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On their way: life after caring

A competence-based study to support social and professional re-insertion of former carers carried out on the districts of Carpi and Cesena

life after care

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Index

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Introduction

Carers and Life After Care project

“Carer” means a person who provides unpaid care to a ill, frail elderly or disabled family member, friend or partner. According to EUROFAMCARE research, over 100.000.000 unpaid carers are esteemed in Europe – equal to 25% of the population.

It’s a therefore a widespread phenomenon that, unfortunately, is often linked all over Europe with a high risk of social exclusion. The heavy care burden implies indeed economic difficulties, isolation, less training and career opportunities.

Carers’ problems do not come to an end when the caring period is over. In fact, according to Larkin (2008) and McLaughlin (2007) *ex carers*[1] also have difficulties in re-insertion in social and working life after many years dedicated to full time caring.

For this reason, “Life after care” (LAC) project, funded under the European Life Long Learning Program–Grundtvig, focuses on what happens when the caring comes to an end (normally because of the death of the care recipient) and is aimed to support the insertion (or re-insertion, or retention) of carers in professional or unpaid activities.

In fact, this research is based on the idea that carers’ everyday tasks need the development of several capacities, knowledge and sensitivity that – if acknowledged and enhanced – might certainly be useful also in other contexts.

The research is therefore focused on one hand on the identification of motivations and effective skills developed within caring experiences, on the other on the characteristics of the demand that might employ these skills (in paid and unpaid care services).

At the same time, the research allowed us to gather evidences of post-caring experiences that contribute to enlighten a phenomenon still rarely investigated by Italian and international researchers.

Aim of the research

The research is based on the idea that those carer who have difficulties in taking back their future after caring experience are not fully aware of capacities, abilities and knowledge acquired while caring. Skills that might turn into valuable resources in new context: a social capital that could be re-invested in the market of professional care service provision or in volunteering in the social field.

Specifically, the aim of the work was:

- collect relevant information concerning carers’ transversal skills and try to also remark the ways through which these competences are acquired.

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[1] We have defined a former carer as someone who has ceased caring in the past two years.

- Identify skills demanded by professional care services
- Identify those paths that might support insertion / retention of former carers in volunteering activities.

Applied methodologies

In order to fulfil these aims, the research applied three different methodologies, one for each target group.

The **identification of skills acquired by carers** during the caring experience is based on the method of the behavioural event interview (aka BEI Method). The basic principle of this method is that you can't rely on what people think or say about their own motivations or skills. But you can rely on what people actually do to face critical events.

The interview leads the interviewee towards a detailed description of events happened during caring (both successfully solved or not), combining narration of facts with description of thoughts, emotions and intentions of that specific moments.

The text of the interview, once trascripted, is examined to find out behavioural indicators related with each skill. A skill is considered to be present, in the frame of the behavioural event, when it is detected at least once.

The interview scheme also allowed to collect general information about problems faced by carers in their transition to post-caring.

These issues are developed in chapters 1, 2 and 3.

For the **identification of skills demanded by professional care services** we used a questionnaire filled by human resource officer or enterprises providing social services and public employment services officer. The questionnaire lists a number of transversal skills and ask to the interviewee to choose those that he/she considers more important to work as a "dependent elderly care assistant"[2].

This issue is discussed in chapter 4.

Finally, we organised two focus groups aimed to deepen the knowledge of problems related to the **insertion of former carers in volunteer organisations.**

This issue is discussed in chapter 5.

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[2] We didn't intentionally mention the specific professional role because we were looking for transversal skills.

1. The post-caring experience according to interviews

As mentioned in the introduction, we made interviews to former carers with a double purpose: to examine the post-caring experience and to collect the necessary elements to analyse acquired competences according to BEI method. In this chapter we will focus on the first issue.

The sample

ID	Gender	Type of relationship with Cared person (family member, friend…)	Age	Job	Date of decease	Health problem of the cared recipient	Presence of livin-caregiver	Caring duration
1-c	F	DAUGHTER	55-65	Small businesswoman	2009	Ictus effects	No – nursing home	4 years
2-c	F	GRANDDAUGHTER	65-75	Pensioner	2009	Alzheimer	No – nursing home	10 years
3-r	F	DAUGHTER	65-75	Pensioner	2009	Ictus effects	Sì – poi Casa Protetta	12 years
4-s	M	SON	65-75	Pensioner	2009	Alzheimer	Sì – part time	4 years
5-d	F	DAUGHTER-IN-LAW	35-45	housewife	2010	Disable person (bedridden)	No	1 year
6-m	F	DAUGHTER	65-75	Pensioner	2009	Cecità	No – nursing home	6 years
7-r	M	SON	65-75	Pensioner	2009	Ictus effects	No – nursing home	5 years
8-e	M	HUSBAND	65-75	Pensioner	2006	Alzheimer	no	5 years
9-i	F	DAUGHTER	45-55	Emloyee social and healt worker	2006	Idrocefalo normoteso	yes Part time	12 years
10-m	F	DAUGHTER	45-55	Emloyee Public social worker	December 2007	Dementia	yes	About 6 years

11-t	F	DAUGHTER	55-65	Housewife	2009	ischemia	no	17 years
12-s	M	SON	45-55	Teacher	1998	Alzheimer ischemia	no	About 6 years

The sample is made of seven carers. Men are two, five the women (among them, one is not of Italian origins). Only one of them is under 50, two are between their 50 and 60, three are between 60 and 70 and one is over 70.

The majority of interviewees (5 over 7) assisted their mothers. The period during which caring was provided is rather long: in average 5,5 years for Carers from Carpi District, in one case over 10 years. In five cases, however, after a period of care provided at home, the care recipient was moved to a nursing home.

The average for carers from Cesena District is 9,5 years; the longer period is 17 years, the shorter one is 5 years.

Four out of twelve carers are still working; as they were/are employees they have had the possibility to carry out at the same time job and care activities. In the 8-e case retirement period coincided with the caring start. The 11-t case was and is still housewife, while the 5-d case – because of her unemployed condition when her mother-in-law contitions got worst – decided to become a full-time carer and renounced to looking for a job.

The interviewees have ended caring in a period ranging from 6 months (in the majority of cases) to 2 years before the date of the interview. Just in one case, the end of care experience dates back to 12 years before the interview took place, but even if the period is very large, the caring activity is so vivid and the interviewee is so emotionally involved that the researchers have considered it very relevant.

Except for this last case, the interviewed persons are in the middle of their transition period from caring to post-caring.

From the interviews we can point out an important difference between the sample from Carpi District and that one from Cesena. For the first group the death of the care recipient happened after a medium – long period of admission in the nursing home. Therefore, in some way, the intensity of the caring experience – in term of material charge - had already reduced. For the second group indeed, the interviewees were responsible for the caring activities during the whole period of the elder disease. Just in one case the carer used the support of a nursing home in order to have some periods of relief. Four interviewees, in the last period of their caring activities were supported by migrant domestic workers. Among these cases two needed a 24 hours a day care support while the other two needed a part time support. The remaining interviewees were directly involved in the caring process through the aid of public care service provided by the Municipality.

Outcomes of interviews related to the post-caring experience

The care work experience is as much widespread as heterogeneous. The twelve interviews collected are twelve different stories that need a general and commun interpretation criteria. We have identified two very important variables: the intensity and the duration of caring period.

Concerning the intensity, Anglo-Saxone litterature point out three types of carers: the moderate carer (less than 20 hours per week), the substantial carer (from 20 up to 49 hours per week) and the heavy carer (50 or more hours per week)[3]. Among the twelve interviewed persons, more than 50% have carried out from 20 to 49 hours per week caring activities, while one has developped more than 50 hours per week. As we have mentioned above, all interviewees caring activities lasted almost 4 years, with summit of 17 years. Especially in those cases in which the care recipient lived at home untill the end of his life, the caring experiences reported are very strong both from the emotional and the physical /psychological effort demanded.

The disease or a violent accident (especially ictus) of a beloved person demands many big responsabilities regarding care tasks. In four cases carers are only children, while in other situations, even if they have sisters or brothers, they represent the main person who provides care.

According to the reported stories, **the caring period can be classified in three different phases**:

- **The omnipotent phase** in which carer, after the initial shock, tries to arrange everything by himself, overestimating his capabilities
- **The realistic phase** in which carer, together with other family members (if they are available), trais to organize the care activities taking into account the needs of all people involved and looking for an integrated support provided by professional workers.
- **The Conclusive phase** that is represented by the period before the death of the elder person, it's usually a stressful period from both sides the emotional and the organizational one, because the elder health conditions worsen: his hospitalizations and the correspondent discharges are very frequent, the hope disappears and the specific care demandes increase.

The reported critical events are very different and don't have an effective lowest common denominator. Neverthless two interviewed heavy carers divelopped a serious disease (two different types of cancer) in the same period of their harder caring activities. This datum can be linked to the official scientific researches carried out on a larger sample of population that underlines the risks of carers considered as a vulnerable target from the health conditions point of view[4].

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[3] Yandle Sue e al. *Stages and transitions in the experience of caring* – report n.1 Carers, Employment and services report series - Carers UK and University of Leeds

[4] Report CARERS UK

The importance of the network

The presence of family members or friends is a protection factor even when they aren't directly involved in the care activities. The interviewed persons without these very important networks of support, show their main difficulties.

