

# Life Oral History as a Strategy to Humanize the Relationship Between Caregivers and the Eldery: A Brazilian Experience

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**Abstract:** In view of the increasing population aging, the present qualitative descriptive study aimed to assess the applicability of the Oral History of Life to bring caregivers and the elderly closer together. The study sample included seven participants. A total of 12 interviews were recorded and transcribed according to the methodology selected. As a result, a personal book was designed and given to each of these participants in recognition for their scientific collaboration. Every individual had the unique opportunity to express themselves freely, when the essence of what needs to be said in every dialogue matters, from the perspective of participants. Some families reported that they were unaware of such specific details about their close family members. It was observed that the Oral History of Life is not only responsible for recalling facts that had been forgotten, but also for bringing back their dignity, thus valuing their role in society. This simple instrument reminds us that health care quality is not associated with modern protocols and technology exclusively, as it brings to light the humanization of care. Emphasizing the objective of health care through personalization, the Oral History of Life enables elderly individuals to be fully seen and respected with all their characteristics.

**Keywords:** Caregivers, Autobiography, Humanization of Assistance, Aged, Health of Elderly

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## 1. Introduction

According to data collected by the World Health Organization (WHO), the current life expectancy of the world population is 66 years and it is expected to be 73 years by 2025 [1]. At present, there are 120 countries whose mean life expectancy is higher than 60 years, of which 26 are expected to have a life expectancy of 80 years by 2025, according to the WHO. The *Instituto Brasileiro de Geografia e Estatística* (IBGE – Brazilian Institute of Geography and Statistics) [2] indicates that life expectancy in Brazil was 72.28 years in 2007. The 2010 Census [3] has shown significant changes in the Brazilian age pyramid since the last census in 2000.

Old age has its own characteristics in terms of social structure, guiding those who play the roles of health agents and participants and providing space for new experiences that

include several social, political, cultural and economic issues [4].

In a collection of anthropological studies on the aging process, Meyerhoff and Simic (1978) reveal that aging has been approached as a universal phenomenon, thus causing common problems, which can be experienced and resolved distinctly through cultural diversity. In the Western world, old age is almost always viewed negatively, in the perspective of loss or lack, which is directly associated with the fact that Western society strongly values productivity and income, establishing youth and physical appearance as their greatest ideal [5].

Retired individuals are often marginalized as symbolic roles change in family and professional structures, where physical beauty, production and efficiency are emphasized [4]. Thus, the older generation loses the authority and admiration/respect they had from the younger generation,

who now acquire technological knowledge and financial independence at an earlier age. As time goes by, these younger generations promote this replacement of values, adopting those based on their own image and morals [6].

Bertachini and Pessini [7] state that “we are constantly facing environments that are technically perfect, yet without soul or tenderness. Individuals made vulnerable by a disease have stopped being the center of attention and become the means to a certain end”. Apart from this, there are also paradoxical situations created by the extraordinary technological development in medicine, which have enabled human life to be extended systemically, although neglecting personal satisfaction and desires and the quality of life itself [8]. Facts like these cause aging to be seen as a biological phenomenon, rather than a complex condition in which each individual reacts according to their personal and cultural reference points [5].

In contrast with these great developments, the demand for health services has led to a lack of resources and posed significant challenges to their management, which are directly, associated with “budget restrictions”, “prioritizing competing needs”, “private appropriation of public assets” and others [8]. Patients who depend on the *Sistema Único de Saúde* (SUS – Unified Health System) see their priorities reduced to waiting to set up medical appointments and the lack of free medications and hospital beds, while elderly individuals, in particular, suffer more intensely as they often recover from several diseases more slowly [1].

Additionally, the lack of preparation for retirement and precarious economic situation of this population group have caused them to face social conditions that are particularly aggressive towards their presence, hindering an integrated and participatory life [6]. Therefore, it is necessary to rethink the reasons for health professionals to adopt individualistic practices without integrating the different types of knowledge produced by them, excluding elderly individuals from the process in which they are involved [4].

