Case study: support and individual guidance as a tool for change and for personal and family progress in coping with care for a relative with dementia

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Abstract

Support and individual guidance are basic tools when it comes to bringing about changes and enhancing personal and family progress in coping with care for relatives with dementia. This is because these components make it possible to bring about an impact on day-to-day aspects, to provide guidance in natural contexts and to offer support for carers in the process, helping to gain an acquaintance of said care process while generating the changes of perspective needed to live with the disease. This line of work lies far beyond diagnosis and treatment since it seeks to keep up with the coping strategy faced by the relative in the personal circumstances of providing care during the highly complex, disturbing pathological process that is dementia.

The work of the referred professional in this process, in this case from the field of social work, constitutes a source of basic help which should deliver a specific, planned strategy in said process, supporting development, and personal and family progress, according to the moment and the circumstance.

Keywords: Support, coping, dementia care, help, progress.

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Introduction

Support is an essential tool in social intervention; it is not only about guiding or advising the person who is being attended, it goes much further. It seeks to establish a bond of ongoing support, in which the intervening professional creates a guided support process that assists service users in a sustainable and supportive manner, enhancing their resilience, and revitalising their capacity and ability to face the situation they are experiencing (Raya and Hernández, 2014). It has become a key element in fields such as social exclusion:

> Social inclusion strategies have assumed a central role in our welfare model and the range of social policies in Spain. Intervention in the field of social inclusion with individuals in a situation of or at risk of exclusion, and by extension, the group of professionals who work on tools and services, moves between demanding and varied requirements. These include supporting individuals with their processes of change and development of their potentialities and abilities, whilst simultaneously encouraging individuals to be socially competent and able to respond to the demands of an exclusionary society in medium and short timeframes and, at the same time, responding to situations of need and/or urgency of individuals participating in the programmes (Navarre Network for Combating Poverty and Social Exclusion, 2016, p. 13).

In this process it is essential that the professional acts as a linchpin to build appropriate relationships between both, in such a way that the professional functions as a guiding light for service users, able to offer them various means of participation, helping them to develop their abilities and understanding of the disease, and the changes and progress relating to it, in order to adapt as best as possible to their reality and interaction with the relative they live with.

> Individual social work, and also work in terms of support, is principally aimed at intervention in individual or family motivation and competences (Navarre Network for Combating Poverty and Social Exclusion, 2016, p.18).

This development should be paused and ongoing, so that service users can feel the help and support provided, whilst also experiencing the changes introduced in the process and the results thereof, empowering them to create their own assessments and decisions according to their vision and objectives. It is a matter of each professional getting closer to the context of individuals and their family and focusing on providing them with unconditional support (Fernández Solís and Castillo Sanz, 2010).

In the case of situations concerning dementia and its care, an inevitable empathic bond is formed between the principal carer and the family member with dementia. In this respect, the neurodegeneration caused by dementia entails various limiting circumstances that create dependency as a result of functional losses that invade the daily life of individuals and dismantle their life and relationships (Rodríguez and Sánchez, 2004; Losada, Peñacoba et al., 2008; López et al., 2009). This is a reality of caring that primarily affects women (Cameron and Moss, 2007; Durán, 2011; Rodríguez, 2011) and mainly occurs within the home (Gómez, 2007). In this process of ongoing care, instances of hypervigilance (Losada, Márquez et al., 2017), stress and even psycho-emotional suffering (Rodríguez, M. I. Archilla and M. Archilla, 2014; Bermejo, 2004) have been identified. Support is therefore necessary for the carer throughout this painful and difficult process.

The establishment of a bond where service users can be enriched and develop, progress and improve in their personal and family sphere, is the main objective of support which – following the initial and intensive process of change – should gradually be reduced as there is an increase in the competence and autonomy of the service users regarding their new vision and practical approach to facing the disease and living with the sick person.

