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How Can We Build More Inclusive Communities Regarding Individuals with Cognitive Fragility? An Exploratory Analysis of The Perceptions of Members in A Lombardian Community

Emanuela Zappella*

Department of Human and Social Sciences, University of Bergamo, Italy.

*Correspondence:

Emanuela Zappella, Department of Human and Social Sciences, University of Bergamo, Italy.

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ABSTRACT

How can we build more inclusive communities regarding individuals with cognitive fragility? Literature describes the characteristics of inclusive communities without focussing on the ways that individuals participate and become involved. By way of written interviews analysed via content analysis, this study investigates the perceptions of the members of a community in the Lombardy region regarding the possibility of being more inclusive towards people with cognitive fragility. The results show three possible approaches: those that are sensitive, the protagonists of inclusive actions; those that have never been personally involved, but would be willing rise to the occasion, and those that consider they have no responsibility and entrust specialists to care for these individuals. The study has three limitations: performing samples, which makes references to a specific geographical community; gathering perceptions, without considering whether the declarations of intent follow specific actions and excluding individuals with weaknesses and their relatives.

Knowing the perceptions of the members of the community could help to understand how to make the communities more inclusive, it could majorly make the members of the communities aware and direct the actions.

The study analyzes the perceptions of community subjects that are indispensable for constructing truly dementia friendly communities.

Keywords

Ageing, Intellectual disability, Cognitive fragility, Dementia friendly communities, Inclusion.

Introduction

The ageing population and cognitive fragility are the main challenges of our time, with almost 47 million people in the world living with dementia, which will reach 131.4 million by 2050. This figure is so important that even the World Health Organisation has recognised cognitive fragility as a priority for public services.

The term "cognitive fragility" refers to a series of symptoms that derive from various illnesses such as Alzheimer's, Vascular Dementia and other pathologies that cause as loss of physical and cognitive abilities. Cognitive fragility could be received in different ways: as a biomedical condition, as a part of adult age or

as a cognitive difficulty. The element which unites these different definitions is the importance of finding useful ways to boost quality of life, the wellbeing of people with cognitive fragility and the possibility of keeping active on a physical, mental and social level [1,2]. People with cognitive fragility often come up against barriers which makes participating in society difficult for them and they are unable to express themselves [3,4]. In order to grant them a good quality of life, it is important for them to keep performing their daily activities and so the environment must be accessible for them [5].

In order to boost the quality of life of the individuals with cognitive fragility, interest from the Dementia Friendly Communities (DFC) has been spread [6-8] which, although they are very different from one another in terms of size and working manners, they can be defined as follows:

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"The DFC include, strengthen and support people affected by dementia and their caregivers in each aspect of their lives, from accessing services to using public transport. They also help to make these individuals integrated into society, to remove barriers and to live in the most independent way possible as well as to actively participate in the decisions that concern their daily lives" [9,10].

The approaches that the DFC use to reach their goals are very different from one another and include working with the individuals with cognitive fragility in order to change policies, practices and services; involving volunteers to promote awareness of the individuals concerning the importance of supporting people with cognitive fragility and making their environment more accessible [11].

Literature describes the characteristics that the communities must have to be inclusive towards people with cognitive fragility, but much less emphasis is placed on the strategies that must be implemented and on the ways in which the various actors must be involved. The study has the aim of including:

- How is it possible to build a more inclusive society regarding dementia?
- What are the perceptions of the community members?
- Which actions can be implemented by these individuals in order to allow the people with dementia to be able to continue to exercise their remaining capacities?

The Sample

The community (45,000 inhabitants), near to Milan, was selected with the municipal authority's intention to embark on an awareness course on the issue of cognitive fragility amongst the elderly. This willingness has been considered a good time to activate an exchange with the different actors present in the community. The sample involved was as follows:

- headmasters, teachers and students from 3 primary schools, 3 secondary schools and 4 colleges;
- 12 postal workers and 15 workers from 4 banks;
- 20 restaurateurs, 22 shopkeepers, 6 contacts from nursing homes, 21 personal trainers
- 18 firemen and 19 local policemen and 21 bus drivers, 19 pharmacists

"Specialists", individuals with fragility and their relatives were excluded from the study. The decision was made from the willingness to involve people that do not have a special relationship with the individuals with fragility.