Lack of adequate care from the Health System and inner changes in family dynamics, which have led to social transformations in the way the elderly are received at home, have been causing them to feel more and more isolated. This is the moment when the caregiver’s role appears. Caregivers are not necessarily health technicians and, while usually having a low level of knowledge about the care required by the elderly for their routine activities, these individuals have become their companions, responsible for their hygiene and diet and the control of prescribed drugs, when this is required. Caregivers can work either at the patients’ home or in long-term institutions, formerly known as asylums [7].

Although much has been achieved in terms of better defining, qualifying and training caregivers specialized in the elderly, the perspectives are still fundamentally restricted to the biological dimensions of care [7]. A more humane approach, taking into consideration the broader and more complex dimensions of elderly life and health, undoubtedly requires a more in-depth reflection of the caregiver-elderly relationship. More importantly than focusing on their

physical needs, caused by possible “health problems”, caregivers must also pay attention to certain social and psychological circumstances (as mentioned above) that have a significant influence on the alarming conditions currently experienced by the elderly, including abandonment and silence [9].

Seeking to reflect on the approaches and attitudes that can help change this situation, Uchôa [5] affirms that interventions with elderly individuals must be based on the fact that one has to listen to them, and the one who listens must be willing to understand the meaning that elderly individuals attribute to this time of their lives and how they deal with this. In this sense, Bosi [10] points to the key importance of past in the life of the elderly, which may usually be “the only thing that remains for them”. To be able to pass such heritage onto others is a very important element of mutual exchange, as any relationship can only be effective when there is an interchange between them.

The narrative, a manifestation that has been following men since the beginning of time, is not restricted to the art of revealing objective and impartial testimonies, but also those related to the process of living, particularly the inner reality of the speaker, which brings listener and speaker closer together, thus playing a therapeutic role for both [10, 11]. In its turn, the experience of Gallian [12] shows how a particular form of use of Oral History as a means to produce autobiographical testimonies can serve as a privileged resource for qualitative research and, in addition, give a great opportunity to create human bonds and commitments.

The challenge of the present study was to seek to identify the role of caregivers as humanizing agents in the dynamic aging process. Thus, it aimed to verify how the Life Oral History, as characterized by Bom Meihy and Holanda [13] and Gallian [12], can become a resource that allows caregivers to approach elderly individuals and a humanizing element in this care relationship.

## 2. Methods

A descriptive qualitative study was performed using the Life Oral History. Among the several definitions that can be found, the core of Oral History is mainly the ability to acquire narratives and testimonies, aiming to obtain material to analyze a certain social process at present, raising knowledge about the environment under study. This acquisition promotes not only identity studies, but also all the memories of a culture [14].

A total of seven elderly individuals were interviewed, of which four were females and three males. There were five who lived in Long-Term Institutions (LTI), two of them in private institutions and one in a philanthropic institution, whereas the other two lived in their own homes, although having certain types of restrictions due to their old age and thus requiring a caregiver. A total of 12 interviews were conducted and sessions lasted one hour and thirty minutes on average. Each participant was interviewed twice, except for two elderly individuals who gave only one interview each.

All interviews were conducted in 2010.

Interviews were open and non-directive and they aimed to allow a broad and free testimony of the life trajectory of participants, in accordance with the directives recommended by Bom Meihy and Holanda [13] and Gallian [12].

Interviews were transcribed and subsequently submitted to *transcreation* which, according to Gallian [12], means “‘to transcreate’ an *event* into a literary testimony, faithful to the narrator’s speech and essential written code rules”. Once *transcreated*, the narratives returned to participants, so they could be checked and approved by them. Subsequently, each of these narratives was “edited” in the form of a notebook or book, with a cover that included a drawing that was evocative of the “vital tone” of their history of life, i.e. a sentence or word that stands out as the meaningful or guiding element in their narrative [13].

Next, some copies of these “notebooks/books”, including the history of life of each one of them, were given to participants so they could give them as gifts to anybody they wished. This entire process was followed by researchers, who also used field notes [13], aiming to record reactions and considerations and to assess the development of the approaching process between researcher and interviewees.

### 3. Results

The results of this study initially show some of the particularities of each participant and, subsequently, the discussions on their reactions and events occurred during this process, from the first to the final stages. Participants were indicated by the capital letter “I”, which stands for Interviewee, and the number that lists interviews in order of occurrence.