> *"…in order to really understand this problem you have to experience such kind of situations. We have even to take into account that each individual deals with a similar situation in a different way. I'm taking part to the self-help and mutual aid group and among the participants there is a man who's taking care of his mother-in- law suffering from Alzheimer…he is less distressed than me, but he has a wife and two children so he has got a network through which sharing this situation. I was alone! (…) At the end of June I fell down from a tree while I was picking fruits and I broke my arm that was in a cast for 30 days. Just in that period I received a support for my mother-in-law by a person." (Interview 12s)*

> *"Our life haS changed for four years. My children, my relatives and my aunts were always very close to me, they heartened me. Someone of them told me that I wasn't obliged to go to visit her all weeks, but for us it was very important to see her everyday, because it gave us the right motivation to go on…" (Interview 1c)*
>
> *"In order to taking care of my mum I had the live-in caregiver support. I have a sister, she's two years younger than me. We planned together the care activities (eg. I went to visit my mum one Sunday and she went the following Sunday). I didn't feel alone because she helped me.." (Interview 3r)*

> *" I've to recognise that my sister had a crucial role in caring my mother because she lived upstairs and that allowed us to manage the situation together…" (Interview 4s)*

In order to better understand how the asbence of any family members networks causes serious difficulties for caring activities we report the following exemples:

> *"…Fortunately I don't have any health problems, but I'm afraid to become ill in the future. I've a daughter but I can't rely on her. Moreover my nephew hasn't got the driving licence. I don't have any support and so I can rely just on myself. Actually now I'm not interested in it but I will need some help if I have some health problems and in that case I've not idea to who ask for a support. I received a lot of support by some friends of my husband, they are mechanics and they help me when my car has some problems.." (Interview 6m)*

Even the friends network can be important. At least two intrviews underline the fundamental role of the friends, both in the initial phase, for avoiding isolation, and in the final phase to take comfort after the elder death.

> *"Anyway I have always had many friends, I didn't want to feel isolated, I always was in touch with my historical friends...(...). I had a clear idea: I didn't want to become a spinster who was just taking care of her mother. (...) I could always rely on my friends, when she fell down during the nights, because of her weigh I asked for an help to my neighbours: I had explain them the situation and I addressed them many times." (Interview 9i)*

Moreover,

> *"There was a network..in some way I always tried to see my friends and the beloved persons. The first years I saw them rarely, but in the last period of my caring activity I did need a social support and my contacts with them were more frequent.*
> *I couldn't take a leave of absence from my job because I had a lot of expenses: the rent of my house, the salary of live-in caregiver". (Interview 10m)*

> *"In the last period, when she started having more serious problems I felt demoralized and some time I said "I give up!" because she was very sick. My efforts were unhelpful. All people supported us even people who we superficially know..." (Interview 1c)*

> *"..I received an important health support by two dear friends of mine. One was our family doctor, we were very good friends when we were children, the other one was a doctor, son of my mother's friends, she considered him as her own son. The counseling center responsible was very helpful too because she was the first person who was able to identify the right therapy. I've never felt alone because a lot of people ware supporting us..." (Interview 4s)*

Only one of the interviewees told us she was emotionally and practically supported by a professional worker in order to understand how to make care recipient more autonomous.

> *"My mentally priority was this one. I thought all day long of my mother caring activities organization. I was very lucky because the domestic workers I employed were very organized and autonomous. Nevertheless I couldn't take any holiday or sleep out of the house. In order to psychologically endure I started wit psychotherapy. My mother brought me in her disease and I didn't want to. I was 33 years old and I didn't want to be a 24hours- day carer. At the end I did it because it was a duty and an act of love, I had been doing it for 14 years!" (Interview 10m)*

When the caring acticivity ends

Analizing the conclusive phase of the caring experience –in all our interviews this phase was represented by the death of the care recipient- we refer to the model proposed by M. Larkin, that describes a three-phases identifiable trajectory, linked or not to the phase of the grief process.

1. Post-caring void

This phase coincides with the period following the care recipient death. The interviewees usually use the words refer to a sense of void, rage and shock. This emptiness is a consequence both of the beloved person loss and of the loss of the carers'life aims. "The beloved person death coincides with the loss of the carer's role"[5].

The folliwing stories can give some exemples of this situation:

> *"Before I had a daily aim, I had to go visiting my mum [who was in a nursing home] because I always felt a little guilty for not keeping her closer. My aim was to go and see her everyday. So I miss all that. That void is awful" (Interview 6m)*

> *"...Then, when she died, I missed her even at home. It's strange because she hasn't stayed at home for four years (she lived in the nursing home), but after her death I missed her at home. I haven't missed her at home for four years. Now I really do miss her at home: I miss her presence during the dinners and the lunches, I miss her room..may-be because we expected to see her at home again..." (Interview 1c)*

The larger the caring period is, the stronger the sense of void will be.

> *"...When they died I felt empty, this emptiness was partially filled by the visits of these people. In 1993 and in 2009 the holiday dates (like Christmas and Easter) occured on the same days of the week...that brought me back to the same situations I lived in the past. During some years I used to go to the cemetry every day, from August to Automn time I used to go there morning and afternoon. I had to do it!" (Interview 12s)*

> *"I feel more vulnerable because I miss my mother. I feel left alone in managing my life and my job. I miss her now, I miss the sense of safety she gave me ." (Interview 1c)*

> *"...I would like to die for reaching my mother..." (Interview 3r)*

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[5] Larkin Mary, in *Life after Caring: The Post-Caring Experiences of Former Carers*, British Journal of Social Work (2009) 39, 1026–1042

Another typical element of this phase is the sense of disorientation because the daily activities suddenly change. Un exemple of this situation is given by the case of the carer integrated in a large medical workers network (doctors, nurses, phisyioterapists, etc.) who is suddenly left alone.

> *"My mother died on August 9th at nine o'clock in the morning and my father died four days after. In a few days I was completely alone. My mother had an heart attack and my father was ill. Someone could think "Now you are free". However when they were alive I used to meet a lot of persons like: live-in caregiver, social and health workers, friends and after a few days all of them stopped coming and I felt alone. During my father's funeral I said "Please don't leave me alone because I'm afraid I won't be able to go on". After this event for 100 days I was always visited by someone: my cousin, a collegue, a neighbour, etc. I've really appreciated this solidarity." (Interview 12 s)*

2. closing down "the caring time

After the care recipient death, the carer has to deal with many bureaucratic, legal and organizational aspects; they are particular ends with a material and symbolic meaning.

The funeral represents the typical ending event and the interviews show that it was arranged by the carer.

> *"The funeral was a very important moment, My mother was communist for that reason we chose a laic funeral. We celebrated it at The Certosa Pantheon. There were only red carnations and PCI (The Historical Italian Communist Party) flag over the coffin. All my life was present..., on one side my friends from the primary school, from my youth, the present friends, the former boyfriends; on the other side some people who knew my mother, some families from Marocco (they were families of the migrant domestic workers who supported us) with their children, the children were run all around and they showed us that the life was going on. During the funeral we listened to the Live in Kolhn played by Keith Jarrett and then to a chorus singing the antifascist songs of the Spanish Civil War. Then all the participants sang all together the "Socialist International Hymn" and at the end everybody clapped. There were about 100 persons, all my life was there, each person brought a flower...It was a good end! I brought some of those flowers at home." (Interiew 9i)*

In one case, in order to close this period the care had to sell the house because the memories kept in it.

> *"The first month I lived out of my house; I didn't want to go back home, even because the live-in caregiver was still living there...Yes, she was there because she had some claims! Let's forget it! Anyway I was hosted by some friends of mine and then I came back home alone. My sister was there just during the day...the house seemed to me different and I*

> *knew I would leave it. It was too big, its rent too expensive for these reasons I sold it. A month after I got sick, I got bronchopneumonia, it was a sort of physical shock. My sister too got sick. My neighbour helped me, I cried a lot, but at the end I felt reconciled with myself. Then I started arranging everything: I tried to find a new order on my life, I threw a lot of things away..In June I left the house." (Interview 10m)*

3. The Constructing life post-caring'

The thirth phase identified by Larkin is the construction of the carer project of life. The interviews point out that the motivation to go on are deeply influenced by the quality of the post-caring process. In particulary a good post-caring represented by a circle well closed brings with it a reconciliation sense and will make carer quiet and ready to start a new life. A bad or incomplete post-caring transition can leave a sense of guilty, a resentment, the situations without a solution that represent an heavy burden and they can negatively influenced the transition to the former carer status.

> *I feel melancholic when I remeber her and I often need to see my pictures to find some confort. It's like if the circle has closed now. The evening when she was dying, I was at home looking for my mother picture and the subtitle to put in her memorial card, then I chose the Cardarelli sentence. I undesrtood she was dying. When the live-in caregiver called me, I was In Praga (it was after her last fell down) and I heard my mum screaming, in that instant I undestood that this scream wasn't usual, but it was something different. In that moment I said "My mother dies" and everybody told me that I was exagerating and that even this time she ridden out this situation, but she didn't.*
> *It was like we said good bye to each other (…). I think it's normal that now when I rememberthis moment I'm still shaking and I'm still affected by her death, anyway it was a good end. I was happy about that. I don't have any prick of conscience because I did my best. I thought she wanted to give me a gift and a surprise: a surprise because I didn't expect it and a gift because she made me free". (interview 9i)*

Unother story in which the post-caring was harder because the carer has a big prick of conscience:

> *"It was the first day of Jennuary at 12 a.m. and we were waiting for "cappelletti –a kind of Italian Pasta- ! After 30 minutes that I came back from the Hospital the doctors called me and told me that my mother was died. It was an horrible experience! I didn't realize that she was getting worse. She has worsened since Christmas when her breathe became harder…but her conditions were stable. I didn't expect it! After these news my husband and I argued. (..) My mother didn't want to die alone, She was afraid of that!!". (Interview 11t)*

Beyond a good post-caring, there are other factors that can avoid or fight against the stress. As we have already mentioned, it's very important to can relay on a family members network both from a material and emotional point of view. Then we have to consider the interests such as: the job reinsertion or the future care activities to carry out – as it happens for the serial carers[6].

