



#SHAPESSTORIES

#SHAPESStories explore the personal, social and technological needs of older adults and their families

In #SHAPESStories we provide a window on the real human beings who are the reason for, and the creators of, a "SHAPES platform". Here you will find the older people who spend many hours sharing their lives with our ethnographic researchers telling us about their lives, hopes and fears. You will also see how men and women in more than a dozen countries across Europe bring high quality health and social care to older people, their families and their communities, as well as how they introduce and assess new technology to make these services work better for their users. You will also view how SHAPES technicians and engineers, committed to discovering and or adapting appropriate technologies to improve the lives of older people, connect their expertise to real-world problems.

Editors: David Prendergast, A. Jamie Saris and Katja Seidel (Maynooth University)



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Robots and humans: learning how to adapt new technologies

Author: Esperança Lladó Pascual, Clínica Humana

Introduction

Ca'n Granada is a retirement home in Mallorca, where older adults live in their own apartments, share common areas and have access to services and activities. One of these activities is held every Friday by a psychologist from Clínica Humana who runs cognitive stimulation sessions with the residents. Connecting to the activity, we from Clínica Humana decided to run one of the SHAPES pilot studies called "A robot assistant in cognitive activities for older people" at Ca'n Granada. The hypothesis behind this study is that social robots, in this case the humanoid robot called ARI from PAL Robotics, which is integrated with a set of cognitive activities developed by SciFY, can be an improved channel to provide cognitive training in a more personalised and motivating manner. Therefore, the main goal of this study was to evaluate the user engagement and the user-perceived usefulness of the system.

In July 2021, a mock-up presentation was held at Ca'n Granada, where three older persons assisted. In that session we introduced ARI to participants through a Power Point presentation, showing them pictures and explaining what the robot could do and how it could be a useful tool to assist in cognitive training. The participants seemed pleased with the idea of using ARI but expressed some critical opinions about the physical shape of the robot, such as "ARI is big, and the eye movements are disturbing" and voiced doubts about the use of the robot, such as "I would prefer to do the activities on paper" or "I would like to use it during the cognitive sessions with the psychologist, not on my own".

"I would like to use it during the cognitive sessions with the psychologist, not on my own."

Feedback

The feedback we collected during this first session was useful to understand what features needed to be adapted. We passed all the comments to the technical partners and together made the corresponding changes: PAL started to develop a new eye design for ARI, we defined a new game structure based on the participants' suggestions, including the option to print the game to do it on paper, and we planned with the psychologist how to implement ARI in the regular cognitive sessions.

Few months later, after implementing the feedback collected in the mock-up training, we decided to do the hands-on workshop. At this point, most of the participants in the mock-up presentation were no longer living at Can'n Granada so the hands-on session would be held with other participants. In her next cognitive session, the psychologist informed the new attendees that their next cognitive training session in December would be supported by an assistive robot and, even if they didn't have any previous knowledge about the robot, they agreed to the idea. When the day arrived, we entered the room, this time bringing ARI with us to do the practical session. Five participants were already there and after a brief introductory conversation, one of the residents started a discussion about the recent introduction of robots in some areas, saying

that he did not like the idea of robots taking over. Two of the other participants in the room joined the conversation while the other two remained silent. The participants started to get a little bit annoyed with the situation and expressed their opinions loudly saying;

"I don't like talking to robots", "I want to come to the cognitive sessions, not to do them with a robot", "Robots don't have feelings", "Robots are replacing people's jobs", "I don't like using new technologies", "I like talking to people not machines".

We didn't interrupt them but listened attentively to their feedback and worries and provided space for them to express their opinions. Only later we intervened to clarify that a robot was a tool, just like Power Point was in their current sessions, and that Clínica Humana's intention was to find out whether, and in what ways, it could be most helpful.

At that point, the psychologist leading the regular cognitive sessions, entered the room, introduced us, and tried to recreate a more relaxed atmosphere. Then, we started distributing the consent forms but soon the previous conversation started again. The psychologist reminded the residents that this was only a demo and that everyone was invited to share their views on what they liked or didn't like about it. However, the conversation continued to circle around the same points until the residents didn't seem to be willing to participate in the session anymore. Aware of the situation, we rethought the approach and, highlighting again the voluntary nature of the study, asked the participants directly about their wish to participate in the robot assisted session. Three persons answered that they would prefer to do the usual cognitive session; the other two were asked again directly and nodded, they agreed with their colleagues.

Unfortunately, given the residents' reactions, we were unable to complete the session. Seeing the experience as an important learning opportunity, we have since attempted to understand the reasons why this hands-on training wasn't successful. After analysing the situation, we have realised that new technologies need to be adapted to the users of today, responsive to their real needs and social situations, and take into account their fears and concerns. For example, after the attempt, the psychologist told us that just before our arrival some of the residents had expressed their doubts about robots. This was to be expected as they had not participated in the mock-up presentation and therefore lacked proper introduction to the tool and its functions. Also, there was a room change in the last minute, which could have been another unsettling factor. Furthermore, the fact that some of them had already participated in another hands-on training for another SHAPES use case with the robot ARI may have overwhelmed and confused them. The most important reason, however, seems to be a genuine fear of robots replacing the human interaction with the psychologist during the weekly sessions.

Conclusion

Failures are written up in the scientific literature far less frequently than successes, but failure is a great teacher, without which no progress is possible. Working in a real-life situation with the residents at Ca'n Granada, we have learnt some key lessons: to empathise with the intended users, to consider their believes, opinions and concerns, and to think carefully about the way in which new technologies are being introduced. Now, thanks to this enlightening experience, we are confident that we can find the way of fulfilling the user needs and to create a positive and joyful human-robot interaction.

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A Window to the World: Guide Interpreters and Tactile Communication

Author: Lucia D'Arino, WFDB

Introduction

Momi is a 75-year-old man with deafblindness living in Milan, Italy. He was born deaf in a hearing family. At the age of 30, his vision was severely reduced, and today, he has no sight nor hearing, which means direct communication with other people is limited, including with his own family and friends. Momi often requests the services of guide interpreters, including his wife, to be able to communicate, contribute and participate fully in society. Another important aspect of his life are leisure activities, such as handicrafts, which stimulate his creativity and the imagination, and encourages communication and socialisation with others.

Momi is a talented craftsman who uses wicker and clothes pegs to build different objects such as a chess board, baskets and vases. He has been carrying out this hobby independently for many years and is self-taught. Keen on passing on his expertise, after his retirement Momi completed training at a national association of persons with deafblindness to become a formal instructor. Today he is a handicraft teacher for people with disabilities and loves sharing his passion with others. This hobby has been a welcome diversion during the COVID pandemic and also made him feel active and useful. He is very proud of the exhibition he has set up in his own home, which friends and neighbours often visit. Momi also sells his designs at local markets and has entered many competitions for which he has obtained prizes and awards, and regional recognitions.

Communication

In his childhood, only spoken language was allowed for teaching purposes and Momi, like many deaf or hard of hearing persons, was punished whenever he communicated using sign language. However, he did not let that stop him from learning how to sign. Today, he communicates in standard Italian sign language, which he taught himself informally at the age of eight, outside school with his deaf peers. Furthermore, since he lost his vision, he additionally learnt to use tactile signing.

"It is difficult for me to communicate with those who do not know sign language. But there is another system called MALOSSI. MALOSSI works by pinching one or some parts of the hand, and this is another way people who are deafblind communicate. With my grandchild, the oldest one, I communicate very little, and he often uses the dactylological alphabet [signs made with the fingers] on the palm of my hand."

The MALOSSI system is used in Italy, whereas the LORM alphabet (a method of tactile signing in which letters are spelled by tapping or stroking different parts of the listener's hand) is used in the Czech Republic and some German-speaking countries. Momi often raises awareness of deafblindness and the different means of communication that exist.

"If you do not know sign language nor MALOSSI, one thing you can do is spell in the palm of my hand letter by letter".

Momi's deafblindness is a major communication barrier, even with his own family, which has an impact on their relationship. Momi currently lives with his wife Valentina. Valentina was a volunteer at a national association that supports people with deafblindness and was a qualified deafblind interpreter. They started exchanging emails, gradually fell in love with each other and have recently married. Valentina supports Momi as a guide interpreter in his daily life and provides assistance, interpretation and guidance both inside and outside their home. Valentina communicates with Momi via hand-over-hand signing, which is one way of communicating in sign language that also involves touch. In this form of tactile signing, Momi places his hands over Valentina's, which allows for Momi to feel the shape, location, and movement of his partner's hands. Momi is grateful for Valentina's assistance as very few persons with deafblindness can have access to a guide interpreter all day every day.

Impact of COVID-19 in daily life

During the COVID-19 lockdown in Italy, Momi felt very isolated. Due to social distancing and restrictions, Momi could not communicate by touch with other people nor travel. Also, public life and social activities were extremely limited, as well as guide interpreter services for non urgent matters. Due to this, Valentina became his window to the world, as she would interpret for him the news on TV and latest updates regarding the pandemic. Because of her, Momi was able to remain in touch with his friends and family, his representative organisations as well as recent news about what was happening in the world. This situation shows that persons with deafblindness need access to services such as personal assistance and guide interpreters to avoid isolation and encourage the integration of this specific group in society.

"My wife is the person who helps me the most and who I am with all the time. She is the most important person because of the communication issues. I barely see [the rest of] my family, to be honest."

As for many people, Momi's life has changed with the pandemic, as his routine and normal life have been disrupted, for example, he quit going to the gym and swimming which he loved to do and which had a positive impact on his physical and mental wellbeing.

"Right now, because of the Coronavirus pandemic I do not travel to other places alone. I usually did, I was able to go to another village, but now I do not, only when I am accompanied by Valentina. As a sightless person, I rely on touch [to communicate, navigate a space, etc], but now I cannot touch things that I normally would."

