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Original article

Evaluation of stakeholder opinion about Long-Term Care facilities for people with dementia perceived quality: a web-based survey in the Italian context

Silvia Mangili[1], *Luca Ciaffoni*[2], *Andrea Brambilla*[1], *Tianzhi Sun*[1], *Stefano Capolongo*[1]

[1]Design & Health Lab., Department of Architecture, Built environment and Construction engineering (DABC), Politecnico di Milano, Milan, Italy; [2]Politecnico di Milano, Milan, Italy

Abstract. *Background and aim:* Italy is a country where the percentage of the elderly population is very high (23% over 65). The investigation aims to bring out which aspects of the spaces intended to accommodate elderly People with Dementia pathologies should be most present and potentially interested in becoming cornerstones of a new model of Long-Term Care facilities (LTC). *Methods:* This research uses a case studies analysis followed by a web-based survey as a methodological tool. The questions were identified after exploring an analysis of recent European case studies. The survey has been submitted to a panel of stakeholders (users, practitioners, designers, and managers in the healthcare sector). It is articulated in eight items touching on functional, configurational, and perceptual aspects of the LTC. *Results:* The 210 responses provided a basis for comparison with the trend lines detected by the case study analysis, establishing continuity on some configurational aspects and providing divergent views for others. The research found a strong need to introduce new service activities and technologies targeted at caring for and assisting guests with dementia. These specific requirements commonly require the development of new spaces and environments or the redefinition of the same, where already present. *Conclusions*: The results highlight that a new model of residence must incorporate new technological applications, and outdoor spaces, that are perceived significantly by both patients and practitioners and therefore improve the well-being of all users. (www.actabiomedica.it)

Key words: Dementia, Built Environment, Web-based Survey, Evidence-based design, Healthcare design, Stakeholder involvement

1. Introduction

The number of People with Dementia (PwD) is rising worldwide. World Health Organization estimates that around 55 million people have dementia and this is rising to 139 million in 2050 (1).

Dementia is an umbrella term that has within it various diseases, of which the most frequent (about 60-70 percent of all forms) is Alzheimer's (2).

This disease is characterized mainly by a general deterioration in cognitive function. It affects memory, thinking, orientation, comprehension, computation, learning ability, language, mobility, and judgment. Due to age and comorbidity that often characterize PwD, they are the most frequent visitors to healthcare facilities. Although PwD is a heavy consumer of health services, direct costs in developed countries arise mostly from community and residential care (3). In Europe, nowadays nursing homes and assisted home care are among the main lines of investment in the real estate sector. These facilities must be suitable for a fragile category of users like PwD.

It is extremely important to design and build adequate structures, properly designed and implemented

as places where patients find themselves having to live as their disease slowly progresses(4,5).

In Italy, most of the facilities are old and inadequate, with 7,372 structures, divided into residential care facilities for the elderly (3,365), psychiatric residential care facilities (2,035), and other residential care facilities for the physically, mentally, and terminally disabled. Most of the structures are located in the northern regions (2,651) (6).

The beds currently available in Long-term Care (LTC) per 1,000 elderly residents are now 18.6 in Italy compared to 71.2 in Belgium, 54.4 in Germany, and 51.0 in France (Figure 1). The OECD average is 43.8 (7).

Is expected a rise in the need for new structures during the next years, due to trends in demographic development, an aging population, and changes in social and family patterns.

There is a need for a major structural intervention aimed at developing, modernizing, and renovating the current outdated and inadequate facilities to cope with the growing care and healthcare demands of the coming decades (8). Additionally, there is the request to create a structure that is based on the need of residents,