#### 3.1. Interview 1

I1 was recommended by the Institution, as she was born in Italy and lived through World War 2. Nevertheless, the war appears in her history as a minor detail, compared to the greatness of this person and what she represents. I1’s life is rooted in her love and zeal for her family and late husband. She has special care for her children and grandchildren, who seek to be as present as possible in her life, whether by sending her emails or giving gifts such as a decorated cane. She has lived in a LTI for six years and she speaks of death with gentleness, as if fulfilling her journey and as if her loved one was waiting for her.

In contact with family members, we found out that work had a significant repercussion for the whole family, even among those living in other countries, causing everyone to feel “enthusiastic” and “excited”, as they reported.

#### 3.2. Interview 2

I2 could not leave her home, as she reported she had an urgent need to go to the bathroom, which caused great discomfort. Her face showed clear signs of depression, expressed by her inability to speak spontaneously, as she

continually asked us, “*What else do you want to know?*”. In contrast, during the second interview, she spoke naturally and felt more at ease to think and narrate events. After the voice recorder was turned off, the conversation continued until her daughter interrupted us at lunch time. Her comment to this was “*Look at how time flies, now that we were having such a pleasant conversation!*”.

I2 suffers from a physical impairment. She believes she cannot feel useful and that it is pointless to continue living without her husband, who passed away several years before. All this has negative effects on her health. Although feeling melancholy, I2 loves making friends, talking and receiving visitors. She tells us that her favorite day is Mothers’ Day, when she is not only remembered, but also visited by her daughters and grandchildren. Everyone changes their routine to see her and this always touches her and makes her cry.

I2 was very grateful for having her history of life on paper and she gave it as a gift to her children and grandchildren. Her daughter, with whom she currently lives, was astonished by details of her mother’s life that she was not aware of. However, what most touched them (mother and daughter) was the “care” taken in the design of the personalized book; at the beginning of the interviews, they said that they did not expect this work to reach such high level.

However, the most important thing for this participant was not to have received the book with her own history of life as a gift, although this was extremely relevant. In her own words, the best thing was “*to have met you, my friend!*”.

#### 3.3. Interview 3

I3 is 102 years old and she is amazingly lucid, which can be clearly seen in her exceptional ability to tell stories. She had a life full of obstacles, although founded on “*God and faith*”. Her husband passed away while she was still a young woman, leaving her with the task of educating and supporting their six children. She remembers several song lyrics vividly, which were also a part of her interview. She knows passages from the Bible and singing is the way she prefers to use to express herself. Her speech follows its own direction. As she herself revealed to us, I3 only needs a listener. She was not interrupted, nor did she need help to remember facts. She gave an interview that lasted approximately two hours, without interruption. When the *transcreated* work was going to be checked by her, the elderly woman was hospitalized with pneumonia and passed away in less than a week.

Her death was published in a local newspaper. We decided to give the books to her children and the pastor of the church where she used to go, as he was mentioned in her history of life and she spoke of him lovingly. This pastor, apart from feeling thankful, congratulated us on our approach and said that the elderly have not received their due attention, so that every opportunity for us to value them now is unique and special.

The daughter of this participant got together with the daughter of another participant and they wrote a letter thanking for the performance of this study. They were both surprised by facts revealed during the interviews that they did

not know, apart from being thankful for the researcher's care and dedication. Her grandchildren were also surprised when they learned of this study. They were touched by the fact that they could keep her memories forever, although she was not physically with them anymore.

#### 3.4. Interview 4

I4 tells us that she does not remember how long she has been living in the Long-Term Institution. She has difficulty in expressing herself, as observed from the frequent pauses. However, her willingness to participate was stronger and she showed much enthusiasm. Whoever tried to find out what was happening there would be "politely" asked to leave by her.