The importance of technology

Assistive technology and adapted devices are very important for persons with disabilities. For instance, Momi uses a braille line that connects to his computer to write and read emails, which is his main channel of direct communication with friends and family. Furthermore he uses a red and white cane, which also includes a light that can flash at night to increase his visibility to others. He also uses a small device, which he always carries in his pocket and can be activated by Momi in case he needs immediate assistance. By pressing a single button, his wife is instantly alerted.

Momi wishes for technology and devices in his home to be adapted and meet his needs, to be able to live more independently and feel safer. However, these devices either do not exist or are too expensive. For instance, a braille line that connects also to a tablet or a phone (apart from his computer) would allow him to use WhatsApp or text messages, and communicate with other people, participate in group chats, etc.. Furthermore, as he says:

"It would be useful to have alarms adapted for people who are deafblind because in my case, I have a security system at home to avoid burglars coming into my house, but as I cannot hear it and its not adapted, I never turn it on. The same goes for smoke detectors."

Momi hopes that technologies and assistive devices will become increasingly adapted to persons with deafblindness. In the meantime, he will continue to overcome the barriers he encounters and find creative solutions to these challenges. With his positive and enthusiastic character, he is very grateful for the life he has and will continue dedicating time to his handcrafts. He hopes for the pandemic to quickly end, so that he can communicate by touch with more people and resume his activities and social life.

Useful Links

- 1) What is deafblindness?: https://www.wfdb.eu/what-is-deafblindness/
- 2) Deafblind interpretation: https://www.wfdb.eu/interpretation/
- 3) WFDB Report on deafblindness (2018): https://www.wfdb.eu/deafblindness-in-the-world/
- 4) The Red and White Cane: Obstacles and Barriers: https://shapes2020.eu/shapes-stories/the-red-and-white-cane-obstacles-and-barriers/





The Red and White Cane: Obstacles and Barriers

Author: Lucia D'Arino, WFDB

Alegría ('joy' in Spanish) is a 72-year-old woman born and raised in the Canary Islands, Spain. She has lived and travelled around the world and speaks four languages (Spanish, French, English and Catalan). Alegría is also a woman with deafblindness. She is almost completely blind but hears well enough with a hearing aid as long as there is no background noise, and she is spoken to loudly and clearly.

Alegria often meets with guide-interpreters who assist her when she needs to go to the bank, the hospital or other everyday activities outside the home. The role of guide-interpreters is key, not only in terms of communication but also to overcome the barriers she experiences in her daily life. Challenges often amplified by the COVID-19 pandemic when face masks and shop counter plexiglass screens hinder clarity of speech.

Walking and being outdoors is important to Alegría:

"It is not just about going out with them to help me with paperwork or go for a walk, but psychologically I feel that I can recharge my energy".

To navigate, Alegría uses a cane. The cane is red and white, which indicates that she is a person with deafblindness or in other words, that she has *both* a visual and a hearing impairment. Alegría emphasizes the importance of raising awareness about the red and white cane because it can really make a difference when interacting with other pedestrians, hospital staff or society in general.

"Many times, I have had to explain to the doctors the meaning of the red and white cane because they did not know. So, if they ask me or sometimes if I have the chance, I'll say it. I do not think that many people know what it means to be a person with deafblindness, as a joint disability." Alegría is a cancer survivor, having recovered from two breast and one bladder cancers. And she has a son with ALS[1], a degenerative of the motor neurons, meaning he is a wheelchair user. Alegría supports her son financially, as the State or national health insurance do not cover many of his expenses.

"He does not even get a hoist to be able to get out of the bed, which he needs. I had to buy it for him because he does not receive any help at all. I also buy a wheelchair every four years because two years (after the insurance pays for one) it is very worn out because of moving. So, the State gives just very little financial aid".

Alegría loves to read novels in audiobook format and uses her iPhone daily. "Siri"[2], which serves as a screen reader, helps her navigate its functions and content. Amazon's voice activated Al assistant "Alexa" has also proven very useful for checking the weather, turning on the TV or playing music. While these digital technologies have made her life easier and help her to stay independent in the later course of life, mobility remains the biggest challenge.

When Alegría goes out on her own, she uses a pedestrian device which, when activated, makes an acoustic noise to indicate when it is safe for her to cross the road. However, most traffic lights in her area do not have this system activated. The traffic light nearest to her home did some

years ago, however, the creation of a bike lane resulted in the deactivation of this system in the traffic light nearest to her home, which she needs to cross to access a pedestrian area.

"It was requested like 20 times by ONCE, the Spanish National Organisation of the Blind, and by the users to get it back after they built the bike lane. They did nothing. We also asked to The City Hall". The lack of availability of this service has resulted in a loss of autonomy and independence for Alegría, as her freedom of movement is now severely restricted.

"So now I have to wait for someone to cross, if there is someone who really wants to help me.

Otherwise, I cannot access the pedestrian area. But the City Hall did nothing."

Even though the sound activation tool is essential to Algería's safety and independence, some neighbors have complained about the noise these traffic lights make. Wondering about it, Alegría adds:

"(The sound system) would only get activated when a person who is blind pressed the button on its device. So, the neighbours would not be disturbed, because it is just in that instant, which on top of all the noise from cars, buses, lorries, the last thing you would be hearing is a "beep, beep, beep, beep". Still, some people think it is disturbing".

She also mentions that badly parked bikes, scooters and cars have increased physical impediments to successful navigation.

"It can either be a small van, construction work or people who are delivering to offices or little shops leaving a big trolley in the middle of the street. Other pedestrians in general are quite kind and warn me. The main barriers are the bikes and the scooters badly parked or riding where they shouldn't". Alegría's experience illustrates how physical accessibility, a barrier free environment, and the support of guide-interpreters are essential for an autonomous life. Alegría would like to contest many stigmas around women with disabilities. She is a resilient and strong woman and an essential support person for her son. Despite incredible difficulties, she overcomes the obstacles set before her and enjoys a fulfilling and happy life.

- [1] Amyotrophic lateral sclerosis
- [2] Virtual assistant that is part of Apple

Useful Links

Versión PDF en español

- 1) What is deafblindness?: https://www.wfdb.eu/what-is-deafblindness/
- 2) Deafblind interpretation: https://www.wfdb.eu/interpretation/
- 3) WFDB Report in deafblindness: https://www.wfdb.eu/deafblindness-in-the-world/





The Rewards of Playful Exercising

Author: Katja Seidel, Maynooth University (NUIM)

"Hello" – "Hello"; "Can you hear me?" – "Can you hear me?"; "Can you see me?" – "Can you see me?" At the beginning of our fifth video call, Robert introduced me to his 'dubbing speaker', a little stuffed parrot that repeats his every word. I had to laugh. Pleased by the playful nature of my 79-year-old research participant, I ask him about the other stuffed animal I had seen sitting behind him in recent weeks. "He's the ancestor of all our stuffed animals, he's with us everywhere, a curious little fellow. We have about 60 of them now, the little bear even married the hedgehog. My wife sewed her a wedding dress. That's the kind of nonsense we do, and the grandchildren love it, just like our sons did when they were younger."

Retaining a childlike nature is particularly important to the successful author, translator and comedian. The married father of two grew up in the former GDR, studied English and Spanish and became a successful columnist and poet. In twelve hours of video calls spread over a period of two months, Robert took me into the socialist world he experienced and told me with bittersweet irony and a sharp analytical voice about the fine line between critical political thinking and making a living in a regime that fundamentally restricted freedom of opinion. Expressed in his poetry "The GDR which educated us, the GDR which bent us." Never short on self-reflective introspection, well-read and historically versed, he told of the difficulties of finding a flat, writing cabarets about everyday politics and social structures, of his work in the health service sector and how he became actively involved in company politics while trying not to become complicit with an ideology from which he could just as easily, have profited.

By exercising for at least two hours a day and taking around 18 food supplements, vitamins and minerals, Robert and his wife assiduously support their health. Born to a single mother in the post-war years, Robert suffered from rachitis, a disease of the bone structure caused by vitamin D deficiency. This is also why he claims to be unathletic, even though he opens our conversation with an account of his two-hour morning swim, one of his regular activities along with KISA training, jogging and long walks. (He perceives swimming in the nearby lake as absolute freedom). "My wife is even worse. Now, for example, she just went for another walk to get to her 10,000 steps today." In short, Robert enjoys an active lifestyle and is always challenging himself, physically and mentally.

Robert loves to tell stories. As an author and comedian, he entertains the audience, often older adults in retirement homes, with his plays, which he also performs at well-known venues such as the Herkuleskeule in Dresden. One day a week is reserved for his grandchildren, whom he missed dearly during the Corona crisis. When social distancing regulations prevented him from seeing them, he sent them little riddles and jokes via WhatsApp every day to stay close and make them laugh.

The joy of solving puzzles and self-set challenges also led Robert to get involved with computers at an early stage. Fascinated by digital tools and innovations, he saved up to buy an Atari back in GDR days, making him one of the few who privately enjoyed programming and computer games at the time. Through personal connections to Austria, he managed to get a word processing

programme, "You could change everything there. Me as a translator, just imagine. I could turn the word 'sergeant' into 'corporal' and it changed it throughout by entering it once. Changed it on all the pages. That was wonderful."

Although buying a computer was, according to Robert, a luxurious "nonsense" at the time, his fascination with computers has remained and he is used to playing around with new programmes and software: "I'm as curious as a goat about such things. Really true. I always look at it, install it and then say, no, you don't really need that, it's not great, I'll uninstall it, it doesn't cost anything. But I check the Google Play Store once a week: is there anything new there?" Robert is astonished that many of his peers are suspicious and often demonise new technologies: "Would you also think that book art is bad just because Adolf Hitler once wrote a book? You can't demonise the medium just because it can be abused. Instead, we have to see the opportunities of the medium."

