

Place of caregiver who accompanies a person with Alzheimer's disease or related, what should be their role

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SUMMARY

Alzheimer's disease or related diseases hits very hard the society. With alarming statistics and an absence so far, of curative and preventive solution, the non-drug approach nonetheless improves the quality of life of patients by allowing them to regain more autonomy, memory and so on and therefore likely to delay the advancement of the symptoms of the disease. The solution that seems most promising would be to develop a "helping-assisted" momentum that should help protect the caregiver in a more appropriate climate with the caregiver. In this article, we want to redefine the role of the caregiver, missions, but also his needs, when accompanying a person with the disease. Thus, we suggest the use of an "Intelligent and shared" booklet that will help manage this dynamic of the helping - helped couple. This "Smart and Shared" notebook would be computerized to answer certain requests concerning home activities, the medical aspect, the follow-up of the patient, the reports of the non-medical sessions and other activities in medical environment or at home. This connected notebook, once produced, could represent a robust and reliable assistance for the Near Career in his activities of accompaniment of the helped.

INTRODUCTION

Aging and caregiver's statistics

With the aging of the population, Alzheimer's disease is hitting in an increased way. According to the World Health Organization (WHO) [1], an estimated 47.5 million people around the world suffer from neurodegenerative dementia. Alzheimer's disease is involved in 60 to 70% of cases. The number of new cases of dementia per year is about 7.7 million and the World Health Organization (WHO) estimates that the total number of people with dementia is expected to reach 75.6 million in 2030 and 135, 5 million in 2050. Thus, the number of people with neurodegenerative dementia is expected to nearly double every 20 years.

In Canada, 1.1 million Canadians are directly or indirectly affected by the disease with an annual cost of \$ 10.4 billion. About 65% of Canadians diagnosed positive after age 65 are women [2]. In the greater Quebec region (region 03), 125,000 Quebecers are affected by the disease, including nearly 15,000 people in the city of Quebec City and the surrounding area

alone [2]. For each affected person, two or three members of the family must provide care. In 70 per cent of cases, caregivers are women [bibliographic].

Every day in France, there are 616 new cases, per day of Alzheimer's disease, or 225,000 new patients per year, a new case every three minutes. Women with Alzheimer's disease are three times more likely than men. In France, more than 3 million undeclared people are affected by Alzheimer's disease [2] against 850,000 reported cases.

Alzheimer illness and the caregiver

As a reminder, Alzheimer's disease is a neurodegenerative disease that is the most common form of cognitive impairment currently. It is a progressive brain disease that causes problems with memory, reasoning, behavior and motor skills. The symptoms of Alzheimer's disease worsen slowly over time, it is progressive and proves fatal in more or less long term [3-5].

The risk of Alzheimer's increases considerably with age, after age 65, the risk of developing Alzheimer's doubles every five years, reaching nearly fifty percent at age 85. When the disease starts before the age of 65, it's an early Alzheimer disease [5].

There are two approaches to fighting the disease:

- **Drug approach:** the goal is to develop drugs that can stop the disease or even slow it down. To date, there are no drugs that can cure the disease, it is not healed. The latest results from a large Danish pharmaceutical company show that idalopirdine does not give a positive result in delaying the effects of the disease on the patient as underlined by Dr. Alireza Atri of the California Pacific Medical Center in San Francisco in the journal of the American Medical Association (JAMA) [11].
- **Non-drug approach:** its aim is to slow down the effects of the disease, from cognitive stimulation [14-15] or other activities such as those of daily life of the patient ADL (Activities of daily living) and from home life ALH (Activities of life at home). Home care is becoming an imperative in our current societies. At the same time, the disease leads to behavioral problems such as agitation, aggression and instability.