I4 said she would like to go back home, although her son could not find out "*lest he gets angry*". It was this brief moment of trust that enabled her to make a bond of confidence with the interviewer. When we came into contact with the Institution to set up a day for the visit where the participant could check our work, we received news of her death. We contacted her family, who we had not met yet, and explained the study procedures, as the elderly woman was independent and lucid and had decided to participate on her own, although not informing them. Their revelations were surprising, despite the participant having stated it clearly that "*What I most wish in life is to go back home...*". The LTI manager and her family reported the same fact: the elderly woman did not want to go back to her current home. Every time she mentioned that she wanted to go back home, she meant the pleasant time she had lived during a specific period of her life, before the deaths of her son and husband. Therefore, she sadly reported the death of her husband "*God took him away and I was left behind...*".

Whenever she left for a visit, I4 wanted to return to the Institution right away. They reported that she had asked to join this Institution, due to recent health problems. Institution staff and family members confirmed that she loved this place and that she was very engaged and playful, including a Carnival celebration they had for the elderly. Her son and daughter-in-law were thankful for the book, as they were mourning her. Now, they would have a memento full of love and affection.

#### 3.5. Interview 5

I5 also lived in a LTI, although he reported feeling very comfortable in his "home". He said his stay was temporary and that he intended to have his own house. In fact, he is somewhat independent where he lives, free to come and go as he pleases, wash his clothes and make his bed. He went to the Institution as he had nowhere else to go. His wife had passed away and his children were distant.

He had a Bohemian lifestyle, as he himself reported, and ended up being despised by his parents. He currently has many friends and states that they have replaced his absent family and that he is ready to help other Institutions that shelter the elderly. Additionally, his speech is truly a lesson

for health professionals, going beyond and reaching individuals who would like to overcome their addictions and restart their lives. Although his past was filled with sadness, his speech had a tone of acceptance or contentment. This enabled him to live a different life, which was unknown to him, and to overcome obstacles so that he is ready to live healthily for longer, as he reported. The concrete results of our work process surprised him, but he stressed that the most important thing was the bond of friendship formed, which he did not imagine possible at this stage of life.

#### 3.6. Interview 6

Born in Russia, I6 said he could not understand why there are wars, as he had spent some time in several countries. He currently lives in one of the LTIs in the city of São Paulo. Looking at him wearing a cap, it is hard to believe he has lived so many years and is no longer young.

Before the second interview, we were told that I6 had asked about us. However, when we visited him again, he said he did not have anything else to tell us. Then, he joked, "*Would you like me to lie?*". Next, we sat with him and had an informal conversation, without being concerned about recording it. His speech was full of good humor, although there were slight signs of sadness, which were quickly forgotten. He preferred not to go into certain details about his life, clearly showing that unresolved issues could cause discomfort.

The participant was impressed by our final work, which according to him "*was faithful to the true history of his life*". He said he would exchange one of his books with another elderly man living in the same Institution, so that they could learn more about each other, as the only close family he had was his son.

#### 3.7. Interview 7

Permanently sitting in a chair due to the amputation of his left leg, I7 used all his knowledge and wisdom, teaching us a great deal about life. Appreciating cultural and educational issues, he is tuned in to the world through television, newspapers and magazines. There is a photo collage in his bedroom revealing precious moments of his life. Despite his excellent professional performance, he mainly admires his first family, i.e. his father and mother, as observed in the photo frame sitting on his bedside table. He regrets the fact that education is an issue in Brazil and jokingly says that he can solve all the problems in this country.

He appears to accept his condition and refers to the food served at the LTI as "*suitable for the target population*". He tells us that he is making the best out of his life at this moment: reflecting on it, one of his passions. He defines himself as "*an observer of the world*".

On the day the personalized book was delivered, we found I7 with the Institution's physiotherapist who, browsing at this book, was astonished and fervently asked to read it. She was very affectionate towards him and congratulated us on our work, saying that it is important to show them how important

they are. As we were leaving the Institution, this physiotherapist passed by us with a copy of his book, feeling radiant and telling us that he had given it to her. She jokingly said that she had all his secrets in her hands. One of the nurses from this Institution was also interested, so she asked to browse at the book and said that it was fantastic and that she had not expected us to take advantage of this instrument in our area.