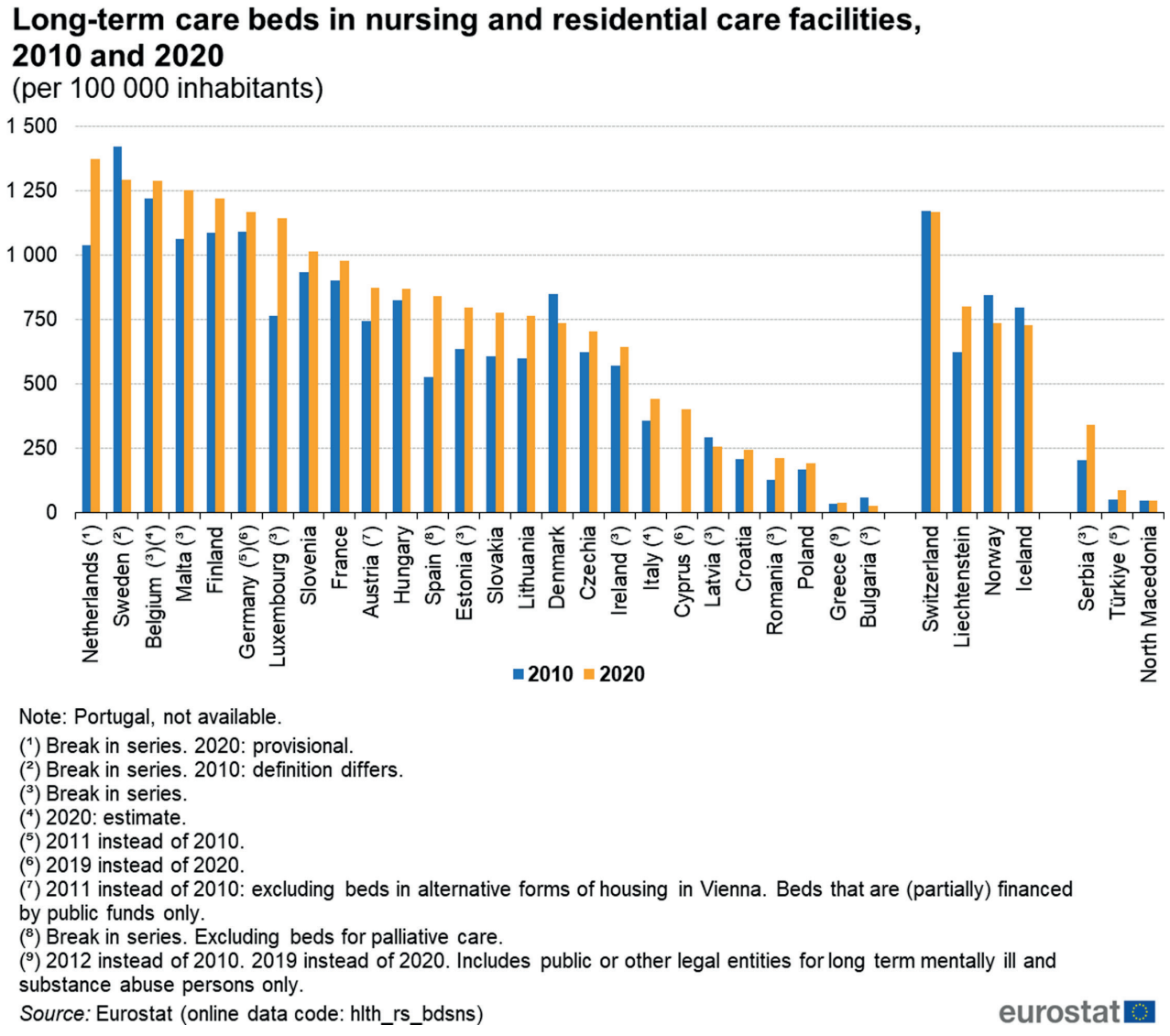

Figure 1. The comparison of the bed numbers of LTC between 2010 and 2020 (Eurostat).

that can provide a better environment to facilitate and improve the health and well-being of patients (9). In this sense Evidence-Based Design can play an active role, providing spaces that are capable to promote healthy living (10–14).

Nowadays it is clear that a built environment can be crucial in the health and well-being of the elderly as well as PwD. (4,5,15,16). As a physical health issue related to elderly people, falling is among the most frequent problems and it can result in other health concerns. In the past years, falling has been discussed by many researchers, pointing out the significant link between the falling rate and the risks of the physical environment (17,18). Other physical health factors, like infection (19,20), have also been proven to be strongly related.

In recent years, more evidence is found between older adults' mental health and the built environment, such as depression (21–24), psychometric properties (25–27), sense of home (28–30), cognitively stimulating (31), satisfaction (32) and so on. Furthermore, the social health component is highlighted, with an emphasis on the question of the connection between spatial arrangement and the social interaction of people experiencing dementia(33). There is an urgency to create facilities that are capable of answering the needs of both patients and staff (34).

1.1 Research gap

In the Italian context, the main instrument used is certification standards and Italian regulation. Unfortunately, these materials are quite outdated (1989) and do not take into consideration the advancement that has been done in research.

There is also an urgency to collect the needs of both patients and stakeholders, to find expectations and requirements that facilities must have.

The current model of residential care management in Italy often appears inadequate to current scenarios. The current model is still based on structured standards and commensurate with a rigid picture of the elderly population, linked to a parameter of "Non-self-sufficiency" that is too generic. Meanwhile, the current situation described by the most recent statistics and literature shows a more blurred and labile picture, which is constantly changing and capable of fragmenting the framework that held together the generic needs ascribable to the guest into a series of specific needs and requirements very often linked to precise neurodegenerative diseases.

Therefore, the study aims to bring out which aspects of the spaces intended to accommodate elderly People with Dementia pathologies should be most present and potentially interested in becoming cornerstones of a new model of Long-Term Care facilities (LTC).

2. Materials and methods

This research uses a case studies analysis followed by a web-based survey as a methodological tool. The methodology used for the development of the survey was based on multiple choices questions with different solutions or conditions related to LTC for the various fields of analysis explored in depth in a case studies analysis. Through this dual identification of data, we were able to obtain a direct comparison for each aspect that emerged in the first part of the research.

The goal of the survey is to better understand what elements residential facilities for the elderly should contain to satisfy the requirements of users.

A web-based survey was conducted to find out the opinions and perceptions of users and stakeholders of healthcare facilities for PwD in Italy.

The survey consists of:

1. identification of the questions based on the indicators derived from the analysis of the comparison between Italian and foreign case studies; (assessment framework development)
2. choice of the most useful way of administering the questionnaire, identified in the online transmission of a form, the most immediate way to disclose and receive feedback quickly; (web-based survey definition)
3. processing of the data collected through graphs and tables obtained directly from the Google Form platform and then profiled to have an analysis of the responses; (data analysis)

The target audience for the questionnaire is diverse and broadly includes users and insiders of healthcare

facilities. Both managers and social and health care staff, as well as technical designers, were included, in addition to users/guests. This choice was made to also compare the different perspectives of those who have direct and close contact with the residential service environment.

2.1 Assessment framework development from the case study analysis

The survey follows broader research carried out through an examination of project experiences related to case studies and best practices in the European field over the last decade. This activity focused on the first part of the research, which aimed to compare the aspects that emerged from the design analysis and the impressions gathered from the human capital (users, managers, social and healthcare staff, etc.) related to residential spaces that provide hospitality and care for the elderly with dementia. The case studies were studied for the aspects related to the characteristics of their location - thus the starting environmental conditions were chosen to locate the settlement - of their sizing - thus for the density ratio between No. of guests and the development of units per floor - of their configuration - thus for their distributional typology - and of their functional organization - thus for the greater or lesser presence of some residential and socialization areas compared to others more related to service areas. The aspects that emerged from this analysis were summarized in graphs that identified trend lines common to the eight case studies chosen (Figure 2).

2.2 Web-based survey definition

The survey was divided into 4 parts:

1. The first one is an introductory section, where the general aim of the project is declared and instructions for the participants are provided. It is clarified that the survey is anonymous and that the results are used for research purposes only.
2. The second section is made with a statistical aim. This section includes basic demographic information such as gender and age for statistical purposes and questions that were not mandatory.
3. The third section is the core of the survey. It's composed of seven multiple-choice questions. Each question is structured with a question and a picture with three different variables to be chosen to answer the question.

   Each statement requires taking a clear position on some specific feature that the built environment must possess to have a positive impact on the well-being of PwD.

   The questions represent key aspects that are related with evidence in the relationship between well-being and PwD, previously emerged in the Assessment Framework Development:
   - location,
   - shared spaces,
   - paths,
   - living areas,
   - external spaces,
   - technologies,
   - bedrooms.
4. In the last part there is an open answer to collect other opinions and personal experiences.