Today, he approaches digital media, apps and smartphones with the same attitude. He's not much of a tinkerer – his wife is the one hammering a nail into the wall while he cooks dinner – but he spends hours with his new digital tools. The latest device, an Amazon firestick, now allows him to watch operas on the TV via youtube and to listen to them on the sound system in his living room. As he laughingly tells me how he struggles to open the remote to insert the new batteries (waiting for his wife to come home and do it for him), he expresses his gratification over the new device. "A delight, a delight. I almost cried the first time I saw Bolero on the big screen with the good sound." Installing and learning new apps and software is a challenge he relishes, and it is the online forums that persuaded him to buy the stick: "The manufacturer could have talked me into it for years, I wouldn't have believed it. But if I go to my forum and say, 'Guys, have you had any experience with the Amazon Stick?' 'Yes, wonderful, plug it in, half an hour later it's up and running. Never had a problem', and that's coming from three people I've known by name on the forum for 20 years, then I buy it."

Besides computers and the world of words, sport is another pursuit Robert approaches with childlike glee. "Have I told you how I make money running?" Recently, he bought a FitBit watch that not only measures his steps, but also his pulse, kilometres run, calories burned and the number of floors he climbed. "And here's the thing," he adds with a smile, as befits his character, "Our leading health insurance company here in Saxony, the cheapest one, so to speak, which used to be the local health insurance company in the GDR, pays me 1 euro fifteen times a month, every second day of the year, so to speak if I fulfil the certain condition. Either I have to walk 10,000 steps that day, or I have to run fast enough in a quarter of an hour to burn a certain number of calories. And then I enter that, and I get about 180 euros a year. And for that, I can go swimming again for free. It's a piffling programme, it's tax-deductible again afterwards and so on, but they reward you and it's a lot of fun. My wife gets up and says, 'I've already earned another euro'."

To emphasise the importance of reward, Robert continues, "It's not about the euro at all. It's about confirmation. Yes, I have 1700 points. The fact that it will be 170 euros is nice, but yes, they confirmed it that's a wonderful feeling. Clever." While the social security company does not financially reward "real" sports like KISA training or swimming, these small-scale challenges are a great motivation to dedicate oneself to a healthy lifestyle on a daily basis, "even on the days when they don't pay, I tell myself I'll stay in rhythm." And so, Robert has found a playful and

profitable way to overcome his inner couch potato, which is not unknown to him either and, competing with his wife, he smilingly congratulates himself on every ten-thousandth step.

Useful Links:

https://www.wired.com/gallery/best-fitness-tracker/ https://www.everydayhealth.com/senior-health/fun-ways-seniors-can-get-in-shape.aspx https://www.fitforfun.de/sport/fitness-studio/motivation_aid_3022.html Article German PDF version

My disability made me a better person

Author: Pinaka Ourania, GP, 5th Regional Health Authority of Thessaly & Sterea

Originally from a small village in the mountains of Greece, Achilleas is a 65-year-old man who now lives with his wife in a detached house on the outskirts of the centre of a large city. They have a 39-year-old son who lives a four-hour drive away. The number 39 is also significant as it represents the number of years that Achilleas has been paralysed, since a terrible accident that took place two months before the birth of his son. "So, with my son's birthday, I count my years of disability."

Achilleas worked in the mines. On the day of the accident, one side of a gallery in the tunnels collapsed and crushed him. He was 26 years old and had to learn to live with a disability. "The first years were difficult" he explains, "I was living isolated for six years. Locked in the house, away from people. Then, my fellow villagers suggested that I run for 'president' of the village. They trusted me. That was my salvation. My life gained meaning again. I left home, socialised with people, and dealt with other problems. All this helped me psychologically." Since then, Achilleas has served in this civic role for eight years. He has also become involved in other important roles as an elected president of the regional association of people with disabilities and a regular member of the Panhellenic association of people with disabilities. He says: "Things do not change if you do not participate. We must be present everywhere!"

In the course of our conversations, I asked Achilleas about the biggest challenge faced by a person with a mobility disability.

"I think the most important thing is access. It is important to have the conditions to be able to move. This gives you autonomy and independence. Transportation from the house to the sidewalk should be ensured. The sidewalks should be spacious and without obstacles and have ramps with a suitable slope at the end, not only in the city center but also in the districts. All public transport must be accessible. Planes and trains have better accessibility than intercity buses. Furthermore, accessibility must include not only the public buildings but also public assembly buildings such as theaters, banks, cinemas, museums so that everyone can have their needs served."

There were many difficulties that Achilleas faced that may be amenable to digital/technological solutions. Achilleas complained: "It is not uncommon for me to have to return home because I could not find a parking space in the city centre." Smart City ideas, such as real-time mapping of the location and status of the disabled parking spaces through a digital platform would do much to answer this problem.

According to Achilleas, to live a good life is to enjoy what other people enjoy: travelling, good food, a show in the theater, a movie in the cinema. He says: "Many times, hotels or restaurants state on the website that they are accessible but ultimately they are not. In these cases, you have to choose expensive solutions in order to be sure of accessibility and this cost cannot be afforded by everyone. Licencing and Legislative specifications and controls should be strict. Also, for these cases, it would be useful to map the really accessible hotels, restaurants, museums and

other public assembly buildings." Achilleas remembers a typical case where he had booked a summer vacation in a hotel where he was assured that the rooms were suitable for people in wheelchairs. Upon arrival, he discovered the room was spacious, but it was impossible to access the toilet in a wheelchair. "That's why I choose to go to the same places where I know that they meet my basic needs."

Additionally, Achilleas points out the importance of supported living centres that consider both people with disabilities and their caregivers. These institutions are crucial so that caregivers can leave the person they assist safely for an afternoon or a weekend if needed. In addition to the security and peace of mind offered to the beneficiaries, he explains, these structures should also function as centres of creative employment and not as a storehouse of souls.

Achilleas is pleased at the progress that has been made in the last four decades. To illustrate, he recalls with great emotion, a story that happened to him 20 years ago:

"I was waiting at the bus stop, the bus is coming, the ramp is coming out from inside, but because the bus was parked further from the sidewalk I could not go up to the ramp and so the bus driver had to get off to push the wheelchair. He asked me: 'Are you alone?', I answered: 'Yes', and then he told me: 'Who do you think that I am, your personal nurse to raise you?' Then, when I got on the bus, a passenger looked at me and said: 'Do you go out alone and get around? Can't you get someone from your house to help you?' That was the last time I got on a bus!"

Achilleas concludes that many health conditions too often appear only as "problems" in the sight of public policy and research, as opposed to the very nuanced ways real people in fact experience living with such states: "What I can say for sure is that my disability helped me. It made me more social, I met people I would never know. I dealt with public affairs, I realised the needs of every person, with or without a disability. I learned to help my fellow man with his problems. My disability was and continues to be a school that made me a better person."

Useful Links

- https://res.mdpi.com/d_attachment/sustainability/sustainability-12-00589/article_deploy/sustainability-12-00589-v2.pdf
- https://www.access.earth
- https://www.ncbi.nlm.nih.gov/books/NBK11420/

"Online is a nice place": On the joys of technology during the pandemic

Author: Rita Tavares, UAVR

Artur is a 73-year-old man born in a small city of the region of Aveiro, Portugal, the same city that saw him get married and bring up two daughters. Divided between this city and Porto, where he worked for 30 years in a banking institution, Artur always found time in his daily routine for his hobbies. He loves to play golf and he is an active member of several recreative associations. Artur is financially independent and lives with his wife in a two-floor house next door to his sister.

Artur experiences hearing loss. He has lost weight to the point that he is no longer obese, but still suffers from thyroid, hip and knee problems. Yet, he faces no mobility issues. Whenever he feels pain, he does some stretching exercises. He also practices aqua aerobics and walks 30 to 45 minutes a day on a treadmill. Artur also has hypertension and has been hospitalised several times. For these reasons, he has check-ups every six months, and goes to the doctor when he feels symptoms of discomfort.

He benefits from access to both public and private health systems. For cardiovascular consultations and some specific exams, Artur goes to a private hospital, and for routine consultations and medication prescriptions he goes to the General Practitioner (GP). Artur mentions that in his opinion the public health system works well, "also because of the location. I have a Family Health Unit and a Hospital about 100 metres away. My GP... I go there, I am called [by the Health Centre], I schedule consultations and exams, and then I go there. In that respect, I have nothing bad to say. On the contrary, they have been great in everything I need". The positive attitude towards the national health system is also reflected in Artur's attitude towards technology. Since the beginning of the Corona pandemic, he uses digital tools every day: "I often say I'm not great at it, but I do my best and I keep trying until I get it right... And then I have some help from my daughters and sons-in-law whom I call whenever needed". To manage his health in an informal way, he uses a smartwatch to track his heartbeat and to know how many steps he walks in a day. The tracking device has been recommended by his Specialist Physician, who told him about the gadget. While Artur has not worn anything on his wrist for years, he now even tracks his sleeping hours. To him, a smartwatch that is linked to an application in his smartphone is very useful as it helps him avoid potential health complications in between the regular six months check-ups.

Artur has no concerns regarding personal data protection and feels comfortable with his doctors accessing data gathered through the smart device. To the contrary: he believes that technology can really help improve the health system, since it enables to gather, organise and exchange a wide range of patient's information.

"You see... there is a hospital that I go to, where my Specialist Physician works, where I do many exams. The exams stay there, and any doctor can access my file and analyse it. I think this is very

important if such data could also be seen by my GP, who is geographically distant. All this... this technology, at this level, is marvellous! So, I am not against technological innovation. What some people do with innovations may be questionable... but I think technological advances are amazing!" The health sector is not the only area in which Artur enjoys new technologies. With a mischievous grin, he confesses that he spends a lot of time on the computer doing "things with no relevance". His daily routine includes checking his finances using a home banking application, reading the news on the Internet to know "what is going on in the world", Internet surfing, and playing games: "I became a bit of an addict, that's what it is!". For this reason, Artur spends a lot of time at his "home office" where the computer is. This room is a "nice place" where he collects several types of objects, such as books, coins, hats, and souvenirs. All these objects are listed in an inventory that Artur made when he got retired and that he frequently updates. This hobby helps him to keep occupied in a pleasant way.

