

PERCEPTION, EXPECTATION AND PREFERENCES TOWARD ICT SOLUTIONS OF THE FRAIL ELDERLY PERSON

PERCEZIONI, ASPETTATIVE E PREFERENZE DELL'ANZIANO FRAGILE VERSO LE SOLUZIONI TECNOLOGICHE

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Abstract

In the last two decades there has been an emphasis on participatory value in the design processes of goods, environments, and services, in order to implement methods and techniques of active involvement in the design of new organizational, architectural and technological scenarios with evident social repercussions and on the quality of individual life. Participatory Design is an approach that aims to actively involve all stakeholders (employees, partners, customers, citizens, end users) in the design process to ensure that the product meets real needs and is usable.

The introduction and use of innovative technological devices to support the aging of frail elderly people does not necessarily correspond to an improvement in people's quality of life. The strong technical curvature resulting from the use of telemedicine models often highlights limits in the usability of technologies in responding to the real needs of users. The theoretical framework of Special Pedagogy allows the assumption of the bio-psycho-social perspective (WHO 2001) and the constructs of quality of life and participation and opens up to inclusive logics that implement a profound and questioning reflection on all contexts of life, with the goal of exposing the set of disabling processes and indicating a valid support in the use of technological resources.

The contribution, retracing the research phases of the Data System Platform for Smart Communities project, (project admitted for funding in the Innolabs 2018-2019 call), completed in 2020, presents the results of the analysis of the needs of strategic stakeholders and the results of the detection of expectations, attitudes and degree of satisfaction and trust towards telemedicine devices by frail elderly people.

Negli ultimi due decenni si assiste ad una enfaticizzazione del valore partecipativo nei processi di progettazione di beni, ambienti e servizi, al fine implementare metodi e tecniche di coinvolgimento attivo nel disegno di nuovi scenari organizzativi, architettonici e tecnologici con evidenti ripercussioni sociali e sulla qualità di vita individuale. Il Participatory Design è un approccio che mira a coinvolgere attivamente tutti i portatori di interesse nel processo di progettazione al fine di garantire che il prodotto incontri i bisogni reali e sia utilizzabile.

L'introduzione e l'utilizzo di dispositivi tecnologici d'avanguardia a supporto dell'invecchiamento dell'anziano fragile non corrisponde necessariamente un miglioramento della qualità della vita delle persone. L'eccessiva curvatura tecnicistica derivante dal ricorso a modelli di telemedicina evidenzia spesso dei limiti nella usabilità delle tecnologie nella rispondenza ai reali bisogni dell'utenza. La cornice teorica della Pedagogia Speciale consente l'assunzione della prospettiva bio-psico-sociale (OMS 2001) e i costrutti di quality of life e di partecipazione e aprono a logiche inclusive che attuano una riflessione su tutti i contesti di vita, con l'obiettivo di mettere a nudo l'insieme dei processi disabilitanti e indicando nell'uso delle risorse tecnologiche un valido alleato.

Il contributo, ripercorrendo le fasi di ricerca del progetto *Data System Platform for Smart Communities*, (progetto ammesso a finanziamento nel bando Innolabs 2018-2019), presenta i risultati dell'analisi dei bisogni degli stakeholder strategici e i risultati della rilevazione delle aspettative, degli

atteggiamenti e del grado di soddisfazione e fiducia nei confronti dei dispositivi di telemedicina da parte degli anziani fragili.

Keywords

Telemedicine, Quality of life, Active Aging,
Telemedicina, Qualità della vita, Invecchiamento attivo

1.Introduction

The presented case of study was carried out as part of the project D-Sys-Com – a project admitted for funding in the Innolabs 2018-2019 call – in Putignano (BA), with specific reference to the Municipality of Noci, in the South of Italy. The study provided an opportunity for a wide reflection on the risks of excessive technical curvature resulting from the use of telemedicine models. The current paradigm of telemedicine oscillates between hyper-technicization and attention to the humanization instances of the patient and their caregivers, trying to meet the challenge of integrating relational *to care* into medical and welfare *to cure*. The critical reflection of this model refers to a series of multidisciplinary studies (Godfray and Johnson, 2008) that can broaden the work perspective: in fact, the idea that the introduction and use of high-level technological devices necessarily correspondent to an improvement in people's quality of life shows enormous limitations. The contribution retraces the research phases of the *Data System Platform for Smart Communities* project, a Smart Social domain¹, completed by the CNTHI “Centre for New Technologies for inclusion and disabilities” (Department of History, Society, and Human Studies of the University of Salento). The main objective of the project was the creation of a technological dashboard aimed at increasing the effectiveness and efficiency of the communication between public institutions, private structures, and end users (patient and caregiver). The challenge has included the creation of a system of aggregation and intelligent use of heterogeneous data, coming from different sources and centralized in Cloud mode in relation to the specific needs of the single territory, and that this proposal could reduce the social and health vulnerability of end users, in a context of high asymmetries and inequalities in the provision of social welfare and health services. The first phase of analysis identified the concrete needs of the stakeholders involved, highlighting the elements of resistance to the introduction of telemedicine at an organisational, cultural, and relational level by operators and users and the awareness of their own know-how by public and private operators. This has allowed CNTHI researchers to build the following step of analysis through the identification of a cross-section of elderly people involved in testing hardware and software technologies together with the provision of analysis tools to survey expectations, attitudes and degree of satisfaction and confidence in these telemedicine devices. The research was particularly complex, both for the interdisciplinary nature of the project and for the lack of knowledge in the use of Participatory Design techniques in the creation of telemedicine-assistance products.

¹ A project developed for the participation to the PO.FESR-FSE 2014-20 calls, measure IV “Electronic government for Elderly People”. The project partners are 3 municipalities within the regional territory of Apulia and hardware and software producers with the scientific support of the Interdisciplinary Laboratory of Design and Integrated Management of Industrial Plants of the University of Salento. The project is divided into 3 domains: “Smart Building” belonging to the Municipality of Nardò (LE), “Smart City” within the Municipality of Conversano (BA) and, finally, “Smart Social” within the Municipality of Noci.

2.The D-Sys-Com platform for Smart Social

The objective of institutionalising *initiative medicine*, which aims at shortening diagnostic and therapeutic times by allowing operators to quickly have the entire health framework of each patient and a greater possibility of consultation between colleagues, has required the involvement of public and private entities and professional figures not limited to the exclusive medical-health relevance.