THE CAREGIVER NAMED DESPITE THEY TRIES TO FIND THEIR PLACE WITH THE HELPER, SOCIETAL SOLUTIONS ARE OFFERED TO THEY

As long as the disease is not diagnosed, the "caregiver" as such does not exist and there is no diploma for that purpose! He is the spouse, sister or brother, the sympathetic caring son or daughter who accompanies the parent, weakened by old age or by their disability, he is "the natural caregiver". According to the specialists, the alteration of the brain is assimilated to the advanced age of the person [17]. The anomalies of this one go unnoticed, life on a daily basis trivializes. Then, the first signs of the disease appear in an "insidious", painless way... The finding is relentless... The verdict "Falls", cold and it is fright and everything collapses around the caregiver. Intuition is confirmed, you have to organize with your family! The announcement is usually accompanied by five phases described by Elisabeth Kübler-Ross quoted in the note below. The placement of the sick person is excluded, he remains at home, an approach encouraged with the family with what this induces: "Living together kills us, separating us is deadly" [JP. Clot, p. 148]. Remains to find the family member who will take care of "the" parent, sick of Alzheimer's, and thus become the close caregiver, despite them. Over time, the load is felt as a burden for the "Caregiver" [18].

The designated caregiver, chosen by family members or auto programmed, engages in a family loyalty in the form of a moral contract whereas he or she will have to take care of the family member reached by the illness to the end. An irreversible situation that will have to be

watched closely so that the caregiver does not darken in depression, loneliness and somatization! The caregiver will ban leisure, free time and excess professional work. For Nathalie Décatoire [22] the caregiver ages at the same time as the disease advances or progresses. He gets tired, discourages himself and runs out. We are not helper, we will become, and then we become "expert" helper.

Several organizations, such as the High Authority of Health (HAS), the Canadian or French Ministries of health, France Alzheimer's, international organizations such as the United Nations or the Caregiver's manifesto facilitated by the grouping of caregivers Montreal's natural habitats offer several definitions of the caregiver. In this article, we will retain that of the HAS which seems to us the most suitable and the most complete to the situation of the caregiver: "The so-called natural or informal caregivers" are the non-professional persons who come to help on the main, for part or Totally, to a person dependent on their entourage for the activities of daily life. This regular aid can be provided on a permanent basis or not and can take several forms, including nursing, care, social support and maintenance of autonomy, administrative procedures, coordination, vigilance Psychological support, communication, domestic activities, etc.

Jean Noël Ringuet [23] complements this definition by integrating the notions of ethics and policy where it shows that in the face of the increasing number of patients, governments, in general, are financially disengaging from aid to caregivers and that Caregivers will increasingly need resources and support. Thus, for the same author, "The Caregiver will change status and become close helping, protecting the caregiver is a matter of ethics". A question will arise: when, a professional recognition of the caregiver is a professional qualification...?

In the meantime, this situation is cumbersome to bear by the caregiver. Under the impetus of various Governments or reports of experts, financiers, donors, community companies, private or public respite devices... Caregivers are accompanied, listened to and advised to alleviate their tasks with Help them by offering them innovative solutions. [24-25].

The helpers are supported to participate in different programs like:

- Stimulation activities Assisted**, at the light, moderate or severe stage is received in reception centres outside the home at half-day until the week as day receptions in France or in the reception centre in Quebec. The Alzheimer society, the evasion reception centre or non-profit organizations "pause time" offer individualized or grouped stimulation activity plans with qualified staff and generally multilingualism. These activity centres provide caregivers with a respite of varying duration. Agencies are involved in different territories. Professionals can also go home for stimulation activities, providing caregivers with a few hours of respite. In France, these are specialized Alzheimer teams [26] who intervene at home on programmes of a few hours spread over several weeks, under the responsibility of an occupational therapist and caregivers.
- The respite of the close caregiver at home**. The company "Baluchon Québec" offers volunteer at home to replace the caregiver for several days up to fourteen days. The caregiver leaves the home during the presence of the volunteer. This replaces the caregiver in their daily life with the helper. In France, it is the principle of "relayeuses" that is experienced in France. The French Labour Code does not favour this kind of service.
- In a temporary or permanent structure**. When the disease is too advanced, the solution is to place the assisted in temporary structures. Rooms are provided for a few days to give relief to caregivers, while taking care of other activities. Then, when the helper is in

the late stages of the disease and that staying home becomes dangerous to help them, he is placed in long stay in permanent structures.

In order to better accompany the caregiver in its accompanying load of the assisted, the same community organizations inform and train them through different services, such as:

- Conferences with caregivers are offered by** Alzheimer companies, and many community associations on a wide variety of topics and news in the direction of caregivers. Teleconferences are proposed by coordinated digital platforms of caregiver networks.
- Support groups and information** on cognitive disorders, resources in the Community network, Alzheimer's cafes on various topics, meditation groups for caregivers on reducing stress, suffering, exhaustion...

