts locally, nationally and internationally, to give medical support and provision of services [41]. A concept in harmony and complement to the PFCC is the "Family-oriented care", indicated by the AAP also as "Family pediatrics", which aims to expand the pediatrician's responsibility in having keenness to extend the medical evaluation also to the parents to identify any physical, psychological or social factors that may adversely affect their children's health [31, 42].

1.2.3 Europe: Child friendly health care

In Europe, humanization's policies of pediatric care were based mainly on children's rights. Although these have been well expressed in the United Nations Convention on the Rights of the Child (UNCRC, ratified in 1989 in New York from 140 countries), many difficulties are still encountered in their implementation, and, over the years, the challenge has always been to translate these principles into a

practical model. Several organizations worldwide have adopted the articles of the UNCRC in various areas of pediatric care. Among the projects promoted to implement in practice the principles of the UNCRC, the "Child-Friendly health care Initiative" (CFHI) was created in the UK in 2000 and promoted by CAI (Child-health Advocacy International), in collaboration with UNICEF (United Nations International Children's Emergency Fund) and WHO. This initiative aims to minimize the fear, anxiety, and suffering of children and their families, through the support and the practice of 12 Standards (Table 2) [43].

Table 2. 12 Standards of Child Friendly Healthcare Initiative (CFHI)

Standard 1	Keeping children out of hospital (and other health facilities or institutions) unless this is best for the child
Standard 2	Supporting and giving the best possible healthcare
Standard 3	Giving healthcare safely in a secure, clean, "child friendly" environment
Standard 4	Giving "child centered" healthcare
Standard 5	Sharing information and keeping parents and children consistently and fully informed and involved in all decisions
Standard 6	Providing equity of care and treating the child as an individual with rights
Standard 7	Recognizing and relieving pain and discomfort
Standard 8	Giving appropriate resuscitation, emergency and continuing care for very ill children
Standard 9	Enabling play and learning
Standard 10	Recognizing, protecting and supporting vulnerable or abused children
Standard 11	Monitoring and promoting health
Standard 12	Supporting "best possible" nutrition

The main results obtained in some countries include development and integration of therapeutic play; participation of parents in the care and visit rounds; realization of multidisciplinary working committees, with

the representation of parents [44]. In Bosnia and Herzegovina 13 hospitals have been awarded the title of “child-friendly” [45]. CFHI initiative introduces the concept of Child-Friendly Healthcare (CFHC), perceived as the best possible medical care for the child and not referring to any organ of formal accreditation [46]. The CFHC has recently become a real health policy as expressed in the Guidelines of the Council of Europe, elaborated by the Committee of Ministers in 2011, concerning child-friendly health care [47]. The guidelines were created to offer a practical tool to the governments of the Member States for adoption, implementation, and monitoring of child-friendly health care strategy. The CFHC model was definitely "a focus on children's right health policy, on their needs, characteristics, activities and developmental capacities, and taking into account their opinions." It includes also the notion of “family-friendly” to emphasize the importance of contact between the child and his/her family as part of the care pathway. Following to the publication of the Guidelines, the "British Association for Community Child Health" adapted the model to the economic and political frame work of the UK calling it “The Family-Friendly Framework”, for the design, development, and delivery of services for children and families [48]. The principles behind the CFHC is based on participation of the child at all levels of

decision-making, according to the age and degree of maturity. The prevention to avoid future health, social or emotional problems; promotion of health and its determinants; protection of children from harm are included as well, along with the efficient performance of services contributing to health and well-being of children and families. A large survey conducted by the Committee of Ministers of the Council of Europe has shown, with 2257 children from different European countries, that there is a greater need to listen and respect in their contacts with health professionals [49]. It was born, therefore, the necessity of a health system taking into account the needs, the feelings, and the opinions of pediatric patients. Some studies analyzing the causes of the child approach inconsistent with the guidelines have found scarce health worker training in communication with the children, a factor negatively affecting their participation [50]. Others stressed that the participation of children in the medical decision-making process places them in the role of holders of rights and duties as well as responsibility bearers. To enhance their participation and understanding of the information received by caregivers and doctors, it is necessary to be as objective and clear as possible at their level of mental and relational development, in order to positively influence the decision-making process [51]. The

realization of CFHC model requires huge investments in the social determinants (about 85% of total costs) and health determinants (about 15% of total costs) as well. In times of austerity, it is essential to outline the contribution to the economy of health care realization suitable for children. The application of the classical models of the economy is technically difficult because child care is often complex and less standardized [52].

1.2.4 TAT- the think and action tank on Children's right to health

The Think and Action Tank (TAT) on Children's rights to health is an international working group, set up in June 2013. It is a global, open network of professionals, policy makers, people working for children and supported by EPA (European Pediatric Association), which has produced a document (a rights- and equity-based platform and action cycle to advance child health and well-being) in which it is proposed a general model of implementation of the child's right to health, which has not yet been implemented. This document aims to introduce an operational model to prepare the institutions, organizations, policymakers, professionals and those working for children to translate into practice the principles of child rights. In order to develop an organic model, the proposed platform must be anchored to a solid

foundation, based on the rights and equity, represented by a number of elements equally important: Child Rights, Health, States, Children's Participation, Equity, Social Justice, and Responsibility [53].

1.3 TOOLS FOR THE ASSESSMENT OF HOC

In different countries, several tools have been created and used for assessing the degree of humanization and related aspects.

1.3.1 USA

In 1995, the Agency for Healthcare Research and Quality (AHRQ) has launched for the first time the program "Consumer Assessment of Healthcare Providers and Systems (CAHPS)" to cope with the lack of feedback from patients about the quality of provided health services. Over time, the program has expanded beyond its original focus on health plans to address a range of health care services and to meet the various needs of health care consumers, purchasers, health plans, providers, and policymakers.

The objectives of the program CAHPS are mainly two:

- to develop standardized surveys that organizations can utilize to collect comparable information on patients' experience with care;

- to generate tools and resources to support the dissemination and use of comparative survey results to inform the public and improve health care quality.

The three most used CAHPS surveys are:

- "CAHPS Health Plan Survey", interviewing those enrolled in certain health programs, [Medicaid, Children's Health Insurance Programs (CHIP) and Medicare] regarding their experiences with the health services and ambulatory care;
- "The CHAPS Clinician & Group Survey (CG-CAHPS)", asking patients to report their experiences of primary and specialized care received in outpatient settings;
- "The CAHPS Hospital Survey (HCAHPS)", interviewing patients about the care received during an inpatient stay at a hospital facility.

Of the many CAHPS surveys, there are the adult version (over 18) and those for children (in which parents report the experience of a child aged 17 years old and under). The CAHPS surveys are available in English and Spanish. The AHRQ also provides support and technical assistance to users through CAHPS User Network and CAHPS database that receive data sent voluntarily by users, and aggregate them to facilitate comparisons of the results [54].

In the USA, again, the American Medical Association (AMA) in collaboration with several other organizations developed the "Communication Climate Assessment Toolkit (C-CAT)", a number of investigative tools that are distributed to staff, managers and patients to provide a comprehensive assessment of the organization's communication capabilities of health care to the patient (patient-centered communication) [55].

1.3.2 Europe

In Europe, the picture is even more fragmented. The Task Force HPH-CA (Health Promoting Hospitals and Health Services for Children and Adolescents), established in April 2004 within the International Network of Health Promoting Hospitals, produced the SEMT (Self-Evaluation Model and Tool in respect of children's rights in the hospital).

The specific objective of the model is to assess the gap between full respect for the rights of the child in hospital and current situation.

As a basis to promote the improvement and internal change through the development of standards, the adoption of measures, subsequent evaluations, and feedback monitoring gaps and producing change.

The stages of this process of assessment, improvement, and change

are represented by:

- mapping of real existing goods using a selfevaluation tool;
- planning for improvement through the identification of a set of standards for the respect of children's rights in the hospital;
- production of improvements by implementing specific actions;
- evaluation of the changes by monitoring progress and gaps.

The SEMT was made available in 10 different languages and the pilot project was conducted in 17 hospitals in Europe and also in Australia. The area of the rights found to be more difficult to deal with by the hospitals, is relevant to the "child's right to information and participation to all the decisions about his or her health care". Hospitals that have obtained the best results in terms of respect for children's right in Europe are Tallinn Children's Hospital (Estonia), Caldas da Rainha Hospital (Portugal), Meyer University Children's Hospital (Italy) [56]. In 2012, the Task Force prepared a manual and new tools in order to further implement the self-assessment and improvement of the respect of the rights of children in hospitals at different levels (workers of services; health care professionals; children aged 6–11 and children/adolescents aged 12–18 years, parents and carers) [57].

1.3.3 National experiences: Italy and France

The available data for Italy show that the AGENAS (Italian National Agency for Health Services) has recently produced a questionnaire for the assessment of the degree of humanization of care in Italian hospitals related to physical accessibility, livability and comfort of hospitals; welfare and organizational processes oriented to the respect and to the person's specificity; care of the relationship with the patient and with the citizen; access to information, simplification and transparency. The checklist assesses the humanization level, addressed to a focus group composed by members of the hospital's administration, doctors, nurses and voluntary associations together with citizen representatives. The study conducted in 2012 in 256 shelters spread all over the country shows that hospitals with > 800 beds obtained the best average results [58]. The most serious problems which emerged deals with the respect for confidentiality, linguistic and religious specificities and foreign citizens' reception, architectural or sensory barriers, booking arrangements, online access to clinical records, training of communication personnel, birth-analgesia. In general, the pediatric wards of hospitals received the best scores, but the analysis was not extended to all pediatric hospitals and only some relevant aspects of the humanization of pediatric care (such as

procedural pain) were partly taken into account. Still in Italy, for the subjective evaluation of the degree of perceived humanization in hospitals, the Politecnico of Milan has developed and tested, in 2014, the LpCptool (listening to people-to-cure people). The questionnaire, consisting of a small number of questions, still represents a suitable tool that addresses topics such as the comfort of the environments, the presence of green areas, the patient involvement in the therapeutic process and security in the hospital. The most critical issues emerged in the wellness area (comfort of the environment, recreation and sports), safety, patient involvement in the therapeutic process and the physician in the design process (involvement in case of changes within the hospital environment). The results of the questionnaires administered to the staff, patients, and visitors in a general hospital in Milan with 600 beds showed divergent perceptions among the groups interviewed with a positive perception of patients about the efficiency of care received compared to the more realistic and critical view of the health operators [59]. These divergent perceptions were recently confirmed also in a pediatric setting pilot study in Campania Region using the same tool [60]. In France, since 2011, the French Ministry of Health has developed a questionnaire to assess the degree of satisfaction of patients hospitalized in health facilities that perform

medical activities, surgery or midwifery. This indicator (e-SATIS) reflects the actions put in place to take care of patients: human, technical and its logistics management. Initially, questions were answered by telephone, later on (since 2015), online questionnaires have been submitted by e-mail to the patient 2 weeks after hospitalization. In 2014, 877 facilities were involved and 5900 patients contributed to the national results of evaluating the following aspects: global patient care, doctor's attitude, patient and healthcare communication, information and comfort of the rooms. The last two areas were the most deficient. The aim is to help improve the quality of health services as close as possible to patients' expectations [61].

1.3.4 HOC perceived by children

In the 25 years since the adoption of the Convention on the Rights of the Child (CRC) (62), significant experience and knowledge has been generated in relation to the interpretation of article 24 on children's right to health and its respect, protection and fulfilment in children's various life settings. The importance of adopting a human-rights based approach to health is reinforced in the recently adopted WHO Strategy 'Investing in children: child and adolescent health strategy for Europe 2015–2020', which states that "as human rights become better

respected, they become more effective in helping governments to strengthen their health systems, deliver health care for all and improve health (63)". Within children's right to health, the CRC places a great emphasis on primary health care (PHC), which is to be the gateway to pregnant women, mothers, newborns and children throughout their life stages. This is reinforced by General Comment №15 on article 24, which declares that "States should prioritize universal access for children to primary health care services provided as near as possible to where children and their families live, particularly in community settings" (64). Furthermore, the centrality of the role of PHC within health systems is recognised by WHO in a number of strategies and legal instruments, including the Declaration of Alma-Ata1 (65) and the European policy for health and well-being - Health 2020 (66). PHC is the closest care to the population and most children will have contact with its services and professionals throughout their development, which makes it a privileged setting to invest in. At the same time, PHC services have a great responsibility to provide quality services to children, to give them a voice and to enable them to reach their full potential. The development of the Manual and Tools for the assessment and improvement of children's rights in PHC is part of an ongoing process at international level that aims to translate children's

rights as enshrined in the CRC into practical principles and actions that health care services can apply in daily practice.