2.3. Data collection and analysis

The typology of web-based surveys used frequently and effectively since the COVID pandemic to intercept the opinion of various stakeholders without having to conduct face-to-face interviews (35), was chosen to obtain as many responses as possible.

The survey was submitted online via the Google Form platform and shared via email and social pages (Linkedin, Facebook, ...).

It was chosen due to the need to collect as much as possible feedback (it has been submitted to around 500 stakeholders) and rapidly an answer.

The data analysis has been done using an excel file, downloaded from the google website, and then analyzed with graphics and tables to examine the answers.

3. Results

The survey has been submitted to an estimated number of people (around 500) and it collected 210 answers.

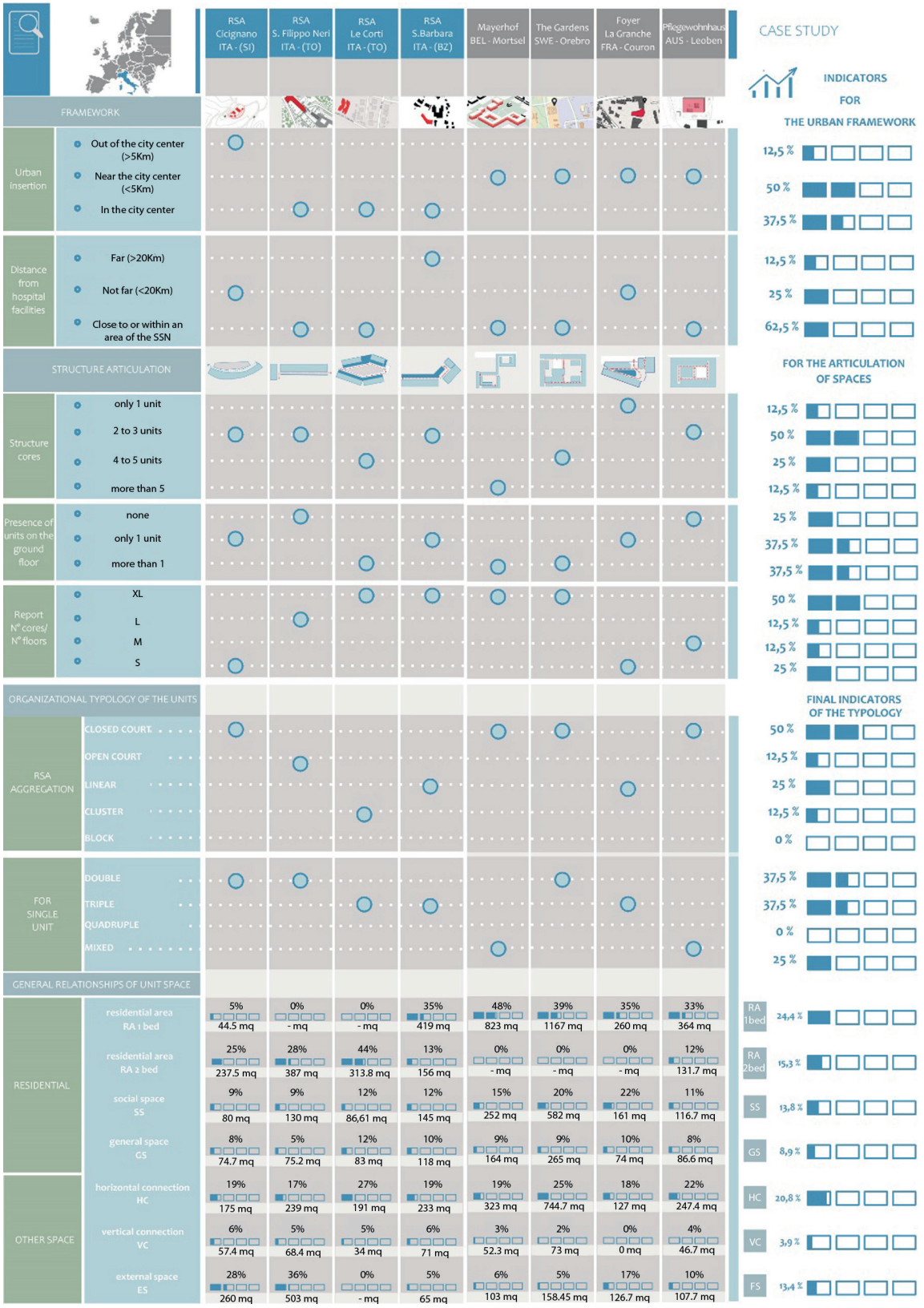

Figure 2. Analysis table for case studies.

The results were profiled from the significant sample collected at the end of the questionnaire administration and dissemination period. The data, considering a margin of error of 5 percent of confidence level above 90 percent appears to be statistically valid.

The aspects that stand out the most when scrolling through the results were the following: a substantial alignment on the choice of location that prefers a populated context not very distant from hospital facilities (assumed to be no more than 15min/20min by car) in place of more isolated conditions. This finding is reinforced by the second preference (36.7%) of the question that hypothesizes internal LTC solutions or at least inserted in close connection with hospital-type facilities; another element of alignment is the respondents' preference, regarding the type of distribution, circular - in itself a direct reference to the courtyard facility - a solution also often found in the Italian and foreign case studies examined.

This evidence leads back to an important consideration that the raison d'être of these facilities is rooted not only in the motivations of the planner but also in those of the operators who live and work within them, as well as the managers in charge of optimizing service performance. Thus, it seems to be a choice that is solidly shared both by the design engineers who see, albeit in the variety of configurations proposed, the courtyard system as an ideal solution for organizing residential spaces.

Another shared aspect is the tendency to prefer a condition that leads to having as many cores as possible on the ground floor (75 %), which pairs with the other consideration that emerged in another question asking respondents what aspects of a residence for the elderly they consider most relevant. The preference centered on the extensive development of the residential complex (45.2%) over having terraces and balconies for the cores on the various floors (33.7%) or having more than one Core per floor with shared socialization spaces (21.2%). Some choices, such as the presence of hospital garrisons near or even attached to the LTC area, hint at a reflection of the pandemic experienced in recent years.

