

Once Upon a Time... me

Ageing and narratives: The Lifebook

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Abstract. The paper considers the use of ICT as a tool of lives representation. Even when we have to do the summary of our lives, all our sensations, memories confused, we try to sort them into stories. The story is the oldest form of knowledge that the man has had. Also the science and story, because it tries, in the final analysis, to reconstruct the world in more orderly that we can understand. As well as when grandparents tell a story, the story of their life, they give us guidance on how to represent the time, the perspective and the distances. So they show us their own image, leaving traces and a Timeline. Traces are signs and memories of life experience. Elderlier's use of ICT in everyday life is a kind of participation in society, giving a contribute to social historical memory. It means an intensification of elder relationships and a strong form of social inclusion. I would like to focus on the sense of narration: elderly people should be considered as resources for experience getting access to stories that could be shared on the web as podacst or as script. The questions are following: Have Elderly people to construct and communicate a sense? What kind of communication we have? How could a script be useful for Ageing Society Healthcare?

1 Introduction

The desire and ability to communicate are common to all cultures that are expressed through a language of codes, grammar, syntax, semantic and styles widely shared. But what generates the need to communicate is, at least in part, the fear of loneliness, of not being able to share with others the richness of mental life. It is a communication that generates deep meanings and that, therefore, constitutes a significant social function. We have got to imagine how can changes the daily life of a person that has finished to work and spent lot of time staying at home longer, sometimes meeting a friend going to the cinema, a library or to a museum, however still being in good physical and mental health.

2 Social inclusion for elderly. An overview on EU and WHO

On the World Health Organisation (WHO) site we can read that “In almost every country, the proportion of people aged over 60 years is growing faster than any other age group, as a result of both longer life expectancy and declining fertility rates”. [19]

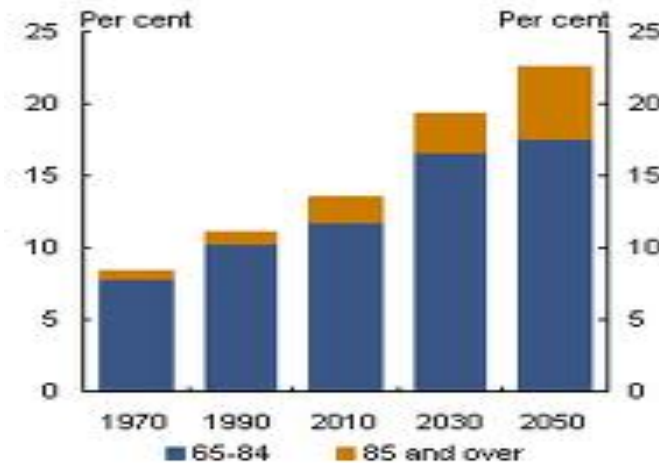


Fig. 1. WHO (world Health Organisation: <http://www.who.int/topics/ageing/en/>).

This puts our social health under pressure with a focus on the quality of life for elderly in the future. We have to do something that improves the capacity to communicate and interacting with the society as inclusion strategy. We don't forget that chronological age is not a reliable indicator of capability or performance so it's possible thinking about a co-construction of relationship and sharing knowledge with the use of ICT. [19]

A recent research by professor E. Mordini, SENIOR, acronym for 'Social ethical and privacy needs in ICT for older people', worked on this direction: "As an FP7 support action, SENIOR was part of the wider EU strategy established by the Lisbon Treaty aimed at eradicating poverty and social exclusion by 2010. The Riga Ministerial Declaration on e-inclusion of June 2006 identified six themes for social inclusion. One of these themes was just e-Ageing, whose goal is to empower older people to fully participate in the economy and society", that's always understanding how ICT can meet the needs of senior citizens without compromising privacy and ethics.

So by this perspective, the WHO declare: "We need to reinvent our assumptions of old age. Society needs to break stereotypes and develop new models of ageing. Everyone benefits from communities, workplaces and societies that encourage active and visible participation of older people." [19]

It's important to discuss on active ageing and e-inclusion policies. It acknowledges that ageing actively and living independently are of great value to elderly persons as the BRAID (Bridging Research in Ageing and Information and Communication

Technology Development) project that seeks to unleash the potential of technology as a vehicle to enable people to achieve their full capacity (<http://www.braidproject.org/?q=publications>); it also acknowledges that technologies can play an important role in this and recognises the right to establish relations with others.

