

# Entering a Nursing Home: family members and operators tell their stories

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Non-self-sufficient elderly, Health Care Residences, reception, family members

## ABSTRACT

*The article investigates the experience of family members of non-self-sufficient elderly people at the time of entry into the Nursing Home through the data of a qualitative research conducted by the University of Milan Bicocca in agreement with a Lombard NH in the period November 2021-February 2024.*

*The paper presents the results of the survey, which aimed to identify the elements useful for improving the quality of reception and care of the elderly and their families, highlighting which critical issues can affect entry.*

*With the phenomenon of population aging, the lengthening of life expectancy and the related quantitative and qualitative change in the care and assistance needs of the non-self-sufficient elderly, it is important to highlight how the political, economic, social, cultural and pedagogical changes makes it necessary to combine the planning of response actions to new needs with a shared and multidisciplinary reflection on the issue that focuses on the meaning and meanings of these transformations.*

## INTRODUCTION

One of the services' responses to the new care, assistance and needs of the non-self-sufficient elderly is the Nursing Home which, in Italy, welcomed about 2.8% of the elderly over 65 for a total of 404.23 people and 5.16% of the elderly over 75 for a total of 368,880 people for at least one access (Longeva 2023 data).

The entry of people into the Nursing Home (NH) corresponds, in most cases, to a radical change in the life experience of the elderly and their families. The research project "Entering a Nursing Home: family members and operators tell" was carried out as part of a PhD Executive course within the agreement between the "Fondazione Fratelli Enrico e Antonio Nobili Onlus" Nursing Home in Viganò Brianza (Lc) and the University of Milan Bicocca. The research aimed to identify useful elements to improve the quality of reception of the elderly and their families and to identify which critical issues can affect entry, especially with reference to the risk of exclusion of family members, highlighted in the experience of the Covid-19 pandemic.

The research also aimed to collect useful data to prevent the discomfort that the experience of life in the institution entails from its earliest stages, increasing for the people involved the possibility of living in a community capable of welcoming in a home dimension, becoming an opportunity for positive change. At the same time, the survey focused on the need, in addition to focusing on improving the organization of services, to promote a deep and shared reflection on new meanings in the light of the political, economic, social, cultural and pedagogical changes underway.

Non-self-sufficient old age is still a very unknown terrain pedagogically, culturally and socially, it is a

field that is little explored and little told, but extremely rich in meanings experienced through very contrasting feelings [1-3]. The distance that is generally kept from this precious life experience is linked to resistance related to the fear of getting sick and dying, as well as the common perception that tends not to consider it something that concerns us until the moment it happens.

The risk of marginalization is even more present in the event that, in the context of lifelong education and the education of adults and the elderly, we are unable to stay at that age when we become fragile and, apparently, finished.

The elderly person, frailty, care, is a central triad in the medical, human and training sciences, both in terms of reflection and practices that have relevance to the exercise of care in the health, social, educational and training fields [2] and focusing on this link questions pedagogy in relation to dimensions that belong to us as human beings and that must be rediscovered in order to overcome the sense of distance and strangeness.

Finally, the experience of the Covid-19 pandemic, which this research study cannot ignore, has shown us how neither the bioeconomic paradigm of the non-self-sufficiency of the elderly nor the hospital business model are suitable for care and assistance in this fragile phase of life, denying their humanity [4] and pedagogy could act at the forefront of this process of deconstruction.

NHs represent a precious and often necessary resource, provided that their potential is fully understood to redesign their identity in the light of new needs.

The research, which investigates the specific experience of family members in the phase of entry into the facility, aims to be a way to increase knowledge



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of the phenomenon in order to improve the quality of reception, but also an opportunity to open up to eyes and consciences the phenomenon of inclusion in residential facilities for non-self-sufficient elderly people. A way to deepen the pedagogical reflection on the change that this experience puts in place and on the meanings that, socially and culturally, we attribute to it, even prejudicial precisely because we do not know it.

### MATERIALS AND METHODS

The field in which the research is placed is that of adult and elderly education, and the choice to investigate the phenomenon through listening to and analyzing the testimonies of the protagonists has led to confirm for this empirical research the framework of the ecological paradigm that gives good ideas for research and for human life [5] and in which the lived world of educational practice is a fertile place that presupposes a vision of knowledge rooted in the natural contexts of life and relationships and in which reality is seen as a network of relationships that are structured and transformed and where everything is interconnected.

The work develops in the panorama of qualitative methods [6] using the contamination between the narrative and biographical approach [7-12] and the hermeneutical phenomenological method as it is suitable for understanding reality while remaining faithful to its nuances and contradictions [5].

