



Architectures for paediatric palliative care: how to improve quality of life and environmental well-being

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Abstract

Introduction. The influence of the environment on wellness, not only for patients themselves but for all care-givers as well, refers to the humanisation principles of spaces of care. Commencing with an analysis of existing paediatric hospices, the paper examines design suggestions for prosthetic environments, considered as a fundamental component in the healing process.

Methodology. A prosthetic environment can be created only through a specific knowledge of the real needs of users. Therefore, some scholars have conducted research work for defining the best practices for healing environments, supported by an assessment and comparison of case studies. The methodology is based on two phases: the first is based on interviews with experts in hospice design and management and the second, through the application of a questionnaire to several users.

Discussion and Results. The output of the work is the achievement of a logical, sequential and participatory broad-spectrum process in the design of health facilities in order to cause a sustainable awareness in paediatric hospices.

Conclusion. Starting from the research work, it is necessary to define a scientific method for implementing knowledge on health, psychological, perceptual and behavioural needs to contribute towards proper planning for meeting the real requirements of users.

Key words

- participatory design
- healthcare structures
- paediatric palliative care
- healing environments
- hospices

INTRODUCTION

In the last decades, the concept of health, and the tools for ensuring it, has obtained a gradual change in perspective. From a purely biomedical and sanitary point of view, based on the definition that the cure of a disease means the treatment of the diseased organ [1], new tendencies have reached a psycho-social approach that introduces a more complex and multi-dimensional health, shifting the focus from illness to the individual in his complexity [2]. This concept was defined in 2007 by the International Alliance of Patients' Organisation (IAPO) with the definition of patient-centred care, meaning that the system of care should be designed around the patient respecting his preferences, values and needs [3, 4].

As several scholars affirm, user-centred environments should be applied to all architectural projects, even more, to those concerning the spaces of care, made extremely complex by the amount of variables to be considered in the planning phase, in particular in hospice buildings.

Thanks to the contributions of social and psychologi-

cal disciplines to the Evidence Based Design, it was possible to highlight how the users, behaviour and well-being can be influenced by the characteristics of the physical and socio-physical environment [5]. The spaces and their correlated components can affect and influence human activities, by contributing to determining positive or negative effects on living conditions and the resulting life quality level of individuals, social groups and communities [6].

Therefore, the environment can be defined as *prosthetic*: an essential element of the environmental well-being of the users subdivided into patients, family members and health workers as well [7]. A prosthetic environment can be designed and built only if there is a deep knowledge of the psychological aspects of all the users involved in the system's processes of a paediatric hospice. The quality of spaces is closely connected, first of all, with the recognition of the needs to be guaranteed and, then, with the important role played by users' habits, preferences or limitations in the definition of environmental characteristics.

Together with other factors such as the effectiveness of the treatments, the humanisation of care, the intellectual and professional enrichment of the medical and nursing staff and management efficiency, a prosthetic space contributes to the quality of services, especially those concerning the treatment and care of children with serious illnesses [2, 8]. A hospice, contrary to a hospital, cannot be considered a complex building because it does not present any specific technological devices. However, its complexity is derived from all the relationships involved in the management of the terminal patients, whose healing process is led by a holistic dimension for health, social, emotional and spiritual needs, including those of family members too [9]. These typologies of centres are a hybrid between the complexity of a technological hospital and the presence of psychosocial factors and variables similar to home environments.

An analysis of the current situation at the paediatric palliative care in the Italian context, in particular in the Region of Lombardy, has shown the necessity to know and assess the requirements, opinions and thoughts of professionals in the field at several levels [10]. Moreover, the lack of State-of-the-Art and research references on the topic implies that the design of these structures does not respond to the health and psycho-social needs of children and caregivers, including doctors, social and health operators as well as family [11].