Initiative medicine is a welfare model considered suitable to manage chronic diseases (diabetes, arterial hypertension, heart dysfunction...), constantly increasing as a result of the growing level of senility in the population (WHO, 2006).

In relation to the available literature, such an innovative paradigm necessarily requires the task of a therapeutic education of patients and families (Bodenheimer, Wagner, Grumbach, 2002). The greater the needs for assistance, the greater the effort made in helping people to become “expert” in their own health and in managing their own pathologies should be. Smart communities that adopt this approach activate processes built on “proactive” forms of territorial aggregation that take care of people with chronic diseases in an integrated way together with other appropriately trained professional figures (Wagner, 2002).

In line with this model there is the *Data System Platform for Smart Communities* project, Smart Social D-Sys-Com domain. Its macro-objective was the creation of a technological dashboard of telemedicine and welfare service, aimed at increasing the effectiveness and efficiency of the communication among public entities, private facilities and end users (patient and caregiver). The challenge is to reduce social and welfare vulnerability of the end users in a context of high asymmetries and inequalities in the provision of social care and welfare services, through the creation of a system of aggregation and intelligent use of heterogeneous data, coming from different sources and centralized in Cloud mode in relation to the specific needs of a single territory. The D-Sys-Com platform should offer the organization of some chronic diseases based on multi-professional teams; implement initiative medicine projects on relevant chronic diseases (diabetes, cardiovascular risk, heart failure, COPD); represent an information system to support the activities of health care and organization and intelligent use of data; trigger a virtuous process of involvement of community resources.

As a result of these considerations, a research plan has been drawn up to provide an initial general picture of the situation to understand the most important characteristics of the phenomenon, thus developing two lines of analysis: a quantitative structural line, in which the socio-demographic and economic conditions of the target population emerge; a qualitative line, which deepens the cultural, cognitive and behavioural aspects of the users.

To this end, the following paragraphs will concisely present the results of the surveys and analyses carried out so far. First of all, however, a brief examination of the reflection about the application of digital hardware and software technologies in the medical and welfare field is necessary.

3.D-Sys-Com research

Participatory design is an approach that aims at actively involving all stakeholders (employees, partners, customers, citizens, end users) in the design process to ensure that the product meets real needs and is usable.

At a global level, a legislative discipline has been established in the field of participation, especially in the digital field; the main standards produced by the ISO *Technical Committee* 159/SC4, which highlight the importance of a user-centred design (Kensing, 2003), are well known.

Consideration of human factors in the design of interactive systems enhances their effectiveness and efficiency, improves human working conditions, and counteracts possible adverse effects of their use on health, safety, and performance, because capacity, limitations and the various human needs are taken into account. Participatory design is a design technique that gives a very important role to the contribution of end users in defining the utility and functionality that the system can have and does not only contribute to a better definition of effectiveness of systems, but also to make users more aware of the processes that will take place, as they will be central actors in the executive phases. The involvement of users is essential to collect qualitative and quantitative data on the effectiveness of the product and to ensure a design for all (Rapp. 2014).

User-centred participation starts from an essential premise: knowledge of the target. For this reason, a desk analysis was carried out on the socio-demographic characteristics of the population and on the welfare characteristics of the territory in question and a subsequent focus group with some strategic stakeholders within the supply chain of welfare and relational care. The following graph (Fig.1) shows the analysis work of the CNTHI researchers in order to reach the subsequent involvement of the end users in the experimentation and testing of telemedicine models within the D-Sys- Com project.

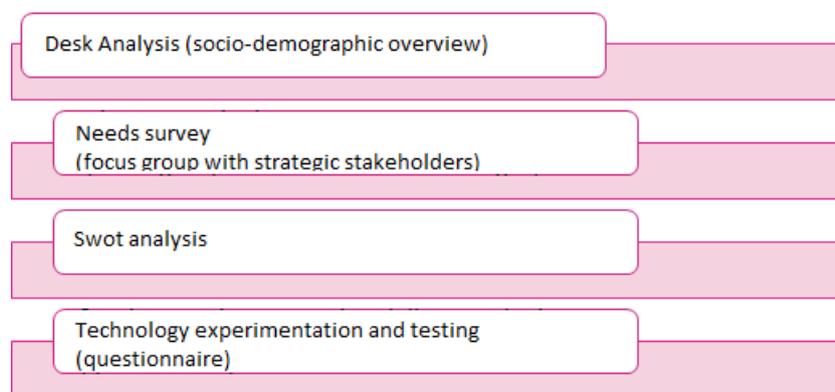


Fig.1 Research step and end users' involvement

4.Active ageing and technological support

Intervening in the context of an ageing population means dealing with chronic diseases affecting elderly people. Chronical disorders are not curable, but a wise management of these diseases (disease management) can have an extremely significant impact on the quality of life of a person and their caregivers, extending their life expectancy.

Coronary heart diseases, osteoporosis, COPD, cognitive impairment and mellitus diabetes are the most common chronic diseases that are increasing considerably due to the growing senility of the population (WHO, 2020).

According to the available literature, disease management is based both on the set of the correct health interventions towards patients and on the educational processes aimed at elderly people and their families so that they can reach a good level of self-management of the disease with positive results (Quaglini, Cesarielli, Gicomini 2017). The elderly person is therefore encouraged and supported to take an active role in the management of their pathology. All this requires a real transformation of the paradigm, from a waiting medicine to an initiative medicine, the latter made possible by a cooperative approach, by collaborative models between professionals and families and by a prompt sharing of relevant clinical information. However, it should be stressed that, while, on one hand, medical knowledge and technology implementation have undergone a sharp upsurge over the past decade as they have progressed rapidly, on the other hand, it should be noted that scientific and technological innovation do not always result in an adequate application of technologies to support ageing and chronic disease. There are many reasons for this. First of all, healthcare professionals, not only doctors, but also pedagogists, psychologists, and caregivers, often rely on a partial clinical picture of the person, due to the fact that nowadays we have digital infrastructures that are not rewarded or timely updated. In support of this thesis, there are a whole series of experimental observations on the use of Edotto and on the bad assimilation of the regional computer system in which they have to upload the therapeutic plans and implement the electronic health files. Many IT services are poorly integrated and fragmented and people-related information is not shared, but it is often dispersed in heterogeneous archives. This has a major impact on the management of chronic diseases affecting the elderly population, which, on the contrary, require frequent monitoring.