Due to the pandemic, Artur now also uses digital tools to speak with his daughters, sons-in-law, and granddaughter. He uses a mobile videocall app, which he finds quite useful: "On the phone you hear the voice, but on WhatsApp® there is also an image, so we have a more direct connection". As an active and enthusiastic man, before the global pandemic Artur used to leave home every day to be with his friends for social gatherings, lunches, dinners, celebrations, and other regular meetings. He also loved to travel in the company of his wife and friends: they usually took at least one trip abroad every year.

Every trip is carefully planned by Artur. It all started with the participation of his wife, a medical doctor, in a congress in Macau in the year of 1984 and, since then every year he spends a few days with her planning in detail the upcoming trip. They have travelled around Europe, Asia, Africa, and America. Unfortunately, the pandemic situation has severely curtailed Artur's travel plans. With some regret, he explains that the worst part of the lockdown was to see himself unable to go out and having to cancel their vacations. Still, Artur is already planning their next trip as soon as the global situation enables them to once again venture out. Next stops will be Australia and New Zealand.

Useful Links

- State of Health in the EU Portugal Country Health Profile 2019: https://ec.europa.eu/health/sites/health/files/state/docs/2019 chp pt english.pdf
- Portuguese National Health Service: https://www.sns.gov.pt/
- Coronavirus (COVID-19) website: https://covid19.min-saude.pt/



"Like being in a cage": Report from a retirement home during the pandemic

Author: Markéta Pešoutová, OUSHI

83-year-old Monika lives in a retirement home in a large city in the Czech Republic. She shares her place with a roommate and due to the coronavirus, has not seen her family for many months. Visits to retirement homes have been prohibited for over a year now. "It feels like I'm in a cage." Monika tells me, adding, "I feel sad and scared. I keep calling my family to make sure they are okay."

To get around, she uses a medical walker. But unfortunately, she cannot go to the garden at the moment because the lift is in another part of the building, which is dedicated to residents with severe Covid-19 symptoms and thus cuts her off from going outside: "If I want to get outside, I'd have to go one floor down the stairs, but the elevator only goes from there. I would need to go through the other part (of the building), and if I can't do it, I won't get anywhere. So, I'm honestly closed in all the time, so really, just to the toilet."

In this situation, it is the television that keeps her company at times when she needs comfort. However, "I do not even want to listen to the news anymore", Monika admits, as hearing all the bad news about increased numbers of patients with Covid-19 make her feel blue. She also explains that the staff at the nursing home do not keep her sufficiently informed. "When we ask the nurses, they tell us that everything is fine and that we should not worry." She notes, however, that fewer nurses come to work as most of them at one point or another have had to stay in quarantine.

To feel better, Monika makes an effort to clean and disinfect her room every day. "I know that the cleaning lady is doing the best she can, but she doesn't reach my expectations." Despite physical difficulties, Monika manages to wash the floor and clean her bed regularly. "Sometimes I almost fall down because my legs are not so stable. But it is worth it!" she adds proudly. For Monika, a clean environment brings a sense of security.

Even though Monika tries to keep everything clean, and she doesn't meet anyone except the staff, one day Monika's roommate tests positive for Covid-19. "I am curious how long I will be able to take this" Monika whispers. "There is no other place to go now. I have to stay here. And so must she," she adds.

Monika tries to strengthen her immune system by taking vitamins every day. "I do not regret spending money on it!" Since her blood-vessels clog easily, she is afraid of the effects Covid-19 might have on her. "My sons call me every day and tell me to stay strong. How can I stay strong when we share a room and there are shared toilets on our floor too?"

As the testing continues, Monika manages to stay negative. "Every time they do the test I worry about the results." As time passes, her roommate also gets better. "Now I'm just looking forward to seeing my sons and grandchildren. Hopefully this will all be over soon!"

Useful Links

https://www.lekari-bez-hranic.cz/koronavirus-seniori-osamoceni https://www.irozhlas.cz/zpravy-domov/testy-domov-duchodcu-seniori-koronavirus-covid-nakaza 2011110600 sto

https://unece.org/general-unece/news/covid-19-pandemic-wake-call-crisis-long-term-care



Making a Good Patient: The hidden tactics that unlock functional health and care.

Author: Pedro Rocha, UPORTO

Introduction

For 15 years, **Roberto** has been the primary carer of his wife **Maria** who has Alzheimer's disease. In this task, he has been supported by their daughters, the National Health System (from primary care through medical specialists) and the National Association of Alzheimer disease. Additionally, he paid for private therapists for cognitive stimulation for Maria. Maria is now in a care home, but Roberto continues to support her through different care activities: regular visits (reduced to one per week and socially-distanced because of Covid-19), alone or with family and friends. He also brings her gifts and daily necessities while helping her to keep her medical appointments. Maria's care is further bolstered by regular communication between all members of her social network, and, through this contact, Roberto has become familiar with communications technology to maintain contact with and coordinate Maria's care network, using WhatsApp, Skype and Facebook. He also shares text, images, videos, and audio in this fashion

When Carers Need Care

At 65, though, Roberto himself has become frailer. He is now (largely successfully) managing various age-related diseases and, after he injured his left leg in a recent fall, there was a genuine concern, in both his medical team and across his network, that Roberto himself might become infirm. Thankfully, he has managed his recovery well, following medical advice to walk for at least one hour a day, eat a balanced diet and get his sleep. In short, Roberto has been a good patient. He continues to live alone, supported by some social and health networks and assisted by a cleaning lady who visits once a week. He continues to meet with friends every week, sharing traditional Portuguese food and even taking a few drinks. He has even accepted a smart bracelet for monitoring his sleep patterns and physical activity, information that is shared with his GP and other health professionals.

What Makes A Good Patient?

As a retired worker from the private industry, Roberto derives his income from a National Social Security pensions system based on 43 years of social security contributions. This system works on a pay-as-go model for health care and ensures free and universal access to the National Health System, mediated by a local GP. As importantly, Roberto also has an 'old friend', a GP colleague from his working days, as well as a doctor in the family, his nephew who is an ophthalmologist, both of whom provide him with healthcare options and news about useful innovations. This relationship with medical experts is also a great advantage in navigating the healthcare system and gives Roberto confidence to discuss aspects of his treatment with his

doctors. He often calls them for advice before contacting health providers from the National Health System.

His social network and his experience of being a carer eased his transition towards digital communication and allowed him to adapt well to the enforced social distancing due to the Covid pandemic. He now manages most of his own health needs through phone and e-mail, while using an online platform to schedule medical appointments, receive prescriptions and access clinic data, alongside now using these same tools to help manage Maria's care.

Conclusion

This case shows that receiving and managing health services and using ICT devices and digital solutions is less a case of age than familiarity with certain contexts. For example, Roberto's 'adoption' of technology is not solely within the frame of technology or even design per se. Instead, Roberto's long history of caring for Maria led him to learn digital technologies to coordinate his family's contribution and to engage with the medical system. A certain level of education certainly helped in being comfortable in such contexts, but having some of his 'informal' social network in the 'formal' medical system also allows him to tap into both medical expertise and confidently translate registers to work out informed questions and partner with medical teams. Finally, from his friend and nephew, he also gets an insider's view of how the system works as a system from those who deliver care within it daily. Hence, Roberto reminds us that a successful care experience, as well as confidence with the use of various kinds of technologies, has a myriad of influences. Care systems would do well in being aware of and responding to the strengths patients bring with them.

Useful Links

https://www.sns.gov.pt/apps/mysns-carteira-eletronica-da-saude/https://alzheimerportugal.org/pt/

https://www.aarp.org/home-family/personal-technology/info-2020/smartwatches.html

https://www.safecommunitiesportugal.com/we-are-the-first-line-experiences-of-those-operating-

the-sns-24-call-centre-in-portugal-during-covid-19/

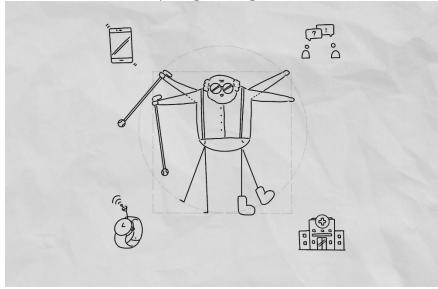


Illustration Credit: John Foley

"When I go to work, I go to China": Communication and Agency in Hospital Environments

Author: Katja Seidel, Maynooth University

Charlotte is an energetic 68-year-old recent retiree. The single mother lives in a beautiful old villa in the countryside in Germany through her Francophile heart beats for Paris where she worked for four years as a teacher in her early 20s. As an enthusiastic scholar eager for lifelong learning, she returned to University at the age of 38 where she graduated with a master's degree in educational sciences and the psychology of old age. Charlotte knows the health system well, and the crisis people experience when they are being hospitalized. Specialized in non-violent communication, competence training for older adults and cognitive performance disorders, for almost three decades she has worked as a crisis interventionist at the geriatric wing of a hospital. Furthermore, at the age of 17, she got into a car accident that nearly paralyzed her and bound her to a hospital bed for one year. The year she spent in the clinic taught her the importance of solidarity and positive encouragement as well as about the difficulties of participating in one's own treatment plans. "They always gave me pills I didn't want to take. I told them, I will not take them, I do not want them, there is no need. But despite my insistence, they kept handing me the pills. And so, I gave them to my mother who took them home in her bag." Charlotte's feet are still paralyzed and to this day she walks with the aid of a stick for better balance. Despite the hardship, Charlotte always believed in her abilities as a person and as a woman and even her handicap turned into a resource. Using a walking aid inspired confidence in patients who felt that she understands crisis and knows what she is talking about. However, while the visibility of her personal experience made her immediately approachable, it is primarily her way of speaking that made her trustworthy: "I don't use a pathology-oriented language, but the rather resource-oriented language".