It is generally assumed that achieving an increase of value in the design of healthcare environments requires a constant reference to a scientific, logical, sequential and integrated approach that allows the definition of targets and steps necessary to achieve them [12]. Therefore, in order to understand the State-of-the-Art, the research group conducted a deep review of several national and international existing case studies, such as “Casa del Bambino Hospice” in Padova (IT), “Bear Cottage Children’s Hospice” in Manly (AUS), “Canuck Place Children’s Hospice” in Vancouver (CDN), “George Mark Children’s Hospice” in San Leandro (USA), and “Robin House Children Hospice” in Balloch (UK) [13]. This work has led to the formulation of several considerations and evaluations aimed at the recognition of the recurring architectural and design characteristics which characterise those healthcare facilities [14].

Commencing with these notions, the scope of the research work is to develop a design methodology based on the concept of participatory planning, a method that is strongly focused on the mobilisation of all the actors and stakeholders involved. In fact, administrators, operators, users, technicians can all participate in the drafting of the project by contributing their experience and knowledge, expectations, needs and creativity in defining architectural spaces through organisation and operational criteria [15].

METHODOLOGY

The research work refers to several methodologies already developed in the medical fields and which have emerged in social health design with the aim of generating more scientific evidences for certain criteria and design principles that are commonly employed in order

to be implemented through the direct testimonies of those who, as users, may know the needs and current conditions of those healthcare facilities [16].

The approach, based on Evidence Based Design, represents a method for obtaining an outcome founded on “evidence” for quantifying and analysing the manner in which people live and perceive these buildings [17]. Therefore, the attempt of the research work is to identify those qualities which patients and their families consider as important elements, characterising the social and architectural aspects of hospices.

This analysis is based on the certainty that health facilities should be an integrated process which involves all the people revolving around the process of patient care in order to respond better to the real needs expressed by caregivers. The analysis consists of two different steps:

- the first is developed through the interaction with a panel of experts who interact and actively argue the complex issues, thus creating a communication vicious process;
- the second is the elaboration of the several topics which previously emerged and which were acquired through the administration of questionnaires.

With regard to the chosen methodology, as a first step the research study proceeds with an investigation aimed at professionals working in the palliative care and pain therapy field in Lombardy, including both Palliative Care Units (PCUs) that are active in public health and Non-Profit Organisations (NPOs), in order to evaluate the hypothesis extrapolated by the existing scientific literature. In order to proceed with the analysis, the centres received the proposal to join the research work during the month of November 2014.

In relation to the availability of operators that agreed to take part in the survey, several meetings and interviews were organised of around sixty minutes between December 2014 and January 2015, in which the questionnaire with open questions was submitted and the operators had the opportunity to express their opinions, considerations and suggestions.

Starting from this first phase, through the professionals’ backgrounds, it was possible to understand the shortcomings and criticisms, as well as the size and scope of critical issues in the field. The statistical sample which is included in the survey incorporates seven different realities concerning palliative care. At least one representative, generally in a management position, was interviewed for each hospice operating in Lombardy. The professionals involved in the interviews were expert doctors, university professors, architects specialised in healthcare facility planning, psychologists, social operators, hospital head nurses, and hospital and home volunteers.

The interviews and questionnaires were structured for investigating three specific items:

- **Characteristics and needs of the paediatric population in the hospice:** the questions are aimed to describe the paediatric population from a demographic, epidemiological and clinical point of view for collecting relevant information about clinical care, emotional, relational aspects and family needs.

Which type of child disorders need paediatric palliative care?

From among hospitalised children, how many children need a paediatric palliative care structure?

With regards to family-child relationships, what do they need?

Does the child need contact with other children?

Does the child need to be supported in terms of education?

How many different age groups do you identify? What do families need specifically?

In your opinion, what is the optimal situation for a child who is to be hospitalised in structures of palliative care, for how long and what are his needs? What should it be before and after hospitalisation?

- **Characteristics of healthcare facilities in terms of technology, logistics, spatial and functional aspects:** the purpose of the questions is to understand the care needs from the point of view of the expert operators, solutions currently used and expected future scenarios.

What is the need of intensity of care when children are hospitalised [high-medium-low intensity of care]?

At what level of investigation are diagnostic tools necessary?

Do children arrive in the department only in the acute phase or even for scheduled visits, day hospital or day-surgery?

Is a place of worship necessary?

Is a gym necessary? And what about a painting room, playroom, cinema or theatre?