The D-Sys-com platform, Smart Social domain, aims to provide concrete answers to the needs expressed by end users, through an integrated visualization of medical and welfare data in real time in order to increase administrative efficiency between structures and provide immediate and consistent information to citizens. A “smart community” must be able to manage in an integrated way all the available information, so as to re-elaborate and redistribute them on the territory (Noci - Area of Putignano) converted into quality social-health and welfare services and in a better governance of the territory itself.

The creation of a strong involvement among all the stakeholders of the project through the creation of a shared system of knowledge, is a key step towards understanding that technological support can have positive effects on the well-being and quality of life of the elderly people. This approach describes an active health system, the aim of which is to optimise the health status of the person, in contrast to many existing reactive systems, in which treatments are undertaken only when the patient manifest obvious symptoms that lead them to consult their doctor.

New technologies have a profound impact on communication processes and on structuring new settings, not only training settings, but also care ones². They are not just tools or devices, but real languages, which is why self-management of the pathology becomes a fundamental criterion. The patient must be able to share physiological parameters with the medical staff, to access general and specific knowledge, or simply to possess that basic digital literacy. As Pinnelli suggests (S. Pinnelli 2015, p. 174), computer science has a much faster pace of

² S. Pinnelli - L. D'alozzo - F. Bocci, *Didattica Speciale per l'inclusione*, Editrice LA SCUOLA, Milano 2015

evolution than other domains of knowledge or compared to the consolidation of good practices in the health and welfare field. This highlights the risk, from care professionals or designers, to chase technological solutions free from that pedagogical and humanistic curvature able to qualify the cure as autonomy, independence and quality of life. These aspects represent the trajectories of inclusive action towards the fragile elderly people, who should not be forced to accept a device by changing their behaviour, on the contrary, they should receive a technology to meet their needs effectively and efficiently.

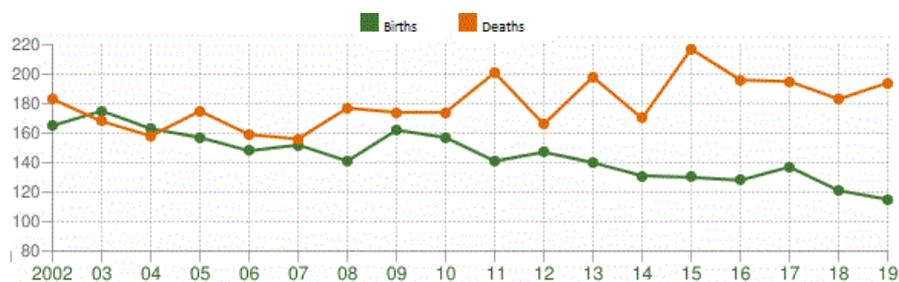
Based on this need to make ICTs valuable allies to support elderly people's well-being and quality of life, in the European scenario, Ambient Assisted Living (AAL) supports the concrete needs of the person in their ageing process by actively collaborating to achieve an independent and autonomous life (De Munari, Matrella and Ciampolini, 2013).

In this regard, WHO has provided a strategic framework, known as Active Ageing, which considers the elderly person as an individual with rights, freeing us from that conception of the elderly person as a subject necessarily in need of help, against which the focus is on their deficit and pathology. WHO, thanks to ICF and the bio-psycho-social model, proposes work and intervention trajectories to support a better quality of life, which pay attention to all context of life and development of the person with a particular disadvantage. In this context, technologies can intervene with a leading role in different areas of personal functioning.

5. Socio-demographic characteristics of the research context

The research context has been the territory of Noci; it has 19,115 inhabitants and has a wide extension (150.60 km²) resulting in a low population density (Istat, 01/01/2018). This is an important data: in fact, a population located also in rural areas poses many problems for users and operators for the mutual reachability in the provision of services, in particular for users with a strict health care framework and individuals living alone.

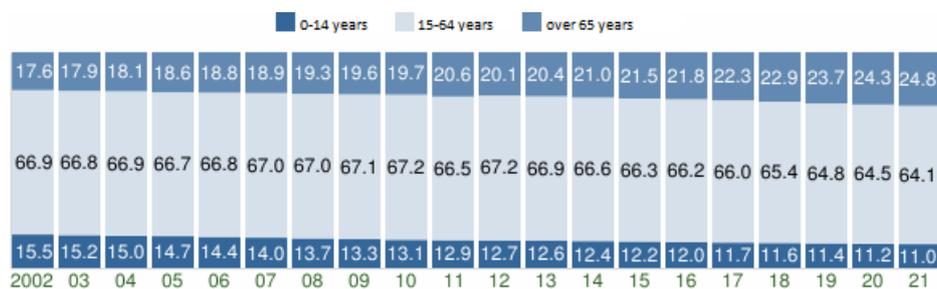
Other factors contribute to this one in the accentuation of the risk of marginality of some categories, for example the demographic decrease (450 units between 2001 and 2017 – Istat data), derive from decreased birth-rate, increased deaths and braked ingoing migration flow (Fig.2).



Source: Istat – 1st January of each year

Fig. 2 Decreased birth-rate and deaths in Noci

All this means that for years the younger generations have been formed of fewer and fewer members and this gap is no longer compensated by foreign immigration.



Source: Istat – 1st January 2019

Fig. 3 Age structure of the population in Noci (% values)

Considering a greater ageing of the population (old age index – Istat data: 113,5 in 2002; 197,6 in 2018) it can be easily understood that elderly people (and in any case all those who are not self-sufficient) cannot count on proper human and relational support. This thought is also confirmed by the reduction in the number of members per family (2,86, 2003 vs. 2,51, 2017 (Istat, 1-1-2019)). Youth forces that could offer more support to people in difficulty are becoming increasingly less and this results in an increase in the need for institutional support to marginalized groups. From a careful reading of the Area Plan (2016-18) in the Area of Putignano, there is a general economic impoverishment (about 5.300 inhabitants with less than € 10,000 per year) so that families with greater health and welfare vulnerability are incapable of turning to private structures, if public ones are insufficient or even absent.