The Manual and Tools should serve as a means of assessment, identification of areas for improvement and of raising awareness on children's rights of health professionals and otherworking for and with children in the health sector. The Manual and Tools for PHC have been adapted from the *Children's Rights in Hospital: Manual and Tools for assessment and improvement*, published in 2012 [16]. The aforementioned tools addressed five groups of stakeholders namely, hospital management, health professionals, children aged 6-11, children and adolescents aged 12-18 and parents and carers. In 2012-2013, WHO Europe implemented successfully the tools in hospitals in Kyrgyzstan, Tajikistan and Moldova, in the framework of its work on improvement of hospital care for children [67]. This experience demonstrated both the importance and the need to address and assess the respect of children's rights in healthcare settings. Taking into account the growing recognition of the importance of children's rights in healthcare and the good acceptance of the Manual and Tools in the aforementioned countries, WHO Europe initiated a process to prepare a similar set of tools on assessing and improving the respect of children's rights in PHC. For the preparation of the present Manual

and Tools for the assessment and improvement of children's rights in PHC, working groups were established in Armenia, Norway, Portugal and the UK. Health professionals working at different levels of health care service provision gave their inputs regarding the development and applicability of the standards and sub-standards, as well as, the suitability of the questions in their contexts. The development of the Manual and Tools was prepared in consultation with a team at the WHO European Office and Headquarters. The standards adopted by our research group reflect closely the standards of the above mentioned *Children's Rights in Hospital: Manual and Tools for assessment and improvement* (16). The tools analyzed are organised under six standards, as follows.

- **Standard 1** evaluates the best quality possible health care delivered to all children, which includes, *inter alia*, clinical evidence available, adequately trained staff, monitoring and evaluation systems and the adoption of a Charter on Children's Rights in PHC.
- **Standard 2** evaluates to what extent the health care services respect the principles of equality and non-discrimination of all children.

- **Standard 3** evaluates PHC services in supporting the realization of the mother's right to health, pregnancy and the role of parents, as a key determinant of children's health, nutrition and development.
- **Standard 4** evaluates the rights of all children to information and participation in health care decisions affecting them and the delivery of services.
- **Standard 5** evaluates to what extent health care services are delivered in a safe environment designed, furnished and equipped to meet children's needs.
- **Standard 6** evaluates the right of all children to individualized, gender-specific, culturally and age appropriate prevention and management of pain and palliative care.

For each standard, several sub-standards and specific questions for the groups of stakeholders were identified. The questions are adapted to each of the groups, however they aim to address and gather information on the same issues.

Chapter 2

Materials and methods

2.1 DATABASE SEARCH

We searched within the PubMed and Scopus academic medical databases. A general Web search using Google was also performed only in order to get a larger vision and understanding of the issue around the world as we have shown in a previous paper of narrative review nature [68]. The database search strategy was formulated around terms for Bchild^ and several other text words (Table 3).

Initially, we tried to do a mesh search, but we decided to use only a word search because the MeSH strategy was too limited for the terms of our interest (e.g., humanization 0; family-centered care 0; child friendly 0). Text words were chosen based on the existing literature and were obtained from related bibliographies. The earliest publication date was January 2000. The search ended in October 2018.

Table 3. Database search strategy	
AREA	**KEYWORDS**
Humanization of care	Humanization + children and/or child and/or pediatric and/or paediatric; Humanization + care and/or pediatric and/or children and/or child; humanization + hospital and/or pediatric and/or children and/or child; humanization + unit; child-friendly; child friendly; child-friendly + hospital; child friendly + hospital; child-friendly hospital; child friendly hospital;
Patient and Family Centered Care andFamily Centered Rounds	patient and family centered- care; patient and family centered- care + pediatric; family centered rounds; family centered rounds + pediatric; family centered rounding; family centered care;
Psychological support	psychological support + children and/or child and/or pediatric and/or paediatric;
Environment	environment + care + children and/or child and/or pediatric and/or paediatric; environment + hospital+ children and/or child and/or pediatric and/or paediatric; space + hospital+ children and/or child and/or pediatric and/or paediatric; signage + children and/or child and/or pediatric and/or paediatric; signposting + children and/or child and/or pediatric and/or paediatric; orientation+ hospital + children and/or child and/or pediatric and/or paediatric; hospital + setting + children and/or child and/or pediatric and/or paediatric; hospital + design+ children and/or child and/or pediatric and/or paediatric;
Doctor patient relationship	doctor- patient relationship + children and/or child and/or pediatric and/or paediatric; Social determinants of health + children and/or child and/or pediatric and/or paediatric;
Technology	Teleconsultation + children and/or child and/or pediatric and/or paediatric; teleconsultation + hospital + children and/or child and/or pediatric and/or paediatric; Integrated personal health record; Tele-HomeCare; Wifi + hospital + children and/or child and/or pediatric and/or paediatric;
Pet therapy	animal assisted activity + children and/or child and/or pediatric and/or paediatric; animal assisted activity+ hospital; pet-therapy + children and/or child and/or pediatric and/or paediatric; pet-therapy + hospital;
Reading	reading + hospital; reading + hospital + children and/or child and/or pediatric and/or paediatric; reading+ children and/or child and/or pediatric and/or paediatric; reading + care; reading aloud + children and/or child and/or pediatric and/or paediatric; reading aloud + hospital.

Only studies carried out in general pediatrics wards and able to meet our criteria (i.e., experimental studies with either qualitative or quantitative descriptions of interventions and the analysis of results) were included. To be eligible

for inclusion, studies had to describe an intervention aiming to improve humanization of pediatric care in a hospital setting, with measurement of changes pre- vs. post-intervention or at least evaluating patient/family/staff satisfaction. Study details and quality characteristics were independently extracted by three of the authors for all the articles and in a stepwise approach, first by reading the title, then by reviewing the abstract, and finally by revising the full text, where appropriate. Pertinent data were extracted using a standardized data extraction. At the end of revision, findings were compared, and a consensus was achieved on selected studies. In case of controversy, a third author decided. Studies were rated with the Quality Rating Scheme (1–5, where 1 is the best and 5 is the worst) modified from the Oxford Centre for Evidence-Based Medicine ratings of individual studies [69]. Evaluation of bias was evaluated using Joanna Briggs Institute (JBI) critical appraisal checklist for randomized controller trials and other type of studies (Tables 4-8) [70].

Table 4. JBI critical appraisal checklist for randomized controlled trials					
Criteria	**RCTs**				
	Gottlieb [76] 2014 USA	Cox [73] 2017 USA	Branson [72] 2017 USA	Viggiano [95]2015 Italy	Goldberg [99] 2014 Israel
1. Was the assignment to treatment groups truly random?	✓	✓	?	?	?
2. Were participants blinded to treatment allocation?	X	✓	✓	?	?
3. Was allocation to treatment groups concealed from the allocator?	X	X	✓	?	?
4. Were the outcomes of people who withdrew described and included in the analysis?	X	X	X	X	X
5. Were those assessing the outcomes blind to the treatment allocation?	X	✓	✓	?	?
6. Were control and treatment groups comparable a ten try?	✓	✓	✓	✓	✓
7. Were groups treated identically other than for the named interventions?	✓	✓	✓	✓	✓
8. Were outcomes measured in the same way for all groups?	✓	✓	✓	✓	✓
9. Were outcomes measured in are liable way?	✓	✓	✓	✓	✓
10. Was appropriate statistical analys is used?	✓	✓	✓	✓	✓
Overall appraisal (I = include, E: exclude and SI: seek further information	I	I	I	I	I
NA = not applicable to community based randomized trials; ? = unclear; X= no					

Table 5.JBI critical appraisal checklist for non-randomized experimental studies

Criteria	Studies																
	Klein [80]2014 USA	Mann [82]2013US	Rostami [91]2012 Iran	Flippo [75] 2015 USA	Ottolini [84] 2011 USA	Roohafza [90]2011, Iran	Sobo [85]2006 USA	Kotzer[81] 2011 USA	Monti [93]2012	Oshimua [83] 2014 USA	Bretler [98]	Dudas[74] 2010 USA	Caprilli [92] 2006 Italy	Kaminski [77] 2002 USA	Leonard [97] 2014 South Africa	Biddis [87] 2014 Canada	Stinchi [94] 2012 Italy
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2. Were the participants included in any comparisons similar?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
4. Was there a control group?	✓	✓	✓	X	X	✓	X	X	X	X	X	✓	✓	✓	X	✓	X
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	✓	X	✓	X	✓	X	✓
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	NA	NA	✓	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
7. Were the outcomes of participants included in any comparisons measured in the same way?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
8. Were outcomes measured in a reliable way?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
9. Was appropriate statistical analysis used?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	X	X
Overall appraisal (I = include, E: exclude and SI: seek further information	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I	I
NA = not applicable to community based randomized trials; ? = unclear ; X= no																	

Table 6. JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies			
Criteria	**Studies**		
	Tom [86]2012 USA	Kelly [78] 2017 USA	Kern [79] 2015 USA
1. Were the criteria for inclusion in the sample clearly defined?	✓	✓	✓
2. Were the study subjects and the setting described in detail?	✓	✓	✓
3. Was the exposure measured in a valid and reliable way?	✓	✓	✓
4. Were objective, standard criteria used for measurement of the condition?	✓	✓	✓
5. Were confounding factors identified?	?	?	?
6. Were strategies to deal with confounding factors stated?	NA	NA	NA
7. Were the outcomes measured in a valid and reliable way?	✓	✓	✓
8. Was appropriate statistical analysis used?	✓	✓	✓
Overall appraisal (I = include, E: exclude and SI: seek further information	I	I	I
NA = not applicable to community based randomized trials; ? = unclear			

Table 7.JBI Critical Appraisal Checklist for Case Control Studies		
Criteria	**Studies**	
	Svavarsdottir [89] 2012 Iceland	Batún-Cutz [96]2016 Mexico
1. Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?	NA	NA
2. Were cases and controls matched appropriately?	✓	✓
3. Were the same criteria used for identification of cases and controls?	✓	✓
4. Was exposure measured in a standard, valid and reliable way?	✓	✓
5. Was exposure measured in the same way for cases and controls?	✓	✓
6. Were confounding factors identified?	?	?
7. Were strategies to deal with confounding factors stated?	NA	NA
8. Were outcomes assessed in a standard, valid and reliable way for cases and controls?	✓	✓
9. Was the exposure period of interest long enough to be meaningful?	✓	✓
10. Was appropriate statistical analysis used?	✓	✓
Overall appraisal (I = include, E: exclude and SI: seek further information	I	I
NA = not applicable to community based randomized trials; ? = unclear		

Table 8. JBI Critical Appraisal Checklist for Cohort Studies	
Criteria	**Study**
	Lai [88] 2018 Canada
1. Were the two groups similar and recruited from the same population?	X
2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	X
3. Was the exposure measured in a valid and reliable way?	✓
4. Were confounding factors identified?	?
5. Were strategies to deal with confounding factors stated?	NA
6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	✓
7. Were the outcomes measured in a valid and reliable way?	✓
8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	X
9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	NA
10. Were strategies to address incomplete follow up utilized?	NA
11. Was appropriate statistical analysis used?	✓
Overall appraisal (I = include, E: exclude and SI: seek further information	I
NA = not applicable to community based randomized trials; ? = unclear ; X= no	

2.2 ANALYSIS OF EXISTING/PERCEIVED HOC

Between July 2017 and October 2018, we studied seven pediatric wards reflecting three different categories of regional medical centers: children's hospital [n = 1 (A)], pediatric department of a university hospital [n = 2 (B and C)], and general hospital [n = 4 (D, E, F, G)] (Table 9). The first group represents a pediatric setting characterized by a medium-high level of general pediatric assistance. The second group represents a more specialized setting in the context of a university department. The third represents a limited pediatric context.

2.2.1 Adult rating of existing HOC

To assess the degree of existing HOC, a pediatric oriented inventory was specifically developed in collaboration with the National Agency for regional health services (AGENAS) based on an existing validated National checklist [14]. It is structured into *4 core areas*:

1.care and organizational processes oriented to the respect and specificity of the person;

2.physical accessibility, livability, and comfort of the places of care;

3.access to information, simplification, and transparency;

4. care of the relationship with the patient.

Table 9. *Categories of the seven pediatric settings included in the study conducted in the Campania Region*

Hospital	City	Facility category	N° beds
General Pediatrics of AORN *"Santobono- Pausilipon"* **(A)**	Naples	Children Hospital	16 pediatric beds/287 total pediatric beds
Department of Pediatrics of AOU *"Federico II"***(B)**	Naples	University Hospital	27 pediatric beds/47 total pediatric beds
Department of Pediatrics of AOU *"Luigi Vanvitelli"***(C)**	Naples	University Hospital	12 pediatric beds/24 total pediatric beds
General Pediatrics of AOU *"S. Giovanni di Dio e Ruggi D' Aragona"* **(D)**	Salerno	General Hospital	28 pediatric beds/642 total general beds
General Pediatrics of AO "*San Giuseppe Moscati"* **(E)**	Avellino	General Hospital	19 pediatric beds/483 total general beds
General Pediatrics of AO *"Sant'Anna e San Sebastiano"* **(F)**	Caserta	General Hospital	14 pediatric beds/486 total general beds
General Pediatrics of General Pediatrics of AO *"G. Rummo"***(G)**	Benevento	General Hospital	16 pediatric beds/402 total general beds

These areas are divided into *12 subareas* further divided into *28 criteria* and *122 items* [14]. AGENAS checklist was accurately filled in by a focus group (one for each hospital) comprising representatives of four categories (medical staff, nursing staff, health management, and voluntary associations). Each item could receive a score from 0 to 10. The arithmetic means obtained in each area and in each criterion were calculated. According to the AGENAS, average scores (< 2.5) were considered "critical" and in need of interventions to improve the degree of existing HOC [14].