Charlotte's position as a mediator between hospital staff, patients and their families enables an unusual perspective on wellbeing and recovery in the health sector. Mindful of the power of words, she was often left frustrated with the way hospital staff communicate: "When I go to the hospital I go to China - they don't understand me, and I don't understand them." Recalling her experiences, she describes the language used as warlike, technological or borrowed from the military, explaining "Nurses' rooms are bases, and hospital beds are emplacements. People have medicines on board, and there is a glut of old people. It is all characterised by an attitude that I don't think is conducive to a prosperous coexistence." Furthermore, upon arrival, patients are regularly stigmatised and labelled in quick judgments. During the morning meetings, when staff discussed newly admitted inpatients, Charlotte remembers hearing sentences such as, 'Watch out, the son is a colleague. They are the really difficult ones, they know everything better' or 'that's a sweet granny' or 'daughter is a teacher'; but also 'patient is aggressive', or 'we still have to tame them'. Such pejorative descriptions lack any value freedom and often position people in pigeonholes difficult to escape. Contrary to a humanistic approach to patient care, such language sticks like a verdict and prevents coequal communication and empowerment. "If you're unlucky, you can keep that label for the entire inpatient stay. Stamped like that, how am I supposed to get better?"

Given the strict hierarchies and the pressure environment in hospitals, Charlotte sees a particular need to respect patients' capacities for coequal communication, something often desired but seldom achieved. Difficulties specifically manifest when doctors want to change established treatment plans of newly arrived patients. When a patient resists a hospital's suggested changes in medication intake that they had established with their GPs, they might already find themselves in a difficult situation: "if you continue this way, we will call your children, they can pick you up right away." Threatened with a release in reaction to their stated noncompliance borders on emotional blackmail and, as Charlotte explains it, communicates top-down from the critical parent ego state. Working directly with patients and aware of the emergency situations they often find themselves in, Charlotte instead emphasizes a different position and highlights agency and equality. Rather than focusing on what is lacking, she looks for abilities and thresholds and makes use of the patient's substance and means to regain strength.

"I look at the whole person and not just at the holes in the cheese. That is my metaphor. I see the substance that is there, otherwise, no hole can form. The doctors and the medical professions are more interested in how to plug the hole. And I rather observed what was going on around it, so that the hole might become smaller or more bearable."

Always closely engaged and rarely diplomatic, Charlotte advocated for her patients almost like a lawyer. "I really respect human dignity. I have a very serving posture without buckling, that's what I appreciate about myself." Standing up for the ones disempowered by the system, other staff members sometimes adopted her suggestions and implemented change but often she felt as if she fought a fight against windmills. Wishing for thorough transformations in-hospital communication, Charlotte also stresses the need to address these issues on a political and systemic level to evoke change in an institution governed by strict hierarchies.

Useful Links

https://journals.sagepub.com/doi/full/10.1177/1757975916683385 https://www.nhsconfed.org/news/2013/08/importance-of-language-in-healthcare

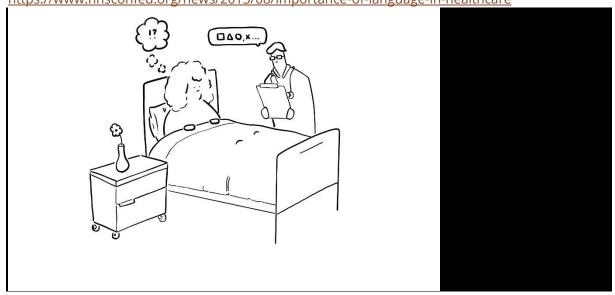


Illustration Credit: John Foley

"Your needs show you where you go": Navigating access to health care.

Author: Ourania Pinaka, GP, 5th Regional Health Authority of Thessaly & Sterea, <u>DYPE</u>

Nikolas, an 84-year-old man from Greece lives with Mary, his wife of the same age, in a privately owned house near the city center. They have two sons, one resides in Athens, about 400 kms away and is divorced. The other son, unemployed for two years, has been hosted with his wife at his parents' house until their financial situation improves. Nikolas is economically independent with his pension sufficiently covering the couple's daily living expenses but the additional support of their son strains their finances. Two years ago, Mary had a stroke. She recovered very well and continues to receive treatment. Nikolas helps Mary with the housework and also goes shopping in the bakery or at the grocery store. He is also the one who pays the bills and goes to the pharmacy for prescriptions.

Nikolas is a cancer survivor. He had a very serious problem with colorectal cancer in 2005, which he overcame after surgery. In 2007 he presented with episodes of bradycardia for which he had to put a pacemaker on the advice of his cardiologist. In 2014 he had vision problems in both eyes and underwent a cataract operation. A year later he had a problem with his bile which also required surgery. All these health issues were first attended to in the emergency rooms of the public hospital, but the surgeries were performed in private clinics. This happened not because Nikolas chose it but because the waiting time for the operations was too long at the Public Hospital.

Nikolas says: "Your needs show you where to go and what to do. When you face a problem, especially a health problem, you want a solution immediately". He adds, "I trust and appreciate the doctors in the hospitals. Every time something serious happens to me, I visit the public hospital but the procedures that are followed are not convenient and beneficial to the citizens and this must change". Nowadays, Nikolas is in very good health. The only health problems he faces are hypertension and prostatic hyperplasia for which he takes medication on a daily basis. He also occasionally takes painkillers when he has a problem with his cervix. For his chronic health issues and the prescriptions needed, Nikolas visits the primary health care unit of his region called TOMY*. Nikolas says: "TOMY is wonderful! Access is easy and fast. Appointments are pre-arranged and without delay. My doctor knows me well and I trust him but there is a problem here too. When I want to visit a specialist there is no connection between the structures and I have to arrange it by myself". Furthermore, he adds: "This lack of clear referral mechanisms and pathways between the primary health care unit, the specialists and the hospital, obliges me to pay a lot for my health. This is money that I don't really have and it deprives me of other things, such as getting my wife a gift or going on a trip sometime."

It is very important for Nikolas that both he and his wife are in good health. He wants to be able to take care of his wife and himself until the end of his life. He does not want to burden his children. However, if the need arises and his family cannot provide the required care, he will be forced to go to a nursing home or a clinic. But Nikolas believes that older adults in these institutions are unfortunate. "They are suffering", he says, "It is ok to be able to go to a facility, something like a nursing home, for as long as you can eat on your own and go to the toilet on

your own. Then they better let you die! Besides, you are not doing anything else there, you are just waiting to die!"

Healthy ageing is Nikolas' wish for the rest of his life. When being asked by his doctor about his wellbeing, his response is, "I'm not well. Can you make me better?", adding, with a mischievous smile on his face "If you can't, I'm fine". For as long as possible he wants to take care of his garden and to keep riding his bicycle, which he loves because it makes him feel free, much like when he was a small child. Every year he eagerly awaits the summer to visit his seaside house and enjoy the sea.

*TOMY: The opening of new primary health care units in December 2017 was an effort towards establishing modern, people-centered primary health care services in Greece. The Primary Health Care Units, called Topikes Monades Ygias (TOMY) in Greek, are key elements of the newly designed primary health care system and serve as the first point of contact and the main coordinator of care for people in the area. Multidisciplinary teams (general practitioners/family doctors, pediatricians, nurses, health visitors and social workers) provide health care for people in a continuous manner, looking at disease prevention, health promotion, diagnosis, treatment, monitoring and care.

Useful Links

https://www.healthypeople.gov/2020/topics-objectives/topic/Access-to-Health-Services https://publichealthreviews.biomedcentral.com/track/pdf/10.1186/s40985-018-0097-4.pdf



"I Wish to Fall in Love Again": Loss, Passion, and Sexuality in Later Life

Author: Pedro Rocha, <u>UPORTO</u>

Growing up during the political and economic transformations of Twentieth Century Portugal, many older adults vividly recall living through periods of dictatorship, fascism, nationalism, and paternalist government. Likewise, many experienced transitions and adaptations in family structures, marital arrangements, and in the meanings, rituals and behaviours for performing and expressing love relationships.

Leonor, now aged 66, explains that when she was young, she lived in a rural and conservative village in North Portugal. Until 18 years old, she was brought up by her family and community of friends, church, and local habits to believe that marriage with a "good husband" was the only acceptable practice for expressing love relationships. Marriage was a functional system, an economic unity, where each member had a role. Women, as wives, should be mothers and carers, even if they were workers.

An important element of Leonor's life has been learning that there are many diverse ways, meanings and practices for crafting and maintaining relationships. During an ethnographic interview, she recalls:

"One time, I was in love with a boy from my village. I didn't like him as I like my husband, but he was a good person, my friend, and a beauty. I almost got married with him, but I found a letter written between him and a person from my village with information about me. Can you imagine? He was asking people from my village how I was as a 'good woman'!"

At this point, Leonor had moved away to live in a dense urban area and found herself exposed to a different paradigm of love relationships, based on emotional ties and feelings between individuals rather than arrangement, allegiances, function or economics. In this context, she caught her first glimpse of her future husband, Afonso, when she was member of a local political association during the first heady years of democracy. She describes that first encounter, "I felt something, I couldn't explain. He affected me, as a person, not only physically". They initially became friends and then started a romantic relationship. Several years later, they got married.

"When I met him, he was enduring a deep depression, and I was his primary caregiver, like a mother, like a domestic. It's funny and ironic, because I didn't identify myself with this women's role. Do you know why I did that? As a depressive person, as a playboy, as a poet, as a painter, as a journalist, as political militant, as a bohemian, as a humanist... he gave me my first idea about who I am as a woman, and what is the meaning of emotion and passion. Indeed, he was already experienced as a member of the new urban class and generation, politically and cultural engaged and emancipated. And, for me, a young girl from a rural and conservative village, it was a new world that was pushing me towards being myself, rationally and emotionally."

Leonor and Afonso found each other in the midst of a wide range of opportunities for love and for lovers, "especially for him who had several girlfriends" says Leonor, and within a city and a time where certain groups of young adults were deeply engaged with a new political wave and its freedoms. The forty years of dictatorship had recently ended, and democracy was passionately embraced by many, especially welcomed by those rejecting traditional marriage arrangements in favour of freedom, choice and love as the foundation of relationships.