Ethical approval

Ethical approval was granted by the university ethics committee. Participants were provided with an information sheet outlining the purpose, design and timescales of the research; how the findings would be used; and the measures to ensure confidentiality and anonymity. All subject participated in the study. The interviews were anonymised prior to analysis.

Methods

All participants took part in individual, semi-structured, written

interviews based on some questions regarding: chances of coming across a person with cognitive fragility, actions performed, weaknesses found, actions that could go head in order to make the community inclusive and responsibilities that they believe to have. The collected data were analyzed using an interpretative phenomenological approach (IPA) aimed at exploring in detail the participants' views on their experiences. IPA can be used to analyze data in order to develop thick descriptions (i.e. not just behavior, but context as well) that may help to shed light on human experience. An IPA researcher must approach their data with two topics. The first aim is to try to understand the participants' world and opinion. The second aim is to develop a more overtly interpretative analysis, which positions the initial "description" in relation to a wider cultural, social, and theoretical context. This second-order account aims to provide a conceptual and critical commentary upon the participants' personal "sense-making" activities.

The first step involved a repeated reading of each transcript, then identifying, and finally writing down all the interesting and significant elements that emerge from the data. The second step was to identify patterns of recurring content (abstraction process) and organization of the patterns in emerging themes (from the comments to the issues).

Two independent raters conducted analysis. The two raters coded the data independently and then met to compare analyses. Any discrepancies were resolved through discussion. The themes were not selected on the basis of their frequency, but their meaning and their relevance and similarities and differences were highlighted between groups of participants. Then data were organized into thematic categories in order to capture the meaning of the experience. Finally, the last step was the identification of the relationship between the issues identified.

Rigour

Throughout the interviews and discussion with participants the research group asked follow up questions to clarify and examine the answers provided and ensure a richness and depth from the data. One member of the research team independently analysed the data, this analysis was then scrutinized by the other two members of the research group until a consensus was reached [12].

Results

From the analysis of the interviews, three types of approach emerged, outlined as follows:

We can do something together

The first attitude is that they have recognised the importance of being the protagonists of inclusive actions regarding people with cognitive fragility. The school headmasters have, on the one hand, recognised the importance of schools for training the students and making them aware that they represent the society of the future, but they have also brought to light the difficulties that schools must face:

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"Our school has always been open to innovations, that's why we have been interested in welcoming the initiative. The proposed theme is interesting because the children are always more involved with this type of difficulties, not only with regards to their grandparents who are getting old, but also because society is getting older and they can have an important role in doing anything to help. It is important that they understand this from being young".

"Schools alone cannot take on all the responsibility, there are already so many difficulties to face, foreign families, children with difficult family situations due to economic problems, separations which are often painful. Schools are left alone to face all of this and they aren't able to do it."

The school context seems to be the place that has been assigned the task of making children aware, who amongst other things, seem to be "naturally prepared" and open to the relationship:

"Children speak only about when they are with their grandparents, what they do with them, whether they are at the allotment or they have gone fishing. It's clear when they come to collect them at play time that there are some of them with problems, but the children are just as happy".

"Children are sensitive and open to relationships, even with the elderly that have some difficulties. We must think about the difference between the people we know and strangers. I think that they are more open if they know the people, on the other hand, if they don't know them, maybe there needs to be more effort, perhaps there is more chance of being scared"

"Grandparents spoil their grandchildren, they make them have fun, they are nice when their parents shout, they defend them"

This inclination towards the relationship was also confirmed by the primary school pupils who have directed their reflection from their specific experience with their grandparents:

"I help to look for their glasses"

"I pass them their stick or their crutches"

"I take her by the arm, she says that I'm her walking stick"

"I push the wheelchair down the street"

"I tell him what I can see, and I ask him questions"

"I draw a picture, then he can understand, or I ask questions and he moves his head"

"I draw a picture and I write my name on it so that he remembers"
"I ask daddy to go with him"

"I tell him that he has got my name wrong but then I feel bad"

"I get angry, I want him to call me by my actual name, even though mummy tells me to let it go"

"At first I got angry, then I realised he doesn't do it on purpose, so now I correct him"

"He gets my name confused with my sister's or my auntie's, I don't say anything, it doesn't matter"