According to the interviewees –even to the heavy carers- the post-caring phase brings a new awareness and a new strenght that, unexpectedly, they found themselves:

> *"Nowadays, through this experience I gained a strength I didn't have before. Before, emotions overcame the engagement, now the engagement crush the emotions. I learnt so much that now I would be able to assist a person in the same conditions [of her mother-in-law], avoiding emotions to overcome my engagement" (Interview 5d)*

> *"I learnt how to live in suffering. In my option this is a life lesson: to be able to accept life as it is, without overacting and being aware that you are doing the best that you can. I learnt not to be influenced by other people's opinions, that used to told me how and what they thought I should have done. I was in peace with myself. I also got angry less often because I understood that there were things that were more important". (Interview 7r)*

And again,

> *"An experience from which I received –in a human side- just positive things. I know that it can be seen as a kind of justification, because after a complicated period we want to give the caring a sense, but I think it's not just that. The experience was very interesting and important from several points of view. It was very hard for me, it was a real sacrifice but I had a feedback from it, after the experience ended. Through this special relationship with my mother I discovered a new kind of love. And it's strange that this discovery happened with a person who looks like unable to communicate (…). I realized the real value of the human being…" (Interview 10m)*

> *"What I learnt is the demonstration that social /human relationships are the most important part of the life." (Interview 9i)*

None of the interviewees, however, declared to have more free time now, or to feel free from a heavy load. It's possible to read it in relation with the fact that most of the care recipients were living in a nursing home since quiet a long time, nevertheless these aspects are neither faced by carers providing care at home.

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[6] Serial carer, with this word Larkin describes that carer who will take caer of another person after his/her first care recipient death.

> *"Few has changed in my daily life because we managed to organise ourselves quite well. The only obstacle she gave me was in the free use of the house, because I tried not to had guests in order to leave my mum more quiet". (Interview 4s)*

Even in those cases where carers mentioned to feel released and to start a new life, they always showed a sense of peace and satisfaction because they did their best.

This experience has been a source of human and professional learning. In fact many carers (7 out of 12) declare their availability to be engaged in volunteering activities or, as far as the youngest carer is concerned, to see a future in the professional care services provision.

> *""I tried to work in a nursing home before, but the impact with 10 people had been too strong for me and I turned out depressed. Now, instead, I feel brave enough to help: I see the sufferance but it becomes an inspiration to work. I see the work with elderly as a job in which I could have a lot to give" (Interview 5d)*

At the interview moment, two persons belong already to an association of Alzheimer Patients Relatives (CAIMA) and they spent several hours per week in the association activities: both in the self-help mutual aid group and in the organizational and fundrising activities. One of the two persons has become member of the organization since the first phase of his wife desease and he considers very useful the support received by the association – especially the self-help and mutual aid group activities - because it helped him to better deal with the situation of his wife.

The second person jointed the association a couple of years after her parents daith but he considered that it would have been better if he had engaged in CAIMA during her caring activities.

Even those people not yet engaged in volunteering activities, express the desire to talk about their experience to other persons both in an oral and practical way in order to keep the acquired skills and experiences:

> *Q: "How do you see your future? Would you like to do some volunteering?" A: "I would love to. For instance I would like to share with others my experiences and what I learnt, in groups or nursing homes, in order to improve the quality of services provided to carers". (Interview 7r)*
>
> *"In my opinion volunteering is great because, besides providing help to others, it is useful for your self. You might have the need to do it". (Interview 4s)*
>
> And again
>
> *"In the last phase of my mother's desease and even after her death I wanted to share this experience with other people…The aunt of a friend of mine had similar health conditions to*

> *my mother so I told him that I could be able to help her once a week…Unfortunately I hadn’t enough time to support them. My caring experience left me the desire to experiment the things I have learnt, in a different condition and context. I realized that , in this period, it is very important to be on the side of a person able to understand your need and accept your situation..and I asked to my-self: “And What will happen If I experience the same situation?” In that case I would like to rely on a person like this one I mentioned above. I didn’t have the opportunity yet but if it happens I will accept it. I didn’t have the following reaction “No I’m sorry but I’ve had enough of it”. This experience had given me the desire of sharing it. As all the experiences of your life when you find an advantage from it you want to share it to help people. It’s sure that if you are haunted by this situation you don’t want to carry out similar activities anymore.” (Interview 10m)*

At the end we would like to report an emblematic case: a woman after a long caring activities towards her mother came back to her normal life as housewife but her children have grown up and she can’t find the right way to keep doing something useful for the others:

> *“The situation has changed and I don’t have the control over the things as in the past. I would like to do something to keep feeling useful, for that reason I said to my children “Please, bring me something to do, to wash, to iron”. They live at their house, one of them comes here at twelve in the morning to have a lunch together. Yes, I’m still a bit wobbly, I’m trying to be strong! I would like to keep doing something…” (Interview 11t)*

So, carers themselves confirm the initial research idea: caring often leads to a change in priorities and values but it also develops new skills.

At the same time, the “post caring void”, identified by Mary Larkin as one of the typical phase of transition to post-caring, seems to find an answer in professional or volunteer caring. We will talk about this in the next chapter.

2. Carers' skills

Carers, in the making of their caring activities, develop abilities and knowledge – therefore skills.
We will see in this chapter which are the learning contexts, what we mean with "skills" and which are the main existing skills.

Informal learning and tacit knowledge in caregiving

The learning contexts can be various.
The traditional form – that we find in structured and organised context (such as schools or vocational training institutes), that has clear learning goals and that normally ends with the acquisition of a qualification or a certificate – is called **formal learning.**
Then we have the **non formal learning** that, even if it is developed within activities not explicitly aimed to learning, is – as the formal learning – an intentional activity. Examples could be notions acquired through a web search or the participation to a seminar.
Last, for **informal learning** we mean all that forms of learning that take place outside institutional channels. It includes those knowledge coming from everyday life activities linked to work, family, spare time… that are often acquired in a non-structured and non-intentional way. In informal learning it often happens that the "learner" him/herself is not aware of gaining skills and knowledge.
Among the contexts in which informal learning can develope, we can of course include caring for a dependent family mamber: the carer "learns by doing", experiment and test on the field notions, techniques, effective behaviours to answer to the needs of the care recipient.

The concept of informal learning is strongly linked to that of tacit knowledge.
However, before explaining the meaning of this expression, it is necessary to define "skill". Even if we could have many definitions of this word, generally speaking we can say that a skill is the capacity of individuals to combine, autonomously and in a particular context, the different knowledge (in the sense of information with a specific usefulness) and abilities (in the sense of the capacity to undertake complex tasks in a finalised, organised, rational way) they own.

The expression **"tacit knowledge"** is defined by its inventor, the Hungarian philosopher Michael Polanyi as *"something we know, but we don't express it because we can't or because we think it's useless to do it: we can know more then we can actually tell".*
They are untold knowledge, that the person owns without even realising it and understanding their value".

A clear example of what a tacit knowledge actually is can be found in an article by Harry Collins[7] and it refers to cooking. Collins underlines that *"most people have had the experience of attempting to follow a recipe, attending to each stage of the process, and yet failing to obtain the desired and predicted result. Why is this? One possibility is a breakdown of the practical skills involved. Perhaps the cook lacks, eg, the physical strength or dexterity to whisk the mixture at sufficient speed. In most cases, however, this is not the cause of the problem. But on the – fallible – assumption that none of the explicit instructions has been violated what other explanation is there? The most obvious explanation is that the recipe is incomplete. Perhaps a key step has been omitted even if it is one that would not need to be explicitly stated for a skilled cook (which perhaps explains its omission by its skilled author). Such a cook can 'fill in' the missing step unthinkingly whereas the novice comes unstuck. Tacit knowledge fits this picture as an abbreviation of explicit knowledge".*

This kind of skills can be acquired through practice, experimentation, the research of "customer" satisfaction and can hardly be transferred to others but with experience itself. Tacit knowledge is considered by researchers[8] as a fundamental element to provide high quality care. It is therefore of major importance to enhance them to support former carers' labour insertion.

Types of competences

There are of course many "types" of skills. To identify and define them it is useful to refer to Lyle e Signe Spencer[9] research that led to the publication of the so called "Dictionary of Competences". This book provides a list of almost 360 behavioural indicators that refers to 21 main competences, which in turn can be gathered in 6 clusters:

1. action area
2. influence area
3. management area
4. human relationship area
5. cognitive area
6. efficacy area

We will refer to these clusters in our reasearch with carers. Let's therefore see them in detail:

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[7] Collins H., *Changing Order: Replication and Induction in Scientific Practice* cit. in Thornton T., *Tacit knowledge as the unifying factor in evidence based medicine and clinical judgement,* Philosophy, Ethics, and Humanities in Medicine 2006, **1**:2

[8] See: Reinders, H. *The importance of tacit knowledge in practices of care*, Journal of Intellectual Disability Research, Volume 54, Supplement 1, April 2010 , pp. 28-37(10)

[9] Hay/McBer. (1996). *Scaled Competency Dictionary*. Boston: Hay/McBer e Spencer, L. M. and Spencer, S. M. (1993). *Competence at Work*. New York: Wiley.