2.2.2 Adult rating of perceived HOC

The rating of perceived HOC was evaluated through the Listening to People to Cure People (LpCp)-tool [15], which consists of three short questionnaires (available from the authors on request) addressed to patients, visitors, parents, companions, staff, and technical evaluators.

The survey includes an introductory section to acquire general information of the interviewed person (gender, age, nationality, occupation role, etc.) followed by a section investigating 4 *indicators* of users' perceptions and experiences in the hospital:

a. well-being (comfort of environment/recreational activities/sports);

b. social aspects;

c. safety and security;

d. health promotion (for technical evaluators only).

Each indicator was assessed through a group of related questions, the answers to which present four levels of satisfaction (very satisfactory, fair, not very satisfactory, or unsatisfactory). The answers very satisfactory/ fair and not very satisfactory/unsatisfactory were considered as positive and negative answers, respectively. An Excel spreadsheet elaborates the answers given by assigning a score to each theme based on the amount of positive answers obtained out of the total number of valid answers, with the following limits: full score, half score, and no score when positive answers were > 66%, 33-66%, and < 33%, respectively. The sum of the scores obtained amounts to the indicator's final score (from 0 to 5 points total).

The hospital facility's final evaluation score (from 0 to 100 points) is calculated as the weighted amount of scores achieved in all four indicators. The process of calculation considers the user-given and health care facility's incidence on the improvement, besides it looks at a minimum resource cost. The weight of the different indicators used by the tool was evaluated as shown in Table 10.

Table 10. Weight of the different indicators used by the Table P-tool	
INDICATOR	WEIGHT(%)
Well-Being	13
Social Aspects	38
Safety and Security	42
Health Promotion	7
Total	100

Areas scoring > 50% negative answers were considered “critical”, that is, as having the need for possible improvements by increasing reception and comfort quality. In order to be effective, the tool must be distributed to a large percentage of hospital personnel (at least 10% of medical personnel and three evaluating technicians of a facility) and 10% of the parents of patients, based on the average number of daily patients.

2.2.3 Children rating of perceived HOC

Perceived HOC by children was evaluated throught the Tools for the assessment and improvement of children’s rights in hospital, prepared by the Task Force on Health Promotion for Children and Adolescents in and by Hospitals [16]. The tools are based on seven standards, which derive from the CRC, charters and working documents, and the findings from an earlier pilot. The standards translate the rights enshrined in the CRC and related dimensions into actual measures and

activities that health professionals and managers can apply in the delivery of health care for children (Table 11). The Manual and Tools consists of a guide for assessment and improvement and five assessment tools on children's rights targeting hospital management, health professionals, parents/caregivers, 12- to 18-year-old children and adolescents, and 6- to 11-year-old children. The first four tools assess the eight standards through 22 sub-standards and approximately 72 measurable items each (statements or questions) for each group of stakeholders. The tool for 6- to 11-year-old children consists of a short questionnaire. A template for focus group discussions with parents/caregivers and 12- to 18-year-old children and adolescents is also provided. The questions are adapted to each group, but they aim to address and collect information on the same issues in order to gather complementary and reliable data. The tools implement a human rights-based approach to health and address the following elements specifically:

1. ***quality of care***: the overall aim of the tools is to assess children's right to health and related rights as a means to improve quality of care for children delivery (article 24 of the CRC);
2. ***participation***: children, parents, health professionals, and managers participate in the assessment of standards and identification of gaps

for improvement. Standard 4, on information and participation, assesses children's participation in their own care and in the design, development, and assessment of services (article 12 of the CRC);

3. ***access***: Standard 2, on equality and non-discrimination, assesses the dimensions of access (Article 2 of the CRC);
4. a***ccountability***: the tools enable to verify the implementation of the actual national programs and hospital policies against the real delivery of care for children and moreover facilitate a monitoring and evaluating system of the quality of care for children;
5. ***capacity building***: the tools facilitate the raising of the stakeholders' awareness , both duty-bearers and rights-holders on children's rights in health [71].

Table 11. Description and aim of the standards, Manual and Tools for the assessment and improvement of children's rights in hospitals (2012).

Standard	Description	Aim
1	Quality services for children	• To assess: - adoption of evidence-based clinical guidelines; • monitoring and evaluation activities; • adoption of a Charter on Children'sRights in Hospital; • parents'/caregivers' right to accompany their child at all times during hospitalization; • provision of adolescent-friendly healthservices.
2	Equality and non-discrimination	To assess: • rights of accessibility and acceptability; • delivery of patient-centered care that recognizes the child's individuality, diverse circumstances, and needs; • right to privacy
3	Play and learning	To assess: • adoption and implementation of play and learning activities; • whether children's views are taken into account in the planning and improvement of playrooms/play spaces.
4	Information and participation	To assess: • policies and practices on right to information and participation in children'sown care and in the development of services.
5	Safety and environment	To assess: • friendliness, safety, cleanliness, and appropriateness of hospital infrastructures; • right to food.
6	Pain management and palliative care	To assess: • the appropriateness and effectiveness of pain management and palliative care services.

Chapter 3

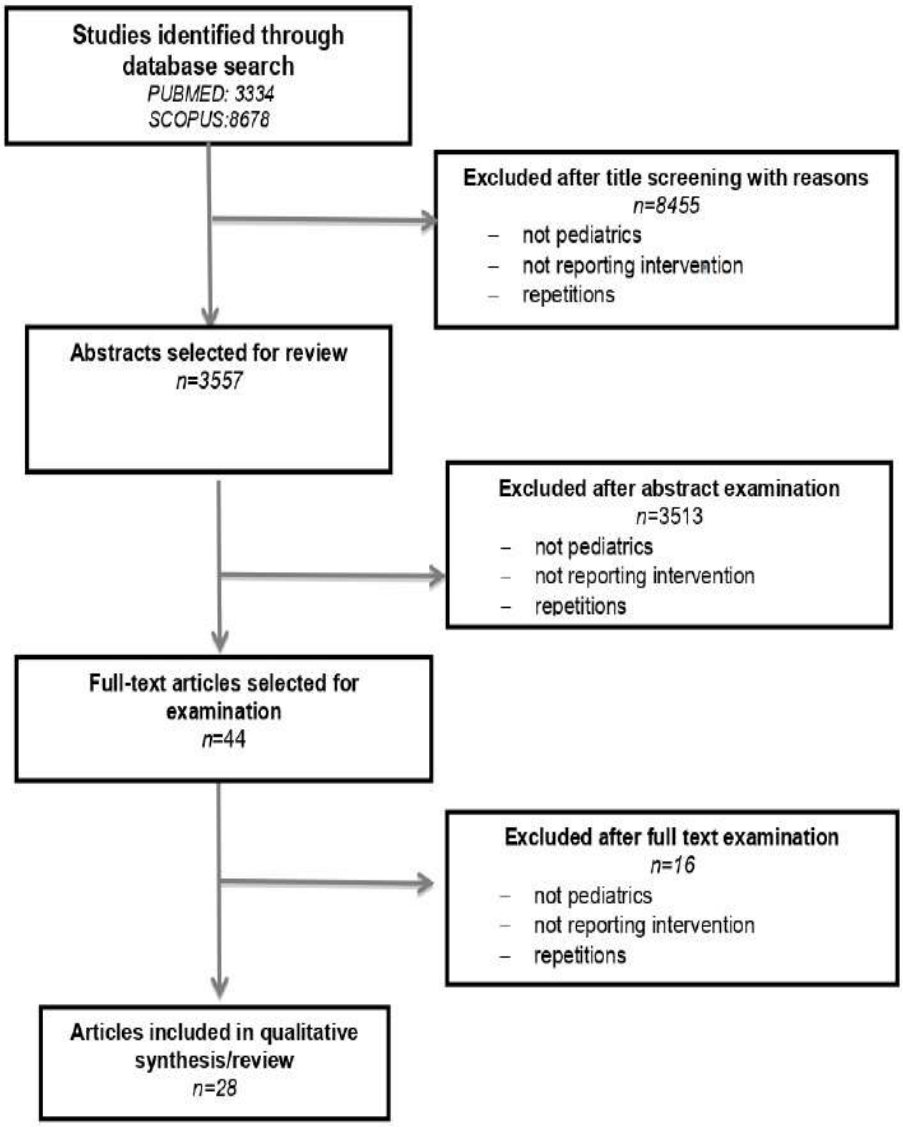
Results

3.1 SEMI-SYSTEMATIC REVIEW OF HOC INTERVENTIONS

From the 12,012 retrieved studies (3334 in PubMed and 8678 in Scopus), 28 were considered eligible for analysis as part of a comparison of pre- vs. post-intervention (n = 21) or verification of user satisfaction (n = 7) (Figure 1). The selected papers are shown in Tables 12-17. According to the Quality Rating Scheme for studies and other evidence [69], most of the included studies were of moderate to low quality [most of the selected studies were case–control studies and a minority were case series (type 4)]. Only six of the included studies were of high quality [five were randomized controlled trials (type 1), and one was a well-designed controlled trial without randomization (type2)]. Only for two RCTs, randomization is adequate, but in all RCTs, statistical analysis is appropriate (Tables 4-8). The seven most prevalent areas of interventions were environment, FCR, pet therapy, provider–patient relationship, psychological support, staff training,

and technology (Figure 2). Studies were mostly conducted in the USA [72-86], Canada [87, 88], Iceland [89], Iran [90, 91], Italy [92-95], Mexico [96], South Africa [97] and Israel [98, 99].

Figure 1



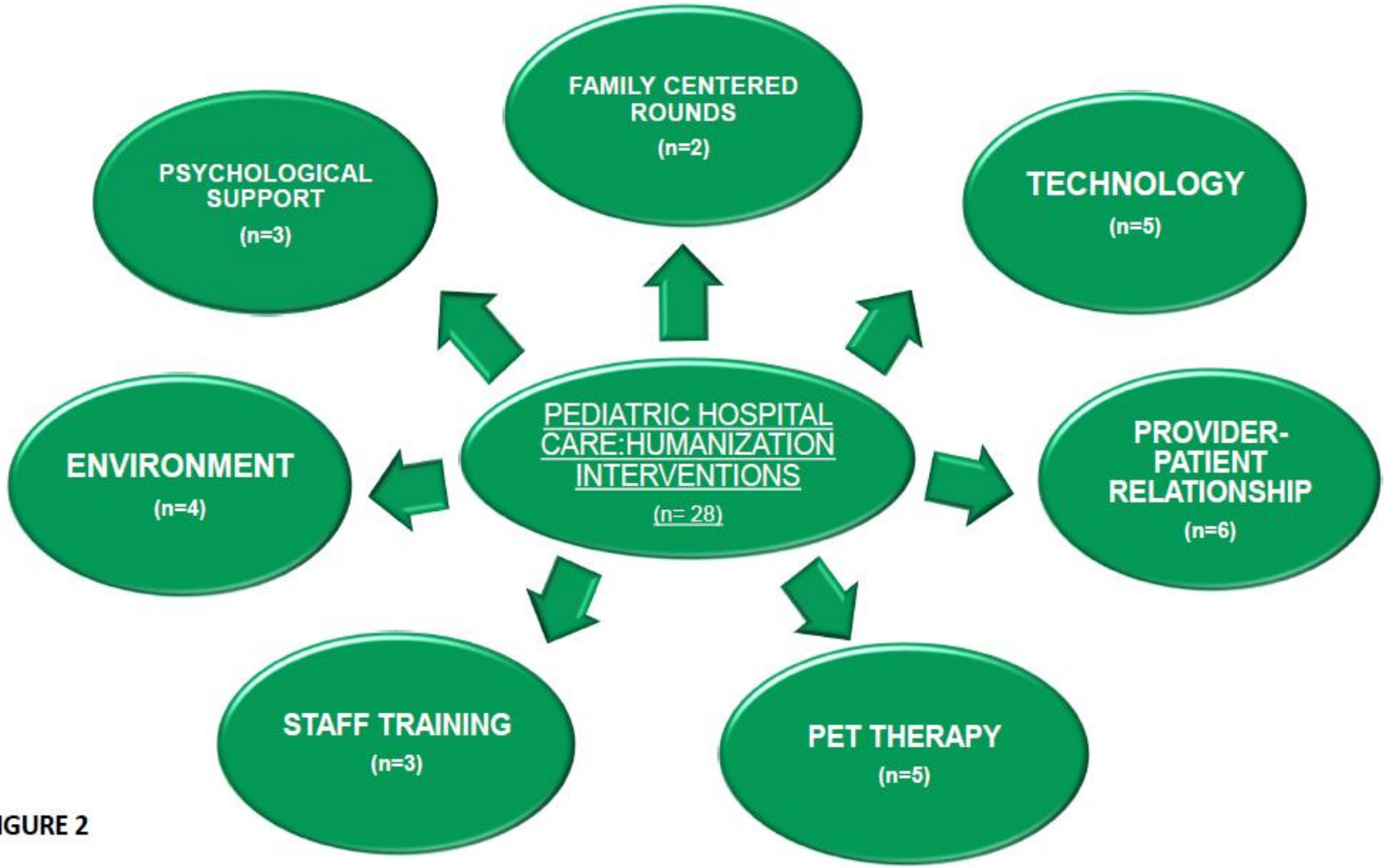

FAMILY CENTERED ROUNDS
(n=2)
PSYCHOLOGICAL SUPPORT
(n=3)
TECHNOLOGY
(n=5)
ENVIRONMENT
(n=4)
PEDIATRIC HOSPITAL CARE:HUMANIZATION INTERVENTIONS
(n= 28)
PROVIDER-PATIENT RELATIONSHIP
(n=6)
STAFF TRAINING
(n=3)
PET THERAPY
(n=5)

FIGURE 2

3.1.1 Populations

The included studies were conducted exclusively in general pediatric wards. On the whole, they regarded providers, parents, and children. In particular, four studies involved staff and parents [80, 81, 93, 97] one of which pediatrics residents as well [80]; four studies were conducted among parents and children [73, 94, 98, 99]; six among only parents [74-76, 78, 86, 89]; eight studies only children [72, 77, 83, 85, 90, 91, 95, 96]; four studies among staff, of which two also involved pediatrics residents [79, 82, 84, 88]; two studies included evaluation by staff, parents, and children [87, 92]. In total, the included studies considered 3345 parents, 2107 staff members, and 2934 children.