In the light of the epistemological perspective of reference and in relation to the research question, the method identified as most appropriate, for consistency, was the phenomenological hermeneutic method. The aim is to operate “interpretative descriptions” starting from lived experience to investigate networks and meanings that have been deposited and who are being structured [5].

The phenomenological approach has “as its indispensable starting point lived experience” [5]. Attention to the description of the object phenomenon, in an attentional and not interpretative arrangement, leads to the essence of the experience. The quality of phenomenology is that it is a method and can constitute a valid reference precisely because of the complexity of the human experience that research investigates [13]. The “going to the things themselves”, which starts from the ontological vision of a reality that is entirely phenomenal in nature, can contribute, in this work, to responding to a need to listen to and understand “what appears”, going to the essence of the things themselves.

The research questions declined were:

1. How do family members experience the entry of the elderly relative into the NH?
2. What does the change that occurs when their elderly relative enters mean for family members?
3. What guidelines and actions can improve the quality of the entry phase for family members?
4. The tool used for the research work was the

phenomenological interview [14-16] as a method to access a deep understanding of the experience lived by the other, of his relationship with reality and of the visions of the world that he continuously builds [5,16].

### Research participants

Twenty-three in-depth and unstructured phenomenological interviews were carried out with eleven family members and twelve operators chosen because they were in functional positions regarding role and experience. The survey also involved four facilities located in territories other than Lombardy in order to collect useful data with particular reference to exemplary practices tested by the services.

The choice was to involve family members from other nursing homes or no longer in charge of the NH, which promoted the research to protect the freedom of their participation, at the risk of conditioning given the operational role of the researcher within the company.

The choice was made to involve some operators to reduce the risk of a one-way investigation and particular importance was given to the connection and comparison between the data that emerged in the various interviews. It was chosen to meet people in places far from their experience in time or space to increase their possibility of telling in a dimension that is not strictly involved and potentially in the possibility of distancing themselves, useful for reflection. It was then decided to interview the managers of four structures chosen according to the criterion of innovation and excellence in order to be able to bring useful examples of planning and management of reception and experience in NHs to the survey work.

The strategy of involvement of all people (and institutions) was to use existing relationships or connections with people who were introduced, thus guaranteeing the level of trust and willingness to tell their experience necessary for the study.

Attempts to involve institutions and people with whom there were no elements of previous relationship were unsuccessful also due to the criticality, especially of the structures, to open up to the outside world and make their experience public, for reasons of scarcity of time available and, in my opinion, also in relation to the Covid-19 pandemic which has made the system more vulnerable.

The interviews took place both in person (audio recording was used for this mode) and remotely (video recording was used for this mode).

The choice of the interview in depth and not directive gave relevance to the voice of those who were interviewed who spoke within their own world of life. Her being free allowed the interviewee to be at the center of the work. The limit found in this characteristic was the emergence of descriptions not only limited to the moment of entry, the focus of my



investigation, but to the entire experience in NH. This characteristic opened a reflection reported in the results.

I chose the participants, as indicated in the research design, according to a targeted sampling criterion, and identifying them in three areas:

Family members of elderly people previously in charge, because they died, at the NH where I work  
Family members of elderly people in charge of other nursing homes

Operators chosen for their role and skills that are interesting for the purpose of the general search question.

Another criterion I used for the choice was that of previous knowledge that helped the participants to have confidence and to offer an open availability to the investigation.

## RESULTS

The comparison between the collected and crossed meanings has made it possible to have a greater knowledge of the operator-family relationship on which the heart of the entrance experience appears to be structured. In this sense, it emerges that the significant change in the entry phase is not only of place, but also, and above all, of relationship which, when placed at the center of the process, functionally conditions the experience of the change taking place.

The construction of meaningful relationships between peers and with professional figures is conducive to the elaboration of change and the community dimension is considered an added value peculiar to the new place of life but is perceived only later.

In this sense, the care and communication of this element even during the entry phase can lighten the level of criticality of the change and reduce the objective risks that follow.

Entry is described as an obligatory choice given by a strong and clear change in the need for care and assistance: from a weak or medium need for assistance, the elderly arrive, often suddenly, at a need for assistance and medical care of a strong entity. This bond seems to soothe and mitigate, for family members, the criticality of the new experience. In this sense, the period prior to the transfer is described as the real change, characterized by the worsening of the health of the elderly and the psychophysical exhaustion of family caregivers, so much so that it is defined as "limbo".

The entrance is therefore described in its situated meaning of relief and improvement of the previous situation.

It emerges that the social and cultural vision relating to entry into nursing homes, evaluated as a gesture of abandonment of the elderly by family members, negatively affects the choice and experience of entry itself. A comparison of the data revealed an imbalance between the possibility of reflection of operators on the experience of family members and the diffi-

culty of doing so by family members. The lack of an organized comparison between peers and with operators can also determine the risk of a separation that does not facilitate the potential alliance, as well as not allowing the enhancement of the experience itself.