1. ACTION AREA

This group of skills concerns the tendency to act, i.e. to aim more to the accomplishment of a duty then to relationships with people. “Initiative” is a fundamental element to any skill of this area.

2. INFLUENCE AREA

Influence concerns the purpose to produce effects on other people through its own behaviour. The practice of the influence power can be mitigated by the interest for the success of the organisation and of the team. Those who have skills in this area do not believe the personal prestige should be seek in spite of other people well being.

3. MANAGEMENT AREA

Skills in this area are related with the purpose to produce specific effects through actions. People with competences in this area should be able to coordinate others, develop other people’s capacities, define and supervise work plans.

4. COGNITIVE AREA

The area of cognitive competences express individual engagement in understanding a situation, opportunities related to it and problems that might be faced. Cognitive skills represent competences related with applied intelligence, analysis and synthesis. They express an effort to self-understand things, instead of accepting other people’s explanations.

5. EFFICACY AREA

Skills in this area are related with the ability to control the efficacy of actions, reacting to upcoming pressures and difficulties.

6. HUMAN RELATIONSHIP AREA

This area include the purpose to answer to other people’s needs. This aim might be reached either showing interest for people and their needs, either acting to answer to these needs. This involves a strong desire of being “part of the group” and it’s a competence supporting influence and management skills.

3. Offer of skills: the BEI Method

In order to verify the initial hypothesis, according to which carers do develop skills, we applied the “behavioural event interview” methodology. As described in the introduction, this technique is based on the idea that the best predictor of a future behaviour is a past behaviour. The BEI Method has therefore the aim to reveal past performances in which a special ability in the solution of a problem was shown and – consequently – a key competence applied.

Types of detected skills

Interviews conducted with the sample of former carers described in chapter 1, allowed us to detect and validate an overall of 18 different skills, which can be referred to those described in the “Dictionary” we are using as a reference (see previous chapter). These skills can be gathered in turn in six clusters.

Concerning clusters, we used those already identified in Spencer’s “generic” dictionary. The only change we made (on the basis of the fact that carers do not have management tasks, but rather self-management characteristics) was to turn “management competences” with “organisational competences”. We also integrated these organisational competences with competences detected in the same Spencer’s publication, in a research concerning entrepreneurial profiles.

The types of skills detected, gathered in clusters, are:

ACTION CLUSTER
Achievement orientation: it’s the effort to work with accuracy and to reach excellence through competition and challenges.
Efficiency orientation: it expresses the effort to use available resources in the best possible way and to achieve goals.
Initiative: is the effort to act and do more, even if not requested, to improve and/or create new opportunities.
Information seeking: is the effort to know more to act better
Concern for order: is the innate need to reduce the uncertainty of the surrounding reality

HUMAN HELP CLUSTER
Interpersonal understanding: it expresses the capacity to understand others, even through inexplicit signals.
Customer service orientation: it expresses the desire to help others and answer to their needs.

IMPACT CLUSTER
Influence: it expresses the intention to influence others and to have an impact on them
Persuasion: it expresses the orientation to find leverages to convince others to act in a way which is favourable to us.

ORGANISATIONAL CLUSTER
Team work: is the effort to cooperate with others and to be part of a team
Perseverance: it's the capacity non to give up in front of difficulties
Credibility: it's the tendency to put integrity (reputation, liability, loyalty) at the basis of the behaviour in the work place
Concern for organisation: it's the capacity and will to align own behaviours to needs, priorities and aims of the organisation.

COGNITIVE CLUSTER
Conceptual thinking: it's the capacity to understand a situation by putting together different elements and link them in a single picture.
Expertise: it's the capacity to apply effectively one's knowledge and abilities to reach the goals of the organisation.
Problem Solving : it's the capacity to face problems with method and to see them as an opportunity
Concern for quality: it's the capacity to provide quality results through analysis and comparisons

PERSONAL EFFICACY CLUSTER
Flexibility: it's the capacity to adapt oneself to work in a variety of situations and with various individuals or groups.
Self confidence: it's the strong belief to own the necessary capacities to reach a goal
Self control: it's the ability to control emotions and to limit negative reactions

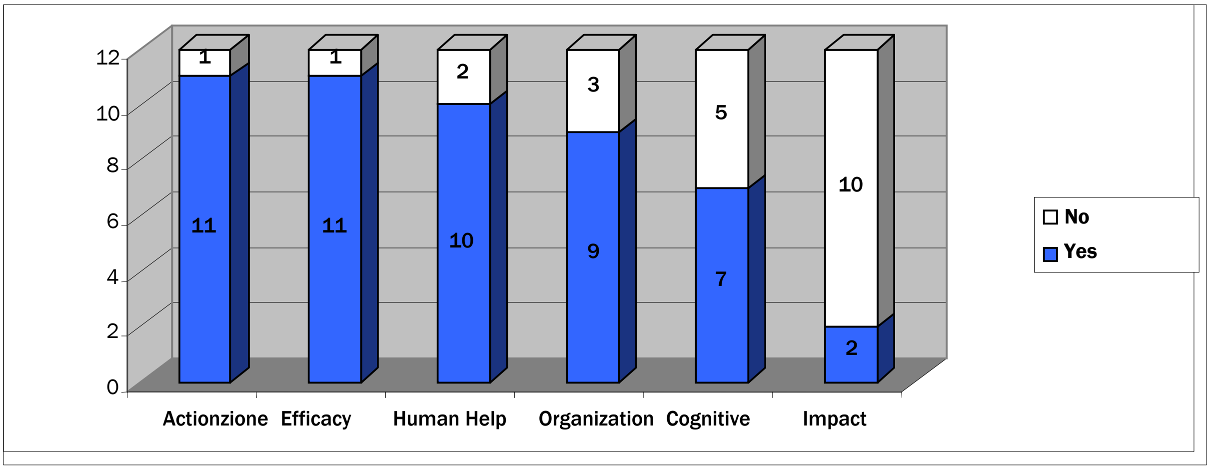
Detailed analysis of interviews

Here are the competences detected in the interviews:

Cluster	Skill	Interview nr.											
		1	2	3	4	5	6	7	8	9	10	11	12
ACTION	Achievement Orientation		X		X		X						
	Efficiency			X			X	XX		X			
	Initiative	X	X	X	XX		XXX		X	XXXX		X	XXX
	Information seeking									XX			XX
	Concern for Elder					X							
HUMAN HELP	Interpersonal Understanding		XX	XXX	X		XXX		X	X	XXXXX		
	Customer Service Orientation	XXX		XX	XX	XX		XXX					
IMPACT	Influence												
	Persuasion					XX	X						
ORGANIZATION	Team Work	X		X	X	X		X	XX	X		XX	
	Perseverance				XXX				X				
	Concern for the Organization								XX		XXX	X	
	Credibility												
COGNITIVE	Conceptual Thinking				X								
	Expertise									X			
	Problem solving			X	X	XX				X		X	X
	Concern for Quality					X	XX						
EFFICACY	Flexibility	X			X		XX				XX		
	Self-Control	X	X	X	XX			X	X	XX		X	
	Self-Confidence		XX		X				X			X	XXX
TOT. DETECTED SKILLS		5	5	7	11	5	7	2	7	8	3	6	4

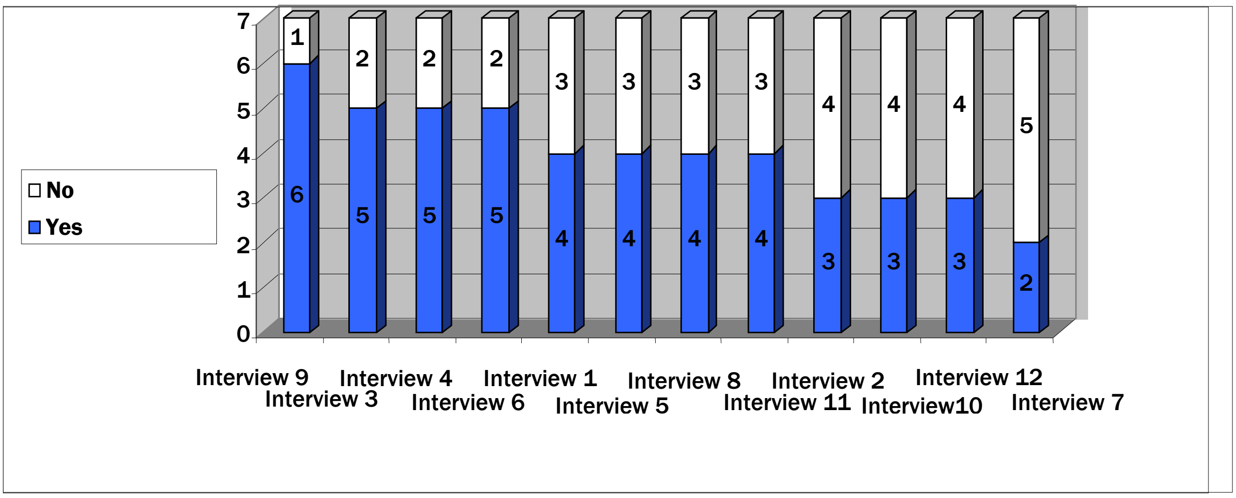
The first aspect that should be noticed is the confirmation that the methodology used is appropriate to identify skills, even if applied to an anomalous "professional profile" compared to usual organisational roles. In fact, it was possible to detect in the interviews type of behaviours that can be linked, without efforts, to those pictured in the Dictionary of Competences we used as a reference. In some cases, the number of detected competences is relevant (11 and 7).