3.1.2 Interventions

As shown in Tables 12-17, there was a wide range of interventions across the included studies, which can be categorized as follows:

- in four studies (Table 12), HOC intervention regarded the environment: structural features [81] (e.g., light, noise, comfort), colored walls [93], children and family - friendly signage [97], and an interactive screen as killtime [87];

- two studies (Table 13) regarded the use of family-centered rounds as a model to conduct the rounds on pediatric wards [73, 83];
- in five studies (Table 14), pet therapy was realized for hospitalized children [72, 77, 85, 92, 94];
- three studies (Table 15) were aimed at improving the psychological and emotional support for children [96] also helped by clown therapy [95, 99];
- the provider–patient relationship (Table 15) was the issue of six studies including interventions such as continuity of care [75], family-centered care approach [91], dialog between nurses and parents [89], use of colored clothing for nurses [90], badges for providers [74], and displaying staff photographs [98];
- three studies [82, 84] (Table 16) regarded interventions through staff training, one of which addressed to residents [82];
- technology implementation was the topic of five studies (Table 17), including interventions regarding the use of tablets [76], handheld electronic devices [79], integrated personal health record [86], e-consultation [88], and an inpatient portal [78].

TABLE 12. Four studies reporting measured interventions of humanization of pediatric care about ENVIRONMENT

REF/COUNTRY [STUDY DESIGN]	SAMPLE SIZE	INTERVENTION	OUTCOME/ OBJECTIVE/ EVALUATION OF	RESULTS	Pre Post	Sat
ENVIRONMENT						
Monti [93] 2012 Italy [pre-postdescriptive]	Pre: 200 Parents, 25 Staff Post: 200 Parents, 25 Staff	**Painting**	Effects of a painting intervention on the perception of emotional qualities of the place	Parents: all 4 positive emotional domains*** reported significant better scores post-intervention(P<0.001); all 4 negative domains*** showed lower scores post-intervention Staff: environment significantly more exciting, pleasant, stimulating and less gloomy post- intervention P<0.05);	X+	
Kotzer [81] 2011 USA [pre-post descriptive]	Pre: 812 Staff; 138Parents Post: 890 Staff; 67 Parents	**Improving hospital environment**	Impact of an existing and newly built hospital environment on family and staff satisfaction.	Family satisfaction scores→B: from 2.84/5 to 4.34/5 vs A: from 3.97 to 4.89; p<0.01 Staff satisfaction scores→ statistically significant improvement (p < .05) in most areas (layout of room, natural light, storage and writing surfaces, and comfort and appeal).	X+	
Leonard [97] 2014 South Africa [Satisfaction study]	25 Parents 25 Staff	**Family- friendly signage**	Family friendly environment pre/post developing a new signage: 44 signs replacing old ones.	The new signs were considered noticeable, attractive and easily understandable (rapid appraisal questionnaire mean score approximately 4,5/5)		X
Biddiss [87] 2014 Canada [Satisfaction study]	10 Staff 6 Parents 11 Ctrls	**Screen Display (SD)**	Effects on healthcare waiting experience related to an interactive SD in a pediatric hospital waiting space.	Positive experience accessible to children, youth and adults of all motor abilities. All participants strongly agreed that Intervention would improve the healthcare waiting experience. (children: 100% would play again, 100% was safe, 100% got along with others, 100% had fun, 0% bored, 0% disinterested 0% felt left out)		X

ABBREVIATIONS.

A: after; B: before; Ctrls: control group; Pre-Post: Before vs After intervention or control group vs. experimental group; Sat = satisfaction; **X = study with (+)/without (-) positive satisfaction or results Before/After intervention with a control group vs. experimental group.**

NOTES.

*** Four positive affective domains (Relaxing, Exciting, Pleasant, Stimulating); Four negative domains (Distressing, Gloomy, Unpleasant, Sleepy/Boring).

TABLE 13. Twostudies reporting measured interventions of humanization of pediatric care about FCR						
REF/COUNTRY [STUDY DESIGN]	**SAMPLE SIZE**	**INTERVENTION**	**OUTCOME/ OBJECTIVE/ EVALUATION OF**	**RESULTS**	**Pre Post**	**Sat**
FAMILY CENTERED ROUNDS						
Oshimura [83] 2014 USA [retrospective study]	Pre/Post 912 Children	**Family centered rounds (FCR)**	Time to discharge; Time to Study Completion MRI/EEG.	Pre: 40% discharged before 3:00 PM. Post:47% discharged before 3:00 PM (P = .0036). Time to study completion for MRIs and EEGs: 2.15 hours pre-FCR vs. 1.73 hours post-FCR (P.001).	X+	
Cox [73] 2017 USA [randomized trial]	298 families	**Family-CenteredRounds (FCR) Checklist**	The performance of 8 FCR checklist elements and family engagement from 673 pre- and post-intervention FCR videos	The intervention significantly increased the number of FCR checklist elements performed (P < .001). Intervention rounds were significantly more likely to include asking the family (odds ratio [OR] = 2.43, P < .05) or health care team (OR = 4.28, P = .002) for questions and reading back orders (OR = 12.43, P < .001)	X+	

ABBREVIATIONS.

Ctrls: control group; CI: confidence interval; EEG: Electroencephalography; EG: experimental group; FCR: Family centered rounds; MRI Magnetic Resonance Imaging; OR: odds ratio; Pre-Post: Before vs After intervention or control group vs. experimental group; Sat = satisfaction; X = study with (+)/without (-) positive satisfaction or results Before/After intervention with a control group vs. experimental group

TABLE 14. Five studies reporting measured interventions of humanization of pediatric care about PET THERAPY						
REF/COUNTRY [STUDY DESIGN]	**SAMPLE SIZE**	**INTERVENTION**	**OUTCOME/ OBJECTIVE/ EVALUATION OF**	**RESULTS**	**Pre Post**	**Sat**
PET THERAPY						
Caprilli [92] 2006 Italy [pilot study]	138 Children 55 Staff 46 Parents	**Animal Assisted Activity**	Reactions of Ctrls, Parents and Staff and infection rate pre/post pets introduction.	Meetings with the animals create a sense of children well-being and comfort. Positive event due to patient's participation, parents (100% favourable) /medical staff (92% favourable) satisfaction. The Hospital Committee of Infectionsdidn't find an increase in infections transmitted by dogs during Intervention	**X+**	
Kaminski [77] 2002 USA [critical review]	EG: 40 Children Ctrls: 30 Children	**Play and Pet therapy**	Pet therapy and play enhancing experiences effects on hospitalized children	Both therapies have been enhancing experiences for the child (p =0 .165). Heart rates, (significantly higher in the EG 99.27 ± 16.38 vs CG 88.44 ± 12.68) parent's ratings of the child's mood (B vs A p<0.001) and display of positive affect were enhanced in EG. Salivary cortisol decreased in both groups (CG:18ng/dl vs EG 22ng/dl P>0.05)	**X+**	
Sobo [85] 2006 USA [pilot study]	25 Children	**Pet- therapy**	Pet therapy effectiveness on acute post-operative pain.	Pet therapy significantly reduced perceived pain (Physical pain score Pre: 3.79 vs Post: 1.64 p = .001; Emotional pain score Pre:3.89vs Post : 1.24 p = 0.000)	**X+**	
Stinchi [94] 2012 Italy [satisfaction survey]	1236 Children 836 Parents	**Animal-Assisted Activity(AAA)**	Effectiveness of pet therapy on several aspects of hospitalization.	Positive effects on children (improvement of their phobias to the animals overcoming Pre:60% vs Post 20% scared; 85%loves animals; 93% liked playing with them), on parents (89% favourable) and staff (87% favourable, 93% AAA useful for child, 62% AAA 97% improved work in ward)		**X**
Branson [72] 2017 USA [randomized controlled study]	EG:24Children Ctrls: 24Children	**Animal-assistedActivities (AAA)**	Effectiveness of animal-assisted activities (AAA) on bio-behavioral stress responses (anxiety, positive and negative affect, and salivary cortisol and C-reactive protein [CRP] levels) in hospitalized children.	Differences between the AAA and control conditions were not significant. Increases in positive affect were larger in the AAA condition. Decreases in negative affect were larger in the AAA condition. In addition, pre- and post-intervention differences between the conditions in salivary cortisol and CRP were not statistically significant. Baseline levels of anxiety, cortisol, and CRP had a significant and large correlation to the corresponding post-intervention measures. Scores on the Pet Attitude Scale were high but were not associated with changes in anxiety, positive affect, negative affect, or stress biomarkers.	**X+**	

ABBREVIATIONS.

Ctrls: control group; Pre-Post: Before vs After intervention or control group vs. experimental group; Sat = satisfaction; X = study with (+)/without (-) positive satisfaction or results Before/After intervention with a control group vs. experimental group.

TABLE 15. Nine studies reporting measured interventions of humanization of pediatric care about PSYCHOLOGICAL SUPPORT (n.3) and PROVIDER-PATIENT RELATIONSHIP (n.6)						
REF/COUNTRY [STUDY DESIGN]	**SAMPLE SIZE**	**INTERVENTION**	**OUTCOME/ OBJECTIVE/ EVALUATION OF**	**RESULTS**	**Pre Post**	**Sat**
PSYCHOLOGICAL SUPPORT						
Viggiano [95] 2015 Italy *[randomized controlled study]*	40 children (15 for clown show, 12 for dog interaction, 13 for musicians) Ctrls : 65 Children	**Clown show, animal assisted intervention and live music**	Impact of psychological interventions on reducing anxiety, fear levels and the need for sedation in children undergoing magnetic resonance imaging	In the EG, the activities had a beneficial effect on the patients' emotional status with a decreasing of both anxiety and fear level (P<0.01 and P<0.001 respectively. The effect of activity experience on need for sedation was statistically significant (P<0.025). The need for sedation was less in those children who engaged in one of the activities compared to the control group. Furthermore, the main effect of age was found (P<0.001): a decreasing of need for sedation was observed to a greater extent in older children compared with younger ones.		**X+**
Batún-Cutz [96]2016 Mexico *[case-control study]*	47children (20 emotional intervent; 27 play intervention)	**Emotional intelligence (IE)** and **game (G)**	Interventions and aimed to reduce negative affect and maintain or increase positive affect	93% of the patients who received IE increased or maintained their positive affect, 55% of the patients who received G increased or maintained their positive affect. Considering both treatments, 77% of the patients presented therapeutic improvement. Game intervention decreases Negative affect (p<0,001), while the emotional intelligence intervention decreases Negative affect (p<0,001) and increases Positive affect (p= 0,014). Both interventions improve the emotional state of hospitalized children.	**X+**	
Goldberg [99] 2014 Israel *[randomized controlled study]*	91 children and parents	**Clown show, video tape**	To evaluate whether medical clowns can diminish pain and anxiety perceived by children undergoing allergy skin prick tests.	A significant reduction in State-Trait Anxiety Inventory was found in the clowns group, in both parents and children, when compared with Ctrl (P = 0.004, and P = 0.002, respectively). Both anxiety score (videotapes recorded during the procedure, m-YPAS) and pain score (FLACC) were reduced in the clowns group compared with Ctrls. In the clowns group, m-YPAS positively correlated with both Visual Analog Score for pain and FLACC (P = 0.000 and 0.002, respectively). m-YPAS was positively correlated with FLACC in the regular group(P = 0.000).		**X+**
PROVIDER-PATIENT RELATIONSHIP						
Flippo [75] 2015 USA *[pre-post intervention study]*	15 Parents	**Post discharge phone calls**	Efficacy of post discharge phone calls on 30-day preventable readmissions	Pre: 4 readmissions, pre intervention readmission rate = 26% Post: 1 readmission, post intervention readmission rate= 6% Sample size was not large enough to show valid statistical significance (p = 0.53)	**X+**	
Rostami [91] 2012 Iran *[quasiexperimentals tudy]*	EG: 35 Children Ctrls : 35 Children	**Family Centered Care**	Effects of Family Centered Care on satisfaction of parents of children hospitalized in 2012	EG: mean score of satisfaction among parents pre/post intervention: 20/90 vs. 83.2/90. Fourfold increase of satisfaction Significant difference satisfaction scores Ctrls vs. EG (p <0.001 paired sample t test)	**X+**	
Svavarsdottir [89] 2012 Iceland	EG: 41 Parents Ctrls: 35 Parents	**Short- term therapeutic conversation**	Effectiveness of a short-term therapeutic families-nurses conversation	Significant difference EG vs Ctrls in: perceived cognitive support (P=0.011 ANOVA); emotional communication (p=0.04 ANOVA); collaboration and problem solving (p=0.049), verbal communication (p=0.024 ANOVA) No significant benefit for	**X±**	