## 4. Discussion

Eclea Bosi, in his well-known book, *Memória e Sociedade: Lembranças de Velhos* [10] (Memory and Society: Memoirs from the Elderly) emphasized the key location that memory, whether collective or individual, occupies in the dimension of identity of elderly individuals. Identity is structured around memory and plays a key role in the promotion of an individual's whole health. Almost a century ago, Walter Benjamin [15], in a memorable essay on the works of Nikolai Leskov, emphasized the relationship established between the dehumanization which is characteristic of modern times and the demise of narration: the disappearance of the ability to narrate negatively affects human beings' own dignity, as it destroys the most essential dimension of one's own identity, i.e. the experiences one had.

As observed, the exclusion of the elderly, determined by the production-oriented and utilitarian logic of the modern world, ends up creating a vicious cycle of social marginalization, with inevitable consequences for their health condition in a broader whole perspective.

Through the narratives collected with the Oral History of Life approach, one can realize in a more concrete way how the elderly experience this process of marginalization and negligence caused by the "productive young world" and how this has a direct influence on their health condition. The narratives indicate that, more than the physical restrictions caused by several diseases, solitude and isolation are the main causes of suffering and sadness.

In a way, we could observe what Bosi [10] pointed out: when memory is not shared, it is not only lost as a means of affirmation of an individual's identity in society, but it also ends up becoming "petrified" in the silent and lonely inner world of the one who experienced it, turning against oneself in the form of pain, suffering and disease. In this sense, the first effects of the study approach could be observed in the speech of almost all participants as "a relieving and freeing experience". In other words, the Oral History of Life, regardless of all repercussions in the dimension of the bond and relationship between the one who listens and the other who speaks, has an undoubtedly therapeutic nature; a characteristic that has already been pointed out by several authors who performed studies of this type [12, 13].

Practically speaking, the Oral History can reveal not only the inner reality of each participant, but mainly their representation with their peculiarities, approaching both interviewers and the family, who usually report they were unaware of several aspects found in the elderly individuals'

life. For this reason, when the caregiver is not a family member, they can act as a speaker or one who forms bonds, understanding the elderly individuals' reality in a different way.

We could observe how the practice of listening to the elderly indicates not only the results, but also the emergence of a social movement, in an attempt to destructive forms of prejudice, preparing society to deal with the new "old". Therefore, we bring the elderly's voice and will to our environment, apart from including them as an essential part of society, certainly learning from a voice that transmits knowledge and passes on much wisdom, which has been forgotten by our generation.

Additionally, it is not only the fact that information has become public, but also bringing to light things that could be forgotten or left behind, stressing the importance of simpler facts, apart from attempting to raise elderly individuals' lives not only to the level where we are all considered as adults, but even higher, where they are viewed as role models that dignify life. With their experiences, each elderly individual points to different perceptions of life that, undoubtedly, arouse the admiration and affection of those listening to them.

The great merit of testimonies is to reveal the staggering difference in the experiences of beings who shared the same time in history: that of people engaged in historical awareness and that of others who only sought to survive. We can gather a vast amount of factual information, although what matters is to enable a view of the world to emerge from this [16].

Thus, we observed that I1 managed to protect herself from the bombing by hiding in tunnels. Now, she is the strongest link that unites her family, who are scattered around several countries in the world. I2 showed us that there is no right age to make good friends. I3 revealed her determination to support six children and live over a hundred years to teach her faith to everyone. With all her grace, I4 revealed that we all want to go back home and experience the best time of our lives again, the most significant moments present in our memory. I5 showed how society judges behavior and how we ourselves do not accept the fact that someone can change for the better and begin a new life, even at the age of 60 years. I6 gave us a lesson on love and character when he tried to protect his ex-wife's financial situation after his death. I7 had a way to face life that could be an example to those who are afraid of aging.

All participants became involved with their feelings during the interview, diving deeply into their own stories. Some stories were narrated in a very emotional tone, as if they were reliving those moments. The positive parts of their speech caused laughter and the willingness to experience the same moments again, whereas negative ones were somehow incorporated with or without their acceptance, so that this became an effective and indispensable process to the implementation of humanization in health. This humanization should be included and connected to several routine care activities for the elderly from the moment one

intends to listen to them [7].

