Dementias in a systemic view a survey in Brindisi social health service district

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Introduction
The natural world is still considered a large complicated machine, of which we can have linear explanations, knowing its functioning mechanisms. Human organizations as well are considered a complicated gear: for this reason actions are taken in order to increase control systems and tools, to make the procedures more specialised, to produce more advanced software, to engineer the type of analysis. However, an organization – besides goods and services – produces meaning; a combination of meaning sometimes coherent, sometimes contradictory and chaotic imposes itself among social players, but that emerges from the interaction between them. Although it is the basis of every social form (Luhmann 1995), communication – and the related production of meaning – is taken for granted and therefore misjudged. The communicative analysis is crucial to the extent that it is an expression of shared working practices among subjects with different perspectives, languages, experiences and knowledge. In different fields of study – sociology and occupational psychology, managerial sciences – recent investigations show how human organizations set up a complex system, where beside the official organizational and regulatory structure (top down), a latent informal structure is strongly attested, which is formed in a context of constant relationships (bottom up), in which the subjects perceive the working environment, themselves, their role, norms, values and the other (Alvesson and Berg 1993; Argyris 1994; Piccardo 1995; Piccardo and Benozzo 1996).

Based on the perspective of complex systems, in 2012-2013 a group of sociologists of the Salento University carried out a survey on the issue of people with dementia and Alzheimer’s and their relationship with health care facilities. In order to prepare a program of interventions in some sectors of the Local Health Authority – with consequences on families and associations interested in the issue – and to provide training for health employees and patients, the general aim of the research project was to get information on three areas: the environment that surrounds people with dementia (health and associative resources in the area); the system of action of families in which there is a patient with dementia/Alzheimer’s; the interaction between them and the health care facilities. Before the explanation of the survey outcomes, the perspective of complex systems, especially in the social sphere, and the aspects considered will be clarified.

A less reductive vision in order to know the reality
Much of the order we observe is spontaneous, a natural expression of the surprising capacity of self-organization which is in the universe, considered as a complex network of relationships (Kauffman 2001). After the research of Ilya

1 The action-research “Voglio vivere” – decided by the Local Health Authority ASL in Brindisi – had a research team consisting of 9 sociologists and a statistician. The undersigned has assumed the role of scientific director and coordinator of the research group, building tools and choosing methods and techniques of the various phases of the survey. A psychiatrist and a trainee, graduated in psychology, supported the investigation on behalf of the Local Health Authority.
Prigogine, many scholars analyse the reality through the approach of complex adaptive systems (biological and social): characterised by numerous and different elements and multiple connections, they try to adapt by maximizing their evolutionary possibilities. In order to do it, systems self-organize: self-organization is an essential feature of complex systems and a prerequisite for the ability to evolve, since it generates adaptive parts and structure in a selective way. In the field of natural selection, self-organised features can be moulded more quickly because self-organisation emerges from below and has consequences on (and produces) higher hierarchical structures (bottom-up) (Colombo, 1991; Bocchi and Ceruti 1985; Capra 2001).

Self-organization depends on the close connection between elements, so that the result is much more than the sum of its parts; these parts must be considered within a set of relationships that determine significance and position of each component. As a result the systems may be, as the conditions change, in a dynamic intermediate situation between a completely predictable one and another which is chaotic and unpredictable. In this situation, the system shows “emerging” properties: between order and chaos there is the sudden appearance of unexpected regularities. While complicated systems (an assembly line or internal combustion engine) are made up of a set of elements, whose functioning is predictable and can be organised – it consists of a series of processes and straight chains of cause and effect (A→B→C→D...) – complex systems (weather, brain, families, stock markets, hives, companies) are characterized by non-linear dynamics. For those systems it is noticed the presence of an internal order that can not be inferred a priori, because, although stimulated from the outside, the systems create new dynamics in an endogenous way through self-regulation mechanisms. It means that each system, although in need of resources from the environment of reference, it is capable of producing by itself the elements which are necessary for survival (autopoiesis) through regularities and its own operating laws (self-referentiality): if a man eats a chicken, he does not become a chicken, but it is the chicken that is transformed into the elements necessary for the life of the human organism. Moreover, besides the ability to adapt, the success of a system depends on its ability to make adaptive changes in the environment of reference (mutual influence).