[case-control study]			intervention	families of children with chronic illnesses *vs.* Ctrls.		
Roohafza [90] 2011, Iran *[clinical trial]*	EG: 47 Children Ctrls: 45 Children	**Colored clothing for nurses**	Effects of white vs. colored nurses clothing on anxiety levels	Higher global anxiety levels in Ctrls vs EG (entry 10.04 ± 4.71 discharge 14.14 ± 4.13 *vs* entry 11.24 ± 5.51 discharge 12.35 ± 5.64; P ≤ 0.05 paired t test)	**X+**	
Dudas [74] 2010 USA *[prospective mixed method study]*	EG: 49Parents Ctrls: 51 Parents	**PHACES tool** (information sheet with photo and training level of medical providers)	Effectiveness of PHACES tool on parent's ability to identify child's providers and on tolerating trainees in the staff	82% were able to name at least one provider, more likely to correctly match the face with the name of the trainee (67% vs 14%; P < .01Multiple logistic regression) and doctors (80% vs 24%; P <.01 Multiple logistic regression), to report medical students involvement acceptance and an improved understanding of their roles	**X+**	
Bretler [98] 2016 Israele *[prospective, comparated study]*	Pre/Post 100 (Children/Parents)	**Staff Photographs**	Displaying staff photographs in prominent locations helps children and their parents to recognize staff	Phase 1: no photographs were displayed. Phase 2: staff photographs were placed in prominent locations throughout the pediatric ward. The children named a significantly larger number of staff members in phase two than phase one, while the parents' score was unchanged. Overall parental satisfaction was significantly higher in phase 2 (3,7 vs 3,1, p< 0,001)	**X+**	
ABBREVIATIONS. Ctrls: control group; EG: experimental group; Pre-Post: Before vs After intervention or control group *vs.* experimental group; Sat = satisfaction; X = study with (+)/without (-) positive satisfaction or results Before/After intervention with a control group *vs.* experimental group.						

TABLE 16. Three studies reporting measured interventions of humanization of pediatric care about STAFF TRAINING

REF/ STUDY DESIGN	SAMPLE SIZE	INTERVENTION	OUTCOME/ OBJECTIVE/ EVALUATION OF	RESULTS	Pre Post	Sat
STAFF TRAINING						
Klein [80] 2014 USA *[non randomized controlled study]*	Pre: 141Parents, 47 Staff Post: EG 72 Parents, 24 Staff Ctrls 79 Parents, 23 Staff	**Video curriculum** on resident Social Determinant of Health (SDH) screening competence	impact of a Video curriculum on resident SDH screening competence, parental perceptions, resident referrals to a Medical legal partnership(MLP) and formula distribution to food-insecure families.	EG self-assessed significantly higher vs Ctrls (P≤.05). Parents' rating of trust and respect did not differ between groups. Screening for each SDH significantly higher in EG with domestic violence (OR 2.16, 95% CI 1.01–4.63) and depression (OR 2.63, 95% CI 1.15–5.99), MLP referral rates increased (P=.06), and formula distribution (P=.02) reached statistical significance in the EG.	X+	
Mann [82] 2013 USA *[quasi experimental non randomized approach with a pre test post test design]*	EG: 24 Staff Ctrls: 18 Staff	**Patient and Family Centered Care** (PFCC) **Curriculum**	PFCC Curriculum impact on residents' self-perceptions of PCC behavior.	Both groups completed the Patient Practitioner Orientation Scale (PPOS). No difference in total/subscale PPOS scores. The 17 female interns in EG were more patient centered than the 6 male interns (P =.005), scoring significantly higher in the sharing domain (P=.001).	X-	
Ottolini [84] 2011 USA *[pre post intervention study]*	14 Staff	**Observed Structured Teaching Exercises**	a program to address the need of hospitalists to efficiently teach during FCR	pre- and post- Observed Structured Teaching Exercises scored statistically different (P<.0001). Particular improvements noted in the correction of incorrect clinical reasoning (new patient diagnosis) (56% pre, 86% post) and orientation (65%pre, 95% post).	X+	

ABBREVIATIONS.

Ctrls: control group; EG: experimental group; OR: odds ratio; Pre-Post: Before vs After intervention or control group *vs.* experimental group; Sat = satisfaction; X = study with (+)/without (-) positive satisfaction or results Before/After intervention with a control group *vs.* experimental group.

TABLE 17. Five studies reporting measured interventions of humanization of pediatric care about TECHNOLOGY						
REF/COUNTRY [STUDY DESIGN]	**SAMPLE SIZE**	**INTERVENTION**	**OUTCOME/ OBJECTIVE/ EVALUATION OF**	**RESULTS**	**Pre Post**	**Sat**
TECHNOLOGY						
Gottlieb [68] 2014 USA [randomized trial]	EG: 285 Parents Ctrls: 253 Parents	**Social screening via tablet computer versus a face-to-face interview**	Impact on social needs reporting via computer-based questionnaire vs. face-to-face interviews	Rates of reporting on the more sensitive issues significantly higher in EG vs CG (household violence P=0.03, substance abuse P=0.05); disclosure marginally higher in EG for financial insecurity (P=0.10) and neighborhood and school safety (P=0.09) Higher endorsement in the EG (70%) vs CG (30%).	**X+**	
Tom[78] 2012 USA [cross sectional study]	256 Parents (65% users vs 35% non-users)	**Integrated Personal Health Record**	Use of Integrated Personal Health Record among parents of children with chronic disease.	65% Integrated Personal Health Record users vs. 35% non users Top Integrated Personal Health Record uses: viewing immunization records, medical records, messaging, scheduling appointments. Top reasons not using Integrated Personal Health Record "too busy," "forgot password," "my child does not have health care needs."	**X-**	
Kern [71] 2015 USA [anonymous electronic cross sectional survey]	140 Staff	**Handheld Electronic Devices**	Handheld Electronic Devices use by pediatric hospitalist, benefits/barriers in FCR on trainee education and family interactions with the staff.	92% use a smartphone; 56% a tablet. 76% use an Handheld Electronic Devices in daily work activities, 24% never used Handheld Electronic Devices at work. 81% practice FCR → 34% use it during FCR. Common Handheld Electronic Devices uses: medical reference, personal use, pharmacology database. Barriers: connectivity, concerns of infection control.		**X+**
Kelly[70] 2017 USA [cross-sectional study]	296 Parents	**MyChart Bedside: inpatient portal application on a tablet computer**	A portal application on a tablet computer that provides information about a child's hospital stay	Parent survey respondents (N= 90) were satisfied with the portal (90%), reporting that it was easy to use (98%), improved care (94%), and gave them access to information that helped them monitor, understand, make decisions, and care for their child. Portal use improved health care team communication (60%).		**X+**
Lai [80] 2018 Canada [Prospective observational cohort study]	367 primary-care-practitioners 23 pediatric specialists	**BASE™ (Building Access to Specialists through eConsultation)**	eConsult in pediatric setting to improve healthcare system process and high provider acceptance	For 515/1064 (48.4%) referrals, primary-care- practitioners received advice for a new or additional course of action; 391/1064(36.7%) referrals resulted in an averted face-to-face specialist visit. In 9 specialties with complete data, the median wait-time was significantly less (p<0.001) for an eConsult (1 day, 95%CI:0.9-1.2) compared with a face-to-face referral (132 days ??; 95%CI:127-136). The majority (>93.3%) of primary-care- practitioners rated eConsult as very good/excellent value for both patients and themselves. All specialist survey-respondents indicated eConsult should be a continued service.		**X+**

ABBREVIATIONS.

Ctrls: control group; CI: confidence interval; EG: experimental group; FCR: Family centered rounds; OR: odds ratio; Pre-Post: Before vs After intervention or control group vs. experimental group; Sat = satisfaction; X = study with (+)/without (-) positive satisfaction or results Before/After intervention with a control group vs. experimental group.

3.1.3 Outcomes of interventions addressing parents/children/staff

3.1.3.1 Environment

In the hospital setting, a BFamily-friendly^ signage was used to improve parental satisfaction by facilitating orientation to and around the hospital and the access to information [97]. Similarly, the effect of Screen Play, an interactive display located in the waiting room, was appreciated for improving the waiting room experience for both parents and children [87]. Pictorial interventions led to a significant increase in measured humanization [93] and were appreciated by children's parents and staff. Similarly, improved lighting, sound, room temperature, color and decoration, entertainment, and privacy safeguards provided a statistically significant increase in comfort for both parents and staff members compared with baseline findings [81]. Overall, attention to these environmental aspects appears a useful and easy to realize tool for implementing a child-friendly hospital setting.

3.1.3.2 Family-centered rounds

The practice of FCR led to a modest but significant reduction in time of discharge compared to traditional rounds [83]. Checklist implementation was associated with changes in family engagement

and more positive perceptions of safety climate, ultimately leading to FCR delivery improvement [73].

3.1.3.3 Pet therapy

Pet therapy classically promoted the well-being of children by improving social skills and interactions during the hospital stay [92, 94], significantly reducing pain perception [85] and contributing to overcome fears of animals and increase selfefficacy [94]. This strategy provided additional support when associated with play [77]. Although animal-assisted activities appear to have a beneficial effect, usefulness in reducing biobehavioral stress in hospitalized children however could not be well documented [72].

3.1.3.4 Psychological support

Hospital clowns played a significant role in reducing stress and anxiety levels in children admitted to hospitals as well as their parents. In particular, clown show joined with dog interaction and live music had high effectiveness in reducing the level of anxiety and fear and decreased the need for sedation in children undergoing magnetic resonance imaging [95]. Emotional support interventions, therapeutic

games, and medical clown shows involved a significant increase in positive effects and reduction in negative effects in hospitalized children [96, 99].

3.1.3.5 Provider–patient relationship

When staff members (including trainees) were provided with identification badges (including pictures and level of training), parents could better identify their children's caregivers and showed a more significant acceptance of the presence of doctors-in-training than a control group [74]. When children better-recognized hospital staff in respect of a control group, this indirectly improved parental satisfaction, although the number of staff members identified by parents remained unchanged. Displaying staff photographs was a simple way to increase parental satisfaction during the child's hospitalization [98]. A brief 15-min meeting between nurses and parents during a child's hospitalization (Bshort-term therapeutic conversation^) significantly improved some aspects of family support: perceived cognitive support, emotional communication, collaboration and problem-solving, and verbal communication. A significant benefit was observed only for families of children affected by acute illnesses and not for those with chronic diseases [89]. The use of a family-

centered approach led to a fourfold increase in parental satisfaction regarding their children's care during hospitalization [91]. The introduction of a post-discharge phone call to the family (conducted according to the family-centered approach) resulted in a marked although not statistically significant reduction in the rate of re-admissions after discharge [75]. Compared to white uniforms, colored nurse uniforms appeared to effectively reduce child anxiety and promote relationships with the young patients [90].

3.1.3.6 Staff training

The use of a Bvideo curriculum^ to train doctors in investigating the social determinants of health (SDH, related to the social conditions at birth, during growth, and depending on work and age) during medical history collection led to a twofold increase in doctors' perceptions of their SDH screening ability. This positive result, however, was not mirrored by a parallel increase in parental satisfaction [80]. Another study was focused on physicians' perceptions of their own training level, after a training program on patient- and family-centered care curriculum. An evaluation of the program's effectiveness revealed that there was no significant difference between intervention and control groups. However, female doctors of the experimental group were

found to be significantly more patient-centered and scored significantly higher on the same domain in respect of male colleagues [82]. The use of workshops and tutorials (Observed Structured Teaching Exercise, OSTE) appeared to be useful for improving medical education programs during FCR, leading to the correction of errors in clinical reasoning (new patient diagnosis) and coordination [84].