We must destroy the stereotype that an elderly individual is only a sick body that will end their days in an Institution. We should be celebrating their achievements, not only individual ones, but also the collective ones that translate into benefits for the entire society [17]. Recent research to demystifies that the elderly people residing in ILP, as just being dependent, weak or sick people. The contemporary elderly person, sometimes who is living a healthy aging, with desires, and especially creative in the face of changes to his daily life, developing the capacity to provide to himself a better way of life to be experienced [18].

The fact is that many humanizing actions unfortunately have not been applied by all health professionals, thus revealing the level of deficiency in health care quality. Professionals need to improve care aimed at humanization, so that not only the “law” that protects the dignity of the elderly is applied, but the opportunity of developing humanely through speaking and listening is also provided. Brum [19] states that the nursing profession must integrate its personal and academic qualifications and promote reflection on human care.

Other studies [19] point to negative attitudes towards the elderly from both health professionals and students. In particular, the area of nursing, and not only Brazilian nursing, started to undervalue care, prioritizing remedial treatment associated with the development of new technologies.

Proof of this is that both public and private geriatric and gerontological institutions and elderly homes do not work as service-generating models for elderly individuals to improve their quality of life. All health professionals must be committed to providing alternatives to generate effective services that focus on the right of these individuals to be treated as human beings [20].

Through their speech, the elderly are representing life, they deal with death naturally with their full maturity and continue living. When delving into the speech of each elderly individual, it is almost impossible not to be involved with their History of Life or deeply touched by them. Perhaps health professionals fear both the natural and social deaths so much that they avoid listening to the elderly, in an attempt to exclude the possibility of dealing with their own existential questions.

Denying one's fear of death only serves to mask reality, stifling human nature itself. A great part of this problem is certainly not in being afraid of death, but rather in not accepting life and its meaning. Lies and false assumptions such as “You'll get better!” or “Nothing will happen to you!” or even truths such as “It's the end of us all!” are useless. We need to provide the opportunity to welcome them and stimulate their memory, so they can experience the most meaningful moments of their lives again, their greatest pleasures and happiness. They need a smile and someone listening to them.

The Caregivers needs to be really careful to the interaction with the elderly, for being real, because other research shows that the formal caring relationship and over-concern with

them about maintaining a harmonious atmosphere only contributed to a superficial and distant relationship between the two parties [21].

For this reason, our project aimed to increase the importance of the history of life of each elderly individual, valuing their existence as a unique being and giving them the opportunity to tell their own story, which works as the therapeutic process and strategy to bring the elderly and caregivers closer together.

This is an exercise for health professionals as they are continually seeking to improve care and not allowing their daily routine to freeze their heart and soul or stifle their ability to see much more than what is apparently shown. In recent times, sharp listening and eye contact have been replaced by a series of technical procedures as the basis of health care. Although such procedures are useful and necessary, they cause discomfort when performed in an isolated way to the detriment of listening to others, something typical of a dehumanized culture.

At times, this study acted exclusively as an opportunity for a meeting; at other times, it was the comfort of being with someone whose presence was not restricted to a standard procedure, a merely technical and cold approach to “caring”. However, in the majority of times, the experience caused and systematized by the Oral History of Life approach with its collaborative dynamics became a way to form a bond and bring people together, thus enabling the humanization of care to become practical and effective.

## 5. Conclusions

We realized that speech, as a very simple and practical instrument that requires no financial resources, is at the same time highly complex and full of value, causing us to rethink what kind of professional practice we have pursued. It is usually a matter of questioning the quality of health care, which is not restricted to the adoption of new technologies and protocols, but rather goes as far as a simple attitude that makes a difference in such quality.

The present study helped to show participants how important they are as human beings. Everybody changes after having the experience of a narration, including the narrators themselves. Histories of life humanize people and enable them to be unique individuals.

One of the benefits of the Life Oral History is to guide people towards one of the greatest intimate truths of humanity, when they experience a memory that only belongs to them and fascinating moments of their lives through their speech. We can take advantage of the good relationship of professionals as an opportunity not only for Nursing, but mainly for the promotion of Oral History as an instrument that can bring the elderly and caregivers closer together. At the same time, this event proves the initial study hypothesis that sought to observe the Oral History work process, a means to form bonds and enable caregivers/interviewers and those cared for/interviewed to approach each other.

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