Objectives

The case study within this paper involved the achievement of five objectives:

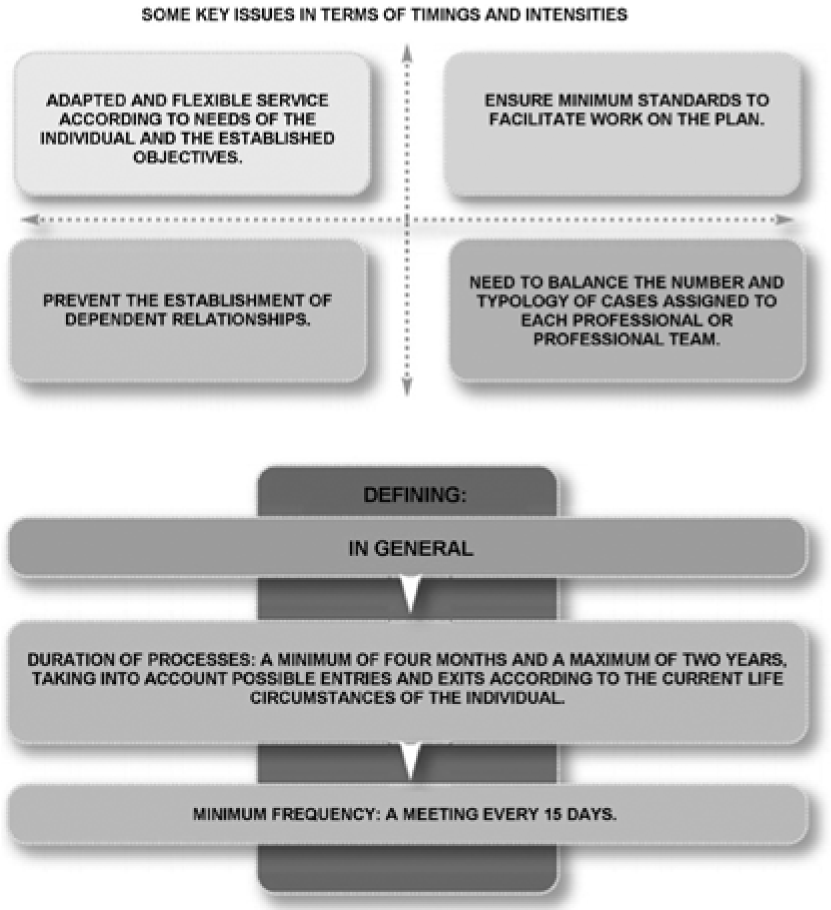
1. Attending to the explicit demand for support that the service user requested.
2. Establishing and defining a temporary support process for the service user, in line with her personal and family circumstances.
3. Developing a support methodology to improve circumstances for the service user.
4. Providing sustainable strategies and tools for coping with the family situation of the service user being attended to.
5. Verifying the existence or non-existence of improvements in intra-family relationships of the service user with her mother, as well as the acquisition of strategies and tools.

These objectives are all linked to the creation of a supporting bond, via support and empowerment of the individual attended to from the perspective of sustainable personal and family development. The overall approach is to empower the individual to adapt to and cope with the life circumstance that she is experiencing, and to enable progressive development in the short, medium and long term.

Methodology

Support is a “temporary professional intervention method, of varying intensity, based on the right of citizens to have a personalised relationship of social care or support. Starting from a proactive and trusting relationship and through a jointly-designed personalised inclusion plan with objectives in line with needs, it should provide an opportunity for improvement or harm reduction. It should be geared towards developing the potentialities and capabilities of the individual and discovering and reinterpreting the key situation of change, in order to assume a leading role in the social project itself" (Navarre Network for Combating Poverty and Social Exclusion, 2016, p. 23).

Figure 1. Support and its timely intensity



Source: Navarre Network for Combating Poverty and Social Exclusion, 2016, p. 26.

To implement this support and ensure it is effective, three key initial factors need to be taken into account: situation of vulnerability, "abandonment" and/or bewilderment of the carer, expressed need and request for support in the process, and a professional individual with knowledge of the pathology and intra-family dynamics.

Based on these premises, the support process is a slow, gradual and sustained approach. It develops over a specific but flexible time period, periodically assessing the progress of the service user and fostering their development and progress at all times, avoiding directivity and generating new approaches to be considered for adoption or otherwise in their own personal and family development.

It is for this reason that ongoing and regular appointments were arranged, once a month, in a private space (always the same), which afforded the necessary privacy and familiarity to be able to move forward in the support process.

The *initial appointment* was marked by the commencement of the support, with a meeting taking place between both individuals to become familiar with the situation, establish the need and offer the support.