3.1.3.7 Technology

In a survey on the use of handheld electronic devices (HEDs), 75% of pediatricians declared to use it, but only one third during FCR. Most of the physicians interviewed in the study supported the use of HEDs as an educational tool for doctors-in-training [79]. Compared to the traditional anamnestic interview, the use of tablets represented a more effective tool for anamnestic data collection while in the emergency department, especially for investigating SDH (e.g., when assessing sensitive topics, such as child safety and household member substance use) [76]. Champlain BASE™ (Building Access to Specialists through eConsultation) was a Web-based Asynchronous for an electronic communication service that allows primary-care-practitioners (PCPs) to submit Belective^ clinical questions to a specialist. Similarly,

eConsult improbe PCP access and timeliness to elective pediatric specialist advice and influenced their care decisions, while reporting end-user satisfaction [88]. Parents of children with chronic diseases were persuaded to use an electronic Personal Health Record device (PHRs), which could have helped them to evaluate laboratory tests, recall visit reports or treatment plans, and communicate the current health condition of their child. The system also helped to plan therapy or send messages to physicians. However, there was no statistically significant difference in addressing the healthcare needs of the child when comparing the parents who used this technology and those who did not [86]. Parents instead were satisfied with an in-patient portal. Portals might engage parents in hospital care, facilitate parent recognition of medication errors, and improve perceptions of safety and quality [78].

3.2 EXISTING/PERCEIVED HOC DEGREE

3.2.1 Degree of existing HOC (AGENAS checklist)

The items that obtained the lowest scores in different areas in the seven departments are summarized in Table 18. Overall, the most critical issues that emerged in the seven departments concern are summarized below.

Area 1 ("*Care and organizational processes oriented to the respect and specificity of the person*") obtained scores ranging between 2.5 and 4. In particular, the items on psychological support function, hospitalization without pain, continuity of care, and respect for privacy and linguistic specificities obtained the lowest scores.

Area 2 ("*Physical accessibility, livability, and comfort of the places of care*") identified that the level of comfort at waiting rooms and orientation and signage in hospital was deficient in all facilities.

Area 3 ("*Access to information, simplification, and transparency*") was characterized by Item 3.2.2 (*Access to information*) that obtained scores ranging between 0.5 and 6.5.

Area 4 ("*Care of the relationship with the patient*") had scores ranging between 2.5 and 6.7: staff training and communication care were poorly implemented aspects.

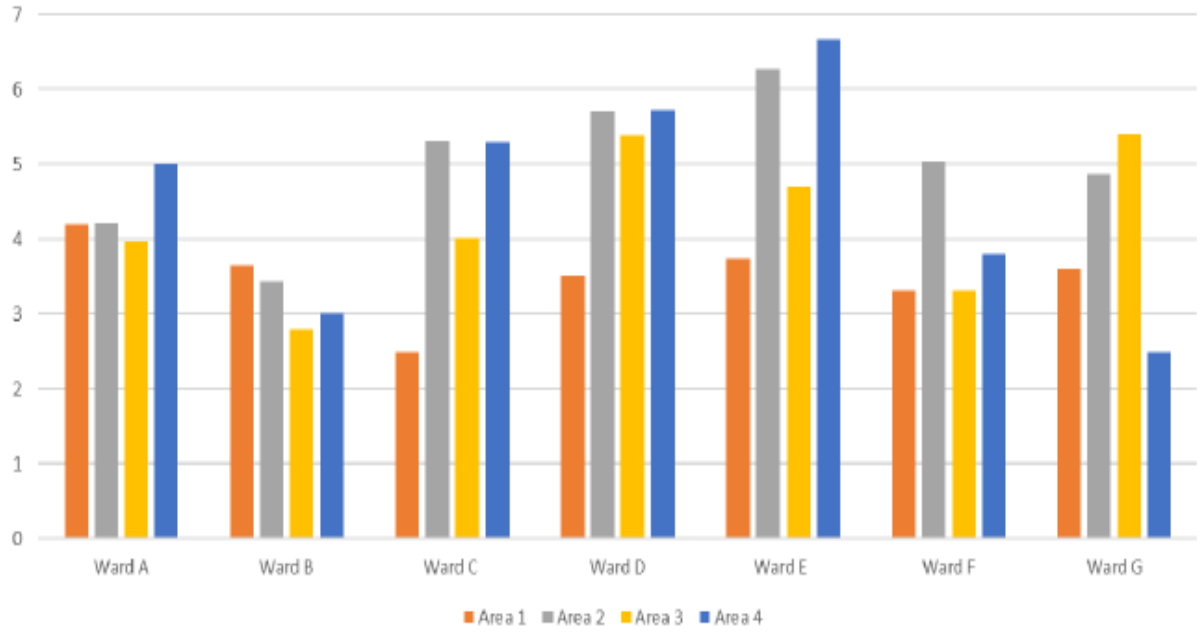
Average values obtained in each area of the AGENAS checklist for the seven wards analyzed are shown in Figure 3. Altogether, the specific critical issues were regarding respect for anonymity, respect for linguistic specificities, continuity of care (including dialogue with the family pediatrician), and staff training. In addition, the equipment and characteristics of the hospital wards were not sufficiently "child-friendly," although they were not included in the most critical items. (Data not shown; available on request.)

Table 18. Items obtaining the lowest AGENAS' scores (red boxes) in the different areas in the seven (A to G) departments*.

Items	Departments' lowest scores						
	A	B	C	D	E	F	G
1.1.1 Psychological support function	6	0	6	5,63	5	5	5
1.1.4 Hospital without pain	4,67	6,5	2,69	1,67	1,25	4,38	2,86
1.2.2 Respect for privacy	2,2	2	0	0	2	3,33	3,33
1.3.1 Respect for linguistic specificities	2	0	0	6	0	0	0
1.4.1 Continuity of care	1,76	1,76	0,59	0	2,94	1,18	1,18
2.2.1 Orientation and signage	0	0	6,67	10	0	0	0
2.4.1 Comfort of waiting rooms	5,71	0	0	1,43	8,57	5,71	4,29
3.2.2 Access to information	2,5	1	4,5	6,5	5,5	0,5	3,5
4.1.1 Communication care	2,86	1,67	4,33	1,83	5,71	1,43	1,43
4.2.3 Staff training	0	0	0	0	0	0	0

*Categories of hospital facilities:
Children's Hospital [n=1 (A)]
Pediatric Department of University Hospital [n = 2 (B and C)]
General Hospital [n= 4 (D, E, F, G)],

Figure 3 AGENAS pediatric checklist. Average values of scores obtained in each of the 4 areas of the AGENAS pediatric checklist for the seven pediatric wards analyzed. [Children's Hospital (A), Pediatric Department of University Hospital (B and C) and General Hospital (D, E, F, G)]. The vertical axis indicate scores values 0–10. Area 1 ("Care and organizational processes oriented to respect and specificity of the person"). Area 2 ("Physical accessibility, livability and comfort of the places of care"). Area 3 ("Access to information, simplification and transparency"). Area 4 ("Care of the relationship with the patient"). Values < 2.5 are considered "critical".

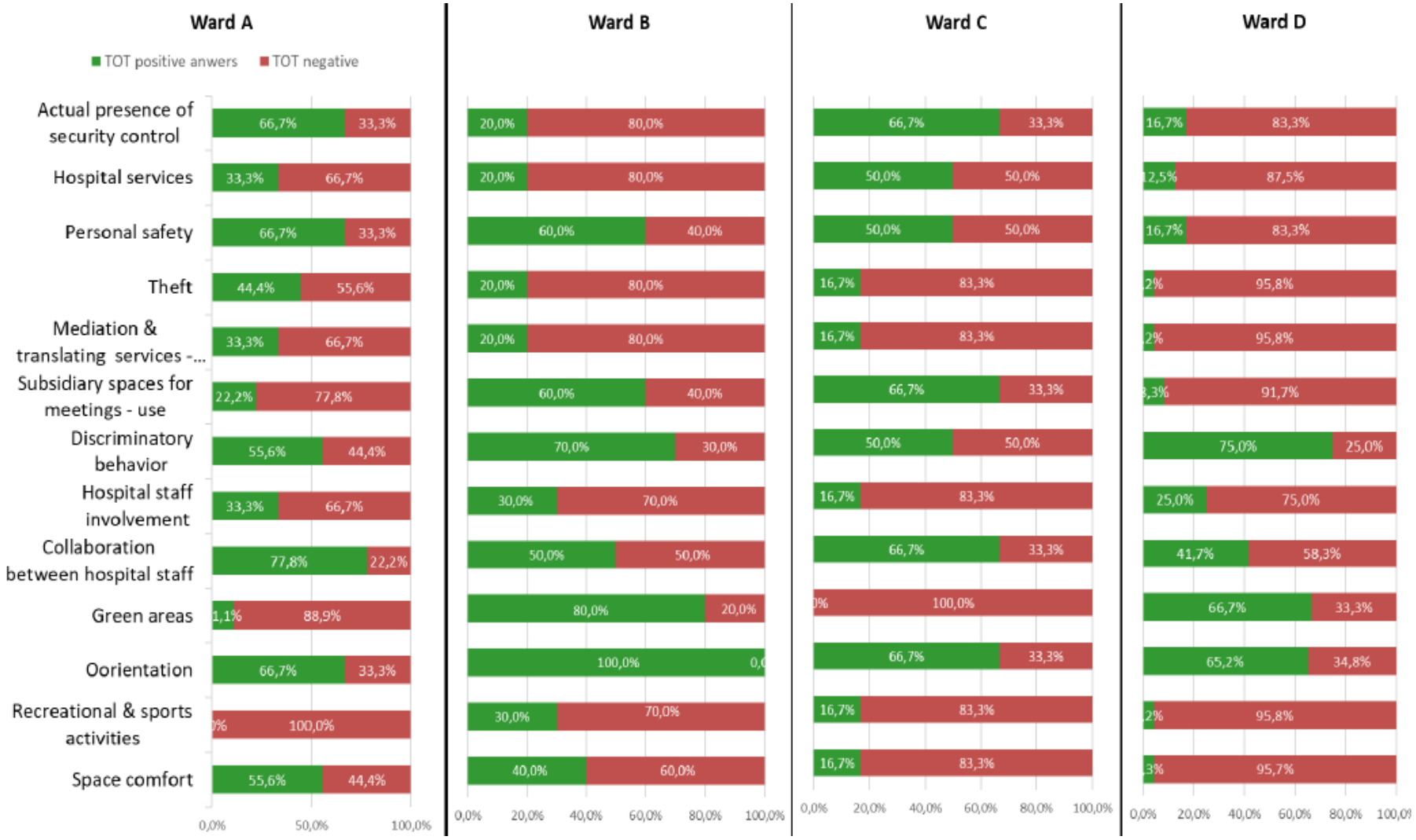


3.2.2 Adult perception of HOC (LpCp-tool)

The analysis of the LpCp-tool results revealed the following information.

1. **Well-being** was perceived by parents as critical in most of the seven facilities, although with some differences. In Ward D (general hospital), parents/ caregivers had a generally negative perception of all aspects; the comfort of the rooms being the most inadequate (66.7% of negative responses; Figure 4). In the remaining six wards, parents'/caregivers' perception of the various aspects of well-being was quite regularly more positive (> 50% of positive feedback). The only exceptions regarded single aspects in Ward C (university department), concerning the (unquestionably) deficient presence of adjacent green areas, and in Ward F (general hospital), regarding the organization of recreational activities (Figure 4).

HOC perception by the staff was quite homogeneous in the seven departments and was generally negative regarding the poor organization of sports and recreational activities. However, the reduced comfort of the environments received more than 50% of positive feedback by the staff of Ward A (children's hospital) and Wards E, F, and G (general hospitals)].