- **Health professionals' technical, organisational and social needs:** the questionnaire is designed to analyse occupational stress, the expected responses from the system and solutions proposed by experienced operators.

How many days are they hospitalised for? [mean value]

Are other medical specialists necessary in the department?

Which type and how frequently?

How is the team currently composed in the healthcare facility?

What is needed to work correctly and safety in a health care facility?

How do you work out these needs nowadays?

The outcome of this first phase was necessary for the identification of the highlights that are useful for the second phase of investigation, which consisted in the distribution of a closed answer questionnaire. This was based on ten multiple choices and a scale of values. The number of questions was determined to achieve the scope of receiving the highest sample of responses, avoiding a lengthy tool, thus focusing attention on those important features that define an environment and have a greater influence on the perception of space by users. The questionnaire is composed of:

- **four questions with a multiple choice formula**

Which is the suitable number of beds for a paediatric palliative care facility in relation to the number of admissions planned? [6, 8, 10 or more than 10]

What do you prefer between these two models of residence?

Apartment including inpatient room, bedroom for the family, small living room and kitchen, or an inpatient room with the beds for family members.

What is an appropriate size for an inpatient room? [12 m², 20 m² or 25 m²]

Do you consider a vertical or horizontal distribution as being most appropriate within these structures?

- **three require positive and negative answers**

Is it necessary for an outpatient clinic to have an area dedicated to paediatric palliative care?

Is it necessary for a day hospital to have an area dedicated to paediatric palliative care?

Is it necessary to have medical gas' engineering plants in each inpatient room?

- **the residuals consist of sub-categories to be assigned a value from 1 (low) to 10 (high) to assess the importance of the components proposed**

From the patient's point of view, how important is the presence of visible and liveable green areas?

Assign a value of importance for each area of the healthcare facility (therapeutic and entertainment areas): hydrotherapy, multimedia room, art therapy, recreational room, music therapy, learning room, pet therapy and sensory room.

Assign a value of importance for each area (general support) of the healthcare facility: green outdoor areas, training room for family members, library and laundry.

Through the collaboration of the experts involved in the interviews, it was possible to distribute the closed answer questionnaire during the months of February and March 2015 to several caregivers subdivided into doctors, nurses, psychologists, health operators and volunteers, with the aim of drawing up a profile of a model structure for paediatric palliative care. In this analysis, a sample of doctors and nurses are the two most represented professional profiles because they are more closely connected to patients and their families and because together they form more than two-thirds of the total sample (36% nurses, 32% medical doctors); meanwhile, the percentage of volunteers involved is 26% and finally, 6% of other professions. The respondents also include architects specialised in health architecture, psychologists, social workers and voluntary associations, such as hospital and home volunteers.

Commencing with the background of the respondents, Figure 1 illustrates that two-thirds of professionals work in hospitals (66%), 13% as volunteers, 8% in hospices, 8% in home care and the remaining 5% are scholars coming from the Master's programme in "Palliative care managed by the University Centre for Interdisciplinary Palliative Care" organised by Università degli Studi di Milano.

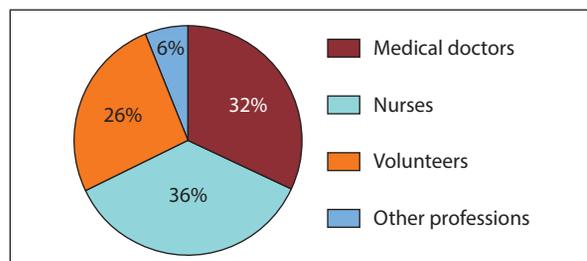


Figure 1
The sample of the surveyed population.



At this stage, the research study proceeded to test the degree of consensus on the previously expounded principles and the considerations of the previous stage of investigation. The collected data were organised in a database, entering a field referring to the profession and working area.

Moreover, the research required the homogenisation of all data collected for comparison, therefore, the true and false answers have been standardised in numerical values (0-1).