"I act like it's nothing, because maybe he will get sad and I don't

want that to happen"

"I don't know what to do so I don't do anything"

"I will ask mummy to help me to know what to do"

Children offer help, or they get directly involved in the strategies to support the elderly. One of them considers it important to make their granddad realise his mistake, even though he might feel bad, whilst the others prefer to act like nothing has happened to not create offence. Lastly, some children said they didn't know what to do and they ask their parents. It is interesting to see how the pupils that already have experiences with difficulties with their grandparents are more accustomed to it and they consider it as the norm. The children then described what they could do:

"I call the policeman to stop the traffic and let him past"

"I tell mum and dad to help them"

"I help her to cross the road or I show her the traffic light is on green"

"If I see an old person in church, I give them my seat, my mum says that old people have to sit down"

"When we play football, they cheer me on, they also hug me; I let them hug, to make myself understood I need to shout loud"

The bus drivers are also very aware of the importance of their role:

"Elderly people and those with difficulties often use public transport, more so in the morning"

"They are creatures of habit, they go on the same journeys, at the same time, on the same days of the week. They go to the cemetery, the hospital, or to the market. You see them every week"

"They would like to speak to other people but the other people on the bus, usually young people, don't think the same. They prefer their mobile phone and headphones and to pretend they can't hear" "There are the ones with problems, you can tell by the way they look at you or the questions they ask"

People with dementia have difficulties that are obvious to the bus drivers:

"They find it difficult to get on and off, the buses don't have the right rails, and they are often full"

"At rush hour there are lots of people, the rule of letting the elderly people sit down doesn't exist and sometimes they wouldn't be able to anyway, given the amount of people"

"The people on the bus aren't always willing to let them sit down or to give them help or information"

"They ask me for help, about a route they don't know about or to be sure where they need to get off"

"They are often not alone, they have their foreign carers that don't always know what to do and they ask how to get their bearings if they don't know the place"

The people interviewed have also tried to identify some potential improvement strategies to make the transport service more inclusive:

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"They ask for information about timetables, the first thing we can do is be nice to them it doesn't cost anything"

"Strikes are a problem or a change in route, the information is on the website and a person with problems or a carer doesn't tend to look at it. There needs to be something else, maybe a notice board" "The graphics on the notice boards can be worked on to make the timetables visible, colouring the stop in a different way"

"We need to be more aware of fragile people, with stickers to make youngsters understand that they need to give up their seat or answer questions"

Another rather welcoming group were the pharmacists who recognised the importance of their figure almost like that of a doctor, able to provide a remedy for any symptoms.

"We are mindful of elderly people and those with difficulties, it's easy for us to think of them as special clients".

The pharmacists have brought to light the difficulties that the individuals may have:

"People are a problem, you can't serve them straight away and they need to wait, the wait can create problems"

"If you spend time with them and you know it's important, the others lose their patience, which isn't very nice, they complain"

"The additional information and the administration procedures are another problem, and we must call the GPs to understand what they have said"

"They arrive claiming to jump the queue or spend half the day here, we can't do anything else, the rest of the people get angry" "When they have so much medicine to take, we don't always have all of them and they need to come back"

They have also described the strategies that they have already put in place:

"The products are within the client's reach, they see the product they want to buy and the prices"

"There's always a smile on our faces, everybody is welcome with a smile"

"I speak slowly, I separate the words, calmly, explaining the information in the simplest possible way"

"I've put some chairs out, so they can sit down to wait to take their pressure or whilst they're in the queue"

"We have provided a series of additional services, like blood sugar, aimed specially at them and they are really appreciative of them"

These strategies depend solely on the pharmacists themselves; but there are also potential actions that require the involvement of other external people:

"We already do what can be done, we can work on how to get to the pharmacy"

"Other people could also be involved, perhaps the elderly, who can be in charge of delivering the medication or accompanying people with the most difficulties to the pharmacy and then home again" "We make a journey, with different stages towards the pharmacy, like what children do when they go to school"

Even bank employees have shown to be interested in and aware about the theme of including people with difficulties within their facilities:

"They are regular customers, a good part of the people with difficulties don't come alone, but accompanied by relatives, usually their children"

"They usually come in the morning, when it's not too busy"
"We have a trusting relationship with them, they trust us"