The growth of research and development in the area of Information and Communication Technology (ICT) and Ageing has highlighted the potential of ICT to provide tools that can enhance quality of life for older people but we must be aware of their ethical dimensions. Values are the heart of the European Union, as Article 1a of the Lisbon Treaty makes clear: “The Union is founded on the values of respect for human dignity...”.

3 Have Elderly people to construct and communicate a sense? E-inclusion and e-participation as historical memory

First of all we have to consider how can we measure the quality of life for elderly? What are their needs? We can easily imagine some needs are independent by a physical and mental point of view, but when we talk about relationship, we can't despite the fact that we have something to tell to other.

“It is hardly innovative to speak of the narrative quality of human existence (Sarbin 1986)” [11] . But the question could or, better, should be: what are narratives? What we tell? We can tell a journey, we can tell a thought or what we like and what we have done in our life, in a particular day. That's because we are in stories and so we are stories. We make them up, we use them, we are in some senses made by them. It's very hard to think, talk or write for very long without starting to put things into a sequence that relates something, retells something. And there are a lot of things we say and write which are in effect residual cores of stories: if you say a proverb, it seems to conjure up a story that you don't have to tell.

So also when we think about science, well we have stories of discovery, invention and exploration alongside chronologies of scientists' lives. But what about the 'pure' science: also in the experiment, there's a moment where it goes into a narrative about what they actually did by way of running the investigation. The way of writing and describing is deliberately impersonal and without expressions of sentiment. It's the narrative of series of observations, in order as a list, but it certainly follows the pattern of narratives.

We can talk about ideas, we can talk about feelings, shame, irritation. Put the two together attached to beings that we can believe in, can think we know and grow to care about and we have the potency of story just with feeling and thought.

Stories are part of human culture. Human beings have told stories since before we invented writing! From Gilgamesh to the Iliad, from King Arthur to The Lord of the Rings, we've always told each other stories have become part of humanity? But most importantly stories let us experience what it's like to walk in the shoes of another person, to see things from his or her point of view, to think and feel like another person. That's another perspective.

Storytelling is a part of life, intrinsic to most cultures. They help people make sense of the world's experiences, dilemmas and hardships. Stories can educate, inspire and build rapport. They are a means of communicating, recreating, and helping preserve cultures by translating memories into a more concrete script that can be handed down verbally or in written form. Telling the story can provide the opportunity to gain a deeper understanding of one's experiences and oneself.

"Stories are vehicles of identity. We shape, transform, defend, and pass on our identities through our stories." [11] So "... our identities themselves are understood to have a narrative structure (Ricoeur 1988)

The use of ICT could support this aim and provide to a new form of communication and narration across long distances, too. This put on evidence the questions about the absence-presence, the distance between tellers and listener in space and time, the perspective. A friend could be in every part of the world and I can tell him or her a story in the same moment as I can tell a story and leave a trace for a long time, for the family and for the nephew. Thinking about senior citizen means thinking about citizens over 65 and 80 years old, but maybe, we have to imagine different needs between citizen whose main issues are likely to be universal access to ICT and e-participation, and other citizen, probably over 80 whose main issues are mental and physical deterioration and assistive technology. An approach geared towards the protection of human rights could match the different needs of senior citizens and provide concrete guidance to evaluate information technologies for them.

Anyway senior citizens have different interests, experiences, needs and desires and ageing is a continuous process that take with us for a long time.

By older senior citizens, we mean people in their eighties and nineties. This demographic group is rapidly increasing in all developed countries and in Europe as a whole. This group of senior citizens is often suffering from various negative changes in their physical and mental abilities. Gerontologists often refer to these changes as increasing frailty.