Progressively, for each answer, it was decided to analyse responses by grouping them according to profession (doctor, nurse, volunteer, etc.). In this way, results are not affected by the number of responses for each identified category. It was possible to calculate the trimmed mean of the response values for each answer of each category, excluding 5% of the extreme values of the examined collective in order to reduce statistical peaks [18]. Then, the average scores of each category were averaged to obtain the final absolute values, excluding a percentage. Starting from these considerations and the scenario in which structure should be included in the regional health network, the respondents gave suggestions for defining dimensional values, assistential levels, models of residential and hospital care, and technical and health requirements.

RESULTS

The solutions and profiles of Paediatric Palliative Care facilities resulting from the analysis can be summarised in two different types: intensive health care and low intensity health care with high well-being care activity. In particular, the last one can be further subdivided into two organisational models: one designed for short hospitalisation (the transition period between the hospitalisation phase and the domiciliation one), and the other aimed at longer hospitalisation, the well-known 'relief hospitalisation' which ensures medical and nursing care to patients and families. Naturally, each of these organisational models requires specific technical, spatial and organisational solutions. In any case, in both cases, the structure is a key component in a complex system that must work in harmony and synergy to set up a network organisation of services.

Starting from this scenario, a Paediatric Palliative Care facility can become the hub of a network in a system that is not based on hospital needs but is citizen-centred [19]. This is a complex and difficult system whose structure is a technological and organisational-critical component but not the principal one: in fact, other facilities and points of the network system are equally important [20, 21].

First and foremost, the mission, and its consequent targets of care, should be defined: in fact, paediatric palliative care must ensure, in all circumstances, the most appropriate care to every patient, without discrimination of sex, race, nationality and social status, through integrated clinical practices, research and training [1, 9]. It will provide care and treatment of a disease through updated technologically therapeutic and rehabilitation interventions as planned inpatient treatment, day hospital and outpatient treatments.

The structure must also be a place for the development of a healthcare culture, including external and internal hospital professionals, the nursing staff and all the community. The high training of operators is the most valuable asset available to the structure to fulfil its social mission.

Starting from these concepts, it is also necessary to define the vision clearly: despite being a new structure of its kind, such structures are often popularly perceived as being negative, hostile and alienating. The structure should, instead, be dimensioned to human scale and focused on the user and his needs, care, acceptance and trust.

Currently, the scientific community has achieved a substantial degree of consensus on the concept of simultaneous treatments so that these support an organisational model aimed at ensuring the overall care of patients through continuous, integrated and progressive assistance between active treatment and palliative care especially when the main outcome is not primarily the survival of the patient but his dignity.

A hospice is considered to be a reference point and a transition phase between hospitalisation in the acute phase of the disease and domiciliation. It is effective because it is supported by a regional network of palliative care that allows the patient to be hospitalised and monitored during follow-up home care in the shortest time possible.

A perspective of this scenario influences the purposes of a hospice facility for optimising quality of life at every stage of the disease, through meticulous attention to the physical, functional, psychological, spiritual and social needs of the patient and his family. Moreover, in order to ensure continuity of care through the flexible management of patients and their needs, it is necessary to apply adequate targets in each situation through assessment, planning, coordination, monitoring and selection of options and services, and, finally, for avoiding the sense of abandonment in the disease's advanced and terminal stage (*Figure 2*).

Regardless of the classification of diseases which is to be included into a system of palliative care networks, great importance has been associated with the high degree of flexibility that the building should have for ensuring the uniqueness and specificity of each patient's needs.

The socio-cultural background of patients and the location proximity to these type of structures affects the length of hospitalisation and the communication between relatives and caregivers [22]. In fact, starting from the interviews, several respondents have agreed that, until now, these patients spent most of their lives in inadequate hospitals, mainly in Intensive Care Units (ICUs). They assert that in their experience, suitable facilities with a high degree of domesticity would give greater comfort to the patient and would relieve the hospital's ICUs from expensive hospitalisation costs.

Moreover, as regards the level of care intensity, the interviews highlighted that the most important feature should be the high level of specificity with a flexible intensity of care during the time. Proximity to a hospital is essential for providing high levels of intensive care and all the diagnostic tools that may be necessary [23].