The bank employees, like other groups of people interviewed, have brought to light a series of actions and focus points that are already in place within these contexts:

"There are no architectural barriers and we have attentive operators that are aware of the issue, when a fragile person comes in, we are aware of it"

"It is a group of people that we really care about, we have a series of services dedicated especially to them, for example, special current accounts without extra costs, special lanes so they don't have to aueue"

"There are specific lounges with comfy chairs whilst they are being attended to"

"There is the possibility of visiting them at home, the bank goes to the client's house if they have problems getting to us"

"We have advantages for the services that are offered in the sociohealth sector"

From their accounts, there are also criticisms of the relationship with these individuals:

"At 70 it is difficult to make new investments or sell new products because they are very sceptical people"

"They don't trust people, they don't use cash machines, they come to the window but that takes time, which is something we don't always have"

"For them using the cash machines isn't conceivable, sometimes you can see the effort they make to remember, they often realise they are struggling, that they don't have their memory, it's difficult for them to understand"

"We even have problems with the company policy which asks us not to generalise, so we must construct individual relationships with the client. The problem is that these people often ask for more explanations, maybe about the same things. They have difficulty understanding and they ask you to decide for them, and that is then more complicated"

"A lot of the time, when they come with their children, there is the risk that the decisions that the children make aren't really favourable for the parents, and that creates real issues. In these cases, we try to do everything possible to guide the individual and to avoid problems, but it's not really our job or our responsibility.

Of the strategies that could be put in place, the bank employees

have shown that:

"It would be necessary to give clearer information, more slowly, perhaps repeating it more times"

"The staff change, the individuals lose their point of contact. We do a little too because if you know the individual, you know their characteristics."

"The welcome is important, it is the basis for a trusting relationship and making the individual feeling able and sure that they can choose"

"Compassion is important, becoming in sync with them and putting yourself in their shoes. It's not just a question of being willing, but also understanding how to make the procedures implemented in the bank more accessible, which only consider the bank's point of view"

"Language is important, it must be simple and clear. The approach must consider the other person's peculiarities. Using simple words, examples, repeating concepts, all helps, as well as practical demonstrations and asking the individuals to repeat the procedures, to see if they have understood or to help them to memorise them."

The restaurateurs have shown to be very sensitive to the subject, and they have felt personally involved:

"Elderly and fragile people is a big slice of our clientele, for us it is important that everybody feels welcomed and it's a form of advertising"

Their difficulties are sometimes apparent, and they need to be addressed on a daily basis:

"It is difficult when the menu is in small writing and there are so many things, they get lost and have trouble with it. If you explain and speak too much, then they forget, and they ask you to repeat the first things that you said"

"Sometimes the waiters aren't very welcoming, they are impatient, and they don't have enough patience to explain, repeat and wait" "Paying is a problem, doing the bills, reading the note, paying, knowing how much they need to pay, getting their change"

"They get confused about the change, they confused the bank notes"

"We understand their requests, sometimes they can't be fulfilled, and they get angry or offended. It seems like they don't understand, of they're not interested"

"They have their trusted client, they always want that one. You need to listen to them, exchange a few words, that is difficult at peak times"

"There is a problem with the noise, they have trouble being in busy places, they get nervous"

"Going to the toilet is difficult, they get lost and ask for help from the staff who are maybe busy with other things and don't always have enough tact to answer in a correct manner"

With regards the potential proposals, besides what emerged regarding patience and care during communication, other

possibilities have emerged:

"Organising lunches with more fragile people, with fixed-priced menus, then we avoid problems when choosing"

"Seats can be previously assigned so the people don't go crazy trying to decide where to sit"

"The bill can be given to them beforehand, saying how much each person has to pay"

Lastly, the last group that has shown the most willingness is the local police:

"We see people struggling to cross the road, in busy places, disorientated by the signs or traffic lights that are too fast"

The policemen, however, have brought to light that on many occasions, they are contacted not for real reasons but to get attention. The real requests for help are often reserved for other individuals, like relatives or neighbours:

"I often know that it's not a real request for help but that they want to have a chat, be heard and take into consideration by somebody" "One of the main problems for them are foreigners, sharing space even in the courtyard with people from different cultures for them is a problem, the customs and traditions of others"

"The real requests, when they actually need real help, are made by others, relatives, family members or neighbours that come to us because of a problem"

Lastly, involvement can be necessary for critical attitudes put in place by the individuals with dementia themselves:

"Sometimes neighbours call us about aggressive behaviour or inappropriate behaviour, and it's us who need to intervene"

With regards the potential action to be taken, the local police seem to have clear ideas about it:

"What is needed is having a neighbourly figure for citizens, people that know how to intervene and listen, but above all mediate"

Us? I'd never thought about it, but why not?