Each of the *following appointments* were structured on the basis of three premises: an open space for opinions, thoughts and analysis from the service user since the previous meeting, active listening from the professional involved and emphasis on aspects for improvement (presentation and explanation of alternatives) and positive reinforcement of those aspects which had improved through changes in behaviour or implementation of new procedures or tasks discovered in the process or on the initiative of the carer. These are dialogue-based meeting and aid relationship techniques to encourage interaction and personal growth (Arnkil, 2019).

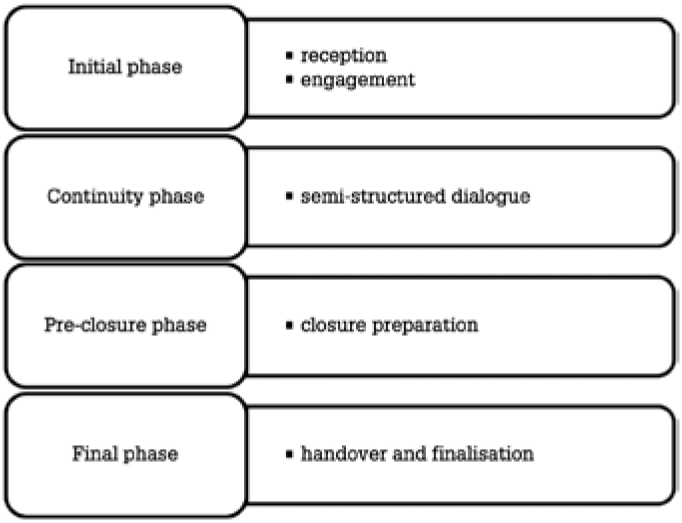
Three months *before the end* of the process, and having observed and established a progression of competences and new focal points for approaching and coping with the disease, to the point of considering the support to be concluded, the professional informed the service user of the positive progress in her development and the approach for ending the intervention, proceeding to two final appointments, by mutual agreement, to consolidate the elements that had been achieved and developed, as well as preparing for the untying of support.

Throughout the process, the *interview* stood out as an excellent technique; this is an intervention method that facilitates communication and the support relationship. In particular, the motivational interview was used as a foundation (Miller and Rollnick, 1990), as the aim was essentially to foster personal resources and the capacity for resilience and self-affirmation of her competences, and also personal growth through the process that had been initiated.

Another technique used was *self-reporting*, through the diary completed by the person being attended to, as suggested by the professional. In this way, her experiences were also captured and her own progress could be seen during the process, as well as any difficulties and established coping strategies. This self-analysis enabled learning and subsequent development of alternatives and lessons for the processes that followed.

Furthermore, the *life story* was used in the initial interviews as a method for obtaining the necessary information for diagnosis, as well as boosting awareness and promoting engagement. The support process that was carried out can be observed in Figure 2.

Figure 2. Chronological support process



Source: prepared by the author.

Results

The results obtained were recorded by the professional and the service user via a diary, as suggested by the professional. This was subsequently of partial assistance to the mentor, for the purpose of analysis. A total of 18 appointments took place on a monthly basis over a period of 18 months, with each appointment lasting for 2 hours 30 minutes. The appointments always took place in the same place, day and time (with the exception of changes suggested by the service user due to personal reasons, though always maintaining the monthly basis and support time). There was, therefore, a total of 45 hours of direct intervention.

These results demonstrate positive progress from the commencement of support, and how the service user was feeling until the support ended. Various stages or phases can be established according to personal circumstances and subsequent progress. The service user experienced a process of acceptance and awareness, as well as reformulation of her own expectations, getting closer to the context of the disease and life situation of her mother. In addition, she gained and developed strategies of action which not only reduced her stress and discontentment, but also allowed the emergence of a positive relationship between both individuals.

Context

The service user is a woman in her 40s who is self-sufficient and independent. She lives alone, and has a partner with relative stability. She has received the news that her mother is suffering from Alzheimer's, following an accidental fall in her house and her subsequent admission to hospital. Following this admission her mother presented with acute confusional states which were assessed by neurology, which detected mild cognitive impairment (MCI) which soon leads to the definitive diagnosis (Alzheimer's). As an only child, she feels the obligation to care for her mother, but she does not know how to do so, lacks daily guidance and seeks to understand the disease and what is happening. Above all, she is worried about what to do and whether or not it is the correct course of action. She feels frustrated and comments that her mother suffered from schizophrenia, which prevented her from having a normal daily relationship with her and other individuals (she spent 20 years without leaving the house), with the resulting interpersonal detachment and mother-child dissociation.