In the 21st century the connection between the parts has gained heuristic significance (connectionism): to understand a complex system, relationships are just as important as the behaviour of the components. In fact, this analysis was used when Euler first formulated the “graph theory” to solve the problem of Könisberg bridges (1736); mechanisms and regularities typical of networks have been used to understand complex social systems, “real” and “virtual”: circularity, speed and information management, power dynamics, resource exchanges, hubs, scale free law, redundancy and resilience, growth without global order are some of the most important aspects of a complex network and, therefore, of a complex system.

The consideration about complex systems has guided the entire survey on the social health and family situation linked to the issue of dementia in Brindisi social health district: the organization of the authority and the resources (private too) in the territory represent the close environment in which families with people affected by dementia operate; national and regional regulations (far environment) were important to compare the possible distance between these and the factual situation.

Far system and environment. Global and Italian health situation

In 2012 WHO and ADI (Alzheimer’s Disease International) detected an annual rate growth of 7.7 million new cases. The incidence of chronic-degenerative pathology has no geopolitical, economic and cultural boundaries, but there are considerable differences between countries in terms of social health interventions and legislative measures: in fact, only 8 out of 194 WHO Member States had a National Plan on dementia (WHO and ADI 2012). After four years, the global Alzheimer’s report places emphasis on the quality of life of patients – Improving healthcare for people living with dementia. Coverage, quality and costs now and in the future (Alzheimer’s Disease International 2016) – on the replies of the various territories and the organizational and community good practices. The urgency is given by current figures and
evaluations: dementia affects 47 million people worldwide and the figure is destined to triple by 2050, while welfare policies still have a secondary role. Moreover, only about half of the patients in high-income countries and one in ten in the middle and low-income countries received a diagnosis. Great emphasis is given to assistance: there are no clear “treatment pathways”, in which roles and responsibilities are defined within the welfare system, setting standards to be monitored and respected. Instead, treatment pathways, structured and organized coordination, resources and continued assistance are common for people affected by other chronic diseases (diabetes, hypertension, cancer).

To carry out a comprehensive analysis of the phenomenon on a unitary basis, in December 2017 WHO launched the Global Dementia Observatory (Gdo), a web platform designed to provide easy access to the most important data and information on dementia in the Member States. Three areas are covered: health policies, service provision, information and research. The aim of Gdo is to provide the various countries with a support tool to measure the progress made in this sector, also in the light of what has been outlined in the Global action plan on the public health response to dementia 2017-2025: the traditional therapeutic models are now abstract and scarcely applicable to a reality that has diversified requests of health and care.

New concepts take over: Disease and Illness. The first one is meant to define the health problem in terms of physiological malfunction with reduction of physical abilities and life expectancy. Illness refers to the subjective experience of the disease, to the way in which a subject represents it and gives it a meaning; however, the subjective sense is also always socially determined (Cipolla, Giarelli and Altieri 2002). The Harvard Medical School adds a third concept, Sickness: it corresponds to the social description of the disease and therefore to the way in which a social group interprets and implements strategies related to the disease; behavioural and biological signs considered disturbing are converted into illness. The analysis of Sickness emphasizes how the medical facts are pre-constituted informally outside the clinical research environment (Maturo 2007). This conceptual intersection brings out the relational nature of health: the centrality attributed to the psycho-social connotation of it induces to elaborate a planning strategy which, starting from a participatory identification of needs, constructs aims and defines actions in an intersectional perspective; this in order to develop a strong interdependence between health services and other services in the area (Cipolla 2005). The flow of communication and resources will have to lead to a systemic pluralism and to the reduction of the typical separation between the health and social welfare system.

Organizational vacuum and regulatory delay created in Italy long distances between patient, healthcare network and institutions: even though innovative pushes have been proposed as well as the formulation of alternative solutions, redefinition of areas of relevance for the different roles, involvement and reconfiguration of skills, the answers in support of Alzheimer’s are still lacking. Furthermore, despite the Dementia National Plan (2015), the progressive increase in the number of patients suffering from dementia and the lowering of the average age of onset (Istituto Superiore della Sanità – National Institute of Health – 2015), the national policy – and the regional policy in Puglia – has continued to reduce health and welfare spending without counteracting compensatory measures; thereby marginalizing patients and those who assist them.