In this category are the gym personal trainers who, often, deal with elderly "functional" people:

"Some people come to us, but obviously not the frailest of people, usually the more trained, fit individuals who use the bicycle or pilates courses"

The people interviewed have never thought about the possibility of working with frail elderly people, but they haven't hidden their curiosity:

"Why not? It could be an idea, we obviously need to understand what to do and how to do it, but for me it could be doable"

"We could do individual and group courses, soft gymnastics,

simple exercises, obviously knowing how, knowing the people and learning how to manage them"

"Improving effort management, trying to prevent falls, strengthening muscles and keeping them active, we can do all of that"

"I think it would be a nice idea and I would be willing, with a good explanation, it can only be a good thing"

The interviewed people, whilst recognising the need of being well prepared, have expressed enthusiasm and willingness to question it

A similar reaction was had by the firemen, who immediately expressed appreciation for the unusual request:

"We had never spoken specifically about this method of involvement, which is increasingly significantly"

"Due to the situation that we are in, thinking about our role is appropriate and even necessary"

"Falls at home, small fires, small floods are all common occurrences and they are often a signal that the person cannot be left alone anymore, or that maybe they have some problems"

The firemen have brought to light the difficulties that they encounter when they must intervene:

"When we intervene, we realise how necessary it is, albeit complicated, to understand the needs of people with difficulties. It is even more so if the person that asks for help is alone, so they are unable to communicate their needs, especially if it is via a telephone call"

"It is important to give a message that specifies the steps to be taken in order to divert the individual away from danger"

"It is so difficult to understand if the person is fully aware of the danger and their difficulties, understanding if they comprehend"

Us? Not us, there are people to do that.

A second group of individuals have shown a lack of involvement and some reluctance to the issue, stating that it is somebody else's duty, usually specialists, to take on. The students from the lower secondary school and the youngsters from the two years of upper secondary school are included in this band. A first element of weakness has been expressed by those that have preferred not to remember a family situation that they live:

"I have a difficult situation at home with an elderly person, I don't want to talk about it here"

"My grandma is at home with us, it is difficult because she can't do too much, for me it's hard work"

"Living together is complicated, I can't do what I would like, there are so many things that aren't ok, it's hard"

However, in other cases, the youngsters have stated that they don't want to think about the long-term right now:

"Why talk about it? It doesn't affect me now. When the time comes, I'll think about it. Not now"

"I will have so much time to think about it, if it will help me, it's daft to do it now"

"Ah, I'm not interested, it's not happening to me and I see it as something so far away, sooo far and maybe it will never affect me"

Others, on the other hand, don't feel a calling to the condition of the people with dementia because they don't think they could be caregivers and there are specific places where care is taken of these individuals:

"If people have problems, they go to the suitable place for them, there are cases where people cure them, I wouldn't know what to do"

"There are hospitals, well not actual hospitals, something similar to hospitals, they are places where those people go and there are people there to cure them"

A sceptical attitude has been found too amongst people that are in charge of providing legal services:

"It's difficult for us to deal with these individuals, if they have problems they are replaced by other people or even represented by those able to understand and want to, and it is them who guide their relatives, the issue doesn't really concern us"

If it is true that the person experiencing a difficult situation could not directly come to an adviser, it is equally true that those responsible for legal services could, in contrast, be very useful:

"Fragile people, and sometimes even their relatives, do not know all their rights and duties, and sometimes they don't even think that what they are told is feasible in the conditions that they are in"

"It happens that there are occasions in which they don't know about their possibilities from the legislation and so they are excluded from possible advantages or benefits of it, like reliefs or exemptions"

"There are often some important decisions to be taken, and so a knowledgeable opinion would be useful"

"Sometimes, as support administrators, we are involved with individuals that are no longer capable of deciding for themselves, sometimes their children and relatives are there but other times they are alone, and we don't have the jurisdiction to be behind them"