Reading and analysing the Social Zone Plan has been a strategic method for the identification of precise criticalities towards elderly and disabled people:

- Lack of a database and monitoring of their quality of life,
- Lack of family support services,
- Deficiency in the management of Alzheimer’s patients,
- Deficiency in assistance-rehabilitation,
- Lack of specific structures for disabled people,
- Lack of the “After Us”,
- Deficiency in the resources for home services

In addition to the lack of services in terms of structures and activities/interventions, what is missing is the possibility of data collection, the only one that allows a real opportunity to better intervene. Therefore, the first important step is precisely the commitment to provide resources in order to have a general picture of the situation, since without them health and welfare intervention would always remain in the emergency and in the contingency. However, the initiative medicine model with the support of digital technology does not only concern users-patients, but also operators who will thus have in their hands an instrument as powerful as difficult to integrate in their daily historically-consolidated practise. For this reason, research has gone far beyond quantitative investigation to explore subjective perceived needs. To this end, a *focus group* has been set up with various strategic stakeholders in health and social care sectors.

6. Collect data about users needs through Focus Group

Given the complexity of the research objectives, the technique used for data collection was the focus group. This method of group interview is particularly suitable for promoting and facilitating interaction between participants, contributing in a particular way to the construction

of thought (Kitzinger, J. 1994). Unlike individual interview that displace people from their social context, focus group discussion creates an important social space of interaction, triggering a higher level of thinking and generating deeper data and insights (Duggleby, W. 2005; Morgan, D.L. 2010). The focus group for exploratory purposes took place on April 8th 2019 at the council hall of the Municipality of Noci. A type of theoretical-reasoned sampling for representative elements has been used, with the aim of studying strategic stakeholders, welfare and medical workers and key informers, that can offer a particular abundance of information about the phenomenon in question. There were:

- two doctors operating in the Area of Putignano
- a pedagogist
- a psychologist
- a family mediator
- two social workers
- a school home educator
- a technician of the Municipality of Noci
- an Adi nurse
- a Health Care Partner operator
- The President Retirement Homes “Sgobba” in Noci
- an exponent of the Third Sector and of the volunteer world of the Municipality of Noci

The composition of the stakeholders is quite heterogeneous. This aspect certainly represented an advantage in a first analysis of the emerging needs, as it helped to draw an interesting multidimensional overview of the needs of the population of Noci. Under the guidance of the conductor/moderator, who, through the guide questions, urged the group to examine in depth the topic of research in a relaxed and non-directional climate, the participants activated meta-reflexive processes on their daily professional practice and on the cultural, social and geographical context in which they live. The focus group lasted about 130 minutes. Based on the research questions and objectives, guide questions were planned with the aim of stimulating conversation avoiding possible argumentative derailments. The scenario with the guide questions was built following the indications in the literature (Krueger; Zammuner 2013). The meeting was recorded via a voice recorder and faithfully transcribed, despite the difficulties related to the quality of the audio and the characteristics of the council hall of the Municipality of Noci.

The analysis of the needs made it possible to identify three macro categories:

- Social Needs
- Communicative Needs
- Technical and Operational Needs

The analysis of the stakeholders' needs made it possible to identify three categories: social, communicative and technical and operational needs. As far as social needs a widespread educational poverty and the difficulty of emerging social needs has emerged, as it highlights the need to increase the communication of the Municipality of Noci in order to accompany citizens in the complex field of services. Most stakeholders have identified welfare access as the weakest link in the chain and this has an impact on people's quality of life by increasing their social and health vulnerability. There has often been some resistance from certain sections of the population towards certain social welfare services because of their refusal to seek help. Requests could reinforce discriminatory prejudice to one's own disadvantage and this feeds

self-prejudice and, consequently, self-marginalisation. Another element worthy of note is the presence of inexperienced care figures, with particular reference to housemaids, who often do not have adequate basic health education and present difficulties in understanding Italian, which are factors affecting the patients' quality of life and the correct use of technological devices. In the field of communicative needs there is an absence of basic information related to the access welfare and what obviates to the gap between need and performance is often the individuals' will, for example a good doctor or a good social worker. Good sector practises, however important they may be, cannot remain in the context of individual discretion, but they must necessarily evolve into efficiency and guaranty of a service. All this has a significant impact on people's quality of life and this has a domino effect on the whole system. There are many scientific researches that converge on the importance of the context effect in the treatment and healing processes of the patients. If, on one hand, the research has highlighted the need not to eliminate the already existing database, but to include it according to Cloud modes in greater Cluster, on the other hand, it brings to light a crucial problem linked to a training service turning to operators, families and caregivers, in order to raise awareness of the available resources and their use. Given the heterogeneous nature of social demand, in relation to the need for *database integration*, the usefulness of interfacing all existing tools has emerged by finding a unique and shared way through *usable Apps*, with simple and intuitive interfaces and a comprehensible language, in order to offer practical diagrams on the operating steps to follow to access the services. The reference to the need to embrace the User Centred Design Methodology and the ISO 13407 legislation during its design is clear, by adopting a design approach of a system that has as its main objective its usability.

Even if ITCs open up scenarios of effective equality and social inclusion, as well as individual and collective empowerment, they can represent, especially in culturally and economically marginal areas, a new form of discrimination by increasing the digital divide: the number of people who do not know how to use IT applications has grown considerably, especially those supporting public service and welfare access.

This is due to the different language and logic between those who produce technology and those who use it. For these reasons, the reference to a really user-centred approach, known as *UCD - User Centred Design*, described in the previous paragraphs, could avoid the risk of negative effects.

7. From the user the study on the ITC's social role and pedagogical background

The involvement of the end users has been fundamental to collect quality and quantitative data on the effectiveness of the product and to ensure a design for all.

In order for telemedicine initiatives associated with the needs of fragile elderly people to produce satisfactory results, it was necessary to take a multidisciplinary approach, in which the synergy between medical figures, producers/designers and pedagogists could be functional to the real improvement of the person's well-being. The assumption of bio-psycho-social perspective (WHO 2001) and the constructs of quality of life and participation paves the way of inclusive logics which implement a deep and questioning reflection on all contexts of life, with the aim of exposing the set of disabling processes and indicating a valid ally in the use of technological resources. In the psycho-pedagogical area, also because of the diagnostic classification of the ICF, we can identify a very interesting line of research whose focus concerns the quality of life of the person with disadvantages and disability; the models and tools for identifying needs in view of ageing; the inclusion and care of the fragile elderly

person; the risks to social isolation and, last but not least, the changes in the caregivers' networks that the new social structures have determined (Pinnelli, 2014, pp. 1-13).