In this regard, a strong North-Centre-South differentiation emerges with regard to social-welfare and health policies. In line with the contemporary local trends, the disease is narrowed by these dominant tendencies. Decentralization and local regulation of social policies are the product of a process started at the end of last century, that has disregarded the principle of universalism on which our National Health Service is built. Diseases such as Alzheimer’s must be managed by the entire nation: access to and fruition of services can not be linked to local dynamics and variability of the limitations of the municipalities. For example, although Alzheimer’s has been a reality for some time now, in our country it is still difficult to have an official census of updated data on the epidemiology; this happens for all mental illnesses, about which some shortcomings in
the information sources have been listed (Psychopathology Italian Society 2017):

1. Sources available from different authorities/institutions and various information not easily usable together.
2. Unsatisfactory information on supply, quality of services and public spending.
3. Absence of a longitudinal vision of individuals, essential to design policies and to assess their impact.
4. Integration and partnerships are also crucial to fully implement the Mental Health Action Plan of WHO which involves the statistics as well in several places.

The particularly alarming aspect concerns the heterogeneity in the field of ad hoc social and health policies. Also the “41st Annual Report on the Social Situation of the Country” (Censis 2007) detects a two-speed health care in the North and South: the distance between the two parts of the country has led to a worsening of the health situation among the citizens of the southern regions. The modification of the constitutional framework (State-Regions pact introduced by the Reform of Title V of the Constitution n.3/2001, ratified by the Stability Pact between the two orders) unequivocally contributed to increase the differences. The situation got worse ten years later (Censis 2017) with the growth of the family spending on health and the North-South gap concerning the satisfaction about health in different regions.

The same outcome emerges from the results on non-self-sufficiency: while the needs increased, the state funds were cancelled in 2012, 275 million were allocated in 2013 for non self-sufficiency, but it was 60% less than in 2008 (Non Self Sufficiency Network 2013). Two years later Censis (2015) noted that to deal with the private cost of assistance to non self-sufficient people, 910,000 families had to “tax” themselves and 561,000 families spent all the savings and/or had to sell their house and/or got into debt. The last data (Non Self Sufficiency Network 2017/18) shows a worse situation: declining trend in the financing of various types of services (residences, home assistance, economic support), prevalence of cash transfers on services (55% versus 45%), ideas regarding the need to lower the quality of services, perennial uncertainty about the dichotomy coverage/intensity. Furthermore, there is an increase in the need of families for help in informative “paths” and consultancy about activities that are often sacrificed for budgetary reasons: health, contributions, aids, facilities at work, caregivers, barriers, disability, etc...

To further understand the process of interventions on dementia, the various National Health Plans still remained in ambiguity when they treated Alzheimer's, generically including it in the indefinite category of mental health although years before the civil society had committed to define categories and strategies of action. In 1999 the Chart of Patient's Rights has been drafted by Italy Alzheimer's Federation and published in the European Handbook: the cornerstone of the declaration concerns safeguarding the quality of life of the patients and of those who assist them.

Italy Alzheimer's Federation (1993) and Italian Alzheimer's Association (1985) have concretely contributed to raising awareness about the issue related to dementia and the effects on family and caregivers, through analysis of the situation, consultancy with national and supranational government authorities, sharing knowledge among citizens and health workers and lastly information-assistance to patients and their families. As for the creation of protection and therapy networks for patients, the achievement has been complex and frustrating, given the poorly associative culture of Italians, as always underlined by Istat report.

Within this situation, an important institutional change is represented by Progetto Cronos (2000), the largest clinical-epidemiological study carried out in Europe on Alzheimer's disease. The nation-wide observational study was possible on the basis of a network of specialist centres, UVA (Alzheimer's Assessment Units), in collaboration with general practitioners and pharmacists, thus ensuring care continuity between hospitals and local assistance. The aims were exclusively of medical-pharmaceutical nature, including patient acquaintance, and little or nothing worked in the information-assistance system aimed at families and caregivers.

Extension of Progetto Cronos is Commissione Alzheimer (D.M. 22 February 2002), established for the purpose of developing an accu-
rate knowledge of the health needs of the population affected by Alzheimer’s and the social consequences of the disease; of fulfilling a range of functions, including coordination actions in the regions through the presentation of consultative, study and proposal analysis. However, from a national survey on the characteristics of UVA, Day Centers, Nursing Homes, Integrated Home Care carried out by Centro nazionale di epidemiologia, sorveglianza e promozione della salute (National Institute of Health) discomforting results emerged, as they followed those of 2006 (Faiella 2015).