"Sometimes they react, they don't reason, they are emotionally unstable, difficult to manage, making them understand what you mean is complicated"

"There is no lack of legal jurisdiction, perhaps there is a little less management, how to deal with them, the psychological aspect, these are scarcer elements"

"We take care of the legal side, not the rest and maybe that isn't enough"

From their accounts, it seems to emerge not that the legal advisers are not in contact with fragile people, but that they find it difficult to manage the more relational side which is linked to emotions, and so they don't feel they are prepared. This could be one of the

elements that determines their reticence in thinking about being more inclusive towards fragile individuals.

Within this group, there is also the attitude from those that, despite in theory knowing about the situation of people with dementia, consider they don't have time to think about what they could do. In this direction, the opinion of the students from upper secondary school is radical, who have strongly declared to not having time for this subject:

"I don't have time for these things, at school we're doing other things, there is no time"

"I agree, there is no time, we don't have time"

Besides the lack of time, the students have brought to light the need for an institutional intervention:

"People with problems need to be in the appropriate places"

"There needs to be specialised intervention by the institutions, I don't know, by doctors, social services, that type"

"People like us, of our age, don't have a role, it's nothing to do with us"

"Nothing, we can't do anything"

The youngsters have then shown a series of difficulties which are mostly emotional and relational:

"I wouldn't know what to do, and how to do it, then you do things wrong"

"Communication is difficult, understanding, meeting"

"I would be scared of the reactions, the person's and mine too"

"I don't have any patience, I'd risk hurting them"

The main fears brought to light by the youngsters were not managing to understand the needs of the elderly person and not being able to give the right responses to specific demands. The students have shown the incapacity to build a trusting relationship with them and the fear of hurting a person with dementia. Regarding the initial declaration of unwillingness, it seems to highlight not so much an end to the relationship but a difficulty to put themselves in the shoes of the other person (perceived as needy and fragile) and as a result, they do not have a full understanding of the role that they could take on.

The attitude from the postal service workers was particularly reluctant. The postal service has provided different facilities now for many years and they also run a computer training course called "Grandparents online". The service workers have unanimously stated that they do not intend to participate in the survey, giving reasons for their decision, entrusted to the manager, as follows:

"We are a public body, and so we have no intention of responding to the questions because it is an issue that isn't ours to discuss"

In this case they were completely closed, it wasn't possible to understand the experiences that these people have.

Rather surprisingly, the people who manage the recreational centre for the elderly were also quite unwilling, immediately explaining the lack of inclination to welcome those in the most difficulty:

"We don't want people that cause trouble, because they don't listen, they argue, they are aggressive and the make things more difficult, everything gets slowed down"

"It is difficult to understand if someone is struggling, they cause confusion, people get offended and shaken up"

"We can't be expected to understand and know how to behave, it is complicated"

"You don't know that when you say something, that they are going to accept it, they often react badly"

"The people always play amongst themselves, always the same ones, go and tell them they need to change"

In this case too their attitude doesn't seem so dictated by the fact that the people don't encounter more fragile individuals, that they see on a daily basis, rather the fact that it isn't their duty to take care of them. A second element, however, is again linked to the scarce sense of adequacy regarding how to deal with reactions that sometimes are considered excessive and out of proportion.

Even in some shops, some assistants have stated they are intolerant towards more fragile individuals:

"They asked for cooked ham and then you realise they wanted cured ham, and some time has passed; they say that you were wrong, it's not viable, it's not our duty"

"There isn't always a way and time to help them, it's not up to us. If you know them and they come with relatives, then you can ask them, but we are the shop assistants"

In this case what prevails is the shopkeeper's interest over that of the customer. The will to find help, for example from relatives, is entrusted to the good will of the individuals, but that doesn't seem to be the case.

Conclusion

Care towards people with cognitive fragility is growing and awareness of the importance of guaranteeing these people the possibility to be as integrated as possible into society is on the rise. The concept of the Dementia Friendly Community is widely spread by now, but very little care is given to the types of involvement from the different individuals to truly make them the protagonists of these communities and to make them in turn feel integrated.

A community can become inclusive, in fact, if it recognises the importance of everybody's behaviour and promotes the wellbeing of all the individuals.