Moving from that prospective was create and used an explanatory questionnaire, with the aim to resize some starting hypotheses and work packages of the D-Sys-Com project with regard to an adaptation of the design of the products in relation to the users. The focus of the questionnaire has been to explore the relationship between the elderly person and technology then, using the special pedagogy has the epistemological basis of the work.

As suggested by Pinnelli (cit.), the idea behind the detection tool used to investigate some characteristics of end users so that a real participatory Design Process can be realized that can effectively contribute to a better definition of systems and tools, regardless of the technologies used. The relevance to the need to embrace the *User Centred Design Methodology* and the ISO 13407 legislation during design and testing phase, adopting an approach to the design and testing of a system that has as its main objective its usability³. The lack of inclusive architecture in medical sensors and technologies related to telemedicine not only constitutes a predictor of disability, but also creates it, as the ICF suggests: "it is the environment where the person lives that determines and concretizes the disability" (Bickenbach, 2008).

7.1. The questionnaire: perceptions, expectations and preferences towards ICT

Precisely by virtue of going in the direction discussed above, the CNTHI researchers of the University of Salento have prepared an analysis tool that has taken into consideration various spheres of the person. Sociality, relationships, autonomy, expectations, experiences of use represented compasses to probe the usability of complex tools, with the aim of achieving a true process of media education considered part of a wider form of democratic citizenship (Buckingham, 2006, p. 32).

The tool developed in this study consists of 23 questions divided in 5 sections: 1) demographic characteristics; 2) technology experience; 3) perception of technology; 4) personal expectations regarding their quality of life and technology; 5) characteristics of technologies considered preferential.

The questionnaire: perceptions, expectations and preferences towards ICT

DEMOGRAPHIC CHARACTERISTICS

User no. _____ Date of Administration: _____ Age: _____
Sex: _____

Level of education (tick the option):

-
- No education
 - Primary School
 - Middle School
 - High School Diploma
 - Bachelor's Degree
 - Master's Degree or Single-Cycle Degree
 - Post-graduate Education

³ Usability is meant as "the ability of a product to facilitate a specific user in achieving specific objectives with effectiveness, efficiency and satisfaction in a specific context of use".

Qualification:

Job or occupation:

Please, indicate your current Civil status:

- Married
 - Partner (living together)
 - Divorced
 - Single
 - Widow/er
-

Who lives at home with you? (tick the option):

- Alone
 - Spouse
 - Caregiver/ Housemaid (paid caregiver, not a relative)
 - Spouse and Children
 - Children
 - Brothers/Sisters
 - Sons-in-Law/Daughters-in-law
 - Mother/Father
-

Do you live in a flat or a house?

- Detached house
 - Flat
 - Other (Indicate)
-

TECHNOLOGY EXPERIENCE

In your daily life, which of the following technologies do you usually use?

1.1 Type of technology owned:

- Fixed telephone line
 - Mobile phone
 - Internet
 - Desktop
 - Laptop
 - Automatic lights
 - Wearable sensors (bands, wristbands, plasters)
 - Alarm system
 - Smart thermostat
 - Wi-Fi switches for shutters and socket control
 - Video intercom
 - Fixed sensors at home (smoke and gas leaks sensors)
 - Medic alert bracelet
-

1.2 Considering whether the technologies you use have really improved your quality of life, give a score regarding their degree of usefulness.

Score from 1 to 5 of which 1 = not at all, 2 = little, 3 = sufficiently, 4 = a lot, 5 = very much.

Tick the score in the box.

	1	2	3	4	5
Fixed telephone line					
Mobile Phone					
Internet					
Desktop					
Laptop					
Automatic Lights					
Wearable sensors					
Alarm system					
Smart Thermostat					
Wi-Fi switches for shutters and socket control					
Fixed sensors at home					
Video intercom					
Smoke Sensors					
Medic Alert Bracelet					

1.3 If you could choose a system control of domestic technologies and other technologies, in order to use them in the future, which input/control mode do you prefer among the following options?

Button/Switch

Touch screen

Vocal Control

1.4 If you could use technologies to improve your quality of life, which of the following areas do you consider most useful? And would you like to have it? You can choose more than one

technology by entering a rating from 1 to 5 in which 1 = not at all, 2 = little, 3 = sufficiently, 4 = a lot, 5 = very much.

	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
<u>Technologies for socialization and social inclusion</u> (support to contact and communicate with family members, activate new friendships)					
<u>Technologies for environmental and personal safety</u> (reporting of critical events, immediate communication to family members and alarm, e.g., personal falls, gas leaks)					
<u>Mobility and walking support technologies</u> (inside and outside home, warning and detection of accidental falls)					
<u>Physical and psychological well-being</u> (monitoring of vital parameters, support for memory in a condition of cognitive deterioration, reduction of anxiety and depression)					
<u>Clinical personal support technologies</u> (APP for booking medical exams, digital welfare access tools)					

EXPECTATIONS REGARDING THE USE OF TECHNOLOGIES

2.1 In general, do you consider continuing to rely on the use of technology important for your health and quality of life?

- Not at all
- Little
- Sufficiently
- A lot
- Very much

2.2 Do you think that technology could be useful in personal mobility and motor skills?

- Not at all
- Little
- Sufficiently
- A lot
- Very much

2.3 Do you think the use of technology could have an impact on improving personal health?

- Not at all
- Little
- Sufficiently
- A lot
- Very much

2.4 Do you think the use of technology could affect the optimization in the management of your home?

- Not at all
- Little
- Sufficiently
- A lot
- Very much

2.5 Do you think the use of technology could help you in your daily routine/activities by improving your autonomy?

- Not at all
- Little
- Sufficiently
- A lot
- Very much

2.6 Do you think the use of technological devices could reduce possible anxiety or stress?

- Not at all
- Little
- Sufficiently
- A lot
- Very much

PERCEPTION OF THEIR OWN QUALITY OF LIFE AND USE OF TECHNOLOGIES

3.1 Express your degree of concert with this statement: “if I possessed a control system of my vital parameters, I would feel more serene in monitoring and maintenance of my lifestyle”

- Totally disagree
 - Slightly Disagree
 - Sufficiently agree
 - Slightly Agree
 - Totally agree
-

3.2 Express your degree of concert with this statement: “could the support of specialised people at a distance reduce your sense of isolation?”