Continuing with the **cluster** analysis we can see that those appearing less frequently are "impact" and "cognitive", while the most present are "action" and "efficacy".



A – Coverage of clusters in all interviews

The analysis of **clusters' coverage per interview** is interesting too. In fact, in one interview (interview 9) the detected skills cover 6 clusters out of 7, while the skills come out from the majority of the interviews cover 4 or 5 clusters over 7. This means that through the interviews we have been able to detect a variety of skills covering a wilde range of the behavioural areas.



B. Clusters coverage per interview

Let’s see now the **return of skills** in the interviews, in order to check which are those appearing more frequently in carers involved in the research.

Cluster	Skills	Return
ACTION	Achievement Orientation	3
	Efficiency	5
	Ininitiative	17
	Information Seeking	4
	Concern for Order	1
HUMAN HELP	Interpersonal Understanding	15
	Customer Service Orientation	12
IMPACT	Influence	0
	Persuasion	3
ORGANIZATION	Team Work	10
	Perseverance	4
	Concern for the Organization	6
	Credibility	0
COGNITIVE	Conceptual Thinking	1
	Expertise	1
	Problem solving	7
	Concern for the Quality	3
EFFICACY	Flexibility	6
	Self-Control	10
	Self-Confidence	8

The most detected skills are **initiative**, **interpersonal understanding** and **customer service orientation** (in this case, the care recipient) that respectively appear 17, 15 and 12 times. Those elements seem to be connected with a caring based on personal initiative and on self-confidence, a sort of: “I have to take the situation in hand, I must be able to do it”. In fact even the **self-confidence** skill is frequent (it appears 8 times).

This approach is strengthen and qualified by the fact of using sensitivity, empathy and attention to the needs of care recipient, as a leverage and a characteristic of their way of acting.

A questo proposito sono interessanti le presenze delle competenze problem solving (7 volte) flessibilità (6), e orientamento all’efficienza (significativa come segnalazione dell’attenzione ai costi) che appare 5 volte. In fact it’s remarkable that these skills are often associated with problem solving (7 times), flexibility (6 times) and efficiency (especially in terms of concern to the costs) that appears 5 times.

Self-control (considered even as a sort of training to be more patient) is very frequent (10 times) and is fundamental to carry out this job in a long term period.

Moreover it’s interessant to underline the frequence of **team work** skill (10 times), if we think of care activities as a job carried out in a one-to-one relation between carer and care recipient this element can be strange but on the other hand it can be an important indicator of the network system demanded by the elder care work (several social and health operators work outside the household such as: the MD, the nurse, the social worker, etc.).

4. From post-caring to professional care services

The following step in our research, once identified the main skills developed by carers, is to check their respondance with those requested by agencies providing professional care services.

The role-requirements model

The role requirements model has the aim to identify ideal characteristics of professionals effectively holding a specific role within an organisation. It is based on the idea of role, meaning **the whole spectrum of expectations that an organisation has towards someone holding a specific position.** The survey is made through a questionnaire in which HR managers are asked to choose, among a list of skills, those required to hold a specific position within the organisation.

In our case, the questionnaire was given to social cooperatives[10] and public job centres. Specifically, as long as social cooperatives are concerned, respondents were those people having the responsibility to recruit staff. Basically, depending on the dimension of the organisation, they were either HR managers or service managers.

Respondents were asked to focus on the role of "care assistant to dependent elderly". Wilfully, we avoided mentioning a specific qualification.

In fact, the questionnaire listed a number of **transversal** (and not technical) **skills** which could be referred to the various clusters (action, human help, cognitive…). The outcomes of each questionnaire had been processed with the aim to identify the requirements that, in average, were considered most relevant for the profession of care assistant to dependent elderly. They are:

Being able to identify priorities
Being able to quickly solve problems
Being able to quickly take decisions
Being able to take decisions autonomously
Being able to reach goals without supervision or control
Being able to carry on activities characterised by obstacles and unforeseen events
Being able to involve other people in activities

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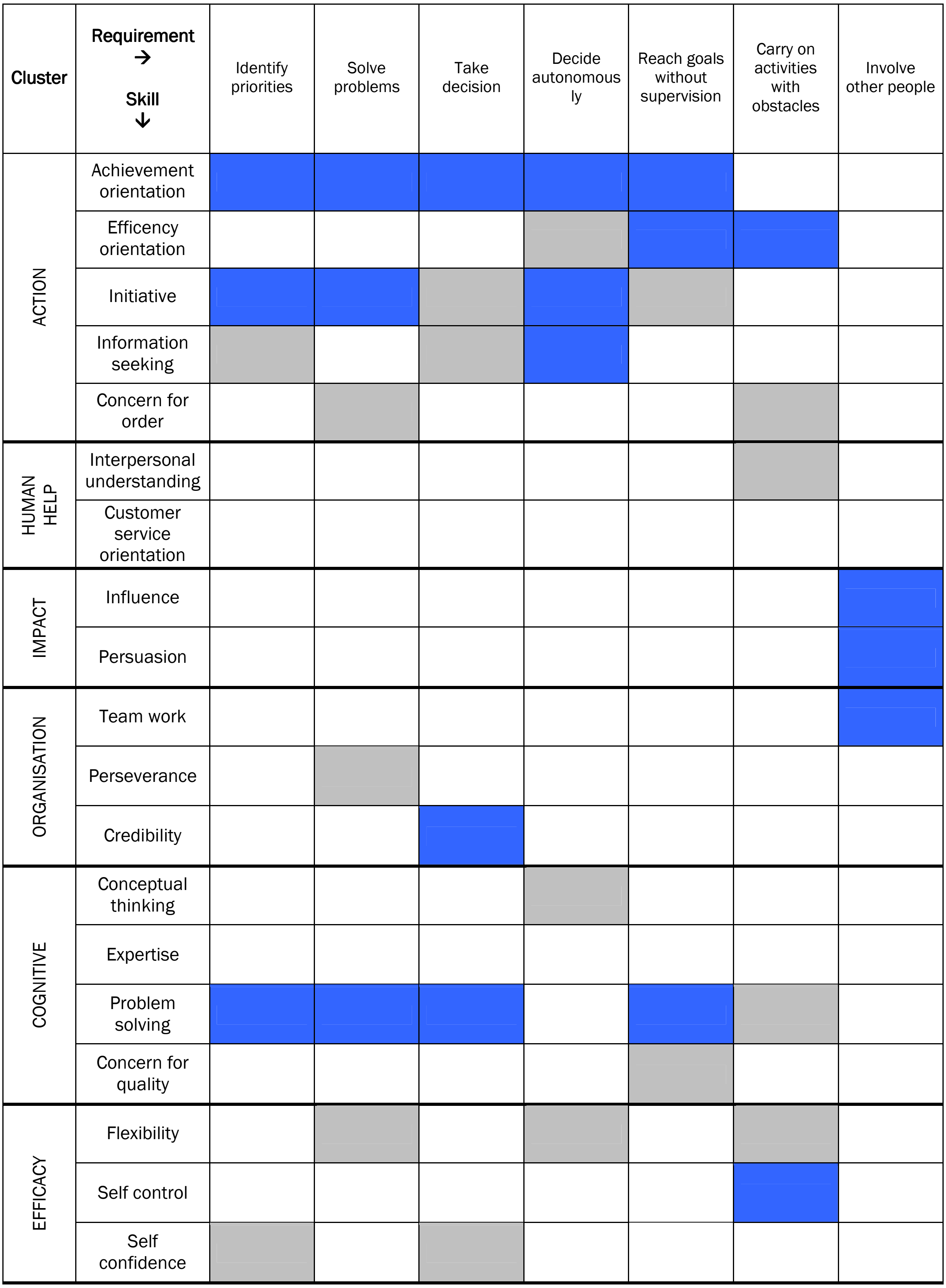
[10] NGOs providing care services to children, elderly and people with special needs

Requirements – skills matrix

Outcomes of questionnaires on role requirements had been crossed with data coming from behavioural event interviews in order to identify possible matching. We coloured in blue those crossing where the correspondence is high, in grey those where the correspondence is medium.



Cluster	**Requirement →** **Skill ↓**	Identify priorities	Solve problems	Take decision	Decide autonomously	Reach goals without supervision	Carry on activities with obstacles	Involve other people
ACTION	Achievement orientation	🟦	🟦	🟦	🟦	🟦		
	Efficency orientation				▨	🟦	🟦	
	Initiative	🟦	🟦	▨	🟦	▨		
	Information seeking	▨		▨	🟦			
	Concern for order		▨				▨	
HUMAN HELP	Interpersonal understanding						▨	
	Customer service orientation							
IMPACT	Influence							🟦
	Persuasion							🟦
ORGANISATION	Team work							🟦
	Perseverance		▨					
	Credibility			🟦				
COGNITIVE	Conceptual thinking				▨			
	Expertise							
	Problem solving	🟦	🟦	🟦		🟦	▨	
	Concern for quality					▨		
EFFICACY	Flexibility		▨		▨		▨	
	Self control						🟦	
	Self confidence	▨		▨				

The matrix shows which are the skills considered as most valuable to hold effectively, according to interviewees, the position of care assistant to dependent elderly: orientation to results, initiative and problem solving are the most important, followed by self confidence, information research and flexibility.