The respective governments, national or professional associations and universities publish guides, booklets, "Tips or tricks" towards caregivers such as the guide for the family caregiver of France Alzheimer, the Guide for The caregiver of the Alzheimer Society of Canada, the six practices to support caregivers on a daily basis, helped her, for the dyad-assisted, qualified staff... written by the Quebec respite organization, tips and tricks for caregivers. Helping a Caregiver "published by the University Institute of Geriatrics in Montreal, Quebec, the" Senior Caregiver "booklet written by a professional organization. It presents the role of the caregiver during the illness and the support it can benefit from. Finally, in the context of companies, wage agreements allow employees to adapt their working time, to give priority to timeshare, to telework...

In order to evaluate the autonomy of the helpers in the context of the activities of their daily life, tools are used to measure the level of autonomy according to the progress of the disease. The AGGIR grid (autonomy, gerontology, ISO-resources groups) in France, which establishes six levels of dependency, and the ISO-SMAF (functional autonomy measurement system, "Evaluation of multi-client autonomy"), developed in 1983 in Quebec and Canada at the Université de Sherbrooke. ESMAFII ® software is currently available to professionals [27].

We have presented in this chapter what we believe to be essential as a response to help for caregivers. If the offer is plural and individualized according to the needs of each aided, it is not sufficient, the dyad "close helping-assisted" should be better structured during the evolution of the disease. We will therefore take an interest in the caregiver by proposing an adapted and scalable follow-up workbook according to their needs to better accompany [28-29] helped they. It is a matter of building a close helping couple – helped in order to improve the quality of the helped as long as possible.

In summary, the caregiver must accompany [Martine Beauvais] to help her to walk, to build and to achieve their goals and objectives in the context of everyday life at home. The caregiver should also be better informed about the illness of the aid and its manifestations, better knowledge of its skills and resources as a close caregiver, be warned and prevent crisis and emergency situations, be helped in the Communication between they and their parents and the medical world, finally, adjust their interventions according to the changing situations, get out of their sense of isolation and reconcile all the conflicting feelings that are a source of guilt [30].

ITS FUTURE ROLE, A FOLLOW-UP ROLE... ACCOMPANYING THE HELPED

The caregiver plays a crucial role in maintaining the health and well-being of the helper. He is a person who provides help from time to time, but in a continuous way.

The role of the accompaniment of the helper must not be limited only to giving medicines, watching they, helping they to dress, to feed they... but to the extent possible and above all without exceeding their limits and prerogatives of caregiver, to offer another "Proximity service" such as anticipating the activities of daily life and workshops to be followed for the purpose of cognitive stimulation, provided that they are informed and accompanied in real time. This new service can only be done if the caregiver is accompanied and protected on a daily basis from their mission as a caregiver and attendant.

With the objective of protecting the helper, a minimum of knowledge and information about the disease is necessary in order to qualify the caregiver. The latter must be able to define and know its limits by defining its role at the different stages of the disease. The perfect knowledge in the details of the different stages of the disease that the helper will face is a valuable data for the caregiver. Each stage will require actions to be carried out, information to be mastered... on the part of the close caregiver.

With the extension of it, the caregiver, is more and more connected and comfortable with the computer tools (Smartphone, Tablet...), it could integrate this digital evolution in the daily life of their personal as professional. It is in this digital context that we wish to propose to accompany and equip the caregiver with a computer tool, computer application rather "intelligent" to inform and train them on the evolution of the disease. A great frustration comes from ignorance of the different stages and symptoms of the disease, managing the taking of medications and appointments with the doctors, monitoring and results of the workshops of cognitive and physical stimulation in the reception centre... This tool could also help to share knowledge and experience among caregivers, assess the fragility of caregivers and provide assistance to caregivers.

Several proposals for liaison workbooks, accompanying booklets or activity workbooks exist [1], however they sometimes have a too descriptive role of events as an activity blog instead of being a more "smart" tool that would allow Respond to real-time queries about the activities carried out and the medical follow-up etc. For example, the application Tabbya [1] allows for the moment only a secure dialogue in real time between the participants and centered on the helper.