- Totally disagree
 - Slightly Disagree
 - Sufficiently agree
 - Slightly Agree
 - Totally agree
-

3.3 Express your degree of concert with this statement: “only the use of technologies would help me to access content and services that are essential for my assistance”:

- Totally disagree
- Slightly Disagree
- Sufficiently agree
- Slightly Agree

-
- Totally agree
-

3.4 Should you decide to buy technological aids, your decision would be influenced by:
(Indicate: 1= Not important; 2 = A little important; 3 = Very important)

	1	2	3
By your own general practitioner/specialist			
By the advice of a family member/friend			
By the costs of the device			
By its usability (ability to use the tools effectively and independently)			
By the possible social stigma (fear of prejudice)			
By your health condition			
By distrust towards technologies that supplant human relationship			

CHARACTERISTICS OF TECHNOLOGY

4.1 Based on your point of view, express a score on the characteristics that technologies helping people should have.

Indicate a rating from 1 to 3 (1 = Not important; 2 = A little important; 3 = Very important)

Simplicity			
Safety			
Protection of Sensitive Data and Privacy			
Usefulness			
Sustainability			
Invasiveness			
Demand for little physical strength			

Due to the restrictions linked to the anti-contagion measures following the Covid-19 pandemic, it was not possible to administer the questionnaires in the presence of the CNTHI researchers, but the social worker of the Municipality of Noci was embroiled in order to guarantee a connecting link with the elderly people involved.

8. General information on the cross-section

The cross-section includes 18 patients living within the municipal territory of Noci, 11 women and 7 men. The age is quite high. The average age is in line with the life expectancy threshold in Italy, measured for the year 2018 by ISTAT: 80,8 years for men and 85,2 for women; in particular, female patients have an average life expectancy slightly lower than Italian women (83,7), while for men it is almost the same (85,5). At least half of the subjects in the cross-section are 83 years old up to a maximum declared of 100, while among the “youngest”, they reach a minimum age of 71.

It is worthy to highlight that age was not a primary criterion for the selection of the cross-section, because the psychological and physical status of the subject involved and the availability of the main caregiver was a priority. During the phase of identification of the cross-section, thanks to the availability of some general practitioners of the Municipality of Noci, patients with a variety of diseases were pointed out: people with cognitive impairment (11): in 4 cases the condition was not accompanied by other pathologies, while in two cases it was accompanied by COPD, one of which even by chronic renal insufficiency, others with kidney or respiratory or heart failure. Among the most common cases, there were also people with diabetes and heart problems (4), almost always in conjunction with other morbidity; finally, there were three cases with respiratory failure.

Cognitive impairment (Tot. 11)	Chron. Obstr. Pulmon. Disease	2 (1 with chronic kidney failure)
	Polypathologies	2
	Resp. insuff.	1
	Kidney insuff.	1
	Heart failure	1
Diabetes (Tot. 4)	Neurovasc. complic.	1
	Heart failure	2
	Visually impaired	1
Respiratory insufficiency (Tot. 2)	Heart disease	1
	Heart failure	1
Paraparesis		1

Tab. 1 Synoptic picture of the declared morbidity

9. Demographic characteristics

The elderly people to whom the questionnaire was administered are predominantly widowers/widows (55,5%). 22,2% is single, and the remaining 22,2% declare to be married and to live with their spouse.

The level of education held by the cross-section is almost entirely relative to primary school (90%), followed by a 10% who declare not to possess a level of education. On average, the duration of the study path of the interviewed cross-section is 5 years.

The working position of the cross-section is distributed as follows: housewife (56,25%), cook (12,5%), farmer (12,5%), auxiliary (6,5%) and tailor (6,5%).

In most cases, respondents declare that they live alone (44,44%), while those who live with their spouse constitute the 22,22% of our cross-section; in the same way, those who live with a housemaid or their children constitute the 16,66% of the respondents.

More than a half of the cross-section live in a flat (66,6%) and the remaining 33,33% in detached houses.

10. Analysis of the need and experience with technology

In relation to the needs mostly felt by respondent patients, technologies should fulfil functions related to the protection and maintenance of physical and psychological well-being, followed by mobility support, environmental and personal safety, clinical support and, lastly in order of preference, socialization and social inclusion.

Respondents attributed a value of importance on a 5-point Likert scale to technologies that could meet their needs.

The following table (Fig. 4) summarises the sector of the needs that technologies should meet.

<i>Need</i>	<i>Activity</i>
<i>Physical and psychological well-being</i>	Monitoring vital parameters
	Support to memory capacities
	Reduction of anxiety and depression
<i>Technologies for mobility and walking support</i>	Help in walking
	Detection of accidental falls at home
	Immediate communication and alarm to family members
<i>Environmental and social safety</i>	Critical event reporting (smoke and gas detectors)
<i>Technologies for inclusion and socialization</i>	Support in the communication with families
	Activation of new friendships
<i>Personal clinical support</i>	Apps for booking medical exams
	Digital welfare access tools

Fig. 4: Relationship between technologies and needs

The following order shows the percentages expressed by our reference cross-section. The order is by priority

Technology relevance and sectors

1. Technologies for physical and psychological well-being
2. Technologies for environmental and personal safety
3. Technologies for mobility and walking support
4. Technologies for inclusion and socialization
5. Technologies for clinical support and welfare access

As regard the **experience** that users have gained in relation to the technologies possessed during their life, the questionnaire found a very limited use of technological tools: 94,44% of respondents, that is almost all the cross-section, declare to use landlines, while mobile phones are used by 66,66%, followed by 11,11% who claim to have wi-fi at home. The same percentage can be found for those who use fixed sensors for the detection of smoke and gas

leaks (11,11%) and, finally, only 5,55% is equipped with an alarm system. Nobody owns Medical alert bracelet, Video intercom , Wi-fi switch for shutters, Smart thermostat, Automatic lights, Laptop, personal computer.

The data on the possession of Internet at home is very important and should be considered for testing and design medical sensors and telemedicine and welfare tools, as the unavailability of a digital infrastructure for users should make designers and partner companies aware of the need to find appropriate solutions.