Let’s now match the required skills with those developed by interviewed carers:

Skill	1	2	3	4	5	6	7	8	9	10	11	12
Achievement Orientation		🟦		🟦		🟦						
Initiative	🟦	🟦	🟦	🟦		🟦		🟦	🟦		🟦	🟦
Problem solving			🟦	🟦	🟦				🟦		🟦	🟦
Efficiency			🟦				🟦		🟦			
Seeking Information									🟦			🟦
Flexibility	🟦			🟦		🟦				🟦		
Self-Control		▨		▨				▨			▨	▨
Influence												
Persuasion					▨	▨						
Team Work	▨		▨	▨	▨		▨	▨	▨		▨	
Self-Control	▨	▨	▨	▨			▨	▨	▨		▨	
Credibility												
Concern for order					▨							
Interpersonal Understanding		▨	▨	▨		▨		▨	▨	▨		
Conceptual Thinking				▨								
Expertise									▨			
Perseverance				▨				▨				
Concern for the organization								▨		▨	▨	

It is remarkable that all the skills considered as most important for holding the position are owned by at least 2 carers up to 9 carers over 12 as long as the **initiative** is concerned. All carers have at least one of the fundamental skills , while 2 carers own 4 over 7.

Considering the minor importance skills but selected from the list provided by the interviewed companies members, we can see that all carers own at least one of these with an average of three.

Moreover it is important to underline that two carers own 4 fundamental kills and 6 minor importance ones. They have therefore a very high correspondance with the demanded professional profile.

Carers and professional care services: an option?

Currently, there is no availability of figures concerning the number of former carers that – once the caring has come to and end – decide to become professional care services providers. Nevertheless, it is common among those working in training of job insertion of care workers to meet former carers that – more or less consciously – try to enhance the skills developed in the household to find a paid job in the care sector.

It's Mary Larkin[11] too to find out that 50% of the sample of former carers in working age she involved in her research found an opportunity of job re-insertion in paid caregiving.

Our research reveals that the transition from unpaid to paid caregiving might certainly be supported by a process of **transparency and valorisation of transversal** (and, presumably, even technical) **skills acquired during caring.**

In fact, carers seem to exit unpaid caring with some skills strengthened – **skills required by the job market:** the capacity to take initiatives autonomously, the capacity to apply problem solving techniques, the capacity to be flexible and face unforeseen events, to team work and to practice self-control seem to be frequent characteristic of people who cared for a long time.

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[11] Larkin M., *op.cit.*

5. From post-caring to volunteering

For many former carers, an engagement on social volunteering activities seems to be the natural outcome of their transition to post-caring.
57% of carers interviewed during this research state to be interested in continuing to dedicate time "to others", also as a way to overcome the feeling of loss followed by the death of the care recipient. But how can we support this transition? And how do volunteering organisation act towards volunteers who are former carers? This chapter will deal with this issue.

Applied methodology

The research involved some local volunteering organisation in order to explore the characteristics of the demand of involvement in social activities that might be of interest of former carers.
Specifically, we carried out four focus groups (two in the Carpi district and two in the Cesena one) which involved volunteering groups working in care elder soft services at home (such as: social transport, social and relational activities and so on) and association of Alzheimer Patients Relatives (Gafa Association in Carpi and Caima association in Cesena).
In particular, we asked these associations to identify people currently working as volunteers and who had been caring in the past. This question was made in order to explore their own personal experience of transition from family care activity to volunteering in the light of their current roles inside the associations.

The methodology we choose was that of **focus group.** This social research method is based on the discussion within a small group of people, who are invited by the moderator to discuss with each other a subject identified as the object of the research. It is therefore a "peer discussion", whose strength is the dialogue among participants that, exchanging opinions and points of view, define their own position on the issue.

Focus group nr. 1

The first focus group involved representatives of three volunteering associations created on the basis of a cooperation agreement between local Elderly Social Clubs and local groups of volunteers promoted by parishes. These associations work at neighbourhood level, in a middle-size city in Northern Italy. They provide various services of "light home care" towards adults with disabilities and frail elderly such as transportation, accompaniment, help lines, help with housework etc…

There were three participants, two men and a woman, currently retired, who work in the associations with coordination duties (of a specific service or of the association as a whole).

After the warm up, we asked them to tell about situations in which, as coordinators, they have supported the insertion of volunteers in a post-caring phase. In fact, immediately, participants shift to telling about their ***own* experience as former carers and the way that took them to work as volunteers in their associations.** The facilitator decided to go along with this "flip" encouraging participants to share their personal experiences.

Concerning the choice of being engaged in volunteering after the conclusion of their caring activities, all participants describe the sense of loss they felt after the end of such an all-engaging experience:

> *"After her death I felt a sense of emptiness because I had spent all my life with her [with her mother]."*
>
> *"When it is all over [the caring activity] you feel lost and you don't know what to do because everything falls down. Suddenly you have no more interests, then – step by step – volunteering becomes a resource, a luck. I believe that volunteering doesn't help others as much as it helps yourself"*
>
> *"I [after caring] didn't need to go back to work, but I had to take my life in my hands again. I did experience the temptation to retreat in my house too"*

On the other hand, focus group's participants describe as almost "unavoidable" their choice to dedicate themselves to others. In fact, caring experience also meant for them a significant change in their priorities and values:

> *"Your scale of values changes and overturns: if you have never experienced this kind of sufferings, you are kind of superficial and think about things that, after living such an experience, have no more importance".*

And even more: caring has, according to participants, made them develop skills that are precious in volunteering:

> *"Caring taught us to listen to others, to be more flexible, to focus on our job, to respect others by considering them as persons and not as competitors"*

This last sentence is especially interesting. In fact, while telling about their experiences as newcomers in associations, participants end up remarking that sometimes initial expectations risk to hit against a different reality. On the basis of their experiences, associations are not always welcoming places, willing to involve new people. Sometimes volunteers feel as if they do not receive the acknowledgment they think they deserve or feel a non-cooperative environment:

> *"These are places in which you don't receive acknowledgments. For sure, you do not get any compliment for your work."*
>
> *"I think there is some envy among volunteers"*
>
> *" Volunteers are like wasps [meaning they are nasty] with each other because they do not get along well".*

Therefore, if in an initial phase motivation is given by a "élan of solidarity" and by the need to feel useful as much as they were for their carees, this motivation must be fed in order to guarantee the "retention" of volunteers:

> *" In an "élan of generosity" they volunteered. Then they realised there were other volunteers and that their work wasn't actually essential".*

Nevertheless, it is clear among participants the potentiality of former-carers as new volunteers:

> *"I think we should try to stay close to people that are lonely [he refers to former carers] and try to make them understand that life goes on. It's indeed the lone person that can give more, because he/she has more free time. In this way we could recruit some lone persons because they need to feel a gap and to feel they are part of something".*

Focus group nr. 2

The second focus group involved three representatives of Alzheimer association, that provides several services to people with dementia and their families, such as conseling, information, respite care, peer support groups etc. This association operates in the same territories as the volunteering groups involved in the first focus.
Participants to this focus group are three women. Two are former carers currently working in the association, the third is one of the founders of the association who has never had direct caring experiences.

The first element that appears immediately as a difference with the previous group is the difficulty expressed by Alzheimer association to retain, after the death of the care recipient, people that used to be involved in the association. In fact, even if carers are conscious of the utility of services provided by the association:

> *“No one, after the caring period came to an end, came back to help us – except them [she refers to the two ladies taking part to the focus group]. This illness is so destabilizing that some people even ask us to stop sending them our newsletter. They do not want to hear about Alzheimer anymore.”*

In fact, even those ex-carers that keep contacts with the association after the end of caring, normally do not want to be involved in activities that might get them in touch with people with Alzheimer or their relatives:

> *“They absolutely refuse to consider involvement in care activities or in peer support groups because it destabilize them. But when we organise card game contests [to raise funds] they come.”*

> *“What everybody says is that when caring comes to an end they do not want to hear about Alzheimer anymore because they are burnt out”.*

Concerning motivation for undertaking these activities, participants to this focus – as those of the previous one – state that the leverage is the desire to feel useful:

> *“We stayed because we want to help others”*

Participants to this focus, however, are discouraged and do not believe that former carers are an interesting target group when seeking for new volunteers. On the other hand, they are conscious that post-caring is a very delicate moment. When the facilitator asks them which activities they might think about to keep a link with former carers the answers are:

> *“We send them our newsletters for two or three years but then, if they don’t show up… Those people don’t come”*

> *“We have to help them to re-take their life in their hand. But it’s very unlikely that they come back to us [as volunteers]. However, if they call us we have psychological support available and our door is always open if they need to talk”.*

Focus group nr. 3

Although we invited several association working in Cesena Dostrict, just the members of three groups took part at the event. They are: The AISM, The Suffering Volunteers Center (CSV) and the Auser: they are three very different organizations.

AISM, a national organization, is represented by a volunteering from Cesena headquarters, his ill wife and a young person working as Civil Service Volunteer. In this association the memebers are both relatives of Alzheimer patients and volunteers (they are equally distributed). During the initial presentation they underlined that all carers volunteers, currently engaged in the association, jointed AISM when their relative got sick. Nobody remembers any volunteers who became member during his post caring phase. The fact that former carers rarely take part in this kind of activities is confirmed even by the members of the other two associations.

"Suffering Volunteers Center" has 150 members (50 of them are volunteers) and is related to the diocesan society present in Cesena. The interviewed volunteer is one of the most active person, historical voice of Cesena disabled people, chaibound since more than 40 years. She pointed out that none of the volunteers is carer or former carer. The majority of volunteers are middle age women linked to the local Parish. The main motivations are the faith and charity spirit. The association is trying to recruit new volunteers among common citizens in order to support Alzheimer patients relatives who are already charged of too many responsabilities and tasks.