A crucial step forward has been done – as mentioned above – with the Dementia National Plan (Gazzetta Ufficiale, n. 9/13-01-2015). The critical issues highlighted in the Plan are not new: services which are not integrated (diagnosis, rehabilitation, welfare); specialist centres (Alzheimer Assessment Units) established without need-based programming and with a strong disparity in composition and function; lastly, after 14 years Alzheimer Assessment Units remain the main access point for patients with dementia and have in the meantime been transformed into permanent services variously named in some regions, so it has become necessary to start a process of unification of these services. It is necessary to tackle these criticalities through 4 aims: 1. interventions and measures of social and health policy; 2. creation of an integrated network for dementia and implementation of an integrated management; 3. implementation of strategies and interventions for the appropriateness of therapy; 4. increase of awareness and reduction of social stigma to improve the quality of life.

The National Institute of Health had immediately started to monitor some key aspects related to the implementation of the National Dementia Plan by the Regions: the health system related to dementia is not very efficient and organized, rather local and very focused on drug therapy and less on assistance. Above all, there are no figures or structures capable of activating assistance-help-advice services to the family members; lastly, there is a cognitive gap for the constant monitoring of the general situation and specific cases, which are also preparatory for the activation of ad hoc interventions. Much is being done on the cultural and terminological level to train social health workers and citizens, thus avoiding situations of stigma and social and institutional exclusion, still rather widespread and determining the poor quality of life of patients and family members.

**Close system and environment. Health situation in Brindisi**

The survey carried out by the researchers of the Salento University aims to investigate the complexity of the socio-structural and relational dimensions that characterize the phenomenon of dementia in the city of Brindisi, first of all by providing a first mapping of the services (public and private) specifically addressed to the disease; identifying also the needs of the families of patients with dementia/Alzheimer’s; lastly, verifying the role of associations as support for families and institutions.

The research – first detection of the phenomenon in Brindisi – is composed of 4 phases. The first phase concerns the analysis of data from the institutions (Osservatorio provinciale sulle politiche sociali, Unità di Valutazione Alzheimer, Centro Salute Mentale). A brief overall assessment concerns the organization and storage of information: the computerization and the standardization of data were absent, making it difficult to find information and extending the time needed to consult the data. In this regard, the information provided in the sections dedicated to the structures and social-health services in the province of Brindisi in sanita.puglia.it website was empty or insignificant. Secondly, information about users with issues related to dementia was still in a paper archive. Both archives consulted were necessary to detect and analyse the extent of the phenomenon in the city of Brindisi and compare it with the rest of the province and with Italy. Furthermore, user lists and their characteristics were useful for constructing a stratified probabilistic sampling. It was not possible to do what was planned because it was only possible to access the data of the Mental Health Centre (CSM). It is striking the uncertainty of the diagnosis which does not allow an exact placement of the user in the health archives. This has an effect on internal communication within the Local Health Authority and external relations between the Local Health Authority and other public institutions with duties related to welfare services. Another problem related to communication, this time
between Local Health Authority and users, is the absence of some telephone numbers of the patients, almost always the only way to have a quick contact.

The second phase involved social health structures (presence and type): the information was collected from the archives and from interviews with the managers in charge of the offices. The creation of the first social health structures in Puglia dates back to 2007 (Regolamento Regionale n. 4/2007, application of Legge Regionale 19/2006). The legislative gap, currently still very marked in terms of specific structures for people with dementia/Alzheimer’s, is partly filled with the art. 60ter of Regolamento Regionale 7/2010, which regulates the institution of Day Centres specific for dementia/Alzheimer’s, but for individuals who do not have severe motor deficit and can be managed through semi-residential treatments. A gap remains in the field of ad hoc residential facilities, conceived to welcome the patient with Alzheimer’s and the therapy needs. A defect to which must be added another limit concerning the institution itself of the structures that, as provided for L.R. 19/2006, is entrusted to “management experimentation”. To try to compensate for such a regulatory vacuum, Alzheimer’s patients over 65 years old can be welcomed in Residential Homes which foresee – as prescribed by the Regional Regulation 4/2007 – that there may also be people with dementia/Alzheimer’s under the age of 65, provided they do not need complex health services. There is also a type of extra-hospital structure with high health intensity, the Nursing Home (D.G.R. 210 R.R. 8/2002), which includes specific residential modules for people with Alzheimer’s.