Initial Phase

This phase falls within the first three months of support. The service user demonstrates a need for support and quickly establishes a bond with her mentor. The need and the situation are obvious and are diagnosed in the first interview through the life story. The service user exhibits distress and nervousness, and literally says: "with the diagnosis I broke down, until that moment it did not seem to me that it was that bad", "this is only going to get worse", "it is me that has to make decisions and I always have to make them very quickly", "I have to deal with everything", "I am not doing well with the fact that she has taken over my house" (her mother had moved in with her).

It is a period marked by anguish, discontent and pessimism, as well as excessive burden. She has to accept an imposed and undesired reality, altering her life plans to adapt to an adverse situation.

The burden created by the absence of a prior relationship has an impact on the present time. Her mother is a stranger who exhibited delusions and hallucinations as a result of schizophrenia, which had pushed apart and almost destroyed the relationship between them both: "she said that there were some balls in the street that were going to kill her, and with that she spent 20 years without leaving the house", "we no longer had a relationship, the occasional phone call and little more", "it is very difficult when a person is not well and you cannot do anything to change it... you get used to it... and you end up carrying on with life". Taking on unwanted care duties, but at the same time choosing to do so over other options, created an ambiguity on the part of the service user that hampered the establishment of a relationship and related coping mechanism: "well, I know that I may have another option, but I do not see it either, it is what I feel I have to do... and I also want to do it... but on the other hand... I despair".

At the same time, her ongoing need was to find out what she had to do and how to do it. She hoped for short-term solutions that would change the degenerative process, with an unrealistic hope for improvement: "I know that it is not going to improve, because I already know that this is the way it is... but I think that with willpower things can be achieved, and if I can help her to do things then she will be able return to being, at least, more independent".

Development Phase

This phase is set in the 12 following months after the commencement of the support relationship. During this period, the service user undertakes a process of acceptance of the disease and the care, channelling her energy towards resolving specific issues, proposing viable objectives and strengthening the mother-child relationship.

It is a time of increased personal and family growth. The service user expresses: "I have got back a relationship with my mother that had been lost for years", "I see that I need to live in the moment", "before it would have not meant a great deal to me if she had died, but now it makes me sad", "I can see that she is happy", "she is very affectionate towards me". From this perspective, the service user has learnt how to change her initial negative view, and her ongoing attempts to teach her mother, and how to focus her behaviour towards normality, through a gradual acceptance of the disease and its limitations. This has enabled her to move towards positive emotional elements which are centred on the relationship and not on the pathological progression. This has had the effect of her gaining greater awareness of the disease and has progressively reduced her feeling of discontentment and directivity.

Specific daily elements were worked on during this period, such as sequences of action and behaviours that the service user expected from her mother and did not receive (such as going to and returning from the bus stop alone or carrying out a specific household task). The service user did not initially understand why she was not capable of carrying out these tasks: "it is very simple; going to and returning from the bus stop is easy and it would solve a lot for me if she could go". Work was done with her concerning reference signals, support and the sequence of steps to be taken. The use of a day care centre in the locality was also suggested to her, to provide cognitive stimulation and care for several hours while the service user was working. Eventually, she chose to hire a person when she observed the limitations of her mother.

In terms of the stimulations implemented by the service user, she was focused on strengthening general aspects and items obtained from scientific studies. For example, she read that learning to play chess is very beneficial for preventing Alzheimer's, and she suggested that her mother could learn to play chess. The professional redirected this matter towards viable and pragmatic elements related to the life story of her mother in order to strengthen such associations and learning, avoiding the introduction of new stress-causing and inefficient factors.

The elaboration of her mother's life story had a restorative effect on the relationship between them both: "look, I am remembering things that I had previously forgotten about her". These matters prompted the service user to speak with her mother and find out information about her (living relatives nearby, specifically two aunties, the mother's sisters), boosting her memory association and reliving healthy aspects of her childhood and youth.

The mother regained lost habits, such as knitting, and became more extroverted and affectionate: "now she speaks with everyone, it is as if she were another person, I cannot remember seeing her like this", "she tells you things from when she was a child and a youngster, she remembers this well", "she is always happy, not like before, and when we sit on the sofa she strokes my hair", "she is always telling me that she loves me very much".