The analysis shows that all the groups of individuals are in contact with people with cognitive fragility in different ways. Their reactions can be synthesised around three big attitudes: those that declare they are aware of the importance of their role and are willing to put more inclusive actions in place; those that have never been involved but would willingly help and, lastly, those that consider

they have no responsibility and time to offer, whilst recognised the difficulties that the individuals with cognitive fragility experience. This last direction, apparent amongst the students at secondary school, the postal service workers and some shopkeepers, is not dictated by a lack of knowledge about the problem but by the conviction that it is the duty of specialists (doctors) to take care of these individuals. This denial of responsibility seems to be mostly due to the fear of not understanding the requests and needs of the individuals with cognitive fragility and the difficulty to manage emotional reactions that sometimes appear to be incomprehensible.

In relation to the actions that could boost the construction of a more inclusion community, some interesting elements have emerged from the research on different levels:

individual: the single individuals can implement a series of strategies that promote communication and understanding of those with fragility and their demands. Using simple, clear language, specific, real examples, separating words slowly, asking them to repeat in order to check the message has been correctly understood, are all useful strategies for efficient communication. Moreover, a patient and willing attitude for listening and dialogue is important; changes in the environment: a fundamental series of strategies consists of making changes to the physical environment to make it more accessible and useable. It is not about removing architectural barriers, but little things like the colours of signs at the bus stop, larger menus in restaurants or arranging set name places for dinner; the support network: the third aspect, and possibly the most crucial, is constructing a support network that is not linked so much to institutional caregivers but to the members of the community. Involving and supporting them during games, going with them to pick up their medicine or to the bus stop are simple support actions but they could really change the quality of life of the people with cognitive fragility.

Limitations

The exploratory study presents different limitations. Firstly, the sample is reduced to a relatively small community. Secondly, as a preliminary step, the attention was focussed on gathering opinions, without checking whether the declared actions had been put into practice. Thirdly, people with cognitive fragility, their relatives and medical figures that already take care of these individuals were excluded from the survey.

The second part of the research will deal, however, with sharing inclusive actions to be implemented within the different situations

and their assessment, in order to understand their sustainability and functionality. Besides assessing the impact of these actions on the lives of the individuals with cognitive fragility, it will be interesting to also understand the repercussions on the life of others, those who make up the support network.

References

- Bethell J, Pringle D, Chambers L.W, et al. Patient and Public Involvement in Identifying Dementia Research Priorities. Journal of the American Geriatrics Society. 2018; 66: 1608-1612
- 2. Gove D, Small N, Downs M, et al. General practitioners' perceptions of the stigma of dementia and the role of reciprocity. Dementia. 2017; 16: 948-964.
- 3. Haugen I, Slettebø T, Ytrehus S. Factors affecting user participation for elderly people with dementia living at home: a critical interpretive synthesis of the literature. European Journal of Social Work. 2018; 1-13.
- 4. Mendes A, Palmer S. Communities and institutions becoming dementia-friendly. Nursing And Residential Care. 2018; 20: 319-321.
- 5. Phillipson L, Hall D, Cridland E, et al. Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. Dementia. 2018.
- 6. Alzheimer's Disease International. Dementia Friendly Communities: Global developments. 2016.
- 7. Doran P, Buffel T. Translating Research into Action: involving older people in co-producing knowledge about age-friendly neighbourhood interventions. Working with Older People. 2018; 22: 39-47.
- 8. Heward M, Innes A, Cutler C, et al. "Dementia friendly communities: challenges and strategies for achieving stakeholder involvement". Health & social care in the community. 2017; 25: 858-867.
- 9. Life Changes Trust (2015), Dementia Friendly Communities: Evaluation Guidance and Resources, Life Changes Trust, Glasgow,
- 10. Felc Z, Stopar M, Felc B. Modest Insight into the Public Level of Knowledge of Dementia-Friendly City in Slovenia. Journal of Health Science. 2018; 6: 220-225.
- 11. Woodward M, Arthur A, Darlington N, et al. "The place for dementia ☐ friendly communities in England and its relationship with epidemiological need". International journal of geriatric psychiatry. 2019; 34: 67-71.
- 12. Lincoln Y.S, Guba E.G. Naturalistic inquiry. Sage. 1985; 75.

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