About the degree of **satisfaction related to the technological tools used in daily life**, we point out the following degree of importance that users attribute to their devices: landline was attributed a great deal of importance (62,2%), followed by (12,5%) who give it a lot of importance and (25%) sufficient importance. Mobile phone was given a great deal of importance (52,25%), followed by (35%) of the cross-section who gave no importance and (12%) a lot of importance. The lack of importance given to mobile phone is remarkable and it can be traced back to socio-demographic conditions of our cross-section consisting of a fairly high average age and levels of education attested to primary school.

The impact of the **socio-cultural and demographic** sphere can also be considered within the judgement given to other technologies: the possession of a digital infrastructure such as Internet is not considered important at all by about 87% of the cross-section, followed by 13% who give it great importance. We can find similar positions also for the use of computer, desktop or laptop: not important at all (79%) and little important (21%). Similar percentages are detectable in other devices: wearable sensors were given very much importance by 14% of the cross-section compared to 86% who give it little or no importance. Finally, both smoke sensors and alarm systems were attributed a lot of importance by 7% of the cross-section compared to 92% who was little or no interested at all in them.

In relation to the **use of technological** devices to be tested, the questionnaire observed useful advice (Fig.6) in order to ensure usable and effective systems, able to positively affect the quality of life of the subjects involved without distorting their behaviour. The respondents declared that for a device that improves their quality of life, the control mode they prefer is a remote control with buttons to press (61%), followed by touch screen (50%). Vocal control is less welcome (11,11%).

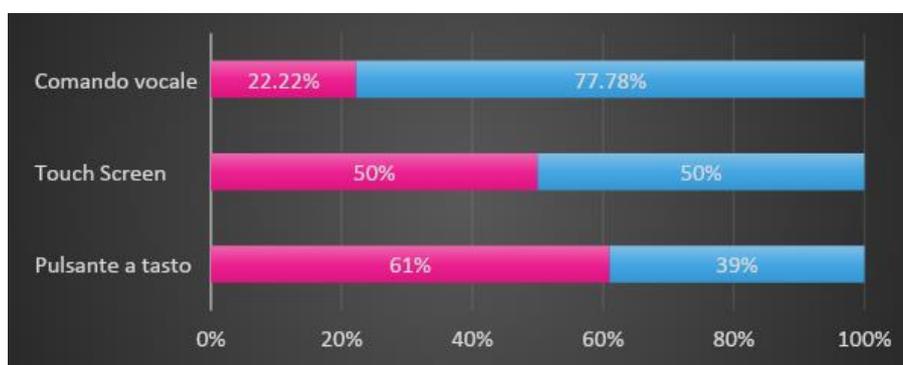


Fig.5 Command mode preferences
Vocal control, Touch screen, Switch or button. Pink yes, blue no.

11. Users' expectations on innovative and technological tools

The *User Centred Design Methodology* and ISO 13407 Regulation requires an approach to the design of a system that has as its main objective its usability (Vandi, Nicoletti, 2013). From the previous focus group and subsequent in-depth interviews with some strategic stakeholders, the main problem with telemedicine and teleassistance tools was mainly related to the distrust in technology, a cause of complications and stress in the specific context of daily use of the user. Moving from this reason, the questionnaire administered sought to investigate the scope of expectations.

With regard to the **overall improvement in the quality of life** through the use of technologies, 44,44% of the cross-section attributed a great deal of importance to their use, 38,88% declared that they have a sufficient impact, while 11,13% claim not at all and 5,55% a little.

Expectations regarding technologies with specific reference to some aspects of the quality of life are the following:

- maintenance/monitoring of physiological parameters and personal mobility represent area where expectations towards technologies are very high (55,55%);
- technologies to support psychological well-being (51%),
- technologies to support daily routine and to increase personal autonomy (44%) and, finally,
- technologies and -the devices useful in the management of living spaces and household (38,88%).

12. Perception of effectiveness

In relation to the results of the questionnaire and the previous phases of the research (focus groups and in-depth interviews with strategic stakeholders) very significant data emerged with reference to the degree of effectiveness perceived by the sensors object of experimentation. There are three domains chosen to evaluate the perception of effectiveness of Smart Social technologies (Fig 6): vital parameters, teleassistance and technologies to support welfare access (booking medical exams online, apps to facilitate service access and orientation).

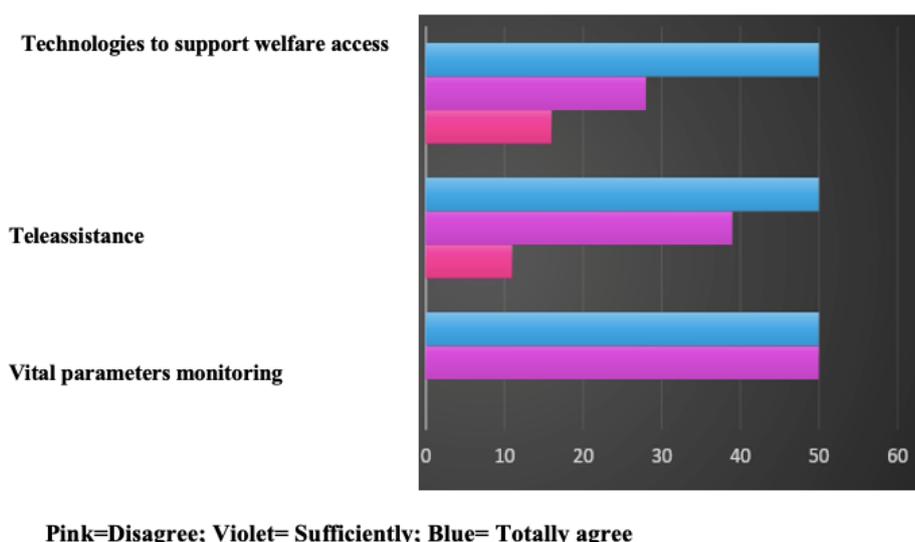


Fig.6 Perception of effectiveness

From reading the graph, elderly people express their opinion of total agreement in asserting the perception of effectiveness of tools used to monitor the vital parameters at a distance (50%); while the other half of the cross-section seems quite in agreement. With regard to teleassistance instruments aimed at reducing isolation and social and health vulnerability, the assessment is as follows: totally agree (50%), sufficiently agree (39%) and disagree (11%). Finally, with regard to technology aimed at facilitating welfare access and accompanying citizens-users in the vast area of services, the perception of effectiveness of these devices registers: totally agree (50%), sufficiently agree (28%) and disagree (16%). The survey linked to the perception of the effectiveness of technological tools has deepened the importance that respondents assign to certain **requirements**. According to the cross-section, the most important features of a technological tool that improves their quality of life are: usefulness (94%), followed by simplicity and safety (83%). They are followed by little physical strength in order to use them (50%), sustainability of costs (27,77%) and invasiveness (22,22%) at the same level of aspects related to privacy and protection of sensitive data (22,22%).