At the time of entry, in this investigation, the meaning of imprinting is attributed that conditions all subsequent life in the NH.

In the stories of both family members and operators, it emerges that the state of compromised health, which also includes, in most cases, the cognitive disorientation of the elderly person, which emerges as problematic, but at the same time protective, leads to an almost total delegation of the decision to enter the family members.

This seems to decrease, in part, the sense of guilt that derives from it, but it can increase the risk of less adaptation of the elderly person and an increase in the discomfort of the family member in the hours and days following the entry itself.

In general, research highlights that non-pharmacological therapies (TNF) [17-22] can be a source of inspiration, through specific training courses, for the construction of a new relationship with people with dementia, also for family members, helping to build adequate support during the period before entry and during entry itself.

From the descriptions of the operators, little data emerges relating to the period prior to the entry of the elderly person and his family, while in the descriptions of family members the data is frequent. The experience of family members appears, in the survey, traumatic and dramatic at the time of detachment when admissions took place during the Covid-19 pandemic due to the lack of contact and physical and relational accompaniment that entry provided before the lockdown, highlighting the elements necessary for entry to be facilitated for all those involved (social and community dimension, vision of the NH as a place of life, communication as a relevant element in the family-operator and operator-elderly relationship, taking charge of family members as a factor of care, the human dimension as a relevant factor, freedom of movement, centrality of the relationship).

In this sense, given the heterogeneity of the existing protocols, which are little shared and different depending on the organization of the facilities, it is very interesting to take the opportunity of the pandemic experience to review the process in its complexity, obtaining useful and valuable indications for the design of reception practices.

It emerges, as already indicated, that it is to the change in the relationships that are being established that the meaning of both positive (hooking) and negative (loss, disorientation) importance is attributed, so much so that they are told as protagonists of the difficult moment of entering the new residence.

Of particular importance are also the relationships



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of which one becomes spectators (operators-elderly, elderly-elderly, family-elderly, family-elderly, family-family) to which the meaning of support and relief is given at the time of entry, as they are perceived as good practices that act as a guarantee of the new environment.

In this sense, the vision of the entire group of interconnected relationships makes it interesting to compare it with the data, which emerged in the interviews of the operators relating to the investment in the story of the philosophy of the service and on the reflection on the practices themselves, identified as a vehicle for the relationship not only with the elderly, but also with their family members, which also allows a taking charge that from individual becomes collective, systemic.

The previous knowledge of the structure and the previous existence of significant relationships within it is attributed, then, both from the data that emerged in the interviews of family members and from those that emerged from the interviews of operators, the meaning of an orientation and reassuring factor. Furthermore, the need emerges to continue to investigate the relationship between operators and family members themselves which, despite the reflective work of the former and the request for support for reflection of the latter, still lacks structural, formal and planned opportunities that can help, through comparison and dialogue, the elaboration of experiences in favor of greater mutual understanding.

From the interviews it emerged that the operators devote themselves to the analysis of the experience of family members, but less to reflection on their own experience [23] even if, in the stories, the connection with their personal experience as caregivers emerges relevant. Also in the literature a strong link emerges between the operator's experience of entry and life in NH and his personal experience as a family caregiver [18] which could open up further interesting investigations.

Furthermore, the recognition of both figures emerges of the personal connotation that is given to the same experience (for both also characterized by a projection of oneself into the future) that can confuse or improve the relationship. When it happens that there is identification with the other, both on the part of family members and operators, the distance between one and the other, in the stories, seems to decrease.

Then, in the descriptions of the operators, a sort of analysis of the experiences and behaviors of family members emerges, which tends to remain an individual reflection and little shared and, in most cases, not formally foreseen and not considered a useful element for the design of care and assistance to the elderly. In this sense, the non-explicitness of this analysis runs the risk of constituting an implicit non-functional factor in the relationship between family members and the operators themselves.

It should also be noted that there is an objective

imbalance between the possibility of this broadened view of operators towards family members, facilitated by their experience with multiple parental figures, and the impossibility of observations and reflections on the part of family members, who are engaged in a mostly individual experience.