For these reasons, they didn't get married quickly. First, "we wanted to live together". It was an exciting time: the new socio-political 'wave', building up the new left and urban generation, political parties (parades, debates, political campaigning); social organisations and civil rights movement. A cultural renaissance in music, theatre, exhibitions nestled alongside other exciting revolutions: disco; co-habitation, holidays with friends, and experimentation with new forms of relationships: free love; free sexuality; trans-sexualities. Leonor recalls that in this time, "we lived as two close partners who intensely shared their own lives with each other".

After being married for many years, Afonso was unfortunately diagnosed with a neurodegenerative disorder. Before Covid-19, Leonor used to visit Afonso in the nursing home every day, remaining there until he had gone to bed. When she talks about him, she says "when I go to visit him in the nursing home, he always greets me just as he always used to do in the past: 'you are so beautiful, and it's so good'. However, I realised that he memorised that sentence for me, and I still love him, but it's not the same. He still is my great partner".

Indeed, their love still exists, but as Leonor reflects, it's not the same. What and why is it different now? When did things change? "When he was diagnosed with Dementia, I felt bad, but not angry; indeed, we had lived each second of our love, I feel it". They still love each other. However, things are different. There is love, but she explains that she feels they no longer share emotions, partnership, experiences, and sexuality. This is a great loss and hole in Leonor's life. She muses, "despite his physical daily absence, my husband still affects me emotionally. I miss the romantic notes left by him during my daily routines: night table, entrance hall, coat pockets, napkins... He misses me, yet."

Her love for her husband is still meaningful today and whilst she didn't want a different person(ality) she remarks that "I wish to fall in love again". Love, passion, feelings and sexuality are not the province only of the young. In fact, one friend of Leonor did try to encourage her to find someone else with whom she could live and enjoy life.

"She convinced me to use a new smartphone App., called Happn, which could help me to meet with someone. 'It's funny' she told me. And, I confess to you, I used it once."

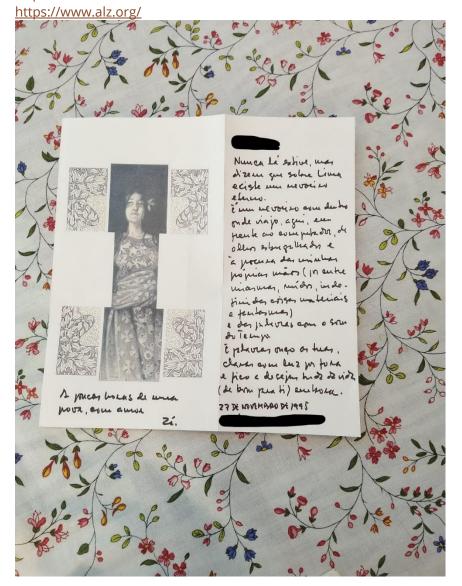
Asked to elaborate about her experience using a dating App, she became shy but responded: "No, it didn't work! But let me explain the context. A friend of me and my husband, she worked with him a long time, is got divorced and her last boyfriend left her. She is younger than me and she used that App for meeting a man. Once, we were talking about my husband and me and she said 'you are alive and you are an attractive woman; for sure, your husband would like you to find a new lover'. Then, she showed me the App and installed it on my smartphone. Indeed, I met an older individual, male, a few years older than me, once. We went to a bakery, but he was so boring and a bad experience. I didn't like it and I uninstalled the App".

This is a difficult and emotional time for Leonor, a time of loss, love, memory but also desire and yearning. Perhaps influenced by her past and current expectations, her first experiment with technology mediated matchmaking – or rather the human encounter resulting from it – was not successful, though she doesn't deny the advantages created by a digital solution for meeting new people. It is easy, fast, simple, informal, (almost) anonymous, and useful for those curious but fearful of risks.

As we consider how digital platforms such as Happn, Tinder and Grindr are being used or will be used by older populations, we should consider how different constructions of love relationships have co-existed together. What are the social and cultural structures, histories and narratives of different and diverse older users? What works and when? And, of course, how do we improve these digital solutions, in order to be useful for older individuals?

Useful Links

https://senioragecarestlouis.com/love-with-the-right-older-person.html https://www.who.int/news-room/fact-sheets/detail/dementia



"And now I am scared": Delay and Avoidance in Uncertain Times

Author: Markéta Pešoutová, OUSHI

Julie K. is a cheerful 87-year-old lady living in a city in the Czech Republic. She has been a widower for the past seven years. She explains that her marriage to Andrej, which lasted for almost 62 years, was underpinned by mutual love and respect. In the last two years of her husband's life, she took great care of him since he was unable to walk. Andrej was initially assisted by a manual wheelchair which he later had to upgrade to an electric version. During the last six months Julie remembers waking up every two hours during the night to help her husband. Even though, this period was a challenging time with lack of sleep and great amount of stress, she wouldn't change a thing.

Currently, Julie lives alone in a small flat. She is happy living alone, having her own rhythm, space and time to enjoy her hobbies. She loves to read, call her friends and family or watch TV shows. She reflects that her family is really caring, taking her to doctor's appointments, shopping or for trips into the countryside.

As much as Julie is enjoying her retirement, her body acts otherwise. "My body is breaking" she says quietly. During the last ten years she has been through five surgeries. Her varicose veins needed to be fixed twice, her knee was replaced, she required an operation on her gallbladder as well as a hysterectomy. Most recently, her doctors found a melanoma in her shoulder. Removal surgery went well, however the prognosis remains unclear and more tests need to be done. Moreover, her left hand is numb, lacking strength to open the front door of the house. She always needs assistance as she is also unable to walk without support. When Julie goes out, she uses two crutches. Opening the heavy front door is an impossible task for her.

Julie needs to see at least four doctors every three months in order to monitor her chronic health problems. She visits an ophthalmologist to get injections to her left eye to prevent blindness. Moreover, as her heart is not in a good condition, she is seeing an internist. Due to the melanoma, she has appointments with a dermatologist. Finally, she also receives help from a neurologist because her back-pain problems also impact her legs.

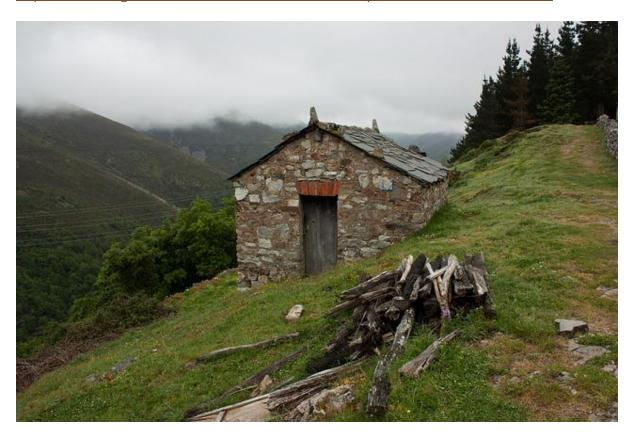
Complicating these intense and multiple health concerns, are the added stresses and difficulties brought to her life by the Covid-19 Pandemic. In March 2020, one of Julie's daughters took her to a cottage in the middle of nowhere. The house was surrounded by forest and Julie spent four peaceful months with her family. She especially enjoyed spending time with her two-year-old great-grand-daughter. During this time Julie felt secure, loved and protected. "It was a blessing" she adds.

In September the family needed to return to their daily lives and so did Julie. At the time of writing, Julie has to see her doctors as she skipped her regular check-ups during spring due to the self-isolation of her family. Faced with a second coronavirus wave and numbers of community transmitted cases, the future looks very uncertain.

"And now, I am scared. I am afraid to go visit the doctors. I am wearing a mask, I keep social distancing, I use disinfection. But that's all I can do. However, before I go to the doctor, I feel sick. Well, I am scared, that's all I can say."

Useful Links

https://www.caringseniorservice.com/blog/dont-ignore-checkups-due-to-covid-19 https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html





"Ageing is Not for Cowards": Older Adults as Caregivers

Author: Katja Seidel, Maynooth University

When we think of caregivers, we often think of young paramedics helping older people walk, or paid 24-hour help, often women with migration backgrounds, who live with and look after older adults in their homes. What appears less before our eyes are images of older adults who themselves take care of spouses, parents or adult children in need of care, wash and feed them, put them to bed or struggle through the bureaucratic hurdles to receive care allowance or medical support. Equally, in the prevailing discourse, senior citizens are often depicted as the social burden of an aging population, dependent on institutional, family and medical support. Their central role as social and cultural actors, as volunteers, child minders and babysitters, community supporters and first responders in home care systems is little recognized and seldom appreciated. Yet, older adults in particular often play a key role and become the most important facilitator in processes in which others need help or lose their independence.

Dignity, Kindness and the Question of Time: Jutta's story

The gymnastics teacher Jutta from Germany is such a woman. The 70-year-old humanist mother of four girls leads an active and joyful life with numerous roles and responsibilities. Growing up in Middle Franconia, Jutta studied pedagogy and then moved to southern Bavaria for her first post as a teacher, got married and had her first child. She continued to work in school until she became pregnant again and the family moved back to the countryside near Nuremberg, where few childcare facilities and a social philosophy that viewed women as housewives prevented her from carrying out gainful employment while raising her children. As a full-time mother, she decided to adopt her third daughter and gave birth to a fourth a few years later. However, full of ambitions in her wide area of interest, Jutta regularly assumed occasional jobs, often working in the evenings when her husband could look after the children.

After the reunification of Germany, the family of six moved to Dresden, where the girls continued their higher education and Jutta found alternating jobs as an adult educator and social worker. With her warm, open-hearted and engaging character, she quickly found friends even under these new circumstances and was soon well embedded in her neighborhood. Then Jutta's parents also moved to Dresden and settled into a beautiful apartment with a garden.

A little later, Jutta's life changed significantly. With the children now out of the house, she went through a difficult time divorcing her husband. Her over 80-year-old father became weaker and was increasingly dependent on outside help. At the same time, her mother suffered a stroke that left her paralysed on one side. With two parents now in need of care, Jutta took on the task of looking after the parents.