13. Conclusions

In the field of telemedicine and teleassistance, inclusiveness should not be a goal, but a methodology: this means that people are not considered on the basis of congenital characteristics, but in their entirety. This completely turns a paradigm upside down and necessarily stimulates two questions: what does it mean considering inclusivity as a methodology and not as a goal? And what does really mean inclusivity? Inclusion requires a holistic approach to design and requires necessarily to embrace a cross-disciplinary approach, adapting to the needs of people what you design.

As regard the processes of technological design, one of the most significant concepts is about atomic design exposed in the homonymous book by Bread Frost (2016), for a much more holistic design approach, in a perspective in which the components of design (atom, molecule, organism, product) synergically coexist and the design of each of them has concentric effects on the whole society (cit.). It is necessary to combine every single atom of design with the person's needs. As a means of social transformation, of inclusion, of broadening the range of opportunities for participation and of improving the quality of life, technology has a strong political character. Papanek (1985), in his book *Design for the real world*, stated that products very often leave behind the real problems of people by placing themselves as the tip of an iceberg, under which excluding logic lies. This occurs whenever you plan in a non-deliberate manner. In the design of complex systems, it is necessary to act in the best possible way, in what is known as the atomic design of technologies, because creating excluding products will create excluding societies (1985). As suggested by Pinnelli (2014), international research highlights the cruxes of the digital divide for elderly people, highlighting how much it is influenced not only by age, but by a whole set of demographic, cultural and experiential factors. Moving from this premise, in the D-Sys-Com research, the use of ICT solutions in the health and welfare field is outlined as follows:

- D-Sys- Com shall should support the needs of physical and psychological well-being, followed by the need to ensure environmental and personal safety, the need for mobility and walking, followed by the need to ensure and support social inclusion and, finally, clinical support and access to welfare by implementing functions, services and applications that meet the related needs;

- D-Sys- Com experimenting and testing technologies must be designed in accordance with the criteria of usefulness, simplicity, and safety, followed by the identification of minimally invasive devices that do not require great physical strength for their use. They are followed by the importance linked to cost sustainability and respect for user's privacy.
- the answers attest preference for solutions that can be managed by users through a simple remote control with buttons to press;
- given the poor experience of using technological devices by the cross-section, it is suggested the adoption of highly intuitive solutions that do not require the modification of user behaviour in their specific daily context.

Considering these conclusions, technologies can become exceptional tools in order to improve people's quality of life and, depending on how they are designed, implemented and applied, can act as facilitators or obstacles/barriers in the performance of the usual activities, placing themselves in the gap indicated by the ICF of the WHO between capacity and performance, i.e. what the person can do based on his functional residue and what the person can do with the support of environmental mediators. While as regard the first one, there is a little leeway, with elderly people, it is clear that we can act to the advantage of the latter.

References

- Bickenbach J. E., Assistive Technology and the International Classification of Functioning, Disability and Health, in A. Helal - M. Mokhtari- B. Abdulrazak, *The Engineering Handbook of Smart Tecnology for Aging, Disability and Indipendence*, John Wiley & Sons, Hoboken (NJ), pp.81-99
- T. Bodenheimer, K. Grumbach, E. Wagner, Improving primary care for patients with chronic illness: the chronic care model. *JAMA* 2002;288:1775-9
- D. Buckingham, *Media education, Alfabetizzazione, apprendimento e cultura contemporanea*, Erickson, Trento 2006
- A. Calvani, G. Vivonet, *Tecnologie: quale il ruolo dell'Evidence Based Education?* In *ECPS Journal*, <http://www.ledonline.it/ECPS-Journal>, 2014
- M. Cesarielli, M. Giacomini, S. Quaglini, *E-Health- Medicina Generale*, Patron Editore, Roma 2017
- Duggleby W., What about focus group interaction data? *Qualitative Health Research*, 15(6), 832- 840, 2005
- Froast B., *Atomic Design*, Apogeo Editore, Milano 2016
- Morgan, D.L., Reconsidering the role of interaction in analyzing and reporting focus groups. *Qualitative Health Research*, 20(5), 718-722.; 2010
- Kensing F., *Methods and Practices in Participatory Design*, Copenhagen: ITU Press, 2003
- Kitzinger J., The methodology of focus group-the importance of interaction between research participants'. *Sociology of Health & Illness*, 16(1), 103-21, 1994
- Papanek V., *Design for the real world. Human ecology and social change*, Academy Chicago 1985
- Pinnelli S., *Ambient Assisted Living, innovazione tecnologica e inclusione: tra linee di riflessione e opportunità di sviluppo professionale (2014) in MEDIA EDUCATION – Studi, ricerche, buone pratiche*, Erickson, ISSN 2038-3002-Vol. 5, n. 1, anno 2014, pp. 1-13

Pinnelli S., D'Alonzo L., Bocci F., Didattica Speciale per l'inclusione, Editrice LA SCUOLA, Milano 2015

Pinnelli S., Pedagogia speciale, ICT e invecchiamento attivo, un'indagine esplorativa della prospettiva degli stakeholders - Progetto Active Ageing at Home, in Maria Tomarchio, in Simonetta Ulivieri, Pedagogia militante Diritti, ed. Edizioni ETS 2015, pp.922-931

Quaglini S., Cesarielli M., Giacomini M, E-Health- Medicina Generale, Patron Editore, Roma 2017

Rapp W.H., Universal Design for learning in action, Brookes, Baltimora 2014

Vandi C, Nicoletti N., L'usabilità. Modelli e progettazioni, Carocci Editore, Bari, 2013

Wagner E., The role of patient care teams in chronic disease management, BMJ 2000;320:569-72

World Health Organization Europe. 2006. Tackling Europe's major diseases: the challenges and the solutions. Copenhagen: World Health Organization Europe

World Health Organization Europe.2020. A strategy to prevent chronic disease in Europe. A focus on public health action. The CINDI vision. Available at http://www.euro.who.int/CINDI/publications/20020322_3