The thirth association taking part to the focus group, represented by the president of Cesena base is AUSER. This is a national organization widspread in all Italian Regions. The Cesena District has around 3600 official members and about 700 volunteers. The organization is complex and is split in civic services (transport, support in road safety activities etc.) and social ones (keeping elderly company at the nurse home, helping elder people doing shopping, etc.). Moreover there are the Social Centers for Elderly people who carry out social and recreative activities. In this case the volunteer profile is an healthy and young pensioner, who aims to be involved in an organized, strong and recognized group. The AUSER President doesn't agree with the main LAC project idea that considers volunteering activities as a good opportunity for former carers. In fact according to his experiences in AUSER there aren't any former carers members. He realizes that he's never though about it and he's never considered important to ask potential AUSER members during their motivational interview some information about their previous caring activities.

The other people taking part to the focus group shares the same vision. Therefore the majority of them think that people with caring experience are not keen on carrying out volunteering activities. The main reason of this reticence has to be founded in the physiologcal consequences of grief process (time necesseray to re-start a new life…) and may-be in the different personal motivations. Following this logic an AISM volunteers said:

> " One thing is taking care of a relative and another thing is taking care of a stranger…"

AISM referent said that in his association former carers engaged as volunteers were around ten after their relatives death (usually the death of the husband/wife), but their engagement has decreased and it ended.

> *"After a couple of years, they gradually give up (…) in my opinion this attitude is completely understandable and normal…they had a new life and they just wanted to put their past behind them!"*

Once interviewer established that carers are not present in these associations, he invited the group to think about the potential relation between caring activities and volunteeing, in particular if volunteering can be a useful activity to support the transition from carers to former carers and to see their [carers/formers carers] acquired skills recognised and valorized.

After some initial general doubts, CSV referent answers in an affirmative way.

> *"…it's sure that this experience is useful because those people have a lot to give, but it's possible that they don't want to do it anymore or they aren't ready to do it! It's a such heavy activity! If I think about my personal experience I can say that former carers know how carrying out care activities! I'm thinking of my old mother who teached the social-health worker - sent by the Municipality for me - the right way for doing the phisioterapy exercices…"*

AUSER underlines that among his volunteers only a limited percentage are carers/former carers

> "…People don't actually want to be emotionally involved in their volunteering activity. The majority of people aim to carry out concrete services as the transport or the students crossing support in front of their schools…There are some people who really like to wear an uniform/ to be a sort of sergeant, while the persons engaged in the nursing home or in elderly households support activities are very few. They are usually women and they often give up. It means that who was carer in the past for a relative may-be he/she won't be a carer in the future for a stranger person. This kind of experience demands a very strong emotional and relational involvement."

The AISM referent considers that self-help and mutual aid groups and the helplines are the best supporting volunteering sector to valorized the carers/former carers acquired skills, in fact in these contexts carers can share their experience and can offer a concrete aid to people who have just started their caring activity.

The group debate is about the motivations that lead people to spend their time in volunteering activities during their post caring period. The majority agree that people who keep taking care of other people (strangers) after a long period caring are deeply motivated, they are guided by a strong religious faith or very keen on caring because this kind of activities gives them a sense to their life.

CSV volunteer adds a last reason, the cultural one.

> *"The post World War generation lives disability with modesty almost shame. It's anusual that they go out and try finding a support in their enlarged family. Young people are different. I know some families with mentally disabled children that after the children*

> *discharge from the hospital they addresse to some specific associationsin order to share their experience.*

Focus group nr. 4

In this group there were associations of relatives of people suffering from seriuos cancer deseases, disabilities or dementia. People who took part in it were three volunteers of CAIMA association (an Alzheimer association): one former carer and two current carers.

Once the interviewer explained the focus group aim the participants start comparing their experiences. One of them tells how he the association saved him and in particular he underlined the importance of the mutual aid groups carried out by the psychologist.

> *"Within the group I told that I was very angry and at home I always screamed and she (the psychologist) said to me that it was a normal and human reaction and it happened in the same way to everybody experiencing the same situation I had experienced. I started getting involved both in the association and in the group. I started working as volunteer…It took me quiet long time to understand that this new activity was good for me and for my wife. They supported me to take some time for me and to unwind. "If you want to be useful for your wife you have to be strong and you have to take care of yourself", they told me. For exemple, they convinced me to restart swimming. I liked going to the beach and swimming a couple of hours with the flippers. Then I stopped. In the last months I've been back to the swimming pool, it's near to my hause…"*

Indeed the former carer tells us some anecdotes about his large and heavy care experience addressed to his parents seriousely sick, one of them suffering from Alzheimer. He remembers how he was contacted by the hospital when he was experincing one of the most heavy periods of his caring, the persons at the phone proposed to him to take part to a self-help and mutual aid group dedicated to relatives of dementia patiences. In that moment he wasn't able to joint this group because he couldn't delegate his parents care and even because he didn't understand the proposal value:

> *"While I was having all these problems, I remember someone called me from the hospital to invite me to some meetings supervisored by a psychologist. I remember that I thought about the difficulty to go out during the evening time because I had to find a care worker for my parents, therefore I thought "I see that at school psycholigists are not so good in finding a solution for the young students problems so I won't go to these meetings…". Nowadays, I regret that! Probably who made me that proposal wasn't so persuasive and I wasn't ready to accepte this proposal."*

After about 3 years his parents death a new invitation comes and this time his attitude has changed:

> *"After my parents death, I used to visit the social worker once or twice per year just to keep in contact with her. Once she gave me some copies of a book about Alzheimer ("Non so cosa avrei fatto senz a di te/ I don't know what I could do without you", by Emilia Romagna Region) and she made me aware about this association. After a few days I found a message of the psychologist in my answering machine therefore I started attending this meetings, after some weeks we had some social dinners and then I became part of the group. (…) I met people talking whit my same language. I felt that I was understood and that I had the opportunity to share my story and my experience with someone and it helped me to stay in the association. Anyway we have to consider that each experience is different from the other ones. Nowaday I go to the association once per week. I really need it!"*

Everybody agrees with the idea that former carers are particulary useful in this sector because they can help with concrete suggestions and direct experiences those people who contact the association during the first phase of their relative's desease. In fact former carers can give information about the desease evolution and about the way they dealt with the situation (so how they made it) and it's a source of relief!

The main problem is, in case, the recruitement of new volunteers. The association can relies on a large number of members but just a small minority of them is actively involved in the activies. Moreover only a very small number of volunteers remains involved after his/her care recipient dies.

> *"Neverthless we've never locked the door, people rarely overpass it. If we had for exemple one volunteer of each family we would be a flood of people. Unfortunately it'doesn't happen! We have some volunteers who drive the minibus for our transport service. At the moment we have to close this service because we aren't able to cover all needs…"*

The issue of the new members is a very burning issue. The association has become bigger during the time, but more in the side of activities and collaborations dimension than in this one of the volunteers number. That makes the oldest volunteers very stressed and charged of responsabilities, while new volunteers arevery few. The majority of active volunteers are carers, just a minority are former carers.

They told us that in the last years several volunteers-carers died, that underlines how those people's lives are vulnerable and heavy. All the interviewees list us all the tasks they have to do within the association, the activities are so many that the interviewer can realize how much they are busy.

The debate sparks off when one of the interviewees talks about the economical issue. In fact the altruism and the solidarity are fundamental motivation factors but it's even important to take into account the material aspects.

> *"…It depends on how long social and human motivations will prevail over the economical costs. In my opinion this is a crucial aspect. Volunteers can receive some money to go to the bar, to buy cigarettes to cover some little expenditures…"*

When they are asked which reasons convince them to remain in the association they all answer that it's a human reason: the activities association target gets in better thanks to the volunteers involvement.

Another very important reason refers to the sense of belonging to the association. The contribution to its foundation and to its current work represents a reason of pride and satisfaction.

> *"We are here because we believe in our volunteering activity, because we have created something important and the fact that today it works and Health local services and other local governements ask for our support confirms its importance…The idea of Caffé Alzheimer, one old idea launched by our psychologist, was considered as a model by our Region (Emilia Romagna Region)…We get a great gratification from that. Moreover the book by Gianni Pavanello with the pictures of his wife suffering from Alzheimer…All these things give us the sense to be here."*

Therefore former carers are considered as an important resource for the association activities promotion and support: especially for the self-help and mutual aid groups. About this issue someone remembers with a bit of nostalgia the previous periods when the helpline operators were almost exclusively carers while nowaday there is a profesional operator working in the counseling service. Former carers are involved even in the other association activities carried out by common volunteers such as: administrative dossiers, fundrising activities and campaigns, local authorities partnership and other services. Even in this kind of activities former carers show a more developed sense of solidarity and sacrifice.

Outcomes from the focus groups

All focus groups remark that caring activities often develop in carers a special sensitivity and the consciousness of the importance of helping others. These elements, linked with the sense of emptiness most carers feel when caring ends, suggest that volunteering might be an answer to need of re-taking life in their hands and also an important opportunity to create new social relationships.
As a participant to the focus says, referring to a volunteer that entered the association after the death of his wife that he cared for a long time:

> *"We are like a family to him. One month ago we celebrated his glycaemia because he suffers of diabetes. He came with a cake and a bottle of wine. He came to us when it's time to celebrate, he goes nowhere else".*

Not surprisingly, a survey made in the United Kingdom underlines that 70% of former carers get involved, in someway, in caring activities after the death of the care recipient.[12] This is probably also

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[12] Larkin Mary, *op.cit.*

due to the fact that – as stated by participants to the focus – caring makes “something change” in carers’ heart. They develop feelings and consciousnesses that were unknown before.

