

The importance of life history

Introduction

This module explores the way in which life history can be employed in care to ensure a better life quality to the person with dementia and a better relation between the person and her caregivers in multiethnic care contexts.

The life history of each of us shapes us as individuals and allows other people to get to know us. Due to the impact of the disease on memory and communication skills, people with dementia may face difficulties in retrieving information from their life and sharing it with others. However, many people manage to maintain a connection with their past, even if a loose one or even if this connection comes out only rarely.

The possibility for caregivers to access to the life history of the person they care for is very important in every approach that puts the person, with their needs, their wishes, and their dignity, at the center of the care process. This is particularly significant in multiethnic contexts where the risk of ignoring (or misunderstanding) many aspects of the past life of other people can be higher.

The story of our life

All of us has a certain story to tell about themselves. When we want someone to know us, we tell stories of our past lifetime: our families, our childhoods, our study and work experiences, and so on.

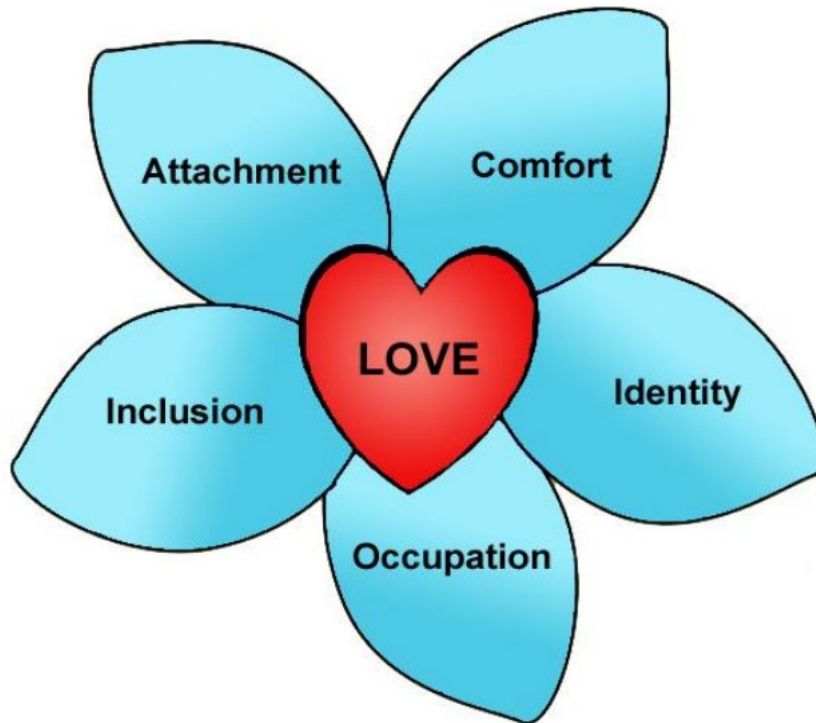
During our lifetime, we usually attribute a certain meaning to the things that happen to us ("this is good", "this is bad", "this is something to be proud of", "this is something dangerous", and the like) and these evaluations, not only the facts themselves (in fact we can change our judgment about the same event over the time), shape our future behavior. Whether good or bad, our past experiences shape the person we are today, our wishes and desires, our needs and fears.

Existential continuity is the feeling that the events of our life form a coherent pattern. Without a story that brings meaning and purpose to the events of our lives, we would feel lost. This is, in fact, what happens when we face big changes without knowing how to integrate them into the idea that we have about ourselves, and without knowing where they will bring us and whether they will put at risk the results we have achieved so far. Having a story about ourselves allows us to face changes with motivation and hope.

Connecting with their past, people have the opportunity to be proud of what they have achieved in their lives, such as their academic or professional successes. Furthermore, recovering their experiences allows

them to connect to positive moments from their past and this can have an effect on their state of well-being.

Person-centered approaches



In the social and health fields, working with life history consists of working with a person and possibly also with their family members to reconstruct a person's past and present life and improve the ways they are cared for accordingly.

The work on life history has been especially influenced by the so called "person centered approach", developed from the work of Tom Kitwood.

Until the very beginning of the 20th century, when it was finally defined as a disease by Alois Alzheimer, dementia was considered a natural consequence of aging, a view that is still widespread in many social contexts today. Nonetheless, for most of the last century, the dominating scientific approach when the person's behavior was inexplicable, was to hospitalize the person in psychiatric wards and to treat the disease as a psychiatric disorder.