Some authors talk about caregivers [20] [34] because of their involvement with the helper and their daily knowledge of the disease through the help he accompanies. He adapts to help them by having as a line of conduct that Alzheimer's is a disease of memory and not of intelligence or of the mind. They are constantly helping them to find meaning in their lives and to relocate themselves in the space of life at home or in structure.

THE CAREGIVER'S NEED

After explaining the importance of providing caregivers with a digital application in order to protect them on a daily basis for their activities, it is a question of identifying the need in a more specific way. However, you have to be sure that the need will satisfy the user, commonly called the customer.

If we refer to the scientific bibliography, we find that different authors have focused in recent years, on the experience of the user, called: User Experience. This refers to the total experience of a person using a particular product, system or service. Its use must be intuitive, the answers must be found naturally and quickly. In fact, it's about optimizing the design of a tool, product or other to make it as efficient and usable as possible.

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The purpose of the practice of the user's experience is to determine its satisfaction with the use of the functions on the one hand and how to make them evolve both on the form, on the merits, and on the way to access them (visibility, accessibility), as well as the impact on the product. The product is no longer solely based on ergonomic criteria.

The terms "effective", "desirable", "credible" and "enjoyable" in addition to usability criteria such as "useful", "usable", "used", "findable" and "accessible" are all criteria or value judgments to be taken into account in a starter Functional analysis.

To do this, we use the functional analysis of Need approach [35]. and in particular the need analysis [36]. This approach is concerned with competitiveness and quality; it accompanies the ISO 9001 certification approaches to models of excellence, such as the European Foundation for quality Management (EFQM). The AFB represents the first step in an action to analyze the value defined by the standard NFX 50-152 [37], such as the functional expression of the need (EFB) and the functional analysis, defined by the functional load specification (CWDC) defined by the Standard NFX 50-151.

In our study, the purpose of the activities of the AFB is to define the population covered by this follow-up workbook and the "user" type. We will complete our study, using the tool of the suitable firm ® [Biblio] "Analysis of the need", answering three questions:-to whom the system, the product, the service... it makes service?. It is essential to specify the type of user of this need, its peculiarity or specificity,-on whom, on what the system, the product, the service... it works? It is important not to omit any element on which the product, service or system works,

-and, finally for what purpose or objective result this need exists? It is necessary to describe the intended goal and not the how we're going to achieve it. In our study, we will quantify this goal in the form of outcomes to achieve.

This work was carried out with two groups, a group of 3 non-expert persons on the approach (members of the Medico-social Corps) and a group of 4 experts on the approach of the analysis of the value.

Before answering the three questions, the approach recommends to clarify the orientation of the action of the analysis of the value. It is a matter of clarifying the objectives and the framework for this action. In our case, the objective is how to equip the caregiver with a tracking system in order to accompany and secure the follow-up of the help he has in charge. The aim of this monitoring system is also to ensure the protection of the caregiver in its accompanying missions of the assisted. An exhaustive study on the follow-up workbooks, the patents deposited, the copyright... will be necessary in order to properly position our project of Health booklet. A complementary article to this one is being drafted. The cost aspects will also have to be mentioned.

Who's doing the service?

-Caregiver of proximity or family, the caregiver who has the responsibility to help they and accompany they in the daily life at home,

- Caregiver who has legal responsibility or who has the authority recognized by the law or by the family of the taking over,
- 'La Baluchonnoise' in Quebec, the French relay in France who will have the authority to take care of the assisted at home between 4 and 14 days,
- members of the medical Corps who are in direct contact with the helper such as caregivers, occupational therapists, nurses, doctors, Neuropsychologists..., -family members in the proximity of the caregiver.

On who, what is it about?