Frail citizens face an immediate future of deteriorated physical and mental conditions, reduced mobility, increasing disability, lack of autonomy, lost of memory

4 How could be useful for Ageing society Healthcare? Main issues are mental and physical deterioration...

Memory is one of the most important function of our mind, it's the thread running through all our actions, sensations, feelings, emotions, in the past and in the present. It is the link between our time and our space, is what gives meaning to everything that surrounds us, to life. About us, we know through our own experience, the environment and the people around us among them there is always an interaction.

But in case of dementia something doesn't work. Alzheimer disease is one form of dementia that is relentless and merciless: the progressive loss of memory is the first and most obvious symptom of the onset of the disease. It is the first sign that makes one suspect that something is wrong, that maybe it would be good to consult a doctor. It is the memory of recent events to be the most affected and this affects the ability to

speak and think. It can be of great help to establish points of reference such as diaries, billboards, signs on the doors, self-adhesive sheets on the refrigerator (post-it), calendars (deleting the days one by one), photographs (with the names written below). Therefore, the possibility of making a living history, to preserve the memory of a happy moment are all opportunities to fill the blank pages of a diary, in which every single idea or memory worthy of attention are shared and instantly forgotten after a few seconds. Fix the everyday moments of our history, to the memory of our days, our thoughts, our ideas our best reconstructs the history without it the information and events of our lives would be meaningless, and we would lose our individuality, somehow, caught in a chaotic and incomprehensible reality, devoid of connections.

The Narrative Medicine (or "Narrative Based Medicine", a term coined by Rita Charon) is born with trying to make up for the lack of evidence-based medicine to take into consideration care personal aspects of the patient. It caters for both the patient and the medical staff, the two figures involved in the care process, which relate to each other.

Today, medicine is present in our daily lives, however the relationship between doctor and patient is going to fading and cooling: the patient is seen more as a set of objective data and not as an individual with unique needs and requirements. "I first used the phrase Narrative Medicine in 2000 to refer to clinical practice fortified by narrative competence—the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness. Simply, it is medicine practiced by someone who knows what to do with stories" [9]

"At Columbia University in New York, NY, we provide narrative training (rigorous training in close reading, attentive listening, reflective writing, and bearing witness to suffering) to doctors, nurses, social workers, psychoanalysts, therapists, literary scholars, and writers who attend our intensive training workshops. We also provide such training to students of medicine, nursing, physical and occupational therapy, pastoral care, oral history, social work, literary studies, and law. Our research projects are accruing evidence that students and clinicians who have undergone narrative training with us strengthen their therapeutic alliances with patients and deepen their ability to adopt or identify others perspectives." [9] Narrative medicine curricula and projects are proliferating throughout the United States, Canada, Europe, Great Britain, Latin America, the Middle East, and Australia. In addition to being a psychological or interior state, attention in clinical practice is a peculiarly narrative state. However material its concerns with flesh and bone seem to be, medicine attends to words—the spoken language of patients, the dictated language of discharge summaries, the scrawled longhand of intern progress notes, the increasingly keyboarded "sign out" onto the electronic medical record, the messages of love and loss given and received near death. Charon defines narrative medicine as "medicine practiced with these skills of recognizing, absorbing, interpreting, and being moved by the stories of illness"

In this sense, Medicine Narrative approaches to holistic approaches, typical of non-conventional medicine, which in front of a rigid classification of diseases, propose a subjectification of the patient, seen in all its complexity and uniqueness. The stories provide an opportunity to contextualize clinical data and especially needs, and allow you to read their history through the eyes of others, bringing a richness and diversity of perspectives that still do not exist. The narrative allows the patient to not feel isolated, but at the center of the structure, and this gives, in turn, operators hospital the

opportunity to have a more complete view of the problems. The narrative of the pathology of the patient to the doctor is then considered equal signs and clinical symptoms of the disease itself.

Communicate their disease state and relate empathically also helps the patient to make decisions with greater awareness; relate to others; express moods and problems; share testimonies that will be useful to other doctors or patients.

In fact, the story comes to life through different tools : from writing to music, the visual arts, photography, theater to film. In everyday life we use our narrative skills to tell others, to say something about us, about our past but also our future expectations. Similarly, the patient tells the doctor your "history of disease," and this is the most true and complete description of his illness. The Narrative Medicine (NBM, Narrative Based Medicine) refers not only to the patient's experience but also to the experiences of the doctor and their relationship.