Ward A
TOT positive anwers
TOT negative
Actual presence of security control
Hospital services
Personal safety
Theft
Mediation & translating services -...
Subsidiary spaces for meetings - use
Discriminatory behavior
Hospital staff involvement
Collaboration between hospital staff
Green areas
Oorientation
Recreational & sports activities
Space comfort
66,7% 33,3%
33,3% 66,7%
66,7% 33,3%
44,4% 55,6%
33,3% 66,7%
22,2% 77,8%
55,6% 44,4%
33,3% 66,7%
77,8% 22,2%
1,1% 88,9%
66,7% 33,3%
0% 100,0%
55,6% 44,4%
0,0% 50,0% 100,0%
Ward B
20,0% 80,0%
20,0% 80,0%
60,0% 40,0%
20,0% 80,0%
20,0% 80,0%
60,0% 40,0%
70,0% 30,0%
30,0% 70,0%
50,0% 50,0%
80,0% 20,0%
100,0% 0,
30,0% 70,0%
40,0% 60,0%
0,0% 20,0% 40,0% 60,0% 80,0% 100,0%
Ward C
66,7% 33,3%
50,0% 50,0%
50,0% 50,0%
16,7% 83,3%
16,7% 83,3%
66,7% 33,3%
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16,7% 83,3%
16,7% 83,3%
0,0% 20,0% 40,0% 60,0% 80,0% 100,0%
Ward D
16,7% 83,3%
12,5% 87,5%
16,7% 83,3%
2% 95,8%
2% 95,8%
3,3% 91,7%
75,0% 25,0%
25,0% 75,0%
41,7% 58,3%
66,7% 33,3%
65,2% 34,8%
2% 95,8%
3% 95,7%
0,0% 20,0% 40,0% 60,0% 80,0% 100,0%

The aspect most positively judged by the staff of all seven wards was the orientation within the facilities (Figure 5).

b. **Social aspects** received the highest percentage of positive responses from the parents/caregivers of all seven wards under review. In particular, the absence of discriminatory behavior toward patients and colleagues was the aspect perceived more positively by parents/caregivers and staff [with the exception of Ward E (general hospital) staff, which totalized about 65% of negative feedback] (Figure 4,5). The presence of mediation, translation, and interpretation services evaluated by the questionnaire for hospital staff received the highest percentage of negative responses (Figure 5).

c. The **safety** aspect of all facilities was perceived positively by parents (> 50% of positive responses), with the exception of the presence of surveillance and the risk of infections, which were negatively perceived in Department D (general hospital). Security and safety were negatively perceived by the medical and nursing staff of all seven departments.

d. Organization of prevention and **health promotion** campaigns (questions addressed to assessment technicians) were unsuccessful in all seven departments under examination. The final score obtained by each of the individual facilities is shown in Figure 6. It was based on

the weighted average of each criterion and indicated that the overall perception of the degree of HOC in the different departments in question was positive. Regarding specific aspects investigated by both tools, in most cases, the existing degree of HOC did not concur with what was perceived; that is, the lack of some resources was not evaluated negatively by parents and staff as one would expect. While mediation and interpretation services evenly emerged as lacking in all facilities without inconsistencies between evaluators, parental perceptions and observer ratings of space, comfort, and orientation resulted evenly in the general hospital evaluations, but not in the other two settings.

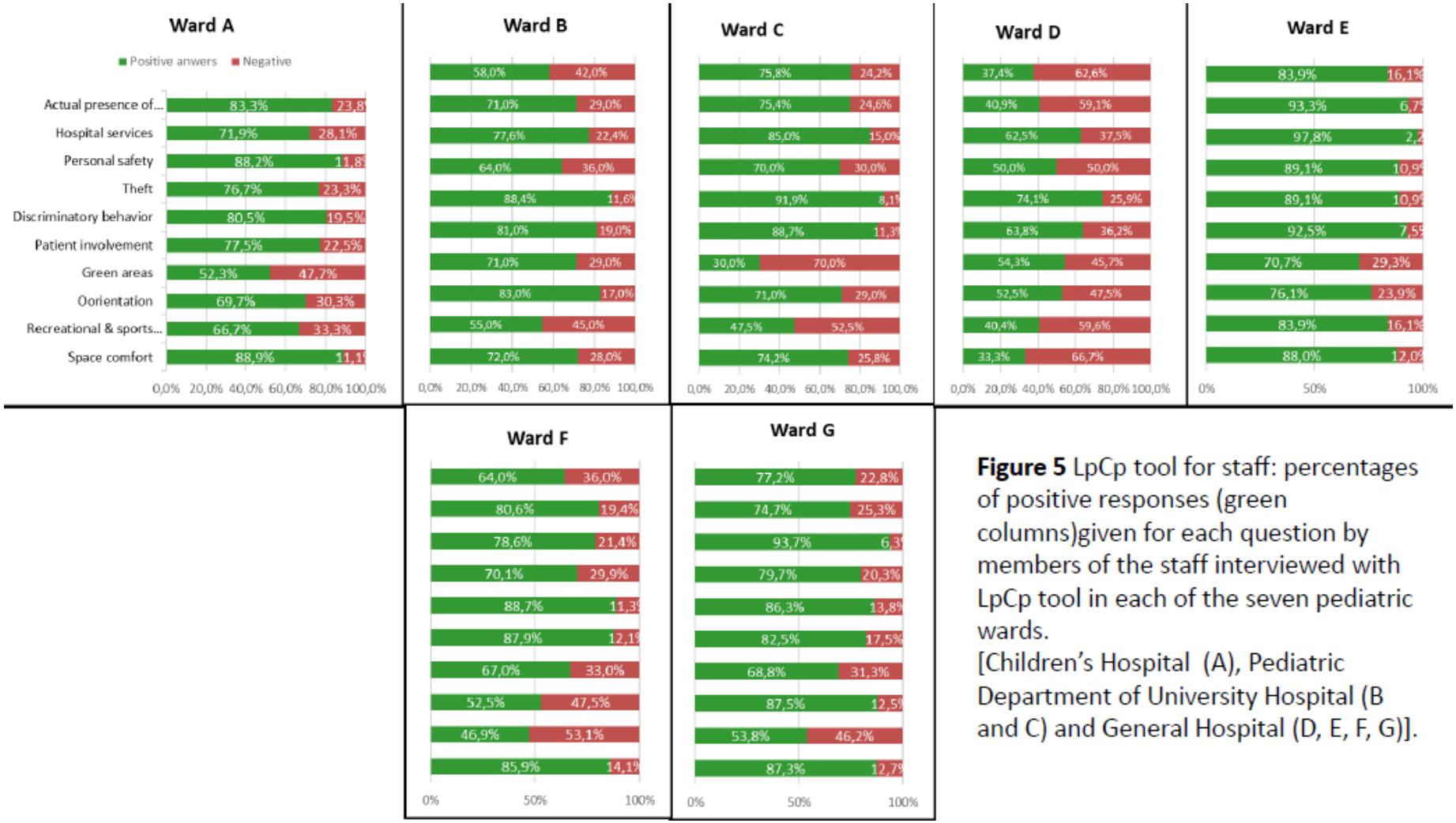
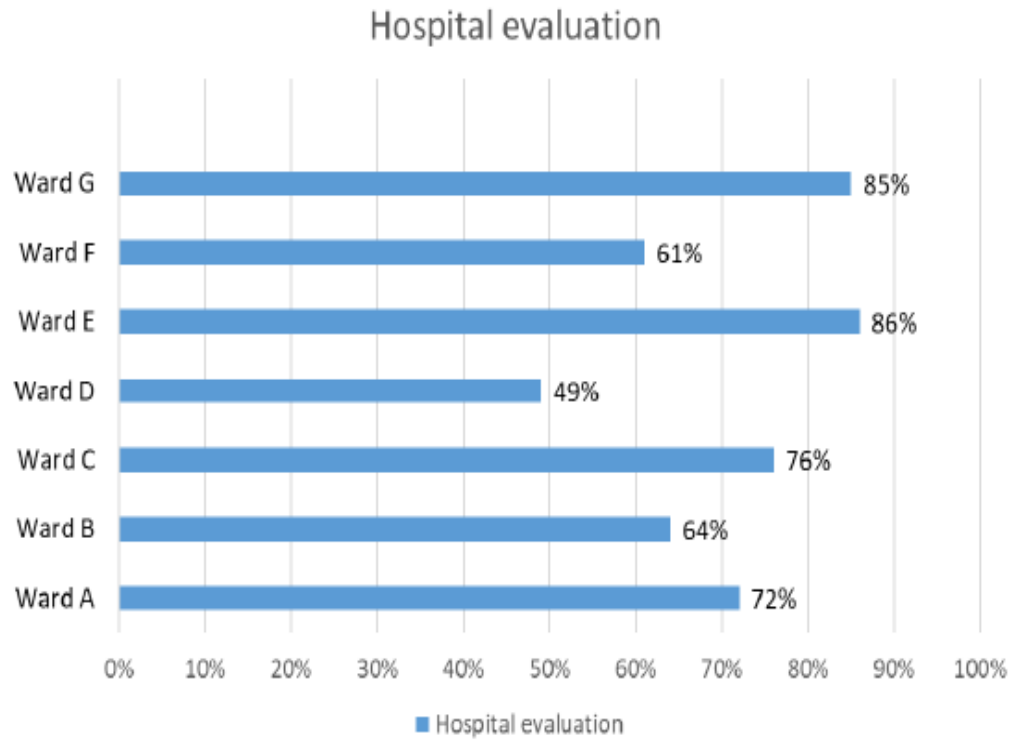


Figure 5 LpCp tool for staff: percentages of positive responses (green columns)given for each question by members of the staff interviewed with LpCp tool in each of the seven pediatric wards.
[Children's Hospital (A), Pediatric Department of University Hospital (B and C) and General Hospital (D, E, F, G)].

Figure 6 LpCp tool final score. Overall assessment of the degree of humanization perceived by users and staff of the seven pediatric wards examined with the LpCp tool. [Children's Hospital (A), Pediatric Department of University Hospital (B and C) and General Hospital (D, E, F, G)]. The hospital facility's final evaluation score (from 0 to 100 points) is instead calculated as the weighted amount of scores achieved in all four indicators. The process of calculation considers the user given and healthcare facility's incidence on the improvement, looking at a minimum resource cost.



Chapter 4

Discussion

4.1 HOW TO IMPLEMENT HOC?

The pediatric HOC presupposes interventions in different areas and the patient-centered approach is one of the ways of understanding HOC, according to the American model. Although at present there is no structured studies of RCTs evaluating and comparing the outcome of humanization interventions aiming to improve pediatric care, the literature overall [100] seems to support the view that adopted interventions may have beneficial effects on several outcomes of the cure (e.g. FCR and discharge timing [101] or family satisfaction [102], programs for staff training [103]. Limited data in several fields diminish the strength of recommendations, and in many cases clinical judgment alone therefore continues to be paramount. Nowadays, the HOC, is considered an aspect that cannot be overlooked, but it still receives not all the attention it deserves, with scarcity of data on the level of humanization of pediatric structures that have been properly evaluated, and “humanization patterns” often not put into practice.

The reasons for this can be many and different depending on the circumstances of each health setting. One aspect that is likely to "hinder" the adoption of this approach is the small space given to the topic of humanization during the university education of physicians and healthcare professionals (there is no specific course of "humanization of care"). It is necessary to move to a holistic view of the patient from the evaluation of the disease itself to the evaluation of the disease in the context of the person and of the daily life. In pediatrics, this implicates the necessary involvement of the family as an active part of the care program. Attention to the humanization aspect can probably improve the quality of care offered and consequently the satisfaction of the users who have received the assistance. Especially in our country, the attention and improvement of the degree of humanization of care can be a useful tool to limit the vast South-to-North extra regional migration. Pediatric migration is, in fact, an important phenomenon with obvious and multiple implications: in addition to causing stress for patients and their families, it results into consistent costs for the native Region by subtracting, at the same time, economic resources for the development of human resources and for the technological upgrade [104]. Potential

levels to use to implement humanization measures could be the following [53]:

1. basal evaluation of the grade of HOC of the hospital/outpatient setting;
2. from the previous assessment, identify the deficient aspects in terms of humanization on which to act;
3. raise awareness/training in hospital management and nursing staff;
4. undertake improvement interventions;
5. evaluate post-intervention efficacy.

According to this program, we systematically reviewed and specifically examined the effectiveness of a large spectrum of interventions dealing with different aspects of the HOC in general pediatrics hospital wards. Previous reviews specifically considered the effects of individual components of HOC, namely the FCC/FCR in pediatric [105, 106] and/or neonatal age and/or in some specific subspecialty settings [107], probably losing sight of the customary type of hospitalized child and of the broad facets of the interventions that doctors usually plan there. Differently from Rea's systematic review, we detected parents'satisfaction or outcome improvements in most studies, either with or without comparators [105]. In fact, according to the Quality Rating Scheme for Studies and Other

Evidence [108], studies with pre- vs. post-intervention data or intervention vs. a control group (n = 21) showed significant efficacy in most cases (n = 19). Studies with verification of user satisfaction (n=7) showed positive opinion in all cases. None of the interventions showed evidence of harm or safety concerns. Regarding the quality of the studies, only five were RCTs [72, 73, 76, 95, 99] and they too show that interventions are reliable and improve the quality of care in multiple areas. One well-designed controlled trial without randomization [82] however did not show significant difference between the intervention and control groups. The majority were case–control studies or retrospective cohort studies [74, 75, 77, 80, 81, 83-85, 88-93, 96, 98]. Fewer interventions were cross-sectional studies [78, 79, 86, 87, 94, 97]. Opinions of respected authorities and case reports were not included among selected studies. The selected studies could be assembled into seven categories, with some unavoidable overlaps. All studies concerning the provider–patient relationship [74, 75, 98, 89-91] confirm that this is a key factor in determining the quality of care, in agreement with a recent narrative synthesis [100] which identified five common core components of interventions in the PFCC setting. These included the patient and family education, provider–family information sharing, social-emotional support, shared

decision-making, and adapting care to match the family background. Since the concept of FCC was first introduced, it has subsequently evolved under the various hospital settings all over the world, including in developing countries [109]. Dialog with the family and patients and families involvement in diagnosis and treatment plans [91] are in all cases important aspects in the development of HOC and may be useful for reducing the time to discharge [83] and improving the emotional impact of hospitalization experiences including instrumental examinations [95]. The reviewed studies confirm that training improves PFCC orientation [82] and the approach to relationship with patients in some difficult issues, such as that of SDH [76, 80]. Within the framework of humanization, environmental issues raise an obvious particular interest, including the welcome/ reception, orientation, and architectural features. The studies reviewed here agree that, when possible, there should be attention on defining the environment with design and architectural solutions focusing not only on the strict functionality and efficiency of the healthcare system but also on the comfort of patients, visitors, and healthcare staff [81, 87, 90, 93, 97]. Also initiatives as the use of pet therapy and medical clown shows can improve the hospital stay [77, 85, 92, 94, 95, 99]. Also, to be a support for the hospital environment discussed above