A rather lacking picture emerges in several respects. The critical issues are evident on several sides and offer a discouraging glimpse of the territorial situation examined in the two-year period 2012-13. Among the multiplicity of the problematic aspects connected to the phenomenon, the absence on the territory of ad hoc residential structures constituted (and constitutes) the biggest limit (Centro per il controllo e la prevenzione delle malattie del ministero della Salute 2017). An additional load in terms of management derives from the coexistence of subjects suffering from different pathologies: this can be a source of discomfort for the guests, as well as a physiological disorganized and sometimes confused work for the operators. This situation puts a strain on the caregivers’ ability to orientate in the articulated universe of care, as well as the ability and patience to combine and calibrate the efforts alongside those of specialistic figures, especially in relation to the steps that mark the degenerative process.

This dimension emerges from the other phases: the survey on the management of the patient; case studies about the experience of some caregivers; a survey based on privileged witnesses (doctors).

For what concerns the survey only 58 caregivers have been reached, living in Brindisi, out of 210 listed in the archives of Centro di Salute Mentale (tab. 1). This figure has been increased up to 76 individuals, by contacting subjects living in other municipalities through the collaboration of some general practitioners.
The aim was to identify the emerging needs of the people with dementia/Alzheimer’s and of caregivers. The areas of the questionnaire were:
1. level of pathology and therapy needs;
2. caregivers and work-life balance;
3. social capital of reference;
4. role of institutions, in particular Municipality, local health unit (Asl) and general practitioners;
5. general assessment of services by the respondents.

Most of the sample – composed of 29 men and 47 women with an average age of about 59 (minimum age 35 years, maximum age 83) – is included in 45-50 and 60-65. Most of them are sons of the patients (56%), followed by spouse (28%), daughters/son-in-law (9%), brothers/sisters (4%) and 3% declared to be nephew or other. 92% of the sample lived with the patient. Generally caregivers were over 60 and women (wife, daughter, daughter-in-law).

The analysis of the data clearly shows how the disease afflicts not only the patients but also the family members and those who assist them, so that caregiver and patient become a single system of action. Caregivers claimed to dedicate to patients more than 16 hours a day, keeping for themselves very few hours a week. Facing the progress of the disease, they felt more and more helpless and this feeling was exasperated by the awareness of the absence of effective drugs, by effort and stress in the day-to-day management of the patient and by the frustration in not seeing recognized their effort. Lastly, the deep sense of loneliness derived from the inadequacy of parental and institutional supports (public and private), also in the form of information on the approach to the patient and on the territorial resources. This loneliness increases gradually with the progress of the disease, which becomes a disruptor first on a psychological and physical level, then on a social and economic one: with the collapse of the psychic faculties, the patient is forced to abandon all daily activities, including work, with the risk of irreversible impoverishment; while the caregivers, especially if alone, can not bear the emotional and time load of the situation: in fact, both for emotional collapse and for lack of time they are absorbed by the needs of the patient, who tears them away from relational and social life. Free time disappears for almost all respondents and almost everyone has complained about the burn out situation: psycho-physical fatigue, muscle aches, headaches, low or alternating mood, insomnia and eating disorders were the reasons listed and that constitute a deterrent to the enjoyment of leisure moments. Lastly, the respondents found great difficulties at each stage of the patient’s illness: at first incompetence in dealing with the disease and approaching health facilities (disorienta-
tion), which is witnessed by the doctors interviewed; later with the advancement of mental and behavioural deficits, for which the caregivers often do not find informal and formal institutional supports (isolation and mistrust). Thus assistant and assisted live in symbiosis: the deconstruction of the personality of the second is counterbalanced by the identity decline of the first; s/he, especially if alone, begins to interpret the self according to her/his role as “nurse”: by changing her/his environment (illness of the family member), s/he changes the identity system (caregiver and no longer worker/partner/friend/etc.) and this in turn modifies the environment itself (made of care needs, health care assistants and facilities). The current society is increasingly based on productive efficiency (Giddens 1990) rather than on the enhancement of social relations, especially intimate, now mostly aimed at achieving exogenous purposes such as prestige, money and power (Fromm 1976). This structural and cultural situation determines in psychic systems (individuals) an ability of action characterized by rationality, which develops attitudes not aimed at a deep knowledge of others and the creation of solid bonds (Bauman 2003).