Responding to the new circumstances, she cut back on her paid employment and, over the next 13 years, spent every day in her parents' home, helping her mother to wash herself, preparing breakfast and lunch, cleaning the flat, attending to her medical needs, and running errands. In the first few years, when her father was still alive, she also helped him shower and took care of his personal hygiene. "I think in the beginning it was difficult for my father. He comes from a generation where you never really showed yourself undressed to the children."

Although Jutta and her mother were never particularly close, they now did everything together. With mutual respect and decency, they soon formed a tight-knit group known throughout the neighborhood, as they went on their daily walks to catch fresh air and keep the body active. "Everyone knew us. I was never alone. Wherever I went, I came as a double pack and, as long as my father was still alive, even as a pack of three." Since the left side of her body was paralysed, her mother used a rollator to move around. But Dresden is badly designed for walking aids or those less stable on their feet, turning any excursion into a challange: "It was a disaster. Even with a walking aid, she could never go anywhere alone, there is no way to push the rollator through the holes in the floor, over the curb or along the cobblestone sidewalks." And public transport, especially the trams with their high steps, is in Jutta's experience entirely unusable. "Impossible, that just couldn't be done. You always need a companion."

Knowledgeable of anthroposophic medicine – a holistic approach to healing and wellbeing – Jutta worked for years in various social institutions and taught prospective geriatric nurses. There she was able to observe how nurses and trained caregivers deal with the physical needs of patients. This helped her when she became an informal caregiver herself, using her own body to help her aging parents get in or out of a chair, to help them up after a fall, or to assist with basic hygiene needs. But they didn't have to do everything together: "There are these raised toilet seats, for example. As a result, my mother was more independent again and was able to go to the toilet on her own as she didn't always plop down like that. Because it always saddened me to see that and how hard it was to come up again. The raised toilet seat has really helped a lot and has also preserved her dignity in this regard."

With only a few aids, the two women managed everyday life mostly on their own. Additionally, twice a year someone from the nursing service came for advice and Jutta was in constant contact with her parents' GPs. "I have a good feeling for the body, my own and that of others. When I took care of my parents, I did most of the work myself, although I always discussed things with the doctors." Like the time when her mother fell and injured her head. Jutta took care of the bleeding, examined the wound, and called a doctor to discuss the problem. "I knew quickly that it was just a minor laceration, so I bandaged and patched the wound, and then it was fine."

Jutta assured me that she had no problem with the physical aspects of caring. "I don't mind that, it seems natural to me. For me, the real challenge was that I always felt unfree. I was always on alert and ready to jump on every call." For years she was used to drop everything, hop on her bike and drive to her parents' aid. And when the phone rang at ten o'clock in the evening, she was alarmed and worried. "A few years ago we bought a wristband with an alarm button, which my mother wore at all times and that was directly linked to a emergency alert service. That brought some relief."

The daily responsibility for her parents also changed her role as a granny and made it difficult to spend time with the grandchildren. "They always had to come with me to my parents' apartment. It was good for them because that way they got to know their great-grandparents well and therefore might have a different view of older people. But for me it wasn't always easy to keep the balancing act between these small, active humans and two older rather immobile adults all in need of my attention."

While the generational gap was an additional challenge, the proximity to children brought happiness and equillibrium to Jutta and made it possible not to lose herself in the task of caregiving. "I always looked for a counterpart to the oldies, something life-affirming, something new, something young. For many years now I have volunteered as a "godmother" in families that have just had a child. I spend time with them and support them. You know, kids run around, jump and sing and are curious about everything. That makes me happy, that's how I regain the strength to keep going."

The shared years with her mother and the chance to accompany her father until his last breath was also a positive experience. "I have seen that death and dying is nothing to be scared about and that in the best case, you just slide away. For me it was precious that I could experience it so directly. But I've also learned that aging is not for cowards, it's a very difficult thing. Well, it affects me now myself."

A few months ago, Jutta and her mother decided that it was no longer possible to continue with homecare and that it would be better for her to move to a dedicated care institution. The 95-year-old now lives in a retirement home close to Jutta's sister, 500 kilometers from Dresden. "That was my condition. If she moved, I wanted her to move further away, close to where my sister lives. Because I wanted to leave behind this psychological burden, always to look after someone, the constant state of tension that I experienced for years. I wouldn't have gained that freedom if she had stayed here in a nursing home. – You know, you don't realise it at first, but after a while you are trapped and your whole life is only that. I knew it was time to change."

After 13 years in which Jutta has adjusted her daily activities to the needs of her parents, she is now free to do what she wants: "This is my first time being a pensioner". Knowing that her mother is well looked after in the retirement home, and with her sister established as the first point of contact, she now faces a time of adjustment and change. And so, while Jutta continues her position as a lay judge at the juvenile court, she also wants to travel, visit her daughters and spontaneously accept invitations from friends.

Like so many others in their 70s and 80s, Jutta has taken on different roles at different stages in her life. No longer a primary caregiver, she now starts the next phase, a phase of unknown freedom, new possibilities and opportunities. "What are you going to do now that you have so much time?" friends ask her regularly, often with an undertone of concern about how she will keep herself busy. Not sure about her next steps but excited for the future, Jutta puts on a smile and says: "I don't know. But what's so bad about having time?"

Useful Links

- 1. https://www.rehabmart.com/post/what-is-a-raised-toilet-seat-how-to-choose-one
- <u>2. https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/personal-alarms-security-systems-and-keysafes/</u>
- 3. https://www.mobil-bleiben.de/hilfsmittel/notrufsysteme/arten-von-notrufsystemen/
- 4. http://ennhri.org/news-and-blog/are-the-rights-of-family-carers-adequately-protected/



Weighty Matters: Changing habits in Later Life

Author: Ourania Pinaka, GP, 5th Regional Health Authority of Thessaly & Sterea, <u>DYPE</u>

Elena lost her husband ten years ago. Now 69 years old she lives in a village in central Greece, close to her married daughter. Her other child, her son lives with his wife and her two grandchildren in a nearby village. Elena is now retired and feels she has a comfortable economic situation and is able to sometimes help out her daughter financially.

Earlier in life, Elena and her family lived in Germany for many years. When they returned to Greece, they set up a shop based in the ground floor of their house where she worked as a cook. After her husband's death, Elena stopped working and converted this space as a place to meet her friends, have coffee and to make sweets and pies for the ladies' club. In retirement, she says "I love cooking for family and friends". Unfortunately, since the onset of COVID-19 she is no longer to host these meetings with her friends.

These days, Elena lives alone on the top floor of her two-storey terraced house. Climbing the stairs has become a serious challenge. Obese at 120kg and a smoker who enjoys ten cigarettes a day, she has been diagnosed with knee osteoarthritis and suffers from lower back pain for which she takes daily painkillers. After a few recent unpleasant falls, Elena developed a fear of falling over, so she decided to limit her movements. This bothers her because it prevents her from going on trips to monasteries with her friends.

Elena also suffers from a number of other serious health problems. She has been diagnosed with heart failure, atrial fibrillation, hyperlipidaemia, obstructive sleep apnoea and depression. Every month she visits her GP for her medicine prescription. Although her doctor advises her to stop smoking, control her eating and to exercise, she doesn't follow the medical guidance. Elena also pays an annual visit to a cardiologist and a pulmonologist. Because of the obstructive sleep apnoea, her pulmonologist prescribed a CPAP machine which she has been using now for four years, in order to improve her sleep quality.

Elena is well aware that many of her health issues could be alleviated if she could lose weight. She is also at risk of developing diabetes in the future which will complicate her health condition. On several occasions, attempts to lose weight have been unsuccessful. After trying on her own, Elena resorted to spending money from her pension to secure the services of a dietitian, but she has still not managed to meet her weight loss ambitions. This situation is likely exacerbated by her reducing mobility due to fear of falls.

When asked how technologies could assist, she suggests "an electronic box that could check all my health problems and inform me of my health condition." As important as advances in how to monitor and manage her chronic diseases and health conditions at home clearly are to Elena, her lived experience also reminds us of the value of technologies that could help bolster her confidence with walking and movement as well as helping identify, track and encourage her progress with weight loss goals.

Things were further complicated in Elena's life when she experienced a serious episode of depression three years ago following the deaths of her husband and sister. For a long time, she did not go out of the house, she was not in the mood to do the housework, she did not meet her friends. She visited a psychiatrist who diagnosed her with depression, and since then, she has received medication.

Despite these accumulated physical and mental health problems, Elena is a lively person who loves life. She regularly volunteers for her church charity and she likes knitting. She continues to drive and likes small trips with her friends in nearby villages. Looking into the future, Elena wants to be in good health and dreams of being able to travel all over the world.

Useful Links

https://www.aarp.org/health/healthy-living/info-2018/weight-loss-after-50.html



Trains, Planes and Mobility Scooters

Author: David Prendergast, Maynooth University

Monica lives by the sea, in a small village in Northern Ireland, a short distance from Belfast. A retired schoolteacher in her late 70s, poor health and a degenerative spinal condition has stolen much of her height and mobility. Her presence is undiminished, however. Indeed, an enquiring mind and precise diction, coupled with the ability to switch between a cheerful disposition and a commanding manner at will, promises a rapid education for those who make the mistake of underestimating or patronizing her. A bus driver learned this the hard way. She recalls struggling to board an empty bus at the start of its route with her rollator walker full of shopping. Pointing to the sticker of a wheelchair proclaiming the accessibility merits of the vehicle, Monica asked the driver to lower the ramp and was met with a curt refusal. That's only for wheelchairs' she was informed. After some struggle to embark she managed to get on board the bus and a stern lecture ensued. "I sat down in the front seat and I told him strongly but politely what he had done wrong. Well, I said, you know, I've got two solicitors in my family and I do know what's right and I think you're being very foolish to be so uninformed about this."