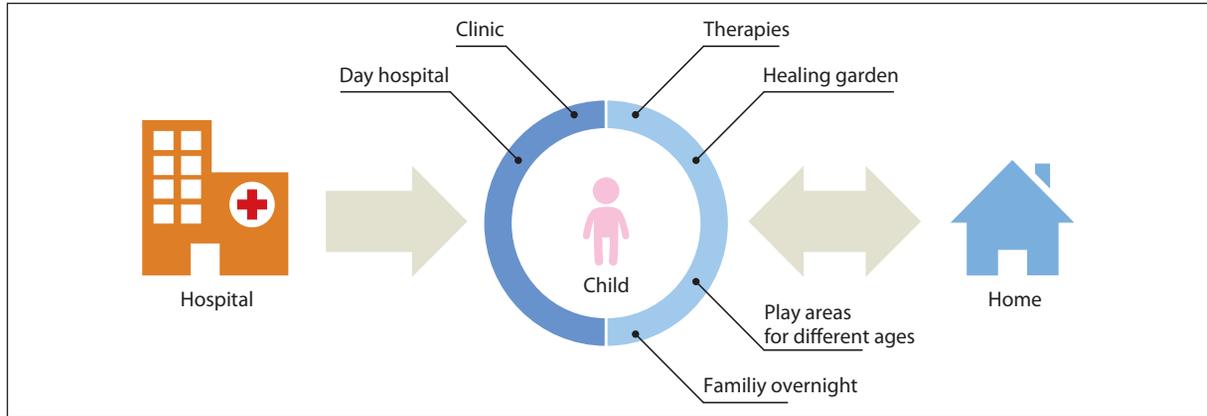


Figure 2
Scheme of the healing processes around the child.

In the analysis conducted, the outpatient area has been identified as being essential for managing the frequent visits that these patients are subjected to. Regarding the three areas of investigation, both in the first phase of the interviews and with close ended questionnaires, the main topics are:

- characteristics and needs of paediatric users;
- characteristics of a specific structure from the functional, organisational and logistical point of view;
- technical, organisational and social skills of the professionals and caregivers.

Addressing these points, it is possible to define an organisational model that is useful for a successful result. First of all, it is necessary to emphasise that the proposal of including a functional area within the healthcare facility, consisting of outpatient clinics and day hospital units and providing medical gas equipment in every inpatient room, have been favourably accepted for providing a fundamental requirement for these patients: to be able to adequately manage care treatments that are compatible with the child's return to home in the shortest possible time. One of the most common proposals argued by professionals is the integration of a green space inside the building that allows visual and

active uses. As several authors sustain, the presence of green spaces, such as healing gardens, obtains a key role in the process of humanisation of space in a patient-centred approach [24, 25].

In addition to these views, the offered therapies, ranging from music and art therapy to pets, with the exception of hydrotherapy, received scores between 7 and 9 (Figure 3): this is a sign of the great importance that professionals attach to them. Moreover, the responses show that centres for paediatric palliative care should be structures with less than ten beds, allowing a resident to remain organised in small units and characterised by good architectural, functional and health flexibility. The structure is expected to be as welcoming as possible towards the child and his family (*user-centred*).

The child's room shall be above standard requirements and so it is necessary to design the inpatient unit as mono-apartments consisting of two semi-autonomous rooms for a total of about 40 m². The room must have the facility of preparing and eating meals inside it. It must also have accommodation and meeting spaces for relatives as well as healing environments for undertaking the necessary therapies. Everything must guarantee a good level of privacy.