[87, 97], studies show that technology can provide direct aid in the management of pediatric patients and their families. The use of HEDs [76] and electronic PHRs [86] may be a useful tool to help parents manage their children. This warrants further exploration to promote ongoing communication and sharing of information between patients, parents, primary care providers, and subspecialists [110]. In this regard, Btelemedicine^ should be considered more broadly, not only as a replacement for in-person visits but also for other uses, such as optimizing the value of in-person visits through pre-visit telemedicine communication and post-visit telemedicine follow-up [111]. Another important aspect of HOC is psychological support to reduce the negative impact of children's hospitalization [96]. Our results show that HOC is central to the holistic management of pediatric hospital care and that most of the existing initiatives implemented in individual institutions/hospitals are not based on specific HOC models/programs, so further and more robust research are needed for assessing their real importance [10]. Furthemore, our results confirm that parents or caregivers should be considered important partners of the child care clinic, making them part of the care program and the decisions to take. Since hospitalization is a trauma, especially in childhood, the hospital should be made as much "child - friendly" as possible, with adequate

furniture, spaces that recall the home environment and facilities for the parents' child care h24. These needs are also complicated by the different possible perceptions/points of view on the measures adopted [12, 13]. Data from 469 healthcare providers were used to investigate the extent to which FCC principles are currently applied in clinical practice by healthcare providers working in inpatient units. Results showed that scores for daily FCC practices (current activities) were significantly lower than FCC practices performed for their perceived necessity (necessary activities) ($p < .001$) [112]. Measuring the degree of HOC is crucial for setting priorities and intervention strategies to improve the quality of pediatric care. Currently available literature data summarized for pediatric aspects by Tripodi et al. [10] show that measurement tools used hitherto have been heterogeneous [54,55,113]. In general, the existing tools committed to HOC evaluation in various care settings (outpatient, day hospital, inpatient/hospitalization etc.) should relate to both the objective evaluation of the existing services offered, and the perception of their quality by a portion of users and healthcare workers, which have been rarely compared. The main tools available to measure the different aspects of HOC [13, 54, 55, 113], unfortunately, are poorly comparable. For the assessment of the existing degree of hospital

HOC, we used the pediatric version of a comprehensive checklist created by AGENAS specifically for Italian structures [14], which has been successfully used by other independent investigators in recent times to measure the degree of patient-centered care in a number of related structures before planning necessary improvement measures [114]. In association with the AGENAS checklist, we used the LpCp-tool [15], which was developed for the evaluation of the degree of perceived HOC as it is easy to understand and to fill in, as well as capable of involving different figures dealing with childcare in the hospital setting. As our study is the first time the LpCp-tool has been used in the pediatric field, the patient questionnaire had to be administered to patients' parents. Importantly, both tools used were applicable to different categories of pediatric facilities for identifying critical and implementable areas and allowed us to appreciate several facets of the same goal. The most critical issues that emerged from the analysis of our findings were related to the area of wellbeing, safety, patient involvement in the therapeutic process, and physician involvement in the design process. Interestingly, scarce agreement was found between the overall degree of HOC perceived by the staff and that perceived by parents in the considered facilities (Figure 7).

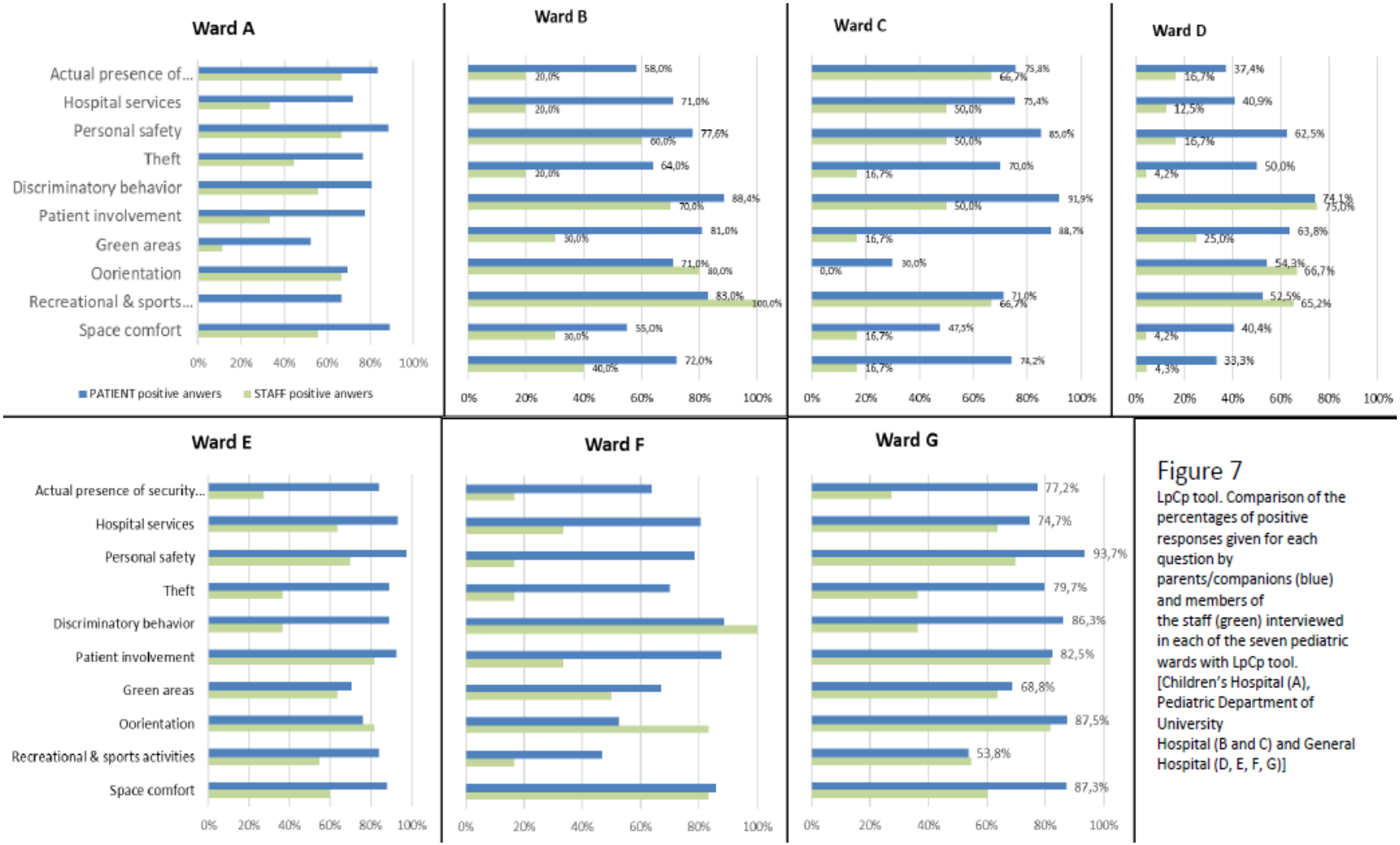


Figure 7

LpCp tool. Comparison of the percentages of positive responses given for each question by parents/companions (blue) and members of the staff (green) interviewed in each of the seven pediatric wards with LpCp tool. [Children's Hospital (A), Pediatric Department of University Hospital (B and C) and General Hospital (D, E, F, G)]

This confirms the trend observed in adult hospital settings in studies conducted with the same tool [12,13,15]. We believe that such a finding probably reflects healthcare staff's superior knowledge of the real potential of the hospital vs. the opinion of users, who might tend to globally provide more positive responses on the basis of the healthcare received. Even the simple therapeutic communication and relationships between parents and nurses may improve the perception of the quality of care provided to children and their families [115]. Similarly, in another study, hospital employees scored hospital quality consistently lower than patients, and were also more heterogeneous in their assessments. Hospital size had no clear effect on the perception gap. Compared to patients and other employee groups, doctors have substantially different perceptions on hospital quality [116]. Finally, the results from the seven pediatric wards analyzed in our study seem to reflect the different categories of facilities. Children's hospitals and the pediatric departments of university hospitals appear to have, by their nature, greater sensitivity and attention to the problems of the more frequently medium or long-term hospitalized child and of his/her family, which could justify the most positive perception of the users. However, two smaller general hospitals totaled the highest total score relative to the LpCp-tool. This could probably be explained by the

recent structural improvements and a more serene climate due to the smaller size of the work department. In sum, it is possible that the positive perception of the degree of HOC of the different facilities is influenced by the positive view of the users. Some aspects investigated by both tools (the AGENAS checklist and the LpCp-tool) could possibly hazard the comparison between the degree of existing and perceived degree of HOC. In most cases the existing did not concur with what was perceived, that is, the lack of some resources was not evaluated negatively as one would expect. However, a few exceptions emerged. For instance, mediation and interpretation services emerged as lacking in all the facilities without inconsistencies in both tools. In the children's hospital, space comfort and orientation, which received modest appreciation on the checklist, were not perceived very negatively by parents and staff. In small pediatric wards of general hospitals, space comfort and orientation received higher scores on the checklist (6.2 and 2.5 on average, respectively). In addition, users' and staff perception was always positive (> 50% of positive responses).

4.1.1 Study limitations

Our systematic review should be considered in light of several limitations as variability in the type of interventions and outcome measures, which made the studies difficult to compare and prevented meta-analyses. Additionally, there is likely much publication bias against research with negative results. To be as comprehensive as possible, we did not exclude any study solely on the basis of low research quality. The majority of the 28 studies, however, reported interventions with statistically significant results. The narrative results of some excluded studies might have deserved attention as hypothesis generating [110] with concepts such as keeping children busy and less anxious by distracting them from thoughts about their disease, suffering, and distance from home [28, 117]. Extending the search beyond major databases, perhaps also into the gray literature, and reducing language restrictions would have likely increased the effectiveness of this review. Finally, pain management in children achieved through various pharmacological [118, 119] and non-pharmacological [120] approaches is a critical and widely studied issue in the humanization of pediatric care. However, this specific topic was outside the scope of this review and would require a dedicated study.

Family-centered, patient-centered, and collaborative approaches are now well established within the vocabulary of child healthcare. Children are central to this, yet their role within the FCC approach is not clear [121-123]. As parent and child experiences may differ, a major limitation of our study is the lack of direct evaluation of HOC by child and adolescent patients, the latter being a special population with significantly different healthcare needs. HOC for them needs a particular focus on the necessity of preserving personal privacy and autonomy with respect for their identity and to not adversely influence their recovery and dignity in general [124]. We are currently addressing this aspect by using the only available children's tool developed in 2012 by the Health Promotion for Children and Adolescents by Hospitals Task Force for children aged 6–11 and 12-18 years [116], utilized so far only in a few Eastern European/ Asian hospitals [123].

Chapter 4

Conclusions

4.1 HOC PERSPECTIVES AND NEEDS

Pediatric HOC includes a wide range of meanings and aspects which are related to the care of the child hospitalized and not. In general, it refers to policies/measures intended to ensure accessibility and equality of treatment for all children, regardless of social class, nationality, religion, etc. Our thesis first showed that the examined models, though acting in different ways, do share some common principles, including the involvement of the child and the family and the recognition of the children's rights to an environment that suits their needs, limiting the trauma of the disease as possible and the suffering. Pending a universally agreed humanization definition and the spreading of policies, efforts for humanization of structures and activities are necessary to improve the period of the child's hospitalization and his/her family through locally implemented actions. The efficacy of these such variegated actions often differ from country to country [125] so a deepener evaluation is required to standardize and optimize as much as possible the quality of pediatric

care measures. Moreover, an agreement on a limited number of well-validated assessment tools appears urgently needed. In fact, most of the studies are not based on or merged in specific humanization models/programs and are of moderate to low quality with some risk of bias. Interventions finally are frequently limited to the time of the research, probably benefiting the enrolled subjects only. Even so, as most results demonstrate overall a positive balance between beneficial and harmful effects, they may likely help in the meanwhile to orientate policymakers seeking to close the gap between current and optimal levels of pediatric care humanization. The use of an evaluation tool with the achievement of measurable data is a sine qua non condition to allow any quantitative post-intervention verification of the effectiveness of the undertaken improvement actions. If these really satisfy the percepived need, they will probably be associated with greater participation in hospital care [126]. This thesis, attempting for the first time to evaluate the degree of existing and perceived HOC in the pediatric field and identifying features that need to be improved in different pediatric care settings could be the first step in focusing attention on the HOC issue and implement targeted interventions to create more child-friendly hospitals.

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