Only in the 1980s did a more psychosocial approach begin to develop, the person-centered approach, conceived by Tom Kitwood. This approach is based on the vision of the person with dementia as a person equal to others, a person who has feelings, who has his own life story, rights and desires. The person-centered model is based on a new definition of disease and of the factors that affect each person's condition:

- Personality: personal resources and defense mechanisms of the person.
- Biography: the person's life history and experiences.
- Neuropathology: changes in brain cells
- Social psychology: how we enter into relationship with the person and the environmental conditions.

Kitwood points out that the people with dementia do not lose their worth as human beings because of

the disease. They still deserve the esteem, trust and respect of others.

In this framework, each person (included the worker!) is seen as unique, self-determination is respected and everyone is seen as someone with whom it is possible to build a positive relationship.

In the field of dementia care, working with this approach means developing and adopting an individual care plan based on the preferences and objectives of each person with their direct involvement. Care structures should be seen as residents' homes, so work and daily life should be respectful of their habits and needs.

The centrality of the person and the safeguarding of their existential continuity is also fundamental in the Gentlecare model founded by Moyra Jones. The Gentlecare model identifies the well-being of the person and those around them as the main objective of the care process. The tool through which this objective can be achieved is called a prosthesis. In the Gentlecare model, the prosthesis consists of:

1. the space in which the person lives,
2. the people with whom he interacts
3. the programs and activities in which he is involved.

The 3 elements are in a dynamic relationship with each other and their presence guarantees the functioning of the prosthesis. Accordingly, it is important to work on each of the three levels to reach the goal of giving people a better quality of life.

For Gentlecare it is essential to consider the person as a whole, to give importance to emotions and relationships, to use a non-directive approach and not to judge. In this model it is essential that all those who take care of the person have a deep respect for her. The knowledge of dementia, the understanding of its impact on people, the sharing of goals by all those who live around the patient allows you to build a therapeutic alliance, in which each element brings specific knowledge and assumes individual and collective responsibilities.

Dementia and life history work

Many people crave to tell stories of their life, as if they are just waiting for someone to ask them to start narrating. However, it is important to remember that autobiographical work can be painful for someone and evoke negative memories, so it is always important to evaluate the appropriateness of the intervention with the person you are caring for.



Life story work can support the building of a deeper relationship, allowing the people involved in the relationship to understand the wants and needs of the person with dementia, as well as the creation of a truly person-centered care pathway. Engaging a person in activities that are meaningful to them affects their health and well-being, helping them to feel useful and allowing them to maintain a relationship with the other by restoring their trust. Clearly, this can help people with dementia improve their perception of themselves. They feel recognized as unique individuals.

In the more advanced stages of dementia, people may no longer be able to contribute to the reconstruction of past events in their lives. It is therefore important to start the process in the early stages of the disease, when cognitive functions are less impaired. The mediating role played by the staff, by families and by friends who are called to support the person in the reconstruction of some aspects of his life is thus very important.

Working with life stories has an important value for the care staff as it allows you to see the person beyond his illness, in the "normality" of his life before getting ill, allowing the treatment to be humanized.

Knowledge of the person's history offers many stimuli for daily conversation. It gives caregivers a valuable tool for challenging moments (for instance when the person with dementia has disorientation, manifestations of anxiety, hallucinations, delusions, etc.). In these moments it can be useful to know which aspects of the life history of the person has a positive value, for example the memory of a dear family member, a cared for animal or a song that calms person.

Furthermore, working with life stories can undoubtedly allow the staff to personalize the interventions, adapting them to the characteristics of the person and to understand the reasons for behaviors that at first glance might seem unusual or irrational.

The life story collection itself is an activity that allows the person to spend good time browsing pages and looking at photos and memories.

Finally, working with life stories can form a common ground for knowledge and work with the family which may feel more involved and understood. For family members it is in fact an important opportunity to stay connected with their loved one.

Life story work and multiethnicity

In multiethnic contexts the risk of ignoring or misunderstanding many aspects of the past life of



other people can be higher because of cultural or linguistic barriers.

In the reconstruction of life history of people with different ethnicity knowing something about their cultural background can be particularly useful, because it allows to better understand the meaning of the person's behavior

and to give adequate answer to the person's needs.