3.1. Section 1 – Statistical data

The map of the sample concerned turns out to consist mostly of planners (38.5%) and secondarily of social and health care personnel. On the other hand, it turns out that the share (less than 1%) related to elderly guests, the initial main reference, is not at all relevant and considerable (Figure 3). 60 percent of the sample is between the ages of 31-50, with a prevalence of women (53.4%) over men (Figure 4). This figure brings out the limitation of the choice made to disseminate the questionnaire exclusively via web channels. Conditioned certainly by the limitations due to security measures during the pandemic, this choice did not allow us to approach all stakeholders and thus obtain complete meaningful feedback. On the other hand, the comparison between the significant presence of responses provided by Managers (about 14%) and those provided by Socio-Healthcare personnel (22.5%) is important (Figure 5).

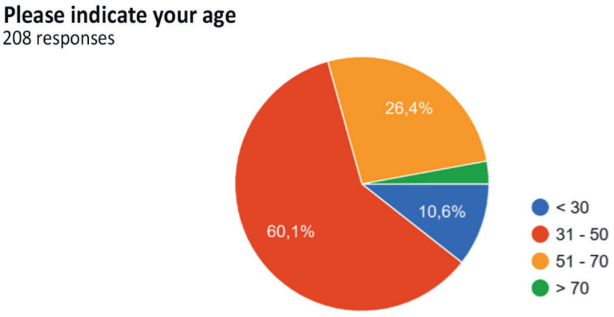

Figure 3. The age of the people who were involved in the questionnaire.

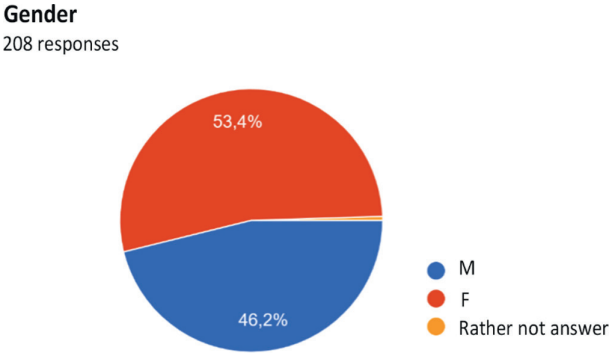

Figure 4. The gender distribution of the people who were involved in the questionnaire

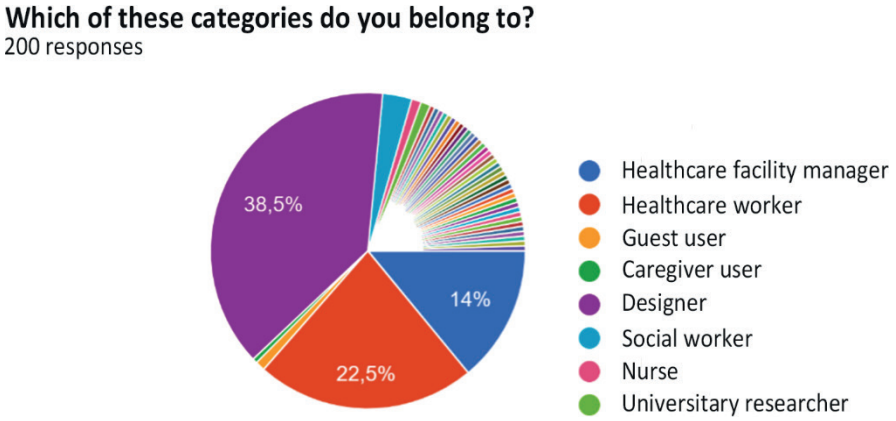

Figure 5. The position of the people who were involved in the questionnaire.

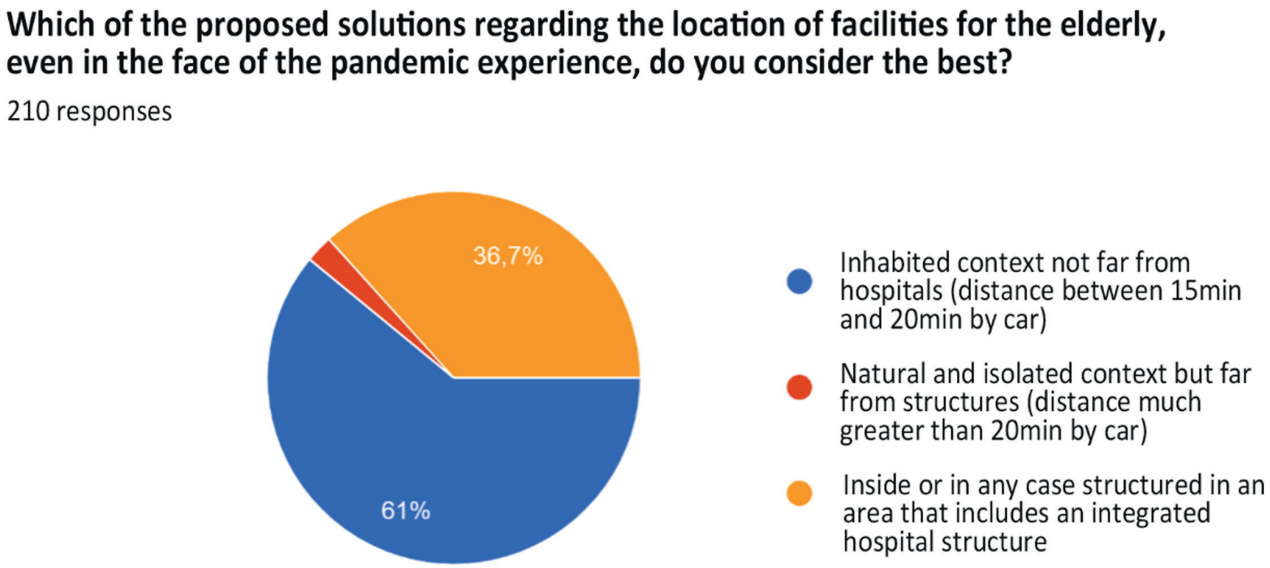

Figure 6. The questionnaire results about the location of the healthcare facilities for the elderly.