On the other hand, the possibility to involve or not former carers in volunteering seems very much related with the caring experience they lived and by the type of proposed activities: caring for someone with Alzheimer disease seems to be such a demanding experience that they don’t want to repeat it, even if in a mediated way like volunteering. The gratitude of carers who had been helped by the association is expressed more gladly through economic contributions or – eventually – in participation to fund raising activities that do not imply a direct relation with patients and their carers.

In the last focus group the interviewees underline that they feel very empowerd and rewarded to know their caring experience is effectively helpful for others. In this contexte we report the words of a volunteer belonging to CAIMA:

> *“I keep doing it because it made me feel good. I tried to carrying out volunteering activities at the counseling center and I found more strenght and motivation when I knew that my words have contributed to other people empowerment. When I discovered that my support was very positive I was motivated to keep doing my best. A lot of people are shy, they don’t’want to openly talk about their problems…it’s difficult to make them more self-confident and open to others. Our association is working even to improve this aspect.”*

Moreover the interviews point out that the mutual aid groups and the stories directly reported by the carers are fundamental experiences for the volunteers motivations and they represent an important set of services for the local community. That’s why the associations have to put more enphasis and energy in these services, avoiding an axcessive professionalization or rather avoiding to delegate all kind of care activities to the care professional workers (such as: psychologists, doctors,nurses, etc.).

Beyond valorizing carers personal experience and supporting them to understand their role and to overcome the post-caring void phase, the association can carry out another task mentioned in the two last focus groups. In fact, both groups point out the sense of belonging to the association as a strong motivation factor. There is a large literature about the relation between individual identity and organization sense of belonging; in this context we can see that this sense of belonging depends on the perticipation and the engagement level of each single member. The associations very often forget these aspects that become essential when the main target consists of carers/ former carers.

It’s relevant however that none of the associations do really have a “recruitment or retention strategy” of former carers and that the consciousness of difficulties related to the post-caring phase did not lead them to put in practice actions specifically dedicated to the support of former carers.

Moreover, it's clearly stated by members of volunteering organisations that – in order to keep new volunteers in the association – it is important to work on the motivations that made former carers take the decision to start volunteering. For instance, one of the participants to the focus, positively describes her first period as a volunteer:

> *"[The association] honoured us by giving us a lot of trust and importance"*

Another one tells how important it is for him that his engagement is acknowledged:

> *"When I commit to do something I do it: I always liked to start and finish things. I didn't want to get a gold medal, but an acknowledgment of what I did."*

The other declares his frustration for the incapacity of other members of the associaiton to understand the importance of his job:

> "*For instance, when the financial account [that he prepared] was presented to the board of the association, I thought there were people up tp making questions I could have answered too, instead I was disappointed. The level of the members of the council is very low".*

PRIS: a tool to investigate motivations

Motivation means "motion to action". This word express a connection between an impulse and an aim (a need to satisfy). Motivation can be described as an inner push that leads the individual to apply himself to an activity with commitment. It is a sort of inner force that stimulates, regulates and support the most important actions made by an individual and that can be described as a circle: from the origin of the need, felt as a inner tension, the individual look for the way through which this need can be filled.

To understand which is the motivation that leads a former carer to be engaged in volunteering can be very important to understand his/her expectations and elements that can be used as a leverage to allow a easier insertion and, above all, a retention in the association.

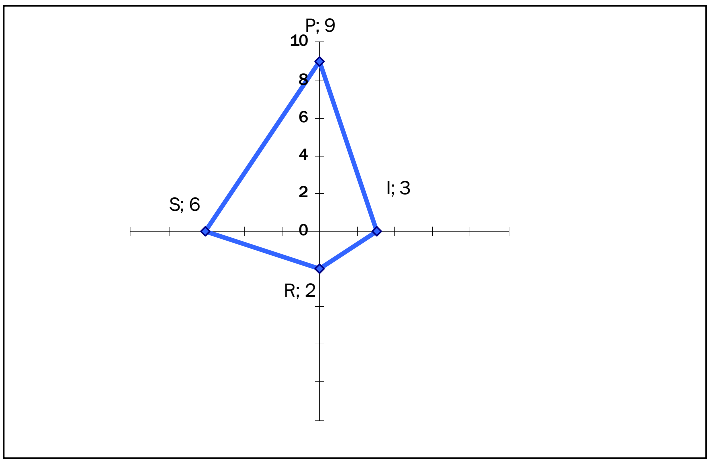
The tool we used in our survey to analyse motivations in carer available to work as volunteers is called **PRIS.** It's a questionnaire with multiple options in which the interviewee is asked to declare how he would react in specific circumstances. Each possible answer contain indicators that allow to position the individual in relation with two vectors:

- the first axis has on one end **Proactivity** (the tendency to take decision autonomously, the commitment towards aims, the orientation towards innovation) and on the other **Reactivity** (the orientation to do one thing at a time, the loyalty to the team, the preference for a regulated and foreseeable environment).

- The second axis has on one hand **Individuality** (the tendency to a deep and meticulous analysis of situations, to caution, to the commitment to reach high quality standards) and on the other **Sociality** (the tendency to spread enthusiasm and to the activation of relations, even in new environments, and a strong orientation to team working).

The PRIS questionnaire, as an output, tells in which of the 15 "average profiles" the respondent can be positioned. Each of them is made according to the different combination of intensity of each of the four factors mentioned above.

Significantly, all carers involved in our survey who expressed an interest and an availability to volunteering have the same profile. The so called **"C Profile".**



Graphic representing PRIS "C" Profile

Scores for each factor are the following:

P (Proactivity) = **9**

R (Reactivity) = **2**

I (Individuality)= **3**

S (Sociality) = **6**

People belonging to this profile are motivated in situations in which they do not have to exercise a direct control. They do not like routine works and details that make them "loosing time". They are energetic and straightforward and they show self-confidence. They are impatient and critical. Their self-assurance can be considered excessive. Sometimes they are patient enough to clearly communicate their needs to others. They try to influence other people's way of thinking and acting, directing their behaviours towards a specific aim. They take initiatives and are able to mobilize others. They look for opportunities that allow them to test their capacities. Last, they like difficult tasks and they accept responsibilities.

People with this profile are generally motivated in a context that allow them to express their ideas, to be autonomous, to be involved in challenges and allow them to "lead" the team.
An effective employment of "C Profile" people implies that they are supported in trying to be more patient, more sensitive, more available to help others, to cooperate more and to pay higher attention to quality.

Referring to the associations involved in our research, we could imagine an effective employment of these carers in activities that can leave them more autonomy in the organisation of the job and that imply a certain degree of responsibility. On the other hand, it is possible that this kind of people can feel frustrated by a repetitive task, by an activity which requires a lot of accuracy or by a job depending by others.

Analysis of motivations in supporting the former carers' engagement in volunteering

The small dimension of our sample does not allow us any kind of statistical analysis on the issue of motivation neither – of course – we mean to state that all those former carers that decide to get involved in volunteering belong to the PRIS Profile "C".

The attempt to apply a research model designed for work contexts to our survey has instead the aim to **suggest an operational tool** to volunteering organisations that can support them in the analysis of motivations behind the choices of former carers, in order to allow an effective insertion – satisfying for the association and – of course – for the carer him/herself.

6. Conclusions

Life After Care project's rationale is that carers encounter difficulties in their transition from caring to post-caring.
Tangible and emotional difficulties that are undeniable and documented by the (few, unfortunately) researches available and by the daily life experiences of organisations working with and for this target group.

Nevertheless, our survey allowed us to enlighten the reverse side of the medal: caring experience – dramatic, hard, not-acknowledged as it is – if it will be adequately supported, can be for carers a great leverage for change and empowerment. Caring activities can't be carried out just by a person but it demands an integrated work of professionals, services, associations and especially by friends and family networks. Moreover we can add that when carers understand the effective sense of their activity, even under the worst conditions, they can have a good transition to post-caring. In this case it's important to underline the crucial role of social and health workers who can facilitate both the individual carers empowerment and the recognition of the skills they have acquired on the "job" that means the recognition of the importance and value of their activity.

Many, among social workers and carers themselves, recognise caring as a valuable experience from the human and emotional point of view. Few are those, instead, that are able to acknowledge and enhance the legacy of knowledge, abilities, competences and resources left by this experience. A legacy that might be put in practice to positively overcome a difficult moment as transition to post-caring.

The caring experience can become a resource both for the carer (even considering the employment aspect) and for the territory (the voluntary care activities'offer can be larger and more qualified). However it's important not to underestimate the risk of carers'burn out and their possible temptation to give up any kind of caring activities.
In order to avoid the mentioned risks, carers have to be supported in their activities through a concrete aid and an adequate training that can be both useful tools to deal with post-caring situation. Following this logic social and volunteering organizations and even companies working in this sector should re-think their "recruitement" system taking into consideration the social value that carers can receive from this important experience.

The volunteers and professional workers responsible for supporting carers during their caring experience have to be trained to recognise these competences and to valorize carers'role, that can be an effective strategy to increase carers self-confidence and to avoid their burn out..

The final remark is about the applied tool: this research has demonstrated the effectiveness of BEI methodology even in an informal context as care work is, in fact, it has been the first time of its application in a such field. For that reason it will be desiderable to have the opportunity to carry out further experimentations in order to achieve a more calibrated/scientific methodology.

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More information on Life After Care Project are available on the web site: www.lifeaftercare.eu