Why the study of narratives? "In the meeting diagnostic, the description is the phenomenal form in which the patient experiences the health and encourages empathy and promotes understanding between the doctor and the patient, allows the construction of the clues and analytical categories useful for the therapeutic process; suggests use of a holistic approach. In the research, narrative medicine helps to build an agenda centered on patients and generate new hypotheses " [12]

The narrative of personal experience should play a significant role in the relations of care, because suffering needs to be inserted into real stories to gain a precise sense, become shared and transformed into a resource. "Listening to a history of illness is not an act but it is therapeutic to give dignity and honor that voice (Frank A.)" Take the word is one of the most significant and 'high' mode of participation. The experiences of illness are always part of a 'life'; collect and compare makes it possible to build truly shared paths. To listen to stories, to reserve space for those who want to take the word, even without knowledge of methods and have attended courses of empowerment, it means build pathways to participation.

"Partial view. A diary of Alzheimer's, "a precious book, the diary of a history professor who has documented his illness through feelings and fears. This is the first direct evidence of the disease: Cary Smith Henderson, this is the name of the author, had a very early diagnosis and without possibility of error, through a biopsy of the brain tissue. Known diagnosis, his dream was to create a book that could be helpful to better understand the disease. The book, which was completed by his daughter and his wife contains wonderful photographs of his face during the various stages of disease progression. Cary through his diary communicates not only the difficulty of living with Alzheimer's, but also the ability to retain feelings of serenity and hope, and the importance of those who care for them. It's a diary, but also a real journey of a year in the world of Alzheimer seen from documenting the ways in which, those who are sick, perceives the world with whom we share it.

5 The Lifebook

Alzheimer's disease takes away memories. Lifebook is a project and a process that will help a person tell those untold stories for both the future generations and as a way to hold on to the memories. The loss of memories can cause a person and his family a lot of heartache. Lifebook cannot cure Alzheimer disease and might not be able to help a person remember, but there is a sense of safety, knowing that those memories are tucked away in a book. A study done in Ireland also spoke of how using life story books improved understanding of a person in a nursing home that would probably be just as helpful for a person receiving in home care whether by a relative or a person from an in home care agency. Residents drew on memories to construct stories about themselves, which allowed them to validate their self-identity. Lifebook is going to give a voice to older people.

Future research is needed to expand the findings from the present study, and to include people with dementia, older people with learning disabilities and people suffering from chronic disease. "The focus of our research is on the structure of the life stories of elderly people living in old age homes and its impact on their well-being or quality of life and the quality of the caring relationship following a specific narrative intervention called the Life Book method" [11] The 'product' of this method is a Lifebook which contains stories and valuable and memorable photos, letters, poems, objects, etc. which are metaphorical for persons and events in relation to the individual him/herself. The reason for opting for this method lies in the observation that the life book intervention can serve as an integral and structural part of regular care in nursing homes, to be implemented by trained nurses and not necessarily by professional therapists.

The elderly person gets the opportunity to review his/her life with a nurse and a volunteer (a family member) along the lines of six life themes. Each theme is addressed in one of the weekly meetings with the nurse, resulting in a 'chapter' in the life book. The first theme is the chronology of lived life. The second theme regards important relationships. The third theme is lifework. The fourth theme is growing old and the meaning of life. The fifth theme is that of norms and values. The sixth and final theme is called a profile of the self. [11]

The process of creating a Lifebook allows you, the author, to savor the experience of exploring your own life story. This is a stimulating journey of discovery and a deeply therapeutic process as lost memories are reawakened. The purpose of this feasibility pilot project was to observe Alzheimer's disease (AD) and mild cognitive impairment (MCI) patients' responses to personalized multimedia biographies (MBs). It's developed a procedure for using digital video technology to construct DVD, documented their responses to observing their MBs, and evaluated the psychosocial benefits. An interdisciplinary team consisting of multimedia biographers and social workers interviewed 12 family members of persons with AD and MCI and collected archival materials to best capture the families' and patients' life histories. "We filmed patients responses to watching the MBs and conducted follow up interviews with the families and patients at 3 and 6 months following the initial viewing".