On this occasion, an apology was issued from an chastened driver, but Monica has not always been so successful on public transport. In general however, over the course of her gradual deterioration, she claims that most people are only too pleased to provide assistance as long as you make direct requests in an unembarrassed manner and treat them as if they are a favoured relative from the outset.

Monica's history with mobility aides is long and circuitous; a string of humorous tales of experiments, falls, dead batteries and burned out motors. Her ability to manage with a walker alone now behind her, Monica first used a mobility scooter in England rented by her daughter. She loved it so much, her family bought and shipped the machine to her in Ireland at great expense. Having never driven a car, it was not easy to learn, especially negotiating tight areas and backing up. Her first proud adventure in it into her village ended with her trapped on the edge of a road kerb after a miscalculation over its height. The scooter died and she had to call a friend to tow her home, only occasionally bashing into the back of his car due to the lack of onboard brakes.

Back home she tried to fix it, initially replacing its batteries. "No, it was nothing normal like that. And so I bought a new replacement motherboard for it. And really, they're not very complicated. There's only a few wires, you see, and they're all matched up with a label on it ABC. And then you have only to take it off very carefully and attach the right wires. My Golly, it didn't make it work, so that was very disappointing." Disgusted at her failure she resorted to paying experts who informed her the scooter was beyond repair.

Monica loves to learn and frequently uses the internet and Google to explore the world beyond her doors. She also thinks Open University TV programmes have improved dramatically. She's currently fascinated with the idea of multiple universes and feels the answer to what happens beyond death may lie here. Her iPad is constantly by her side and Facebook keeps her connected to her children and friends overseas.

She bemoans however, the death of the instruction manual.

"I remember when I got my first iPhone, I went to the shop to get it I remember asking the girl 'is there not a better instruction book with it?'. 'Oh No', she says. Just what the young say as they are not bothered by that. And the shop girl said, 'I know it's difficult, more difficult for you, but I just play around it. And that's all you do. You just play around with it and you'll find out everything' and I thought 'Hrm! You know. I'm not used to just playing around with stuff. I love to have instructions. You know, like a recipe. I want instructions to everything."

Undeterred by the death of her first scooter and an avid fan of eBay and other online secondhand sales apps, Monica has now compiled an enviable garage of mobility aides. Her next scooter was smaller but sturdy. That is until she drove it down the garden where the wheels got stuck in the soft earth and tipped her into her hydrangea hedge. Her next purchase was a much bigger machine with headlights and indicators. She could not believe her luck as she managed to buy it very cheaply second hand for £600 from an older lady who moved into sheltered accommodation with rooms too small to host such a device.

Monica also bought herself a powerful electric wheelchair with independently driven large wheels; her equivalent of a 4X4 off road vehicle so she can join her daughter on long hikes and countryside walks. This has carried her up steep hills and rocky pathways in forests and sites such as Giant's Causeway, but she learned the hard way not to use it in the city. Uneven pavements with kerbs send the wheels in different directions and steering becomes difficult, dangerous with so many people around.

"I thought, oh, my God. I'm not going to drive a wheelchair in the city again. It's much easier on a mobility scooter if you are going through a crowd of people. At least I have found that because you have got the small driving part in front of you, the bit that comes up. A bit of metal and something to hold onto. Whereas in a wheelchair you are exposed."

People reading their mobile phones, inattentive to their surroundings, walk into the back of the chair or force her to suddenly brake, risking injury to all.

Navigating other forms of public transport rarely causes Monica trouble, although she notes that small train stops or 'halts' without proper stations can be very difficult to traverse in Northern Ireland. Trains are usually well setup for people with wheelchairs and the staff tend to be accommodating and well trained. The secret she explains is to always do your research on the internet or even better call ahead on the telephone and alert them to your times and points on your journey.

A keen traveler, Monica has always enjoyed travelling on planes and argues that no one disabled should worry about going through airports. Trips to visit her children in Europe, the Middle East and Australia has given her extensive experience negotiating assistance to the gate. The support and attention can vary according to how busy the staff are, but she always has "a bit of craic with the people pushing her" and suggests that "I never feel that I'm sort of like a weak invalid or anything silly. No, I don't feel that way." Eager to help others, Monica wants it to be widely known that it is free to take wheelchairs or scooters on planes. "I've travelled by plane a lot since I have been really unable to walk very far, and the airports are wonderful. They put my vehicle in the hold and bring the batteries in with the pilot... you can ride your wheelchair to the foot of the steps in the UK and you can wait for the steps. If you can't walk at all, they'll take you in another wheelchair in a lift up to the cabin, and they don't want you to sit in your own wheelchair in the plane even if it's booked for you. I suppose it would block the way."

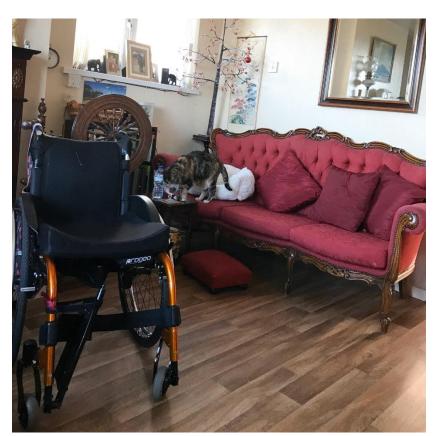
Now grounded by COVID-19, Monica is avoiding planes, trains and buses alike, keeping herself busy with reading, writing, her garden and a few close friends and carers. She does her grocery shopping online and has also received some food parcels from the community. She claims she loves to be alone and only remembers being bored once in her life. When asked about what concerns her, she worries about how many young people are coping during the lockdowns due to an inability to cook. Perhaps, much like well-designed step by step technology instructions, her much loved cooking recipes may help here.

seful Links

- 1. The impact of mobility scooters on their users. Does their usage help or hinder?: A state of the art review. http://europepmc.org/article/PMC/4510203
- 2. https://www.gov.uk/mobility-scooters-and-powered-wheelchairs-rules

3. https://www.myproscooter.com/best-electric-mobility-scooters/





A Captured Glance, A Lifetime of Memories

Author: Arianna Gherardini, AIAS

Introduction

When thinking about technologies, we often focus on how they can facilitate the <u>doing</u> of things: how they help us exercise or excite body and mind, to communicate with other people, to watch movies or YouTube tutorials, to get a service online. In societies and life worlds where the pace of life seems to get ever faster, we sometimes forget about how it is important now and then to just stop and don't <u>do</u> things, but <u>look</u>, <u>listen</u>, <u>reflect and remember</u>. Especially as people grow older and life-stories lengthen, looking at who they have been, what they have done and what is recalled fondly or otherwise, represents a way to give significance to their present and to know that they are leaving something to other people in the future.

During my research, there was a case where this concept was represented in a clear and touching way, with a very old woman who has perfectly learned to use her tablet to look every day at the photos of her family and, above all, of her beloved husband who died some years ago. During our meeting, she always wanted to show me a specific picture to illustrate the points she made. For her, images could better explain her meaning – as she could let things "come alive". A way of creating, sharing and mutually experiencing a moment inside her past. She, like many of the other older adults in our research, has a treasury of valuable and valued memories and a desire to share with those ready to listen.

Technology, Self-Identity and Memories: Donna's Story

Donna is a 92-year-old Italian woman. Her husband died six years ago, after more than 50 years of marriage and, she recalls, an even longer almost perfect love story. They met each other at an art exhibition in Venice – the city of love – and they have always been together since then. They had two beautiful children and numerous nephews, who still visit and enjoy spending time with her, sharing experiences and moments together.

Memories are an important part of Donna's life, as she is very fond of her family and remembering times when her husband was alive, and her children were younger, makes her really happy. She spends a lot of time reading a book that her husband wrote about their life and looking at the letters that her children wrote to them when they were at school. But, above all, she loves to look at photographs.

Donna has thousands of photographs covering all aspects of her life starting from her early childhood. Every day there is a moment when Donna sits on her couch and takes time to visit her favourite images, remembering special memories. She doesn't always look at them alone. Donna likes to share these photos with her family, especially younger relatives ignorant of her earliest years, but also to other people that she talks to. For Donna, this sharing is a way to describe who she is and who she was, not only now but during all of her life, to share what she has lived in a deeper way, and on occasion to give them advice.

"I always say to my girls ... especially to the youngest, I always say ... when a man looks at you like this, like mine looked at me, that's the "right one" ... It's a photo in the mountains, he has his hand on my shoulders and he is watching me! And it's a look ... loving, let's put it this way, that's it!"

Her family, then gave Donna what she considers to be a huge gift. They gathered all of her images and placed them into a tablet, where she can look at them whenever she pleases without wrestling with heavy albums. She no longer has to spend a lot of time searching for the specific photographs that she wants to see. Donna explains that she has been given the possibility to take all of her memories with her wherever she goes and can now show her photos to everybody in an easy and efficient way. Despite her advanced years, she liked this tool so much that she took the effort to not only learn but perfect how to use it. She is able to move from an album to another, to enlarge photos and to rapidly search and locate what she is looking for.

"I like to use the tablet much more than traditional albums, because I can sit on the couch and go through all of my photos. I know where to go, which ones I want to see. I can always have my photos next to me, to remember, looking at my things... my memories. I can look at them whenever I want, and I can do it faster than before."

This is useful not only to look at and ignite her memories, but it also reassures Donna that her story – and also her beloved husband's life – will not be forgotten when she is now longer here. While photographs can be lost and ruined by time, decay or water, having all this material on different devices allow her to leave a legacy or heritage to her family, who will have the opportunity to know their roots and to continue building a common memory.

"While he was writing the book of his life, my husband always came to me asking about information... I knew everything about his ancestors, because I've got photos of his parents and uncles. So, I knew everything about his life!"

Technology is not only about health, communication and services: old people need to keep their memories, look at them and share them with their friends and family. By allowing others to know and enjoy such traces helps to keep memories "alive" even when those who created them are no longer on this earth. It should not be underestimated how old, current and emergent technologies can create possibilities to do so in new and accessible ways.

Useful Links