Positive feedback between the mother and daughter enabled the initial feelings and elevated stress levels of the service user – due to the situation experienced – to reduce. In this respect, the attitude of the mother also became increasingly tolerant and affectionate.

The service user learnt how to place herself in the moment and how to focus on solving issues as they arise in order to appreciate current experiences: "they told me to put her in a care home as soon as possible, as soon as a place became available, but I told them no, as I am now starting to enjoy being with her, I do not want to, there will be a time for that, at the moment she is fine in order to be with me". Avoidance of anticipatory grief and looking towards enjoying the moment, focusing on tackling each circumstance as it arises, were key aspects in the process that the service user followed and gradually discovered.

Final Phase

Coinciding with the final three months of support, the service user demonstrated personal abilities of resilience and progress; she felt supported and was able to develop a more positive relationship. She expressed: "now I feel good, I feel calm", "I needed someone to talk to and to tell me if it was going well or not", "you have made me feel good". She expressed her gratitude for the support that she considers to be a key aspect in this process and that has enabled her to progress from a personal and family perspective, facing such a complex issue as dementia.

She understood the closure of the support process, having acquired competences and tools for coping with the process, whilst remaining aware of the fact that she might need support in the future. At this point, her achievements and competency were strengthened and essential aspects of support to enable continuity were recalled (developed strategies, learning, objectives, etc.).

Conclusions

Regarding the stated objectives, all of the elements that were initially presented have been accomplished. In reference to attending to the need for help that the service user requested (objective 1), establishment of a support process over 18 months on a periodic basis (monthly), which facilitated the monitoring of the aid relationship and the establishment of listening spaces, approach guidelines, consolidation of achieved elements and readjustment of unsuccessful strategies. In reference to the establishment and definition of a temporary support process in line with the personal and family circumstances of the service user (objective 2), creation of a specific and comprehensive space from the outset of the intervention, setting a time limit, enabled the provision of a relationship structure aimed at specific objectives which focused on coping with the development of the disease and living together with the affected family member. In reference to the development of a support methodology to improve the life situation of the service user (objective 3), this was implemented, adjusted and reviewed throughout the process, which enabled flexible adaptation to the various aspects of knowledge and the life experiences the service user encountered. In reference to the provision of sustainable strategies and tools for coping with the family situation of the service user (objective 4), throughout the intervention the professional figure reinforced those elements where the service user independently experienced or requested confirmation of use, and which were appropriate for the development of positive strategies; at the same time as proposing other approaches and elements that addressed difficulties expressed by the service user, investigating aspects of daily family life. Finally, regarding the verification of improvements in the intra-family relationship and acquisition of the proposed strategies and tools (objective 5), it should be noted that, in line with the improvements experienced and told by the service user herself, she was able to accept the reality of living with the sick person and able to create effective coping strategies, improving her intra-family relationship. However, it is not possible to guarantee the existence of subsequent long-term sustainability, since, although she did not return to request support during the period of two years after closure of the intervention, it has not been possible to establish whether she did so afterwards through another professional. This means that it can only be confirmed that this support has been effective in the short and medium-term.

This case study demonstrates the efficacy of the intervention by means of personalised support. Other studies, such as that of Pulice (2016), point to the relevance of supporting carers to cope with neurodegeneration caused by Alzheimer's and other types of dementia. It is observed how it is possible to offer a framework for action that is compatible with care and support approaches that are specific to social work.

A particularly important aspect is the ability to increase flexibility, both in terms of the time dedicated to care and the intensity in each process. In the case presented here, the gradual adaptation to change and user needs yielded positive results that, with their ups and downs and difficult moments, fed into a resilient process. The need to establish a working path that is adaptable to the context and circumstance is essential for support provision. Moreover, it is necessary to provide guidance based on knowledge and intervention in a specific social, family and personal context, and not from generalised guidelines with limited efficacy.

Regarding limitations of the study, working with a single case clearly provides a partial view and an exercise that is limited to a single life situation. However, it is from this very support exercise (observed as a positive process in many other cases) and its development and recording, that it is possible to define the scope of action and shape increasingly precise methodologies and techniques. It is necessary to visualise and draw attention to these methods and share different experiences to enable improvement of interventions and evaluation of efficacy and efficiency levels. In this way, support is emerging as a methodology that is capable of promoting and developing resilient aspects in the face of complex, difficult and increasingly frequent processes, such as caring for family members with dementia.

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