3.2. Location

The main responses show a tendency to favor inhabited settings and the possibility of having hospital presidia not very far away if not even thinking the facility is already integrated within hospital areas. A very small portion believes that the following is to be preferred a location of the facility in an isolated urban setting away from hospital facilities (Figure 6).

3.3. General aspects

As shown in Figure 7, the sample surveyed on this question is divided by a slight preference-about 10 percent deviation-for an extensive single-storey solution over the choice that proposed having terraces and balconies but with multi-level development.

However, the number of preferences (from both managers and planners) for the solution with shared socialization spaces is also significant.

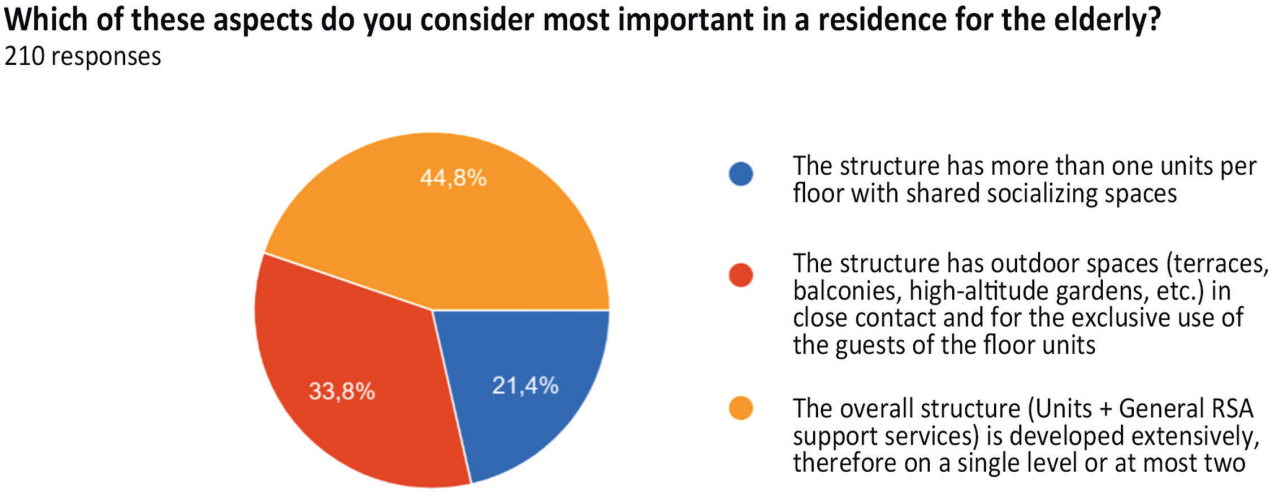

Figure 7. The questionnaire results about the general idea about the structure of healthcare facilities for the elderly.

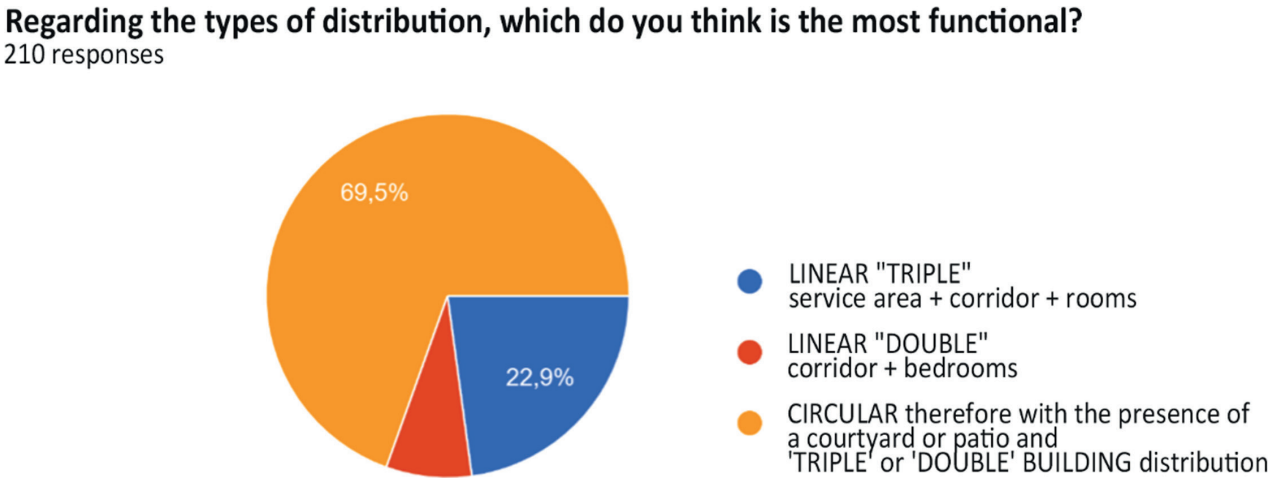

Figure 8. The questionnaire results about the distribution of healthcare facilities for the elderly.

3.4. Distribution

56 planners indicate a circular distribution as the preferred solution, and this view is found even among the Managers and OSS staff (Figure 8).

It is probably less functional or otherwise convincing to have a distribution where there is only one side of the rooms in sequence along the distribution corridor, compared to the solution instead of a Triple body that appears from the responses to be preferred.

3.5. Living area

The most convincing solution for Managers (18), OSS staff (27), Designers (54), and the remaining components surveyed is certainly one that leads to a preference for living spaces shared among several units (Figure 9).

Solutions involving the nucleus broken in half by a living area do not appear convincing or preferable, as reflected in the data offered by the questionnaire,