However it is fundamental not to make assumptions about a person's needs based on their culture or language. There are three aspects to pay attention to:

1. No person is the same as another, even if they share the same background.
2. Cultures themselves are often less rigid than we usually think of. They often vary across social classes and groups, across genders, across generations.
3. The relation of someone with their cultural background can be a very complex one (think of people leaving their countries of origin because of persecution or discrimination).

These three warnings suggest that we must be careful not to over-generalize or fall into stereotype traps when we deal with multiethnic contexts. This would be incompatible with a person-centered approach.

Instead, it is essential to understand what is important for that specific person, talking to them, their family or friends, observing their images or traces of their past life. Cultural knowledge can be a useful tool but must not be a screen which hides personal differences.

Knowledge of other cultures can be useful to improve the understanding of the life history of the person and thus to understand how the care setting can adequately meet the person's needs.

Some aspects where the integration between personal and cultural information can be particularly useful are:

- typical food and drink

- common every day objects (included pieces of furniture) and materials the person can be most familiar with
- weekly and daily routines, included specific moments devoted to praying
- typical landscapes (urban, rural, etc.), scents, natural environment
- major historical and political facts

It may also be useful to know something about the macro-context such as:

- major historical facts
- politics
- organization of the society

Knowledge of these facts may help avoid troubling issues. Furthermore, showing interest to the person's country or background can certainly help in building a positive, meaningful and satisfying relation.

Finally, it is important to remember that, although story telling is perhaps a universal attitude of the human species, not everybody might like to share details of his life. Sensitivity and respect are fundamental here. Furthermore, the same perception of privacy and of sharing information concerning oneself to others is not culturally neutral and can be influenced by people's cultural background.

Practical tips: a life history book (perhaps to be put into the Teacher's Guide)

Working with life history usually ends up in assembling a real object like a book, an album, a DVD, or even an electronic format document. It may be organized by periods of life (e.g. childhood, adolescence, adulthood ...) or according to other criteria (e.g. places where a person lived, or other).

The information needed to complete the book or album should be provided by the person and/or family members. Here you find some examples of the information to be searched. The questions can be adapted, expanded or avoided based on the characteristics of the person and their background.

- Name and surname, nickname, origins of the nickname, place and date of birth
- Family of origin
- (Father) origins, work, character, lifestyle, relationship with the person, if dead when
- (Mother) origins, work, character, lifestyle, relationship with the person, if dead when
- (Brothers, sisters) origins, work, character, lifestyle, relationship with the person, if dead when
- Significant events in the family of origin
- Current family and cohabitants

- Partner(s): origins, how they met, when they married, work, children, family management, characteristics of the couple, common interests. If deceased when and how.
- Children: order of birth, names, relationship quality, job, place of residence, etc.
- Grandchildren
- Special ties
- Significant events
- Places where (s)he lived
- Known languages or dialects
- Schooling
- Favourite friends
- Teachers
- Favourite games and places as a child
- Work experiences
- Character
- Personal care and clothing habits
- Social and friend network
- Interests, hobbies and leisure activities
- Sports practiced or followed
- Music and dance
- TV programs and movies
- Travel and vacation
- Spirituality
- Politics/social engagement
- Pet animals
- Fears / reasons for discomfort and disturbance
- Ability to ask for help and to collaborate
- Money management
- Use of technology: Phone management, PC
- Typical day before the illness
- Recent typical day
- Preferred food and drink

- Daily habits (when getting up, when eating, post-meal rest, when going to sleep)
- Objects that (s)he always keeps with him
- Wishes never fulfilled or unresolved situations

The charity Dementia UK has developed some tips to create a “My Life Story” book. You can find them here: <https://www.dementiauk.org/for-professionals/free-resources/life-story-work/>

Conclusions

Throughout the course of our lives, the experiences we have lived and the people with whom we have had significant relations, in other words our life experience, contribute to determine the person we become, our beliefs, our interests, our needs, who and what is important to us.

In care settings, the knowledge of this information about a person's life history allows to personalize care, according to the paradigm of a person-centered approach.

Obviously, the life story of each of us is also influenced by the cultures to which we belong. Our beliefs, our desires, our preferences can be greatly influenced by those of the groups to which we belong. However, it is important to emphasize that the impact of the culture we belong to on each of us can be very different. We should not make the mistake of locking people into predetermined patterns or stereotypes.