- On the evolution of the different stages of the disease in order to accompany the caregiver,
- On the memory of the helped, the reminder of episodes of daily life, memories close or old,
- On the activities of the daily life of the assisted, on their well-being, on their sociability..., on the effects of the disease in order to slow it down,
- On the protection of the caregiver by accompanying them in their steps to help them in everyday life,
- On the financing of the various supports of the helped,
- On the benefits of the late arrival of helpers in structure,
- On a better management of the assisted by the caregiver, more targeted and more adapted,
- On the dialogue between the medical staff and the caregiver,
- On the regular and daily update of the follow-up workbook,
- on taking into account the health of the caregiver, their concern, their doubts...,
- On the relationship between the caregiver and the medical staff of the reception or respite structures,
- On the family policy of the caregiver and the helper,
- On the relationship between the caregiver and the medical staff of the reception or respite structures,
- On the family policy of the caregiver and the helper,
- On the close dynamic couple helping – helped,
- On the role of each member of the family in relation to the helper,
- On the knowledge of the evolution of the disease, on the knowledge of the degree of physical and cognitive autonomy of the assisted from the tests carried out by the medical personnel,
- On the definition of the new role of the dynamic couple "close helping-helped",
- On the continuity of daily activities at home in the same context of activities carried out in day-care or in respite centres,
- Learning about home activities "We remake at home what we learned in day care,"
- On the training of the digital helper in the context of the use of Smartphones,
- On the training of caregivers, lectures, courses, training practices,
- Information about Caregivers

In what objective-result or for what purpose, design this product?

Design a link book, in the form of a digital, intelligent application (takes into account the information of daily activities or other stimulation exercises), increased (adjusted in real time) and shared (takes into account the different Interveners with the helper).

Ultimately, it is a matter of designing a mock-up of a digital application for caregivers to ensure continuity in the non-medicated activities of the assisted in real time.

In order to validate that this need is very real, we answer three indispensable questions:

-Why does this need exist?

For today, it becomes necessary to inform and train the caregiver on a daily basis in order to protect them in their heavy task as an attendant of the helper. While solutions exist, they do

not always take into account this lack of crucial information which is lacking in order to better monitor the evolution of the disease and how to deal with it on the one hand and on the other hand it is not sufficiently informed of Activities or care during their or her stay in reception or respite centres.

SOLUTION: AN 'INTELLIGENT', 'SHARED' AND 'AUGMENTED' FOLLOW-UP NOTEBOOK.

Throughout this article, we have shown that facing the implacable disease, a close actor of the helped, the helping close play an important role as the load is heavy. He is generally referred to as the most apt to carry this burden without being asked for their opinion. Over time, acquired experience will make they become a close helping expert. It is on this actor, true pivot of the system of monitoring of the assisted, that we want to focus to present on the one hand the plural and current services proposed but also the need to complete this offer by an "intelligent", "shared" follow-up book and ' increased '. This proposal seems to us to be innovative insofar as this booklet will be in breach of those which exist, and above all should allow breaking the devastating isolation of the close caregiver.

This follow-up notebook will achieve the following features:

- Propose pedagogical answers to questions that the caregiver asks, in a list of "Frequently asked questions",
- Propose to create a virtual community of caregivers to break their isolation and create social links to exchange advice and help each other,
- Propose practical advice updated regularly concerning the disease, its evolution... and practical Measures,
- Build an updated and shared monitoring of information on the activities carried out within the various organizations and also at home. This information can contain the nature of the activity, its level of success and appreciation by the helper,
- This application could take into account the individualised Intervention Plan of the Assisted PII (clothing, cooking, cutting, cognitive stimulation, physical activities, singing, art, etc.) carried out in structure or at home by the medico-social staff,
- This application should be able to transmit the know-how or tacit knowledge of the closest expert caregivers to the more novice caregivers [27].

You are not born an expert, you become and benefit from the advice of the Medical Corps on the Help, information about the disease at each stage, exchanges with other caregivers... can avoid uncomfortable situations and make the life of the caregiver more Acceptable and therefore also to help it accordingly.

CONCLUSION

In the course of this article, we presented a brief state of the art of the disease, in support of its importance and its evolution in the years to come. This finding prompted us to take an interest in the caregiver, their role and missions to the disease and to help them and to infer that the non-drug approach seems most apt to achieve positive results on the effects of the disease.

In the Face of this assessment, we wish to reinforce its role of accompanying the helper affected by this pathology by proposing a redesigned follow-up book taking into account all the dimensions defined above. Thanks to this "intelligent" follow-up workbook, we hope in the first place that the caregiver can be "better" prepared. As a result, the helping-help couple should be more effective and ultimately helped should also benefit from these benefits. Thus, this "smart" follow-up workbook should generate significant societal savings on the direct and indirect consequences of Alzheimer's disease. In addition, this "intelligent" tracking workbook approach could potentially be duplicable for other diseases.

Our next step will be the functional analysis of this product that will give more details on the computer applications in terms of database to create in order to meet the requirements of specifications.

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