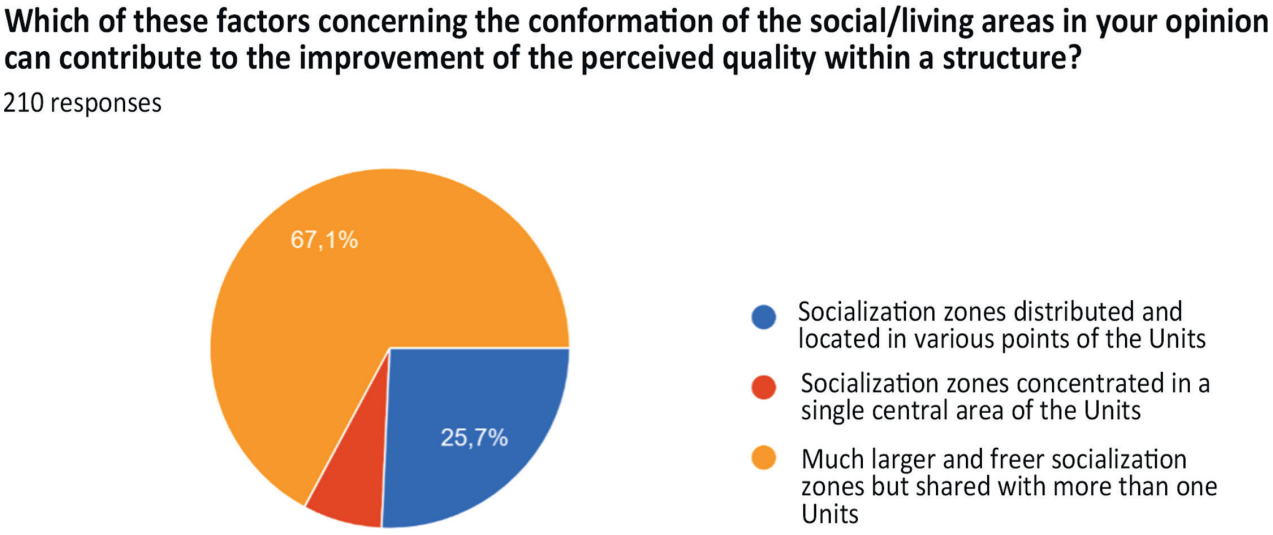

Figure 9. The questionnaire results about the distribution of healthcare facilities for the elderly.

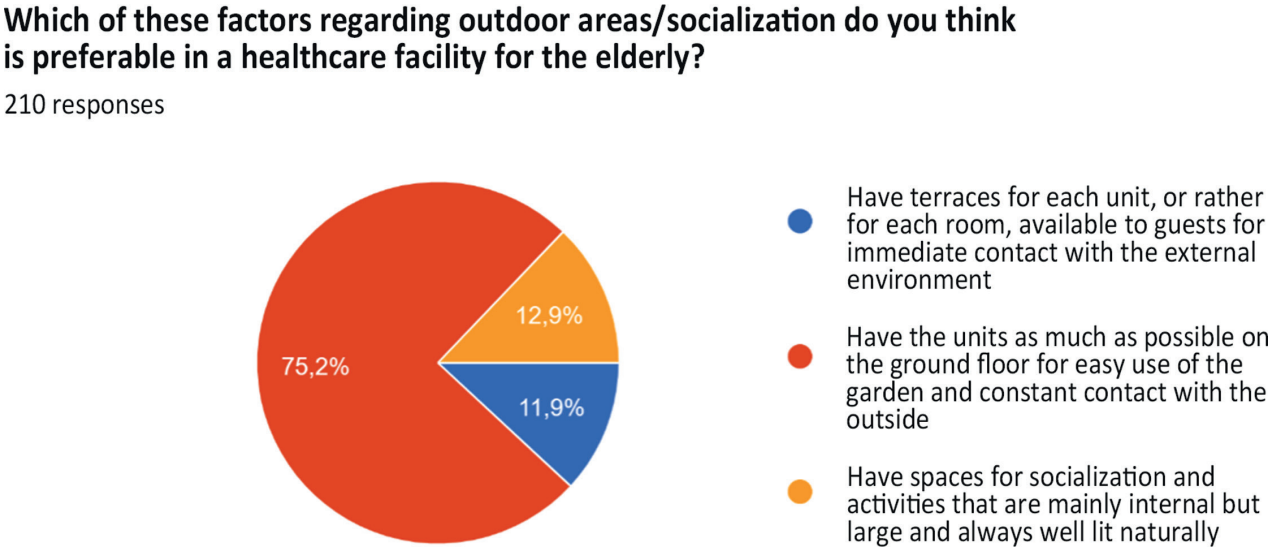

Figure 10. The questionnaire results about the distribution of healthcare facilities for the elderly.

where both Managers and Designers do not consider this condition useful.

3.6. Outdoor space

The evidence indicated in Figure 10 is a desire to have a strongly extensive condition instead of a multi-level development for residential facilities dedicated to the elderly. This need seems more vivid than other needs, such as having terraces for each core or having larger and brighter core living spaces, clearly indicating a better quality of space concerning the well-being parameters.

3.7. Future trends

Green continues to be a need felt by both Managers and operators as well as designers, coming out as a

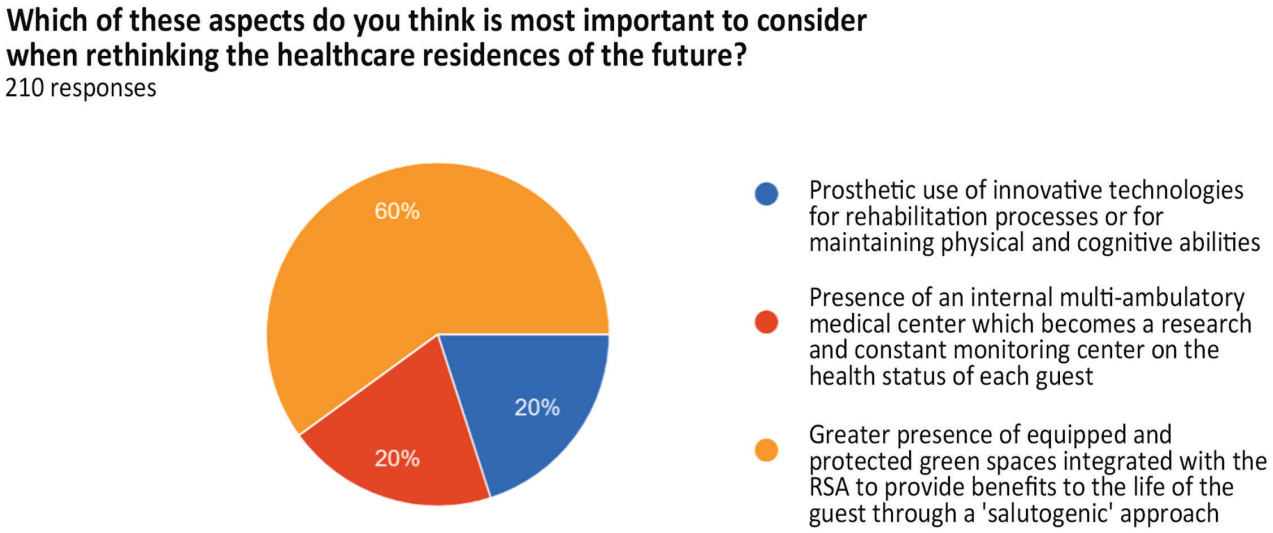

Figure 11. The opinion about the future of healthcare facilities.