This brief digression introduces one of the elements that contribute to the disorientation and solitude of the “assistant-assisted” system (Bauman 2006) and emerged from the interview with the general practitioners: also the doctor-patient relationship is based on the efficiency, on time and patience in examining the changes experienced by the patient through a fruitful dialogue. General practitioners are the first and fundamental step for an adequate health care path, but often they do not know how to recognize the first signs of dementia/Alzheimer’s and not few times several years pass before the diagnosis is recognized.

From the in-depth interviews to doctors and caregivers, another topic emerges, which is an effect of our social and cultural system: the lack of a) an informal community, made up of relatives, friends and neighbours and b) an institutional community, represented by an adequate health organization and by sufficient territorial structures suitable to welcome/assist the patient, enhancing the individual.

Caregivers need concrete references, guides and specialists to turn to in order to understand how to deal with everyday life and relieve it from the burden of the management; they express the need to have real assistance in their territory, possibly a dedicated medical coverage that can break down waiting lists and guide caregivers and family members on obtaining financial aid and information on social-health care. To this situation it must be added the lack of associations, whose significant presence would instead compensate for some shortcomings related to material, informative and moral support.

Conclusion.
A new health humanism from the observation of complex systems
The 18th National Congress (2014) of Collegio dei Primari Oncologi Medici Ospedalieri (Association of Oncology Head Physicians) clearly stated its vision in the title: “Complexity management in Oncology: ‘swarm intelligence’.” The Congress invited to abandon a top down and “monocratic” approach to follow a flexible organisational model, that is a complex model suitable and consistent with the unpredictable and chaotic resources at stake. Until then workers were considered simply production tools functional for the organisation, and the head physicians were supposed to check the external uncertainty through a frantic research of a simplifying rationality. Later it was intended to adopt new organizational dynamics characterized by adaptability, diversification, designed to enhance the subjects involved in their diversity, integrating roles, making communication flow between the different organizational levels, also in order to allow a prompt internal change and an efficient openness to technical, technological and strategic innovation. This happens because the environment – represented by patients, people and organizations of different kind – is mutable, turbulent, uncertain. This does not mean choosing a managerial anarchy, but an organisation whose vertexes simplify and foster bottom-up solutions, promote collective intelligence, starting a process of amplification of power and allowing an efficient interconnection among the internal levels and among them and the environment.

The focus of the leadership should be to delegate tasks to foster the development of distributed intelligence in organizations, that is, the
skills of human being in networks. This is crucial for the issue of health and welfare management of people affected by Alzheimer’s and their caregivers: self-organisation is reached 1) promoting the creation of a network within the company, where the hub is the intelligence of people and the connections are represented by different interactions among them and through 2) an external network, involving all the potential relevant stakeholders from the private sector too and not directly linked to healthcare activities (computer scientists, architects, sociologists...), in an interdisciplinary view.

The initial aim is to adopt a simple strategy to generate complexity; the opposite of the classical vision, which starting with complicated rules generates simple behaviours (Ashmos et al. 2002). The simple strategy of participation consists in connecting people to each other, leaving them autonomous at the same time with control mechanisms and small procedures.

To remedy the abandonment of caregivers and patients for what concerns dementia, it is necessary to re-establish a trust relation with the territory and to build spaces of profitable interconnections. Classical science and modern rationality outdistanced organizations and their territory – conceived as a synthesis of space, history, culture and relationships – leading us towards a constellation of non-communicating fiefdoms. We now understand that the territory is a place of distributed intelligence, because it constitutes a field of relational and communicative resources, capable of integrating thousands of decentralized and interdependent intelligences: when these interact with each other, they produce organized and efficient behaviours (Quadrio Curzio and Fortis 2002).

In order to reach this ambitious goal, a new organisational humanism is required, a culture of participation and first of all, a culture of continuing training, not only related to professional contents. Indeed, it is necessary to have humanistic attitude and inclination able to foster a wise use of techniques and technologies and to overcome a general relational and communicative illiteracy.

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