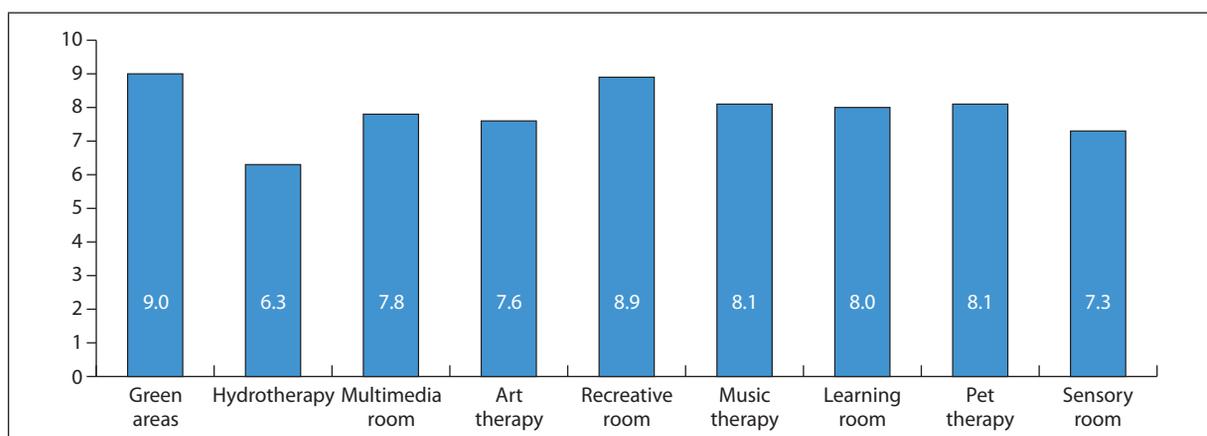


Figure 3
Some results of the questionnaires' application.

The layout of the building should certainly include the presence of volunteers and home care, in order to be a reference and control point and the necessary link between hospitalisation and domiciliation in the shortest time possible [26].

Several scholars suggest that there is a strong convergence of visions about a structure with a horizontal development for facilitating orientation and usability by people with disability problems or neurological diseases [27]. Regarding ancillary activities, in addition to health interventions, all the professionals interviewed suggest the importance and presence of common areas as games rooms, or similar to those where the most adequate therapies can be provided. In the investigation, great importance was attached to the usability of outdoor and green spaces for family meetings and training; however, these spaces should comply with special requirements due to the different age groups included in paediatrics cases. Therefore, they must range from environmental characteristics based on preferences and different ergonomics according to different ages and needs [28].

In conclusion, the key principle for supporting the

analysis conducted and the guidelines developed, which emerged in focus groups and interviews, is a child-centred design process, starting from the early stages (Figure 4).

CONCLUSIONS

The research work finds its original motivations in the assessment of how healing environments and architectures for health can influence human behaviour and how the built environment can condition the patients' predisposition to heal [29]. In particular, the research study is focused on hospice facilities because they are considered as being a hybrid between domesticity and psychological factors and the complexity of a hospital's processes and management [30].

The methodology is based on a multidisciplinary approach. Its complexity requires the application of highly structured processes which allow the thorough investigation and analysis of every aspect and the transformation of results obtained into design guidelines that meet needs adequately. As a consequence, the research work demonstrates that there is still a substantial discrepancy on the same issues between designers' architectural practices and the current users' needs and behaviour