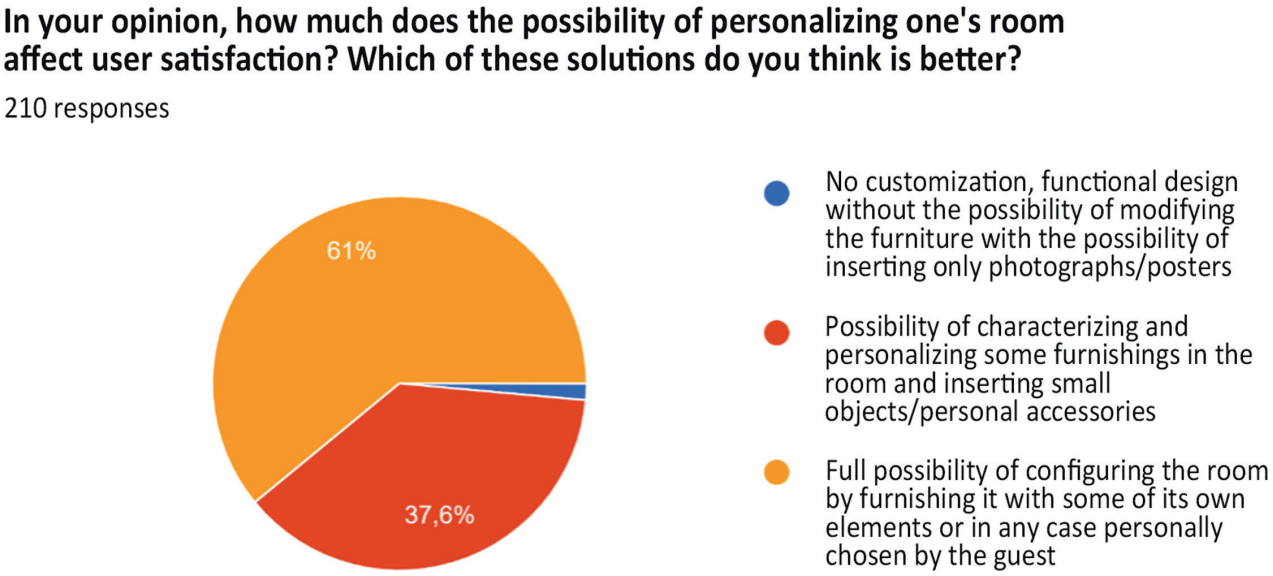

Figure 12. The questionnaire results about the personalization of the healthcare facilities for the elderly.

prominent element in the choice made by interviewees (Figure 11).

This component of the LTC space appears to be favored over other seemingly more innovative aspects such as the prosthetic approach of spaces and services to the elderly, or the possibility of constant medical monitoring through the presence of an integrated center at the LTC.

3.8. Personalization

The possibility for the guest to freely furnish his or her accommodation seems to be a choice that is more than agreeable to both operators and managers as well as planners.

In contrast, only two responses expressed clear dissent to this possibility, suggesting that it is not a

viable solution in the context of LTCs (Figure 12). Another segment of respondents expressed a compromise solution but emphasized the importance of considering how guests can personalize their living spaces.

3.9. Other considerations

The following are some important comments or suggestions provided by the respondents along with their answers and expressed preferences that can better guide the value of the analysis of the feedback provided by the questionnaire.

These can be divided into three main themes:

A) Issues related to the content:
   - I believe we need to reshape the concept of care, focusing more on the new elderly, more technologically, and more active than in the past. Environmental designs are also welcome, but there is a need to focus on the staff;
   - In general, it is desirable that the principles of environmental and architectural psychology become an increasingly integral part of the design process;
   - Single room and private bathroom, free access to their closets, ability to move freely in outdoor spaces in safety, spaces dedicated to the rest of the operators, and the presence of the family both in the room and outside;
   - I believe that personalizing one's daily living spaces makes the place closer to the memory of the user, thus making the place "home";
   - A facility that facilitates and arranges for the use of aids such as lifts in the rooms and allows the caregiver to move easily with wheelchairs and stretcher showers. The severity of conditions of residents in LTC is increasingly common. Costs of tuition and staff minutes must be taken into consideration;
   - Fundamental are aggregation and sharing of spaces and activities very important to understand the background of the elderly person I explain myself who has been a mechanic does not have the same needs as someone who has been a clerk or housewife;
   - I would suggest the inclusion of an area for local community services, where to generate contact and exchange of knowledge and training between the residents of the LTC and the local community;

B) Issues related to the form and process of the survey:
   - Enhance the possibilities of relating to the outdoors by grading the usability of public space according to the different needs of the residents and their families the answers can vary greatly about the context and size of the LTC. This reference is completely missing in the questions;
   - Suggest that the questionnaire also be filled out by current and upcoming/future users (range >60 years old) of LTC to compare the response of technicians and that of ideal/current users- Integration with city/country communities;

C) Issues related to staff training and education:
   - All staff, I mean all professionals in the multidisciplinary team, nurses, doctors, nurses, educators, and psychologists, should know, regardless of their specific skills, the users with whom they work, through mandatory courses on dementia, and the effects that incorrect relational approaches of care can have on the patient (e.g.: a joke in sympathetic intent by a nurse to an Alzheimer's patient could be traumatic and devastating for the patient himself);
   - Trained staff to make the best use of the facility and outdoor spaces. Humanization and listening to the needs of the assisted to grasp their needs that become a guide for optimizing places and spaces;
   - It is critical, even more than all the points above, that staff is properly trained and

chosen: you need motivated people who put the passion with which they carry out care first. Personnel of every level, from management to auxiliary: get back to being human.