Where there is a confrontation with other family members, it is usually organized spontaneously and not aimed at a shared confrontation with the operators. A vision centred on taking charge of family members in the process of integration [24,25] into the facility would favour not only involvement in the new life of the elderly person, but also, and above all, co-protagonism in care and assistance. This consideration was reflected in the interviews, which also highlighted the significance they attributed to the entry and experience of personal life experience in nursing homes. This data is linked to the description of the link between the emotional state of the elderly and that of his family member. In this sense, the phenomenon investigated in the present research work would seem not to be able to include a separation, within the experience of entry and life in NH between the elderly person and his or her family members. What emerges in the descriptions of the post-entry period is characterized by the meaning of a change for the improvement of the life of both the elderly person and the family member. When the NH is attributed the meaning of a place of life and dwelling and not of a hospital and a place to die, it becomes possible to recognize dignity and attribute meaning even in this phase of existence that requires different conditions.

In the interviews with family members, a strong connection emerged between the sense of guilt felt at the time of entry and the social and cultural vision that gives entry into the NH a meaning of abandonment and selfish delegation of the care and assistance of one's elderly relative to the residential institution. This vision corresponds to that reported by the operators and linked by them to a lack of understanding by the world of the complexity of reception and management of the entire life project. The data relating to the negative relevance of the external vision of the NH, although reported in the interviews of both figures, does not appear to be shared and problematized together.

The research also highlighted the need to find other words to define the NH, especially in the moment before and during entry, even by the operators, as if there were no suitable ones yet. The extensive use of metaphors ("big family"; "family"; "hospital"; "home"; "hotel"; "family pension"; "villa", "nursing home") seems to bring out the search for a new meaning to this place and to the experience in this place that is connected and confirms what is collected in the literature in progress [26-28].

Finally, a differentiation of gender and kinship emerged in the operators' descriptions of the experience of family members at the entrance and, in general,





in the experience of life in the NH. Depending on whether you are a child, grandchild, brother, sister or spouse and depending on whether you are female or male, the attitude changes, in the story of the operators, the reaction and the experience of the family members themselves. Since it is not a topic covered by the present research, the potential in possible future studies is highlighted.

## ELEMENTS OF PERSPECTIVES

The data collected can influence pragmatic processes within the structures starting from the following questions prompted by the results that emerged:

### *The community inside the NH*

If at the moment of entry the community, the community perspective and community action are put at the center, it is possible to build entry paths centered on the relationships that are established and welcomed, as is done in infant-toddler centers with early childhood. If it is true that the community dimension is perceived by everyone as an added and peculiar value to the point of making the experience of entry and in the NH precious and not an obligatory and suffered choice (what is this if not a revolution?) what general and specific characteristics must a NH have to be a *community*?

### *Is reception educational?*

Is reception just collecting and communicating data? The pedagogical dimension is central in a nursing home in which the experience itself revolves around changing life and adapting to the new life, including the learning of new skills. If we do not want to consider the NH hospital and, therefore, solely aimed at treating diseases and the pedagogical dimension is central, it is necessary to organize and manage the entry into the NH and the adaptation phase taking this into account.

### *Are family members and the elderly the protagonists?*

The desire to become active as hosts and not only hosted could make it possible to involve tutors among family members and the elderly and rituals that involve them with the aim of accompanying the newcomers.

### *Does the NH “open up to the territory” or “live in the territory”?*

Placing the NH in the life of the neighborhood, the town, the city, is not only an investment for those

who live in the NH at that time, but is to be considered a social, cultural and political investment for everyone, even for those who will live there in the future. Not a marginalized place for the sick, but a living place that welcomes in a given moment of life, to be recognized and lived before needing it as part of life itself.

### *Are non-pharmacological therapies just therapies?*

TNF, when adopted as a method of intervention by the entire structure, are also a useful ground for family members as they are a way of communicating, of being and understanding even before acting. Their non-specialist nature and not centered on the medical health model makes them, therefore, through specific training courses, within everyone's reach, offering a useful and concrete opportunity to build a project together.

### *Is entry into the NH comparable to inclusion in the nursery?*

The mother “delivers” the child to the operator, interrupting the dyad and trusts in this new relationship that is established according to the concept of a secure base [29] just as the family caregiver hands over the elderly to the operator. Even with due caution, as Tramma suggests because “the search for suggestions, assonances, metaphors, symbols, etc. to be associated with life and its manifestations is not neutral” [30], the experience of inclusion in the nursery could be an inspiration for a reflection on the entrustment to professional care operators that takes place in facilities dedicated to the elderly who are not self-sufficient.

### *Is moving from your home to the NH just a change of place?*

It is in the new relationships that the success of entering the NH is played. The place hosts these new relationships, but often not at the center of the process of change, constituting, instead, a potential support for change.

### *When does the entry into the NH begin?*

Why not try to conceive of the path to entry into the NH as a longer and more complex segment of the path that begins before and imagine, even before that, to design a supply chain capable of welcoming the elderly and families before the gate of the NH [30,31]. The idea could be to schedule the presence of a care manager who play a role from the early stages of the process itself.



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