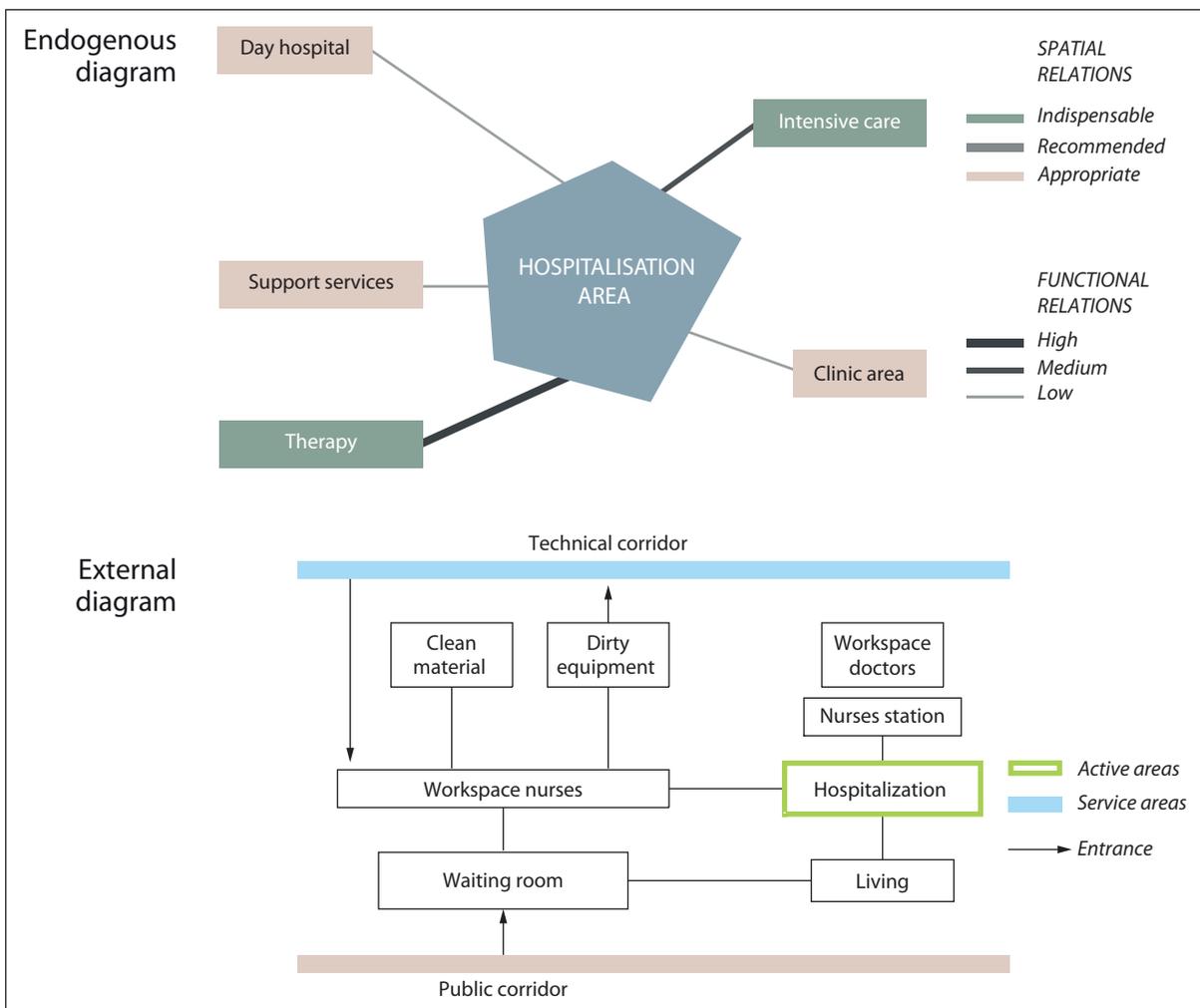


Figure 4 Endogenous and external diagrams for pediatric palliative care's environments.

within such a complex building as a hospice. Therefore, it is important to define a number of scientific investigation methodologies covering active interaction with future users of the facility and a comprehensive knowledge of health, psychological, perceptual and behavioural needs.

The final output generates a catalogue of technical tabs, useful for designers, with a set of information for each individual room: classified by type of activity and user's needs, environmental indoor requirements and the equipment and furniture required for the proper performance of activities or services and, finally, design strategies for guaranteeing hospital functionality.

For reaching new perspectives for future research activities, it is necessary to define a high degree of sensitivity and competence for translating the results obtained into design indications suited to needs; in fact, this work sets the stage for future evolution towards a growing interest from institutions and sector operators.

Currently there are no specific regulations that deal with the architectural requirements of paediatric hospices. However, this paper together with other researches on the topic, contributes towards creating guidelines for the design of such structures.

This setting aims to disseminate sustainable awareness, characterised by efficiency and environmental innovation, and social and cultural development, in order to have fitting use of the available assets in an economic and human perspective [31-34].

The next step of the study should include a specific analysis of the needs of children involved in palliative care and their families, aiming to achieve full integration with the system of domiciliary palliative care, in

accordance with the principles of simultaneous care.

Finally, in order to complete the set of needs and confirm the hypothesis, it should be necessary to carry out a further assessment: Post-Occupancy Evaluation.

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Conflict of interest statement

There are no potential conflicts of interest or any financial or personal relationships with other people or organizations that could inappropriately bias conduct and findings of this study.

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