3.10. Comparison of the results

The analytical data derived from an in-depth study of the projects related to the case studies, and thus of realizations selected in a previous activity of the research, determined the main comparative comparison with the data that emerged from the questionnaire, having both studies as a basis common indicators (Figure 13). It is precisely in the choice of identifying indicators functional as much to the analytical understanding of architectural space as to the ability of the same to bring to light the value of the perception of the operators, deriving from them the questions to be submitted, that the lowest common denominator lies, which allowed a direct comparison of the data and cross-referencing of convergent responses.

Several choices, as previously reported, have remarked an alignment between those who design LTC spaces and those who inhabit the same spaces (at least between operators and managers), a sign of a substantial convergence that thus allows us to mark pivotal points on which to elaborate models for the future of these facilities. Think for example of the circular distribution typology or at any rate with a courtyard, favored by both designers and operators. Other aspects although not completely overlapping however find a good match both in the selected projects and in some significant percentages present in the various questions. For example, the choice of having shared socialization spaces between cores or the choice of having outdoor spaces adjacent to the residential units on the various floors. The topic of education has been also stressed by the respondents confirming the need for synergies in educational programs between health and built environment disciplines (36).

4. Discussion and conclusion

The strongest evidence appears to be related to the strong consideration and weight given to the need for ever-present and larger green spaces and care (60.1 %), as opposed to the urgency for more technology (19.7 %) that might have hinted at the prosthetic approach, or more monitoring with the medical center within the facility (20.2 %). This aspect that emerges from the questionnaire is consistent with the choice of preferably having the cores on the ground floor, which was not always maintained, as observed in the case studies examined. Moreover, the tendency in the LTCs studied seems to be toward intensive rather than extensive solutions, with perhaps the possibility of also accommodating outdoor spaces on the upper levels in close contact with

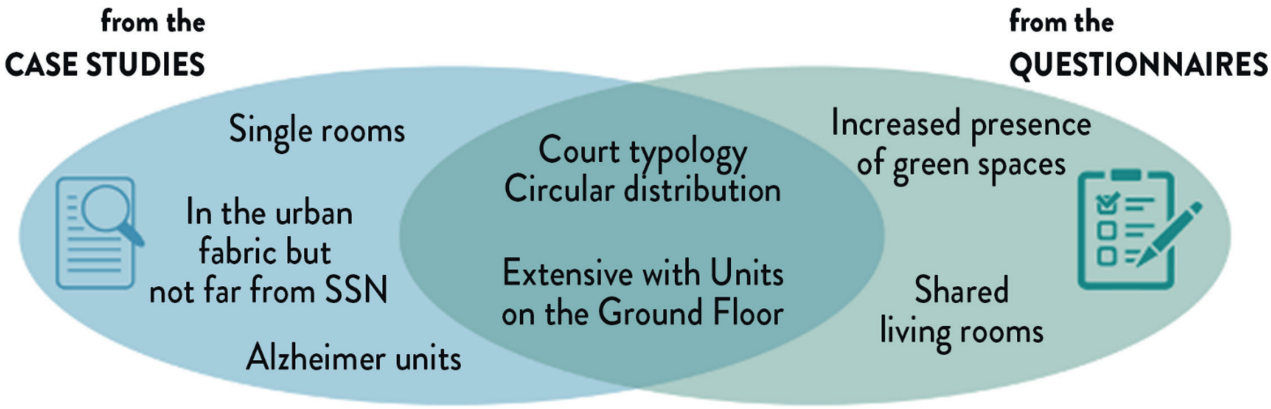

Figure 13. The comparison between the results from the Case studies and Questionnaire.

the upper cores. The last relevant consideration in dementia cases is the response regarding the incidence of room customization versus less permissive situations. 61.5 % believe that there will be significant benefits if full customization of the room by the guest can be allowed.

The research has returned a snapshot of the LTC not only national, providing an identikit that is enriched by values also detected in similar facilities abroad, offering scientific evidence through the analytical comparison of the case studies examined and the comparison with what has been expressed by the actors of residential care aimed at the elderly population. This framework offers some insights to identify, in the constants, possible fixed points from which we can start to structure a new model that aims to configure the Next Generation LTC. Moreover, many other insights should be deepened through research that moves from the indirect study to the direct study of the LTC environments, contemplating this time also the return of impressions and suggestions that can be transmitted by the real protagonists of this space, namely its guests. While this aspect was a strong limitation, it allowed us to probe the more analytical aspect of the design of an LTC by placing the magnifying glass more on which spaces and how many spaces should be contemplated in the Next Generation LTC model, leaving out for the moment other factors that require more in-depth study related to the perceptual sphere from which the state of well-being within the architecture derives.

5. Research limitations and future developments

The survey was useful to collect opinions from different stakeholders in a fast and easy way, as it could be rapidly shared via email or the web. The research certainly has some limitations. Firstly, the web-based survey may not represent the entire panel of stakeholders, lacking an essential piece of data that should be acquired by a mode of administration, such as interviewing the guest directly. Elderly residents in these structures have not been able to fulfill the survey due to their condition and technological requirements. Not having this kind of feedback hinders this comparison with the other significant group of staff who manage and operate LTC facilities. Therefore, the results show interest in the comparison between the responses given by those who design and those who then work in or manage residential facilities for the elderly. One of the main goals for future development will be to increase the sample size of answers and include as many people and stakeholders as possible. For example, using a paper-based survey to reach the elderly and residents.

However, it is considered relevant to bring out the ever-increasing use of knowing user opinion, and the use of web-based surveys could become an easy and inexpensive way to verify it.

Conflict of Interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

Ethic Committee: not applicable

Authors Contribution: Conceptualization, S.M. and L.C.; methodology, S.M.; validation, S.C.; investigation and analysis, S.M., L.C., T.S., and A.B.; writing—original draft preparation, S.M., L.C., and T.S.; writing—review and editing, S.C. and A.B. All authors have read and agreed to the published version of the manuscript.

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Correspondence:
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Silvia Mangili
Design & Health Lab., Department of Architecture, Built Environment and Construction Engineering (DABC), Politecnico di Milano
Via Ponzio 31, Milan, 20133 Italy
Phone: 0223995180
E-mail: silvia.mangili@polimi.it