Qualitative analytic strategies were used for extracting themes and key issues identified in both the filmed and the interview response data. These were the results:

analysis of the interview and video data showed how evoked long term memories stimulated reminiscing, brought mostly joy but occasionally moments of sadness to the persons with cognitive impairments, aided family members in remembering and better understanding their loved ones, and stimulated social interactions with family members and with formal caregivers. Implication: This study demonstrates the feasibility of using readily available digital video technology to produce MBs that hold special meaning for individuals experiencing AD or MCI and their families".[11] Lifebook as an application aimed at promoting the creation, sharing and co-construction of life-centered narratives. It is rather closer to the meaning, "a mode of knowledge" by which we understand the world. TheLifebook project is based on the concept of "product for memory", something to remember (as search and retrieve), like a picture, a recipe, a note, a web page, an email. These technologies seem to adopt a naïve conceptualization of memories as objective facts rather than recognizing them in the act of remembering itself, in the discursive representation (and re-invention) of stories that relate to both private facts and to the reflections and interpretations of the other. This is a digital "book" in which users can narrate true stories and their personal memories. In other words, it's possible to focus on technologies conceived to help "tell stories", and "share narratives that evoke memories" which, for their own nature, are continuously mutable as they are built, comprehended, interpreted, "sense of the origins", particular when senior citizen suffers because of dementia and he misses the words.

Conclusion

As I said in the first part of this paper "The story is the oldest form of knowledge that the man has had". Everything we live in everyday life is a story, that means it could be something to tell. Surely it represent a moment of life that could be memorised and that could tell something about me So everyone is in a story and everyone is a story. For elderly people these stories represent the stories of their lives that should be a sort of timeline of their lives: their experiences, sensations, feelings, dreams and emotions are inside there. They tell "who they are", "where did they come from", "what they did", their family as a storytelling, in a sort of Timeline. The use of ICT as a tool of lives representation that can enhance quality of life recognised through a narrative method that contribute to the construction of the historical memory of a place, of a life and a community. So when I mentioned the article 1a of the Lisbon Treaty "The Union is founded on the values of respect for human dignity..." I was referring mainly to the respect of the mental condition of the elderly. In particular, I alluded to the condition of the patient of Alzheimer's disease that is seen increasingly unable to communicate.

The senior lost the use of his words, his ability to express feelings and emotions, to tell their stories. He loses himself completely in a tangle of old memories that are mixed with feelings and emotions become uncontrollable. Several Research Centers and Studies, as instance in USA, show that the only way to alleviate the suffering and probably delay the progression of Alzheimer's disease is based on the method of "Gentle care".

At the moment there is no cure for the cure of Alzheimer's disease, but there is a drug treatment that slows the disease. At the nearest "Camillo Golgi" Abbiategrosso Centre it's working in the care of the elderly through the use of music, audio and video tools that reproduce the first stages of life through songs, images and objects that belong to the person and are linked to a particular memory or are significant to a given time. Here are repeated stories and rhymes that heard and recited during childhood. I think we can see with new clarity deep aspects of the illness, the sick person, the situation of care, and the person who cares for the sick. During the research of the material for this paper I was able to realize that the narrative is the method used by caregivers who have a religious type of training and holistic. But there is also another category of people who reproduce the model of care through narration and they are counselor or writers who decide to use the Lifebook as a tool of participatory culture. In the last days I got the opportunity to know a small company, called " Digital storytelling that works on the reconstruction of the historical memory of some areas in Milan. The company has shown a real interest in providing digital stories and has offered to participate in the creation of a line of Lifebook Healthcare, therefore, directed to the elderly. "Listening to a history of illness is not an act but it is therapeutic to give dignity and honor that voice" said A.Frank, but above all" Take the word is one of the most significant and 'high' mode of participation". The Lifebook project is based on the concept of "product for memory" and it is rather closer to the meaning, "a mode of knowledge" by which we understand the world.

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